Atmospheres of dementia care: Stories told through the bodies of men

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Abstract

Atmospheres of Dementia Care: Stories told through the bodies of men is an ethnographic study exploring what role the experience of place plays, and the role gender has, in the lives of men living with dementia in a variety of care settings. The aim was to interpret the everyday embodied life for men living with dementia in care and their connection to atmosphere. The study was undertaken alongside a wider project colloquially known as 'The Hair and Care Project' (ESRC Ref. 2011-2013; Dr Richard Ward, PI). The PhD study collected data across three fieldsites focusing on the experience of seven men living with dementia. It used a range of qualitative methods including 165 hours of participant observation from 39 observation sessions, along with informal conversations, five discussion groups and 12 interviews with a range of health and social care professionals, family carers and men living with dementia. The three fieldsites comprised of two residential care homes and one specialist dementia NHS assessment ward. Narrative analysis has been applied through close attention to affect and atmosphere in order to consider how collective bodies perform together the 'small stories' of everyday life within these care settings. These stories have been developed to create and understand the emergence of atmospheric dimensions. Firstly I consider how the normative conditions and regulations within the care organisations direct and orientate staff and residents and produce atmospherics. These emerge through: i). The organisation and structure of time; ii) The tension of home-place versus work-place; iii) The management of men's bodies; iv). Gendering of atmosphere. I then go onto to show how these regulations and conditions produce resistive atmospheric moments, where the men push against and sometimes challenge the normative expectations of everyday life. In contrast to this, I then explore the creation of restorative atmospheric moments that emerge throughout the day and which are created through assemblages of sensory, embodied, non-human and human moments of connection. This work presents an opportunity to consider the bodily and intangible aspects of care that have tangible consequences for men with dementia who live in these spaces and their relationships with those who care for and support them. The study presents a rationale through which to understand care settings through a different lens, that of atmosphere, and to understand these spaces and the experiences of those working and living in them as multi-dimensional and affective.

Declaration

I declare that that no portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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Dedication

This thesis is dedicated to both my father, Peter John Wright (1932-2016) and my father-in-law James Campbell (1938-2008) both of whom lived with dementia.

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Thank you to my husband, Mal, for being alongside me. I am truly grateful for your love, support, tolerance and sense of humour.

Background

This doctoral study reflects both a professional and personal journey within dementia care organisations. My study, which was initially situated within an Economic and Social Research Council (ESRC) funded study 'Personal Identity and Dementia Care: Improving care practice by exploring the activities of hairdressing, hair care and personal grooming in the everyday lives of people living with dementia using NHS and social care services' (RES-061-25-0484; Dr Richard Ward Principal Investigator), has become more familiarly known as 'The Hair and Care project' (https://thehairandcareproject.wordpress.com/; accessed 12th March 2019). I was employed as the full-time Research Associate on The Hair and Care project between 1st November 2011 to 31st May 2013 and this work explored the role of appearance and personal identity in the lives of people living with dementia using the lens of hairdressing services in care organisations. The Hair and Care project was a 28-month ethnographic mixed methods study which was carried out in a variety of care organisations across Greater Manchester. The Hair and Care project is reported upon in more detail in Appendix 1. As the full-time researcher on this study, I was granted permission by the ESRC to access a sample of discrete data for my own PhD studies. It is this process, augmented by an add-on study that informs this thesis and its original contribution to the literature.

Early on in the fieldwork for The Hair and Care project, it became clear that the care-based hair salon was a highly gendered and atmospheric space, and, indeed, the participating care homes and day centre where I was initially carrying out fieldwork were also particularly feminised spaces. Moreover, men with dementia appeared to be a minority in such settings and were attended to by a feminised workforce (Cohen and Wolkowitz, 2018; Twigg et al 2011; Lee-Treweek, 1998; Archibald, 1998). The communal lounges and day rooms were vastly occupied by female residents although men and women both lived in these environments. It was also possible to consider the environments as atmospheric places; they were rooms that were filled by the sensescapes, materialities and bodies of both staff and residents. During these early observations the notion of 'keeping men in mind' and 'atmospheres' arose as key considerations for this study. These were discrete enough to be independent from the main reporting of The Hair and Care project, but also interlinked in the focus that could, and did, emerge.

The initial research question that informed this PhD set out to explore what role the experience of place plays, and what role gender has in the lives of men living with dementia in a variety of care settings. This issue had particular personal relevance for me as my father-in-law had lived with a diagnosis of Alzheimer's disease whilst, at the time of data generation, my father was living with vascular dementia and had moved into residential care in 2008. As my mother had died some years earlier, my father's children were his primary supporters; this included me, one of my brothers and two sisters-in-laws (my other brother lived overseas). My father's experience of life in residential care proved traumatic and difficult for all to reconcile and, as a family, we experienced the way in which his body was now something 'possessed' by care services and his liberty was no longer his own. This provided me with a unique insight into the care system that I have sought to bring to this study as a 'partial viewpoint' (Haraway, 1988). I will discuss this in more detail in Chapter 4 on working methods.

Within this study I am not only exploring residential and nursing care, but also mental health NHS dementia assessment wards, an environment much overlooked in study reporting (Jones, 2019). These study sites vary insofar as they serve different purposes, for example the residential and nursing care environments provide long term homes to their residents whilst the mental health NHS dementia assessment wards undertake assessment and treatment before the person with dementia is discharged home or to a new living situation. However, there are aspects of care practices that are common across the spaces such as the same 'institutional routines' that dictate the pace of everyday life (Wiersma and Dupuis, 2010). The study has been interested in exploring how these care places produce, or create, particular atmospheres and atmospherics through the way they operate and conduct everyday care practices, in particular for - and with - the men living with dementia in these places.

Outline of the thesis

This thesis has eight chapters.

Chapter 1 commences with an overview of dementia, in terms of demographics, and widely understood knowledge about the condition. An overview of the influential discourses within the field of dementia over the last 30 years is then presented. This stretches from bio-

medicine to psycho-social responses and on to more recent critiques that encompass citizenship, embodiment and contemporary critical thinking in dementia studies. These understandings helped to inform the foundations of this study.

Chapter 2 provides the narrative literature review undertaken for this study in order to provide understanding of the empirical work in the field relating to the everyday experiences of men living with dementia. This narrative review has been undertaken using thematic analysis. The chapter outlines an account of these themes underpinned by a critical analysis of the included papers that supports the development of the research question and underpinning study aim/objectives.

Chapter 3 outlines a discussion of the theoretical and methodological underpinnings for this study that have contributed to its design.

Chapter 4 shares an account of the working methods for the study, which includes the ethical procedures and consent processes, entry into the field, information about the three fieldsites and introduces the study participants. The theoretical frameworks used for data analysis and reporting are also included in this chapter.

Chapter 5 provides an introduction to the notion of atmosphere as an analytical tool. Four themes related to the organisational regulations and structures of the participating fieldsites that generate atmospherics are presented. The chapter explores how these themes produce particular experiences and impacts for each fieldsite.

Chapter 6 provides a discussion on the concept 'atmospheric moments of resistance'. Four types of atmospheric moments of resistance are outlined. The chapter reveals how these are produced as an outcome of the normative regulations and conditions of the care organisations.

Chapter 7 provides a discussion about 'restorative atmospheric moments' which are revealed as other types of atmospheric moments that emerge and are created throughout the observed days. Four assemblages are then described where atmospheric moments emerge and their meanings and experiences are shared from across the three fieldsites.

Chapter 8 presents a discussion of the key findings from this study and the relationship to previous work undertaken in the field relating to the experience of men living with dementia. The chapter engages with literature from other fields relating to atmosphere in order to explore the potential and transferability of this original work. The chapter highlights implications of the research for research, policy, education and practice.

Definition of Terms and Writing Conventions

- This thesis has been written in the first person, an approach in keeping with the reflexive methodological and theoretical approach I have taken as a feminist ethnographer.

- I have used the Manchester Harvard Referencing system. This means that up to three authors are named in the in-text referencing, where there are beyond three authors I describe as Author et al (date). For example, Ward, Campbell and Keady, 2014 or Ward et al, 2005.

- References are given in order of most recent research, and where two authors have published in the same year, these are listed alphabetically. If an author has more than one work in the same year, the most recent work will be referenced first.

- Use of quotations from other research work, reports, grey literature and webpages: if the quotation is over 30 words this is placed in inverted commas on a new line and indented, with the page number in brackets at the end of the quotation.

- Use of quotes from interviews and discussion groups: short quotes remain within the text and are in inverted commas and in italics. Interview information is given in brackets after the quotes. For longer quotes these have been placed indented on a new line, in italics and indented.

- Use of ethnographic observation fieldnotes: short quotes remain within the text and are in inverted commas and italics. Longer sections of text are indented and italics but not in inverted commas. Fieldnote details given in brackets after selected text.

- I have referred to those who took part in the research as participants and residents. I have not used the term patients to describe those living in the hospital ward. I refer to the men living with dementia by their pseudonyms, in line with the study protocol. Family carers have also been assigned pseudonyms for similar reasons and staff members are aligned to their role.

- All the care organisations that have taken part in the study have been given pseudonyms.

- [] brackets are used to show where I have added to my field notes for sense making in the telling of the ethnographic stories in my finding's chapters.

- Where I have used … in a quotation it indicates either a pause, or some text has been left out of the quote in order to create meaning in a more exact way, though, this has not altered the intended meaning by the participant.

- I have written numbers 1-10 as words, and numbers over 10 are written as numbers, except in relation to the chapters and Tables/Figures which are all written as numbers, i.e. Chapter 6, Table 1 and so forth.

Glossary of terms

'pub': refers to a public house, a social environment for drinking.

‘bic razors’: reference to mass produced and inexpensive disposable shaving razors.

‘Fags’: refers to cigarettes, term used by participant who was a smoker.

TV: refers to television.

Care Organisations: used to depict the different care facilities across all three fieldsites.

Carer: informal/unpaid carer, usually friend or family.

Communal area: denotes lounge or dining, corridors or reception areas.

Dementia: this term is used to refer to all the dementias that may fall under this umbrella term, i.e. Alzheimer’s disease, vascular dementia, semantic dementia and so on.

‘meds’: medication, i.e. medication cup, medication trolley.

Ward: mental health NHS dementia in-patient assessment ward.

OT: Occupational therapist/therapy.

UK: United Kingdom.

Young onset: used when referring to a person with dementia before the age of 65.

MCA: Mental Capacity Act, 2005.

Sensory terms used in thesis:

Haptic: relating to touch

Olfactory: relating to smells

Auditory: relating to sound

Visual: relating to sight

Chapter 1. Dementia: An Overview

1.1 Introduction

This opening chapter outlines the context for this research study with relation to how dementia is understood and its societal impact. I have also set out the development of thinking in dementia studies, taking the starting point as bio-medical and then exploring some of the challenging discourses to this over the last 30 years. These have been important discourses for me to have engaged with whilst undertaking this research. There are different ways in which to view and understand dementia and in this chapter I will outline some of the major contributions to dementia studies. In particular, I have included the scholars that have influenced my theoretical standpoint for the study, moving from the inspirational psycho-social influence, through citizenship models to embodiment and then on to some more recent critical debates within dementia studies.

1.2 Dementia: context

The term 'dementia' is used to describe a progressive set of symptoms such as memory loss, disorientation, mood changes, and difficulties with communication and with reasoning (Alzheimer's Society, 2017). There are a number of different dementias such as Alzheimer's disease, dementia with Lewy body, vascular dementia and frontal lobe dementia, including Pick's disease (Alzheimer's Society, 2017). Dementia affects each individual differently, but because it is a progressive condition, the symptoms will worsen for each person over time. Often, an individual's abilities to undertake many activities of everyday life, such as bathing, dressing, eating, taking part in conversations, leisure activities and walking will be affected (Alzheimer's Society, 2017). In what are described as the later stages of dementia, people will require more and more help with all activities of daily living, and life expectancy is shortened (Alzheimer's Society, 2017). This has an enormous impact not only on the person living with dementia, but also on those around them in their families, social networks and neighbourhoods (Patterson, 2018). It is due to the progressive nature of the condition that individuals require increasingly higher levels of complex support (Alzheimer's Society, 2017). However, as Zeilig (2015) reminds us, dementia is a 'contested category' (p13) and it

is significantly impacted by the socio-cultural-political conditions in which people live in the world.

In contemporary thinking, dementia is also understood as a global crisis due to rising numbers of older people around the world and the concomitant incidence of dementia (Patterson, 2018). For example, a recent World Alzheimer's report (Prince et al, 2014) estimates the global numbers of people living with dementia at 50 million with that number due to increase nearly threefold over the next 30 years. The worldwide costs of dementia in 2018 amounted to a trillion GBP (Patterson, 2018) and £26 billion of that total aligned to the UK alone (Prince et al, 2014). In the UK, the current number of people diagnosed with dementia is estimated to be 850,000 and this number is rising rapidly owing to the ageing population (Prince et al, 2014). Around 70% of people living in care homes are thought to have some form of dementia and two thirds of all people living with dementia still live in the community (Prince et al, 2014). Around 35% of people living with dementia are men and 65% are female (Prince et al, 2014). In terms of residential and nursing care, in 2011, a quarter of people over the age of 65 were living in care (ONS, 2014). Around a third of these residents were men and two thirds female, although significantly, there is a slight variation in demographic changes since 2001, and whilst there are fewer numbers of women living in care, the numbers of men are increasing.

Not unsurprisingly, these demographic trends place considerable pressure on health and social care systems (Hutchings, Carter and Bennett, 2018). By means of a co-ordinated response, at the end of the last decade, the UK Government implemented a 'National Strategy for Dementia' for England due to the recognition of the high costs to society, economically and socially, of this condition (Department of Health, 2009). In England, the aims of the National Dementia Strategy (Department of Health, 2009) were to promote an overall message of 'living well with dementia' and had 18 objectives which were set across three key areas, namely: i) improved awareness and challenges to stigma; ii) early diagnosis and intervention; and iii) higher quality of care. At the end of this strategy, the then Prime Minister of the UK, David Cameron, set out his 'Challenge on Dementia' (Department of Health, 2012) emphasising his commitment to the National Dementia Strategy and recognising the need to drive forward specific objectives aimed at improvements in dementia provision. His focused Challenge areas were directed towards: i) health and care; ii)

improved research; and iii) creating dementia friendly communities (Department of Health, 2012), issues that were taken forward in the second Prime Minister's Challenge on Dementia published a few years later (Department of Health, 2015).

Whilst there has been commitment to increasing spending to dementia research in the UK, it is still falls far short of other diseases and conditions (Alzheimer's Research UK, 2017). Indeed, a decade ago now, The Nuffield Council for Bioethics (2009) reported key areas where social science research could be helpful in developing dementia research which included 'more understanding of the experience of living with dementia from the perspective of the person living with dementia' (p129) and research that examines 'how best to educate and support those providing paid or unpaid care in responding to the ethical challenges that they face on a daily basis' (p130). Moreover, there has been a recent shift by organisations such as Alzheimer Research UK and Alzheimer's Disease International to recognise the need for more to be done to support and develop better care for those living with dementia, rather than focussing solely on finding a cure (Patterson, 2018; Hutchings, Carter and Bennett, 2018).

1.3 Changing Discourses in Dementia

Understandings of dementia have changed considerably over the last three decades and the following section will briefly set out the most influential discourses in dementia to date.

1.3.1 Bio-medical understandings of Dementia

Bio-medicine understands dementia as an organic brain disease and, as such, it is not considered a normal part of ageing. It is constructed as a condition that will gradually transition through mild-moderate-advanced stages, is degenerative and ultimately a terminal condition (Innes and Manthorpe, 2013). Bio-medicine has garnered a notion of a 'disappearing self' which is a term that has emerged because of bio-medical understandings of dementia that link a person's selfhood to their cognitive capacity (Millet, 2011). Bio-medical understandings of dementia have tended to shape the development of research, policy and practice (Innes and Manthorpe, 2013). Whilst there is recognition that bio-medical research has failed to find anything close to a cure, there is continued investment into 'disease-modifying' treatments (Alzheimer's Research UK, 2017). The bio-medical model

has been a major influence on the development of the National Dementia Strategy for England, which has at its core the need for increased and early diagnosis of the condition (Innes and Manthorpe, 2013; see also Prince, Bryce and Ferri, 2011). For bio-medicine this is a fundamental premise of the dementia-as-disease model and there has been a growing focus across all sectors to support better access to, and encourage, early diagnosis (Innes and Manthorpe, 2013). However, studies have revealed that attempting to gain an 'early' diagnosis of dementia is not always a straightforward or linear path, and that early presentations of dementia can be complex and varied, especially in young onset dementia (Campbell et al, 2016; Samsi et al, 2014).

Although there have been developments within bio-medicine to recognise the need to provide support and care to people living with dementia, the underpinning value-base still renders people living with dementia without agency and exposed to a paternalistic service model (McGettrick, 2015). In response, there have been calls for more multi-disciplinary approaches in order to address the challenges faced due to growing numbers of people living with dementia. Drawing on experiences from an inter-disciplinary workshop 'Bioethics and the Science of Aging: The Case of Dementia' (held in October 2012), researchers concluded the need for collaboration across disciplines citing the need to:

> 'Reframe biomedicine within the science of dementia. In this new frame, the intense dialogue between biomedicine and public health, social sciences, medical humanities and bioethics would inform the new orientation of a more mature and self-reflective bio-medicine' (Portacolone, 2014, p272).

A significant influence on these shifts in thinking emerged in the UK from the Bradford Dementia Group during the late 1980s and 1990s and the work of Professor Tom Kitwood, as I will now go on to address.

1.3.2 The psycho-social model of dementia.

The seminal work of Professor Tom Kitwood led to a rethinking of dementia that challenged the dominant discourses of the biomedical model and the mind-set that people living with dementia lacked a sense of self and agency (Kitwood, 1997). In particular, Kitwood (1997) defined the term personhood which referred to a person's sense of self and identity as:

> ‘a standing or status that is be-stowed upon one human being by others in the context of relationship and social being. It implies recognition, respect and trust’(p8).

This development helped to reframe thinking about dementia to one that values identity based upon social relations and interactions that are positive and supportive (Twigg and Buse, 2013; Hughes, Louw and Sabat, 2006; Kitwood 1997).

Kitwood’s work developed the notion of ‘malignant social psychology’ that stood in opposition to personhood and outlined the kinds of negative interactions that harmed the person with dementia’s well-being. This concept suggests that people living with dementia often experience undermining and depersonalising behaviours towards them, such as infantilization, objectification and mockery, and whilst the interactions may not (always) be intentional, they are deeply damaging (Mitchell and Agnelli, 2015). Kitwood (1997) argued this was often due to a lack of education and training for care staff. To help promote a more positive image, Kitwood (1997) developed a flower diagram to hold the values that should be instilled in the provision of person-centred care: the petals and pistil held the core values that would be found in the provision of person-centred care and in the support of personhood. The pistil from which all other positive values stem, held the word ‘love’ and the other valuing terms were: attachment, comfort, identity, occupation and inclusion (Kitwood, 1997). In many ways, personhood has become the lens through which dementia care practice is now understood and measured (McGettrick, 2015; Hughes, 2011; Brooker, 2007).

After Professor Kitwood’s untimely death in 1998, a year after his seminal text was published (Kitwood, 1997), person-centred care was taken forward by Brooker (2003) through the development of the VIPs model, which stood for:

- **V**alue of all human lives;
- **I**ndividualised approach recognising uniqueness;
- seeing the world from the **P**erspective of the service user;
- **S**ocial environment that promotes wellbeing.

The **VIPs** model provides a helpful memory aide highlighting the importance and value of people living with dementia as well as reflecting a more holistic appreciation of the relationships that infuse daily life. In a later text, Brooker and Latham (2015) extended the reach of the **VIPs** model to challenge the prevailing culture of care home attitudes and outlined the importance of 'getting person-centred care into everyday practice' (p.24).

1.3.3 Citizenship

In more recent years, commentators have begun to develop critiques of 'personhood' and to develop new theoretical thinking in dementia studies. Bartlett and O'Connor (2010), for example, argue that although 'personhood' had already been critically evaluated for the possibilities that it has brought to dementia care practice, it had not been examined for its limitations. They suggested that one of the problems with a personhood lens is that it is 'individualised' and, as such, provides understanding only on a micro level with less understanding about macro-structural issues (Bartlett and O'Connor, 2010). The authors argue that there is a need for more research exploring social structures and their influence on the experience of dementia, such as age, gender, ethnicity and social class, which have been largely overlooked (Bartlett and O'Connor, 2010).

To enhance understanding, Bartlett and O'Connor (2010) propose a 'citizenship model' which would enable deeper implications to be explored relating to the inclusion and participation of people living with dementia in wider society. On the one hand, the authors suggest that this approach would pose a solution to the discrimination experienced by people living with dementia (Bartlett and O'Connor, 2010). On the other hand, some commentators have argued that citizenship models can favour some people living with dementia above others because of a possibly narrow view of who become included as 'acceptable citizens' (Gilleard and Higgs, 2000). Behuniak (2010) therefore developed the idea of a citizenship model of dementia that included a political dimension which, she argued, offers a critique on the power dynamics that exist between people living with dementia, their families and the state. Behuniak (2010) suggests that there been such an over-privileging of the notion of autonomy and independence that requiring support - or aid - immediately reduces agency in a person. She therefore argues for a 'theory of rights for dependent citizens' (Behuniak 2010, p236).

The person living with dementia has become more visible through these humanistic approaches to thinking about the experience of living with dementia. The shift in discourse has led to bio-medical influenced policies such as the National Dementia Strategy for England (Department of Health 2009) acknowledge that it is possible to 'live well' beyond a diagnosis of dementia. Yet, societal perspectives of dementia remain solidly fixed in a negative mind-set and the media has a tendency to represent problematic notions of dementia as a living death (Woods, 1989; Hill, 2008) or as 'zombies' (Behuniak 2011, p71) and as a slow death (Newell, 2012; Taylor 2008). These kinds of headlines emerge from a disappearing-self narrative and there is still a great deal of stigma and fear about dementia held by individuals and society as a whole (Batsch and Mittelman, 2012).

Over recent years, the number of people speaking up and out about their personal experiences of living with dementia is rising (Bartlett, 2014). These individuals challenge the type of stigma associated with a 'disappearing self' narrative and campaign for more inclusive communities and for their voices to have power in making meaningful changes to their) services. Such voices are becoming heard not only as participants in research, but within wider user groups and networks and via social media, such as twitter and facebook (Thomas, 2017). Researchers are encouraged to include people living with dementia in all stages of their research work, from design to data generation and analysis (Swarbrick, 2015). Third sector organisations are also being encouraged to enable peer support groups in the community, and The Mental Health Foundation has developed a network for these groups, 'Dementia Engagement and Empowerment Project (DEEP) (Williamson, 2012).

Arguably, citizenship models of dementia are turning such citizens into activists and, for those involved, provide an important opportunity to make connections with others living with dementia and develop a 'culture of resistance' (Bartlett, 2014, p640). However, as Bartlett (2014) notes, 'dementia activism' has a temporal dimension and these voices are often those in the early stages of dementia, living in the community and with significant support and resources to enable their activism. Although it is positive that these voices are becoming a strong element of the social disability movement, there is concern that these individual voices cannot speak up for those who are living with more advanced experiences of dementia, or those who may need extensive support in their day to day lives. Bartlett (2012) also notes that there are possibly many other dimensions to consider in relation to who has the confidence

and support to take part in activism. Bartlett and O'Connor (2010) suggest that more creative ways to understand citizenship, participation and inclusion need to be theorised and developed.

1.3.4 Embodiment and Dementia

Another approach in dementia studies has been developed around embodiment and has been led by authors such as Katz (2013), Kontos (2012, 2005, 2004, 2003), Kontos and Martin (2013), Martin et al (2013), Millet (2011), Twigg and Buse (2013) and Ward et al (2014, 2016). These authors argue that there has been too much focus on cognitive abilities and that bodies have been neglected from a focus in understanding dementia due to two main concerns; first around biological determinism; and second, due to the over-privileging of social positioning. Kontos and Martin (2013) argue that bodies are 'central to everyday life and the wider social order' (p2) with Kontos (2003) taking a phenomenological perspective that considers embodied experience - in essence, arguing that the body is a site of knowledge and understanding. Throughout her empirical work, she gives voice to people with more advanced dementia whom she illustrates as having agency through intentional actions through the use of their bodies in terms of gestures, movements and sounds. Kontos' (2003) work brings together philosophical accounts of embodiment proposed by Merleau Ponty (1962) and Bourdieu (1990). As an illustration, she takes Merleau Pontys' phenomenological ideas of perception and corporeality in which he cites that the body is a site of knowledge and experience that does not require cognitive consciousness. Merleau Ponty (1962) argues that the body acts with intentionality that is pre-reflective; as an illustration, Kontos (2004, p838) uses the example by Merleau Ponty (1962) of the bite of a mosquito to which our body immediately responds by scratching the itch. She uses Bourdieu's (1990) concept of habitus which argues that the regulating forces of societal and cultural norms become embodied through the ritual and practice of everyday life in gestures, movements and actions (Kontos, 2004). As with Merleau Ponty, Bourdieu's ideas are related to a bodily state that is pre-cognition and argues that through the practice of repetition, these cultural and societal norms become naturalised (Kontos, 2004).

Kontos and Grigonovich (2018) demonstrate in their study how individuals continue to have intentionality in their actions because their selfhood is deeply rooted in their body as a site of expression and knowledge. Kontos (2004) uses the concept of 'embodied selfhood' as a

model to bring the body back to the 'theoretical revisioning of selfhood' (p558) in dementia care. She states that currently concepts of personhood are cognitively driven because they do not give credence to the intentionality of the body or recognise it as having agency (Kontos, 2005). The notion of the body holding within it its own knowledge and experience are implicit in this conceptual framework, with the body as a site that acts in pre-reflective and corporeal ways (Kontos, 2005).

Phinney and Chesla's (2003) work 'The Lived Body' provides an exploration of embodiment that could be seen to be in contrast with the work of Kontos. These authors suggest that the onset of dementia leads to bodily disruptions because bodies are no longer able to do as they once did. Phinney and Chesla (2003) take their lead by citing the work of Leder (1990) who states that 'our bodies are mentalised through and through' (p114). Kontos and Martin (2013) argue that it is this link between bodies and minds that returns to a dualistic Cartesian notion of mind and body, and suggest that the focus by Phinney and Chesla (2003) reduces the experience of people living with dementia to their symptoms of dementia. However, it is notable that Phinney and Chesla (2003) are 'tuned into' the experience of bodily loss that is often referred to by people living with dementia and to the disruption of habitual flow. There is no reason that bodies cannot both be disrupted and intentional, and it is more than possible that a person living with dementia may struggle to manage their shirt buttons, but be able to stand and salute because they hear the national anthem that prompts a bodily response imbued with cultural meaning (Kontos and Naglie, 2009).

Further work by Zeiler (2013) on embodiment seeks to establish an 'intercorporeal personhood framework'. Zeiler (2013) develops thinking from the field of disability studies, along with personhood and embodiment frameworks in dementia studies. Taking forward work by Matthews (2006) that brings about the notion of a 'body-subject', suggesting that together a person's thinking, feelings and bodily expressions become a unified state of being, Zeiler's (2013) complex interrogation of thinking on personhood seeks to establish a personhood in dementia that understands the interaction between two bodies as supporting and maintaining an individual's personhood. Similarly to Behuniak (2010), it is a model that acknowledges the need to move away from a focus on autonomy and productivity as a barometer for personhood. The concept provides a definition of personhood that recognises that sometimes an individual will require support to prompt their bodily memories (Zeiler,

2013). Underpinning this notion, Zeiler (2013) explores in-depth a piece of film involving Naomi Feil, founder of validation therapy, and Gladys Wilson a person living with advanced dementia so that they become one body (see: http://youtu.be/CrZXz10FcVM; accessed 20th January 2019). Moreover, new ways of thinking critically about the experience of living with dementia seeks to draw upon work from other fields in sociology and philosophy, as will now be approached.

1.3.5 Critical theory in dementia studies

Recent work in dementia studies has been keen to draw on work from other disciplines in order to more fully consider the experience of living with dementia. Capstick (2012), whose participatory approach to researching alongside people living with dementia using video, has argued that more efforts are needed to ensure inclusion is not only discussed in principle, but also made possible in practice too. In her work, she has adapted video methods in order to include people living with dementia as 'film-makers' of their life-stories (Capstick, 2011). More recently, Capstick and Chatwin (2016) have further developed the concept of 'cultural resistance' to explain how people living with dementia communicate in ways that challenge and resist the culture of the social environments that they are situated within. Capstick and Chatwin (2016) take their understanding of cultural resistance from Bakhtin (1984) in order to propose a model that argues that people living with dementia are acting with agency - sometimes in protest at their circumstances and, at other times, in order to maintain their dignity and self-esteem. Capstick and Chatwin (2016) suggest that whilst the bio-medical model reduces people to their behaviours, such as describing them as 'noise-makers' and as 'disruptive' (p4), the humanistic psycho-social model tends to see people living with dementia as 'passive' (p4). They argue for further advancement of a socio-political discourse and present their own arguments positioning people living with dementia as undertaking acts of cultural resistance within formal care organisations. Using conceptual thinking, Capstick and Chatwin (2016) suggest that:

> 'the carnivalesque, polyphony, heteroglossia and dialogism - have fostered a different way of seeing action and interaction within the dementia care environments where our studies were carried out…People living with dementia , just like the unruly 'folk' attending Rabelais' feasts and fairs, cannot conveniently be bidden to the place set out for them by the official

> order. The various speakers who arrive here are not the ones imagined by either biomedical or psychosocial orthodoxy; they are prone to turning the world upside down.' (p9).

Capstick and Chatwin (2016) go on to share data from three studies which provide examples of the ways that people living with dementia actively, knowingly use humour, share biographical narratives, speak out and up in order to challenge the institutional structures and to be heard in their everyday care settings.

Similar to Capstick and Chatwin (2016), other scholars are also seeking to draw from a wider disciplinary discourse to introduce other ways through which to consider the experience of living with dementia. For instance, Ward and Price (2016) draw on queer and crip theory to reconceptualise thinking about dementia in order to produce their notion of a 'politics of senility'. In particular, they seek to bring understandings to dementia studies that should look beyond normative conceptions of experience and to open up space for other, and different, experiences and how diverse bodies experience everyday life (Ward and Price, 2016). They challenge being stuck within the binary discourse of able-minded and able-bodied as opposed to senile and disability, and posture that senility, like queer and crip, has long been stigmatising and has pushed people to the margins of society. However, the authors argue that the margins of where resistance evolves, and how this allows an opportunity for the development of a radical shift in thinking and discourses to emerge, provides an opportunity to move beyond the present understandings about the lived experience of dementia. Instead, Ward and Price (2016) draw on experiences of 'othering' and 'difference' to find commonalities so that it may be possible to think about alternative ways in which to consider the everyday experience of living with dementia, as in this extract from their work:

> 'We have suggested that reorienting ourselves to the politics of senility creates an arena that exists outside of or 'beyond' dementia. Such critical territory could support efforts to deconstruct and reconfigure current thinking and enable a critique of the binary relationship in which dementia has become fixed in regard to notions of 'healthy ageing' and 'able-mindedness' (p75).

This literature has provided some useful and critical insights for thinking about dementia and the intersections of identities and calling for a radical move from normative fixed binary modes of thought. However, it is important that these new theories continue to be developed alongside empirical work to ensure that they remain grounded and grapple with the everyday experiences of people living with dementia.

1.4 Summary

This chapter has introduced the study and the context for undertaking this work. It has set out the current global and national situation in relation to the experience of living with dementia, and current UK policy agendas. The opening chapter then provides an overview of the development of theory within dementia studies over the last 30 years in order to establish the work I have engaged with whilst undertaking this research, and in particular some of the scholars that have influenced my theoretical standpoint for the study which I will discuss further in Chapter 3. The work to extend personhood and explore embodied perspectives has given voice to those who have more advanced needs and are living in care organisations and this has been vital in influencing this study. However, there has been little attention given to embodiment and gender. As noted by Ward and Price (2016), there is still a great deal of work to be done to explore diversity and dementia. Bartlett (2012) and Capstick and Chatwin (2016) explore notions of resistance from those living with dementia, and in particular the work by Capstick and Chatwin (2016) explores resistance within care environments.

Building on this foundation, my study set out to explore what role the experience of place plays, and what role gender has in the lives of men living with dementia in a variety of care settings. This is explored in the next chapter.

Chapter 2 Making Men Visible: The everyday experience of men living with dementia: A narrative literature review

2.1 Introduction

Using a systematic approach, this chapter reviews the empirical literature on the experiences of men living with dementia in different contexts. The chapter describes the search strategy used to identify current knowledge and understanding in the field and outlines the analytical approach used to gain relevant insights into the experiences of men living with dementia. The four themes identified from the literature are: i) identities; ii) relationships and dementia; iii) bodies; and iv) spaces, places and atmosphere. The chapter concludes with a summary of the gaps identified and sets the scene for the research question and design that follows and comprises the empirical component of this PhD study.

2.2 Narrative literature review aims and objectives

This narrative literature review provides a foundation for the study, using a systematic approach to identify the 'major and recurrent' themes in the empirical literature on men living with dementia (Weed, 2005; Dixon-Woods et al, 2004). The primary aim is to explore what is currently known about the everyday experiences of men living with a diagnosis of dementia. Appraising the empirical evidence provides support to refine the research questions. Furthermore, the narrative literature review compares and contrasts the designs and methods used in the included empirical studies. Using a 'thematic analysis' the review is carried out much like analysis in primary research; it creates a structure for the research findings from the literature using themes (Weed, 2005). Thematically analysed literature reviews can be 'data-driven' or 'theory-driven' and the approach taken here provides a data-driven review which draws on some of the theories driving the doctoral work as a framework for interpretation (Thomas and Harden, 2008). I have provided critical reflection throughout the review with the aid of a critical appraisal tool. A useful aspect of a narrative literature

review using thematic analysis is that it allows a freedom for the inclusion of a diverse range of evidence to be appraised and presented (Dixon-Woods et al, 2006; Weed, 2005).

2.3 Literature Search Strategy

A search of titles, keywords and abstracts was initially conducted during 2013 and updated in September 2018 using the same electronic databases and search strategy at The University of Manchester Library. The following databases were accessed: OVID, CINAHL Plus, Science Direct and Web of Knowledge. Further searches were carried out via bibliographies of core texts, through Google Scholar and a search of the SAGE journal *Dementia: the international journal of social research and practice* to make sure that all salient references were accounted for. Appendix 2 illustrates the searches that were undertaken. The studies included in the narrative literature review were all based on empirical research studies.

2.3.1 Inclusion criteria

Studies that:

- include findings about the lived everyday experience of men with dementia, from the perspectives of people living with dementia and carers.
- have been conducted between 1990 to January 2014 [updated to September 2018] These dates were set to take into account research in the decade leading to shifts in dementia policy and practice (See Chapter 1: Discourses in Dementia p24).
- Studies are in English, set in any country.

2.3.2 Exclusion criteria

Studies where:

- Men are noted in the study only as a sex-variable within the research but gender is not explored.
- the carer not the man/men with dementia is the main research focus.
- the subject matter was not dementia.
- The focus was on men, but with a medical focus and unrelated to the experience of living with dementia.

2.3.3 Key search terms

I anticipated that I would mainly be including qualitative studies (Cooke, Smith and Booth, 2012). Search terms were developed using the 'SPIDER Tool' search strategy which aims to provide a more effective search tool for qualitative research studies. It was difficult to find relevant search terms; for example, when the search term 'men' was implemented through OVID it retrieved a total of 16,447 papers. Using science direct database with the search term 'men and dementia' brought 48,246 journal articles. A cursory perusal of the titles and key terms revealed papers had been retrieved because de'**men'**tia was selected. In addition to this in many papers where men were participants, their experiences were not explored as men living with dementia, rather all participants, both men and women, were homogenised and explored as 'people' living with dementia. Using the search terms 'men' AND 'dementia' was not a successful strategy and required further consideration in order to find more useful search terms to reach the studies where men's experiences were explored and reported. The identified papers were reviewed in four stages in the initial search phase (2013), and then again in September 2018:

1. Database searches were undertaken using the terms developed (search terms can be found in Appendix 2).
    a. Further filters were applied at each search point dependent on different database filters that were offered. For example I requested only research papers were returned. I limited these to specific journals that were related to experiential, theoretical concerns of dementia, rather than bio-medical journals.
    b. A vast number of returned work was excluded immediately for lack of relevance. It was immediately discernible from the paper title that they were not relevant to the topic.
    c. Further to this high number of abstracts were excluded from the review because they were not about the experiences of men's everyday lives living with dementia. Most papers returned did not fulfil the inclusion criteria and often if they included men they were not related to the everyday experiences

of men with a diagnosis of dementia or gender was only a variable in the study.

d. In the end only a small number of papers (n=42) were retained from searches of keyword, title and abstract for further assessment.

3. Once read, a number (n=13) were retained for the full review. Papers were excluded for a number of reasons. These were sometimes because although the paper referenced gendered experience they were not empirical studies. More often they were in relation to caring rather than the experience of living with dementia.

4. A further search was undertaken using Google Scholar, bibliographies of the papers already selected and a search of Dementia: the international journal of social research and practice (Sage publications). This journal was selected because of having direct relevance to the topic.

5. A further nine papers were selected using the keyword, abstract and title for full reading and review from Dementia: the international journal of social research and practice, and/or from using Google Scholar and/or from following the research citations within the studies already selected. After using the exclusion and inclusion criteria, six papers were retained to be included. At this stage there were 19 papers to be included in the review, however after a discussion with supervisors, five papers were rejected because although they either included a focus on gender the experiences of men with dementia were not suitably present to warrant a place in this review, or they were not based on empirical data. For included papers in the narrative review see the core literature table in Appendix 3.

Of the 14 included papers at this phase: 12 were qualitative studies, two were mixed methods: one was an intervention study using quantitative psychological measurements and one was a survey-based study.

2.3.4 Updating the review

These searches were carried out again in September 2018 and are included in Appendix 2. There were 299 papers identified through the searches, 23 of these were duplicates, and out of the 277 remaining papers, most were discounted for not being relevant through the steps

shown above. A brief assessment of the selected 47 papers (using the inclusion and exclusion criteria) led to 32 being excluded as they did not relate to the everyday experiences of men living with dementia. Fifteen remaining papers were then read in full: two papers were excluded for not meeting the criteria because one was a literature review (Bartlett et al, 2016) and the other theoretical work (Sandberg, 2018). They have, however, been vital in developing a gendered lens for dementia research, which I will discuss in Chapter 3 (p70). Five other papers did not turn out to be relevant to the research interest. Eight papers were retained for inclusion in the review. Four further papers were found through bibliographical searches of the current literature. These were all qualitative studies, with one based on secondary analysis of qualitative studies. One paper by Milligan et al (2015) remained part of the review, and whilst the study was not explicitly about dementia, men with dementia were participants and their experiences were highlighted within the research paper. Twenty-six empirical papers form the basis of this narrative literature review and they are displayed in Appendix 3.

2.4 Quality Assessment

A quality assessment of research literature is often applied in the positivist paradigm of quantitative research to assess, firstly, 'the trinity of truth' namely validity, reliability and generalizability of the research (Tobin and Begley 2004, p389), and secondly, in the undertaking of systematic reviews in health research, to underpin evidence-based medicine (Denzin 2009). In contrast, the notion of applying a quality appraisal to qualitative research in a review process has been debated (Denzin, 2009; Dixon-Woods et al, 2004; Seale and Silverman, 1997). For example, it has been argued that to appraise qualitative research through a defined criteria, such as those applied to quantitative research, is to suggest there is a 'right way' to undertake the research act, or that there is a universal truth to be found (Walsh and Down, 2005). However, as Dixon-Woods et al (2006) express it is not possible to denote one study design above another for qualitative research, research designs are dependent on the research questions. In the same vein, there is not one agreed set of criteria for assessing and appraising qualitative research (Thomas and Harden, 2008) and tools tend to assess the undertakings of the research process as key criteria, asking questions such as 'What methods did the researcher use for collecting data – and are these described in enough detail?' (Eakin and Mykhalovskiy, 2003, p188). The papers considered in this review display

a range of perspectives which show that there is no one way to understand human experience, rather there is the need to understand it as 'multi-dimensional, contingent, relationally implicated and entwined' (Mason, 2011, p78).

Finlay (2006) presents a number of criteria available to qualitative assessment starting with Guba and Lincoln (1985) who suggested: credibility; transferability; dependability; and confirmability. However, Hammersley (2008) argues that it is fundamentally problematic to critique qualitative research from different methodological frameworks by the same comparative criteria. Finlay (2006) affirms Hammersley's (2008) argument stating that it is imperative that assessment criteria is able to 'address the *special qualities* of qualitative research and to explore the broader impact and social relevance of a particular project' (p323, original authors' emphasis). She states that qualitative research could fall down in one area but be highly valuable in another and that each research project should be taken on its own merit (Finlay, 2006). It is therefore important to have awareness of the potential pitfalls in quality appraisal when selecting an appraisal tool and reviewing literature with a systematic approach.

Despite these challenges identified in reviewing qualitative literature within narrow perimeters, after discussion with my supervisors I did use a Critical Appraisal Skills Programme toolkit (CASP) for this narrative review. Using the CASP toolkit was something of a compromise; the toolkit did provide a framework of useful guiding questions through which to review the rigor and quality of the qualitative research (Gerrish and Lacey, 2010). The toolkit provides thorough questions with which to interrogate the main criteria associated with good quality qualitative research (see Appendix 4). It is also comparable to other available assessment schemas (Dixon-Woods et al, 2006) and arguably can be used for a broad range of methodologies (Gerrish and Lacey, 2010). Dixon-Woods et al (2004) state that it is important that the questions asked remain 'explicitly methodology neutral' (p225), i.e. not having any methodological bias but rather asking questions that are relevant to the quality all qualitative work should demonstrate, although approaches and emphasis may differ. Helpfully the CASP toolkit does not present itself as a definitive measure and its use is suggested alongside 'thought and judgement' as a 'guide and aide memoire' (Burls 2009, p3). Therefore in making judgements about the papers that were included it would have been unhelpful as a qualitative researcher to use the tookit without any discretion and intellectual

engagement. Academic papers themselves are restricted within a word limit in terms of what can be shared about a study, and sometimes authors may choose to write briefly about one aspect of a research study in order to provide focus on another important angle. Thus, meeting the toolkit guidelines was not the single route to decision-making regarding the value and robustness of the work. It has been important to consider what each paper had to offer and to explore the merits of each paper against what it set out to communicate. Hence in this review I have included papers that have rated poorly against some aspects of the CASP checklist, but have had something useful to offer for this review in terms of the everyday experiences of men living with dementia. CASP has been used with caution and as guidance, rather than as a prescriptive set of criteria (Barbour, 2001).

Of the 26 empirical papers critiqued using CASP (see Appendix 3), two did not meet the majority of the toolkit's criteria. The first paper, by Solari and Solomons (2011), offered little conclusive evidence due to the acknowledged small numbers involved in their survey and discrepancies between what carers and people living with dementia said. Despite containing little inferential analysis, this study remains in the narrative literature review as its design offers a novel contribution to the limited available research evidence. The second paper, by Barrett et al (2015), also did not report on a number of aspects of the research, such as details of the methodology and any theoretical frameworks used for analysis. The paper simply reported on findings, although it did give some indication of how the research could be useful. The paper is included because the subject matter relating to Gay, Lesbian, Bi-sexual and Trans people living with dementia is under-reported and there was significant value in including the findings within this review. The other empirical papers included in this review achieved high scientific rigor in many areas of the criteria although as suggested by Walsh and Downe (2005), many of the papers lacked a detailed consideration of the relationship between the researcher and research participants. On the other hand, papers by Chisholm and Bischoping (2018), Hulko (2009)and Chatterji (1998) did discuss this issue and, as such, recognised the value in accounting for the experience that the researcher brings to the field. Transparency regarding subjectivity is of high importance for the integrity of the qualitative researcher in order to ensure rigor (Morse and Field, 1998). By not offering insight into researcher reflexivity, the researchers in the majority of the literature included in this review had not accounted for their own potential bias or 'culture-bound' perspectives of the men that they have studied and the knowledge that is produced (Finlay, 2002; Spradley, 1979, p10).

The majority of papers included in the review give limited attention to the methodological approach and hence the epistemological perspective. In some papers this amounted to a sentence or two naming the methodology, although all the papers are limited by journal word counts. A number of papers (10) did discuss the methodological framework in more detail (Chisholm and Bischoping 2018; Herron and Rosenberg 2017; Boyle 2017, 2013; Buse and Twigg 2016, 2015; Regan 2016; Phinney, Dahike and Purves, 2013; Koehn, Kozak and Drance, 2012; Hulko 2009). Beyond this, most papers (other than Carone et al, 2016; Barrett et al, 2015; Solari and Solomons 2011) discussed theoretical understandings and frameworks which they employed through which to discuss their findings. In the most part, theory is used to support the telling of stories and to connect findings to wider implications (Hammersley and Atkinson, 1995). In papers, such as Chisholm and Bischoping (2018), Boyle (2013, 2017); Herron and Rosenberg (2017); Buse and Twigg (2016, 2015); Regan (2016); Milligan et al, 2015; Ward, Campbell and Keady, 2014; Capstick and Clegg (2013); Phinney, Dahike and Purves (2013); Koehn, Kozak and Drance (2012); Gleibs et al (2011); Kinney, Kart and Reddecliff (2011); Hulko (2009); Kontos and Naglie (2007); Pearce, Clare and Pistrang (2002); Chatterji (1998) the researchers provided explanations of how they had employed theory to shape their research and their data. The study by Capstick and Clegg (2013) is a prime example of the difficulty in using critical appraisal criteria in qualitative research. It does not fulfil a number of the requirements of CASP such as it fails to describe the process of selection for the men's narratives. However, the study has an empowering and political agenda as it makes the voices of men with dementia visible and valuable (Finlay, 2006). The lack of gendered analysis within so many of the papers, other than those that specifically set out to explore gender, is a crucial limitation of a number of these studies. The strengths and limitations of the studies will be discussed further throughout the narrative review findings.

Qualitative research can often be criticised for subjectivity. Open and clear processes provide a route to assess rigor and combat the challenges of credibility and trustworthiness (Morse and Field, 1998). As such, Phinney, Dahike and Purves's (2013) demonstration of a thorough approach to analysis by using a 'back and forth' process in the interpretation phase (p353) is a good example of open processes. Hammersley (2007) argues that qualitative researchers come from divergent perspectives with a 'complex landscape of variable practice in which the inhabitants use a range of labels' (p293). The selected studies demonstrate this as they

contain a variety of methodologies and ways of presenting research, which in turn makes a comparative critique difficult. Observation was a popular way to generate empirical data (n=17) with the majority of the qualitative or mixed method studies including this approach. It was often used alongside other means of gathering qualitative data such as interview, focus group and documentation reviews. Using observation as a tool for understanding the experiences of men living with dementia meant that verbal communication and non-verbal communication were taken into account. Hulko (2009) states that using observation means that what people say in interviews can be checked against what they do (e.g. recorded in the field notes). She also suggests it provides the researcher with direct experience of the context in which everyday life takes place (Hulko, 2009). As already noted, the studies had varying methodological perspectives, such as conducting ethnography, grounded theory, and phenomenology.

Three papers used questionnaires and measurements, which included two postal surveys (Solari and Solomons, 2011; Archibald, 1998), and one questionnaire which used well-being measures (Gleibs et al, 2011). Gleibs et al (2011), Solari and Solomons (2011) and Archibald (1998) all note that their studies are limited in sample size. Gleibs et al (2011) suggest that although their sample is small and thus difficult to make inferences from the data, their findings are congruent with the literature on the social identity and health (Haslam et al, 2009). Finlay (2006) suggests a study may fall down in one area but be of high quality in another.

2.5 Review Themes

A 'thematic analysis' approach looks for commonalities across the research knowledge base about what is known about the topic (Dixon-Woods et al, 2005). This was achieved by reading and re-reading the 26 papers and noting distinct categories that emerged from the text. Further analysis of these enabled more detailed themes to be developed (Morse and Field, 1998). The themes that emerged were: (i) identities, which unpicks aspects of identity such as gender and sexuality; it also illustrates understandings of how categories of identity impact on experiences; and how identity can be renegotiated; (ii) relationships and dementia, which explores the impact dementia has on different types of relationships; (iii) bodies, this section considers the embodied nature of selfhood and also the ways in which people living

with dementia use their bodies to resist the regulation and surveillance of everyday life in care organisations; and (iv) place, space and atmosphere, this section explores the experience of literal places and spaces of dementia care and the metaphorically gendered spaces of care and what it feels like to be in these places and spaces; There is some overlap between these themes, which will be acknowledged.

2.5.1 Theme 1: Identities

All papers discussed the importance of identity and its relationship to dementia and how it is expressed in everyday life. Challenges to identity due to the onset of dementia were discussed. Sometimes, living with dementia meant that new identities were formed or emerged. This section is broken down into a number of sub-headings which are: i). identity as a working man; ii) renegotiating identity/multiple masculinities; iii) sexuality and identity.

2.5.1.1 Identity as a working man

Throughout this review many of the men made reference to previous working lives or sought to find meaning and purpose of a similar nature within their current lives. Participants in Kinney, Kart and Reddecliff's (2011) study took part in the 'Get Out Of The House' (GOOTH) programme which was a social group designed for people with Young-onset dementia. The study evaluated the experience of taking part in the programme. The programme gave the men opportunities for purposeful activity at their local zoo such as repair work, painting-work and helping out with the animals. The programme was not designed only for men, but no women maintained engagement with it. The men described the importance of doing meaningful activities with the experience of being 'useful' signalled as a major benefit gained from the programme. A number of men in this study were pre-retirement age and so the significance of regaining a sense of purpose is cited as particularly important to them having given up, or lost, their paid work since the onset of dementia (Kinney, Kart and Reddecliff, 2011).

The study used a life-course perspective to understand the impact of Young-onset dementia such as the interruption of age appropriate activities, which are specific and problematic to this condition (Kinney, Kart and Reddecliff, 2011). However, the study does not fully explore the relationship between the life-course perspective and social identity. It is significant the participants are all men and whilst this is referenced, there is no attempt to explore

intersections of the men's identities. In fact, the men's voices become homogenised within the group and there is no 'dissenting' voice reported. The men who stop attending the group are not interviewed and there is no investigation to find out how this affected the men that remained. In the study by Milligan et al (2015) on 'Men's Shed's' some of the more able-bodied (and able-minded) men were less keen to support those that were less able. According to Hulko (2009):

> 'We each possess different degrees of oppression and privilege based on our relative positioning along axes of interlocking systems of oppression such as racism, classism, sexism, ethnocentrism and ageism' (p133).

It is therefore important to explore the impact of identity through an understanding of the intersecting nature of social identity and social position (Hulko, 2009).

Work by Phinney, Dahike and Purves (2013) set out to understand how patterns of everyday life changed with the onset of dementia for two male participants, Roger and Tom, and their families. Both participants described their lives previously as focused on being active in a variety of roles: from hard working men who provided for their families, to men who were active in their local communities though sport, local organisations and supporting friends and neighbours. As Roger revealed 'I was always president of something…' (Phinney, Dahike and Purves, 2013, p355). Many discussions involving Roger and Tom focused on productivity and the achievements from their past public and private lives. Both men were struggling to adapt to changes brought on by dementia, such as having less energy and being less able to manage complex practical tasks that had previously been part of their everyday lives. Both men had worked in construction and felt acutely the loss of their occupational identities. As Tom said:

> 'I still feel a little emptiness, maybe it's something not turning my crank. You don't get highly excited about something, or can't sleep tonight because of something that you're going to do tomorrow' (Phinney, Dahike and Purves, 2013, p357).

This quote links Tom to a previously spontaneous, risk-taking lifestyle. Although Tom, recognised the goals he had accomplished and in many ways felt contented he also felt he

was missing out on opportunities afforded him as a younger working man. Similarly, Roger, who described himself as 'always the president of something' refers to the routine nature of his current life stating 'getting up in the morning, you know, going through the day, eating the meals as they come, reading the paper' (Phinney, Dahike and Purves, 2013, p356). His once active life had become sedentary and home based. Both men are heterosexual and their previous positions of power within their families and the workplace were integral to their identities and could be linked to expectations of hegemonic masculinity, a discourse connecting male identities to productivity and the public sphere (Connell and Messerschmidt, 2005).

Developing this further, in the study by Kinney, Kart and Reddecliff (2011), the men had Young-onset dementia and were coming to terms with an immediate sense of loss from working identities In contrast, the older men in Pearce, Clare and Pistrang's (2002) study had more likely been retired for some years before the onset of their dementia and may have already renegotiated aspects their identities as they entered into retirement. Yet these men still described a sense of loss related to their abilities - and possibly the lack of control that they can maintain over their lives - with an increasing reliance on support from wives and partners (Pearce, Clare and Pistrang, 2002).

Boyle's (2017) study on everyday decision making within couples has the theme 'men at work' associated with the importance placed on previous occupational identities and the feelings of loss described by the men. One of the men, Mr Pasha, linked his depression to no longer working. Boyle (2017) suggests that a gendered lens links these feelings to gendered identities of 'doers and providers' (p1790).

Tolhurst and Weicht's (2017) work also found their male participants linked their social contributions to relationships with previously held occupations, referring back to their lives as working men. One man, David, was still employed at the time of the study, and notes competence as a respected aspect of his identity that is derived through his work. Crucially Tolhurst and Weicht (2017) note that competence is not only important for men, however they suggest that within this cohort it is revered as a culturally constructed aspect of identity. Similarly to the men in Phinney, Dahike and Purves's (2013) study where the men prized an association with traditional masculine characteristics. Tolhurst and Weicht (2017) argue that

because norms and values are shaped by cultural and societal principles, the gendered experience of living with dementia is not fixed and will shift in the future.

Furthermore, in the study by Chisholm and Bischoping (2018), Alexander's occupation as a farmer was described as integral to his identity. His wife stated: 'He's spent his whole life making this farm. That's his expression. He's a farmer' (p6). His identity is perceived as bound with his occupation. A key finding was also related to Alexander's 'usefulness' and his ability to continue to maintain his 'usefulness' was important for upholding his personhood (Chisholm and Bischoping, 2018). Herron and Rosenberg's (2017) study also based on the experiences of men in rural Canada, similarly note farming as a vital aspect of identity.

Buse and Twigg's study (2016, 2015) explored meanings of clothing in the lives of people living with dementia. They collected 'dress stories' from participants, which included asking them to talk about and show the contents of their wardrobes. Some men in the study had retained clothing related to their previous working lives. One man kept a number of suits, preserving them in garment covers. Another man, whose work had been as a builder, kept a row of 'work clothes' which were older worn jeans and t-shirts. His wife noted how he wore these when 'pottering in the garage' and she said he liked to 'feel like he was at work' (p1121). The identity of working men was illustrated through the memorialised work clothes, which appeared to embody these identities.

The 'Men in Sheds' project offered tool-equipped workshop spaces to older men, including some living with dementia (Milligan et al, 2015). The space provided opportunities for older men to participate in 'do-it-yourself' (DIY) activities where they could socialise and learn new skills. The study offers a new dimension to 'therapeutic landscapes' through the introduction of everyday spaces and through bringing a gendered theoretical perspective. One participant stated it was a way to replace what had been missing since retirement, 'job satisfaction when you go home…'. Although, as with the GOOTH programme (Kinney, Kart and Reddecliff, 2011), the 'Men in Sheds' initiative differed from working life as the pressure of working life was absent, one man stated:

> ‘It’s the activity without any pressure. You do as much as you want to do. We all find our own level and we work or don’t work…When I have been coming, if I don’t feel up to it, I don’t do very much’. (Milligan et al, 2015, p11)

Despite challenges to the men’s identities, there was evidence, that some of the men were reconstructing their identities, creating new roles and expectations for themselves that maintained a link to their identity as working men (Tolhurst and Weicht, 2017; Boyle, 2017; Milligan et al, 2015; Capstick and Clegg 2013; Phinney, Dahike and Purves, 2013; Kinney, Kart and Reddecliff, 2011; Pearce, Clare and Pistrang, 2002).

2.5.1.2 Renegotiating identity/multiple masculinities

Some of the men in the review studies expressed masculine values that challenged normative values and they renegotiated or expressed their identity in new ways. Sandberg (2018) has noted that when people living with dementia are re-gendered, there is a tendency to frame these experiences within normative expressions. Hence it is important to explore the multiple masculinites that were performed throughout the included studies. In the study by Capstick and Clegg (2013) they described the participants as experiencing freedom from the constraints of the masculine expectations of their generation. This work explored military narratives of three men who had maintained a lifelong silence in order to adhere to socially acceptable versions of events during their service in World War II (hereafter WWII). The work presents an embodied sense of self through the metaphor of ‘stiff upper lip’, meant to describe holding back emotion often associated with masculinity. Capstick and Clegg (2013) argue that the men in their study were from a generation where ‘stiff upper lip’ was expected.

The culture at the time generated a pervading viewpoint that WWII was ‘a clean war’ and as such accepted sanitised accounts from the time to depict a society able to ‘make the best of things’ and where people ‘did not complain’ (Capstick and Clegg 2013). The ‘stiff upper lip’ metaphor meant that men’s memories of war became hidden as ‘the domain of unspeakable things’ (Capstick and Clegg 2013, p242). This suppression is embodied by the ‘stiff upper lip’ and through the masculine behaviours of men who, throughout their lives, did not share their emotions or engage in challenging these constructs of war (Captstick and Clegg 2013).

This paper by Captstick and Clegg (2013) goes on to discuss the relationship between the men's onset of dementia and the previous hegemonic masculinity they performed through the 'stiff upper lip' way of representation, and how this began to change as they started talking about their experiences as young military men. Capstick and Clegg (2013) argue that a less constrained cognitive state meant that the versions of this previous time in their lives now reveal a more emotional and complex account of what happened to them. This analysis also revealed how the onset of dementia did not always bring feelings of loss related to identity but rather provided an opportunity for creating new, and alternative identities.

Work by Barrett et al (2015) explored an area that has been given limited focus: the experiences of Lesbian, Gay, Bi-sexual and Trans people living with dementia. Although unable to recruit any Bi-sexual or Trans people to their study, the researchers discuss with staff shared experiences of working alongside people from these communities. The Lesbian and Gay participants in the study spoke about the challenges of being themselves and their fears of discrimination. The research raised important concerns about the heteronormativity of service provision along with a fear of prejudice and discrimination that made it difficult for the men in this study to be themselves. Whilst the paper lacked a theoretical analysis of the findings and did not unpack the intersection of identities, or explore further the performance of identity in non-normative ways, it does highlight the need to recognise and further investigate diverse experiences within dementia research, policy and practice. An issue noted by Ward and Price (2016) in the previous chapter.

Work by Regan (2016) sought to investigate different experiences of identity through a case study approach which explored the experiences of Mr Q, a Muslim male. The focus was on Mr Q accessing UK dementia health and social care services and it highlighted the need for more culturally responsive understandings of dementia. The work was taken from a wider study exploring the experiences of south Asian communities with dementia. Regan (2016) noted previous work was limited regarding the experiences of people living with dementia from within these diverse communities. For Mr Q there were many significant aspects of his identity which intersected with the experience of living with dementia; for instance, his faith, gender and cultural heritage. Mr Q had also lived with serious mental health issues for a number of years which also had a profound impact on his everyday life. In this study, there were many aspects where the complex intersections of Mr Q's identities and the experience

of living with frontal lobe dementia brought to bear the significance for requiring deeper understandings about diversity and individual needs. Mr Q felt alienated within his community, and no longer wanted to attend prayers at Mosque because he feared making mistakes publicly.

Combined together, these studies highlighted that not all men living with dementia shared the same experiences and in directing attention to gendered experiences, it is vital to ensure that experiences are not homogenised, or only perceived through a normative lens.

2.5.1.3 Sexuality and identity

The issue of sexuality has been overlooked when considering everyday life in dementia care. The studies by Ward et al (2005) and Archibald (2003, 1998) highlighted that sexuality is an important aspect of identity. In particular, studies that have explored sexuality in dementia care have shown that sexual expression is regularly perceived as problematic and is often related to men being disinhibited (Ward et al, 2005; Archibald 2003, 1998). Archibald's (2003, 1998) work, which explored sexuality in residential care, highlighted the gendered spaces in which dementia care takes place. Similarly, Ward and colleagues (2005) argued there is a demographic element to how sexual expression is perceived due to the striking ratio of female workers to male residents in many care organisations. Archibald (1998) argued that gender and sexuality are entwined because of the way in which a person's sexual expression is perceived will be influenced by their gender. This intersection of gender and sexuality shows how being seen as aggressive, or as sexual predators, can have a profoundly negative impact on the lives of men living with dementia.

Kohen, Kozak and Drance's (2012) study which explored 'the problems with Leonard' showed how his sexual expression was perceived as an aspect of his unmanageable and manipulative behaviour. He was a man considered to have awareness about his actions and as such this influenced how staff responded to his behaviour (Kohen et al, 2012). As Archibald (1998, 2003) notes, such culpability of actions has a clear impact upon how staff understood sexual expression (see also: Hulko, 2009). These studies suggest the need for further understanding around sexuality, sexual desire and sexual expression for men (and women) living with dementia. Moreover, some of the men in the study by Barrett et al (2015), worried that services, or other service users, might be homophobic and that being open about their

sexuality could cause discrimination. However, equally, they did not want to have to hide who they were, with one man describing not wanting to 'pussyfoot around' being themselves in their own home where they were in receipt of care services. Another man described how his partner, who had been living with dementia, had become more private whilst living in residential care for fear of experiencing prejudice. As Barrett et al (2015) have stated: 'while sexual orientation was constant, some interviewees reported that dementia changed the way sexual orientation was expressed' (p35). This study has highlighted the complex intersections of identity and the diverse experiences within everyday life situations, alongside the need for more responsive service provision. In addition, it draws attention to the need for further research that might begin to unpack the diversity of gendered experience alongside other aspects of identity.

Few studies have explored how people living with dementia feel about their sexual and intimate relationships and the impact of dementia (for men living with dementia) on experiences of sexuality. Rather, sexuality is usually viewed, as described by Archibald (1998), or Koehn, Kozak and Drance (2012), as 'challenging' or 'problematic' with men acting out in inappropriate ways. In Carone et al's (2016) recent work, which explored the experiences of men who were part of a walking football club, one man described the lack of intimacy and sex within his relationship with his wife since his diagnosis of dementia and his frustration and despair relating to this. As he shared:

> 'Um, there's no [sighs] – there's not a proper loving relationship any more, between me and my wife. Um, there's no sexual relationship between me and my wife. Um, because I was angry' (Carone et al, 2016, p1364).

This experience suggests there is more to be understood about the impact on relationships regarding the experience of sexuality and identity.

2.6 Theme 2. Relationships and dementia

The theme of relationships and dementia explores the different kinds of relationships in the lives of the men in the studies. These were spousal partnerships and family relationships but also connections with services and professionals. The sub-themes within this section are i)

changing roles; ii) social exclusion and abandonment; iii) male friendships and dementia; and iv) gender and care relationships.

2.6.1 Changing roles

Many of the studies described the impact of living with dementia for men and their relationships with their partners, spouses and children. Pearce, Clare and Pistrang's (2002) study explored experiences of diagnosis for men living with dementia. However, the interplay of gender relations in the married/cohabiting lives of the 20 male participants, were not critically explored. Some participants in the study described how their roles were becoming 'reversed' as wives took on their husband's previous roles and vice versa. One man said he did the washing up to give himself 'a purpose' and he felt irritated if he found his wife doing 'his' job. Some wives of the men in Kinney, Kart and Reddecliff's (2011) study also talk about becoming the 'breadwinner' for the first time in their lives and role reversal in their homes. This highlights the gendered division of labour that existed in many of the households, and it also links across to gendered spaces and the relationship between gender and public and private space.

Alexander's family in the study by Chisholm and Bischoping (2018) gave examples of how Alexander, once known locally as 'the guy', had begun to take on new roles to create a new sense of usefulness for himself. Usefulness was valued highly and linked to the quality of this status as the patriarch. His daughter described him as cleaning her sunglasses for her, taking them from her head, and wiping them down, or providing her husband with a beer on the table in front of him after he returned from work, and even attempting to do the laundry. These 'domestic' tasks were not the kind of work usually linked to the men in this community, or the kind of work that Alexander had previously engaged in. However, Alexander was seemingly carving out a new place for himself and continuing his need to keep doing. Similarly, work by Herron and Rosenberg (2017) described participant Sam taking on many household roles as a way to keep busy and to support his family, he said that he was 'in-house chef and dishwasher'. However, in Boyle's (2017, 2013) study on everyday decision making, she noted a number of the men living with dementia avoided housework and those that stated they did it were exaggerating their contribution, according to their wives. Possibly, the men were keen to show their competence and usefulness during the interview, even if in reality they were not doing these tasks. She suggests that decision-

making patterns have often been established early in relationships including how household tasks are shared and these are likely a continuation of these.

These shifts in dynamics and the changing roles within relationships after the onset of dementia could often lead to conflict or difficulties between couples. Carone et al (2016) referred to changes within the roles in relationships of the men in their study, and even reports the wives describing their husbands pre-dementia having died and that they were now engaged in unrecognisable relationships. As such, they were taking on more and more caring responsibilities. In the study by Pearce, Pistrang and Clare (2002) it was reported that wives experienced their husband's changes as a 'loss of his manhood' (p183). Similarly, in the work by Phinney, Dahike and Purves (2013), the wife of Tom stated 'I have to be the boss now. I don't want to be the boss' (p360). In Roger's family, his adult children were struggling to accept the changes to their father and his loss of skill, and suggesting he had fundamentally changed as a person. This emphasises it is not only relationships between couples that are affected by shifts in relationship dynamics (Phinney, Dahike and Purves, 2013). It is not only the men who measure their status against particular normative cultural and social expectations, other men and women can hold these expectations too (Capstick and Clegg 2013; Pearce, Clare and Pistrang, 2002). The wives of the men in these studies were required to reconsider their own identities and the roles they held within their families. Likewise, the children of Roger felt there was a 'meekness' to him now that they stated 'this isn't the old dad' (Phinney, Dahike and Purves, 2013, p358). Similarly, the men themselves reported feeling that they had lost the role of leader within their social groups and they felt acutely the worry of becoming a burden to their wives and families (Phinney, Dahike and Purves, 2013; Pearce, Clare and Pistrang, 2002).

The men in these studies were not alone in experiencing concerns relating to their independence and worries about becoming a burden (Regan, 2016; Kinney, Kart and Reddecliff, 2011; O'Connor, 2010; Hulko, 2009; Pearce, Clare and Pistrang, 2002). The impact of the experience of dementia goes beyond the individual self. In some instances, there was an increased anxiety shown in the men regarding their relationships and worry their partners would leave them and so, although they were fearful of becoming a burden, they also feared abandonment (Regan, 2016; Pearce, Clare and Pistrang, 2002; Chatterji, 1998).

(1) social exclusion and abandonment

In Bartlett's (2007) care home study and Milligan et al's (2015) work on Men in Sheds, they argued that experiences of social exclusion are more likely to be experienced by men than women. The onset of dementia has been described as exacerbating social isolation - as with the men in the GOOTH programme - whose wives described their social lives becoming more limited after the onset of dementia (Kinney, Kart and Reddecliff, 2011). The men in a number of these studies reported their own lack of motivation at going out due to lower energy levels and also cited fear of stigma (Phinney, Dahike and Purves, 2013; Kinney, Kart and Reddecliff, 2011; Cedarvall and Åberg 2010). Similarly, for Mr Q in the study by Regan (2016), he did not want to become a burden to his children; however, he was also feeling isolated from his community due to no longer attending prayers at a Mosque. This was also a problem for Alexander in the study by Chisholm and Bischoping (2018) who had been such a key figure in his rural community, and now when he attended market once a week, people appeared to avoid him.

The men's increased presence around the home sometimes caused difficulties for their wives and partners. In the study by Cedarvall and Åberg (2010) exploring barriers to physical activity, Eva, one of the wives, said that she found it difficult that 'he [her husband] is often in the way' (Cedarvall and Åberg 2010, p232). This is very similar to the feelings of Mr Rijder's wife in the study by Chatterji (1998) who also complained that everywhere she turned her husband was next to her. However, for Mr Rijder, it was possibly his deeply felt fear of abandonment - or his need to feel safe - that led him to physically following his wife around their small flat which put an enormous pressure on their relationship (Chatterji, 1998). Once in residential care, Mr Rijder felt the loss of his wife and family so profoundly that he searched the corridors asking for them, and constantly asked to be taken home (Chatterji, 1998). There is a disruption to the way that these men and women have 'done' gender in their everyday lives previously and this appears to have had an impact on relationships.

In many of these studies, although identifying the disruptions or changes in relationships and activities that the men are involved in, authors have not linked these experiences to gender; there is a level of analysis that is missing from these texts. However, as well as the cases of abandonment and fears of becoming a burden, there were also many examples across the

literature which showed that new relationships could flourish after the onset of dementia. This will be examined further in the next section.

(2) male friendships

Friendships between the men in the GOOTH study (Kinney, Kart and Reddecliff, 2011) are linked to the shared sense of purpose and belonging they feel about being a part of the programme. There is camaraderie as they travel and work together; humour is referred to as an important connection within the group (Kinney, Kart and Reddecliff, 2011). Humour has significance as a bond of male friendship and masculine hierarchies (Bartlett, 2007). In Bartlett's (2007) case study, Mr Brown is also described as developing friendships with the other men in his residential care home, and he states that he spends his time 'working with the boys' (p22). The reference by both the GOOTH men and Mr Brown to associate these male friendships with work may reveal something about masculine identity. The men may make sense of their relationships according to their sense of masculinity in relation to their identity as working men and the ways they previously performed masculinity. It may relate to the public space of work, where men previously formed friendships with other men during their working lives. This was played out in the 'Men in Sheds' study where men also enjoyed a sense of camaraderie and where there was 'banter, humour and conversation' as they carried out practical tasks in the workshop; however, as one man stated, it could also potentially lead to more revealing conversations:

> 'I think because someone's looking at a bench and working at a bench and there's a conversation going around, I think things come out unconsciously, verbally…that they wouldn't verbalise otherwise. The workshop activity, you think is a vehicle for conversation and integration'. (Milligan et al, 2015, pp12-13)

This suggests that workplace, or activity-based friendships, help to take the pressure off, allowing men to open up in ways they might not usually. Milligan et al (2015) quote Golding and Foley (2008) who suggest that women 'communicate face to face whilst men communicate shoulder to shoulder' (p12). Certainly, the gender profile of the project appears to hold value and significance for the men. The participants in the 'Men in Sheds' programme alluded to 'roughness of banter and language' that wasn't suitable for women

(Milligan et al, 2015, p20). However, some participants said women members could join as long as they were able to engage with the 'concept of the shed' (Milligan et al, 2015, p20).

The 'GOOTH' initiative had not aimed to be a group only for men; however, since it became established attempts to introduce female members had been unsuccessful. The agency that organised the group did try to integrate one woman with Young-onset dementia, but it was not received well and there was general unhappiness at the change to group dynamics. So much so that the woman did not continue with the group (Kinney, Kart and Reddecliff, 2011). The men in the GOOTH programme established rapports that were linked to their masculine identities and this was shaken by a woman joining the group (Kinney, Kart and Reddecliff, 2011). However, the researchers do not address this issue or investigate it further than a note in passing; yet, it appears an important aspect of the project that the group remains firmly men only.

In Gleibs et al's (2011) study, the provision of male social groups in residential care appeared to have positive effects for the men involved. The men were keen to get involved in the gender specific groups, one man stating 'Yes, we become a team, a team' (Gleibs et al, 2011, p462). This finding could be seen to be at odds with the argument by Solari and Solomons (2011) that men are more reluctant to get involved in groups. The men attending a walking football club at Nott's County Football ground described it as helping them to feel more 'normal' (Carone et al, 2016, p1369). The men in the study said it was 'a no-dementia zone' and offered relief together with other men in the same boat (Carone et al, 2016, p1370).

The language used by the man in Gleibs et al's (2011) study (i.e. 'team') may denote something of his relationship to a masculine identity associated with sports and the kinds of environments where men usually socialise with other men. The men engaged in the walking football project stated they were drawn to taking part because of its association with the respected football club (Carone et al, 2016).

Gliebs et al's (2011) state that enabling shared gender experiences through the 'gentlemen's clubs' act to counter feelings of marginalisation that men may experience in care organisations due to a feminisation of life in care (Gliebs et al, 2011). This study suggests that institutionalised care can have a devastating impact on masculine identity because it does

not fit cultural concepts of a 'hegemonic masculinity' which emphasises independence, power and control. This also holds resonance in the narrative of Mr Rijder's experience because of the oppression he felt from the hierarchies of the medical institution who asserted control over his independence (Chatterji, 1998) and the isolation felt by Mr Brown in the care home where he lived (Bartlett, 2007).

In the 'Men in Sheds' project there was what might be thought of as a hierarchy amongst the men (Milligan et al, 2015). The men who used the programme with cognitive impairment or physical impairments were less engaged with its social aspects. One man living with dementia reiterated throughout his interview that he did not join in or engage with the other men using the facility. Some of the men without a disability inferred they felt 'uncomfortable' if a co-ordinator was absent because they did not want the responsibility of anyone who had support needs, and this was expressed as a health and safety issue. One man stated:

> 'I think people should be … reasonably fit and active to come here … it's for reasonably fit people and reasonably mentally fit as well. That's my view' (Milligan et al, 2015, p17).

This indicated that though some men experienced a sense of release from the pressures of performing to masculine expectations (with regards to their productivity or achievements) there was still a standard against which the men were measuring one another. This was not something that the men in the GOOTH programme referred to. This might be because not only were they all men, but they also shared the experience of having Young-onset dementia (Kinney, Kart and Reddecliff, 2011). Thus, it might be argued that engaging with a theoretical perspective, such as that outlined by Hulko (2009) who argues for an 'holistic' model to explore the various intersecting and interlocking privileges and oppressions that each individual possesses due to their relative and changing social positioning, might be an insightful way to understand the complexity of experiences within these social groupings. The study by Kinney, Kart and Reddecliff (2011) had not employed this 'micro-level sociological concept' at a theoretical level (Hulko, 2009, p133).

(3) gender and care relationships

The final sub-theme in this section is about relationships with professionals such as domiciliary care workers, care workers other staff and other residents in residential and nursing care, which also emerge as integral to everyday life for men living with dementia. There are some striking examples of gender relations manifesting during personal care in care settings. Kontos and Naglie (2007) gave an example of a man who would get upset when he had to be (un)dressed. In a focus group, a member of care staff stated he was a very private man. The 'problem' was solved by adding Velcro to his towels so that he could remain behind a towel when taking his underpants on and off. Archibald's (1998) work on sexuality stated that nakedness and close proximity of bodies in personal care may be related by the person living with dementia to a sexual encounter. She argued that it may be confusing for a person living with dementia when being supported in this way and could lead to them 'acting out' with sexual expression, such as sexual touching of themselves or the staff member (Archibald, 1998). There are clearly issues of privacy and dignity that manifest in the relationship between care worker and resident and these may be exacerbated by the issue of gender in many circumstances.

In Bartlett's (2007) work, there are examples of Mr Brown's use of humour to cope with the embarrassment of bath-time. These issues of gender relations are pertinent when exploring sexuality of people living with dementia within care organisations. Men and women were often reported as being treated differently regarding sexual behaviour or expression. Men who masturbated in public were likely to be reported for medical attention to regulate their behaviour, whereas female sexuality, even when the female had capacity, was policed and regulated by reporting to families (Archibald, 1998). Generally, the lack of consideration given to sexual expression and sexuality might be related to perceptions that sexuality is of less importance to older people in general and of even less importance to people living with dementia (Ward et al, 2005). Ward et al (2005) stated that sexual orientation is not an explicit part of the assessment or care planning process and becomes noted as visible when it is perceived as a problem (Ward et al, 2005; Archibald, 2003, 1998). Yet sexuality is a key aspect of a person's identity and therefore implicit when supporting personhood in people living with dementia. More consideration needs to be given to these experiences because sexual expression and intimacy was clearly still of importance to people living with dementia residing in care organisations who were seeking out others to be close to (Kinney, Kart and

Reddecliffe, 2011; Ward et al, 2005; Pearce, Clare and Pistrang, 2002; Archibald 1998, 2003).

In Capstick and Clegg's (2013) paper, the men in their study reflected on what it was to be young men with burgeoning sexualities; notably one man shared a narrative about how he had kept hidden his sexuality due to his homosexuality. In another study, there is a description of the impact on a relationship with a key worker relationship being tainted because the man who was living with dementia made a sexual advance to his male key worker (Archibald, 2003). The key worker found the approach difficult and felt unable to discuss it with colleagues due to his embarrassment (Archibald, 2003). The lack of open discussion around sexuality, sexual behaviours, sexual expression and the lack of acknowledgement of lesbian, gay and bi-sexuality meant that it was very difficult to bring different perspectives to the fore (Ward et al, 2005). It appeared that same-sex sexual expression, or relationships in dementia care organisations, are rarely noted. It is suggested that this is because they are either not noticed due to the dominant culture of the heteronormative care environment, or they are not perceived positively and are ignored (Ward et al, 2005; Archibald 1998). The participants in Barrett et al's (2015) study, who were in same sex relationships, suggested that it was difficult to be themselves and to be freely affectionate with their partners within care environments because they were nervous about the reactions of staff. One gay couple expressed concern, even within their own home, when the care workers attended to support them. The participants did not give specific examples of discrimination but were affected by an overwhelming atmosphere of heteronormative environments and hence the fear of prejudice.

The complexity of gender relations in care organisations appeared highly charged in examples relating to sexuality. Although when addressed, such as with the man who needed more privacy for personal care interactions, it led to more harmony within the relationship. Few of the papers in this review have looked in detail at the complexity of the relationships between men in care and the carers looking after them. In the study by Bartlett (2007) where the focus is on gender, bath-time is noted as a time where Mr Brown has to manage the experience of being bathed by female workers. There is no detailed interrogation of the complexity of this issue in relation to Mr Brown or the staff. This further highlights the need for more gendered analysis of everyday life in care to enable better understandings to be

developed that can, in turn, enhance care practice as in the case of the participant in Kontos' and Naglie's (2007) practice development evaluation.

Kontos and Grigonovich's (2018) paper on musicality in people living with dementia draws on data from Kontos' previous ethnographic field work within a residential care setting. Abe is described as 'feared' by most other residents, because he is loud, has outbursts, and is prone to behaviour such as flinging his cutlery across the dining table. He appears resistant to routine care tasks within the facility. Abe is included in the study due to his particular musicality; he is often heard singing a traditional Yiddish song, which encouraged other residents join in or to orchestrate his singing which would embolden him to sing louder. The work by Kontos and Grigonovich (2018) uses the notion of relational citizenship and embodiment to explore the experience of musicality in the everyday lives of people living with dementia. In the example of Abe, his musicality flourishes when he connects with other residents who encouraged him to sing more. There was an opportunity for the work to discuss further the gendered experience of Abe in care, and how he is positioned as 'feared', a powerful emotion linking him to particular perceptions of men living with dementia in care as challenging or problematic, similar to Leonard in the study by Koehn, Kozak and Drance (2012).

2.6.2 Theme 3. Bodies.

Many of the papers reviewed referred to the bodily experiences of men living with dementia, including papers which do not appear to have a particular bodily focus. This theme explores some of the ways that the men experience everyday life through and with their bodies and the relationship this has to gendered experiences. There are two sub-themes, i) embodied selfhood; and ii) resistant bodies;

(1) embodied selfhood

Work by Capstick and Clegg (2013) described how narratives of war for the participants became supressed because of cultural expectations to maintain a 'stiff upper lip'. This highly gendered behaviour demanded men to uphold order and show no weaknesses. The memories since described by these men showed how an embodied and sensory connection to their past could be found in their narrative descriptions such as smells and sounds that represented poverty and war. The men shared stories for a collection of oral histories designed to gather

the narratives of people living with dementia (see The Trebus Project: http://trebusprojects.org/; accessed 1st March 2019). The paper argued that the men's story telling became more open because of the disinhibition they experience now they are living with dementia. Capstick and Clegg (2013) argue that the cultural conventions and filters from their previous lives had fallen away. The stories they told showed how deeply embodied and sensory their experiences were as they provided bodily narratives of their lives in this period. Despite the cultural conventions that led the men to supress these memories, they existed deeply within them and were connected to a firmly rooted sense of embodied self that was influenced by its social and cultural place in history. In the paper, Capstick and Clegg (2013) referred to Caruth's (1996) term 'the wound that speaks' - it is almost as if the memories which existed within the bodies of the men are now seeping out reflecting valuable aspects of the men's embodied lives.

The desire to maintain social etiquette revealed aspects of embodied lives in Kontos and Naglie's (2007) study. This could also be seen in the study by Chatterji (1998) in the maintenance of appearance, or awareness of appearance of disarray for Mr Rijder's. Maintaining a sense of self through appearance signified well-being and continued control over one's identity. Bartlett's (2007) study referenced how Mr Brown was 'fussy' about having a shave every day. Other participants were concerned with social norms and their presentation, and worried about a self that illustrated the notion of 'disruption to the habitual body' (as described in Chapter 1 in relation to the work by Phinney and Chesla, 2003). These experiences of embodied selfhood are linked to gendered experience by Ward, Campbell and Keady (2014) who gathered 'appearance biographies' of study participants. Here, Vic described how his appearance and presentation of self was linked to standards of appearance that developed from childhood and linked to respectability and being of good standing. The appearance standards for Vic were connected to his gender and class where men were expected to be smart, wear a shirt and tie, keep their hair short and always be clean-shaven. In the interview, Vic's wife joked about how Vic, even now, wears a shirt and tie on the beach. As Vic talked about shaving, and his memories of learning to shave from his father, he rubbed his chin, showing how being clean shaven was as much a bodily feeling as a visual aspect of his appearance. Buse and Twigg (2016, 2015) also linked class and gender to appearance and dress, describing how the middle-class men in their study remembered wearing suits to work, with one participant describing the experience of wearing a suit as

'just felt right' (2015, p10). However, this bodily connection to gender and selfhood could become disrupted, as despite the desire to be smart, the men in this study could no longer easily manage fastenings or laces.

In other studies gender is also associated with embodied experiences. In work by Chisholm and Bischoping (2018) and Herron and Rosenberg (2017) identity is embodied through the experience of being a farmer. Alexander is described in ways that suggest his identity is deeply rooted in his bodily experience of being a farmer and in connection to the land. The identities of men in these studies as 'working men' were often described in embodied ways. Tolhust and Weicht's (2017) work discusses competence in relation to gender. The value of feeling competent was embodied within identities as in the description of working competence given by David, who described being able to hit a nail 'dead-on', a bodily display of his identity. Similarly, the men in the walking football study valued the activity because of its physicality and the opportunity to use and display skills (Carone et al, 2016). The paper does not then link this to gender and it would be useful to consider the experience of these men through a framework of embodied and gendered selfhood.

(2) Resistant bodies

All papers in the review present evidence of how bodies in dementia care are policed and regulated; this is particularly evident in the studies concerning sexuality, but also is evidenced through the prevalence of locked doors in care homes. This is referred to by Mr Brown in Bartlett's (2007) study as he was greatly aware that he was being kept inside the care facility. Amongst those still living at home, men often felt that they were 'under surveillance' for what they were able, or not able, to do. One man in Hulko's (2009) study feared the manager of his social housing for older people would make him move out if she knew that he was having difficulties living on his own. People also experienced loss and 'downgrading' of expectation when they were no longer able to carry out role they once did. The men in Pearce, Clare and Pistrang's (2002) study referred to a need to change their own expectations of themselves; however, this was difficult as wives and partners sometimes also struggled to accept the loss of their partner's previous abilities. Response to the bodily control, regulation and loss is also evidenced through how the men were either resisting or re-visioning their identities. I have called this 'resistant bodies' which chimes with the images presented by Kontos and Naglie (2007) of participants continuing to use their bodies to

intentionally communicate and present aspects of themselves to others. This is resonant in the work by Kontos and Grigonovich (2018) through Abe's resistance to the quiet and stillness of the care facility and his resistance manifests through his insistent musicality and other bodily outbursts.

Ward et al's (2005) work on sexuality showed how residents found spaces in care settings to enable them to be intimate despite the institutional culture of surveillance that sought to prevent sexualised behaviours between residents. Study participants managed to create opportunities to hold hands or sit together touching and resting against each other (Ward et al, 2005). In Chatterji's (1998) study, Mr Rijder's attempt to escape from the constraints of the institution can be seen as bodily resistance. He climbed onto the roof from a first-floor window and was eventually carried off the roof after no amount of coaxing could persuade him to return willingly. This incident is later labelled by the institution as an 'attempted suicide' although it appears more likely an attempt to escape from the care setting where he did not want to stay and did not understand. After this form of bodily resistance failed for Mr Rijder, he found other bodily ways to resist through not eating and refusing to go to bed.

These resistant bodies reveal intentionality and agency and demonstrate an experience of living with dementia that shows a sense of resilience, even against the odds, rather than one of only loss.

2.6.3 Theme 4. Place, Space and Atmosphere

The varied settings for the research meant participants had different experiences of place and space. This theme is developed further in the next chapter but drawing on the reviewed literature, four sub-themes emerged: i) gendered spaces; ii) creating spaces; iii) embodied place; and iv) atmosphere.

(1) gendered spaces

The idea of 'gendered space' emerged across different settings. The wives of the men in the GOOTH study described them as going out of the house much less often and thus valued the programmes offer to 'get out of the house'(Kinney, Kart and Reddecliff, 2011). The 'Men in Sheds' study was about creating literal spaces for men to perform 'manly' activities (Milligan

et al, 2015, p4). The men at walking football relished the opportunity for a 'dementia-free zone' and to take part in sport and exercise - alongside other men (Carone et al, 2016).

In Hulko's (2009) work, 'Gus Holden' is described as trying to maintain traditional gender roles within his household. This maintenance of domestic roles was associated with his occupational role as a university administrator: there was a sense that he tried to establish or maintain his sense of self in the home environment (Hulko, 2009, p140). The link between masculinity and the public sphere may be significant for the men in this review who were becoming less independent and less able to go out or had lost their 'identity as working men'. Buse and Twigg's (2016, 2015) study showed men creating space that upheld this identity within their home environments maintaining clothes from their working lives within their wardrobes. A number of the studies considered the impact of gender and space in their work (Buse and Twigg, 2016, 2015; Milligan et al, 2015; Hulko, 2009). Taken together as a whole, these studies (Buse and Twigg, 2016, 2015; Carone et al, 2016; Milligan et al, 2015; Kinney, Kart and Reddecliff, 2011; Hulko, 2009) suggest that the changing opportunities of place and space can be related to the 'identity of working man' and the public sphere, which links to the expectation of a hegemonic masculinity to be productive and 'out in the world'.

In Bartlett's (2007) case study, Mr Brown describes memories of going to the pub, an outing that he no longer made. Mr Brown felt excluded from the world outside and he felt unable to relate to many people and appeared socially and emotionally excluded (Bartlett 2007). In Herron and Rosenberg's (2017) work, the men in the study described not feeling comfortable within dementia support groups because they were 'emasculating'; as an illustration, Sam stated 'Yah if I could take my chainsaw in and carve out some figurines, or something or the axe but not, you know, not writing poetry or something' (p85). The men in Phinney, Dahike and Purves's (2013) study had become more home based and less able to continue their community roles despite their families encouragement and support to help them retain their public identities. In the study by Cedervall and Åberg (2010), the two male participants, one of whom was described as an 'outdoor' type and the other who had done 'outdoor' activities intermittently during his life before the onset of dementia, described trying to maintain outdoor activities. Cedervall and Åberg (2010) do not explore these as gendered experiences despite the study specifically choosing to look at these men's experiences.

(2) creating spaces

Care organisations often had more female than male residents. Along with a predominance of female workers, the sense of being 'other' in the care home was difficult for the men. This was specifically mentioned in Gleibs et al's (2011) study when one man noted that he seemed to be the only man in the dining hall and the women all sat together leaving him 'on his own' (p462). The gendered groups set up in a care setting in Gleib's et al's (2011) study showed the value of creating gendered space, particularly for the men involved. For example, Mr Brown and Mr Rijder both felt that they had been shut away or abandoned and there were visceral descriptions of long corridors: 'All the twisting and twirling round the corners…it is the corners for me…' that cause the participant to become lost and disorientated (Bartlett 2007, p21). However, spending time outside of lounge areas may also be perceived as another form of resistance as the men in these two studies escaped from the over-feminised spaces of the lounge areas.

The men tried to create space for themselves at home, including the man in Pearce, Clare and Pistrang's (2002) study who had created a new role for himself at home, which was washing the dishes. In Tolhurst and Weicht's (2017) work, the men described their 'social contributions', such as Simon's leadership role supporting others at his walking group and Tim maintaining his gym membership. These examples show the men continuing to create space for themselves within the public sphere. An important aspect of being a 'Goother' in Kinney, Kart and Reddecliff's (2011) study was about the contribution they were continuing to make through the project in this case to zoo maintenance, as part of a group. Considering these findings in relation to how the men shaped and negotiated space for themselves is a useful way to consider gender, place and everyday life.

For the men in Barrett et al's (2015) study exploring Lesbian, Gay, Bi-sexual and Trans experiences of living with dementia, there was the need to find and create safe spaces within the heteronormative care environments they found themselves in. This meant either creating space to be with their partners or finding ways to maintain relationships with their friendship groups in order to be able to be themselves. This was reported to be difficult, and like Mr Brown who struggled with the feminised space of the care home, Jeremy described feeling cut off from the gay networks that had been so important to him throughout his life. Richard stated that when attending dementia support groups he had 'felt like a fish out of water' (p37)

because these groups were focused on heterosexual couples. It was not always possible or easy to create space, and these experiences show the importance of ensuring diversity is considered in care environments.

(3) embodied place

The experience of place was deeply embodied for some of the men in these studies. For example, Alexander, in the study by Chisholm and Bischoping (2018), was deeply connected to the land and his Scottish heritage. He was a farmer and came from generations of farmers who came to Canada to work the land. One of his daughters stated 'if you want to know who Papa is, look all around you. He is this place' (p13). This sense of connection to place was also deeply gendered; Alexander was the patriarch in his family and his wife and children wished to uphold his identity despite the challenges he was now facing due to his dementia. The family understood the importance of maintaining Alexander's connection to the land, because connection to and knowledge of local geography gave status. Similarly, in the work by Herron and Rosenberg (2017), the rural landscape was integral to the participant's identities; they took pleasure in the rural landscape and in continuing to 'work' on the land, such as Sam continuing to chainsaw wood for the wood store. Rurality went hand in hand with independence and being able to do things for oneself, which is also often associated with a hegemonic masculinity.

(4) atmosphere

Atmosphere emerged as the fourth sub-theme. In the study by Milligan et al (2015) the men described the atmosphere of the 'Men's Sheds' as not really a place for women. The atmosphere is gendered through their description of it filled with the 'roughness of banter, and language' (p143). This notion might also apply to the 'GOOTH' programme and have played a part in why an attempt to integrate a woman into the all-male group failed; she may have felt excluded from the male atmosphere (Kinney, Kart and Reddecliff, 2011). Conversely, Mr Brown in Bartlett's (2007) study experienced the opposite when he was unable to adjust to the feminised atmosphere of his care setting.

In Koehn, Kozak and Drance's (2012) study of Leonard , a man with frontal-temporal dementia, staff had suggested creating a more 'homely atmosphere' in the communal living area might encourage Leonard to behave in more appropriate ways (i.e. not taking

possessions to hoard). However, staff also appeared to blame Leonard for the lack of the homely atmosphere when they needed to keep rooms locked to prevent him from taking other people's possessions. There was the conception by staff that atmosphere was something that could be controlled and created, for example the home's refurbishment was felt to have created a 'homely atmosphere'. However they also appear to suggest that the atmosphere had been disrupted by the unruly behaviour of Leonard, a man perceived as problematic by staff and some residents.

The notion of atmosphere is not mentioned explicitly in other studies, although it is alluded to; for example, in the study exploring everyday life for Alexander, a feeling of atmosphere emanates from the social construction of land (Chisholm and Bischoping, 2018). The descriptions of heritage that linked Alexander to six generations of Scottish farmers created a sense of atmosphere of place, and the embodied experience of place feeds into such a feeling. This is also something that emerged from consideration of the market-place where Alexander's wife sold produce, and where Alexander in the past had performed a key role. Now the market is a place where Alexander appeared to be excluded and out of place in the hustle and bustle of market life. The study provided an in-depth analysis of how the experience of living with dementia intersected with other aspects of Alexander's identity, and how the experience of place, and I suggest atmosphere, might play a pivotal role.

2.7 Summary

This review has found a number of cross-cutting themes from empirical research exploring the everyday experiences of men living with dementia. These themes highlight important aspects of everyday life that could be relevant for new research. There is more to be understood about the experience of identity, embodiment, relationships along with connections to place, space and atmosphere in the lives of men living with dementia. Dementia is a diverse experience that will be experienced differently because of social and cultural influences. This review has sought to unpack the experiences of men living with dementia to reveal how gender plays a role in adapting to a dementia diagnosis and finding new ways to create a social identity and to managing a sense of place, whether this be living at home or within care organisations. The review also shows there is a need for further gendered analysis of the experience of living with dementia. Gender is an important aspect of

identity and has considerable influence on the experience of dementia; yet, to date, issues of gender and identity have been a neglected area in research.

Some of the environments within the review suggest that male banter in these kinds of environments might create atmospheres that are not suitable for women (Milligan et al, 2015). The Gooth programme researchers did not explore the gendered context that had emerged, contributing to a homogenised viewpoint of the men in the study. As I have identified there is a need to explore more diverse experiences, and to consider the social identities and differences between men and different masculinities of study participants. Studies that brought a gendered analysis to their work, have been vital in supporting the development of this doctorial study. For example the revelations of Chisholm and Bischoping (2018); Tolhurst and Weicht (2017); Hulko (2009); and Bartlett (2007) about how the experience of gender plays out in everyday life for men living with dementia and the links made to other aspects of their participants lives has provided a more nuanced and multi-faceted approach to understanding men's experiences. Further consideration also needs to be given to considerations of place, and atmosphere, regarding how responsive services are and how those using them feel and asking whether or not they create inclusive atmospheres.

An important finding from this narrative literature review relates to the growing discourse in dementia research around embodiment. The paper by Capstick and Clegg (2013) touched on how masculine expectations are passed on from father to son throughout generations, but how at least two of the men in this study had fathers that did not measure up to 'hegemonic' standards of masculinity perhaps reinforcing the men's needs themselves to meet this ideal in the face of fathers that failed them (Capstick and Clegg, 2013). This reinforced the notion of 'habitus' and how cultural and societal practices are reinforced throughout lives through the lived experience of family, social rituals and practice (Bourdieu, 1990). This was also resonant in the work by Ward, Campbell and Keady (2014) as Vic described learning appearance standards and how to shave from his father. Embodied experiences can also be perceived to show links between a person and place and show that being deeply connected to a place can be entwined with experiences of gendered selfhood (Chisholm and Bischoping, 2018; Herron and Rosenberg, 2017).

Finally this review has identified the need to understand dementia as a more complex experience than only one of loss and decline. There were many instances where the men renegotiated or adapted their expectations of themselves. The men show a continued sense of agency and desire to engage in new relationships and fulfil themselves in new environments (Capstick and Clegg 2013; Gleibs et al, 2011; Kinney, Kart and Reddecliff, 2011; Koehn, Kozak and Drance, 2012; Kontos & Nagile 2007; Ward et al, 2005; Chatterji 1998). Therefore, understanding experience in a more nuanced and dynamic way as promoted by exploring the inter-corporeal nature of personhood within relationships between people living with dementia and their partners, families and within care organisations might lead to an understanding of dementia that brings about change in how people are perceived and supported in their everyday lives. In particular few of the studies explored the experience of collective care environments, thus highlighting the need for more understanding of these places. Using methodologies that enable multi-sensory, embodied and critical explorations of everyday life that can support these more nuanced readings for men living with dementia.

This review offered the opportunity to consider where there are gaps in dementia studies in relation to the experience of men living with dementia. Taking forward a gendered analysis alongside an embodied framework would take into account the inter-relations of care organisations and how expectations and cultural interpretations of men with dementia impact on how they are treated in care, and also how their behaviours are experienced. It seems vital to expand our understanding of personhood and the experience of dementia as embodied, sensory and multi-faceted when developing existing models of person-centred care. It is also important to explore issues of space, place and atmosphere in order to create more holistic understanding of the experience of living as a man with dementia. Grounded in empirical studies, this narrative review highlights ways that the doctoral study exploring everyday embodied life for men living with dementia in care organisations could provide valuable insights about men's experiences that have to date not been fully acknowledged.

Chapter 3 Methodology and Orientations: A journey into Atmosphere

3.1 Introduction

In the last two chapters I have discussed the context for the work, along with the current thinking in dementia studies and its literature, with relation to the everyday lives of men living with dementia. My intention in this chapter is to set out more of the critical thinking that has underpinned this study. I will explore the challenges in orientating myself and the journey that I have taken to create this study out of the wider project 'The Hair and Care Project'. I will discuss where I began my research travels and I will begin by introducing the theoretical perspectives that have shaped the work. This work is inter-disciplinary and thus a range of concepts and theory have been used in order to explain the data generated. The second part of this chapter will explore the ethnographic methodology that I used to undertake this work, thereby putting these ontological and epistemological perspectives into practice.

3.2 Research Aim and Objectives

The research question informing this study is:
What role does place play and what role does gender have in the lives of men living with dementia in a variety of care settings?

The primary research aim is to interpret the everyday embodied life for men living with dementia in care and its connection to atmosphere (this term will be discussed later in this chapter on p78).

The study is supported by the following objectives:

- To provide an enhanced understanding about the experience of gender for men living with dementia

- To interpret the everyday experiences of men living with dementia in care organisations
- To explore the types of relationships that the men experience in care, using creative social research methods
- To describe staff approaches to care and the everyday care environment

Within dementia studies there are a number of commentators engaging with theories from outside of the field, developing new theories to understand the experience of living with dementia. Thus, in moving on from the discourses in dementia studies that have been influential for this work, this chapter will provide an explanation about the key concepts being used and will demonstrate my understanding of these concepts with specific reference to my work. In so doing, first I will consider understandings of gender that draws on the work already discussed in Chapters 1 and 2. I will engage further with the issue of gender and examine how other theorists have extended thinking in this area. I will discuss the importance of taking a gendered lens to this work, throughout the fieldwork and analysis. I will consider insights from other key theories and concepts for this study that provide understandings for: normativity, embodiment, everyday life, place, atmosphere and affect. In the second part of the chapter I will explain how these theories have led to the methodological approach for the study to underpin the research aim and objectives.

3.3 Key Concepts: Gender and Dementia

As presented in Chapter 1 there is still a significantly lower population of men with a diagnosis of dementia (39%) and care home statistics in the UK show that around only 25% of care home residents are men (Office of Fair Trading, Annexe K 2005). Alongside the majority population of female residents, there are also significantly higher numbers of women working in these care organisations (around 80%) and therefore gender relations contribute to the experience of daily life in these care organisations (Cohen and Wolkowitz, 2018; Skills for Care, 2018; Twigg, 2000; Archibald, 1998). Despite this, within dementia research there is still, at present, scant consideration given to discussions around gender, even though there is long-standing recognition that gender is central to self and identity throughout the course of life (Bartlett et al, 2016; Arber and Ginn, 1995). Dementia studies has tended to centre on the person, and recent work by Bartlett et al (2016) has found that gender is most

often discussed and analysed in dementia research in relation to care-giving, rather than to the subjective experience of dementia itself. Even within psycho-social reviews of the literature on dementia, concepts of identity and social difference have been largely overlooked (Innes, Archibald and Murphy, 2004; Downs, 1997).

A decade ago, Hulko (2009) argued that even when difference is identified in dementia, the research data is often lacking in a sociological analysis of the power relations at work within these spheres. More recently, Sandberg (2018) developed this position and stated that when there is a re-gendering of people living with dementia, it is usually within normative understandings. She states that there is rarely consideration given to how gender may be disrupted or subverted. Where it does occur, such as in the work of Capstick and Clegg (2013) seen in chapter 2, the experience of living with dementia has seemingly enabled the men a disinhibition that frees them from the constraints of hegemonic masculinity. Commentators such as Ward et al (2005) and Hulko (2009) have argued that identity constructs such as race, class, gender and ethnicity significantly shape the experience of dementia. It becomes important that these intersections of social difference are taken into account when exploring the everyday experiences of living with dementia. As already noted in Chapter 1, work by Ward and Price (2016) calls for a critical and radical rethinking of dementia, one which allows space for different bodies and different experiences to be visible and understood. Sandberg (2018) also calls for more research to be done to explore the dynamics of gender and dementia, and states that researchers need to be wary of re-gendering people living with dementia through a normative lens that does not give attention to where gender may be performed in subverted or disrupted ways. A position I will now develop further.

3.3.1 Taking 'a gendered lens'

Within the literature explored in Chapter 2, not all the studies exploring the everyday experiences of men living with gender brought a gendered lens to their analysis. Yet, as has been argued, by using a gender-focused model, crucial insights are gained into the lives of men living with dementia. Gender is often understood as a socially constructed aspect of identity that shapes experience (Arber and Ginn, 1995) and, as such, it is not a static component of a person's identity but one which changes and is influenced by experiences throughout the life-course (Bradley, 2007). Sociological thinking that informs understandings

of gender have argued against an 'essentialist' model, which is to say against a biological determinist rationale that suggests there are two binary opposites of male/female and as such each has certain 'naturalistic' bents (Applerouth and Desfor Edles, 2011). Therefore, understanding gender as a category of identity which will change and evolve and which is influenced by different modalities of society and culture is important in this study.

Understandings of gender were significantly advanced through Judith Butler's writings, which enabled gender to be understood through her concept of 'performativity' which provided a dynamic analysis with regard to how individuals 'do' and 'become' gendered (Green and Featherstone, 2014). Butler (1990) contends that 'man' and 'woman' are constructions and that gendered subjectivity is always fluid and in flux (Butler, 1990). She extended the concept of 'performativity' (Austin, Urmson and Warnock, 1979) and applied it to gender arguing gender is something that individuals 'do' through repetition and ritual actions of everyday life. Crucially, for my study, gender in this sense is also temporal and situational, i.e., it is performed differently in different periods of life and in different locations (Butler, 1990). In addition, the social ritual of gender will be influenced by other societal norms. So, for Butler (1988), performativity is not simply how an individual performs their gender, but also how bodies become gendered through the relational reproduction of gendered norms.

3.3.2 Masculinities

Masculinity is an integral concept to this study because of its association with men and their bodies, although crucially, this is not to say that only men perform masculinity. Men's bodies and embodiment are important to this study, as the men living with dementia find themselves in settings where their bodies are notable, managed and cared for under the jurisdiction of care agencies. Their bodies in particular are key to relationships and how they experience everyday life. In order to set out my understandings of masculinity, I turn first to consider Connell's (1995) seminal work on masculinity in order to think about ways in which gender is constructed through interactions between people and, as such, is relational and dynamic in character. Connell (1995) describes a dominant masculinity that is related to the principal cultural expectations of men. This she calls a 'hegemonic masculinity' and it is most often linked to 'doing' and 'performance' - not as in the 'performativity' of Butler (1990), but as the pervading dominant expectations of men, to be active, productive and independent

(Calasanti and Slevin, 2001; Connell, 1995). This dominant masculinity is a version of what it is to be male that focuses on strength, power, rational thought and action. Connell (1995) argues that 'true masculinity is almost always thought to proceed from men's bodies' (p45) and so masculinity itself is unavoidably connected to male bodies in which the dominant, 'hegemonic masculinity' is considered as white, youthful, heterosexual, strong, fit, active and productive.

In this dominant hegemonic masculine ideal, male bodies have most often been associated with the 'rational public sphere' (Twigg, 2004, p68) and the public sphere is perceived as the space where males 'become men' (Whitehead and Barrett, 2001, p141). Connell (1995) argues there are many masculinities, but one is always considered dominant. 'Hegemonic masculinity' then becomes the standard by which all other male bodies and masculinities are measured (Robertson, 2006). These masculinities are always in flux and are influenced by the cultural and social norms of the time (Applerouth and Desfor Edles, 2011). They are affected by social class, sexual orientation, race and other categories associated with identity. It is therefore useful to understand these experiences through the intersections of cultural and social influences on lives (Dasgupta, 2000).

Arguably, the notion of hegemonic masculinity might be somewhat outdated, as understandings of gender have enabled much more complex readings of what it is to be male (Whitehead, 1999). As Whitehead (1999) argues, it is, on a macro level, a kind of idealised notion of masculinity, and hence what it is to be male. Whilst there is still some relevance in acknowledging that there are normative expectations of gendered performativity, this is different to the notion of hegemonic masculinity. Whitehead (1999) states that hegemonic masculinity as a discourse becomes problematic as it does not allow for the many varied experiences of masculinity. There are arguments that hegemonic masculinity as a concept does not recognise the 'complex patterns of inculcation and resistance which constitute everyday social interaction' (Whitehead 1999, p58). In this study, masculinity will be explored in the context of the men's everyday embodied lives within the care organisations, and through the relationships that are developed there.

3.3.3 Gender, Long-term care and Intersectionality

This study focuses on the gendered relations and gendered spaces of the care organisations where the men are living. Another key focus is on how the experience of gender is understood by the staff working in these care organisations. Gender dynamics are highly pertinent in dementia care contexts because of the demographics of care, as already described. Gender is shaped by power dynamics and this is particularly so within care organisations (Armstrong and Braedley, 2013). A problem that occurs in care organisations is in relation to the binary and normative understandings of gender which continue to be pervasive within the everyday culture and language of the care organisations (Ward et al, 2005). By way of a response, Armstrong and Braedley (2013) suggest that an intersectional approach is an important mode for considering gender and care 'because gender relations are dominant in shaping who needs care and who provides it' (p59). They suggest that care organisations are shaped by gender relations beyond the everyday spaces where care takes place, by policies and practices, as well as where and how care takes place (Armstrong and Braedley, 2013). The authors call for an intersectional analysis of long-term care in order to consider gender, ageing, disability and dementia within institutional structures of power.

An intersectional approach understands human experience as the intersection of aspects of social identity (such as race, ethnicity, sexuality, class and gender) and social location (Hulko, 2009). Advocates of intersectionality theory argue that there is a need to explore the intersections of identity to understand the complexities of everyday experience (O'Connor, Phinney and Hulko, 2010; Hulko, 2009; Ward et al, 2005; Archibald 1998, 2003). This is aptly presented in dementia studies by O'Connor, Phinney and Hulko (2010) who set out to explore the experience of an aboriginal Canadian woman and her everyday experience of living with dementia. The paper presents the importance of understanding cultural difference as a crucial factor in the experience of dementia. The research presents a narrative of dementia experienced by someone from a first nation culture in Canada who understood dementia in terms of a spiritual awakening, which opened up opportunities for creative expression. However, despite the more positive understanding of dementia by the woman in the study, her experiences were also influenced by a range of other factors that negatively impacted on her interactions with others and her requirements for support. These other factors included her sexuality, gender and class (O'Connor, Phinney and Hulko, 2010). The advocates that support a framework of analysis using intersectionality theory suggest that

there is significant value in recognising the impact of social difference and the power dynamics at play in people's lives (O'Connor, Phinney and Hulko, 2010; Hulko 2009). However, there are important critiques of intersectionality which argue that it has become 'both over - and under used' (Carastathis, 2014, p305), that is to say, it has become pervasive across social theory and yet it is arguably used in an under-theorised way.

There are a number of relevant issues in relation to intersectional approaches. Those noted by Carastathis (2014) are that the complexity of experience in everyday life is such that understanding where and how oppression occurs is not always possible. Secondly, that the level at which intersectional theory operates is difficult to understand if it is at macro, meso or micro level of interpretation, and there is disagreement between theorists in relation to this. The third critique is that these notions of identity can lead to thinking in fixed and normative ways about identity. This fails to recognise the fluidity of person, identity and experience.

For this work, then, understanding intersectional approaches has been important in terms of considering how gender and dementia have been constructed within institutions. For example, gender and the complex power dynamics of care organisations have been important, in terms of how space is organised and experienced, how the female workers may view male bodies, and with regards to the men's experience of living with dementia, how this intersects with their experience of gender and other aspects of identity. For the men in the PhD study, there are particular issues relating to the limitations of their autonomy due to their situation in care and the impact this has on their selfhood.

3.4 Normativity

I use the term normativity in this study to refer to desired standards or the dominant expectation. Normativity is a cultural concept which refers to a standard that is expected and can be associated with aspects of identity such as gender and sexuality or with structural aspects of society such as institutions. Crip and queer theorists such as Ward and Price (2016) and Shildrick (2005), as mentioned in Chapter 1, illustrate how the dominant point of focus is always on able-bodied, heterosexual, white men (and women) and yet there are diverse experiences of bodies (Shildrick, 2006). Importantly, Shildrick (2005) notes that there is a 'taken-for-grantedness' of able-bodies, and as such biomedical science has been let off from

any kind of deconstruction of its ideas and values. Ward and Price (2016) and Sandberg (2008) argue that normative ideals create able-minded standards and normative standards of ageing.

The concept of normativity is also often used in relation to gender and sexuality and relates to the dominant focus on the 'heterosexual matrix' as the desired standard, and its pervasive presence in everyday life (Butler, 1990). Ahmed's (2006) work on queer phenomenology argues that we are all orientated in space toward particular objects and there is a straight line that we are supposed to follow, and if we are 'out of line' that means that we have veered off from the expected course. For Ahmed (2007), bodies that are 'in line' take up more space, their bodies are 'at home' (p153). This is particularly pertinent theorising for this PhD work, as normativity is pervasive within structures and institutions. This becomes an important concept for the study, due to the research focus on gendered embodied experiences of men living with dementia within health and social care institutions and in relation to their experience of place and how their bodies are orientated.

3.5 Everyday life

I will now offer a way to understand the term 'everyday life' which I began to define in the previous chapter exploring the literature relating to men living with dementia. Pink (2012) argues 'everyday life' is what anthropologists have always studied. She states that 'it is not a neglected domain of practice that needs to be brought to the fore or a category that needs to be defined' (Pink 2012, p7). She argues for a study of everyday life that attends to the 'practices of everyday' alongside the materiality of everyday and the spaces in which everyday life occurs (Pink, 2012, p29). Kathleen Stewart's (2007) work 'Ordinary Affects' takes a creative approach to its construction, weaving theoretical thought with storytelling, using accounts of everyday life composed in short vignettes. Her gaze is on the ordinary and the mundane, but she focuses on moments where there is a shift in the ordinary and where affect and atmosphere emerge. Her writing directs attention to these moments describing 'goosebumps' rising through someone's body, or a moment of connection when a look is shared between two people. She illuminates how it is in these small moments that important insights can be gained into the experience of living. It is this sense of the everyday that I am interested in, the routines and relationships of everyday life that are important for

understanding at a micro level the experience of everyday life in care organisations (Hughes et al, 2006; Nettleton and Watson, 1998).

For people living with dementia, where certain aspects of everyday living may become more difficult to take part in, or perform without support, it is vital to note how people are experiencing everyday life in a new stage of living, or in a new set of circumstances. In Kontos's (2003, 2004) work, as discussed in Chapter 1, there is a focus on the embodied and on pre-reflective processes and deeply embedded cultural performances of everyday life, and my work will also explore the embodied aspects of everyday life for the men living with dementia in this study.

3.6 Place, Space and Atmosphere

I will move now to consider the key concepts of place, space and atmosphere which inform my primary research question. Place, like space, is a complex term defined and redefined in geography as a continuously evolving concept. Here, I will discuss the meanings I have used in order to consider these concepts in relation to this PhD study. My own understanding of place is taken first from phenomenological geographical thinking which understands place in subjective terms. Place is understood not as a location but as a 'way of being in the world' (Cresswell 2004, p31). I am also drawn to a definition of place by Lippard (1997) as 'spatial, temporal, personal and political' (p7). She argues that place is about layers of experience, it is ever-changing and inter-linked with relationships that stretch from past to present and future. Beyond this, I consider a theory of place developed by Thrift (2008) arguing that place is related to the embodied practices that happen within it, and which are continually remaking it, so that place is never fully completed. I am also influenced by Massey (2005) who also agrees that place is without boundaries, and might be understood as an 'spatio-temporal event' (p130). As such, she is suggesting that place is open and is about movement, as bodies, objects and flows are its configuration (Cresswell, 2004). That is, place is created through the multiple histories and materialities that flow through it; it is made up of human and non-human elements. According to Massey (2005), place-making means individuals create an experience and connection of and to place, whilst Thrift (2008) suggests that the practices carried out there are what give the place its meaning. For Massey (2005) space and place are interdependent and suggests that we consider 'places not as points or as areas on

maps, but as integrations of space and time' (p130). She further argues that places are about 'collections of stories' and spaces are 'stories so far' (p131).

In the participating care organisations in this study, rooms perform as multi-purpose environments which become places through the everyday practices that occur in them, or through the 'spatio-temporal events' that occur, in an unending becoming. For example, when the tables are set for dinner, the 'space' performs as a dining room (for some). However, staff also use these same 'dining' tables as desks when they are writing care notes and it then becomes their office-space. In these ways, the room has not only multiple functions, but multiple meanings, and multiple stories. Meaning is given to these spaces by the practices that are carried out there, by the material objects that are there and by the sensory experiences that flow through it, but they are not fixed meanings. I draw from Massey (2005) here to understand space and spatiality as always being linked to time. For example, these spaces alter over time, but just as time is not linear, space is not a fixed container. She argues that space becomes constituted through both location and the flows through it, it is made through these relationships and inter-relationships and space is never complete (Massey, 2005). Space can have multiple meanings at any one time and what is experienced in that space may also flow out, continuing its effect beyond environmental boundaries. For example, the sounds of a distressed resident in a bathroom cannot be contained within the bathroom walls but can be heard drifting into and through corridors.

I will now move on to consider the related notion of atmosphere. Atmospheres emerge then in spaces and places. Atmospheres can direct bodies and are also created and produced through the bodies that are in spaces. In Johansson's (1996) work on gyms, he describes how certain bodies will feel out of place because of the kind of atmosphere that is created in part through the music that is played. Atmospheres then are created and produced through particular atmospherics, such as sound in the description of gym life. In Edensor's (2017) work on light and atmosphere, he considers how light might be used to 'stage' atmosphere, and how it adds hues and tones to the environment creating moods. According to Lupton (2017) the difference between space and place and atmosphere is in how they are felt and experienced through emotion and how they become affective atmospheres. However, for Mason (2018a), the term atmosphere requires further expansion: the term 'atmosphere', she suggests, is too fixed a notion, and 'atmospherics' suggests something more 'lively' in order

to illustrate they are always becoming. Further to this, she develops the notion of 'socio-atmospherics' (Mason, 2018a, p179). Mason (2018a) suggests that by arguing for a 'socio-atmospherics' it ensures atmospheres are not disassociated from the social, cultural and historical.

The work of Pink (2012) and Stewart (2007) is also relevant, in that it notes the significance of flows and energies that exist within spaces, leading to affective experience. Pink (2012) considers her work within a framework that is 'an ecology of interrelated practices, discourses, materiality and energies' (p70), while Stewart (2007) seeks to illuminate and illustrate the interconnection of the sensory, embodied and emotional that give rise to atmospheres as a 'force or frisson'. Stewart's (2015) work also references engagement in the imagination and memories of place and how these also constitute the experience of individuals and collectives. These works both note the significance of flows and energies that exist within spaces that lead to affective experience. Mason (2018a) also describes the powerful potency of the sensory and the connections between humans and non-humans that give rise to experiences of affinity, and, I would argue, create atmospheric affect. However, Mason's (2018a) point is that connections do not have to create affect to be potent. She uses the term 'potent' to conjure something of the power of affinities and connectivities.

Non-representational theory developed within human geography has been particularly interested in atmosphere. This work, led by Thrift (2008), suggests it is a 'geography of what happens' and writes 'roiling mass[es] of nerve volleys [which] prepare the body for action in such a way that intentions or decisions are made before the conscious self is even aware of them' (p7). Atmosphere is an outcome of 'what happens' within place and space and, for this study, within the care organisations which are 'made up of all kinds of things brought into relation with one another by many and various spaces through a continuous and largely involuntary process of encounter" (Thrift, 2008, p7). Atmospheres are sensory and embodied: they are physical, not as in a physical form, but they are felt. They can be subtle or highly charged and forceful. Hence, atmosphere as a concept and an analytical lens has the potential to bring together elements of multi-dimensional, inter-connected and multi-sensory experiences of everyday life in order for us to understand (at least for a moment) how it feels. Lupton (2017) has helpfully explored research within a health context using an affective atmospheres approach in the experience of digital health. This work notes how the embodied

and sensory experiences of humans both responds to, and contributes to the emergence of affective atmospheres, and, importantly, that affective atmospheres are shared across and between humans and non-humans (Lupton, 2017).

In this PhD study, I have also become interested in the in-betweenness of things in everyday life. I have been interested in what happens to the men during the day, in-between the everyday care tasks, in their in-between places, and in-between homes (for some). In Mason's (2018a) recent work she describes the value of in-betweenness, suggesting that affinities are not so much about the actual connection, but rather about what *creates* the connection, what is its potency? This may be in relation to the in-betweenness between people and, or, between people and objects or other living creatures. Mason's (2018a) work thus facilitates an understanding of atmosphere and atmospherics. This study has drawn attention to a neglected space of in-betweenness, where atmospheres lurk. This leads to a consideration of affect, and how it arises, although Mason (2018a) argues that a connection does not have to be affective in order to be potent.

3.7 Affect

In order to think about affect, I return to the work of Ahmed (2013, 2010a) which explores the embodied experience of emotion, and how emotion is felt and affects, and how feelings have a role in how people are orientated. Ahmed (2013) describes the ways in which feelings orientate people towards others or objects, and how some people will cause certain emotions to arise. She states that encounters are imbued with histories, and the encounter is not only in that individual moment, but holds the past too through how it brings to the fore previous encounters. She argues that feelings are then 'rehearsed associations', experiences that have been encountered previously and are known within a person's body (Ahmed, 2004, p39). As such, certain bodies will make other bodies feel a particular way because of particular cultural, social, personal, and political experiences of these bodies: 'emotional encounters are always mediated by the unconscious and bodily memories' (Laliberte´and Schur, 2016, p74). Ahmed (2004) describes affect as being within bodies, but also between them, in circulation and as something that 'sticks' to the other. For example, someone might enter a room, and their entrance creates a ripple of emotion which will create feelings for some that become shared and lead to the circulation of affect, such that feelings become collective feelings (Ahmed, 2004) or public feelings (Stewart, 2007).

Wetherell's (2012) work on affect has been critical of the idea that emotion is a 'circulating force'(p159). She understands emotions that stimulate affect to be 'affective practices' and she locates them firmly in the body. She states it is problematic to have the idea of 'mysterious forces' that circulate and that do not relate to the ways in which individuals are evaluating, making decisions, communicating and so on, and suggests that it is through the 'direction and history of affective practice over time' (p159). Wetherell (2012) wants to direct the researcher's gaze to something that can be observed and can provide an analytical focus for empirical work (Li, 2015). Emotions hold meaning and subsequently have an impact on others and it is in the doing of everyday life that they become shared and known.

Mason (2018a) develops an ecological approach in her work in order to perceive the whole; the inter-woven, multiplicity, complex and messy experience of everyday life. Her approach enables a way to bring together sensory understandings with a critical approach to understand the influences within situated encounters, and how these are affected beyond the encounter by the influences of care practice, policy, the organisational structures of the care environments, and also the politics of wider society, such as the experience of ageing, gender and disability. The key tenet of this argument is that the everyday experiences of care for the men living with dementia in this study are not in isolation of other influences that have an impact on their day to day life. I suggest that by attuning myself to atmosphere as a research lens allows for the possibility of understanding what contributes to the small stories of everyday life in care.

The emergence of methodologies that enable an attunement to atmospheres have been developed not only in cultural geography (Anderson, 2009; Thrift, 2008), but in sociology (Mason, 2018a; Vannini, Waskul and Gottschalk, 2013) and anthropology (Sumartojo and Pink, 2018; Stewart, 2007). These theoretical framings on gender, masculinity, normativity, everyday life and place, space and atmosphere have been helpful in orientating my thinking, in order to interpret the everyday embodied life for men living with dementia in care and its connection to atmosphere. It was necessary to find a methodology that would be able to encompass how these theoretical underpinnings understand the social world. Importantly, the methodology would enable me to generate data to answer the research aim and objectives, as shared on p67.

3.8 Methodological thinking.

This section of the chapter will move to elaborate on the methodological approach for the work. This study is, as stated, an inter-disciplinary enterprise and as such there are overlaps between the thinking in much of the work that I have discussed already. The commentators that I have drawn from have been interested in the complexity and multi-dimensional aspects of everyday life; they have been interested in the sensory, embodied and inter-weaving of relationships and issues of power. My aim was to establish a methodology that could employ an approach that would enable a focus on these different aspects of experience of being a man living with dementia in care. As such, I will now develop the case for an ethnographic methodology, bringing together learning from ecological approaches in the social sciences, sensory ethnography and critical ethnography that enable me to engage with this research endeavour.

3.8.1 Sensory approaches to ethnography

I have taken an ethnographic approach that has been influenced by the work of anthropologists such as Csordas (2011) and others who have developed both a corporeal and sensory approach to their empirical work. The aim for sensory ethnographers has been to understand the sensorial within different cultural contexts, in order to consider how individuals make sense of the[ir] world. Work by Pink (2009; 2006), Howes (2005), Classen (1997) and Stoller (1989) have been pivotal in influencing their discipline to take a more sensory approach to research. Sensory anthropologist Howes (2006) suggests that an approach that takes a more 'full-bodied' understanding of social life can be gained through identifying what the cultural dimensions are of 'corporeal (and sensory) experiences and physical infrastructures' (p115). He argues that attunement to the senses is not simply a physical awareness of smell, sound, or a feeling of temperature, but that these are culturally and socially bound (although there are differing viewpoints within the field; see Ingold, 2011).

Further to this has been influential work from an ecological anthropological perspective such as from Ingold (1987) and Abram (1997). A central thesis of Ingold's (1987) work is that human beings, although most often categorised as social, are also a subset of ecological

relations. Ingold (2015) understands that being human is not separate from being in the world, and that the social is bound up with its environment. Similarly, Abram (1997) is also attuned to the connection between humans and the world and he explores 'the perception of language', stating that perception is a 'concerted activity of *all* the bodies senses as they function and flourish together' (p59, emphasis original author). He describes how the experience of the senses is 'blended', by which he means they are not divisible in how they are actually experienced and they only become separated through language in an attempt to describe them. It is difficult to describe the intangible, the multi-sensory, the interaction between objects. Abram's (1997) work on perception explores issues of the spatial and temporal. He is interested in the need to bring together 'a more immediate mode of awareness' that is neither 'strictly spatial or strictly temporal' and he describes the need to bring a 'full-blooded awareness of now' (p205-6). These ideas of perception, space and time are crucial within this ethnographic work, which seeks to interpret the everyday embodied experiences of the men living with dementia, and which will draw on these blended models in doing so.

Whilst there have been a number of ethnographic studies in care homes and hospitals, the work in this study will contribute to the growing awareness of the importance of material space, but it will add to this by exploring the interwoven nature of bodies in these material spaces and places with a particular focus on the connection to atmosphere. Pink (2009) notes that to analyse the sensory experiences of others, the researcher must also tune into their own sensory experiences. This is evident in the work by Edvardsson and Street (2007) who, as embodied nurse ethnographers, experience the sounds, smells and atmosphere of the hospital ward and corridors. Furthermore, sensory analysis has as its starting point that 'people inhabit sensory environments' (Pink, 2009, p131).

Dementia is often shown to have an impact on language, and so a more 'full-bodied approach' to understanding experience should attune to the immediate bodily and sensory experiences of participants (Ward and Campbell, 2013). Within research in dementia, the neurosciences have tended to dominate discussions around the sensory, with particular disorders associated with condition (Alzheimer's Society, 2016). Sensory perceptions are perceived as symptoms and are medicalised. In Capstick and Chatwin's (2016) work for instance, they describe the way that sound might be understood through the lens of cultural

resistance and shows how narratives may be shaped quite differently when taking a different viewpoint. As seen in chapter 1 of this thesis, biomedical writings about the experience of living with dementia continue to consider life in ways that are diminished, and this is in sharp contrast to notions about lived experience as vital, creative and not always easily explainable. Mason (2018b) argues for methodologies that allow us to be more open to surprise and that enable interest in the messy entanglements of relationships and things and that can open opportunities to see with a different lens, or perhaps using a different facet or viewpoint.

3.8.2 Critical approaches to ethnography

Power dynamics are interwoven into the thinking of a number of the commentators that I have drawn on to develop the methodology. However, there were also important learnings to be gained through a critical ethnographic approach, and so this is a point of departure for this study from the sensory approach of the Hair and Care project. For people living in care organisations, much of the experience of everyday life is focussed around everyday bodily practices. For those living with dementia in care, this can appear to be even more of a vital issue. Desires and wishes may become more challenging to articulate through spoken language (Campbell and Ward, 2017) and people living with dementia may not experience clock-time through which everyday life is organised in the same way as those without dementia (Keady, 2010). It might be argued that a constraint of sensory approaches is that they often do not deal directly with the politics of identity or everyday life. This is why I have also taken a feminist and critical approach within the work, for example drawing on Ahmed (2013) to understand how issues of power are experienced at a bodily and spatial level. Power dynamics within dementia care organisations are often experienced at an everyday level around how bodies are managed, surveilled and cared for. There are implications around place and space, and who they belong to, and taking Ahmed's (2013) notion of bodies extending in space is a useful gauge for understanding the everyday power dynamics of these places.

This PhD study is concerned with how these issues are experienced at the level of everyday life, as well as more macro questions of identity around the experience of gender and gender relations in care, and the experience of living with dementia. This includes consideration of how the spaces themselves are constructed and how these spaces contribute to the experiences of everyday life within the care organisations. It also means consideration is

given to the external forces that flow into the care organisation and influence the experience of everyday life through the kinds of social and health care policies that exist and are put into practice at a care level (Armstrong and Braedley, 2013). Critical ethnography brought to ethnography the understanding that there is not one dominant culture within different societies and cultures, but there are multiple voices (Quantz and O'Connor, 1988). It is then essential within a critical ethnography to be aware of the how power structures are impacting on lives, and the different experiences of this. Madison (2011) states that it is for critical ethnographers to understand their ethnographic positionality, that is, the researcher's own privilege and power in the process, as it raises questions about representation and how participant voices will be represented. I will discuss this further in the following chapter under the section on reflexivity (on p117).

In this study, there are complex experiences of power; the men with dementia are living within care organisations where they no longer have freedom to choose much of what happens to them. There are duties of care for the care organisations to implement care practices and attend to the health of individuals. Care itself has been a feminist issue because of particular power issues relating to care and who carries out care activities, both formally and informally (Armstrong and Braedley, 2013). In these care organisations, there are certainly different power dynamics and multiple voices; for example, there are those working directly in the delivery of care who are most often female workers in the lowest paid roles (Armstrong and Braedley, 2013; Wolkowitz, 2002; Twigg, 2000). In my PhD study, the recipients of care are men living with dementia, who are sometimes a minority in the care organisations where they live. Dementia is a condition often associated with losing individual agency and sometimes those living with dementia may also be subject to legislation that limits their agency. It is possible that people living with dementia will be deemed unable to make decisions about particular issues according to the Mental Capacity Act 2005 (Department for Constitutional Affairs, 2007), and others will be appointed with decision making on their behalf. Hence, power trickles down through care organisations from external societal and cultural structures. Care organisations are not in a vacuum but are within historic systems and power structures. This means that the everyday level of relationships, care practices, and the lived experience of daily life are also affected by power dynamics (Armstrong and Braedley 2013).

It was vital, then, to have this in mind whilst carrying out this research and to understand the need to have a critical lens whilst exploring everyday life for the men who were participants in the study. Thus, this work has developed an ethnographic methodology that extends beyond a sensory ethnographic approach to also include critical ethnographic framings. Sumartojo and Pink (2018) have recently argued that researching atmosphere allows an approach that can consider collective experiences and the configurations of everyday life that contribute to its atmospherics. They also suggest that atmosphere research enables understandings of power dynamics, as atmospheres can show who is included and excluded.

3.9 Conclusion

This chapter has set out the theoretical and methodological underpinnings of this study. I have provided a background to the way that I have understood the concepts that I am using in this work in order to explore the experiences of place in the lives of men living with dementia in a variety of care settings. I have set out the methodological approach that has drawn from the bodily turn in the social sciences, the sensory turn, and I would argue that this work fits into what might be 'the atmospheric turn'. I have shown the aspects of sensory ethnography that are useful for this work. However, I have also drawn from critical ethnographic approaches which I also outline in this chapter. In the next chapter on Working Methods, I will set out the methods used to generate the data, the ethical implications for the work and the reflexive approach that I have taken as well as the analytical process for the work.

Chapter 4 Working Methods

4.1 Introduction

The previous chapter discussed the theoretical and methodology orientations that underpin and guide the research question, aim and objectives. This chapter will move on to discuss the working methods for study design. This will include consideration of both ethics and access to the field and it will also describe where the fieldwork took place, and with whom. I will discuss the range of methods used to generate the data and the approach taken for analysis, including researcher reflexivity and how this is approached throughout the study. The chapter will start by considering my entry into the three participating fieldsites.

4.2 Entry to the fieldsites

Ethical approvals are an important aspect of the research practice required at the start of the research process (Mason, 2018b). Ethical considerations take into account key elements of the research and its impact on participants such as harm, privacy and consent. Formal ethics were required ahead of entry to the fieldsites and the PhD study was approved as part of the wider 'Hair and Care project' (see: Appendix 1). The doctoral work benefited from the resources of the wider project, being funded by a established social research funder, the Economic and Social Research Council, and under the auspices of The University of Manchester. It also gained the approval of an NHS Research Ethics Committee which considers studies where capacity may be an issue, such as in dementia (see Appendix 5).

Ethnographic work is often about balancing the needs of many stakeholders, and the experience of gaining access to field sites is in developing relationships and trust (O'Reilly, 2009). Relationships can change and shift during the process, in both directions, and suspicions can arise if participants feel that they are under surveillance. Accordingly, relationships need to be constantly managed, making the role of the ethnographer one that involves a degree of emotional labour (Mason, 2018b; O'Reilly, 2009), which I discuss

further in the 'Relationships in the Field' section (p100). Relationships are also integral to supporting the recruitment process.

4.2.1 Recruitment

Recruitment to the study was purposive (Mason, 2018b): for staff it was self-selective; and for people living with dementia, it was mostly through family members on the advice of staff in the research sites. Recruitment took place differently according to the settings and the method which best suited the local site. A lead contact in each site participated in identifying potential participants to the study. For the inclusion of people living with dementia in the study, the majority of recruitment took place after meeting family members. It was helpful to have an opportunity to discuss any issues and concerns about their relative being involved in a research study. Some family members decided, after talking to the researcher and reading the research information, that they did not think their relative would wish to take part. In a number of cases carers agreed that their relative with dementia would wish to be involved but would not consent to being filmed.

4.2.2 Informed Consent

Gaining informed consent to take part in a research study is an integral part of the ethical process and a right of participants (NHS Health Research Authority, 2017). Information about the methods for data generation, use of data and the inclusion of the doctoral study was contained on the participant information sheets (see Appendices 6 and 7 for an illustration). The ethical committee expressed concerns about the use of video, particularly around participant confidentiality which is discussed in a later section (p90). Some family carers felt that camera observations were more invasive as an observational tool, and although they had agreed that their relative would want to be a part of the research, they felt that s/he would not want to be video recorded (Silverman, 2016). It was possible for participants to be included in some but not all aspects of the data generation. Individuals also had the opportunity to ask any questions of the researcher before giving their consent to participate. It was anticipated that many of the men living with dementia being recruited to this study would no longer have 'mental capacity' to give informed consent. Mental capacity is the ability to make informed decisions for oneself about one's own life. The Mental Capacity Act 2005 (Department for Constitutional Affairs, 2007) states that it should be assumed that someone has mental

capacity unless found otherwise. The study therefore included a mental capacity protocol (Appendix 8) which was developed within the wider study and assesses an individual's mental capacity; this was used alongside advice from clinical staff in each research setting. I also undertook Mental Capacity Act (Department for Constitutional Affairs, 2007) training before entering the field.

The mental capacity check with potential participants was undertaken whilst talking with them about the study, and they were not subjected to 'formal assessment'. In the majority of cases where participants were deemed not to have the capacity to make informed consent themselves, it was apparent early on that they would not be able to process all the information required in the informed consent process about the study - even if they were able to understand that I would like to spend time with them and talk with them about their lives. Where individuals were not able to give informed consent for themselves (which included all of the men living with dementia in this PhD study), they became engaged in the study through the involvement of personal consultees. These individuals know the person who lacks capacity well but are not involved with them in a professional or paid capacity, i.e. often a family member who might be deemed the primary caregiver. The ethical guidance states that this should be a person that knows the person well, and whom they would trust to make decisions on their behalf, knowing what they would have decided (Medical Research Council, 2007). They were invited to agree or decline involvement in the research on behalf of the individual. (See Appendices 9 and 10 for examples of the consent form and personal consultee declaration).

Of the seven men who were engaged in the study by personal consultees, five family carers noted that their relative would not want to take part in the videography aspects of data generation. Thus, there was scope to be involved in some aspects of the study but not others. As with informed consent, participants were able to be withdrawn from the study if they became unwell or distressed by any of the activities. I also carried out a process consent with all participants throughout the undertaking of the work (Dewing, 2002); I will discuss this further in a later section (on p91).

4.2.3 Confidentiality

The data were collected in an ethical manner which sought to maintain the confidentiality of participants. For publications and presentations, data has been anonymised. In line with the research protocol (see Appendix 11), pseudonyms have been given to the care organisations and to the participants. Visual data has not been used in publications or presentations without prior consent, unless anonymised. Further information about the storage of handling and storage of data is written in Appendix 12.

4.2.4 Confidentiality for non-participants

It was important to inform other people within the research environment about the research and to maintain an open and honest dialogue. Pictorial posters were put up during filming sessions and people in each setting were told about the camera (see Appendix 13 for an example). The camera was usually set in a position to focus on participants. However, as with the participant observations that were not being filmed, non-participants would speak to me as the researcher and wonder who I was, or would mistake my role, believing (understandably) I was a staff member or a visitor. I would explain that I was a researcher and I was interested in what it was like to live there. If a resident appeared to find my presence uncomfortable, I would move away to sit elsewhere or pause from any note-taking. Overall, non-participant residents seemed less concerned about my presence and often seemed to enjoy talking with me. However, for staff, it was a more complicated experience, as some seemed to feel uncomfortable around me and/or possibly frustrated by my presence (see also: O'Reilly 2009).

4.2.5 Process Consent

Another issue in this research in relation to the condition of dementia is that of being remembered whilst in the field. I applied a process consent to the on-going situated work in the field as this is an important addition to the more formalised informed consent process (Dewing, 2007). This method understands capacity to be 'situational and that capacity can be present even after the usual legal threshold has been crossed' (Dewing, 2007, p3). The researcher gains 'process consent' by ensuring the person continues to want to be part of the research process. Therefore, even if the person was consented into the study by proxy, I would 'check in' with the individual before I observed a shaving activity or sat with them in

the day room. I would introduce myself to the participants and tell them in simple terms why I was there and ask if it was okay for me to spend time with them for the purpose of the research study. There was only one occasion when one of the men living with dementia showed clearly that he did not want me to be in the room with him and he shouted, with no hesitation, the word 'no' in response to each introduction I made and each question I asked. I therefore did not continue with the observation at that time, adhering to the code of ethical conduct which was developed for the wider study (see Appendix 14).

To take another example, Harry, a resident in Lincoln Manor, would sometimes sit with me and chat. At other times, Harry would choose to sit somewhere else, indicating, a wish not to participate at that time. Similarly, on Sandbridge ward, Larry or Don would sometimes choose to come over and talk with me, and at other times, I would go and join the participants and sit with them if they were happy for me to do that. These issues of consent and active participation were ongoing ethical considerations throughout the fieldwork.

4.2.6 Everyday ethics

Whilst the study had undertaken a number of ethical considerations in advance of the fieldwork in order to gain approval, many ethical considerations are situated and take place within the field. Griffiths (2008), a nurse researcher, argues that researchers need to be responsible for their own ethical actions in the field and she refers to an 'ethics of care' which could be a way of enabling ethics to be more fluid and contextual (p356). It is consideration and transparency relating to these issues that contributes to the rigour of the research study. Ethical practice within qualitative research, and in ethnography, is an ongoing process which includes within the analysis and writing up stage too and does this not only in relation to gaining ethical approvals (Davies and Dodd, 2002). In this study, I kept an ethics log which recorded ethical considerations and action taken whilst in the field. This log was discussed at regular supervision sessions.

Despite ethical tensions that can be involved in observing people living with dementia, the opportunity is created for people living with dementia to hold conversations about topics whilst embedded in everyday life in a natural setting (Hubbard, Downs and Tester, 2003; Wilkinson 2002). Observations were undertaken with prior agreement and no participants were observed in the practice of (un)dressing or during intimate personal care. That said, men

were observed in their pyjamas or vest tops and trousers during shaving routines (with permission). For example, one man was observed whilst wearing his dressing gown in the communal lounge area of the care setting where he lived. This example emphasises the situated nature of ethics and that the researcher is not the only person responsible for ethics. I had noted that, during this particular activity, the care staff undertaking the shave were not necessarily taking into account the everyday ethical situation of this participant's dignity or privacy, due to him being in a 'public' space in his dressing gown.

Equally, it is an important observation to have made because it opens up the opportunity to discuss this kind of practice in the context of the wider research (Ward and Campbell, 2014). It shows the complexities of life in a communal care organisation where public and private spaces sometimes merge. On the one hand the participant, Bryn, was 'at home'. On the other hand, he was seated in the communal lounge room where others present may be people known to him, but, equally, could be felt to be strangers. Whilst there are ethical concerns for myself as the researcher, there are also ethical concerns around Bryn's dignity as a resident, which are not necessarily addressed in everyday care practice. These kinds of situated 'micro-ethical dilemmas' (Örulv and Nikku, 2007) are a constant source of everyday decision making for staff working in these settings. The Nuffield Council for Bioethics report on dementia (2009) also documents these kinds of encounters in everyday care stating 'the 'small things' of care are particularly important….the humanity with which assistance for everyday living is offered, especially with eating and intimate care' (p.xx). Ethics, and the impact on a participant's dignity, was a continued process for consideration for me as a researcher in these settings.

As an ethnographer, there were many occasions when participants may have forgotten who I was and why I was there, and there are references in my fieldnotes to participants and other residents asking me if I was writing my life story (when writing fieldnotes), or their life story, or who I was visiting. It was important to be as open and as transparent as possible, and to reiterate regularly why I was there. That said, none of the study participants saw my fieldnotes and as such there is an ethical dimension to this practice; namely, interviewees are offered copies of transcripts for member checking whereas ethnographers rarely share their fieldnotes (Emerson, Fretz and Shaw, 2011). Would they approve of what I wrote down about them and their everyday worlds?

Whilst confidentiality and harm are important ethical issues to consider, so are issues around transparency and openness. Ethnographers are often very private about their fieldnotes, and even when they do share them, will often 'tidy' them up before sharing with others (Emerson, Fretz and Shaw, 2011). I found myself feeling unsure about whether I would want the men or the staff to see what I was writing down, particularly in shorthand notes; although I was writing in an immediate and situated context, the notes were not fully formed and they existed 'in the moment' without the later reflection and analysis that would take place. Fieldnotes are then only one stage of the ethnographic work required to represent participants' stories (Emmerson, Fretz and Shaw, 2011). There were also other issues in relation to the condition of dementia, of being remembered, or of what I told participants being remembered by them; hence the need to remind participants of my purpose, and to give them the option not to talk to me, or sit with me if they did not want to.

4.3 The three fieldsites – description of settings

I initially began fieldwork at Primrose residential dementia unit and Sandbridge, both sites part of the ESRC Hair and Care project (see Appendix 1). Lincoln Manor joined after the activity worker from the care home attended an event for care-based hairdressers hosted by the Hair and Care project. The activity worker contacted to say that the home was interested in creating a barbershop and would the Hair and Care project team help them with this activity. This was of great interest because my research focus was to explore the everyday embodied experiences of men living with dementia in care. It was agreed we would follow their process of developing a barber space in the home, as a case study for the Hair and Care project. Further to this, myself and Dr Richard Ward, the Principal Investigator for the Hair and Care project, agreed to do some additional data generation here, which would be included in the Hair and Care project dataset and the doctoral study. It was a timely opportunity to recruit more men to the study. Lincoln Manor was originally a home for ex-service men but in recent years had opened its doors for all ex-service personnel. It could be a complementary fieldsite to the other care organisations, because of its contrast and unusual make-up of mainly male residents. Each of the three included fieldsites will be considered in more detail in the following section. As Table 1. shows there were 16 Nursing and Care Assistants, six other Health staff, three Hairdressers and four Family Carers involved in the data generation across the fieldsites:

Table 1. Fieldsites and Participants

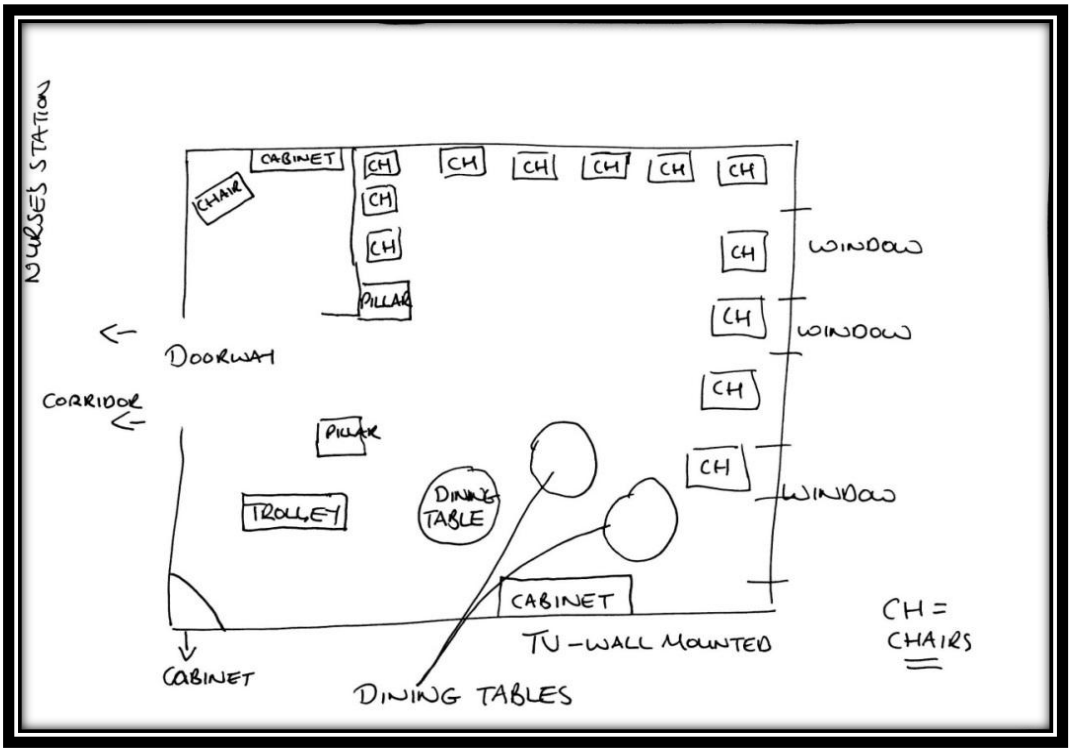
Fieldsite number and name	Observation locations	Participants (n=36)
1. Forest Fields: Primrose residential dementia unit.	Bedroom (Samuel), Bathroom (Bryn), communal areas.	Samuel and Brynn: n= 2 men living with dementia. n=6 Care workers: two female, and two male care workers. n=1 Family Carer, wife of Samuel. n= 1 Hairdresser
2. Sandbridge ward. Specialist Dementia Hospital. In-Patient Ward.	Communal areas, Bathroom (Larry), Bedroom (Don)	Larry and Don: n= 2 men living with dementia. n=5 Nursing assistants n=1 Hairdresser n=1 Occupational therapist n= 2 Occupational therapy Assistants
3. Lincoln Manor Care home (with nursing). Home for ex-service personnel. Communal areas.	Communal areas, Bedroom (Harry and Charlie).	Charlie, Harry and Bert: n= 3 men living with dementia n= 1 Hairdresser n=1 Matron n= 2 Nurse n= 5 Care workers n= 3 Family Carer

4.4 Fieldsites: Pencil Sketches

4.4.1 Fieldsite 1. Primrose Residential Dementia unit:

Primrose Residential Dementia unit was a locked dementia unit on the first floor of Forest Fields, a private sector residential and nursing home. The unit had two communal 'lounges' although one appeared to be rarely used. The main communal area was divided into a 'lounge' (with seating around the edge) and a 'dining area' with round tablecloth-covered tables and a wall-mounted television. The windows looked out onto trees and a garden area. The room was decorated with pictures, vases with artificial flowers, and other ornaments on the window ledges and in cabinets. A number of residents had mobility difficulties and were brought into the communal room in wheelchairs, or lounge chairs with wheels, and positioned in the same places for long periods of the day. The layout of the room meant that some people's view of the television was obstructed, and it could be too far away to hear. If seated at the tables in the dining area, the television was too close to see well and the sound could be overwhelming. Several people in wheeled lounge chairs remained static during meal times, often supported by staff to eat. Residents who could walk without assistance would move to sit in the dining area for meals. The positioning of people in the room determined the view they would have and sounds they could hear. For example, some could see out of the windows and see the weather, others had their backs to the window and could only see across the room, or to the entrance, watching who came in and went out. Interaction was difficult unless sitting next to someone because it was hard to hear, although sometimes people shouted across the room to each other. Engagement was not easy. My hand-drawn representation of the Primrose unit is on p97.

Image 1. Primrose: Floorplan communal lounge and dining area on residential dementia unit



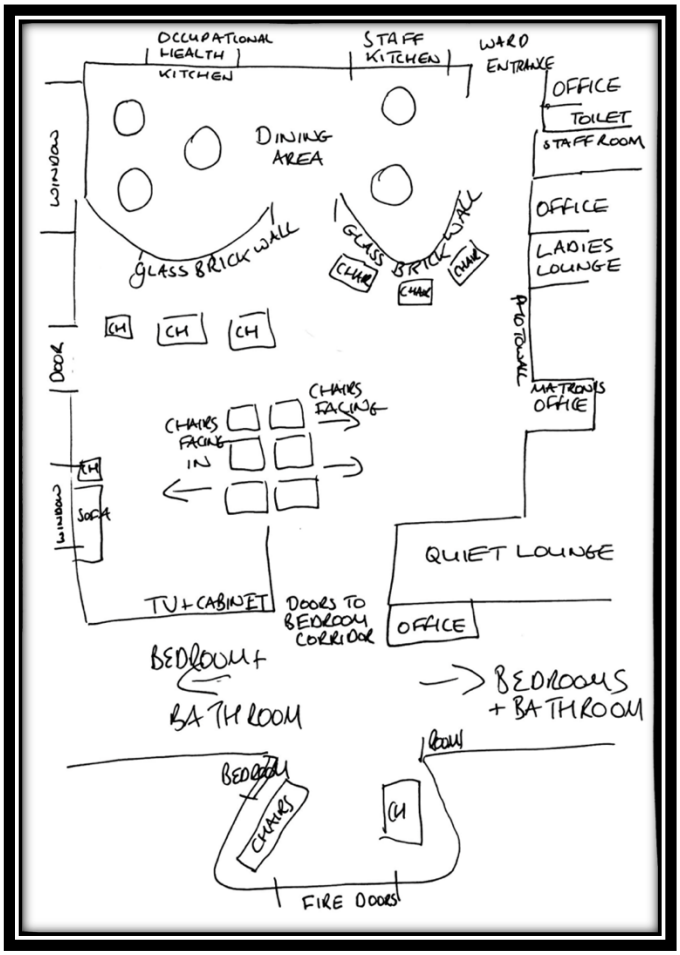
The two participants living on Primrose residential dementia unit were Samuel and Bryn. Samuel was in his early eighties, jovial and chatty, but spent very little time in the communal lounge. His wife visited most afternoons. Bryn seemed less happy; he was not often seen in the lounge and engaged less in conversation and sometimes his speech was unclear. Bryn's wife was organising to move him back to their family home.

4.4.2 Fieldsite 2. Sandbridge ward:

This was a mixed-sex, in-patient assessment ward within a NHS specialist dementia hospital, which I have named 'Old Bay Hospital'. When fieldwork took place, there was a high number of male residents on the ward due to the merging of two wards; one specifically for men with more complex needs, the other a mixed-sex assessment ward, Sandbridge ward. Residents on Sandbridge ward were admitted due to the challenging presentation of their dementia; some had been sectioned under the Mental Health Act, 1983 (Department of Health, 2015). There were a number of different staff roles on the ward, including nursing assistants, medical and occupational therapy teams and house-keeping staff. The ward was a

functional space with wipeable fabrics, laminate flooring and limited decoration, with three main spaces. The first space was a communal day room with offices along one side, separated by room dividers into a 'lounge' and a dining area with two kitchens along one side. The second space, through double doors, was the residents' bedroom corridor, with bathroom and toilet facilities and a small seating area. The third was an outside garden, a paved patio area with some seating, a wooden gazebo and pots with plants. My hand drawn image of this environment is below.

Image 2. Floor plan Sandbridge ward



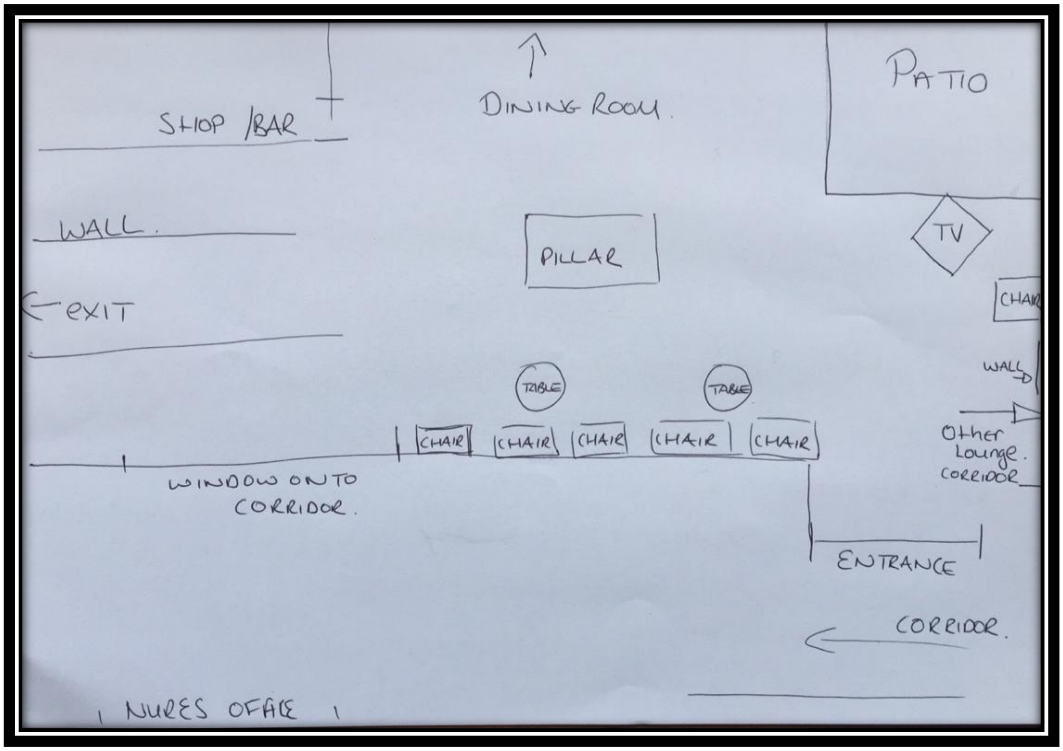
Larry and Don lived here at the time of the study. Larry seemed amiable and popular with other residents. Don could appear anxious and restless and his spoken language was more difficult to understand. Both would sleep if unoccupied for any length of time. Don's wife

visited the hospital most afternoons; unlike the other two settings, visiting hours were fixed, unless a resident was unwell or thought to be reaching the end of their life.

4.4.3 Fieldsite 3. Lincoln Manor:

Lincoln Manor was a residential care home with some nursing, operationally managed by a charity. It had a specific care remit for ex-military personnel (at the time of observations, Lincoln Manor had only one female resident). It was housed in a large Victorian building which had once been a military hospital; aspects of the interior were reminiscent of a hospital, such as the shiny wipeable flooring and the curtain rail dividing two beds in one of the rooms. It had a large communal dining hall with communal day rooms alongside. Most of the observations took place along a 'corridor' seating area that looked onto the dining hall, as shown in my hand drawn image below:

Image 3. Lincoln Manor : Floor plan main communal area



There were three participants with dementia living here: Charlie, a man in his nineties who could often be heard singing between sleeps; Bert, who rarely joined the communal

gatherings preferring, it seemed, to spend his time in his own room; and Harry, in his early seventies, who enjoyed social interaction. A more detailed account of the fieldsites are included in Appendix 15.

4.5 Relationships in the field

Working within these spaces required the development and maintenance of many relationships. I tried to ensure my presence did not impact on staff working in the care organisations (O'Reilly, 2009). I found it was important to listen to staff who could give valuable information about residents, but it could be a challenge to balance their views with my own perspective and feelings. On an occasion when I wanted to observe Don, a staff member had some concerns. Don, who was living on Sandbridge ward, was there because of challenges that had arisen for him in the community, as with all the residents on Sandbridge ward. He could sometimes appear distressed and was described as 'agitated'. He spoke in a very low voice and it was often not possible to understand what he was saying, even if some individual words could be heard. He spent most of his time waiting at the entrance and exit to the ward. A challenge occurred because I wanted to film the participant in the hair salon whilst he was having a haircut and his wife had given his consent for this to happen, acting as his personal consultee. However, even before I asked Don if he was okay with me filming him, staff asserted their concerns about how he might react to the camera and that he may feel that he was 'under surveillance'. The reality was that he was already under surveillance on the ward, as he was there to be assessed and was under observation by staff all the time, and I too was observing. I will return to this observation in the Discussion; however, at this time, I raise this in relation to the role of staff and their expertise, and in relation to how decisions are made 'on the spot', and the challenge of staff advice conflicting with what I wanted to be able to do.

The role of the researcher is a complex one in these circumstances. I had not been on the ward for some time and I did not know how unpredictable the resident was. I was reliant on the staff member's knowledge and experience, more than my own intuition and relationship with the participant. It was important that I maintain a good long-term relationship with staff in order to support my continued activities on the ward. They were the gatekeepers to the family carers and I needed their support to ensure I was able to observe grooming tasks with

the men. I also needed to be alert to feelings about the camera and be as discreet as possible. This relates to how the camera was perceived by health and social care staff as potentially more intrusive than observation without a camera. Staff themselves appeared shy about being caught on camera.

This was one of many examples where relationships in the field required work, and what might be termed as 'emotional labour' (Hochschild, 1983). Another example was around asking staff to participate in interviews which required careful negotiation with managers due to the need to take them from the 'floor'. They were often only spared for up to twenty minutes. Sometimes, in interviews, staff appeared to worry about giving 'right' answers and needed reassurance around confidentiality issues. It was often better to interview staff once I had been observing in the organisation for a while, so that trust had developed. In my fieldnotes I recorded one care worker who said that 'talking to you makes me more tired than my work' (27.01.12, Fieldnotes). This emphasises how challenging staff found being interviewed and explained the reluctance to take part that I sometimes came up against, particularly at Forest Fields. Focus groups were often easier because staff seemed more at ease amongst their colleagues and would expand on each other's answers.

I often felt uncomfortable about asking staff questions or for help. One example recorded in my fieldnotes was an incident with the manager of Forest Fields, who I was asking to print some information sheets; he was rude to me in front of a family member with whom I was discussing recruitment. The exhaustion and stress of seeking access is something Cerwonka and Malkki (2007) write about in relation to the emotional work of undertaking ethnographic fieldwork. I reflected on this whilst travelling home from fieldwork and I would discuss the experience in supervision. Ensuring that there is space to reflect on fieldwork is an essential aspect of ethnographic work.

4.6 A Note on Study Participants

To address the research aim and objectives, the main focus of the study is related to the seven male participants living with dementia in the three described care organisations. The seven men were known to be living with dementia and were all recruited to the study through personal consultees providing declarations of approval (discussed earlier in the chapter, p88).

Their stories and everyday lives as observed have been interpreted through the embodied and sensory narrative analysis which will be described in in the final section of this chapter. Table 2 describes the seven male participants who took part in the study.

Table 2. Participants: Men living with dementia

Name	Age	Fieldsite name	Communication abilities	Mobility	Previous occupations	National service	Geographical origins	Marital status	Appearance
Samuel	85	Forest Fields (1)	Fluent verbal communication	Wheelchair user Support required	Hardware store owner and joinery tutor-Probation service	Yes	North-West	Married	Clean shaven, balding. Smart clothes, shirts, Cardigans and trousers. He is a slender man.
Bryn	d/k	Forest Fields (1)	Verbal (limited and unclear)	Wheelchair user Support required	Unknown	Unknown	Unknown	Married	Mostly lean shaven although sometimes not, sometimes wearing pyjamas, but also smart clothes. He is a large man.
Larry	d/k	Sandbridge Ward (2)	Fluent verbal	Self-mobile on foot	Unknown	Unknown	Unknown	Unknown	Clean shaven, often has shaving rash. He is slim with thick white hair, smart casual clothing: polo shirts and jeans.

Don	d/k	Sandbridge Ward (2)	Uses verbal language. Words often unclear and very quiet	Self-mobile on foot	Unknown	Unknown	Unknown	Married	Slim with thin grey hair, smart but casual with polo shirts, smart jeans and cardigans.
Harry	72	Lincoln Manor (3)	Fluent verbal communication	Self-mobile on foot	Army. Followed by occupational health role	Yes	North-West	Divorced	Clean shaven, dark grey hair, casual clothing always wears an outdoor jacket and shoes.
Charlie	92	Lincoln Manor (3)	Verbal but sometimes quiet and limited	Self-mobile on foot	Bus Conductor Dock Worker	Yes	North-West	Widowed	Clean shaven, bald, small stature, always wears white flat cap, shirt and trousers with elasticated waists.
Bert	87	Lincoln Manor (3)	Fluent verbal communication	Self-mobile on foot	Presser (Factory Work)	Yes	North-West	Widowed	Clean shaven, thin dark grey hair. Smart jumper tank tops and shirts. Usually wearing outdoor footwear.

As can be seen in Table 2, information on appearance-related care is included, which provides insight into men's appearance preferences and attention to self-care and grooming, either by the men alone or with the support of staff. I included information about the men's mobility and use of language because this has relevance to their agency within their care organisations. It also reflects their ability to communicate with others, including taking part in interviews and conversations in the research. Verbal communication skill is not core to this study, as its focus is on an embodied and sensory narrative analysis of the data. Nevertheless, it is helpful to know which men were able to hold conversations and share verbal narratives about their lives. The men had various degrees of verbal fluency. For example, it was more difficult to understand the words or sounds Bryn and Don articulated. Bryn vocalised mainly sounds rather than words. Don whispered and spoke very softly and made sounds alongside words. The sounds emitted by Don mimicked the rhythm of a monologue or dialogue but were often inaudible or impossible to understand. Larry spoke clearly but was less chatty than Harry and Samuel who were adept conversationalists. Most of the participants were able to move themselves around their homes on foot. Samuel and Bryn were wheelchair users and needed support to move around.

4.7 A collective of participants

Although the difference in age between the youngest and oldest participants means they might not be considered a generational cohort, they do arguably fit into the framing given to a generational cohort provided by Gilleard and Higgs (2002). They cite Mannheim's (1952) seminal work that a generation composes a cohort who share a 'temporal location', a 'temporal historical location' and a 'socio-cultural location'. In this sample, the men shared similar experiences and some grew up in in the same geographical location (this is known for four of the men). All the men have shared social and cultural origins during a particularly notable time in British history, during or immediately post WWII. Three of the men whose histories are known, have very similar class origins. All the men shared a location at the end of their lives, living with dementia in care facilities. According to Gilleard and Higgs (2002), the older participants might be considered as 'the older siblings of the baby boomers' who experienced the social and structural changes in lifestyle over the latter part of the 20th century. This 'cultural revolution' has changed the experience of ageing and it means that this

cohort belongs to a generation that has been affected through these changes in dramatic and notable ways (Gilleard and Higgs, 2002).

In Edensor's (2008) work on his Manchester commute, he notes that the past is always part of the present within the landscape and everyday lives of the current city populous. He suggests that although 'the city endlessly moves on, it leaves traces of previous material forms, cultural practices, inhabitants, politics, ways of thinking and being, and modes of experience' (p315). I think that this is true for the participant cohort here. For Harry, Charlie, Bert and Samuel whose biography I know most about, it is likely they are 'haunted' by the industrial past of the North West, such as by terraced houses, music and memories of dances, National Service, war service, and their own childhoods, which have become closer to the present because of the experience of living with dementia (Capstick and Clegg, 2013; Edensor 2008). The 'ghostliness of the working class' pervades their current existence and is as much part of the present as the past (May, 2016; Edensor, 2008). These men have been influenced by taking part in, or growing up in war time, and as a generation, wore military uniforms (Vinen, 2014).

However, the men that took part in this study have also experienced the 'third age' differently (Gilleard and Higgs, 2002). For example, Charlie had a long period of retirement before his diagnosis of dementia and coming to live in care. However, for Harry, the youngest of the group, the opportunities afforded to some in their third age have eluded him. His diagnosis of dementia and consequent need for care occurred not long after his retirement. His chance for 'ageing well' in retirement was thwarted to some extent through the decision (made by social services alongside Harry's daughter) that it was unsafe for Harry to live alone in the community.

The men have ended up for the last part of their lives in different situations. For example, Charlie and Harry share a room in a charity run home for ex-service personnel in a suburban part of a major city. In contrast, Samuel is still cared for by his wife despite living in care. Nevertheless, he is still living out his last years in a single room in a private care home. His wife still lives in their suburban semi-detached home in an affluent part of the city. Bryn's wife is fighting to get him home to care for him herself. For Don and Larry, at the time of

data generation, life is more uncertain, whilst they undergo assessment and await decisions about where they will live.

Some of the men had had a variety of jobs during their working lives; they had all been married within heterosexual marriages, and only one was known to be divorced. Larry's marital status is unknown and he was not visited by a wife - or partner - during any observations that I undertook, although I did see him with both a son and a daughter and his daughter acted as personal consultee for him to take part in the study. Bryn was married to his second wife. Appendix 16 contains further information about each individual.

4.8 A note on validity and rigour

Different forms of rigour need to be considered in any research project. Within ethnographic research there is an understanding that everyday life is complex and messy and there is no simple truth to be found about any phenomena of interest (Mason, 2018b; O'Reilly, 2005). O'Reilly (2005) states that ethnography 'respects the irreducibility of human experience (p2), hence the iterative process of back and forth analysis that I will go onto describe in a later section in this chapter (on p128). The researcher's own experience is an essential part of the interpretative process. Rigour is about the 'trustworthiness' of the research, and being able to be open and transparent, and to provide a trail through the work is necessary; this has been described as the 'decision trail' (Mason, 2018b; Koch, 2006). The study's influences, the choices made around methodology and methods used, need to be communicated throughout the work. Led by the research question, I have set out in the previous chapters the literature that has been significant in shaping my thinking about the methodological and analytical framework. Another form of rigour for ethnographic work is reflexive rigour and the importance for the researcher to consider their own influence and place in the research process (Madden, 2010). I will return to this topic again in a later section in this chapter (on p117).

4.9 Fieldwork

An ethnographic methodology enables a range of methods to be used in order to generate data that address the research enquiry. For this study, I will set out the different data

generation tools that I used (see Table 3). However, the core of this study is centred around data gathered as a participant observer with the seven men identified earlier in Table 1 who were living with dementia in the three care settings. Data generation took place over a period of around eight months and totalled 165 hours of observation work. Observations were mainly undertaken in the communal spaces of the three care organisations and involved others who were in the settings too, including staff and other residents. I also undertook observations of men being shaved or supported to shave as part of morning routines and also at visits to the hairdressers which took place in bedrooms, bathrooms and hair salons, makeshift or otherwise (see Ward, Campbell and Keady, 2016a; Campbell, 2012). During the observations I held many informal conversations with the men which were recorded in my fieldnotes and also included as data for analysis.

Additionally, I conducted semi-structured and unstructured interviews and focus groups with staff, family carers and, on a number of occasions, the recruited men were also interviewed alongside a family member. Although I gained access to three of the men via their family carers (Larry, Don and Bryn), I was not able to consent those family carers to undertake interviews with me. Larry, who was a resident in Sandbridge ward, was consented into the study by his daughter who acted as personal consultee, and who I had hoped to interview. Unfortunately, I did not see her again at the hospital and she did not end up taking part in the study. Gaining access to carers who themselves have busy lives is not always easy. These are common issues for ethnographers, particularly in settings where the researcher is reliant on gatekeepers to make contact with potential participants (O'Reilly, 2009; Hammersley and Atkinson, 1995). Making contact via the hospital systems was precarious as messages did not always get through, and this was not a priority for staff, alongside this I did not want to make a nuisance of myself (O'Reilly, 2009). Whilst I met with Don's wife and Bryn's wife, they did not agree to an interview due to time issues. For example, Don's wife visited the hospital regularly but her focus was on getting Don out of hospital as soon as possible, and the research study seemed an additional burden.

Table 3. Fieldwork. Primary data generation across the three fieldsites

Observation data: time frame	Observation data: hours	Observation: Men living with dementia	Interviews	Focus groups
Field sites: 1. Primrose residential dementia unit 2. Sandbridge ward. December 2011-February 2012	125 hours (32 observations)	n=4	n=8 Primrose residential dementia unit Care workers x 2 Family Carer x 1 Hairdresser x 1 Sandbridge: Hairdresser x 1 Nursing Ass x 3	n=3 Primrose residential dementia unit: n=2 with 4 care workers. Sandbridge Ward: n=1 with 5 members of staff: OT x 1, OT assistant x 2 , Nursing Ass x 2
3. Lincoln Manor September 2013-November 2013	40 hours (7 observations)	n=3	n=4 Family carers with men living with dementia x 3 Matron x 1 Hairdresser x 1	n=2 4 x care worker 1 x nurse 2 x activity worker

This chapter will now discuss each element of the fieldwork that was carried out. I will describe and discuss each method used for data generation including participant observation, videography, interviews, focus groups and access to care records. I will explore what each method brought to the study as well as their challenges.

4.9.1 Participant Observation

Participant observation is considered a vital tool within ethnographic research where researchers will immerse themselves in a setting in order to understand particular 'modes of

living' (Mason, 2018b). As discussed in the previous chapter, this ethnographic study was time-limited and the observations took place within day time 'work' hours only (Pink and Morgan, 2013). I did not move into the care organisations to live amongst the participants in the study. I did, however, spend considerable hours sitting amongst them, talking, observing and being part of the day to day environment. Observation was particularly important to this study in order to generate data that could illuminate the research aim and objectives.

During the participant observation I would write in my fieldnotes about the everyday small scenes happening around me, observing the movements, the stillness, the schisms and disruptions. I was aware that I was also a contributing factor in these scenes and that I brought my own lived body to the spaces. My time in the communal spaces was spent 'following' the men around, moving between dining areas, day rooms to corridors and occasional more private spaces such as bathrooms and bedrooms. I would arrive at the fieldsite and seek out the study participants, moving to sit close to them or where they were in view. If they were not around in the communal space I would find a seat and observe the general comings and goings. I would move around the setting depending on where the men were sitting or what activities were happening. However, if Harry, a participant living at Lincoln Manor, went off for a cigarette, I found it preferable not to follow him and instead I would wait for him to return to the seating area where he spent most of the day. However, if Larry, a resident on Sandbridge ward, moved from the dining area or communal living space to the bedroom corridor, I would, generally, at some point, follow him to where he had taken up a new seat. It was important to develop ways of observing and being with participants that worked for them and often Harry was taking time-out when he went for a cigarette. Alongside this I knew he would always return to the same seating area where Charlie, another participant resident at Lincoln Manor also usually sat, and so I would remain with Charlie and continue to observe the comings and goings in the main communal area. However, on Sandbridge ward, there were a number of places to sit where interactions might occur. Larry would move off and I felt that if I gave him a moment, he would be comfortable if I went to join him in his new area. In fact, often he would be pleased to see me again. The change of scene would be helpful for him, and we would gain a new connection, a shift in the atmosphere created by this movement of Larry's and mine before things lulled again (see: Sumartojo and Pink, 2018).

Participant observation itself may be considered as part of a continuum of observation work where the researcher, at one end of the continuum, becomes immersed in joining in the everyday activities of the study participants to, at the other end, being separate and outside of activity and observing from the sidelines (O'Reilly, 2009). This can be a practical choice rather than necessarily for theoretical or epistemological reasons (O'Reilly, 2009). In this study, I would be a participant to some extent, mostly when I sat amongst the men as together we were involved in the passing of time and we would talk and observe the comings and goings together. However, I did take notes as I sat, which could act to remove me from the scene and make me more of an observer. With other activities, I was more clearly an observer on the sidelines; for example, during personal grooming activities such as shaving or hairdressing, and during meals as I did not sit and eat with the men. Coffey (1999) states that participation is not only about joining in an activity but is also related to the skill of the ethnographer in the way that the researcher engages themselves and their senses in 'whole body observation.' It is therefore about being there, present and bodily connected and attuned to the observation. Mason (2018b) also argues this point and suggests that the researcher can become a 'knower' as they are sharing in the 'experiences, sensations, emotions, and participant, or by developing empathy with the researched or in the setting' (p142).

Using observation alongside interviews and conversations meant that I was not purely reliant on verbal exchanges. Rather, I was able to record 'what happened during the day' and led by the research design, I became attuned to the embodied and sensory experiences of the participants in the study. A further important contribution of observation as a data generation tool was the means it provided to view the context and collective experience of the men. Observation is not focused only on individual experience but allows the researcher to view what is happening all around, such as what might have led to a particular situation, and what the ripple effect of the event is. As suggested by Mason (2018b), it allows a more 'multi-dimensional' approach to the generation of data.

4.9.2 Fieldnotes

As Emerson, Fretz and Shaw, (2011) suggest 'fieldnotes are writings produced in or in close proximity to 'the field' (p.353). During the time I spent observing in the three fieldsites, I would often write fieldnotes when sitting in a communal area with my notebook, recording as much as possible of what was happening around me. I would mainly focus on the participants

in the study or on activities that were happening around me. Sometimes I would describe the room, its décor and who was around and doing what, or I would write about a particular interaction as it occurred. At other times I might attend a 'grooming activity' and just observe the activity or hold 'in-situ interviews' (Ward and Campbell, 2013a) rather than write notes. Then, once the activity was completed, I would find somewhere quiet to write up the observation. After conversations with the men, I would wait until an opportunity arose to go and record the conversation whilst I remembered it.

It is not always possible for researchers to write their notes whilst observing, possibly because they do not want to be known or because they are getting involved in the activities. I found it helpful to have my notepad with me whilst I sat in the communal areas as it helped to act as a reminder for others about why I was there. The writing would lead to interactions with residents and sometimes this would lead to people telling me about their experiences, which would not be included if they were not consented to the study. However, this gave me further insights into the setting. This was particularly important whilst working alongside people living with dementia, who were unlikely to remember who I was, or why I was there. On one occasion Samuel, a participant who lived on Primrose residential dementia unit, asked if I was writing his life story. I told him 'kind of' and was able to remind him about the research and my interest in his experiences of living on the dementia unit; this gave him the opportunity to reminisce about living in India whilst on national service which he seemed to enjoy. By being visible and recording the comings and goings it also reminded staff that I was there observing, and they too would talk to me and ask me questions about what I was doing and it enabled me to remain 'overt' in the field (Hammersley and Atkinson, 2007).

In total I compiled ten handwritten note books for the observation data for both the wider Hair and Care project and the doctoral work. These were each numbered in chronological order and filled with observations, sometimes drawings such as room plans, personal reflections and feelings as well as dates, times and the location of the observation (see Appendix 17 as an anonymised example from of one of the notebooks). These notebooks are intrinsic to this study and provide the main data for this study. Fieldnotes are an important record of in-the-field observations, but ethnography is also an act of memory, and ethnographic analysis and writing become merged with a recollection of an observation scene or of a particular incident that is not written in our fieldnotes. As Sanjek (1990) states,

'fieldnotes become combined with headnotes' (p127). The practice of analysis brings back the memory, and this becomes combined with time, and reading, and personal experience (Sanjek, 1990). Accordingly, ethnography is a both craft and a practice, and it is temporal and embodied.

My fieldnotes developed over time and as I became more immersed in the settings, I recorded different elements of what was going on, and I reflected more on what was happening around me. Fieldnotes are not certainly not 'factual recordings' and cannot be objective, they reflect the ethnographer's gaze and focus (O'Reilly, 2009). Their development shows how the process of analysis is not separate to the fieldwork but embedded within it and part of the process. The writings developed, as ideas developed, and as I engaged with the research questions and my own experiences in the field (Cerwonka and Malkki, 2007). Writing fieldnotes meant that I was not always observing, and writing would take my attention away from the scene. During observations I took the full-bodied approach that Mason (2018b) describes in order to be attuned to the environments, both the human and non-human elements, and in order to represent the embodied and sensory experiences of being in these spaces. Hence I would write not only about what I could see in the space around me, but also about the smells, the sounds, the weather outside and the temperature inside (Edvardsson and Street, 2007). Even now as I write this a version of the rooms is etched into my memory showing how memory is a vital part of the ethnographic process. Many ethnographers maintain more than one notebook and keep their fieldnotes and analytical notes separate to a reflexive journal (Mulhall, 2003). However I found it easier to keep my notes together, although sometimes I did also record audio notes after observation sessions whilst I was driving home after a fieldsite visit (Hammersley and Atkinson, 1995). As Emerson, Fretz and Shaw, (2011) note, fieldnotes are representations and selective, they are not a complete account of the field and it is not possible for everything to be recorded. However, these authors suggest that fieldnotes are 'intended as descriptive' rather than 'explicit theorising or interpretation' (Emerson, Fretz and Shaw, 2011 (p353). In contrast, Mason (2018b) argues that this intention depends upon how the fieldnotes are perceived, whether as 'raw data' (p160) or as 'developmental devices for formulating your understanding of your setting, for documenting your 'hunches', and for developing and testing analytical ideas' (p160). I viewed my fieldnotes much more in line with Mason (2018b) and considered them to be about documenting observations, but also recording hunches and ideas as they occurred and,

although in the early stages they were quite descriptive, and continued to describe as richly as possible what was happening, they were also about the construction of ideas, theory and were often interpretive and reflexive.

4.9.3 Videography

Out of the seven men living with dementia who were participants, two of the men were consented to take part in video observations whilst they were attending the hairdressers at the care organisations where they lived; Don, who resided on Sandbridge ward and Bert, who was a resident in Lincoln Manor (see Table 1 and 2). Videography is an approach that is considered valuable in generating data that is both multi-sensory and multi-dimensional (Pink, 2006). Within dementia studies, and particularly in qualitative work, it is an increasingly popular tool because it allows for wider participation in research for people living with more advanced dementia (Campbell and Ward, 2018). Videography does not rely on spoken word as it enables the researcher to view the sensory and embodied responses that take place. In preparation for using this method, I undertook intensive training at The Granada Centre for Visual Anthropology at The University of Manchester during May 2011. This training developed my understanding of film as a tool for data generation, and I was able to consider the role of film in constructing knowledge in the field (Pink, 2006). As noted by Clark and Morriss (2015) it is imperative to consider film in relation to how it represents participants, because there is a danger in perceiving film to be somehow more objective, or to capture 'real life'. Hence, taking a reflexive position throughout the videography was crucial in data generation, and during analysis, to understand the role that I played in constructing the knowledge (Clark, 2012).

4.9.4 Interviews

As well as the observation work, I undertook 12 interviews. Many of these interviews can be referred to as 'ethnographic interviews' which were informal and took place whilst undertaking observations (Madden, 2010; O'Reilly, 2009; Spradley, 1979). I would hold conversations and ask about the participants' lives, or they would sit and talk with me about both everyday life and their memories. Only those who were consented to the study have their conversations and stories reported in the thesis. These kinds of conversations, or 'ethnographic interviews,' also took place with staff whilst they worked. These interviews were often spontaneous and would happen due to proximity and opportunity, and I would

then write them into my fieldnotes. They added to the richness of the data by providing a different perspective and viewpoint, or an opportunity to find out about something as it was happening. For example, during an observation of a shaving activity, I would ask questions of both the person being shaved and the person doing the shaving. This was particularly helpful for working alongside people living with dementia and these 'in-situ' interviews were not reliant on memory (Ward and Campbell, 2013). The interviews meant that the hairdressers, health and social care workers and the men living with dementia could give immediate sensory and embodied answers relating to a particular situation. Samuel, a resident on Primrose residential dementia unit, told me how a shave felt as he experienced it by stating that it was all 'chop, chop, chop'.

I also conducted more formal interviews with care staff and family carers, sometimes alongside the men who were living with dementia. These interviews were structured by 'topic guides' which were developed for the wider study,but included questions that were equally relevant to the doctoral work, and additional questions developed specifically for this study. However, these guides, and the interviews, were not restrictive and there was scope to introduce questions within the interviews. O'Reilly (2009) argues that 'ethnographic interviews' are those undertaken with participants where relationships have already been established through the observation work and she suggests this means there is already a level of trust developed. O'Reilly (2009) also suggests that these interviews alongside the observations should both 'inform and enable each other' (p127).

This was true of the interviews with dementia care staff who came to know me in the respective fieldsites, observing their work and holding informal conversations with them. The interviews were often undertaken in short sessions where staff were released from their duties for twenty minutes to half an hour to talk to me, and one interview was even undertaken in a corridor on Sandbridge ward because the staff member could not get fully away. These interviews were a tool to gain understanding and meaning from the perspectives of staff, and it was helpful to contrast and compare them with the observation work. They provided insight into how staff experienced their working lives and into how they viewed the residents they cared for.

I interviewed the family carer of Samuel (Primrose residential dementia unit) at the family home, where Samuel had previously lived. This interview, as with the other interviews with family carers, threw light onto the life Samuel had lived before moving into care. The other interviews with family carers were undertaken later in the research process when working at Lincoln Manor. These were done in a format devised for the wider Hair and Care project in order to gain 'appearance biographies' (Ward and Campbell, 2013). Photograph albums were used, where possible, to elicit information about the person's life history, focusing on appearance, but also asking questions about jobs, family and heritage. These interviews for the three men based at Lincoln Manor allowed greater insight into their lives prior to living at the care facility.

4.9.5 Focus groups

I also undertook five focus groups with staff in each of the three settings. Focus groups, or discussion groups, have been used mainly in market research (Mason, 2018b; Arksey and Knight, 1999). Whilst they cannot generate individual reflections or personal experiences in the way that one to one interviews can, they can be useful for data generation in social science research (Mason, 2018b). The groups worked well in these particular care organisations where I wanted staff to talk to me about their work roles and their place of work. In two of the fieldsites, Sandbridge ward and Lincoln Manor, the groups were mixed staff roles and this created interesting comparisons as staff joined in and talked across each other. I found that staff appeared less restrained within the focus groups than in a one to one interview.

Focus groups can be practically and emotionally challenging as they require managing group dynamics as well as a number of practical issues. For example, I needed to: i) bring staff together when it did not impact on the work of caring for residents; ii) find a space to hold the group; and iii) manage the audio equipment, so that everyone's voice could be heard on the audio recording. After one focus group session I found the audio recorder had not been switched on. I had to write up notes of the session from memory and reconvene a group. In Forest Fields, the focus groups were not really 'groups' as I interviewed two care staff together on two occasions. However, I found that they were still more successful than some of the interviews with solo staff at this particular site. This may have been because the staff who took part were able to find a unity together and elaborate upon one another's responses.

4.9.6 Documentation

Ethnographic research has its origins in non-literate societies where methods such as participant observation and interview techniques, fit well; however, this is not so for contemporary ethnography (Atkinson and Coffey, 2004; Hammersley and Atkinson, 1995). There are often materials available that can form a useful addition to the 'data set'. In the three care organisations, there were many types of documentation from care notes to medical records that were part of the day to day work of these organisations. This study, and the wider ESRC Hair and Care project, were both interested in the characteristics of the care documentation and in how staff represented the residents in their notes, in particular in relation to bodywork tasks and appearance-related tasks. However, for the doctoral work, it was also useful to look at the language used to describe the men and consider if gender played a role in the care documents. These notes functioned as an account of the handover meetings between shifts. They clarified how the purpose of the organisations, and the role of staff and their attitudes, was reflected in the records of behaviours charted throughout the day. However, the care notes were only made available to me on Sandbridge ward and therefore do not play a major role in the study findings.

4.10 Reflexivity

Reflexivity is an essential component to social science research within qualitative work. Undertaking reflexive research relates to how a researcher examines and acknowledges their own role and identity in the production of the work, from the generation of data to the representation of participants and the field in their final texts (Foley, 2002). Reflexivity goes beyond reflection and it is an engagement with the problem of representation, and of our own subjectivity and experience (May and Perry, 2017). Foley (2002) explores the differences in reflexivity and ethnography, and the need to bring together aspects from postmodernism and traditionally Marxist critical ethnography. He states that reflexive ethnography is:

> '… to know, map and explain the lived reality of cultural others…[whilst trying to] to tap into introspection, intuition and emotion, the way auto-ethnographers (Ellis and

> Bochner 1996, 2001) and ethnic (Collins 1990) and indigenous scholars (Tuhiwami Smith 1999) are' (Foley 2002, p487).

Reflexivity is a troubled concept within ethnographic work, how far one's reflexive position should be reflected within the ethnographic writing. The quote above by Foley (2002) is helpful for my work and why I have chosen to bring my own reflexive accounts into my ethnographic work. I argue this is not an overtly autoethnographic project and it is not, as Delamont (2009) describes 'autoethnographic self-obsesssion' (p60). Rather, it is making myself undeniable, which, as Coffey (1999) suggests, is vital because 'to remain silent is to deny our existence and biographical place' (p126). In this PhD study, my experience of caring for my father who was living with dementia in long-term residential care felt an essential analytical element of the way I produced representations and developed my theoretical perspectives. As Mason (2018b) argues, this is due to my own attunement to the particularities of these environments, albeit through a different lens but nonetheless through an emotional and whole-body connection to the field. Hence, I have included within the findings chapters aspects of my reflexive work when it appears most relevant to the story-telling, and to the development of the ideas. I will return to this later in the thesis (on p117 in the section on reflexivity).

This work was undertaken in places that I recognised and which were familiar to me. It was with men that I recognised culturally; for example, many of the men in this study are from the generation that my father was from and they are northern working-class men, like my father. I am familiar with care homes and dementia hospital wards having visited both my father and my father-in- law in these settings. However, I am not familiar with living in these environments and I am not a man with dementia. I am, in this respect, still 'other' within these settings. For many of the participants, my role may have been ambiguous and as already mentioned it was possible I was mistaken for being someone else: perhaps family carer or staff member. For the staff I was not 'one of them', but neither was I the same as the residents, being middle-aged, white and female. As a participant observer, understanding how your position as a researcher impacts on the data collected is vital.

In this work, by situating myself in health and social care organisations where I was both familiar and unfamiliar, there was a need to constantly negotiate my place and to define who

I was and why I was there. And although I was exploring everyday lives in these settings from the perspectives of men living with dementia, I felt as a feminist, an ethical conflict in relation to the staff who worked in the settings. I was concerned about representing them and their practice fairly, as challenging news stories relating to bad and unethical practice in health and social care emerged (Kelly, 2014). Furthermore, this study was about [the potential vulnerability of] men in environments where female staff were the majority of the work force and in low paid roles (Twigg et al, 2011). I wanted to ensure that as an ethnographer I was drawing from a critical ethnographic framework that ensured a reflection on the power dynamics at play in these organisations, and how this filters down. I therefore felt a responsibility to reassure staff where possible about the research, not to excuse any bad practice I might observe, but to assuage my position as an (arguably) middle-class white woman who was not doing 'dirty work' (Twigg, 2000).

Feminist researchers have established a methodology that is 'consciously reflexive' in this way (Liamputtong, 2007, p10). Similarly, critical ethnographers consider reflexivity of high importance because of these power dynamics that occur in the field (Baumbausch, 2010). The intersection of my own identity played out not only in the way that I viewed the everyday life of the men that I was observing, but with relation to how those that I observed responded to my being there (Baumbausch, 2010). Feminist methodologies have argued for the intersection of identities to be made explicit in research (Liamputtong, 2007) and, as such, Stanley and Wise (1983) argue that it is imperative to bring the personal and research experience into the data generation and analysis, and hence to written representations in order to develop theory (Liamputtong, 2007). Furthermore, as Anzul et al (1991) suggest as researchers, 'we' are the 'primary research tool' and whilst we observe other people's lives, we are connected to what we observe 'as human beings with warmth and feeling and our pulses resonate with the heartbeat of our research participants' (p108). With all of this in mind, the next section describes the relationship with my father that I bring to this research project, and how this and my feelings relating to him, are a partial account of the heartbeat of this work.

4.10.1 Beyond Reflexivity: 'Peter' and his place in the story

Further to this kind of positioning in the field it is important that I consider in more depth some aspects of my own identity and positioning in the field and bring into focus my 'ethnographic self' (Coffey 1999). Riessman (2008) says:

> 'investigators carry their identities with them like tortoise shells into the research setting reflexively interrogating their influences on the production and interpretation of narrative data' (p139).

This study has evolved from feminist epistemologies that have rejected objective value-free research. Although there are many versions of feminism, a key tenet is in the understanding that there is not a 'universal' truth. Post-structuralists, such as Donna Haraway (1988), have argued for definitions of objectivity that allow for the multi-dimensional and for the situated nature of knowledge. A key aspect of this work is that I was heavily affected and motivated by my own experiences of dementia and my relationships with both my father-in-law and my father who lived with dementia in care organisations. In particular, my relationship with my dad and his experiences were an important influence on my data generation, analysis and writing. Haraway (1988) argues it is not enough to understand or consider our self reflexively in the ways that I have just described. Instead, Haraway (1988) argues that we must create what she calls a 'feminist objectivity' which is 'about limited location and situated knowledge, not about transcendence and splitting of subject and object. It allows us to become 'answerable for what we learn to see' (p583). In other words, our knowledge and understandings are limited within particular boundaries, and we cannot ever be 'all knowing'. Haraway (1988) suggests that there is not a subjective self and an objective truth, but that these are both partial elements of the research, and that they are interwoven or meshed together.

It is using these partial voices as researchers that we provide interpretations of the world. It becomes essential for the rigor of this study to use this aspect of my experience within the study as a whole; it is an integral part of this work. So, my 'feminist objectivity' allows for this research to include this as one of many partial perspectives leading to the interpretations I make about the participants and their life in the three fieldsites. I have written occasionally about these experiences alongside my findings and drawn on them within the data analysis.

This doctoral work has been shaped and influenced by the experiences I have taken with me into the field and held alongside the men who have been part of the study. It would not be possible for me to have carried out the research and the subsequent analysis and telling of their stories without 'Peter' [my father] being present as a part of the narrative. I would argue that, in many ways, taking this journey as a researcher allowed me to understand something more of Peter's journey too, that the understandings and interpretations were fluid and not one way. There is something deeply personal about this research study and this has had an influence on the data generated and the subsequent analysis simply because it has been shaped by this part of my existence (Taylor, 2008; Haraway, 1988).

However, important reflections have been made to ensure that I did not miss something in the data because I was blinkered by my own experience nor that I saw something that was not there. These reflections took place in supervision meetings, through presenting findings as they developed at conferences, and by furthering the analysis through critique from others including the supervisory team. There are many limitations and criticisms of auto-ethnography and of Haraway's notion of objectivity. Delamont (2009) argues against auto-ethnography, stating that it is self-indulgent, and lacks in analysis. Delamont also argues that it is not ethical, i.e. in this case she might argue that I did not have Peter's consent to be a part of this project. However, I believe it is not Peter whose story I have used, it is the story of my relationship with his experience of dementia and life in care that has become a part of the overall ethnographic project. Further to this, Foley's (2002) consideration of postmodernism and critical ethnography is useful as he argues for something in between the ideas of radical postmodernism, where ethnographers such as Lather (2001) argue for opening up all analytical categories rather than closing them down as fixed categories, and the 'devoutly scientific' (p486). I would like to bring Foley's (2002) in-betweenness into this work, in what he describes as a 'common sense' approach that is able to draw on these many, and sometimes contradictory theories, and which enables this work to be open, attuned, reflexive but also influenced by social theories and understandings of social worlds (p486).

4.11

4.12 Analytical Framework – A Sensory and Embodied Narrative Analysis

This section will focus on the analytical approach I developed in order to extend the methodological underpinnings to the generated data. The development of the analytical approach also required an emphasis on bodies, senses, space and place. It was important to ensure that the sensory and bodily aspects of the data were represented not only within the fieldnotes, but also throughout the data analysis and subsequent findings in order to attend to the primary research question and aim. To this end, I have developed an approach that is built upon narrative analysis which draws on notions of atmosphere and affect to form a 'sensory and embodied narrative analysis'.

When using ethnographic methodologies, analysis does not begin after fieldwork has been completed; instead, it is something that has already began happening whilst still in the field (O'Reilly, 2005). The hunches and ideas that emerge during the data generation process, and which in turn influence the kinds of data that are collected, are an essential part of this process. Pink (2009) argues that analysis is an integral part of the 'knowledge production process' (p119). O'Reilly (2005) suggests 'by the time you reach what we call the analysis phase you should have some idea of what it is you want to convey' (p118). For this work, it was a surprise to me how much of the analysis process continued into the writing phase. It is not only whilst generating data that iterative and mindful processing occurs, this also continues as the ideas materialise in the writing phase and are constantly refined (Mason, 2018b). This process was enhanced by the in-depth feedback and critique shared by my supervisors and other colleagues.

Once fieldwork is complete and there are vast amounts of fieldnotes, reflexive notes and other interview data, there is a sorting process that must be undertaken in order to make sense of the data (Mason, 2018b). The analysis process may require more than one method or approach. This doctoral study has collected different types of data and used different techniques and processes for doing so, congruent with ethnographic work that enables a mixed methods approach. The data has provided different opportunities for sensory engagements and at different levels. Pink (2009) has argued that the process of analysis might

'mean interpreting one set of research materials that depends on the analysis of another' (p130). In order to interpret and understand meanings within the data that was generated for this study, it will be necessary to move between different sets of research materials and memories. As Mason (2018b) notes, an important aspect of analysis is to make decisions about what will be considered as data, and the most appropriate way to organise and interrogate it.

For this study, the observation fieldnotes became the core dataset. As already described, these were notebooks that held my handwritten notes and drawings and contained all my fieldwork observations from the three participating fieldsites, as well as my thoughts and reflections during the fieldwork illustrating the processing that took place during the phase of data generation. Alongside, there were (almost verbatim) informal conversations recorded in the notebooks, and semi-structured interviews and focus groups that were transcribed 'intelligent verbatim' style. I also had access to care documentation recorded about participants that I copied into my fieldnote booklets. In the final analysis, I have included aspects of my own experiences of dementia and care organisations, and my personhood which influenced the shaping of the work. I have documented the data that was generated in Table 3 (p107). However, it has been important at this stage to briefly note the data that I have been working with in order to go onto to explain the analytical approach. Mason (2018b) points out that, for some, working with the data in a cross-sectional approach may not be the most appropriate approach and as such other modes of analysis may be more suitable. I wanted an approach that viewed the data more holistically, where there was consideration of context, and I could draw on what I knew about the participants and the care organisations.

4.12.1 Narrative analysis

In order to take this holistic approach I drew on work from narrative analysis, a long-established framework for understanding why and how people tell the stories they do about themselves. Narrative analysis is an 'umbrella term' due to the wide range of different approaches that exist within it. Smith (2007) states that the 'body is always connected through narrative and that narratives are embodied' (p394), suggesting that the stories we tell of ourselves are always located within our bodies. Phoenix, Smith and Sparkes (2010), drawing on Frank (1995), suggest 'we not only tell stories about our bodies, but we also tell

stories out of and through our bodies' (p3). Within the wider study, 'The Hair and Care project' we carried out 'appearance biographies' with participants using a narrative approach, this was in order to understand meanings of appearance throughout the life-course. These narratives often linked to how appearance was felt rather than what appearance looked like, and as such, the appearance biographies were engaged at a bodily and sensory level with participants' experience. Often the stories we were told held sensory memories, such as hair being put into rags by a fireplace (Campbell et al, 2015; Ward, Campbell and Keady, 2014). However, narrative analysis as a methodology has only recently begun to use embodied theories within its work (Smith, 2007). Apparent within the work of the Hair and Care project during the filming of hairdressing encounters in the care-based hair salon, it was possible to record bodily experiences such as having setting lotion applied and learning that it felt cold on the scalp, or noticing when a hair pin nipped someone's skin because of how the participant responds through their bodies (Campbell and Ward, 2018). Hence, these became the everyday stories of how appearance felt within a dementia care setting.

In narrative approaches there are a number of different ways that stories are categorised in relation to how they relate to the wider world; these are cultural and social narratives, whereas other stories that people tell can be linked to their own identity and how they position themselves within the wider cultural stories (Phoenix and Sparkes, 2009). Phoenix and Sparkes (2009) call these 'big stories' and 'small stories'. Hence, the small stories that people tell about themselves may well be related to broader issues of identity and positioning in the world. In this doctoral work, I wish to show how narrative analysis was enhanced further in order to consider how individual bodies can communicate narratives and collective bodies can perform together the 'small stories' of everyday life within the care organisations.

In order to consider the dynamics of power in these care organisations, I intended that these small stories of everyday life be linked to wider 'big stories' of gender, care and dementia. In order to be able to present the narratives of the men living with dementia in this study, it was crucial to consider how their bodies were experienced in the spaces and places they were a part of, and as this work is carried out in collective care environments, how these experiences rippled outwards. It was with this in mind that theories of affect and atmosphere were used as analytical tools which were crucial to the development of this work.

Baldwin (2006) and Hyden (2013) have argued that people living with dementia are often left out of work using narrative approaches with the assumption that they cannot contribute to these 'narratives' because of loss of verbal speech and memory-loss affecting their capacity to tell detailed stories. However, Baldwin and the Bradford Dementia Group (2008) argue for a more embodied notion of narrative, stating that our personal narratives are told through our bodies as part of the performances of everyday life and that it is through the practices of everyday lives that individuals show something about their identity, culture and history. I have been interested in drawing on the bodily narratives of the participants in this study to reveal something about what it feels like to live in these care organisations. Hyden's (2011) work on narrative and dementia has been important for a number of reasons. He has argued that people living with dementia are capable of telling stories in collaborative storytelling contexts. Narratives are always co-produced (Riessman 2008), and Hyden's (2011) work on 'scaffolding' has shown how people living with dementia tell stories even if their speech is fragmented or unstructured, whereby the co-producer of the story supports the story telling, setting up the story, and helping with the plot development, names of characters and so forth. He also suggests that the 'body is a communicative resource' for narrative and, as the researcher in this study, I was a co-producer for the bodily narratives. Using Hyden's (2011) notion of scaffolding, I was someone who asked questions of participants to help elicit the narrative. Moreover, by being someone that a narrative could be performed to, I supported storytelling that took place in a moment: where a glance is exchanged or through a look shared that tells something of the scene unfolding around us. In this study, the narrative analysis enabled people living with dementia with limited verbal language to be included in the narrative work, and it has sought to present the small and big stories within the atmospheres of dementia care (Phoenix and Sparkes, 2009).

Within narrative analysis itself, there have been a number of commentators bringing the body into their work, such as Frank (1995) and Sparkes (1996). More recently, Lisahunter and Emerald's (2016) extension of embodied narrative work has been to bring narrative together with sensory ethnographic approaches in order to 'address us as bodies' (p31); the authors take this quote from Ellsworth's (2005) discussion on sensational pedagogies that seek to move beyond us 'having bodies' to being bodies. Lisahunter and Emerald (2016) understand the narrative research process as three research moments: field texts (gathering the data); interim research texts (analytical processes); and research texts (representing the data). They

create their own intersecting framework of sensory domains: senses; sensual experiences; sensory geographies; sensational turning points (p28). This intersecting framework allows for thinking through data within each domain throughout all of the research moments in order to establish a sensory narrative approach.

This framework proved a useful way to approach the analysis for this study. The first domain concerns the senses during data generation, this can be with relation to participants and to the researcher's own sensory experience, and this continues on into the analysis stage, in order to try to understand the sensory experiences before finding ways to represent the sensory experiences in the final research outcomes. Lisahunter and Emerald (2016) discuss the need for more creative ways to represent sensory experiences; however, I have represented the sensory via text in the writing of this thesis. Essential for this work, has been the interconnection between the embodied and the sensory. The sensorial experiences refer to the kinds of feelings that are created and how these are expressed and then shown through bodies. Sensory geographies relate to the complex ecological 'entanglement' of material, spatial, temporal aspects of these experiences, and I argue this would also include atmospherics. The final domain is that of sensory turning points, and I suggest that these might be moments of affect, or atmospheric shifts that happen and are somehow represented in the data.

An important extension to Lisahunter and Emerald's (2016) work has been to consider the experience of gender and dynamics of power within the sensory and embodied narratives. Sumartojo and Pink's (2018) new work researching atmosphere argues that an atmospheric lens provides potential to understand the experiences of those 'who are recognised… and who feels included and excluded' (p129). An attunement to atmosphere enhances understanding regarding how the entanglements of spatiality, temporality, bodies, and things are experienced within the dementia care organisations. Similarly, there is the need for close attention to affect and how emotions are experienced both individually and collectively. Feelings are not isolated and experienced within bodies, but between bodies or 'impressed upon' bodies (Ahmed 2004, p29). Ahmed (2004) argues that feelings 'rehearse associations' because they are influenced by all that the person has experienced or encountered previously and what they make sense from (p39).

4.13 Analysis process

In this section I will outline the process that I took to undertake the analysis across all the data collected:

- Ethnographic Fieldnotes
- Video data of two hairdressing encounters
- Semi-structured interviews and focus groups
- Care notes – Fieldsite 1. Sandbridge Ward.
- Working with multiple types of data

4.13.1 a) Ethnographic Fieldnotes

I applied a holistic narrative analysis to the data and in order to get an overall sense of everyday life within the care organisations. I began first with the fieldnotes. I worked with my handwritten notes and transcribed some elements when interrogating particular parts, or in preparation for using data in presentations and other writing work. The notes, handwritten, sometimes with sketches or diagrams of the rooms, would also have my reflections and hunches. I also kept some reflexive notes, sometimes written, and often verbally recorded too. It was clear that the stage where I would develop ideas, concepts and themes from the data needed some organisation. I wanted to address this process with the research questions in mind, and loosely used the framework set out by Lisahunter and Emerald (2016) which I have extended to fit to the requirements of this project as set out above. Initially, I read the fieldnotes and, using 'post-it' notes, recorded ideas or observations of interest. Across the notes I saw that there were similar observations within all sites. Although there were structural differences in the way that the organisations operated, the organisation of the days was almost identical. The notes reflected this as they were chronologically organised by date and time of day.

The sensorial turning points were signified by one activity ending and another one beginning (Lisahunter and Emerald, 2016). By 'activity' I mean anything that might be happening within the observations, e.g. men on Sandbridge ward finishing breakfast, or men at Lincoln Manor waiting for the shop to open. I read the fieldnotes keeping the research aim in mind: to interpret the everyday embodied life for men living with dementia in care and its connection

to atmosphere. I read and re-read the fieldnotes considering what they were telling me about how the men were spending their days; Who were they spending time with? What was happening? Where were they? I also asked myself, How were the men and staff behaving? Using their bodies? What were they doing?

Alongside reading and re-reading the data, I returned to the literature and explored theoretical ideas that then helped me develop interpretative ideas about the data. Although always being wary of pre-existing ideas from the literature leading me to force the data, I found that the back and forth process from the literature to an immersion in the data helped to develop the ideas. Blaikie (2009) calls this an abductive strategy that is both 'developmental and creative' (p156). In particular, this mode of using theory with the empirical data to develop interpretations fitted well with the interdisciplinary nature. I began to develop themes about the everyday experiences of the men who were living with dementia, and it was through this abductive process that I thought more conceptually about what the data was showing me. I have included an extract from the data in Appendix 18 and given an example of how I approached the analysis of data.

Through the analysis process of reading fieldnotes, creating notes and ideas, I began to develop theories and create sensory and embodied narratives. As I read, I would write notes, and 'post-it' notes, building, layering and developing my thoughts and ideas to make sense of the data, and to understand what it might mean about the everyday lives of these men, who were living with dementia in the three care organisations. I began to write about what happened each day in the care organisations, and about the way that the men spent their days. Initially, I focused on bodywork experiences, and I undertook analysis of all the shaving episodes that I observed and hairdressing episodes. I developed and honed the conceptual ideas through reflecting on the data through writing and presenting early findings from the study. I wrote an article (Campbell, 2012) and presented at conferences (see Appendix 19). I found that sharing the work with wider audiences provided an opportunity for further development of conceptual ideas. Over time, as I went on to consider more of the data and contextualise further the bodywork experiences, I extended the analysis in relation to other aspects of the men's everyday lives, their relationship to place and its connection to atmosphere.

4.13.2 b) Analysis of video data

I had two pieces of the video data for analysis, these were both undertaken during hairdressing encounters. One video was with Don, who lived on Sandbridge ward, and it was filmed in the dedicated salon space which was within another part of the hospital. I did not film Don on his walk to the salon, but only once within that space. Alongside Don were the hairdresser and an occupational therapy assistant who were both participants in the research. The second video was with Bert, at Lincoln Manor with the hairdresser, who was also a participant in the research. The hairdressing encounter at Lincoln Manor took place in a communal living area, though the camera was angled to only capture the hairdresser and Bert. I ensured that others in the space were aware filming was taking place through signage (see appendix 11) and discussion if the need occurred. The video footage amounts to around 30 minutes in film.

Lisahunter and Emerald (2016) show how the different types of data generated can be considered using their framework, which is the approach I have taken: I explored all data in a holistic way to develop insights that show rather than tell, as much as was possible within the remit of this work. As noted in the earlier section on videography, I was aware of the strengths and limitations for using this kind of data and therefore of what to be cautious about during analysis. I was always only capturing a part of the scene and there were things off-camera which had not been captured; however, the multi-sensory aspects of the films were a charged reminder of what the environments were like, and the particular hairdressing encounters with the men. Pink (2006) states that a 'reflexive approach' to data analysis means that the researcher understands the limits of the data. The analysis for these two sets of film data meant undertaking a close tracing of the multi-sensory experiences of the men. I watched the video to interpret the interactions between the participants and the material space. I considered the spaces where the films were made and any shifting dynamics during the films. I considered the context in which they were undertaken and referred to any ethnographic fieldnotes relating to these events. The video analysis was also interpreted in relation to the data analysis of the ethnographic fieldnotes in order to understand how this data informed, or enhanced, the interpretations and sensory narratives emerging from the analysis.

4.13.3 c) Interview and focus group data

I then turned to the interview data and I read and re-read the interview transcripts that were transcribed (intelligent verbatim), and I used NVivo 10 to manage this data. I looked for interpretations within the staff interviews and focus group data, searching for narrative accounts that explored some of the key issues from the research: gender; staff approaches to everyday care tasks; atmosphere; the care environments and everyday life for the men living with dementia. I also kept in mind consideration of the sensory and embodied within the interview and focus group text, and looked for any connections to atmosphere or affect, especially with regards to how staff told me they felt or experienced their everyday work. I was interested in how this data intersected with the emerging findings from the ethnographic fieldnotes.

I only had one semi-structured interview with a family carer (a participant's wife), and I studied this transcript with the research questions in mind. I also used this interview to consider what more there was to learn about the man living with dementia. The interview gave me insight into life before care, decisions around the participant going to live in care, and enabled me to reflect on his biographical history. I was also able to look for themes within the interview data that gave insight into the research question and aim, and for anything new that I might learn from the perspective of the family carer.

I undertook three 'appearance biography' interviews with family carers and men living with dementia at Lincoln Manor (Ward, Campbell and Keady, 2014). These were rich interviews that gave me further insight into the men with relation to their biographical stories, and also to how they viewed everyday life in the care organisation. As Hulko (2009) notes, it is possible to reflect on observation materials compared to interview narratives, hence it was interesting to consider what the appearance biographies told me and I compared this with the observation data I had generated relating to the men.

4.13.4 d) Care Documentation

I had access to care notes on Sandbridge ward. I copied these care notes into one of my fieldnote diaries. I used these notes to gain insight into the kind of records staff choose to and are expected to keep about the residents. These care notes were data that had not been created through the intervention of a researcher (Silverman, 2011). Diamond (1992) notes in his work

on care home life 'the narrative of formal documentation was about isolated units, bodies, and behaviours' (p128). Diamond (1992) suggests that the documentation turns the tasks of everyday life into text, and that they also represent the work of the care staff. The data was also comparable to the handover meeting I had observed at Lincoln Manor. These data were very brief notes, and it was useful to see the language staff used to record their notes and how they represented the men in the notes. I used these notes alongside the observations and interviews and focus groups with staff to see what else they could show relating to how staff approached care and the everyday care environment.

4.13.5 e) Working with multiple types of data

This study has had a number of research objectives to fulfil and has chosen to generate data in a number of different ways. I have argued that one of the benefits of using an ethnographic approach is the flexibility within the methodology (O'Reilly, 2005). Within this ethnography, the methods I have used are often selected for data generation, working alongside each other to bring different dimensions to the dataset (O'Reilly, 2005). This study is asking 'distinct but intersecting questions' (Mason, 2006, p5) of the social world within the messy and complex human experience. This approach takes an 'ecological or holistic approach' to generating and working with data in order to tell the research story (Mason, 2018b, p208). I have worked with these different types of data in order to understand the partial stories of the men living with dementia, the staff who work with them, their family relationships and backgrounds and the care organisations themselves, and I have attempted to bring them together as narratives of everyday life. Sometimes there were tensions within the analysis, as the stories were contrasting, or at least, different, but these tensions are also helpful in producing a narrative that shows the complexity of this social world (Mason, 2006).

In the subsequent chapters I will reveal the findings that I am presenting through this doctoral endeavour, although as Mason (2018b) notes, it is during this phase that some ideas, and lines of enquiry have to be 'let go' in order to pursue the story that is to be told.

4.14 Summary and Conclusion

This chapter has set out where, with whom and how data generation and analysis took place. I have explored each aspect of the fieldwork and how each method was relevant to this study

and to the research aim and objectives. I have presented the ethical issues that have been addressed during the undertaking of the work, such as those required in consideration for ethical governance, and have also provided a discussion about the kinds of situated ethical issues that occurred in the day to day undertaking of this study. I have discussed my approach to reflexivity within the study and my place in the research and explained how I shall continue to approach reflexivity in the way I present the data in the subsequent chapters. I have also outlined my analytical approach to the data generated. I will now go on to share the main findings of the study over three separate, but interlinked chapters.

Chapter 5 Findings (1) - Normative regulations of care spaces: 'producing atmosphere'.

5.1 Introduction

This chapter will demonstrate how atmosphere is a useful analytical lens through which to direct our gaze to understand the experience of place across three fieldsites as a man living with dementia. In this chapter, I have fragmented the data to reveal how atmospheres and atmospherics are produced, and when they might become 'visible'. I will suggest that atmospheres are produced as an inadvertent consequence of four aspects of the normative regulations and organisation of these care spaces. I am using the idea of 'normative regulations' to present how organisations direct care in particular ways, using Ahmed's (2006) ideas around orientation that I discussed in Chapter 3, which argue that sexuality is directed along normative straight lines and that deviation from this makes people out of line. I draw on this idea of orientation to be understood within this care context as I consider the kinds of normative expectations and orientations that are required for both residents and staff within their everyday lives and how these are reproduced through elements of the organisation and structure of the care organisations. I will explore how these normative regulations produce atmosphere and atmospherics; firstly, through the organisation and structure of time; secondly, through the way that tension is created due the experience of the care organisations as work-places versus home-places; thirdly, through the way in which the men's bodies were managed in each of the three participating care organisations; and fourthly, through the gendering of the atmosphere. Time was ordered and structured to maintain, contain and manage the collective needs of those living and working in these settings.

5.2 Atmospheric attunement

At an early stage of my time in the three fieldsites it was clear (to me) that there was a sense of atmosphere within the care spaces. My fieldnotes seemed to have atmosphere lurking

within them. The rooms of the care facilities were not empty vessels but were full of lived bodies, personal stories and histories, material objects and sensorial attributes such as the olfactory, acoustic and haptic (Mason 2018a; Stewart 2015; Pink, 2012). I intend, through salient examples from the fieldwork, to demonstrate the intangible aspects of everyday life in these care organisations through a focus on atmosphere and atmospherics and 'potent connections' (Mason, 2018a). These often emerge out of the mundane, from moments of tension, and they shift and merge and lull, affecting space and bodies, and then re-emerge out of and within bodies. The three care facilities in this study are organised and structured as a means to manage and care for collections of people who have diverse and often competing needs.

In this short extract from my fieldnotes from a morning on Sandbridge ward, I draw attention to the themes that this chapter will focus on, and through which I consider atmospheric affect:

> *The walls out here are cream, the paint work in places is peeling off. There are a few pictures on the wall. Some flower prints line one wall, a painting of a boat on a beach and a print of a 1950's family. The floor is laminate and there are a few armchairs and sofas scattered around the ward. It is very quiet, occasionally interrupted by a person passing, or the jangling of nurse's keys*. (10am. 19th January 2012).

This extract is short, but it is imbued with what might be described as atmosphere lurking in the words describing the care space, and it draws attention to a number of the themes that this chapter will go onto explore and produce atmosphere. The extract begins by stating the time of day and the location that the notes were from. It goes on to describe aspects of the material environment, drawing attention to 'the peeling paint' which suggests an environment with wear and tear, and budgetary limitations. The note refers to the flooring as laminate, an easy to clean and maintain surface (as many materials in the care environment are). This kind of material evokes a need to manage the potential for spillages as well as the leaky bodies of residents. It is noted that the walls were hung with paintings, perhaps in an attempt to create a pleasant environment. The note about the 1950s might reference a notion of normative family life that is deemed recognizable for the residents living there. The extract describes the soundscape of quiet and 'jangling keys'. This sound, made by keys held by a nurse, gives insight into the power structures that exist: there are rooms that require unlocking to enter or

leave, and the nurse is busy at work. The sound and movements of the nurse create atmospherics within the text. I suggest that even in this short note it is possible to think about structural and regulatory aspects of the environment that contribute to the feel of the space. As I go on to reveal sensory and embodied stories of everyday care, I want to show how the complex interweaving of relationships between residents, staff and material and sensory places contribute to the production of atmospheres.

5.3 Themes overview

The three care organisations are structured in particular ways in order to deliver collective care and address the needs of residents. In Lincoln Manor and on Primrose residential dementia unit, the care organisations were continually performing a dual operational function: as a work-place caring for a collective group of people and as a home-place to the residents who are living there. This was different on Sandbridge ward, as the residents were not in a permanent residence. This was a temporary environment, in order to assess their needs and find ways to manage the residents' current challenges living with dementia. However, at all three sites there is a normative expectation of what constitutes everyday life and how everyday life should be ordered. The organisational power and decision-making structure are held by the management of each organisation and the everyday care duties are mainly carried out by a core set of staff such as nurses, nursing assistants or care workers. It may also be argued that there are influences of power that flow into the organisation that impact on how care is organised within the care organisations; for example, there are mental capacity laws (see Department for Constitutional Affairs, 2007) that determine levels of freedom for residents in these care organisations, and two of the care environments restricted comings and goings of residents, as well as health and social care policies that influence the way that everyday care tasks should be carried out.

The provision of front-line care is delivered mainly by nursing assistants and care workers and in all three settings these were mainly female. There is a normative set of regulatory and organisational structures that can be found to manifest in the following four dimensions that I argue are contributing factors to the production of what I am calling 'atmospheric moments' which I will go on to describe in Chapters 7 and 8, but these are moments that occur in the atmospheres of the care organisations and can be experienced as a charge, a shift, or ripple in

the air. The four dimensions are: i) The organisation and structure of time; ii) The tensions caused through the sites as work-place versus home-place; iii) The control of the men's and women's bodies; and iv) Gendering the atmosphere. These four dimensions will now be expanded upon.

5.4 Dimension i). The organisation and structure of time

> *Cyndi Lauper's song 'time after time' is playing on the radio, somehow appropriate.* (Fieldnotes: Primrose residential dementia unit. 3.20pm. 20th December 2012).

5.4.1 Institutional time

In each of the three fieldsites, time had a significant role to play in the organisation and structure of everyday life. I have used the quote above from my fieldnotes to emphasise the way that time was often experienced as either interminable amounts of time that could lay ahead each day, and the repetition of tasks. Across all the participating fieldsites, similarity was found in the way that each organisation ordered time around the normative expectations of everyday life. This ordering of time was chronological and followed clock time; for example, days were organised and structured into institutional 'time zones' and divided into scheduled tasks: morning routines → breakfast and medications→ morning teas→lunch and medications→afternoon tea and medications→tea-time→bedtime.

A typical day began for day staff arriving for work to 'take over' from the night team at around 7am, with some slight variation between the three fieldsites. 'Handovers' between changing shifts of staff occurred in all the settings. For example, in Lincoln Fields, night staff to day staff handover sessions began at 7am each morning when information about the residents was shared and care task rotas given out so that staff knew who they were responsible for supporting with bathing, grooming, dressing and so on. I recorded this daily event in my fieldnotes with a typical example shared below:

> *Two care workers to 10 beds and one respite for my section. (All the men who are participants are in the same section). All the nurses and care workers that are on duty are gathered at the nurses' station for handover. A nurse goes*

> *through each resident and shares information with others present, albeit very briefly. Mainly 'medical' and 'emotional' mentioned on a few occasions. [Both day and night staff]. care workers and nurses 'chip in' with information if they have it, adding to the picture of each individual: occasionally stating comments such as 'that's not like him'. After about 15-20 minutes all the care workers are given their positions for the morning by nurse in charge*. (7.30am; 18th September 2013).

The handover session took place in the nurse office, which was depicted in the floor plan (Image 3, p97) in Chapter 5. Staff were mainly female with one or two male care workers and a male nurse. The nurses' office was a glass windowed office located along a corridor and opposite the day rooms. At this time of day in Lincoln Manor, there were few residents around and the building was lit with dim lighting and was quiet with the odd buzzer sound going, indicating waking residents in need of support. Across all the settings, I noted how lighting was used by the organisations to signal particular times of day, such as keeping lighting dimmed as residents began to wake and emerge into the public spaces for the day ahead. I suggest that this shows how the care organisations themselves used atmospheric tools to create atmosphere and, that through these repetitive care practices, other unintended atmospheres would emanate.

After the handover sessions, care staff began the tasks and routines of the day with staff supporting residents to wash, shave and dress. There was some flexibility in how this order might play out, but each setting had a framework for a day that adhered to the expected patterns of everyday life. There was little opportunity to deviate from these expectations. However, one nursing assistant on Sandbridge ward did tell me that she would try not to wake those residents who were not ready to be up and about until at little later:

> *If I'm on an early, I come in at half seven and we have handover. And then I would go into the different dorms or bedrooms and see who's awake. I try not to wake anybody up. If they're asleep prefer to let them sleep until 8 o'clock in the morning. I wouldn't go and particularly wake somebody up…Whoever's… whoever wants to get up*

washed and dressed or have a bath, finish breakfast. (Nursing assistant, Sandbridge ward, 26th January 2012).

Sometimes staff pushed against the regulatory order of things; however, generally morning routines were just that, and care workers and nursing assistants would go around the residents supporting those that required help to get up. There was a drift by residents into the communal areas once they have been aided to dress and appear respectable or 'lounge standard' for the public spaces of the settings (Lee Treweek, 1997). Baths and showers were often scheduled outside of morning routines because it was not possible to bathe everyone at the same time. Therefore, 'bodies' to be bathed were timetabled, and may go on beyond the morning routine, so that care workers were engaged in bodywork from getting up time all the way to lunchtime. Individual residents were put onto a bathing rota in this way, suggesting after so many days they would require a thorough bathing again. Once residents moved into the public communal areas they then waited for breakfast to be served. After breakfast, residents and patients drifted to a period of 'in-between time'; I will develop this theme further in the following chapter, and here within this 'time zone' residents waited for the next structured staff-led activity.

At each of the three care organisations there could be other activities that shifted the sense of waiting. For example, Primrose residential dementia unit would sometimes hold a staff-led activity in the morning and visitors were welcome at any time of day. Indeed, visitors on Primrose residential dementia unit would begin to appear from late morning throughout the day and would sometimes initiate a game of dominos with residents in the communal lounge area and this would punctuate the organisation of time causing a shift to the feel of the environment, at least for some residents. On the two days per week that the hairdresser attended Forest Fields, she would sometimes come up to Primrose residential dementia unit in a morning to see who'd like to have their hair done. Her cheerful presence, walking around chatting to potential and better-known clients would also bring a shift to the feel of the environment. This was generated through her activity and movement which occurred within the otherwise still spaces brought by the lull between routines. At Lincoln Manor, there were no activities during the day in the communal area although there was an activity room where residents could attend activities and there were occasional outings. There were also some other events that occurred regularly; for example, on a daily basis a shop opened in the main

communal area at 11.30am and, in an evening, the bar opened four evenings each week. The shop, for example, could cause quite a buzz, and a sense of something happening, and although it was a routine event, it would create a frisson in the air as men somehow appeared following others towards the queue. The gathering of a crowd meant that there was a rupture to the overwhelming sense of time filling that arose during the times in-between care activities. There would be chatter and movement as the queue of men grew and people checked the time with one another or discussed what they would purchase when the shop opened. There was a sense of excitement as men knew they would once again have full packets of cigarettes or sweet treats for the day ahead.

Once a month, in Lincoln Manor, a hairdresser came in to do the men's hair. This activity was carried out in one of the lounge rooms. Visitors were also welcomed at any time during the day; however, only Charlie had regular visitors during the times I observed. The sensory elements that emerged from the structuring of time could manipulate a sense of mood, or rather a feeling, in residents that contributed to the atmosphere. Sometimes these sensory elements were manipulated; for instance, as already noted light and dark was used to create a sense of the time of day and this also added to a perception of a public and private space. Lights were often left dim in the mornings and curtains closed as people adjusted to the beginning of a new day. This could create a feeling of privacy in the more dimmed light. In this extract from my field notes during the start of the day on Sandbridge ward I state:

> *It is grey and dark outside, and the lighting seems low. The curtains to the patio doors are still closed. I move out of the dining room with a deep feeling that I am invading a private time of day*. (9am. 9th January 2012).

In this extract above, I make a note of my own feeling regarding the time of day and the consideration that this should be a private time for the residents; noting my own cultural and personal understanding of 'breakfast time' as a time of day usually associated with private spheres ahead of entry to the public world. Bille (2015) describes 'light culture' in his work on light and atmosphere in Denmark, and thus argues that the sensorial experience of lighting will in some way be contributed to through understood cultural norms (p57). For the residents at these care organisations, at this usually private time of day which had been signalled through the low lighting and closed curtains, they were already amongst staff and other

residents and were having breakfast within a public sphere. The care organisations attempt to create an experience for the residents through these sensory encounters and they use lighting to support the temporal ordering of the day.

The sensory dimensions of care practices could act to signal the time of day for the men. Through the sounds and smells of the care organisations the men knew to direct their bodies to the next routine of the day, such as when the sounds and smells of meal times happened, and residents would begin moving towards the dining tables. This was particularly striking in Lincoln Manor as the dining hall was large and mostly empty. However, at certain times of the day, it would flood with men moving towards the tables to be seated for their meal. The routine tasks that create the daily structure were signalled through routine smells and sounds of the trolleys holding cutlery and crockery which would alert residents to the time of day. These two extracts from my field notes illustrate this phenomenon, first a note taken at Lincoln Manor at lunch time*:*

> *Most residents are now in the main dining hall… a few people are sat on individual tables [around the edges facing into the hall]. A care worker comes by offering someone a coffee or tea…other care workers are moving around giving out lunch and drinks, pausing to talk to individuals. Harry is at his usual dining table opposite Bert. The sounds of spoons against cups, plates and dishes clang, clatter, footsteps, wheelchairs squeaking on the shiny floor*. (12.30pm. 2nd October 2013).

Secondly, a note from dinner time on Primrose residential dementia unit:

> *The sound of the dinner trolley and the smells of food flow into the room. [there is also a man in kitchen whites] the chef puts out bowls of food and plates, one plate is filled with a scoop of mashed potatoes, mushy peas and a parsley sauce*. (4.35pm. 31st January 2012).

In order to maintain the organisational structure of everyday life, it was important for residents to stay on track and undergo routine tasks or have meals when scheduled. The sensory atmospherics depicted in these notes helped to provide signals for residents of the time of day, through the food smells, the sounds of the dining accoutrements, and the sound

of movement towards the dining room or bringing food to residents such as the squeaking wheelchairs or the dinner trolley.

One care worker on Primrose residential dementia unit stated:

> *We have, like, a daily routine, we come here to work, and we have…we are limited, whatever you say, there is, like, an hour and a half, maybe, in the morning, to help most of them...We need to make them ready for breakfast, for the beginning of the day. Which is just…it's quite a challenge and, then, with dementia people anything can happen. (Discussion group 1. Primrose residential dementia unit. 4th October 2011).*

Here, a care worker on Primrose residential dementia unit acknowledges the pressure of the routines and the limited time-frame to get tasks done within it, also making the point that these care tasks are the reason they are there, to work. The care worker notes that the pressure of time is more challenging because people living with dementia are perceived to be more unpredictable. This may shed light on why on one occasion Bryn underwent a shave in the communal living area, because the time was right although the location was not. The care worker was ready to shave him, and he was not refusing, therefore Bryn's acquiescence and the staff time for the routine co-aligned. Rather than suggest Bryn move to a more appropriate environment, the care worker took advantage of Bryn's mood whilst she was working on 'morning routines'. In my field notes I reflected on this position as follows:

> *It's morning, I am on Primrose residential dementia unit. The care worker has invited me to watch Bryn's shave, he is wearing a striped polo shirt and Pyjama bottoms. The care worker introduces me to him and he smiles and laughs. I ask him how he is, and he says "good". The care worker explains that although Bryn was up with the night staff they haven't shaved him because they are assuming he is having a bath. The shave is carried out in the main lounge whilst Bryn is sat in an armchair next to four women, as well as another woman on the other side of the room and one other man. Two of the women are asleep. Bryn grimaced as he was shaved on one side. His head was hung low and it is difficult for the care worker to reach under his chin. She asks him to lift his head and close his mouth. When she is finished she says "there, how was that?" He asks her to do under his side burn which she does but only on the side*

that he touches. It takes four minutes to complete the shave and the care worker says it is easier with an electric razor. She also tells me that Bryn is going home to live soon. (9am. 6th January 2013).

As the case illustration of Bryn highlights, the use of time in this way by the care organisations is key in maintaining order and structure of the everyday. There is no sense that this activity is 'out of place' because it is 'in-time' for the routines of the day. Here, Bryn is in part-dress wearing pyjamas bottoms in the public space of the communal living area and he is being given a shave which would usually be a private grooming activity, taking place most likely in a private bathroom. This routine, at this time, is in keeping with the routine time of the care work, the normative order of the day that the organisation creates. For the women sitting near to Bryn, their breakfasts were accompanied by the sound of an electric razor. For Bryn, his shave was accompanied by the sounds of people eating breakfast. The duration of the shave represents how little time staff have to spend on each resident. These are the sounds of communal life in the care home and these aspects of the sensescape contribute to atmospheres being produced and created.

5.4.2 In-between time

The tight ordering of the everyday through the scheduling of bodies meant that there were often times when a large number of residents were in-between the routine activities. During this in-between time, there would be television, and sometimes radio playing. The significance of the television during this period of in-between time is that it did not require staff to be present and could appear to act as an activity. Indeed, the television could be used to manage the in-between time that dominates much of the everyday life of the residents living in these care organisations. Staff were only required to turn on the television which would then fill up space and time with noise, pictures and movement. For example, the sounds from the television would fill the communal areas and those that were not seated directly watching it would still be able to hear the television. The sounds would drift into the corridors and be an accompaniment to the care workers everyday tasks as the sound drifted down and through the corridors. If an activity was taking place in a communal space organised by the care organisation then the television would usually be turned off, although this was not always the case. There was also a hierarchy in power about who could - and could not - turn the television on and off. For example, the hairdresser in Lincoln Manor

carried out her activities with the television still playing, she didn't attempt to turn it down to enable her to better hear and speak with her clients. Rather, the television appeared to be outside of her remit and control. I never saw a resident with the television remote control and in charge of the television set in any of the three fieldsites. Television, then, was a common feature of the soundscape of these care organisations and it was controlled by staff, but not by all staff.

Sometimes the television was on when I arrived at the participating care organisations and I would not know if it had been requested to be put on and, if it had been, it was not clear if that person was still watching. At other times, a resident would call to a member of staff to switch the television on. Some residents seemed to have more control than others regarding this particular activity. In one of the day rooms in Lincoln Manor, where the television was on a cabinet on one side of a fairly large room, it had a medium sized screen and the distance from the seating arrangement was significant as it was not easy to see, or hear, unless it was turned up very loud. In another part of Lincoln Manor, there was a television in a corner of a day room which was at a lower level but positioned in an alcove; therefore, it was only watchable for a small number of people at any one time positioned around this area. Not only was controlling the televisions out of question for residents, often the televisions were not even positioned for residents to have good view or sound; in fact, in almost all the situations where I saw televisions there would be an obscured view for someone. In both Sandbridge ward and on Primrose residential dementia unit it was not possible for residents to turn off the television without assistance as they were both wall-mounted flat screen televisions operated by remote controls which were complicated to use. One time in Forest Grove, I saw a family visitor struggle to use the remote control to try and find a different channel on the television. Arguably, family carers had more power to control the television than some residents who did not have either the bodily or cognitive capacity to work the television sets in their home-place. The television was controlled by those with the power and ability to operate it, which suggests there is a power hierarchy with regards who controls this in-between time activity and thus the power to maintain the normative order.

Across the three fieldsites there were residents that did desire to watch television, but often this was only a small number despite the general dominance of the sound that formed part of the everyday sensescape of the care organisations. Television had a role to play in producing

atmosphere and in contributing to how the spaces felt. On one occasion, in a day room at Lincoln Manor during a session with the hairdresser, the television played a film whilst men sat around the edges of the room watching and the hairdresser carried out her salon duties in a corner of the space, and as previously mentioned did not attempt to turn off or down the volume on the television set. This is an example of the multi-functional use of rooms in the care organisation. During a session with the hairdresser, one of the participants from the study had his hair cut and I was granted permission to film the scene.

In the recording it is possible to see that where Bert was sat for his haircut was positioned partially in front of the television, making the sound of television alongside holding a conversation with the hairdresser difficult for Bert to hear. Also, as he was not facing the television and unable to watch it, Bert had different sounds competing for his attention. His body was also blocking the view of anyone sat on the other side of the room in his sight line to the television. Filming the scene enabled an in-depth analysis of the different sensory experiences at play, as I recorded in my fieldnotes:

> *The film on the television is playing at a high volume, and then at other times when the adverts come on it is even louder. There is the sound from the TV and of the hairdressers' clippers whirring, and other little sounds can be heard although occasionally the hairdresser speaks to her client and he speaks inaudibly back. (1.30pm. 7th October 2013).*

The increase of volume on televisions during adverts is a ploy by advertising companies that have their adverts played at a louder volume (information regarding this can be found online here: http://www.channel4.com/4viewrs/faq/name/why-do-adverts-sound-louder-than-the-programme/id/400290070). Advertisers do this in order to use volume to ensure that people are listening to what they are selling. In a space like this one, where no-one has access to the remote control, it meant that the volume at regular intervals was overwhelming. It made the opportunity for conversation between the hairdresser and her client almost impossible. Often I observed when an outside visitor or visitors came to the care organisations there would be atmospheric shifts, as they brought with them something new to the in-betweenness created by the rigid time structures. However, here this scene with the hairdresser at Lincoln fields

appears to show rather than bringing something new to shift the atmosphere in the day room, instead the hairdressing experience merges or blends into the space, as the hairdressing activity becomes subsumed into the dominant soundscape of the television, and the empty space post-lunchtime.

The sound of the television is a powerful contributing atmospheric effect within all the settings, and as already stated it can either be considered as a backdrop to the organisational everyday routines and/or at other times it becomes the dominant feature of in-between time. For example, in my fieldnotes from Primrose residential dementia unit, I describe how the television sounds enter the corridors merge with other television sounds and with other noise whilst the nurse on duty carries out her medication round unfettered by these acoustic clashes:

> *I wait by the nurses' station. The living room is full, the lead nurse is doing medications. Someone's TV sound spills out into the corridor. It is Jeremey Kyle. It is loud and there is shouting. There is a different programme on in the main communal area. Sounds clash. Apart from the TV it is quiet, I don't hear sounds of people talking, except I hear the sound of someone calling 'help me help me, help me' ringing down the corridor.* (10am, 25th October 2011).

In this section I have described how the normative regulations of the care organisations structure time and the order of everyday life into different time zones: 'institutional time' and 'in-between time'. The structuring of everyday life leads also to creation of institutional sensescapes that also in turn contribute to how the spaces feel as shown here in the extract. There is the merging of sounds that are unremarked on, and unattended to, they fall and fade, become stronger and louder at other times, insisting on a response. But here as I describe them they act as a backdrop to the nurse carrying out her duties, yet I will draw on how these elements might be considered further in the subsequent chapters as I discuss how atmospheres are produced and created through the activity and inactivity of everyday life.

5.5 Dimension ii) The tension of work-place versus home-place

The material and sensory environment also had an impact on atmospheres. As argued by Mason (2018a) 'places are never 'just' places, things are never 'just' things' (p188). I will now explore how the materiality and sensory aspects of these care organisations also added to the 'feel' of the spaces. How it impacted beyond mere 'backdrop' as Mason (2018a) states, as a contributing feature in the emergence of atmosphere. The material environment consists of the tangible aspects of the settings. From the furniture, to the decorations, to the noticeboards, light fittings and textiles that are used. Some of these material features might be considered 'materialities of care' (Buse, Martin and Nettleton, 2018) because they are associated with the objects of institutions. This section is divided into three parts which draw on these arguments to illustrate how the materialities and sensory elements of the care organisations were significant factors in creating the tension of work-place versus home-place, and how this in turn contributes to the production of atmospheric moments.

5.5.1 Materialities and Sensories: haptics, olfactory, visuals and auditory

To comply with compulsory legislation, care organisations must include items such as fire alarms, information notices about health and safety, hand sanitising gel dispensers, staff uniforms, latex gloves and stainless-steel medicine trolleys to meet legal and policy requirements and to undertake their responsibilities to patients and residents. Objects, furnishings and furniture in care organisations feature particular textiles and materials which are easy to clean. Tiled or laminate floors or other kinds of institutional haptics, such as 'wipe down' material coverings of armchairs in the communal spaces, enable staff to manage spillages and continence issues hygienically. These items engender an institutional feel rather than a sense of home and possibly convey confusing messages to residents. These material aspects of the organisations feed into an experience of place that relates to notions of 'keeping order' and are about 'standards' and 'the management of bodies'. Buse et al (2018) has pointed to how laundries in care organisations, wash clothes on extremely high temperatures to manage infection control. Samuel's wife complained that his clothes were often in need of repair. She didn't know whether it was connected to the laundering of his clothes or the way that his clothes were removed; but certainly, the hot temperatures used would impact on the wear and tear of residents' clothing.

These elements of the care organisations reflect that they are work-places, made to practically manage the bodies that reside in them (Buse, Martin and Nettleton, 2018). Other aspects of the organisations might signal 'home-place' and these may be deliberate attempts to create a more 'homely atmosphere', but these are not homely places. This observation has also been made often in the literature (see for example: Peace and Holland 2001, Edvardsson 2005). In my fieldnotes from Primrose residential dementia unit I write:

> *There is a slight smell in the corridor, a kind of old smell, a musty smell although everywhere is spotlessly clean. The walls are painted cream, and there are handrails along the wall between the doors. [The] doors are labelled and the walls have tree wall stickers, there are pictures of sunflowers and each room has a memory box with photographs or information about the person [whose room it is]. I hear a scream and more calling of 'help me, help me, help me'. The nurses' station area is full of notices – and information – MCA, safeguarding etc.* (25th November 2011).

I will use this extract to explore a few of the tensions created by providing long term care in these organisations or, in the case of Sandbridge ward, a more temporary home situation. The extract describes how the corridor is equipped with hand rails to help bodies that may need support to move. The environment is signalled as 'friendly' and 'caring' through the use of decorative stencils of butterflies and trees; images associated with positivity, nature, and the outdoors. Many residents on Primrose residential dementia unit do not go outside and this is perhaps a way to bring the outdoors inside.

Domestic staff were regularly visible as cleaning was regularly carried out during the day. Despite this it was not possible to eradicate the very real smells of ageing and leaky bodies that can overpower and leave traces of these bodies in the air. The memory boxes described in the extract are an important reminder that residents on Primrose residential dementia unit have histories and biographical narratives, but they are also a reminder that they are people that need to be known because they are not at home (or with family) and are not necessarily known to either staff or other residents. Residents here live in a communal setting of (familiar) strangers (Morgan, 2009; Lofland, 1989) and can only be known to those that work there through these clues to their previous lives. The extract mentions the 'nurses station', which was in the corridor outside a resident's bedroom. It was a space where the lead nurse

undertook paperwork and administered care for the day. It was another reminder that this was a work-place and not simply a home-place. The station housed notices for staff to ensure that they knew how to carry out their roles correctly. There were also reminders about hand hygiene, the Mental Capacity Act (2005) and safeguarding issues. The station reinforced that the environment was a work-place in which risk and care standards had to be managed (Punch, McIntosh and Emond, 2012).

Although, as noted in Chapter 6, the hospital only provided a temporary home in comparison to the other two care organisations, it did attempt to provide some aspects of a domestic 'home'. There were pieces of furniture which were more in keeping with a home styled environment, such as a faux wood cabinet under the television where games were stored. A particularly surprising resident on Sandbridge ward was the cat that lived there. This was out of keeping with a usual hospital environment, but here in the specialist dementia ward the cat was permitted. A cat is a domestic animal and thus presented a conflicting symbol of the domestic into the atmosphere of the ward. The cat shifts the atmosphere as it moves through the hospital; it creates its own atmosphere as it moves through the space. For, as the cat slopes through one room to another, it takes with it the trace of domesticity that might be associated with having a pet at home. In that moment, there is an inter-weaving of home-life and hospital-life as the atmospherics alter the feeling of the environment. This example shows how finely balanced the atmospheres that emerge are and how they are constantly changing. In a moment there is an atmospheric shift and then there is the lull back again to the institutional everyday feel, as the cat disappears out of view.

The staff at all three organisations wore uniforms. These differentiated staff from residents and conveyed staff roles within the organisations' hierarchies. Colour coded uniforms also depersonalised staff as they were depicted by their status and function, telling residents what they do rather than who they are. This was in keeping with the focus on task and role within the normative regulations and procedures of care. For instance, on Sandridge ward, the qualified nurses' uniforms were a different colour to the uniforms of the unqualified nursing assistants and these were a different colour again to the domestic workers' uniforms on the ward. Confusingly, there were staff on Sandbridge ward who were not required to wear a uniform, such as members of the occupational therapy team, the psychologists or the psychiatrists. In Forest Grove, there were a number of different uniforms, from the care

assistant uniforms, waiting staff uniforms, catering staff uniforms, nurse uniforms to the hairdresser. The managerial staff and office staff wore no uniform. In Lincoln Manor, uniforms differentiated care staff, nurses, maintenance staff and office staff - who were not required to wear uniform.

Uniforms are considered hygienic and tend to be worn by those working with residents in care home settings (Charras and Gzil 2013). Therefore, by and large, it was clear that those not in uniform were the staff least likely to have contact with residents and their bodies. An exception were the occupational therapy and psychology teams on Sandbridge ward. Team members did have frequent contact with residents but were not required to wear uniforms. This was to create a sense of connection with the ward's residents as their role was considered to be 'therapeutic' rather than about the 'maintenance' and the 'management' (including body work) of those with dementia resident on the ward (Timmons and East, 2011). This strategy suggests that professionals understand that uniforms separate and create disconnect rather than bring people together.

In a discussion group held in Lincoln Manor staff described a situation where the boundaries created by uniforms were dissolved. Their description of a holiday with residents suggests a very different kind of atmosphere can occur outside of institutional structures:

> *Care worker 3: I found was when we went away for a week's holiday with them [the residents], and the difference in the men when they were on holiday was amazing, like totally different people, and because we don't wear our uniforms on holiday either, they bond more with you don't they, yeah, yeah.*
>
> *Sarah: Felt like they were more open?*
>
> *Care worker 3: Yes, completely different.*
>
> *Care worker 4: Yes, like when you're here as much as how friendly you are, you're still a member of staff, but when you're out of uniform you're more kind of a friend. They can chat to you.*

Care worker 1: It's like here with meals, when you're on holiday you're all eating your meals together, as I say when you're serving their meals and you're going for your dinner afterwards kind of thing, but [on holiday] you're all part of one kind of group, kind of thing. So, it's a totally different environment, yes.

Sarah: You belong together?

Care worker 1: Yes. (26th September 2013).

In this recorded exchange, staff recognised that their uniforms and institutional routines separate them from the residents and impact on the residents' experience. The shift in the power dynamics when on holiday appears, in this extract at least, to be created by taking away the institutional uniforms and the separation created by routine tasks such as staff serving meals, rather than sitting together to eat and share social time. Staff suggested that, whilst on the holiday, they were more like friends than employee and resident.

Disposable blue plastic aprons were also used in two settings. On Sandbridge ward and on Primrose residential dementia unit they were often put onto residents during meal times whereas at Lincoln Manor staff wore them whilst serving meals, reversing the 'norm' about who needed to be 'maintained' and 'kept clean'. In both situations the introduction of these material, protective, disposable objects contributed to the experience of the spaces and how residents and staff felt. They created a visual prompt that these were care organisations or 'institutional settings' rather than domestic settings, adding an atmospheric quality to these material things. Many of these products are not associated with care at home, although domiciliary care at home also brings a change to the domestic home environment through the introduction of 'materialities of care' and practices of care that have institutional origins.

5.5.2 Public and Private Tensions

The care organisations also differ from domestic homes because the communal spaces contain few, if any, items displaying personal biographies, due to the nature of collective living. Even where furniture is similar to furniture likely to be seen in a domestic home, it acts only to 'stage' home life. As an illustration, the cabinets and shelving in the main lounge

areas of the three field sites held no evidence of a relationship between the care setting and those that lived there. Although there were ornaments in some of the settings, there was not the clutter of everyday family life or framed photos or other types of material objects that linked a person to their home (Hurdley, 2013; Miller 2008). Any objects from the residents' previous homes were kept in their bedrooms, such as photographs of family members, or even kept on their person, as with Harry for example. On one occasion, during an interview with Harry and his daughter, I asked about the jacket he always wore and he patted his jacket pockets and said:

> *This is the one that I stuck to actually, I quite like…I like this jacket…it's comfortable. And it's got plenty of little things where I can put my peppermint…I've got my fags.* (2nd October 2013).

This example of Harry's jacket, an important aspect of his 'appearance signature' (Campbell et al 2015; Ward, Campbell and Keady, 2014), suggested a gendered importance for men regarding pockets and that in this particular instance, that Harry had everything he needed with him. Harry always wore this outdoor clothing inside, always ready to go out for a cigarette, but also of value for what it carried inside its pockets. As in Buse and Twigg's (2014) work on female care home residents and handbags, here Harry's pockets held for him a personal world in the private space of his pockets.

To develop the above point further, on one occasion Harry was upset because his electric razor had gone missing. This incident demonstrated how belongings often held risks for residents of further loss and disconnection. Items regularly go missing in care organisations, particularly clothing, which is a common complaint from family carers (Buse et al, 2018). Moreover, the incident here also revealed the increased importance of keeping material possessions close to the body and to the person wherever possible. This was of particular importance to Harry, who lacked private space in the home as he also shared his bedroom with Charlie, one of the other participants in Lincoln Manor. Personal possessions were limited in the care organisations; a life-time of living reduced to a handful of photographs, and what Harry did value were the accoutrements for his everyday life, and he liked to carry these with him. Harry often made quips about Charlie and told me how he didn't get to sleep well because of someone always getting into his bed at night. Private space was harder for

Harry and Charlie to achieve than most of the other participants who at least had private bedrooms. It was in these spaces that participants would have some items from 'home' such as photographs and sometimes their own toiletries.

On Sandbridge ward, in Don's compact bedroom, there were few personal features, other than his clothing and some toiletries, although he did have two photographs with him. In my fiednotes I note on more than one occasion the visibility of paper towels which are not a homely item, described here in one account:

> *Don's room is pretty small. At the sink are one or two items, but very few, some toothpaste and a toothbrush. His bed covers are pulled back. On his dressing table are two photos, one presumably of his granddaughters and another one of him and his wife looking happy. There are some paper towels under the sink and in a corner by the door, a pile of clothes and some more paper towels.* (13th February 2012).

The lack of possessions can be taken to suggest the impermanence of his place on the hospital ward, although the room is also so small it does not provide much space for items to be brought from home. Samuel, whose bedroom I also visited on Primrose residential dementia unit, had just a few reminders of home despite Primrose residential dementia unit being his new permanent home. Samuel had some photographs of family members, and a framed newspaper article about his wife and his golden wedding anniversary and a few of his treasured model trams. Whilst I knew from conducting an interview with Samuel's wife that he owned many possessions - he had collected models of trams and had hand crafted pieces of furniture in their family home - but most things had not been moved with him to Primrose residential dementia unit. The materials of the institution, and perhaps the lack of objects from home, denote the tension of the environment as a workplace, and as a place of care where home life felt more staged than authentic. Thus, this tension between work-place and home-place contributed to the atmospherics of these care environments. I want to go on to explore in more depth in the next chapter how these tensions of work place and home place push against each other to produce atmospheric currents.

The relationship that staff have to the furniture around them acts as a reminder of how staff view the spaces through the lens of the care tasks that must be performed. The staff consider

furniture with regard to their ability to undertake their work tasks. Here, in this extract from a discussion group with care staff on Primrose residential dementia unit, care workers describe moving furniture around to enable them to undertake their tasks:

> *Care worker 1: I think the facilities are alright but it's just the rooms, sometimes, are a bit small when it comes to, like, hoisting, you know, if we've got to have a cabinet in there and there's drawers and the bed and the side table, it's hard, especially if you've got, like, to operate a hoist, you know, you've got to…sometimes, you've got to rearrange the room about to move yourself around.*
>
> *Care worker 2: Because, I mean, the residents changes, you know, somebody was, like, a lady who could walk by herself, so she was alright in a smaller room but, then, when somebody else comes, we need the…we're meant to use it to get them out otherwise it gets difficult sometimes because the room is too small but, yeah, we just rearrange the room.*
>
> *Care worker 1: You just adapt, you just get used to it, you just adapt to it. There's nothing that can be done about it, so you just rearrange the room.* (4th October 2011).

The material aspects of care present a division between the bodies being cared for and those doing care. They also bring the institution into private spaces, such as bedrooms and bathrooms, and act as a reminder that these are not domestic private spaces but are spaces always under the surveillance of the institution (Lee Treweek, 2008). The staff think nothing of moving around a resident's room to enable them to get on with the task in hand, in some ways it is as much 'their' space as the resident's. Another example of this use of space for staff work purposes was in relation to the tables in the dining area that represented a 'desk' area for them to write up their care notes, and not a place for eating. The furniture had dual function and when laid with knives and forks, signalled meal time for the residents, but once cleared enabled staff to use them according to their needs. Staff ate in a 'staff area' out of access to residents, within the care setting they were separated from the residents through the organisation of space and through the materialities of the setting.

There were other aspects of the material environment that troubled the distinction between public and private as the residents attempt to make sense of their environments and this was often to be seen through the clothing worn by people living in the care environments. The men in Lincoln Manor were often wearing their outdoor shoes; similarly on Sandbridge ward, the men would sometimes have on outdoor footwear as if ready for going out, and a number of men wore their caps. As already discussed, Harry and his outdoor jacket enabling him to move readily from indoors to outdoors between the patio for smoking and the dining hall corridor. It is important to note that Harry's wearing of his outside jacket would also signal to others that he was not feeling at home, but rather was acutely aware that he was in a public place, always ready to leave. He was not able to keep his cigarettes out on a table beside him as he might have at home and so this was not like home for Harry and likely not for those around him (Van Steenwinkel et al 2014).

5.5.3 Symbolic materialities and atmospheric affect

In all settings care staff and nursing staff wore blue latex gloves to undertake 'bodywork' such as shaving. Blue gloves represented the need to protect staff from the potential harm of messy and dirty bodies and the risk of being infected. Plastic aprons protected residents from making a mess on themselves thus reducing them to past infantile times of bib-wearing or being given 'toddler cups' to avoid the spilling of hot drinks that could scorch skin. These material aspects of the environments feed into the environmental atmospherics and the tensions created through the institutional aims to maintain order and keep bodies in place. I will develop this point further in the final section of this chapter. In Lincoln Fields, where staff wore the blue plastic aprons to serve meals, it demonstrates the privileging of their uniforms and possibly the desire to keep a professional standard with a clean uniform. Uniform maintenance is an essential criterion in the armed forces and so it is possible that there is an emphasis on management of uniforms within the home for ex-military personnel.

In Lincoln Manor, the material objects of home and the materialities of care were also contrasted with military decoration. Parts of the care home were particularly grand, especially the entrance hallway with high ceilings and military decoration abound. Residents were rarely seen in this area; the space was filled by a huge wooden staircase leading to the upper floor, plaques and service memorabilia on all the walls. The military materiality creates something understandable to the men who had served in the armed forces, and it appeared so

because the men often talked about their time in the military; which regiment they were from, where they had been stationed or they would show me their medals. These elements of the material environment were significant in aspects of the atmosphere in this particular setting that was one of reverence for the past, tradition and a way to assert military honour and with that also military hierarchy. These representations clearly had atmospheric effect; the men talked about how each other looked, whether they were smart or not and Harry in particular would ask regularly when Armistice Day was lest he forget.

For me, observing in Lincoln Manor was interesting because of my own connection to the military. I had been born in a military hospital in Germany and had adopted throughout my childhood the identity of a 'forces child'. My father was in the Royal Airforce for the first fourteen years of my life. I grew up moving around and spending time visiting air force bases. The military uniform, and the reverence to hierarchy and order, had been part of the atmosphere of my childhood; although my dad had always butted up against the military hierarchies and felt conflicted by them. This meant that during my fieldwork observations at Lincoln Manor, I felt my own reverence towards the men who had served in the military and also my own irreverence towards the military decoration and pictures of royalty around the care home. The men who lived in Lincoln Manor may have a great deal of respect for the history and tradition of military service and to them being around these military decorations might signal an expectation of behaviour required from military personnel and as such reconnect the men to their past.

Another striking aspect of the building in Lincoln Manor was in the grand hallway where there was also an office area where a receptionist worked and who managed entry to the care home. The receptionist worked behind a glass screen which housed her inside a glass box that kept her separate from any of the men who did come into the hallway. This was a striking aspect of the room; it appeared as protection for the receptionist so that the female receptionist never had to come into physical contact with the men and perhaps even to protect her from the masculine threat and predation of men. It was part of a constructed narrative of care that the (majority) male residents were perceived by the care organisation as potentially dangerous, and so needed to be set apart from the female administrative staff (Hollander, 2001). On Sandbridge ward also, female staff mentioned their concern regarding possible violence from residents, particularly the male residents. This contributed towards a material

construction of gender in the care setting regarding how the men who lived at Lincoln Manor might be perceived. It also acted to separate the receptionist role from the work of the nurses and caring staff, and as such, fed into a hierarchy of roles, dirty work and non-dirty work. Much of the work of the caring staff, and some of the nursing staff was work done unto bodies, and this work is often considered to be 'dirty' because it is intimately in contact with leaking, and in this case ageing bodies (Twigg, 2002). The receptionist did not wear a uniform and was protected from the 'dirty work' of care in her glass box.

Upstairs at Lincoln Manor were ornate meeting rooms and a military museum, and during the entirety of my fieldwork, I never saw any of the resident men in the museum or in these rooms. This was where the management and office staff worked and where the trustees and the medical advisory board met. It was a part of the care home that held something of the care home's history. These rooms were far grander than the lower level communal spaces, and they housed the decoration of military history that formed a part of the cultural heritage, showing and honouring military regiments that had fought through both world wars since the home had opened. The rooms upstairs had carved fireplaces, and great portraits of military leaders and the British Royal family. The portraits were that of the military leaders rather than the servicemen, and it echoed the hierarchical divide between the men who were in charge of the care home, and those that lived there. In the following extract from my fieldnotes I write about how I am struck by the materiality of the environment which provides a backdrop of the home for ex-servicemen:

> *There is a brass sign that says 'dedicated by Order of St John Jerusalem and the British Red Cross'. It occurs to me that this [room] might be more like a mess room than a living [or dining] room, which is the place many care homes try to recreate. Here none of the [day] lounges have 'knick knacks' and [there are] also few pictures. The walls of the corridor are covered in pin boards for notices, photos and information. There is also an activity whiteboard. Though rather incongruously in the middle of the dining hall ceiling is a mirror ball [which acts as a transforming feature for party/disco time]. The far wall features a clock and some no smoking signs.* (9th September 2013).

The floors are shiny tiled floors, with no carpets or laminate flooring; they were much more like a hospital floor might be. They perhaps provided further confusion and contradiction to what the space might be and how complicated it might be for the men to create a place that they can attach meaning to. The room I have described is functional and its lack of 'homely' objects set it apart from Primrose residential dementia unit, and yet it is also quite different to Sandbridge ward. The room was multi-functional, as many of the rooms were; the mirror-ball gave a clue to opportunities for social time and even partying. An aspect of the room not referred to in my notes here is that it houses a bar area, which is something that may also be found in a 'mess room'. A 'mess room' is a social area for service personnel, a place where they can drink off duty, wind down with friends and where social functions take place. In the military services, these settings are often organised according to rank; for example, you might have a 'sergeant's mess' or an 'officer's mess'. The brass sign that I describe is an award or symbol that shows a connection to the hospital service past of the organisation and is linked to wartime or active service of some kind. These are significant symbols of a setting that has a history that is beset with its own hierarchies and power. The military memorabilia performs a constant reminder to the men that live here of their positions and their duty to the armed services.

5.6 Dimension iii) The management of men's bodies

For staff, these settings are a workplace whereas for the residents they are a home-place, even if a temporary home. Prior to living in care, residents had (at least some) agency and they were able to have some control over when they ate and drank, when they went to the toilet, got dressed or socialised with others, or when and what they watched on television (Peace and Holland, 2001). As seen in this chapter, the institutional time zones which divide the day into different types of 'body times' are structured by the care organisation. All care tasks are focused on, and about, bodies and bodily functions such as grooming, bathing, toileting and changing continence pads, dressing, medications, meal times and hydration. This shows that the scheduling of the majority of work in the care organisations are focused upon the need to maintain and manage a collective of bodies and in the case of this work, the male participants. In my field notes I write about morning routines in Lincoln Fields in the following way:

> *It's early in the morning and the care workers are gathered in the area for provisions. They pile up stainless steel trolleys with pads, towels, bic razors and shaving foam. Dave, a male care worker goes to see Charlie first and says he will call me when Charlie is ready for shaving, as I can't watch the initial getting ready [Charlie being supported to get dressed], from a state of undress*. (7.45am. 18th September 2013).

This gathering up of collective bodywork tools, the accoutrements of care work symbolises the work ahead for the care staff, and the number of bodies to be managed. In my notes I particularly highlight the cheap 'bic' razors that staff in Lincoln manor complained about, as they are not easy to shave with and hold risk for the men as they do not move with ease across older and more sensitive skin. Indeed, across all the fieldsites, staff complained about the quality of the razors and shaving foam for the male residents, most of whom were clean shaven and wanted to be that way. My fieldnote extract also mentions 'pads', which highlights the vulnerability of the residents and how they no longer have continent bladders. The pads are a sign of the need for hygiene control for those with incontinent bladders, and the sight of them 'piled high' on the trolley for all to see is a visible sign of the residents' dignity being made vulnerable in the public spaces of the home.

Residents were not always keen to undertake routines at these times and the requests by staff could seem incongruous with the time and setting. For instance, in the example that follows from Primrose residential dementia unit, it is breakfast time, just after 9.50am, and a care worker is sitting at a table planning meals for the following day:

> *Bryn is sat in his pyjamas in the dining room in his wheelchair. He is eating a banana. He is sat in a space away from the edge almost in front of another man. A care worker is sat next to Bryn doing paperwork. She is organising tomorrow's lunch. She turns to Bryn and asks him 'what would he like for lunch tomorrow?: Bacon, sausage and egg or jacket potato?'Bryn says 'You what?' and she asks him again what would he like for his lunch tomorrow. Bryn laughs and leans back in his chair. He doesn't know what he wants for his lunch tomorrow*. (29th November 2011).

Bryn's laughter suggests he finds the question silly, perhaps even unbelievable as a real question, as he sits eating his breakfast and has likely not even begun to think about lunch for

that day let alone tomorrow. The staff member asks the question as she is in a 'task-mode' and her question is focused on maintaining the normative schedule for the present in getting her job completed, and in organising the coming day. The opportunity of being sat beside a resident is not taken up with a conversation, despite being at the 'breakfast table', for her she is at her desk 'working'. The organisation and structure of time imposes unrealistic decision-making onto the residents and also shows the limitation of agency even in this supposed opportunity for personal decision-making.

The order and structure of care organisations is different to those of a domestic home setting. Whilst domestic home life might also be ordered around meal times, and similar morning and bedtime routines, these are not the collective routines of an institution organised for the many and temporally ordered by a system and structure and delivered by employees (Punch, McIntosh and Emond, 2011; Peace and Holland, 2001). There is at least a sense of freedom from these routines in domestic home life, if desired; although possibly hampered if domiciliary workers are needed to support routines; however, there is not a collective to be managed in a home environment and there is at least some opportunity for spontaneity. It is the strict adherence to tasks and temporal orders that create an atmospheric current in these environments.

Gender was also a significant aspect of bodily management and possibly particular notable: the control of male bodies. In all three settings, the majority of staff were female, particularly the staff team engaged in bodily care. Hence, gender is often brought into focus through care activities. In the care notes written by staff on Sandbridge ward, terms such as 'co-operation' and 'appropriate' were terms frequently found to describe how Larry and Don behaved during routine body tasks. Compliance was desired and the notes written suggested when the resident was well-behaved. Acting out of line is, at the very least, noted and recorded (Foucault, 1991; Stockwell 1972). However, there is also a continuum of recorded behaviour as in Sandbridge ward, one [staff] to one [person living with dementia] intervention, is seen as usual should the person be acting against the collective requirements of the care organisation or hurting themselves or someone else. Below is an example of care notes relating to Don:

> *Stayed in bed until 1pm, washed and dressed himself appropriately. Had a late lunch, settled on the ward. Refused to change into night clothes*. (18th January 2012)

The notes are brief without context and about Don being in or out of line. He has pushed against the daily rhythms by not rising in the morning and so all the routines are out of the timed order of things. He later refuses to change into his pyjamas; perhaps for Don this symbolises that having risen later he is not tired at the time suggested for this routine act. However, the time is not noted by the member of the care team who wrote the care note. Residents are perceived through how they are in relation to enabling staff to carry out their care duties, and this continues to feed into the normative conditions and atmospheres of care and how these are reproduced through everyday interactions.

The atmosphere on Sandbridge ward was often tense and heightened due to the ward merge between the male only ward that had closed and the mixed ward. It appeared that gender was an important element of the mood amongst staff and may have fed into the normative atmosphere, creating even more desire and need for control. This was illustrated by one nursing assistant on Sandbridge ward when she said:

> *Well, recently, the mixture of patients has been very, very difficult, you know, because [the male] ward closed and we have these quite difficult men to deal with. And it is … that mixture, with the vulnerable patients, that has been very, very difficult, very stressful, and sometimes not having enough staff … And at the moment, there's so much going on in this particular area because certain wards are closing down. They're amalgamating wards and it is … some of our jobs might be on the line. It is all very, very stressful at the moment. And I think people are doing really well to come in, those people that are still coming in and getting on with the work it's*. (Nursing assistant. 26th January 2012).

The same nursing assistant described the unpredictability of working with patients living with dementia:

> *There again I could go in with somebody one day, say a guy, and he will… he'll be… he'll shave himself and he'll give himself a wash and… do you want to wear this*

> *today? Yeah, yeah, yeah. Yet the next day I could go in and he could be completely different. He will be very difficult. He won't let me wash, won't let me shave him, and very difficult to dress. That's how they are, so changeable.* (Nursing assistant. 26th January 2012*).*

This was also reflected by staff at Lincoln Manor, another majority male resident environment. One female Care worker noted during the discussion group:

> *The difficulties in a mostly male environment is the strength the men have obviously. They are obviously a lot stronger than we are, and also when they become aggressive, they can become quite frightening, because of that aggression. It could be like silly little things that turns them, just one silly little thing could turn a man, and you think, where did that come from?* (Discussion Group. 26th September 2013).

During my time observing on Sandbridge ward, on a couple of occasions I wanted to observe Don having a shave and visiting the hairdresser. Staff were concerned about Don; they worried that he was 'paranoid' and did not want to be watched. In reality, on the three occasions I observed these activities, it worked out fine with Don and he was actually more than happy to have me there. But it did not stop me also feeling a more heighted sense of concern, that something could 'go wrong', or that Don may become aggressive. Hence, I became affected by the tension in the atmosphere and it affected how I carried out my filming activity with Don whilst he was having his hair done. For example, I made a decision not to move around in the salon which I would usually do in other process films (Campbell and Ward, 2017), and instead I remained static with the camera. I also switched the camera off immediately after the hairdressing was completed so as not to antagonise Don, or feed into any concerns Don had about being watched (although Don had also agreed to me being there). In fact, during the whole activity, Don appeared amiable and relaxed whilst at the salon. Managing risk as a way of controlling male bodies is an integral aspect of the normative regulatory conditions of care for staff, and perhaps here for me also. Staff - and myself as well - were already nervous around Don, knowing that he had arrived on Sandbridge ward having hit out at a member of staff whilst in respite care. Perhaps we were simply projecting our uncertainty onto his vulnerability and unwittingly adding into the atmosphere our emotions of fear and control? It was clear from talking to some of the staff

on Sandbridge ward that they were concerned about the threat of violence, as noted in the quote above. Hence, these feelings from staff were interwoven with the ward atmosphere.

5.7 Dimension iv) Gendering the atmosphere

Gender has already emerged throughout the chapter in how the experience of everyday life is felt by both the men and the staff in these care organisations. Such as in the example above about how the men were sometimes perceived by staff as on Sandbridge ward to be more unpredictable and potentially violent. The care organisations were constructed materially to protect (some) staff from the male residents such as the receptionist in Lincoln Manor. In this section I will extend these examples further and show how the experience of gender and sexuality emerged as an aspect of the atmosphere due to these everyday relations at play and these constructions of gender. I wish to focus on how gender and sexuality are experienced by the men in the study. For example, through the normative regulations that are in some way used to 'direct' or 'orientate' residents towards certain spaces, activities, and objects (Ahmed, 2010b).

The providers who deliver care within Primrose residential dementia unit had attempted to create a more 'home like' environment. The decor here might be described as more traditionally 'feminised.' The walls in the corridors were decorated with stencilled butterflies and flowers and these kinds of decorations are more often associated with femininity. They can be traced back to the gendering of young girls with butterflies and flowers which are often patterns found on the clothing of young girls and their toys. In the communal spaces the decor might also be described as 'chintz', a trend of decoration that is also linked to femininity and would encompass table cloths, doilies, flowers in vases and ornaments (Sewell, 2008). Neither Samuel nor Brynn spent much time in this feminised space, and it might well be a place where many men would feel 'out of place'. Most of the care workers, or nursing assistants in all the sites, were women. There were only a handful of male workers across all three settings. This communal lounge on Primrose residential dementia unit and the decorated corridor contrasted starkly with Lincoln Manor. At Lincoln Manor, it might be described a masculine environment. Decoration here was in the form of the military memorabilia which may be considered more symbolically masculine and the setting itself had previously been a home for ex-service men, only recently opening its doors to all ex-service

personnel. However, there was still a predominantly female workforce. This may explain why aspects of the design of the environment was such that it reinforced particular constructions of men as already examined with the glass reception box that kept the reception staff 'safe' from the reach of the men.

At Lincoln Manor, male voices and shouts travelling through the radiowaves added to the sense of it as a male space. On one occasion in Lincoln Manor, a man apologised for swearing in front of me, a suggestion that it was the way men spoke to one another and that it was not something that should be done 'in front of ladies'. This was a notable contrast to Primrose residential dementia unit, where the voices in the atmosphere were mainly female, and one particular woman's voice could often be heard calling out 'I want to go home'. There was also another woman who was a participant within the wider study who acted as a spokesperson for many residents in the living area, calling out when someone needed the toilet or asking to play dominos when visitors arrived in the communal area.

All the men living with dementia who participated in the research were known to have lived heterosexual lifestyles, and in the private bedrooms where I was allowed access I saw they displayed photographs that represented these married lives and the men's status as husbands, fathers and grandfathers. Further to this, in Lincoln Manor in particular, where most residents were male, there was also a type of masculine banter and flirtation about sex and women that might be associated with male workplaces; hence, a further reference to the military heritage of the men living here. On one occasion at Lincoln Manor whilst I was sat with Harry, one of the male maintenance workers called out to Harry in reference to me: *'picked yourself up a bird then?'* The maintenance worker who issued this statement did so as a sign of respect for the older man, whom he lets know that he acknowledges his gender and sexuality despite where he is, living in care with dementia. As the very nature of living in residential care with dementia has the potential to undo masculinity, through its links to vulnerability and dependency, and here there is the reinforcing of a heteronormative masculinity by the maintenance man. His words linger in the air, affecting both the resident and me; this call out by the maintenance man suggests that there is an orientation that the men should be directed towards, and this kind of banter maintains the position and direction. The comment suggests a competence and youthfulness in the actions of the man to whom the statement is shouted.

That he has 'still got it', despite being here in this home for people who need support, he is still able to fulfil the requirements of a heterosexual identity.

These were heteronormative environments, with heterosexuality being understood here as a pinnacle of hegemonic masculinity (Connell and Messerschmidt, 2005). This banter and flirtation could also be found in the other two settings as well; on Primrose residential dementia unit, Samuel made jokes whilst being shaved about getting ready for a date, and one of the men on Sandbridge ward always winked at me when he saw me and was described by a care worker as a 'ladies' man'. However, this could also work in reverse as on Primrose residential dementia unit there was some flirting and teasing regarding a female resident who it was said 'fancied' one of the two male care workers. Thus, there was banter, teasing and flirting that occurred in these settings in order to uphold gendered expectations and there was a sense that heterosexuality was in the air.

The atmospheres become gendered and linked to sexuality through the sensescapes and bodily materialities; here I note in an observation at Lincoln Manor about how female sexuality stands out because of the worker moving amongst (almost) only male residents:

> *The staff nurse brings the man sat opposite me a drink. She brings a perfumed smell with her and it floats away as she walks off. Another member of staff walks out of the room and I notice in particular her walk, the swing of her hips. The different gait of women.* (9th September 2013).

Perfumes are highly sexualised in Western culture and advertising relating to perfume is almost always presented in order to promote heterosexuality (Amy-Chinn, 2001). Similarly, women's walks are sexualised through imagery and other media in relation to idea of swinging hips. Therefore, this particular gait is linked to a female sexuality and sometimes a racialized female sexuality (Borelli, 2010). This member of care staff becomes notable in this male dominant setting and appears to come into focus (to me in my observation) as a 'different body'. The scent of perfume wafted in the air, creates an atmospheric component which fits well with the notion of 'heterosexuality in the air' (Amy-Chinn, 2001). The perfume smell might also stand out in this environment against the other smells, such as meal smells, leaking body smells and even the smell of cigarettes as many of the men here smoked.

Despite the more often experience of people living with dementia being de-gendered, here we see how their gender is noted, upheld, and also seen as problematic and the care environments and regulations are constructed with this in mind.

5.8 Conclusion

In this chapter, I have identified four dimensions that manifest from the normative regulations and structures of the care organisations. These dimensions contribute towards the production of atmospheric moments that I will go onto discuss further in the subsequent chapters. These dimensions are significant in how they contribute to the feel of the care organisations and in how they illuminate the everyday tensions that exist across all three care organisations. Despite differences between the three participating fieldsites, the structure and regulation of everyday life operates around the same daily routines in notably similar ways. Each of the organisations look different in terms of the physical spaces, though they share similarities regarding the materialities and sensescapes of care. On Sandbridge ward, there is less intention to create home environment, as this is only meant to be temporary dwelling for the residents living with dementia who are in hospital specifically to be assessed and treated. Nonetheless, as a temporary home there is still the on-going tension and negation of the ward environments being both a work-place for some and a (temporary) home-place for others. These tensions are very clearly felt in the other two settings: Primrose residential dementia unit and Lincoln Manor.

I have also drawn out of these dimensions the way that gender ripples through the atmosphere, as sounds, smells, movements and the way that gender and sexuality are constructed in normative ways by the care organisations themselves and through the attitudes of staff. The experience of dementia also meant that residents were sometimes seen to be even more unpredictable due to their condition. This is especially so on Sandbridge ward where residents are placed there due to 'unpredictable behaviours' in the community. However, this ripples through the staff attitudes within all the settings and contributes to the atmospherics of the care environments.

For the men living with dementia in these settings, they are living with limited choices and have their days managed and routinised through the regulatory and organisational structures.

It is through these four dimensions that the atmospheres become notable through a 'close tracing' of the rhythms of everyday life in the care environment (Carlson and Stewart, 2014). The following two chapters will illustrate the conditions in which atmospheric moments occur. In Chapter 6, I will explore how the atmospheric moments of resistance are produced out of the tensions created through the four dimensions and how the power dynamics of the organisations are resisted by the men.

Chapter 6 Findings (2) - Producing Atmospheric Moments of Resistance

6.1 Introduction

In this chapter, I move on to reveal how the normative regulations of the care environments produce atmospheric moments of resistance, and how these atmospheric moments are created and emerge in the everyday spaces of the care organisations. Atmospheric moments are produced as a set of conditions that come together or which, in fact, push against each other. They emerge as a direct result of the kinds of conditions created through the ordering and structuring of time, and through the material and sensory environments, and through the collections of individuals working and residing in these care organisations. Atmospheric moments of resistance bubble up in a moment, and then they lull or pass; on other occasions, they are more sustained and arise from the tensions created from the problematic dichotomy of the care organisations operating as both work-places (for some) and home-places (for others). As described in Chapter 5 they are produced as residents struggle, or resist, the organisational structures of the care organisation and because of the discordances caused in these different rhythms. These moments emerge from, and through, the bodily responses to being orientated by the normative care regulations as the care organisations aspire to provide order and to manage the collective. In this chapter, I propose four types of atmospheric moments of resistance which emerge from the different experiences of living within the regulatory conditions of time and order: i) Waiting; ii) Uncertainty; iii) Temporal resistance; and iv) Resistance stories. Each will be discussed in turn.

6.2 What are atmospheric moments?

As Mason (2018a) asserts, a moment is not a precise amount of time, instead 'moments are charismatic not because they are measurable fractions of clock time (which they are not), but because 'they are multi-sensory glimpses, windows, apertures or revelations' (p193). Hence, in the three care organisations, I regularly recorded atmospheric moments of resistance within the fieldnotes which emerged as regular disruptions to the normative scheduling and structuring of the care environments 'bubbling up' during both 'institutional time' and 'in-between time'. They were sometimes affective and would produce ripples that could become

palpable and could be felt in the air. At other times, atmospheric moments were experienced as currents of resistance that were felt when someone refused to take part in an activity which may have accounted for a shift in energies in the environment. These atmospheric shifts produce and create the emergent atmospheres that are always becoming, as in they are never fixed - in a moment, they have altered.

For staff in the three care organisations: Primrose residential dementia unit; Sandbridge ward; and Lincoln Manor, the structure of each day was tightly scheduled and ordered, and staff knew what was expected of them as their days were dictated by institutional time and the ordering of care tasks. The construction of time as institutional time and in-between time produced particular atmospheric moments that were a direct result of resisting or existing within these time structures. Atmospheric moments of resistance emerge as a current, a charge, a frisson, and can be glimpsed as they are experienced by residents and also in how residents become part of their making. The chapter will now reveal how each atmospheric moment of resistance was produced and how it emerged in the data, beginning with the atmospheric moment of waiting.

6.3 Atmospheric Moment of Resistance 1: Waiting

Atmospheric moments were often experienced by the men situated within 'in-between time'. In-between time could feel like it stretched ahead in all of the organisations, occurring after morning routines, when residents are washed and dressed before breakfast begins. In-between time existed outside of the institutional rhythms that engaged the staff in daily practices. Once breakfast was completed there would again be in-between time when residents were between activities and so on throughout the day. With the institutional routines completed, residents waited for the next organised task. This lived experience of in-between time reveals a momentary sense of waiting in the atmosphere. The experience of waiting was produced in moments that passed between the men or might be noted as a flicker across one person's face caught by another. These atmospherics could also be conceived through the types of clothing worn by residents; for example, Harry in Lincoln Fields with his outdoor jacket and outdoor shoes as discussed in Chapter 5. Harry carried his important items with him and he was always ready to move in and out of the day room to go and have a smoke outside. Many of the men, Don, Bert, and Larry, often wore outdoor shoes suggesting that they were not 'at

home' and signalling this fact to others too. Rather, they were always waiting and ready to leave when, and if, the opportunity arose. The rhythmic movements of the men pacing, getting up and changing seats, or going on 'walkabouts' for a cigarette like Harry, carried atmospheric charge, as the men attempted to fill and pass time. Sumartojo and Pink (2018) say that moving through the world gives people a sense of understanding, a way to know, and that movement is at the centre of atmosphere. For these men living with dementia, they move off in another direction, possibly hoping to understand more about where they are, or what might happen next. The waiting could have a feeling of anticipation about it, that something was about to happen, or should be happening, a sense that the men were waiting for the next thing on the daily schedule, or perhaps someone to arrive.

Don on Sandbridge ward spent a lot of time hovering at the ward exit, sometimes looking through the door window, moving away and moving back again. On one occasion I wrote in my fieldnotes:

> *Don stops at the [ward] entrance uncertain where to go. He pulls his cardigan down straight and pauses*. (4pm. 26th January 2012).

Sometimes he might have been waiting for his wife to arrive, or at other times he would wait by the exit after she had left. The time of this fieldnote suggests that he had been waiting around the exit since his wife's visit, possibly uncertain, or confused, as to why he had been left behind. In these notes, Don's embodied movements, the pause, the straightening himself up, making himself presentable suggests that he is taking a moment to figure something out for himself. He straightens his cardigan perhaps for comfort, but also perhaps an embodied response to an internal resilience, putting his best foot forward, a moment where he is deciding what now, what comes next?

After visiting time ended on Sandbridge ward, there was often a lack of activity on offer which led to a charge in the air, a tension related to this new discordance as residents were once more abandoned back to in-between time. Don would leave the exit and walk around the ward area for a while and then find himself compelled to move back to the door, seemingly waiting for someone to come in - or for himself to be let out. Although I cannot know what Don was actually thinking, the door did represent, and literally was, the threshold to the ward.

This act of waiting by the door might be perceived as an act of resistance to the position he was placed in. He was not in control of where he was living, and he had no power to leave, and so he would remain by the exit where he was distinctly apart from the rest of the ward activity.

There was often talk of leaving; a number of residents on the ward talked about going home soon, or that they were going home that day. One woman on the ward, could often be seen wearing her coat and with a bag packed ready to leave at any moment. Sometimes there were cries of 'I want to go home', familiar verbalisations, heard regularly both on Primrose residential dementia unit and Sandbridge ward, filling the air and adding to the atmospheric moment of waiting.

6.3.1 Waiting spaces

During my time in Lincoln Manor, I spent a great deal of time in an area of the home where Harry and Charlie spent their days. The physical space where the men sat could itself be described as 'in-between' insofar that it was not quite part of the day room, rather it was situated on the edge of the dining hall looking in. In some ways, it was more of a corridor space as it was a route into - and out of - the dining hall (see Image 3 on p98). There were some pillars in front of the seating that created a division from the rest of the dining area, marking it as distinct from the dining area. It was in this spot that a similar group of men would gather most days and this included Harry and Charlie. The men varied in age and did not all have dementia, although I did not have information regarding any of the other men's conditions outside of Harry and Charlie. Each day Harry and Charlie would independently take themselves to this spot. Despite sharing a bedroom and the occasional tension that this sometimes caused them, they would still spend the days sitting together. These two men had chosen to stay close to each other despite these tensions and the lack of privacy that they had in the home. There was a bond between them that seemed to be garnered through their proximity.

Residents were in a 'waiting space' as they waited for the next thing to happen, which could be a teatime, or lunch time or for an activity to begin, a sense of the atmospherics would emerge. The men often seemed unsettled and appeared to be waiting for something to happen, the frisson in the air was of imminence, a sense of what now? They would

occasionally talk to each other and this talk was often instigated by one particular man who I do not think had a diagnosis of dementia and who was not a study participant. Charlie would mostly have his eyes closed; however, his sleep was light, as if he too was waiting for the imminent thing that would happen soon, and he would at times respond to the movements and activities around him with bursts of song and talk. When I sat with the men, I also felt that I was waiting for something to happen and for something to record in my fieldnotes. I was both caught up in the atmosphere of waiting and imminence, and also a contributor to the atmospherics. I would pass the time by recording the small details around me, trying to capture as much as possible of the scene that I was both inside and outside of at the same time. It is important to note that I had the power to get up from my chair at any point and leave to a life outside of the space, just as the staff that worked there could; unlike the residents whose movements were monitored and restricted to within the care spaces.

Hence, in the seating area of Harry and Charlie in Lincoln Manor, together we would wait for time to pass, or for something to happen. For Harry, the day would roll out ahead of him; sometimes he would comment positively and offer to anyone listening, possibly to me, knowing I was listening, he would express *'I can't complain'* and *'I've had a good life'*. However, at other times and as the hours passed by, he would sometimes look at me, laugh and say *'it does get boring sometimes'* or he would get up to leave and go for a *'walkies'*. He did say one time that he went for his walkabouts because he couldn't be doing with the boredom. Another phrase he would often use at times of frustration was *'life's a bitch'*. On one occasion in my fieldnotes I reflect on this:

> *Harry says 'God, it's a boring existence in here'. I note how his mood has deteriorated through the morning and our earlier chat since breakfast. The workers are busy but many of the men are left to their long mornings since 8am. I think Harry has been up four hours. The smell of Harry's mints reaches me. I feel warm, I look outside and it is so much brighter than it was. It is dark in here, dimmed wall lights and no overhead lights on*. (11.40am. 25th September 2013).

For Harry, there was an experience of boredom that fed into the waiting atmospherics. The atmospherics were produced through the passing of actual clock time between activities, and

also here the dull lighting appears in my notes at least, and for me, to add to the sense of gloom in the space as opposed to the bright light of the outside world. Harry was often literally waiting; as he was waiting for the next time he could have a cigarette, trying to ration his expensive past-time. The smell of Harry's mints was an after cigarette sensory signal and also a before cigarette signal, part of the waiting atmospherics. After a while Harry would take off again, walking in a circle, out on to the patio and back to the place where his friends were sat and this was how he managed the 'in-between time'.

On Sandbridge ward there was also a sense of waiting as a part of the atmospherics as this extract from my field notes suggests*:*

> *I move to sit in the dining area where Don and another man are sat on different round tables to each other…the other man is whistling and tapping his wallet against the table…Don begins to sing and [then] it drifts off. Don sits watching the nurse's office where there is some activity, nurses are coming and going. It is like we are all waiting*. (2.40pm. 23rd February 2012).

In my fieldnotes, I reflect again on the experience of waiting and watching. The men are watching the staff actively getting on with routine tasks; they are busy with their comings and goings. Their movement enhanced the experience of non-movement for the waiting men who were situated in 'in-between time' in an 'in-between' place. It is also an uncertain time for them, as they do not know what is going to happen in the next moment or indeed in their lives, and they appear to have little control over the outcome. In contrast to the busy nursing staff, the men are showing bodily signs of waiting, such as one man tapping his wallet. Within other fieldnotes I make a number of references to tapping and the atmospheric rhythms of waiting. On another occasion in the afternoon on Sandbridge I write:

> *A man whistles and taps. Don gets up and hovers at the threshold and returns, up, down…another man keeps stating that he is fed up, whilst Don keeps walking around pausing every few steps orientating himself before moving off again*. (3pm. 26th January 2012).

Here my fieldnotes depict an observation of Larry on Sandbridge ward, I reflect:

Larry gets up and walks off down the corridor. A nurse calls after him to give him his medication. She says I have got your water tablet here, and he says 'What's that?' and the nurse says 'your water tablet' and Larry responds 'I don't know where to go now?' He returns to the sofa he was sat on before, but sits on a different side of it. Larry taps the side of the sofa with his med cup, tap tappy tap tap tap tap. He smooths down his hair on each side front to back. Then he gets up and finds somewhere to put his meds cup. (19th December 2011).

In this observation, Larry is uncertain what to do after he has taken his medication. Often after an activity or intervention has happened, there is a lack of clarity about purpose and residents can seem abandoned back to the in-between time zone where they may flounder or show distress. Sometimes, residents created their own moments of activity as they searched for something to do. In the extract above, Larry in the next moment decides to find somewhere to put the medication cup that he has been left with. His body responds to the waiting in the air, as he taps the side of the sofa, an associated waiting behaviour, perhaps an attempt to remember something, or a time filling response to the clock-time that stretches outwards, and onwards with no clarity about when it would end. A sense of clock-time is difficult for people living with dementia, never being quite sure how long something should take, or when something might happen (Nygård and Johansson's, 2001). The sense of not knowing how long waiting time will be can have an impact on well-being and can lead to emotional distress; there is a powerlessness that goes alongside the on-going waiting (Vitus, 2010).

These collective examples of waiting (and the boredom) emerge from the inactivity and the occasional frustration of in-between time; the tension felt from the dichotomy of work-place versus home-place and the busyness of staff and the inactivity of in-between time. The waiting which emerges in the atmosphere and is garnered through the bodily expressions and shown in the anxious movements of these waiting men. Tapping, pacing, humming, singing, sighing, verbalisations such as Harry's 'life's a bitch' statement are the sounds and movements that contribute to the atmospheric moments of waiting. The embodied demonstrations of emotion seep into the atmosphere and create a collective experience (even if individually different) of a resistance, perhaps, and frustration to the normative regulations of care. The men's coping strategies and the emotionality of their embodied waiting produces

charges and frissons into the in-between lulls of activity. The men are living time, now-time as they find ways either to pass time such as Harry's cigarette breaks, and Larry's movement around the ward area in order to cope with, manage and resist the normative regulations and ordering of the day and as they push against the boredom and the emptiness of in-between time.

6.4 Atmospheric moment of resistance 2: Institutional Uncertainty

Further to these atmospherics of waiting, were atmospheric moments of uncertainty that also brought a charge to the atmosphere. The normative regulations of the organisations create what can seem like a relentless structure for staff, but this often led to feelings of tension in the atmosphere. The residents were not engaged in activity continually in the ways that staff were which led to uncertain feelings. The feelings of uncertainty and anxiety would 'bubble up' and would have an emotional charge, affecting others and contributing to atmospheric moments, such as the moments where uncertainty was heavy in the air and then they would dissipate and meld into something else.

These atmospheric moments of institutional uncertainty were also produced as the men attempted to make sense of and understand their surroundings and the activities that were happening, or what they might be waiting for. Such as in the above extract where Larry is demonstrating signs of waiting, but then after being given his medication, is uncertain of what to do next. There were many moments of uncertainty during the days for the residents. Sometimes even when activities were taking place there was a sense of uncertainty about what was expected. For example, on one occasion on Sandbridge ward during an occupational therapy activity, Martha, the occupational therapy assistant, had a box of clothing items, cravats and wallets. In my fieldnotes I record this observation and the discussion that takes place between Larry and Martha:

> *Martha shows Larry a cravat and asks if he ever wore one. He says no he does not think so. A woman is distressed [something about her jumper] and Larry sits upright at the table and says 'I can't bloody stand this. It's stupid'. Larry [then tries to engage, almost apologising for his frustration through this act] he asks Martha 'where do the things come from?' and she says 'from a museum'. Then Martha says*

> *'you lot aren't very enthusiastic this morning' and Larry says 'I just want to know when we're going to start working?'; Martha says 'you are in hospital Larry and you're not going to work whilst you're in hospital and you've been poorly'*. (Morning. 19th January 2012*)*.

In this scene from my fieldnotes, Larry shows his frustration at being drawn into an activity that he does not really understand. Larry feels the effect from the emotion displayed by the distressed woman, which causes him to snap as he expresses his frustration and a desire to have more certainty about the task. The occupational therapy assistant is also clearly frustrated and she admonishes the group for not being more positive about the activity. Larry, however, does not feel 'occupied' and he relates this specifically to a feeling he connects to the desire to be working, to be occupied. In the extract he asks 'I just want to know when we're going to start working?' The frustration and confusion that can be discerned from this interaction between Martha and Larry shifts the atmosphere to one where institutional uncertainty is part of the atmospherics for that moment.

Again with another activity with Martha on Sandbridge ward, it becomes apparent that there was again a lack of clarity about the purpose of the occupational therapy activity and this emerges in the reflections I wrote in my fieldnotes:

> *The OT calls to Larry 'What do you think of the train Larry [she holds an old-fashioned toy train up to him], Larry answers 'very nice', she asks did you have one? He says 'I did aye; I'd like another one to play with', he looks at me as he says this and winks, then he says directed to me, 'have to do something'*. (26th January 2012).

In this activity, Larry once again finds it difficult to engage; there is a sense that there must be something more purposeful and here Larry is simply biding time. The Occupational Therapy assistant attempts to draw him into the activity which he subverts through winking (to me in a conspiratorial way) and noting that there is nothing for it but to join in, as he remarks directly to me *'have to do something'*. There are collective moments of uncertainty, but here this shift in the atmosphere is produced through Larry's affective response to being expected to join in with something he finds silly, strange or confusing and in fact despite

creating something to do, only continues to produce an experience of uncertainty in this atmospheric moment.

Another example of uncertainty seeping into the atmosphere was with Harry at Lincoln Manor. Harry would often ask when Armistice Day was, an important day for many of the men in Lincoln Fields, which homed ex-military personnel. It is a day that honours military service in war time and was a day that Harry could relate to, and that he understood as important and purposeful. It was also a day that would award him some status as an ex-army service man who had won medals for his time working in Northern Ireland during the conflict. He appeared to be waiting for this day and it was in fact not too far away, which he must have been aware of, and he most likely would have heard talk about it that had brought it to his attention. He would regularly ask what the date and time were during the days I spent observing at Lincoln Manor. This suggested he felt a sense of uncertainty, and he also did not want to miss Armistice Day. On one occasion I write in my notes:

> *He says…yes, seems a long time for a brew and an activity and things…do you know when Armistice Day is? And then he states, 'I'll be on parade then'. I ask if you keep a uniform when you come out of the services. He says 'oh no'. So I say do you put your medals on a smart jacket and he says 'yes, on a black jacket and I'll wear my hat…'*. (25th September 2013).

Here, Harry notes the long wait in between activities and the tea round; it also sparks a worry about when Armistice Day is; all this waiting, and a lack of certainty regarding clock-time, and what if he missed this very important event? In work by Nygård and Johansson et al (2001) people living with dementia report that it is difficulties in 'knowing when' something like an event was keeping track of time was challenging. We then engage in some chatter about what he will wear on the day and about his medals.

Another example of the production of an atmospheric moment of uncertainty could be felt in the observations with Charlie, also a Lincoln Manor resident. Charlie repeatedly asked during the days when I was observing 'am I alright?' On one occasion Charlie appeared to be asleep whilst a new resident was in conversation with another man on the row of seating where the men were situated. Charlie woke suddenly, turned to the new resident and asked 'am I

alright?' and the man reassured him that he was and Charlie closed his eyes again until a few moments later he woke and said to no-one in particular 'I am alright, I'm ok just like this'. Here, Charlie verbalised the abstract question of 'am I alright' his own inner sense of uncertainty, perhaps subverting normative gender expectations of him to be alright and to make do as he externalised his internal angst. Charlie was a man from a particular generation and class background where 'northern grit' would have been an expected masculine trait (Harris, 2016; Benyon, 2001), and yet here he demonstrates being made vulnerable. These were individual and collective experiences; the flow of affect here from the atmospheric moment was caught and dissipated through the reassurance of another resident shifting the atmosphere again and Charlie felt at least for that moment that he was in fact ok. These men were subverting masculine norms in this moment of uncertainty as Charlie's vulnerabilities were assuaged by another man, showing a kind and caring response to Charlie.

The experiences of uncertainty could occur at the point when activities ended that had engaged the residents collectively, and the men were returned into the zone of in-between time. The atmospherics of institutional uncertainty would arrive again, as residents experienced the emotion of endings. An example of this would occur on Sandbridge ward after the weekly singing group led by the therapy team. I felt the singing group was a remarkable occasion on the ward because it did usually manage to draw in most of the ward residents. It physically took up a lot of space and brought a number of visitors to the ward. Volunteers would arrive to support the sessions (nursing staff and assistants would be free to get on with other tasks) along with a singer who facilitated the group and a piano player. A large circle of chairs would be arranged that took up around a third of the ward area. After each session ended, it would be tea time on the ward and the nursing assistants would reappear to bring cups of tea around. The energy that was created through the group would dissipate and there would be a sense of disquiet in the room as the volunteers, musician and group facilitator left the ward. Residents were once again left to their own devices. One man who appeared to enjoy the group was regularly left in tears after these sessions. He was someone prone to tears, and emotional distress, and so possibly was more prone to this experience of the shifting atmosphere at the end of the session. Don might return to hovering around the ward exit, and Larry would look for a new place to be; many of the residents would appear uncertain. The end of an activity session which had been so engaging and encompassing led to the production of new emotional effect on Sandbridge ward, as anxiety,

uncertainty and other emotional distress became the atmospheric charge on the ward. The men were left without the focus, warmth and structure provided by the facilitator, music and song and the almost one to one staffing enabled through the many volunteers.

6.5 Atmospheric Moment of Resistance 3: Resistance Stories

As well as the atmospherics of waiting and institutional uncertainty, I argue that there were other atmospheric moments that occurred at particular times of day and that appeared and dissipated. Just as Stewart describes in 'Ordinary Affects' (2007), someone enters a room bringing with them a breeze of emotion. Other resistance stories began to unfold in these atmospheres of the organisations that illustrate the micro-politics of space, gender, bodies, atmospherics and everyday life.

As mentioned previously, Harry acknowledged that during the in-between times of the day he would get bored and need to take a walk for a *'fag'*. He would ration his cigarettes to ensure that they lasted him; as already mentioned, they were an expensive past-time. Harry loved smoking and told me that he had smoked since he was a youngster; he showed me this by using his hand to show me a height that he'd been when he started smoking. He used cigarette breaks as an opportunity to step out of the mundanity of waiting atmospherics. His was an individual act of resistance and there were other acts of resistance which were less quiet and contained. They did not always happen during the in-between times, and there might be strong resistance to taking part in an activity or to routine body tasks. On one occasion, in December, I was waiting outside a bathroom, having been told that I could observe Bryn having a shave; I write in my fieldnotes the following quite lengthy extract:

> *A careworker asks Bryn if he is ready for a bath and he lifts his head and nods and says' yes'. The bathroom which is close to where I am sat, and has another [female] careworker there waiting for Bryn and [female] careworker 1. They move to the bathroom and the wheelchair is manoeuvred in through the door which is then closed. Then the door is opened again and one of the careworkers moves some equipment out of the bathroom, presumably to make more space.*

The woman dressed for going out re-appears and a man's voice from the bedroom on the left calls 'come on!'…then I hear voices from the bathroom and shouts from Bryn…I hear a very loud 'Mmmmm' and then some gruff sounds. Oh's and other words that I cannot make out. The sounds suggest discomfort and displeasure, these sounds merge with voices from the television talking about DNA test results for fatherhood. I still don't know why the television is on as no-one there is watching.

Now I hear a sneeze from the bathroom and a big shout of 'Uuuhh' from Bryn inside the bathroom. One of the care workers leaves the bathroom. I hear more loud groaning sounds over and over. I hear the careworker that is left say 'Bryn!' and I hear more words being shouted by Bryn but I cannot make them out. The other care worker returns and enters the bathroom before leaving again after a short time, but this time she has gone to fetch the male clinical manager who enters the bathroom with her. I hear him ask Bryn how his foot is doing and says 'we'll just get it checked out', Bryn's voice is very gruff but he replies though I cannot hear the words. The clinical service manager leaves and one care worker leaves, I hear Bryn shout 'I'm alright now'…this time the care worker reappears with a male care worker who enters the bathroom, I hear shouts of 'let me down', 'I don't like to be on here' and then 'you rotten things, let me down'. I hear the laughter of one care worker and the clinical service manager knocks on the bathroom door and asks 'what's the problem?' Bryn's voice calls 'why not' and then there are the quiet voices of the staff. The male care worker leaves the bathroom and I am called and asked if I would like to observe Bryn's shave…I think 'all that before a shave'…I ask Bryn if it is ok to watch him be shaved and he shouts 'NO!', then he asks 'why?', so I explain and he says 'NO! Rubbish!' and then 'NO' again, he is very upset and has both female care workers are stood beside him, one ready with the electric razor. I do not stay to watch the shave because it could not have been clearer [to me] that he did not want me there to observe. (6th December 2011).

This example shows how the men in the study do not always acquiesce to the routines. Bryn was not happy to be bathed, at least not in the manner it was carried out and he definitely did not like being placed in a hoist to move him. Although he said yes initially to the activity, the reality of being bathed at this moment, time and place, and in this manner was not what he

wanted or perhaps anticipated. The sounds of his cries could be heard ringing into the corridor, and the sounds of his resistance flowed into the atmosphere, from his resistance to the bodily routines of care and to the physical manoeuvring by the staff. The force of Bryn's defiance produces an atmospheric moment of resistance as he attempts to use his body and voice to refuse these aspects of bodily care. It is also notable how gender played a role in this interaction and resistance story. The female care workers who were trying to bathe Bryn, a large man, and who were struggling to calm him sought help from the male workers on duty. It is possible the association they made with Bryn's loud and physical resistance meant that they no longer considered him safe and did not want to manage this male body alone and so brought in the male workers to manage the situation. Bryn at least took some control back in the situation when he refused me to observe his shave. At this point he had truly had enough of the overcrowded bathroom space; his personal dignity had been compromised during the routine that had caused such distress.

On another day on Sandbridge ward, I was sat in the bedroom corridor with Larry and we could hear noises, cries and shouts coming from one of the bedrooms and Larry mimics the sounds and turns to me and laughs, he then says *'getting killed poor devil'* (19th December 2011). He shows in this moment an awareness of the other person; there is empathy expressed through a sense that he knows what is going on for him, as the routines of the ward continue on. Larry's laughter and joke about the cries are a way to maintain some power over the situation. It is not him, and he is able to joke about it, though we both know that he also succumbs to the same daily routines of the institution; hence his empathetic reference to *'poor devil'* because he knows what it feels like. He picks up the atmospheric effect of resistance, and it resonates. There were often times when the men were not ready for a shower or a shave or did not want to go to bed when the routines meant that they were told it was time for bed. In the staff care records about Don, from Sandbridge ward, as I have already written in Chapter 5, staff note that Don refuses to change into night clothes. There were no contextual notes around this record on his care notes, just the statement about refusal. Refusing and resisting routines is sometimes the only agency the men have, although this could cause them to become labelled as challenging, or difficult. Refusals were noted in the care notes of the residents living on Sandbridge ward, and most likely in the other settings also to denote their challenges to the normative routines.

As already described in the previous chapter, in handover meetings, information was shared about the emotional state of individuals including their compliance or otherwise. Routine tasks were scheduled often ahead of time such as the planning for meals, toileting and bath-times; hence, they were not linked (necessarily) to bodily need, but to fit into the time-table of the care organisations. The planning for meals is done one day in advance on Primrose residential dementia unit and on one occasion, noted earlier in Chapter 5, despite Bryn being engaged in breakfast-time, a care worker asks him about his preference for lunch the following day, a question to which he responds with laughs. The everyday sounds of the normative routines in progress produced sounds of resistance which would seep into the atmosphere, engendering more resistance and tensions to ripple out. Sounds that could be perceived as sounds of resistance such calls for help or to go home.

These calls of distress were sometimes created by someone resisting a body routine, but often these were the cries of those in-between routines and possibly feeling alone and clearly distressed within the communal space of in-between time. In particular, on Primrose residential dementia unit one woman's voice was often heard calling out 'help me, help me, help me', and staff told me, that this was just what she did, it was accepted as part of the norm, and almost not heard as a person because of its routine nature, but instead heard by staff as part of the accepted atmospherics. On Sandbridge ward too, there were also regular sounds of distress: there was the male patient who regularly cried, and another man who was blind and who often shouted out for assistance or he called out a particular female name. These sounds of distress would have an impact on other residents, sometimes causing a response to be called out. One time on Primrose residential dementia unit, Bryn shouted 'shut up' to the woman who cried out for help. But at other times, someone's cries and distress might be comforted by another resident. These sounds of resistance, both in terms of the distress cries and the responses to them, mingled with the sounds of staff routines and television sounds that also drifted through the air, sometimes causing a ruckus and shifting the atmosphere and at other times accepted as part of the mundane everyday institutional soundscape.

On Primrose residential dementia unit, there was a weekly visit from a group of local school girls who would come on a Friday morning. The girls were rarely supervised and would be left to talk and play games with residents in the communal living area. The school girls would

tend to stick together and most often spent the most time with a particularly sociable woman in the room. Samuel and Bryn were not often sat in this communal living area and both men used wheelchairs relying on staff to manoeuvre them to and from places. However, on one particular Friday morning, the two were both sat together in the communal area when the girls arrived. The scene that took place is described in the following extract from my fieldnotes:

> *Some school girls have arrived wearing a bright striped uniform they are doing a survey about school days, it is Mavis they begin talking to a particularly garrulous woman who is a participant in our wider study, they ask her what school life was like, was it nice? She is smiling at them, and then the woman who is often distressed asks them if they are enjoying this, they say yes, she says 'aren't they pretty', they ask Mavis more questions about school, she asks them what they call their mum, they continue to ask questions, Mavis turns to her friend [a woman she always sits with] and tells her what the girls are doing. Tea is brought in to the room, and a visitor helps to give out cups of tea, more school girls arrive, the room is very bustley; The woman who is often distressed says again 'aren't they lovely'. The girls are a hit with the three ladies they are talking to and then Samuel shouts 'that's a very distinctive stripe' – a girl turns to him and says that all the other schools call them 'deckchairs'. Samuel wants to be involved in the conversation and he begins to talk about the school, but no one responds then he turns to the tea waiter and asks him if he can remember his school days, the waiter replies 'yes unfortunately' and Samuel laughs. The girls continue to talk to Mavis and the other women, Samuel now appears to be sleeping as his eyes are closed, he twitches and wakes and looks over at the girls who are laughing and chatting with Mavis. Bryn is asleep next to Samuel, Samuel shouts out 'What about dads?'He then shouts across the room to one of the women and says 'they want to know if you had a school blazer', Bryn wakes up, Mavis says to the girls 'enjoying this?' Bryn shouts out and Samuel say's 'come on girls out you go now'.* (6th January 2012).

The atmosphere created by the visiting school girls was not the usual atmosphere in the communal living area which was mostly quiet and would have the background sound of the television or radio, and the occasional shout out from a resident. Samuel who seemed to

enjoy social interaction when the opportunities arose attempted to become a part of the bustling social atmosphere that emerged in the communal area. However, the activity with the school girls only involves a small group of the female residents. The men were not only experiencing uncertainty, there was a search for a sense of purpose and inclusion. Samuel struggled to have his identity acknowledged and recognised. He created a shift in the atmosphere of the day room; there had been a social bustle generated through the arrival of new people into the home and it felt positive. Samuel wanted to share in this social interaction which was creating an out of the ordinary atmosphere into the usual lull of activity in the communal living space; however, the most able person in the day room commandeered attention for herself and her friends. In the feminised communal living area there was a feeling of frustration from Samuel and a recognition of gender identity as he cried out in a resistive moment 'what about the dads?' Samuel shows his resistance to his exclusion when he tells the girls it is 'time to go now'. He asserts some authority and control in the space as he sends the girls away, perhaps taking back some of his gender power in the feminised living space.

Samuel and Bryn both appeared to want the communal area to offer something more inclusive, and on another occasion whilst both men were sat in the living room on Primrose residential dementia unit during 'in-between time' the radio was playing. I never heard radio at Lincoln Manor, or on Sandbridge ward, but sometimes it would be playing on Primrose residential dementia unit rather than the television. However, as with television, it was never clear who had requested the radio or why the particular station had been selected, but it seemed that it was most likely staff controlled. The radio station that was mainly used was 'Smooth Radio', a station aimed at a much younger audience in fact than those that lived on Primrose residential dementia unit (http://www.global.com/radio/smooth/audience-2/). On this occasion I write in my fieldnotes that Samuel or Bryn (I am not clear which of them) shouts out 'Call that music?', because it was not music to their taste, and they were stuck with it, unable to change the station themselves or turn it off; all they can do is disrupt or resist through shouting out into the atmosphere creating a forceful charge and the emergence of a resistive atmospheric moment.

6.6 Atmospheric Moment of Resistance 4: Temporal resistance

Time was chronologically ordered by all the care organisations, and life was organised in a highly structured and linear way. Routines were book-ended with morning routines and bedtime routines. However, for people living with dementia time, is often lived and experienced in less linear ways. The men (and other residents) appeared to move between experiences of past and present time. Sometimes it appeared that they were living both past and present lives simultaneously as the past became tangled with the present. Hence, they were sometimes, in a way, living within a kind of temporal meshing of different time periods that might be understood as 'dementia time'. It was apparent that the men would move in and out of their interior worlds, the institutional routines and activities, and the worlds of those around them as they engaged in conversations or responded to the sensory environment around them. Sensory encounters would bring them in and out of the present into the temporal mesh of both past and present. I suggest this is one kind of temporal resistance, as with Capstick and Chatwin's (2016) work on cultural resistance, the men here were living in their own 'dementia time' which was not the same as the linear clock time of those living without dementia.

One such example of how present time is merged with past time was seen with Harry, who lived in Lincoln Fields. He would regularly tell me that one member of the maintenance team at the care organisation had been with him in Northern Ireland where he was stationed with the British Army. This had been a significant tour of duty for Harry because he had been there during the height of the troubles (http://www.bbc.co.uk/history/troubles) and had been subject to an injury during this time through being hit by a brick. Often when the maintenance man talked to Harry or was close by talking to someone else and Harry heard his Northern Irish accent, this would lead to Harry talking about his time in Ireland, sometimes stating that he had been in Ireland with this man. The sound of the maintenance man's voice acted as a sensory conduit to this particular memory or series of memories for Harry, and also to an embodied memory as he described his pain from receiving the blow from the brick. In some way the past and present existed for Harry simultaneously, enmeshed in 'dementia time' as Harry did not appear to believe himself to be in Northern Ireland as he told the story. Saying that, Harry did believe that a part of his past was here with him in the care organisation in the form of the maintenance man. Harry was not the only person to move between past and present as he negotiated life in the care setting. For most of the men, as they

talked, they would be in a flow between past experiences and current ones, back and forth, and enmeshed in 'dementia time' which rarely seemed to align with the clock-time of the care organisations.

Although the organisations structured time to flow in a linear direction this was not how time was experienced by those who were resident. Hence, these experiences of living within 'dementia time' could shift how it felt to be in the settings and would change and alter the atmosphere of the place for an individual or for a collective, in a kind of temporal resistance to the normative order of things. Each of the three care organisations were keen to orientate the residents and all the facilities had some kind of display that had the date, day and, often, the season. It was routine practice to remind residents where they were, if there was any suggestion by the residents that they were somewhere else, such as in the example discussed earlier in this chapter in the section (ii) on Uncertainty. There is an example of an activity with Martha, an Occupational therapy assistant on Sandbridge ward with Larry a resident. Larry talks about wanting to 'get working' and Martha is clear to remind Larry that he is not at work because he is in hospital. It was common everyday practice to re-orientate residents if they appeared to be disorientated to the normative ordering of things, time or place. However, for the men (and other residents) this was not their temporal experience of day to day life, and this was evidenced in how they engaged in communications. Sometimes they would respond to something in the present which would be in keeping with a current conversation in the communal area, but in the next instance bring into conversation something that suggested they were not completely experiencing the same present time or possibly even considered themselves to be in another place.

One afternoon on Primrose residential dementia unit, I write in my fieldnotes (6th January 2012) about Samuel becoming anxious about where he had left his car keys; he was concerned they were lost. However, at the same time, he was still engaged with other residents in conversations about what was happening there and then in the communal living area. He would move between the present and a nagging feeling that he was supposed to be somewhere else and he did not know where he had put his car keys, despite the fact he had long stopped driving or having ownership of a car (information his wife shared with me). The experiences of uncertainty and anxiety were part of the everyday emotions that occurred for the men. I would observe these kinds of experiences within in-between times, and they

appeared to be caused by a feeling of the tension experienced through being without occupation for such long periods of time such as discussed earlier in this section. However, these examples also suggest something else, a kind of a resistance to the normative expectations of lived time in these settings. As the men were living within 'dementia time', there was a temporal enmeshing of time, both past and present that meant they no longer experienced time in the same linear or clock-ordered manner. Such as here with Samuel, or the previous example of Harry, it was not only the experience of a tension, but the men's everyday experiences were lived in an alternative temporal dimension. Hence, another important contribution through these temporal experiences that could be suggested is that they were a form of resistance.

'Dementia-time' could be viewed as a response to the lulls created by the normative scheduling of the day and resulting in long periods of in-between time and the relationship residents have with time and the physical spaces. For example, on Primrose residential dementia unit where the seating itself created a physical distance between people, and where the opportunity to make connections across the room could be difficult, conversations were in fact heard and responded to across time and space despite the materiality of the space creating an unlikely setting for easy conversation. Residents were not disconnected from each other despite the material challenges, and sometimes someone would say something in the living area on Primrose residential dementia unit, and though it would take some time, another person would eventually respond from somewhere else in the room. In my fieldnotes I reflect on this experience:

> *Someone says something, a mumble, a shout, and someone on the other side of the room shouts 'shut up' in response. Several minutes later someone replies to the original shout, or at least it is something that appears like a reply [because it is in keeping with the topic].* (24th February 2012).

In Nygård and Johansson's (2001) study, participants reported that things took longer than they had previously and also that the experience of living with dementia meant that the participants had no perspective on duration. Hence, in these scenarios, even hearing, processing and responding to a conversation or a comment may take longer when living

within ‘dementia time’. But given the opportunity, residents were able to respond and take part in conversations. I heard people joining in conversations across the room many times, and on another occasion in the afternoon, Samuel was in the living area on Primrose residential dementia unit, and another resident, was sat with a family visitor, I write in my fieldnotes:

> *There is a conversation taking place across the room to where Samuel is sat, the lady’s relative tells her that her nails look lovely and how they match her sweater…Samuel shouts across ‘colour-wise’ joining in the conversation*. (6th January 2012).

At other times there would be a time delay in people answering questions poised in the room, so whereas a conversation between people seated closer together or perhaps those without dementia might be exchanged in a constant flow of verbal responses, in the day room on Primrose residential dementia unit where everyone was living with dementia and seated around a wide-open space, there was often a delayed response to an earlier question.

For example, on one occasion in the communal living area on Primrose residential dementia unit, Bryn responded to a question about what he had eaten for breakfast sometime after an earlier person had posed a question about breakfast. This struck me at the time to note in my fieldnotes because it would be easy to assume that each person sat in their chair was either asleep or simply captured in their own world, and not engaged in the collective atmosphere of the room. There were regularly scenes like this that challenged the notion of people living with dementia in their own small bubble (Perrin, 1997), and it is perhaps these pervading understandings of dementia that mean that the material layout of the rooms are not considered as problematic. Though it may sometimes take more time for a response to be processed and thrown back out into the soundscape, people were communicating: listening and responding. Thus, what is important in these observations is how people are aware of the collective even at times when it can appear as if they are not. There is also perhaps a sense that the conversations and words that make up the airwaves of the atmosphere are ‘floating around’ in the communal spaces waiting to be picked up and interacted with. Sometimes during in-between times as people sat around waiting for things to happen, with sounds drifting in and

out, voices, television and radio words would have an effect and someone would respond and resist the empty time and space. Another example of this is recorded in my fieldnote as this:

> *...the woman who is often distressed is shouting about wanting to go home and Samuel says 'who's got my house keys'…Someone else says something and Samuel says – 'it all crumbles after Christmas' and laughs*. (6th January 2012*)*.

Here the talk of going home reminds Samuel about his own key worries; he often worries about where his car keys are, or here, his house keys, and he joins in the conversation or verbal cries around him. But he also has a bit of a chuckle about what a shambles it all is, and makes an astute remark about 'things crumbling after Christmas', and it is indeed not long after Christmas. He makes a reference to a post-Christmas feeling, after a period of emotional highs and over indulgence, he suggests everything is falling apart which could reference the state of things going on in the day room relating to the woman who wants to go home, and his own loss of his house keys as things there are 'crumbling'.

These kinds of interactions could so easily go unnoticed because they happen over time and often in spaces where there are usually few staff, or staff moving in and out of the rooms undertaking scheduled tasks according to clock-time and so not lingering to hear what is happening. Hence, staff missed the everyday experiences, humour, relationships and connections within the day room, as they happen outside of their scheduled institutional tasks. The residents are engaged in a collective resistance to the waiting time, to the disconnecting material layout of the spaces. To me, it appeared that staff were missing an opportunity to get to know the residents better and, as such, being able to facilitate interactions and offer support – and friendship.

On Sandbridge ward, life was restricted for Don in a number of ways. His movement was restricted as he was involuntarily in hospital and the space he had for himself was limited. He spent much of the day moving around the ward area. Gradually, over the time I observed on the ward, I noted that Don began to get up later in the mornings which could be argued to be a temporally resistive act and it would disrupt routines. On one occasion I consider this in my fieldnotes:

> *Don is still asleep at 11am. I ask if I can observe him having a shave when he wakes up and the Nursing assistant says 'he's in a funny mood at the moment and not very happy'. She says she has left his clothes and wash things out for him. I ask, 'so he can get himself ready then?' and she says yes, but I will tell you when he gets up.* (13th February 2012).

Don's resistance to the routines are perceived as him 'being in a funny mood'. His emotional state is challenging to the normative regulations and a tense atmosphere is perceived around him. Staff are keen not to provoke him and he is left to manage himself because he has stepped out from the ordered time of the institutional routines. In the ward care notes that are written about Don, staff comment on his acquiescence or refusal to do things. They write brief notes that are perfunctory in their tone. An example of Don's resistance to the structure of the day was his late rising, which began to happen more and more when I visited the ward. He would resist the ordered time and create his own slightly off schedule routine for the day, including not wanting to go to bed when it was 'bed time'. Although staff do not provide any information in their notes about Don's resistance to scheduled activities. These resistive acts by Don contribute to creating resistive atmospherics whilst reflecting the various tensions that occur because of the structuring of time. This structuring is created in order to manage and care for the collective individuals that reside in these settings and ordered according to the needs and requirements of the care organisations as work environments.

6.7 Conclusion

In this chapter, I have shown how atmospheric moments are produced from the way that the care organisations are organised and regulated, and through the material and sensory environment and the everyday experience of the rhythms of care. The care organisations need to manage and maintain collectives of residents and in doing this they endeavour to keep people moving along 'institutional lines' (Ahmed, 2007, p159). I argue that through the order and structure of the days that highlight the tension between the environments operating as both home-places and work-places residents continually attempt to make sense of the expectations placed on them by the care organisations or attempt to make sense of their surroundings. The normative conditions and regulations produce particular atmospheric experiences that could regularly be found in the field data such as the experiences of waiting

and uncertainty that I have described in this chapter. The men produce and experience the atmospherics of waiting and discordance with the institutional order. These are displayed through particular materialities of the spaces, such as the wearing of outdoor clothing, such as Harry who wears his jacket at all times to be ready to take a walk about in order to break up the mundanity of the day. There are also examples of the men trying to carve a place for themselves in the communal areas, or examples of how time is experienced through 'dementia time' and the men are living everyday life in a less rigid and linear way. I have demonstrated how the tensions, the charges and frissons in the atmosphere are both produced by the organisations and the residents and contribute to the feel of the spaces, and how these atmospheres shift and merge throughout the day, and how atmospheric moments occur.

In the following chapter I will explore opportunities where within the atmosphere there are more restorative experiences created through moments of social and sensory connection that can offer a different and more restorative charge in the atmosphere.

Chapter 7 Findings (3) - Creating Restorative Atmospheric moments

7.1 Introduction

This chapter explores the meaning and creation of restorative atmospherics. It will do this by outlining what I mean by restorative atmospherics and how they are created in the everyday and in the care organisations that took part in the study. In the preceding two chapters, I discussed the kinds of tensions that are experienced within the atmospheres of the care organisations and how these produce resistive atmospheric moments that illustrate the problematics of the work-place versus home-place dichotomy. I have also demonstrated the role that the temporal experiences of everyday life have within the care organisations, and how the experience of these also contributes to the atmospherics for both the staff and the residents. These have shown how the difficulties of living within institutional time and in-between time manifest in atmospheric moments of waiting and uncertainty, but also how the men also experience dementia time and find ways to resist the institutional clock time focus. In the midst of each day there are also moments of calm, friendship and harmony, that have only been touched on so far, and in this chapter I will focus on exploring the ways in which restorative atmospheric moments occur. Firstly, I will discuss what a restorative atmospheric moment is and their meaning. Next, I will go on to present a series of four sets of conditions in which restorative atmospherics can occur in the everyday and explore what contributes to their emergence: 1). Weather-talk and Encountering Weather 2). Gatherings and Connectivity 3). Appearance stories 4). Moments of recognition: selfhood and identity. Finally, I will summarise discussing what opportunities understanding restorative atmospherics brings to considerations of collective care, and the individuals that reside and work in care organisations.

7.2 What are restorative atmospherics?

Restorative atmospherics can be identified as emerging in moments of recognition and connection. These atmospherics engender a sense of belonging, however fleeting, amongst those in the shared space and this will be demonstrated through the restorative atmospherics that are identified within this chapter. Restorative atmospheres are created often within the

normative flow of the day or sometimes they become created in a resistive moment. These restorative atmospheric moments engender a more hopeful and optimistic experience of the place as they enable the participants to be themselves and to be accepted in the moment; where sometimes the divide between staff and resident is forgotten in a moment of laughter or where the normative power imbalance shifts. These are moments between residents when they are not 'people living with dementia' amongst strangers but, instead, they are friends together. There are opportunities to draw on such moments and to create atmospherics that support identities, purpose and connections.

These restorative atmospherics therefore become key to harnessing the interconnections between residents and other residents, and residents and staff, and their material surroundings that emerge and evolve within each of the care organisations. Restorative atmospherics in this chapter will illustrate the abilities of the men through their embodied narratives that show them 'making the best of it'. These narratives show that it is often the men who are the ones responsible for creating the atmospheric shifts that can be perceived in moments within the normative conditions of the care organisations. These moments lead to the creation of restorative atmospherics that are made up of dynamic encounters that emerge from networks of relationships and connectivities of inanimate and animate objects, bodies and institutions and ideas (Fox, 2011; Potts, 2004). The following sections of restorative atmospheric moments demonstrate how these opportunities for harmony have affect and show how the atmospheres shift for these moments and where opportunities exist for extending the restorative feel further.

7.3 Restorative Atmospheric moment 1: Weather-talk and Encountering Weather

Work by Mason (2018a) describes weather as a compelling and powerful component of people's lives and provides a talking point that is easily engaged with. As Mason (2018a) suggests, weather manages to connect with people on an immediate level; we know what the weather is at any point of time or day, but it also holds sensory and embodied memories. The Weather-talk and encountering weather atmospheric can be characterised through networks of residents, staff, and how they experience light and weather and how it feels within the care environment. A further part of these atmospherics are the subjective memories and

understandings of weather and encounters with different weathers that resonate in these moments. There are moments during the day in each of the care organisations where there is an encounter with weather and there is subsequent weather-talk which can have a profound effect on the atmosphere. As discussed in Chapter 6 and 7, the sensory environment can have an enduring and complex impact on residents whilst they are situated within the normative structure of in-between time. The soundscape, in particular the television blaring out shows such as Jeremey Kyle quarrels and the sounds of some unknown person's distress can cause an effect in the general atmosphere of the communal spaces. This was similar with lighting which was used by staff to create particular atmospherics in relation to the temporal ordering of the day, hence lighting that was kept dim in a morning. Alongside which curtains or blinds would remain drawn to maintain quiet time between waking and morning routines being completed. In addition to this, there was not a great deal of natural light in the participating care organisations. There was more natural light possible on Sandbridge ward, due to the main ward area looking out onto the garden patio area. At Lincoln Manor, although there were windows onto the outdoor space, the layout of the building had an impact on how much natural light reached some quarters due to the configuration of pillars and dividing walls. This was also true of Primrose residential dementia unit situated in Forest Fields, where the corridors were often dark. Sometimes in my fieldnotes I would reflect on the darkness and the grey weather outside and the impact that the darkness would have on the feel of the care environment and those in it. Hence, an aspect of the sensory that could be enriching and restorative in the moment was through the connections made, linked to the experience of weather and the occurring 'weather talk' which was often related to sunlight.

The first extract from my notes that will explore this notion of encounters with weather and weather-talk and the creation of restorative atmospherics is taken from Sandbridge ward one morning and is written directly after a stressful incident with another resident. Larry begins the weather-talk:

> *Larry says 'its bright out there', and the Nursing assistant and Student Nurse who are there say 'yes', and they go on to have a chat about the weather and the springtime.* (11am. 23rd January 2012).

This short extract shows the impact of the bright sunlight on Larry. He feels the sunlight and is compelled to comment to the staff beside him. This moment where the sun streams into the ward environment creates an opportunity for a shift in the atmosphere. It helps to create a restorative atmospheric that feeds into the atmosphere and lifts Larry and the staff out of the tense atmosphere. It is notable that there is a release from the tension in this moment after a stressful incident on the ward due to one of the male residents who is in a state of acute distress and has been throwing furniture. Larry, who often takes on a calming influence, due to his generally relaxed and friendly demeanour, is the one that notes the change in the weather outside, and in the moment that he feels the sun on his skin, he remarks to the staff close by that it is 'bright outside'. He had been feeling the impact on the ward of the distressed resident and had previously himself wanted to go towards where the noise and activity had been coming from to see what was going on. He was also possibly attuned to the staff and the effect of the incident on them. The shift in the atmosphere occurs as the staff too are willing to grasp hold of the promise of spring coming that is encountered through the bright sunlight and which is metaphorically a more hopeful time and often associated with new beginnings. It creates in this moment a connection of shared emotions about spring, and the sensory feel of sunshine. Together the staff and Larry relax a little after the stressful period on the ward.

It is significant that the brightness brought onto the ward by the sunshine helps to create a shift in the atmosphere, as light holds a particularly important role in contributing to the atmosphere in all the settings (Edensor, 2017). The ward is changed by the bright light, it is materially different to before the shaft of sunlight entered and it has an effect that is shared by Larry and the staff members. In these further fieldnotes about another occasion on Sandbridge ward, there is another notable impact from natural light onto the previously dimmed light of the ward caused by the movement of the sun I write:

> *Don sits watching the nurse's office where there is some activity. Nurses come and go. It is like we are all waiting. The stream of sunlight has moved from the dining area now and although it still has a fresh breeze blowing it is less bright. The blue sky is now covered by clouds grey and white, but then a hole appears in the cloud and the sun streams. There is a feeling of the outdoors coming into life on the ward as staff and residents talk about the weather.* (2.40pm. 23rd February 2012).

Here again the sensory feeling of the sunlight pervades the fieldnotes as I write about how the sun streams on to the ward. The moment moves from an atmospheric of waiting during in-between time to one where residents and staff are engaged in a sensory connection and encounter with weather. Residents would often comment on the weather outside, even if they rarely went out anymore, and its influence in the care organisations was certainly a clear contributor to the atmosphere (Hatton, 2014). The embodied sensation of sunlight on the skin of the residents and staff foster memories of sunshine and experiences of outside life to emerge. In my notes from Lincoln Manor I write:

> *Someone in the group of men says 'it's nice when the sun comes out'*. [Later on in my notes] *Harry comes back from a smoke and says 'it's nice and sunny out there now'. Soon he leaves again for the patio. Someone else says they need some air*. (around 2pm. 14th October 2013*)*.

Again, in these fieldnote extracts, the men refer to the pleasure of sunlight and sunshine and of being outside in the sun. Light is significant in the sensory experiences of the men and they turn their conversations to feelings about the weather, and the experience of sunshine and light. However, it is not only talk about good weather that can create a shift in the atmospherics through a restorative moment. On another occasion in Lincoln Manor, a little before lunch, I write:

> *Harry sits tapping his legs up and down and rubbing the side of his head. The man who also always sits in this area and seems to notice everything says 'have the lights gone off' because it has gone darker, it is darker outside as it has dimmed inside. He also notices a light bulb has gone in one of the lights and someone says 'money for the meter'*. (12pm. 14th October 2013).

In these notes, there are a number of things that happen; firstly, the darkening day outside is noticeable inside. It has become darker inside where the men are seated because of this weather effect but also because a light has blown and so the inside lighting has also dimmed. In this moment, where the men are seated in-between time, there a number of observations to be made. Secondly the men are affected by the lighting, they notice it brightening and

darkening, it is not apart from them, the outside comes into their world. It is an important sensory and embodied experience. There is one man who is particularly observant and he often acts to bring things to the attention of the others, here he notices that a bulb has blown. The weather outside becomes a topic of conversation, the darkening light becomes part of the afternoon chatter, and humour is used amongst the men as someone calls out 'money for the meter'. This reflects a generational and class connection amongst the men as the need to keep the electricity on by putting coins into a meter is used to joke about why it might have gone dark inside; it also shows a quickness to wit and the kind of gendered banter that was popular amongst the men that gathered in this spot. This kind of joking and humour was a common aspect of the atmospherics, and in the moment where laughter was spawned it would shift the experience of in-between time to a more restorative atmospheric feeling, at least for that moment.

7.4 Restorative Atmospheric moments 2: Gatherings and Connectivity

The flow of the days could feel long and the men would often complain of boredom or show bodily signs of boredom - this would manifest in their constant movement or tapping as if they were waiting for something to happen as described in Chapter 6. Hence, opportunities for gatherings and connections were important and the men could create a sense of place and belonging in their gathering spaces. The feelings garnered from the connections in these moments would emerge into the atmosphere and could bring about more restorative atmospherics on such occasions through these pleasurable connections which were manifest through laughter, jokes, kindness and care. Something regularly noted in my fieldnotes was not only the joking and banter between the men, which might be more expected normative chatter amongst men (Gill, Henwood and McClean, 2005), but also there was often kindness, empathy and care between the men and shown by the men to other residents.

Sometimes activities organised through the care organisations would be a great success and also a time when the atmospherics created through them were restorative. One such time was during the weekly 'singing for the brain' group that convened on Sandbridge ward and which achieved the engagement of most residents on the ward. During these sessions, there was often laughter and notable experiences of joy. It felt in this hour of the day that the

atmosphere was shifted, and the atmospherics of that were created through this group activity brought a restorative atmosphere to the ward for the duration of the group. A number of volunteers would arrive on the ward to support the session, and their arrival would bring bustle and chatter to the space. The volunteers would sit side by side with residents, a semi-circle of participants and talk and laugh with them. The session did not include staff such as the nurses or nursing assistants, and in fact gave these staff the opportunity to do other tasks. The group was supported by the therapy team as well as the external volunteers, and there was a facilitator-singer and a piano player. No-one in this semi-circle wore a uniform and this probably contributed to creating a sense of togetherness. As discussed in Chapters 6 and 7, staff noted how being on holiday and out of uniform with residents made a positive impact on their relationships. The group facilitator created a rapport with the group members seated in the semi-circle around her and the piano and piano player. The group took up at least a third of the ward space. During the session the facilitator would go to each person individually and try to make a connection with them at least once. On one occasion, I observed Don sat with a volunteer, and whilst he did not sing through every song, he would join in from time to time. He would also move his lips even when he was not singing, following the song sheet with his finger that he was sharing with the volunteer beside him. It is late afternoon on Sandbridge ward and I write in my fieldnotes:

> *Don holds the song sheet. He sees that the volunteer next to him does not have one and he leans in towards her, sharing the paper with her. They sing Edelweiss, which also pulls on my heartstrings [it reminds me of my mum]. There is applause and Don smiles and watches the facilitator. Between songs there is some chatter. Another man is laughing with the psychology student and another worker*. (3pm. 18th February 2012).

In this moment in the singing group, there are a number of elements to draw out. Don is the one who leans to share his song sheet, he is engaged with the volunteer supporting him and he leans to support her. He instigates the connection and there is no divide between them. In this moment, Don is not a person living with dementia who needs to be supported, but instead he is a friend, with friends, taking part in an activity together where they are supporting each other. There is also the song itself that is sung as many of the songs have cultural meanings for different members of the group and people may experience emotions as they pull on

biographical memories, as this song did with me. Then there is the pleasure gained from singing and this is rewarded in the spontaneous gesture of applause at which Don smiles, he seemingly feels 'great' in this moment, and there is certainly a growing understanding of the value to be found in the embodied experience of singing and the levelling effect of singing together (Osman et al, 2016; Götell, Brown and Ekman, 2002). The energy and charge that emerged through the shared experience of singing group created restorative atmospherics that seeped into the momentarily changed atmosphere. Mason (2018a) describes atmospherics as being 'lively' and it seems that they are the charge within the atmosphere, the moment of change as here in the singing group. Sometimes residents who had not elected to sit in the singing group would hover around the edges, being drawn in, moved by the atmospherics and they would move to and from the group which would also bring about a shift in the ward atmosphere.

As the ward is an open space, which uses furniture and wall dividers to separate and divide the space, on this occasion it works well because the whole ward can be affected by the atmospherics created through the group. The sound of the group travels around the ward, and even those seated or walking in other parts of the ward can see or hear the group and be aware of its presence. It also means that residents can come close without joining in if they are not sure. They can also go into the bedroom corridor to escape altogether if that is what they choose to do.

The group is bookended by a 'hello' and a 'goodbye' song, purposefully staged to ensure participants know when the group has begun and when it has come to an end. However, it could sometimes be difficult when the group ended, as mentioned in Chapter 6. At the end of the group, tea and biscuits are brought out to the volunteers and residents and quite quickly the facilitator and piano player pack-up to leave. As the ward becomes emptied of the group volunteers, there can be resistance to returning to normality. Sometimes the group can be followed by moments of distress and a loss of the restorative atmospherics and this illustrates how easily and quickly the atmospheres can shift and change, and merge into something else.

Restorative atmospherics were also often created outside of organised activities, like the singing group, and would arise in other gatherings as moments that happened as part of the small everyday interactions between residents. Often as residents gathered together in

familiar spots during the long periods of in-between time these moments would emerge when humour had an affect or there was some other kind of friendly act or caring connection that rippled out into the atmosphere. Larry on Sandbridge ward had taken to spending most of his time outside of the main ward area in the bedroom corridor, where it was quieter. He would go into the dining area for meals, but generally he would be found seated in a particular corner of the bedroom corridor. One day late in the afternoon he was seated in this spot and I write in my fieldnotes:

> *A woman passes Larry and says 'oh hello'. He says 'oh hello' back in a posh voice. She says 'I thought you'd gone out for the day' and Larry says 'Oh no, I'm a prisoner now', the woman says 'I've always been a prisoner' and Larry replies 'I'm just getting used to it'. Another woman comes and stands beside Larry, and she says [to him] 'sorry', Larry replies 'no it's not you love' then Larry says 'We've got to look after all the people you know'*. (3pm. 23rd January 2012).

This extract shows the frustration felt by Larry in these long hours, where he feels his detainment, in as much as he cannot leave, and he refers to getting used to himself as a prisoner. These kinds of feelings, as discussed in Chapter 7, have effect in the atmosphere and signal the difficulties that are felt and give charge to resistive atmospherics, feeding into the waiting and uncertainty that resonate in the atmosphere. However, despite these frustrations, Larry finds it possible to deliver wry humour in relation to his and other's situation and he also shows caring and empathy as he reassures the second woman who apologised to him, and he goes on to say that *'we've got to look after all the people you know'*. His kindly manner creates a momentary shift in the atmosphere, to be shared by him and the female resident as together in the moment they share in their joint plight.

Often restorative atmospherics were created during these kinds of times when the men were gathered together, or with other residents during in-between time where there was a lull in the everyday activities. At Lincoln Manor, the same men gathered day after day in the same spot, and in my fieldnotes, I have called this gathering space 'the row'. A particular man who often appeared to take responsibility for the seating area was a man who did not seem to have dementia. After breakfast, as people were leaving the dining hall, he would often call out to the men who were regulars at his spot, asking them to come and join him. Both Charlie and

Harry would come to this seating area each morning after they were dressed and they would return to it between meals and other activities throughout the day. Despite sharing a room together, and even coming to blows on occasion, they were drawn to sit close to each other. On one occasion, Harry comes over to the row where the men were gathered, and he shakes Charlie's hand and he turns to me and he says *'He's a good one this one' (26/09/13)*. On another occasion, not long after lunch, I write:

> *Charlie comes to every little while [he appears to be sleeping] and asks something. He looks at Harry and his lips move [soundlessly] and he gets up out of his seat. Harry takes out a mint, he has a new packet of peppermints, and he offers one to Charlie, who takes it and Harry says 'that's what friends are for'. Charlie says 'right' and sits back down again*. (1.30pm 14th October 2013).

This is another example of the comradeship felt by the men in this particular seating area. It is possible these men were used to collective male camaraderie due to their experiences of military service where there is a military component to the need to develop a collective identity, as the men may be required to rely on each other during combat (Sasson-Levy, 2008). Charlie had served in WWII and Harry had spent more than 25 years in the armed forces, and so the deeply embodied experiences of shared service may have been a resonant feature within their relationship. The acts of kindness and friendship that occurred on the row would create atmospheric shifts and restorative moments which happen in a moment and then it would drift by again. Sometimes these moments are picked up by others in the area and conversations begin, or laughter is shared more widely.

On another occasion, whilst I am sat with the men in this area, I write into my fieldnotes about the men sitting together, it is still early:

> *Harry sits next to a man another regular on this row. Five men are sat here, they are up early, and all are dressed. It is quiet but for the sound of plates from the kitchen [which] echo down the corridor and [there] is the occasional voice and door [sound]. One of the lounges has breakfast TV on [sound coming from] the furthest end. A man at the end of the row says 'are we going to the dogs this afternoon?' And Charlie repeats 'are we going to the dogs?' Charlie is wearing his familiar white cap*

and a grey Pringle jumper with grey slacks. Charlie [begins] singing and Harry makes the sound of a cat cry [in response] and they have a little laugh about it. I ask if they ever have bands here and Charlie says 'we get by, we get by…considering we're outcasts…social outcasts but I don't think we are…we're there, we're there, we're there'. (8am. 26th September 2013).

This is a poignant moment as Charlie does not talk that much usually. He sings a lot, drifting in and out of what appears like sleep, with his eyes closed. As mentioned in Chapter 6, he often seems anxious and uncertain as he asks *'am I alright?'* However, here he shares a moment of laughter and camaraderie with his roommate, Harry. He then goes on to suggest something about how he feels about his placement here in the care organisation, 'we're social outcasts' but he goes on to refute this singing 'I don't think we are'. Like Larry in the earlier example, Charlie shows insight and empathy regarding their situation, and again in a moment of camaraderie states his belonging to this group as he uses the term 'we'. It is in these shared moments between the men that the atmosphere shifts; there is laughter, song, friendship and a sense of being in it together and this emerges as a restorative atmospheric shifting for a moment the feel of the place.

7.4.1 Gathering spaces

There were many such examples which gave the impression that the men in this group got each other through the days, with humour and support and through managing any disputes that occurred. Much of the day fell into 'in-between' time, and the atmosphere would shift, dissipate and merge together as the men's moods were affected by boredom, uncertainty or irritations with each other or laughter, humour and friendship. This was a vibrant bunch of men to be sat with; they had a particularly good spot for watching activity including watching the opening of the shop each day. It is interesting that they had chosen this particular space that allowed such a good vantage point for comings and goings and also was at the edge of the dining room and shop area. The opening of the shop was a part of the everyday rhythms at Lincoln Manor, and it would create quite a buzz. It was an event that shifted the atmosphere within the in-between time. The shop opened at 11am most days; this was after breakfast and sometime before lunch was served. There would be a tea and medication round, but not much else would be happening. The participants engaged in the study had their seating spot 'on the row' positioned close to where the shop opened each day; therefore, it

was a perfect spot to watch and to feel the atmospheric shifts created through this event. Often before the shop even opened, people would begin to gather around the shop area. Sometimes there was a sense of impatience as people paced around, or manoeuvred their wheelchairs around, and as a queue began to gather, waiting for the shop- event to happen. It also gave rise to moments of chatter and connections; the men might discuss what they were going to buy or check the time with each other to see if opening time was nearing. Harry might begin to feel the excited anticipation of getting his 'fags' and peppermints. The shop-event showed that even with regular routine activities, there was an opportunity for the atmosphere to be restorative. It showed how, through adapting the environment to create other place meanings within the same space, new meaningful engagements could occur. The shop gave the men a sense of agency as they were able to be consumers again in an environment where there was little opportunity for choice and recreational consumption.

7.4.2 Connectivity and Humour

Humour was important amongst these men, but also the sense that they were part of a group was integral to the moments of connection that occurred. There was a camaraderie that might be expected in military service in this home for ex-service personnel. That said, there was occasion when someone was not welcomed to the gathering, although that could also be seen to make some of the men appear even more of a clique and it showed who belonged to this gathering spot. On one occasion, Harry is standing near me, and he nods to another man and says 'there's Geoff. He's the daft one'. The man called Geoff looked toward me with a serious expression and said 'I'm not that bad!' (18.09.13). This comment from Harry suggests that they are part of a group, and that there are roles to play in the group, as Harry labels 'Geoff' as being someone who brings fun to the gatherings. 'Geoff' is an important character as the men in this area gravitate around him. Later on the same day, I write in my fieldnotes:

> *Harry wanders back in, hands in pockets, he stands in front of 'Geoff' and says I got my chiropody and I'm all dancing and singing now. He does a little jig though his feet don't lift off the ground.* (10.15am. 25th September 2013).

This is a moment of connection, a sharing of news about the morning activities, and as Harry does his jig, he brings a moment of fun to the group. It is in these moments that the

atmosphere shifts; the atmospherics created by the jig are restorative, particularly where so often the atmosphere can be felt through the atmospherics of waiting or uncertainty and here, in the moment, there is a sense of belonging, friendship and humour that is created in the shared moment.

Another example in my fieldnotes of this constant shifting between boredom and fun, is reflected in this extract:

> *Harry stretches his legs. The man who has just come back [to the row] is laughing with another man, and Harry cries out 'Is there anyone there?' Someone shouts 'no', and Harry calls 'Is there anyone there with a brain'.* (3pm. 14th October 2013).

It was in this way that humour was often used to create restorative atmospherics in these gatherings of men. Harry shows how he was feeling through the use of humour, along with his desire to join in with the social interaction, when he heard the other men laughing. He is compelled to call out and to also seek a connection.

There were friendships between male residents on Sandbridge ward as well. As already mentioned, Larry was a popular resident; other residents from the ward, both male and female, would sit and chat with him and pass the time of day. In my observation notes, I write how Larry keeps order and civility as another gregarious resident jokes around and also spoils for a fight; it took place in the afternoon, where not much happened until afternoon tea:

> *I move out of the communal area to the lobby by the bedrooms where Larry has been sitting with another male [resident]. The other man sits with him but every few minutes gets up and leaves going for a walk only to return moments later. During which time he talks constantly at Larry, and he sometimes sounds angry and other times he is laughing. Larry laughs along and sometimes placates him when he is cross. At one point the man turns to Larry and suggests they fight outside. Larry says 'no we don't do that' in a calm and firm tone, and the man settles again.* (12th January 2012).

In this extract, there is the kind of activity and movement that often generates atmospherics of waiting and uncertainty with residents coming and going and finding it hard to settle; uncertain what to do with themselves. The man talking with Larry appears to be finding it difficult to remain in one place and keeps moving in and out of the area. At this moment in the extract his suggestion to fight Larry is quickly put to rest by Larry who is a calming influence. It is the tone of his voice and through his words that he settles the man down again bringing restorative atmospherics to the moment.

7.4.3 Connectivity and Friendships

There were a number of examples of Larry having moments of friendship on Sandbridge ward, another time with the same resident and with a similar role of bringing a calming influence, I write one morning:

> *Larry and another male resident are chatting and laughing together. Larry says to the man 'there's nobody to cuss', he says 'that's yours all yours, nothing to do with me'…he is laughing…Larry and the man continue laughing and talking, Larry turns away from him and looks across the room, he is smiling and his eyes crinkle with his smile. He gets up from the table, and has trouble pushing the chair in, eventually he succeeds, the other man gets up at the same time and they go off together towards the bedroom*. (9.15am. 12th January 2012).

It seems that Larry has a calming effect on this man, who is a person quick to change moods and have an effect on the ward atmosphere for those around him. Here Larry is using calming statements, settling him as they sit together when he says 'nobody to cuss'. He is making sure the man knows that he is not a threat, and he chats, smiles and laughs with him and again it is a moment where there is restoration from the normative structures of the day that leave the men with little activity for long periods during each day.

The restorative atmospherics then would arrive in a burst of laughter, or in more subtle forms such as through a glance and smile, or in gentle words spoken and the atmosphere would shift for these individuals or would ripple out to others in the collective environments. In another moment on Sandbridge ward, I experience a shift in the atmosphere through a moment of connection between myself and Don as he illustrates his feelings about another male resident

sat close by. There is almost a sigh in the air, an audible release from the empty tension of nothingness as he tells a narrative of friendship though his body with actions and signs. It is a while after lunch and a little before afternoon tea. There is not much happening on the ward and Don is moving about as he often does in an afternoon, when he can seem uncertain, and lost, and for a moment he comes and sits at the table where I am sat observing and writing fieldnotes. Perhaps I have become a familiar face to him in this setting and I reflect on this in my fieldnotes:

> *For a few minutes he [Don] chats making lots of words, and through the rhythm of his voice and his animated body movements he shows me that he is telling me lots of things [even if I am uncertain of what it all means]. I make out the odd word or sentence. Another man makes sounds behind Don and Don turns and looks and then [this time] says [clearly] 'he's alright him', he continues [making word sounds] and laughs a little; he does some gesticulations and points and then [does] a pretend punch, which feels like it is in jest about something in his story as he is laughing, smiling and is relaxed in his talk.* (2.55pm. 23rd February 2012).

This moment is about a feeling of togetherness, one into which I am incorporated, as Don talks to me about something, but how he also notices someone else on the ward, hears their sounds and draws them in too through his bodily performance that tells me they are okay. He uses gendered gestures with the animated fist punch, illustrating play fighting, male identity and camaraderie. Humour and playfulness are often drawn on by the participants in these settings and used to create a sense of belonging and to create their own micro restorative atmospherics within the normative conditions of everyday life.

7.4.4 Restorative Atmospherics 3: Appearance Stories

As discussed at the beginning of this chapter, the restorative atmospherics were not only created amongst the residents themselves and within in-between time or during group activities such as the singing group. Sometimes shifts could occur as part of the everyday routines that staff were engaged in with residents. Sometimes during a routine task there would be an opportunity for restorative atmospherics to be created, in particular where personal relationships were a part of the interaction. These could happen during appearance related routines, including shaving. The intimacy of these tasks meant that there could also be

resistance from the men, as described in Chapter 7, during the bathroom routine with Bryn, and staff also could feel anxiety in relation to tasks they considered as difficult. The shaving routines were often carried out by the female care staff, though of course not always as some of the health and care team were male, and there were male nursing and care assistants found in all the fieldsites. The atmospherics generated were not only intimate but also gendered as the men's bodies came into focus as different bodies to the female workers. Shaving in particular was described by staff as a difficult and problematic task; female care staff in particular worried about hurting the men and this was a risk made worse by the often 'cheap' razors used within all the care organisations. As male skin ages, it becomes more sensitive and craggier which makes shaving an even more difficult task; one care assistant said:

> *…with the wet shave because, like, with old people, their skin is more saggier, it's harder, you know what I mean, with the wet shave, you've got to, like, pull their skin and make it tighter to do the shave…* (Discussion group 2. Primrose residential dementia unit).

Shaves were often undertaken quite speedily, and there was not much in the way of 'pampering' that took place during the process. It was more a task to get out of the way. Therefore, it could seem an unlikely interaction for restorative atmospherics to occur. On one occasion, I observed Samuel being shaved on Primrose residential dementia unit. On this particular day, I asked his permission to observe him being shaved by a young female care worker. The shave took place in his bedroom (ethical permissions had been granted to observe shaving and other personal grooming activities). Samuel was seated in an armchair and I reflect in my notes about the experience:

> *Around the room are photos, one of a wedding – a young couple, one of him and his wife in later life and a newspaper article about their 60 years together*. (29th November 2011).

The photos in Samuel's room are a part of the atmospherics; the room is a private space for Samuel. In his room Samuel has some photographs that show who he was before care and that represent aspects of his identity. The photographs indicate his heterosexual identity and the news item framed is celebrating 60 years of marriage. This denotes his success at a

heteronormative lifestyle and it serves to affirm his masculinity in this room and in this moment. The photographs in his room provided both evidence of his subjective and normative gender identity and show his gender identity in relation to his wife. They also provide evidence of Samuel as a younger man, imparting on married life, and other photos through the life-course. The photographs bring him into view as a person beyond his diagnosis of dementia, and his position in the care home.

During the shaving task Samuel himself laughs about how unusual it is to be observed whilst being shaved and he tries to make it light to take the edge of the fact that he is being shaved by someone else whilst also being watched (by me). The circumstances are outside of the norm and so the atmosphere is shifted because of my presence. It is possible that Samuel may feel some vulnerability about being shaved by a young woman who is carrying out a task he can no longer do himself. In my notes I write:

> *Early on the care worker tells him that she hasn't carried out a wet shave before. Samuel admonishes her for not being very good at shaving*. (29th November 2011).

Samuel was keen to demonstrate his own knowledge of how to shave well and talked about the need for decent razors and he tells the care worker not to 'chop', a word used to describe the sensory feeling of (poor) shaving. In fact, Samuel takes charge of the shave when the care assistant revealed her own lack of shaving knowledge; she reveals that it is in fact her first wet shave. Also making her vulnerable in the moment, she is also being observed, and has now acknowledged she is not really experienced in the task. Vulnerability is in the air, but it is then not only the person living with dementia here who is vulnerable. Although Samuel needs the support of the care worker for his shave and to maintain his appearance, they are both in similar positions. However, the care worker's vulnerability and lack of expertise means that Samuel is able to take some authority as he gives sensory explanations of how it feels to be shaved and he makes a reference to his time as a working man, asserting his gendered selfhood and making a connection to the practice of shaving and its purpose in making him presentable for the public world. In my notes I write:

I ask Samuel what having a shave is like and he says 'horrible, you want to get it out of the way quickly with as little discomfort as possible'. Then he said 'you often don't have a lot of time before work and then away you go'. (29th November 2011).

I suggest that through these atmospherics, Samuel's masculinity is supported partly by the material elements in his bedroom, such as the photographs which act to serve as cues to the care worker giving them information about Samuel's biographical selfhood. It is also supported through his own sense of identity and his ability to tell the care worker how to carry out the shave. The gendered equipment for shaving also creates sounds against Samuel's skin as the blade sweeps down over his taut skin and the smell of the shaving foam all formed part of the sensorial atmospherics.

Samuel makes sensory connections throughout the experience of the shave and his gendered embodiment is something that is not simply located within him, instead it is externally supported through the mutuality of the relationships that are in the room: the relationship shown in the photographs between him and his wife; the care worker and Samuel. This is rare in Primrose residential dementia unit, as there are few men living there and the communal living area (which was described in Chapters 5 and 6) is decorated in a particularly feminised style as is the corridor leading to the communal living space with decorations of flowers and butterflies on the walls. Hence, the facets that are supporting Samuel's gendered identity in his private space have value in contributing to masculine atmospherics during the shaving activity. Together, Samuel and the care worker negotiate the intimate bodywork of the shave; the material objects depicting his lifestyle, from the shaving equipment and toiletries, also the in the moment sensorial connection of past self to present self. The atmospherics have restorative qualities: Samuel is restored through the shave, his identity and biography are recognised and his dignity is respected as he teases, admonishes and guides with expertise the care worker who is undertaking this once privately undertaken task on his body. These atmospherics are finely balanced, it is very much in the moment that the restorative emerges, but it can shift so easily in another direction. As noted in Chapter 7, when Bryn, having agreed to a bath, went through an extremely distressing episode in the bathroom with staff, these are intimate moments in the men's lives. It is Samuel here who, with enormous good humour, contributes to this restorative atmospheric moment aided by the memories of Samuel as a successfully married man, adept at his own grooming.

In another shaving story, there is another moment where a restorative atmospheric emerges from the supportive experience that happens between Larry and, significantly, a male nursing assistant on Sandbridge ward. Larry is about to have a shave in a bathroom on the ward. The bathroom appears quite a stark institutional space; it is a large white functional room. There is a bath to one side with a hoist connected to it, and there is a sink with a mirror above it. The scene might feel familiar to Larry because he is shaving in front of a mirror in a bathroom (albeit this time he is being watched by me and a Nursing assistant who is supporting him to shave with verbal guidance). Larry is wearing a vest t-shirt and trousers and in my fieldnotes, I write 'the room smells of men's toiletries – of the shaving foam'. These smells, referred to in the previous shaving story, are recognisable as male toiletries and they form part of the atmospherics; an aspect of the multi-sensory environment supporting Larry with clues for his restorative shaving experience. There is relational work between Larry and the nursing assistant who is supporting and guiding the shave. Larry demonstrates his own tacit knowledge of shaving: knowing when and how to rinse his razor, in an embodied rhythm familiar to him through years of this personal appearance task. He knows which bit of his face to move as the blades of the razor work to rid him of bristles, in my notes I write:

> *Steven, the nursing assistant say's 'that's it…just do above your top lip', and Larry moves the razor there pushing his tongue up inside his top lip to push it out and to keep the skin taut. The shaving strokes are occasionally paused as he swills the razor into the water, cleaning the razor as he goes along. Steven praises and encourages him on, stepping in physically only once to wipe the shaving foam when Larry puts foam across parts of his face that will not be shaved.* (10.15am. 26th January 2012).

The smells, and the accoutrements of shaving, add to the gendered atmospherics of the space. There is an inter-corporeal connection as one man visualises shaving in order to direct the other to do so. The bathroom scene, the vest and trousers, the repetition of an act that is often learned from fathers resonates as the two men are captured in a shared moment. I suggest that there is an extension between the two men as their gendered embodiment encompasses them. The care worker Steven has his own particular appearance identity. In an interview with Steven he says that he likes to be smart:

> *Well, people always say 'God, you always look dead smart'. Because…well, I mean, I get a lot of Mickey take, because I always have my clothes tucked in, but that's just the way I am. I'm old fashioned that way, but it still looks smart, looks clean and tidy, that's the way I look at it. I'm always shaving, even though it doesn't look it, but I always have a shower and a shave before I come in work every time. So I always look smart, yeah. Well, as smart as I can be'*. (Interview. 12th January 2012).

He appears to 'transmit' a knowledge about maleness and shaving that cannot be present in the female care workers. These shaving stories show how in these brief episodes of care tasks there are opportunities to connect with residents and to recognise their gendered selves. The activity also brings a connection that occurs between the present and past selves, and to past relationships as the tacit knowledge of shaving is linked to fathers and cultural practices.

The opportunities that arise from carrying out intimate bodywork and bodily routines such as these can help to create restorative atmospherics, just as the opportunity for resistive atmospherics is there too. The nature of entering into such personal territory with a resident requires careful negotiation and recognition for the individuals involved. In these two shaving stories, despite the potential for difficulties to occur, the care staff are able to offer the support that seems to fit well to the needs of each of the men, Samuel and Larry. It may be because the care worker acknowledged Samuel's expert knowledge relating to shaving, and her own vulnerable position of not having carried out a wet shave before, and this became a way for Samuel to take back some power in the scenario.

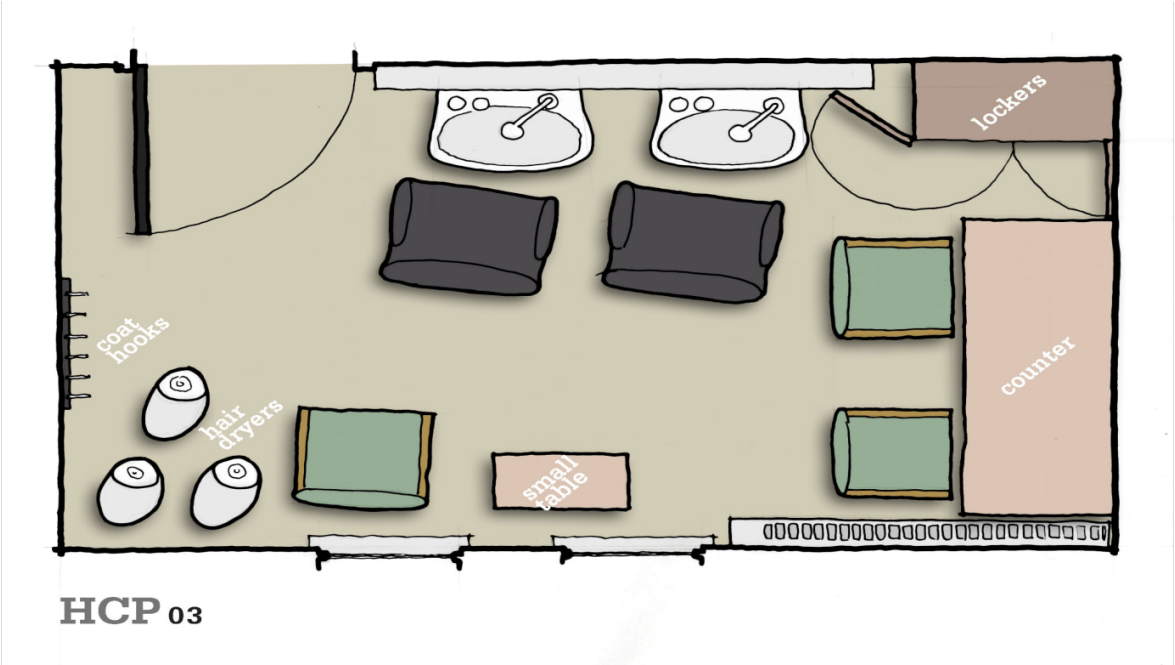
As alluded to in the wider study, 'The Hair and Care project', the hairdressing salon was also a place where more restorative atmospherics were often created through the intimate one to one support of the hairdresser, and there were regular opportunities for biographical stories to be shared (Ward, Campbell and Keady, 2016b; Campbell and Ward, 2017). Sandbridge ward had its own designated salon space and employed a part-time hairdresser. Over a period of time the role of the hairdresser had evolved in order to work alongside the occupational therapy team to offer something that was something more akin to a therapeutic space and service, and more than just a haircut (although it might be argued that hairdressers in all care organisations often offer something therapeutic in their service (Ward, Campbell and Keady, 2016b). Due to the merging of the male-only ward with Sandbridge ward, and the number of

residents who were experiencing heighted mental distress related to their experiences of living with dementia, and being on the ward, it was acknowledged there was a need for time away from the ward for residents. The hairdresser thus provided a unique opportunity for residents from the ward. The resident would be accompanied to the salon by an Occupational therapy assistant and they would talk to the resident whilst they had their hair done. Sometimes the assistant would play music known to be enjoyed by the resident to enhance the opportunity for the salon visit to be a time to relax, to create personal connections and through which to create a therapeutic experience of the hair-event. Also, because the salon was outside of the ward area, this meant that residents had to leave the ward to go somewhere which had its own benefit to it, as although the salon was still in the hospital it was away from the ward routines, and through the ward threshold.

On the day that Don attended the salon, I was granted permission to observe and film the visit. We left the ward to reach the salon by walking along a wide, light corridor, with pictures of art on both sides of the walls. During this outing Don was animated and we left the ward together with Kate, one of the Occupational therapy assistants. Don seemed pleased to be going somewhere; he was actually going through the door threshold that he spent a lot of time waiting by. Residents rarely left the ward, except on a few occasions when residents were being prepared to leave the ward, and might visit their new (or old) home to begin readjustment. Sometimes residents left the ward because they required other health care; for example, whilst I was observing on the ward, one woman went out to a dental appointment. However, Don to my knowledge, had not left the ward since his admittance before this outing to the hair salon. This was immediately outside of the usual routines and temporal structures, it was not only time-out it was time-away. He laughed and smiled as we walked down the hospital corridor together, making his usual conversational rhythms.

The salon space itself may not have been a particularly familiar environment for Don, it had large pictures of young female hair models on the wall and hooded hair dryers familiar to a particular generation of female salon goer. It also had a large window that brought a lot of light into the small rectangular room.

Image 4. Old Bay Hospital: Hair Salon. By Architect student Matthew Hargreaves.



The salon housed two sinks, a front facing sink and backwash and along one whole wall of the salon was a rectangular mirror with a seating area in front. Don was taken to a seat here, where he sat facing the long mirror, with Kate the therapy assistant sat beside him. Don was going to have a haircut but not a hair wash. During Don's time in the salon he sometimes looked in the mirror, and he would also look at Kate the therapy assistant, chatting happily to her about his dog at home, his wife, previous hair cut experiences and also music. All the conversations were initiated by Kate, and once by the hairdresser, and Don seemed happy and relaxed during the visit. There was only one point where Don appeared to be uncertain and this was at the end of the session, he repeatedly put his hand in his pocket and hesitated about leaving. He appeared to be looking in his pockets for something, possibly his wallet in order to pay the hairdresser for his visit, though as he was in hospital he did not need to do as this had been taken care of through his wife. Besides which, Don did not have a wallet with him in his jeans pocket. This was a moment within the hair-event that created a momentary vulnerability for Don. However, in the main, this activity had created a space in the everyday for Don to do something that may have been routine throughout his life but that he had not been to do whilst living on Sandbridge Ward. Don was someone who often gave the impression of being unsettled on Sandbridge Ward, because he either had taken to sleeping a

great deal or he would be walking around and waiting by the ward exit. Hence, the trip to the hairdresser offered him a break from these in-between time activities and from being within and a part of ward atmospherics.

The staff involved with this activity were focussed only on Don and the atmosphere was friendly, light and with less tension than on the ward. Although Don knew this was not where he would usually go to have his hair cut, he accepted when Kate told him that just whilst he was here his wife had thought it would be good to have a trim. He did say in another part of the conversation that he did not think he would be there long. However, the visit to the salon also appeared to have a positive effect on Don's well-being and, through this, also created restorative atmospherics seeped into the space, as Kate talked to Don about his life outside of Sandbridge ward which acted to reinforce Don's identity. The salon space off the ward gave the residents on Sandbridge ward space and time where they could be recognised as a person. It was also a unique opportunity in all three organisations that the salon-space was the only environment where most residents were able to see their own images, although the men on Sandbridge ward did see themselves shaving in a mirror, unlike either Samuel or Bryn on Primrose residential dementia unit, as the shaves were done to them and they did not see themselves. Hence, Don saw himself more often in the mirror and he was not surprised by his appearance, rather he seemed to respond positively to having an appearance renewal and appeared relaxed whilst sat in front of the mirror. This is different to comments heard by female residents who were often surprised by their image, older, fatter, greyer hair than remembered (Ward, Campbell and Keady, 2016b) and usually had less other opportunities to view themselves.

On another occasion at the hair salon at Old Bay Hospital it was Larry's turn to have some time out from Sandbridge ward. In my fieldnotes I write:

> *Larry is going with Kate the occupational therapy assistant to the hairdressers. He is talking in a posh voice, a voice he puts on sometimes, [when he is being polite or having some fun], here he is laughing, there is something fun happening. He appears excited to be going somewhere off the ward.*

At the salon Larry jokes as the hairdresser Dorothy puts the towel around his shoulders. Rock n Roll music is playing and he is finger snapping and foot tapping as Dorothy gets the water temperature ready to wash Larry's hair. She needs to persuade him to put his head over the sink, and she helps him to get his bottom back into the chair and she pushes his head over. Larry dances to the music whilst in the chair and Dorothy lathers up the soap on his hair. He sings 'do da doo'. He keeps his head lent over and his hands are on his knees. As Dorothy lifts Larry back upright and towel dries his hair Larry makes funny sounds below the towel. Dorothy puts a hairdressing cape around Larry and pats his face with the towel and cape. Kate asks if he feels dry and he says 'not dry at all!'

Dorothy asks him 'How do you want your hair cutting?' and he says 'I don't really know…I leave it to you…you're the person'. Kate says that she's seen photos of him with a short back and sides. Dorothy begins, snip, snip, snip and she combs down the back of the hair and takes a good couple of inches off. She pulls, combs and cuts whilst talking about a meal in Manchester that she had the night before and she says how expensive it was. Larry in a very posh voice says 'I don't like the sound of that!' [about the cost]. The hair cutting experience goes on for some time…at the end Dorothy shows Larry his hair in a mirror and he looks and says 'alright!'. And in a funny voice he adds 'He looks like a nice guy!'. (10.30am. 16th January 2012).

Larry seems to enjoy this opportunity to be off the ward. He enters into the atmosphere of the salon, dancing and singing along to music that they have chosen for him (according to suggestions of music he likes, garnered through family members). He appears to perform in the role of joker and fun-guy whilst at the salon, or at least certainly at the start of the visit, which may have also been a way for him to manage any anxiety he felt at what was happening or the pressure to interact with the two staff members. He also hesitated when asked how he would like his hair and he devolves the decision making to the hairdresser. Whilst his hair is being cut he closes his eyes for quite a while, but he is clearly listening as he makes a well-timed joke at the end of the discussion about the cost of a meal out that the hairdresser had been describing. He is attuned to the space and the atmospherics of the salon chatter.

It might appear that Larry is being excluded from the chatter; however, he is listening as we discover by his joke at the end. He is perhaps relaxing and listening to the voices of the two women as he enjoys the touch to his head as his hair is cut and shaped. The salon space, as already mentioned, is a feminised space, with pictures of young women with bold hair colours on the walls, and he is accompanied by a female worker as well as the female hairdresser. It may not seem like an environment that is particularly supportive of his masculinity. However, the hairdresser and occupational therapy assistant have organised to play music that Larry apparently enjoys: rock n roll music, and Larry does appear to relax and is good humoured. It is touching when he looks at himself in the mirror at the end of the session and he affirms his character and selfhood in his statement 'he looks like a nice guy'. Larry is certainly considered a 'nice guy' on the ward, as many of the other residents are attracted to his friendly demeanour and he often acts as a calming influence on others around him. The salon provides a unique opportunity in this care organisation for the residents on the ward to have time away. In both these examples, for the men, taking time off the ward provided them the opportunity to feel good about themselves and to be nurtured. Although the salon space is not perfect for these men, it does not replicate the barbershops they may be more familiar with; but, there is something in the salon chatter and banter that is liberating. They are away from feeling hemmed in on the ward, searching out space, and waiting for the next routine. Here they are immersed in the hairdressing routine and the atmospherics created feel more restorative. Through an examination of the spaces, and the inter-corporeality, and social interaction during these are everyday routines, it is possible to see the opportunities that occur during these body tasks for restorative moments to occur.

7.5 Restorative Atmospheric 4: Moments of recognition: selfhood and identity.

Other opportunities to create restorative atmospherics came in moments when somehow a resident's biography and their identity were brought into sharp focus, either by someone else or by themselves. For example, Samuel was often keen to share stories from his past life; these were passing moments where he was able to shine a light on formative experiences in his life. This gave Samuel an opportunity to be instrumental in shifting the atmosphere of waiting during in-between time to bring a more restorative atmospheric to that 'of being a person in the care organisation'. These restorative atmospherics that could then seep into the

atmosphere that occurred in the moments where the men appeared to hold on to their identities and which could be fleeting. For instance, in Chapter 7, I described how Samuel had called attention to his gendered identity during a visit from some grammar school girls on Primrose residential dementia unit. He cries 'what about the dads?' in order to draw attention to the girls, and perhaps to the female residents in the communal space, having been excluded from the social interaction. In considering these acts of resistance to the normative conditions within the care organisations, it is clear that there is overlap with the creation of restorative atmospherics.

As I saw frequently during my observation times, in the day room there were opportunities for Samuel to 'hold court' and to engage at least with me [who was always willing to listen, that being a primary researcher role] about his life, and to restore his sense of self as he would tell me about his time in India. As I learned from these encounters, Samuel was stationed in India during national service and war-time and it was understandably a formative experience for him. The importance of travelling somewhere so culturally different, that is remembered in a moment 65 years later tells me - and everyone in the room - something about him: 'look at the life I have led' and 'I am more than this'. The opportunity for biographical sharing, for life stories to come alive in the moment is a reinforcing moment; it provides a restorative shift in the atmospherics of the feminised living room for Samuel as he claims space for himself.

The more time I spent in Lincoln Manor, the more I learned from Harry about his life which also suggests something about the development of these relationships in the field, when there is time for someone to be heard and recognised. Harry could talk to me about his past and I would ask questions and respond to his stories. I developed a friendly [researcher] relationship with Harry over the few months I visited Lincoln Manor and sat alongside him. Sometimes, as I have previously mentioned, he would choose not to sit with me. He would acknowledge me with a nod, or a smile, but he would choose to sit apart from me. These moments indicated Harry's agency and his ability to take part in a 'process consent' as a participant in the research (Dewing, 2007). He was clear about when he wanted company and conversation or if wanted instead to take time out. Other times he would sit alongside me and chat but every so often he would go off for one of his 'walkies'. Harry regularly told me about his time in the army or about his children or the work he did once he left the armed

services. He related these life experiences to the present as he tried to make sense of his biography, almost like he was reflecting on his life and reckoning this with where he was now. Sometimes, he would tell me that he had been very well paid, and he would pat his jacket pocket, to indicate his wallet pocket. The information of earning a good salary was possibly to indicate his achievements and to claim a sense of his masculine selfhood, that he had been a good provider for his family. This masculine selfhood perhaps removed him from his current more vulnerable status and maintained normative gender norms that were a part of his cultural background, as a Northern working class ex-military man.

These moments where the men had an opportunity to draw on their biographies were restorative moments as they come into existence beyond being a resident of a care home. These opportunities in Lincoln Manor appeared to happen rarely with staff who did not seem to have time to sit and chat with the men. In the moment of the shared biography, the atmospherics would shift as the men's selfhood came into focus and a restorative moment was shared.

On a similar note, when Charlie burst into song between his anxious questions of 'am I alright?' he was also claiming space for himself. Charlie had always been a social and vivacious man and he no longer had the same abilities to chat and socialise - and he was considerably older than many of the men around him - he would claim space for himself in singing into the atmosphere, creating atmospheric charge which would be caught in the soundwaves of the large communal space. The other men would respond to his song, sometimes joining in, and through these connections he is recognised in the restorative atmospherics of the moment. Of course, occasionally the men might call to him to be quiet, generating a less restorative encounter.

Finally, I want to draw attention back to the photographs in Lincoln Manor which showed staff on a holiday with residents. I have referred to these photographs in both Chapter 5 and Chapter 6; firstly, I drew attention to how staff referred to the occasion depicted in the photographs during a discussion group carried out with staff at Lincoln Manor. As I discussed in this Chapter, staff at Lincoln Manor recognised that whilst outside of the care home with residents there was something different about the relationships they had with them. In Chapter 6, I drew attention to the images to contrast how the photographs of life

with staff and residents outside of the normative conditions of the care organisation were different to how staff appeared to interact with residents within the boundaries of Lincoln Manor. I use the example as a way to discuss the tensions created through the care organisations, providing a home-place for some and a work-place for others. The scenes depicted in the photographs from the holiday can be interpreted to represent a restorative atmosphere. One where staff and residents are not divided through the normative regulations and conditions of care, and instead one where they are free from the time-constraints of the care organisation. They are not divided by some of the materialities and spatialities of care, such as uniforms and spaces that divide them such as staff rooms. Rather, residents and staff are shown to be eating together, to be wearing casual clothing together and to be joining in everyday life together. However, it is not as if on this holiday there is no care work to be done, on the contrary, residents away from the care home will still require medication, support with grooming and bathing, and so on. Instead, there is a shift outside of the boundaries of the institution, a throwing off of the institutional shackles. A freedom from the rigidity of institutional time. There is something in these photograph representations about how on holiday residents are recognised as people before residents and the division between staff and resident is lessened. It feels like the care home is proud of the holiday, and the representations of fun, and care for residents which is why they have them on prominent display for anyone who visits the care home to see, and as a reminder for residents (and for staff) of these happy memories.

7.6 Conclusion

There are many opportunities during daily life for the men (and indeed other residents) in these care organisations where restorative atmospherics do and can occur. Sometimes these atmospherics emerge out of a brief moment where some kind of connection shifts the general atmosphere or the lull in the atmosphere of the normative conditions of care. I have shown that these momentary shifts are part of atmospherics which merge together aspects of the environment and beyond to contribute to a restorative charge within the atmosphere. These restorative atmospherics help to engender moments of belonging amongst the men, sometimes these last a brief moment and at other times longer. Sometimes, they emerge within a routine activity and at other times in the empty in-between time zones. It is important that conditions are created to enable these restorative atmospherics to occur, which

is why it has been important to identify properties and elements that provide the chance for atmospherics that bring a more restorative charge into the atmosphere of the care organisations.

There are some staff who seem better equipped to enable restorative atmospherics, perhaps because they are less constrained by the boundaries within the space, and normative regulations and conditions of the care organisations. They are often those who are not bound by the institutional governance of the care organisations such as external workers like the singing group facilitator on Sandbridge ward. The hairdresser too who worked with residents from Sandbridge ward, although employed through the hospital was less fixed to the ward routines, and could offer an alternative to the ward scenarios. Or even the workers who carried out the shaves in this chapter, the male nursing assistant whose support in the shave with Larry helped to support an extension of gendered embodiment between the two men. Similarly, the care worker who supported Samuel's shave was prepared to make herself vulnerable through admitting that she was not experienced in wet shaves and she allowed Samuel to give her instructions.

Understanding the kinds of features of that create restorative atmospherics is essential in order to enable staff to support the recreation of them. Restorative atmospherics could occur during routine tasks, such as the shaving examples, where staff were able to support the men's identity, sometimes the material objects round and about would help this process, where the resident's life story came alive in the moment. The holiday with staff and residents at Lincoln Fields was a particularly useful example to see how staff responded differently and engaged with residents being more alongside them whilst outside of the care setting. It is also possible to see how the men in this study themselves are often responsible for creating and sharing restorative moments that shift the atmospherics with each other through their resilience, their friendships and their ability to still laugh despite some of the challenges they faced. Hence, it is vital to recognise the ways in which atmospheres are shaped, and how they shift and merge, changing the feel of the everyday spaces. I will go on in Chapter 8 to discuss why turning our gaze to atmosphere to tell these embodied and sensory narratives of care is a useful way to understand issues of identity such as gender, and the micro-politics of everyday.

Chapter 8 Discussion: Bringing together gender, atmosphere and dementia

8.1 Introduction

In this final chapter of the thesis I will return to the original orientations for the work, men living with dementia, everyday care, the places and spaces of care organisations and atmosphere. I want to set out how the findings from this research have value and can contribute to consideration of the experience of men living with dementia within a variety of care organisations. I will firstly set out what the aims of the research were and I will provide an overview of the thesis. I will then discuss how the research contributes to the contemporary literature on dementia with relation to the experiences of men living with dementia and to contemporary literature on atmospheres. Finally, I will set out how this work contributes to new learning within dementia care practice. I will also use this chapter to expand on the methodological learning from the work and outline the limitations of the work.

8.2 Overview of thesis

At the outset of this doctoral study there was very little written with relation to atmospheres and atmospherics within dementia studies. Although atmospheres had been of interest for some time within cultural geography led by the work of Thrift (2008), it was a theoretical framework that had not been greatly explored across other disciplines. Over the last seven years the development of work in this area has grown and more influential thinking has been published (for example see: Wetherell, 2012; Mason, 2018a; Sumartojo and Pink, 2018). This study then, is a radical contribution to providing new understandings within the shifting landscape of dementia studies. Although a number of studies have brought attention to the task-orientated regimes within care organisations (see: Wiersma, 2012, 2010; Diamond, 2009; Ward et al, 2005; Peace and Holland, 2001; Lee-Treweek, 1998). It appears little has changed and this work has explored how these normative and seemingly entrenched modes of care have an impact on the collective experiences of men living with dementia which is one of the original contributions from this study.

Further to this there has been an overwhelming focus on the 'person living with dementia' with limited work exploring diverse experiences, including the gendered experiences of those living with dementia (Bartlett, 2016). This study set out to explore place and gender relations in the lives of men living with dementia in a variety of care settings. The primary research aim is to interpret everyday embodied life for men living with dementia in care and its connection to atmosphere. The objectives for the study were:

- To explore the types of relationships that the men experience in care, using creative social research methods
- To interpret the everyday experiences of men living with dementia in care organisations
- To provide an enhanced understanding of the experience of gender relations for men living with dementia
- To describe staff approaches to care and the care environment

Dementia Care has been described as subject to 'feminised heterosexual norms and normativities' (Westwood, 2016, p1497). There are greater numbers of female residents within the care population, and a predominantly female workforce (Cohen and Wolkowitz, 2018; Prince et al, 2014). In this study I have argued, like others previously (Ward et al, 2005) that within care organisations there is a tendency towards normative constructions of gender. Calasanti (2004) notes that further research is required that seeks to understand the experiences of men as they grow older. She suggests that there are important power dynamics that need further understanding, exploring how men respond to ageing, and the shifting patterns of gender relations in everyday life. Where gender has been explored within dementia it has often been in relation to care-giving (Bartlett, 2016; Campbell, 2012). Recently there have been two significant reports published that explore understandings of women's experiences of living with dementia and the reports both note the disproportional impact of dementia on the lives of women and the need to address gender inequalities (Alzheimer's Research UK, 2015; Erol, Brooker and Price, 2015). However, there is also a need to consider the experience of living with dementia for men and in particular for those residing in care organisations where gender is likely to be a key factor in everyday care relationships. There is a need for more nuanced and complex readings of the experiences of men relating to place and space. This work aims to show how the lens of atmosphere can

account for the dynamic and varied experiences of everyday life. As such this study has provided an interpretation of the everyday embodied and sensory lives of men living with dementia across the three fieldsites and their connection to atmosphere.

The challenge was to tune into the everyday rhythms of care, and to interpret these experiences for men living with dementia. There are many challenges during everyday life in care, these are often due to the limitations of opportunity for agency. Alongside this for men there are difficulties associated with perceptions of them whereby they become visible as men when they present as disruptive, aggressive or as sexually predative and as elopers from the care environment. This was seen in Chapter 2 in the work of Chatterji, (1998) with Mr Rijder, who tried to escape from the care organisation where he was placed and for Leonard, in the study by Koehn, Kozak and Drance (2012) who was perceived by staff to be challenging and manipulative and to knowingly create problems for staff and other residents. Indeed Leonard was blamed for shifting the 'homely atmosphere' within the care organisation (Koehn, Kozak and Drance, 2012). Archibald (1998) also pointed to the way that men were perceived to be more problematic around issues of sexual expression and sexual disinhibition. Similarly in this study staff on Sandbridge ward describe concerns about the men being aggressive, or unpredictable, and Don is noted for his 'non-compliance' when he refuses to change into his night-clothing. Staff also have heightened anxiety around Don and his potential towards unpredictable behaviour which is why he had become admitted to Sandbridge ward in the first place. There is a tendency to see the men through these 'fixed' lenses which impact on their everyday care and relationships.

In order to provide more complex and nuanced accounts of everyday life for men living with dementia it was important to use an analytical lens that provided insight into the relationships that the men had with others, and the places where they were situated. This work considers gender in performative ways, like other ethnographies and qualitative work have also done. For example the case study by Bartlett (2007) in Chapter 2, exploring Mr Brown's everyday experiences of care shows how Mr Brown uses humour to deflect feelings of vulnerability and embarrassment when being bathed by female workers. Or in the work of Chisholm and Bischoping (2018) who show Alexander finding new ways to be 'useful' to his family, now he can no longer undertake farming duties. The notion that gendered experience is bound up in everyday relationships and embodied performances of everyday life has been key to this

study. Using an atmospheric lens provided opportunity to tune into these situated sensory and embodied experiences.

As well providing insight into the more challenging aspects of everyday life, this work has shown there are also opportunities for reciprocity, compassion and affinities to emerge in the form of restorative atmospheric moments during the everyday experiences of care for men living with dementia. These restorative moments arise through everyday encounters and provide reconnection to selfhood and a sense of belonging and recognition. They highlight the value in the relational aspects of everyday life, and the connection to atmosphere, and show how the men in this study play an integral role in the emergence of atmosphere.

8.3 Atmosphere, Institutions and Care Organisations

Atmosphere has been recognised in other health care provision as significant to the experience of place. For example it has been long understood to contribute to the 'psychosocial' work of psychiatric wards (Tuvesson, Wann-Hansson and Eklund, 2011; Røssberg and Friis, 2003). Understandings in relation to psychiatric wards emerged from the influence of Goffman's work on 'total institutions' exploring within the Psychiatric Hospital (and other institutions) the notion of a 'moral climate' (Goffman, 1961). For Goffman a total institution is where a group of individuals have a shared experience and are under the 'bureaucratic control' of an organisation (Goodman, 2013). Residents and staff reside 'under one roof' where all activities of daily life are carried out, set apart from the rest of society (Goodman, 2013, p81). These environments generate an atmosphere or 'moral climate' that will be experienced differently by patients and staff (Caplan, 1993). There are on-going investigations of this phenomenon within mental health research using 'ward atmosphere scales' to measure the experience of being on a psychiatric ward. The scales recognise the impact of emotion on ward atmosphere which is gauged with reference to staff and patient relationships as well as patient's moods and behaviours such as 'angry and aggressive behaviour' (Røssberg and Friis, 2003). Atmosphere is linked more to bodies and relationships than the material environment (Tuvesson, Wann-Hansson and Eklund, 2011; Røssberg and Friis, 2003; Middelboe et al, 2001). These studies provide limited insight into how much something, such as aggressive behavior, might be contributing to ward atmosphere as they do

not look for qualitative explanations of how elements of atmospheres interconnect, or emerge and dissipate during the day.

In other work exploring atmosphere within hospital settings Edvardsson, Sandman and Rasmussen (2005) describe how an 'atmosphere of ease' evolves in a study comparing a hospice site with two hospital wards. The study finds that subjective expectations around care have significant impact on the experience of atmosphere. The material environment, such as the experience of being in corridors, contributes to how these spaces can be negotiated by staff and patients. Atmosphere is also related to the notion of 'being seen' and attended to by staff when time and attention is available (Edvardsson, Sandman, Rasmussen, 2005, p347). This was reiterated in another study by Edvardsson, Rasmussen and Riessman (2003) which explored one woman's experiences of two different hospital encounters: one when her mother was dying; and the second when she herself became a mother. Staff attitudes and responses were key in her experience of the ward atmospheres. The caring attention and recognition of staff towards her during her mother's final days and hours was a healing and therapeutic atmospheric experience. A distinct contrast to the attitudes she experienced on the maternity ward, which she describes as contributing to an atmosphere of horror.

Atmosphere then is linked to the material, sensory and relational encounters between staff and patients in these studies. The acknowledgement of selfhood, of being seen and being recognised, appears to have particular significance. These studies provide useful insight into what creates affective atmospheres. In taking forward ideas from this work I have been interested in illuminating the collective experience of care settings for men living with dementia. This includes the power dynamics that are particularly pertinent within dementia care settings, where capacity and agency are ongoing issues of negotiation for everyday life.

Atmosphere is a familiar term within literature about social care organisations. In a Google search (carried out in November 2018) I found a number of examples of care homes describing their environments as atmospheric, such as this one:
Brookfield …offers a 'homely atmosphere' set in scenic grounds…(Janes Care Home Group. Accessed 10.11.18)
Here it is suggested that 'Brookfield' as an entity creates an atmosphere, and atmospheres in these contexts are often suggested as something fixed in place in order to show the provision

of a desirable environment. They are described as 'friendly', 'homely' or as 'family' atmospheres denoting particular kinds of experience that can be found in the care organisations (Care homes UK ; Janes Care Home Group; Nellsar care homes). In a summary on key messages from the Centre for Policy on Ageing (2012) they state:

> 'It is important that care homes present a 'homely' rather than 'institutional' atmosphere with an emphasis on person-centred care rather than task-based routines' (p2)

The report makes a connection between the experience of atmosphere and task-based routines suggesting that person-centred care allows for the production of 'homely' atmospheres, whereas task-based routines generate 'institutional' atmospheres. This is notable for this work, and I argue that it is in part, through the structure and organisation of everyday life by the care organisations and the development of temporal dimensions such as institutional time and in-between time which give rise to resistive atmospherics. This work contributes to considerations around how atmospheres are created and produced, and ways in which they affect, shift and merge and re-emerge throughout the day.

It could be argued that within the social sciences there is something of an 'atmospheric turn' happening. There is the on-going development of understandings about collective bodies and experiences of space and place (Sumartojo and Pink, 2018; Brennan, 2004). This has included some literature that has explored atmosphere as a theoretical concept within dementia care (Jeong, 2017; Hatton, 2016). Hatton explored creative practice within care organisations with people living with dementia, and the notion of incorporating the existing atmospherics within creative practice. Jeong (2017) looks at the notion of 'co-dwelling' within his doctoral work and describes ways in which people living with dementia are participant in the notion of 'home-making' within the care facility where they live.

In Hatton's (2014) work exploring the creative potential of engaging with care homes as a 'multitude of care environments' (p364), she argues that rather than trying to change the sensory within the care environment creative practitioners should engage sensory atmospherics that are already part of the care home and it's everyday rhythms. She uses the idea of 'indoor weather' to represent familiar sensescapes that enable people to connect with

memories, imaginations and join collectively in creative activities (p362). Weather encounters emerge as a key conduit for restorative atmospherics within the care organisations in this study. As described in Chapter 8, the experience of natural sunlight or even rainy weather can engage the senses of residents as they connect to the weather and their own aroused memories and imaginings (Mason, 2018a).

Atmospheres that are created within care organisations are always in flux and are influenced by many factors. Jeong's (2017) study shows that home-making as a performance occurs even when residents do not 'feel at home' and suggests it is an on-going negotiation of their experience that takes account of residents' past, present and future. These elements of experience are particularly pertinent in this study when considering atmosphere and atmospherics and how feelings of home or moments of connectivity or alienation can contribute to resistive and restorative atmospheric moments. The men in this study were actively engaged in creating restorative atmospherics using humour, in moments of friendship and through care and empathy, such as when Larry on Sandbridge ward says , 'poor devil' when referring to another man's distress (see p178). The men in this study looked out for one another, and these moments of connection were key contributors to restorative atmospherics. At other times their resistance and even distress filters into the experience of resistive atmospherics. For example the experience of waiting for Don, when he returns time and again to the ward exit, or Bryn's refusal to comply with a routine care task because it challenged his dignity - I could not observe the happenings behind the bathroom door, but I, along with others, could hear his shouts of distress. I suggest this work shows new ways of thinking about care homes through an atmospheric lens and that atmospheres cannot be simply fixed through simple environmental changes. Rather the generation of atmosphere is linked to a great many other contributing factors. I wish now to move to consider the study findings in relation to the experience of gender and atmosphere.

8.4 Gendered performances in care organisations

Within the still limited literature exploring gender in dementia studies there has been a call to consider the diverse experiences of people living with dementia. This has been highlighted within the citizenship discourse, but also by Sandberg (2018) who has argued for a more nuanced understanding of gendered experience. She argues there is a tendency to regender

people within a normative framework which fails to explore diverse or fluid aspects of identity, including gender.

Many of the studies in Chapter 2, explored masculinity within the scope of hegemonic masculinity. This does have relevance for exploring the experience of men in care because long-term care often entails a lack of autonomy, independence and opportunity for productivity which are valued within a hegemonic masculine framework (Armstrong and Braedley, 2013). Hegemonic masculinity of men living with dementia can thus become eroded through the experience of long-term care. A number of studies cited in Chapter 2 highlighted the men participants desire to be productive and useful (Tolhurst and Weicht, 2017; Milligan et al, 2015; Phinney, Dahlke and Purves, 2013; Kinney, Kart and Reddecliff, 2011;Pearce, Clare and Pistrang, 2002). However, this particular reading of masculinity can fail to consider the multiple ways in which masculinities are performed by men and how this intersects with other aspects of their identities and relationships. Sandberg's (2018) argues that men's gendered identity may be performed in diverse and sometimes subversive ways. She shows how gendered identities merge and evolve into less normative performances, such as when the heterosexual men in her study let go of some of their previous beliefs and expectations relating to their own youthful sexualities (Sandberg, 2013). Similarly Capstick and Clegg (2013) included in Chapter 2 give a more subversive reading of masculinity in their work exploring the narratives of male WWII veterans now living with dementia. The men retold stories through a new disinhibited lens that allowed them to express their emotional selves (including feelings of fear and vulnerability) rather than the gendered expectation to maintain a 'stiff upper lip'. These valuable contributions to dementia research give helpful frameworks for performative interpretations of everyday experience of gender for men living with dementia.

Viewing the men in this study through an atmospheric lens reveals different experiences of their gendered selfhood. For example on Sandbridge ward we see occasions when Larry shows his frustration at the lack of meaningful occupation. The example shared in Chapter 6 where Larry questions the activity provided by the OT assistant, fits with the notion of 'identity as a working man' developed from the literature in Chapter 2. At other times, Larry is the peacemaker, soothing others on the ward and settling other men's frustrations. Larry shows how his gendered self is performed in relation to everyday experiences that are

situated and relational. He contributes to the shifting atmospherics of the ward, sometimes as part of the resistive moments that emerge but at other times as an instigator of restorative atmospherics.

Harry has periods where he tells me he has had a good life, possibly adhering to a 'stiff upper lip' type attitude, although it often also appears that he is trying to make sense of his current situation (sometimes making remarks that let me know he is aware of his dementia). At other times Harry tells me that 'life is a bitch', allowing himself to become more vulnerable. This often occurs after a few hours of 'in-between time' perhaps reflecting his emotional vulnerability and frustration at the reality of his situation, and his lack of agency to change things. He both affects and is affected by the atmosphere during these times. The atmospheres of waiting and uncertainty impact on his experience of the day which in turn causes him to affect those around him as he exclaims 'life's a bitch' and goes off on his circular walks.

Sometimes the men show caring and kind responses to others, despite their own vulnerability, such as when Don shares his songsheet with the volunteer sat beside him in the singing group on Sandbridge ward. Staff often describe Don as 'paranoid', he regularly appears unsettled as he paces around the ward and hovers by the ward exit. Don takes to remaining in bed for longer periods, similar to Mr Rijder in Chatterji's (1998) ethnography, in a form of resistance to the temporal ordering of the day. However, in this moment in the singing group, Don performs an act of kindness and care by sharing his songsheet and is a part of a restorative atmospheric moment that creates positive feelings through the act of friendship and connection. These occasions illustrate how masculinity is not a fixed experience for the men on the ward: there are times when they feel vulnerable and ill at ease and there are other times when they take part in jokes, or respond to others with kindness, care and friendship.

8.5 Gendered Atmospheres – taking an atmospheric lens

The previous section discussed performances of gender and how this contributes to the experience of atmosphere. This section builds on these insights to show how atmospheres emerge and are interconnected with gender. If gender is considered as both relational and performative then gender will also contribute to the experience of atmosphere. Hence rather than taking simply a gendered lens as discussed in Chapter 3, this study has also taken an

atmospheric lens which has provided insights into atmospheric gendered experiences within the care organisations.

I argue that gender permeates relationships in care and as such expectations of the men. I have shown how the material and sensory environments are gendered through the construction of space, such as the glass box reception area in Lincoln Manor and the Ladies lounge on Sandbridge ward which act to separate men from the female workers and residents. I have also explored how the sensescapes of care contribute to the experience of atmosphere, and that these too can be gendered such as the smell of perfume from female care workers, or male toiletries during shaving encounters which contribute to bodies becoming gendered in these atmospheric moments.

As already discussed staff often consider the men as unpredictable, or as presenting risks of violence. Staff on Sandbridge ward particularly expressed such concerns about the men they were working with, many of whom were on the ward because they had posed a risk to themselves or others (Jones, 2018). This concern would filter into the atmosphere on the ward. As I described during the film activity with Don, in Chapter 7 I too felt a sense of anxiety around him, and the desire not to provoke paranoia in him. In order to suggest that feelings 'filter' into the atmosphere I return to the notion of 'collective feelings' (Ahmed, 2004). Ahmed (2004) suggests 'emotions do things, and work to align individuals with collectives – or bodily space with social space – through the very intensity of their attachments' (p26, emphasis author's own). This could be seen through the group discussions with staff in the study, the opportunity to share and reinforce each other's experiences gave opportunity for 'collective feelings' to arise amongst the staff. The staff's experience of working within an atmosphere of risk would ripple outwards and I suggest this has an impact on how bodies orientate themselves and negotiate space within the care organisation.

According to Ahmed (2007) bodies extend or retract in space depending on how comfortable they feel, or don't feel. Bodies that are considered normative will extend within spaces where they feel that they fit and are accepted. Creating gendered spaces thus inevitably includes some and excludes others, as shown in the study by Kinney, Kart and Reddecliff (2011) when a woman did not continue with the programme, which had become a male space and arguably created a masculine atmosphere in the programme. It is also likely that holding perceptions of

men as problematic, or simply as 'other', will lead to men feeling excluded from or unwelcome in some spaces. This was the case for Samuel in the communal living area on Primrose residential dementia unit, particularly on the day when the grammar school girls visited and he cried out 'what about the dads?' The men appeared to feel more comfortable in spaces such as the seating area in Lincoln Manor where they routinely gathered, seemingly comfortable within their friendship group. Experiences of connectivity and belonging may occur as the men feel recognised and included. Providing such opportunities can contribute to the creation of restorative atmospherics.

Individual acts of resistance, such as the example above by Samuel would occur throughout the day where upholding aspects of selfhood and identity are made vulnerable due to the limited opportunities for self-representation. Similarly, other expressions of selfhood filter out into the atmosphere. Just as described in some of the studies in Chapter 2, humour was an important element of everyday life for the men in all of the settings. Bartlett (2007) noted that humour was important to Mr Brown and how he coped with certain aspects of indignity in the care home, such as bathtime. Humour was also noted by Capstick and Chatwin (2016) as a form of resistance. In Gleibs et al (2011) and Kinney, Kart and Reddecliff (2011) humour emerged as a form of masculine bonding and a way to cope with the potential vulnerabilities experienced during intimate care tasks such as shaving. Humour was present in the rise of restorative atmospherics, in Lincoln Manor, banter revealed a jocularity that could be argued to be an expression of the men's masculinity (Gill et al 2005); and related to their military heritage and behaviour that is about being amongst other men, such as that described in the study by Milligan et al (2015) and the Men in Shed's project. Often at Lincoln Manor it appeared that the men were 'in it together' as they laughed, joked and chatted together. However there were occasions when some men appeared to be included and others excluded from this banter and it was not always clear how the hierarchies or relationships were established. An atmospheric lens provides an opportunity to explore these kinds of affective experiences and the hierarchies that form amongst residents within the care settings. The atmospherics shift and change throughout the day and show how some people are included at certain times and others not.

As already suggested at other times the atmosphere became gendered through material and sensory assemblages as the men engaged in intimate activities of care such as shaving

routines. The smell of men's toiletries would fill the air, or the sound of razor against skin would bring a sense of masculine presence to the fore. This highlights some important aspects from the study in that gender does not only manifest in the everyday performances of individuals but also through the material and sensory aspects of everyday life that are part of the atmospherics of places. During a shaving encounter in Samuel's bedroom he draws on previous experiences of shaving and reflects on shaving at other points in his life, and links to its masculine symbolism (Retallack, 1999). Shaving is something he associates with his identity as a working man, a significant theme revealed in the literature on men living with dementia in Chapter 2 (Tolhurst and Weicht, 2017; Boyle, 2017; Milligan et al, 2015; Capstick and Clegg 2013; Phinney, Dahike and Purves, 2013; Kinney, Kart and Reddecliff, 2011; Pearce, Clare and Pistrang, 2002). It is an activity linked to upholding his appearance, at times in his past to impress and woo his wife to make himself more desirable. He jokes about these things as he is shaved by the young female care worker, he is able to impress upon her that he has not always been vulnerable and disabled as he might now appear, an old man who needs assistance to undertake a task he has been carrying out throughout his lifetime.

Shaving is a risky routine task for care staff; it is described as 'problematic' where men come into focus as different bodies to the mainly female workforce. Female care workers note being nervous about shaving and are aware of the sensitivity of ageing skin (Campbell, 2012). In this encounter Samuel takes control of the shaving experience because the care worker tells him about her inexperience in undertaking a 'wet shave' and he directs her to take longer sweeps with the razor and he shows his skill in this activity. The atmosphere in Samuel's room is gendered through this sensory and embodied encounter. The material environment holds further links to Samuel's heterosexual identity through photographs depicting his success as a married man, despite no longer being able to live with his wife, or sleep beside her at night. This work develops an enhanced understanding about the experience of gender for men living with dementia, through showing the fluidity of experiences, and the fleeting moments where the men emerge as men, and where their selfhood becomes recognised within a restorative atmospheric moment.

This work provides interpretations relating to the everyday experiences of men living with dementia in care organisations illustrated through these small stories of life in care. Taking

the work of Sandberg (2018) as an important guide I have brought creative social research methods using sensory and embodied narratives in order to explore the types of relationships that the men living with dementia experience in care. As Sandberg (2018) notes, the regendering of people living with dementia must take account of the many diverse and fluid expressions of gendered experience. This study presents the intercorporeal connectivities that illustrate when gender and atmosphere come into focus. These examples show gender not as simply individual and located in the person, in this study gender emerges as relational - sometimes expressed in the collective banter of the men and negotiated from moment to moment and also here in an intimate shaving encounter. During the shave Samuel is not simply a body in receipt of care rather he is engaged in relational care as he and the worker manage the task together and the atmosphere of the room becomes affected through the encounter. On the one hand, Samuel shows himself regendered as a capable heterosexual man, as such perhaps in a normative vein, but he also acknowledges his vulnerability, as he describes the potential for the shave to hurt him. The men show their capacities for multiple masculinities through their abilities to care and show empathy for one another, as well as the banter and humour that might be expected of men together. The next section moves on to consider how this work has provided insight into the temporal experience of care organisations through using an atmospheric lens.

8.6 The importance of temporality within an atmospheric lens

As discussed in the overview of this chapter, this study shows how the normative structures and regulations of the care organisations create conditions through which particular kinds of atmospherics and atmospheres are produced and emerge. This study, like many before, have shown how routinised task-based care continues to be entrenched within care organisations (Wiersma, 2010; Lee Treweek, 2008; Peace and Holland, 2001; Diamond, 1992). I have used the term normative as defined in Chapter 3 (p74), in order to explain the ways in which the care organisations are structured and organised in particular ways to create a desired standard for residents. This refers to standardised care provision which is performed through the temporal ordering of everyday life and the kinds of expectations of behaviour as borne out in the care documentation maintained about the men in this study, and through the ways that care practices are carried out with little variation across the three participating fieldsites.

Mason's (2018a) work on affinities argues that temporality is crucial to understanding the experience of potent connections and atmosphere. The experience of time is significant, because on the one hand there is linear clock time that is structured by the care organisations and which sets out the momentum for the day, but within which there are shifting experiences of time for residents and staff contributing to the tension of home-place versus work-place. The division of chronological time in the literature on care organisations is divided into this 'institutional-time' (Wiersma 2012, p80) and in-between time, similar to what Cohen (2011) calls 'baggy time' (p197) for bodyworkers who are between bodywork tasks, such as a hairdresser between clients. Zerubavel (1979) also identified how time was structured and ordered within hospital settings and noted how even non-routine tasks become routinised into the schedule. For example, within the care organisations 'unpredictable' individual needs such as going to the toilet becomes a scheduled activity.

This study shows how 'in-between time' is when residents are in-between organisational tasks or activities and is often a time when residents are left to themselves, the impact of which is discussed in Chapter 6. During these times I have shown how an atmosphere of waiting and uncertainty emerges. This can be illustrated through individuals performing small movements such as pacing and tapping, and sometimes through the protestations at boredom and anxious talk that give rise to feelings of uncertainty. These embodied experiences are felt individually but also shared collectively. Work by Ash and Anderson (2015) explores the experience of atmosphere within NHS waiting rooms. They note how the atmospheres change within the various types of waiting spaces, and it depends on what kind of NHS service is being waited for and who people are with. For example, they describe the atmosphere of an A&E waiting room as anxious, whilst noting that in the Optometry waiting room that there are co-existing atmospheres; two older women chat away, seemingly unworried about their appointments, whilst a young man appears more anxious in his waiting experience. Their study shows how different experiences of atmosphere can exist in one space, and how atmospheres can draw some people in and keep others out. Across the care organisations within this study, I understand the atmospheres to be fluid and they can be shifted through a change of mood within the spaces. They are also not spatially contained as atmospherics can seep out of rooms and through corridors carried on the radio waves such as cries of distress or laughter, or the smell of meal time, and other times through the movement of bodies, such as men pacing up and down corridors. Some experiences of atmosphere can

appear more enduring and may resonate with more individuals such as the atmosphere of waiting that seems to circulate around the care spaces in each of the organisations during 'in-between time'.

Staff move through the environments differently to residents and are not attuned to the same experience of atmospheric affect as the residents. The temporal dimensions of the care organisations are key and the experience of waiting and of uncertainty that ensues during the in-between periods is similar to the waiting described by Vitus (2010) in her work on refugee children in Denmark. Vitus (2010) explains temporal frameworks of waiting where there is no known duration to the waiting period. As such they appear as limitless to those within them (Vitus, 2010). Through this experience emerges a powerlessness created through the lack of information as to when the waiting will end and/or a lack of agency to stop the waiting period. Vitus (2010) describes the children in her study as experiencing moods of boredom, fatigue and restlessness.

During in-between time the men either appeared either bored and unoccupied or frustrated, worried and uncertain. Harry tells me 'it does get boring sometimes'. An attunement to atmosphere enables the small movements, the shifting in seats, or finding a new place to sit to become notable. Waiting as an experience becomes even more complex for people living with dementia as the lived experience of time means that duration can be particularly difficult to judge, and therefore waiting can have a significant impact as they might have less sense of when something might end (Nygård and Johansson, 2001). Vitus's (2010) work on waiting, illustrates how the refugee children describe their subjective experiences of being in the refugee camps. I suggest it is possible to see the collective impact of waiting when using an atmospheric lens. By becoming attentive to atmosphere it is possible to see how the emotional experiences related to waiting and uncertainty have affect within the dementia care organisations.

For the young people in Vitus's (2010) study waiting is perceived as 'wasted time' where their lives are literally passing them by, whereas the men living with dementia might be considered to have already lived out their lives (Froggatt, 2001). As such, within this kind of framing like the children in the study by Vitus (2010) the men may be perceived as 'non-persons' which is similar to the notion of a 'disappearing self' which continues to be

pervasive within the bio-medical literature in relation to the experience of dementia (Millet, 2011; Froggatt, 2001; Goffman 1959). The idea that once inside a care organisation, the person exists in a space outside of society, waiting to die and set apart from the living, is the same that has been stated for those deemed to lack selfhood, in the case of those with advancing dementia (Froggatt, 2001). In Bartlett's (2007) case study, Mr Brown talks about being able to get into the care home easily enough, but once in, you can't get out. The men in this study show their awareness of their situation too, such as when Charlie sings 'We are social outcasts'. There is certainly overlap between the young refugee children and the older men living with dementia being considered by this notion of non-people (Vitus 2010, Goffman, 1959). Dementia care homes have been described by others as 'non-places' arguing that care homes do not hold meanings of home-places instead they are environments to be 'passed through' as temporary dwellings, therefore they are not home-places and possibly never can be (Milligan, 2009, p116; Peace and Holland 2001; Reed-Danahay, 2001).

The tension of work-place versus home-place created through the rigid structures of time also have a powerful impact on the feel of the organisations. These tensions have been described by others in the literature (see Peace and Holland 2001) arguing that the sense of the institutional nature of care environments, in particular, in larger care organisations was almost unavoidable. In more recent work by Paddock et al (2018) they argue that the rigidity of institutional routines and the prioritising of risk management mean it is difficult to create a sense of personal identity for residents that can begin to reflect their previous home experiences. There is a lack of biographical connection for residents to the care environments. These are not recognisable as home-places, though possibly for the men in Lincoln Manor there was some connection to a previous life within military service, as the care setting reflected the military heritage of the men that lived there. However the notion of home is complex, home itself is not always a comfortable place and it is also unbounded, fluid and holds multiple meanings (Jeong, 2017). In Lovat's (2018) work she takes practice and relational approaches to care homes. She shows how older residents in her study experience feelings of homes within the care home where they live through the interactions and relationships they have with other residents, and their connections with the materiality of the environment. Crucially the experience of home was related to being able to engage in the everyday practices of being at home such as housework and hosting visitors, home was an on-going negotiated process (Lovatt, 2018). The tensions caused through the experience of

work-place for some and home-place for others mean that most often residents and staff are engaged in different temporal trajectories.

The pressure of the institutional temporalities were also felt in other ways such as those suggested by Nygård and Johansson's (2001) study which describes also how participants living with dementia are aware of needing more time to undertake certain activities, such as getting dressed in a morning, because of the challenge they face in being able to judge duration. The experience of living with dementia has slowed their body down, just as described in Phinney and Chelsa's (2003) work on the lived body. This is referred to by Charlie in Lincoln Manor, as he says he often feels hurried during morning routines, and certainly it was possible to see during shaving observations that little time was available for these tasks. The normative routines and pace of the care organisations are not in sync with the men living with dementia (Cohen, 2011). The difficulties of the inflexible and pressurised routines of dementia care mean that when more time might be needed for an activity it is often not available. Staff often have too many people to care for and too many bodies to manage. This is the opposite of the availability of time for residents within in-between time where time appears to stretch out with no known endpoint. This experience of the temporal structure of the day is an essential component of the atmospherics that are produced.

The powerlessness and lack of agency during these times though could lead to charges in the atmosphere of resistance, and as Ward and Price (2016) note in their work, it is often in the margins that resistance can bubble up. Temporal resistance emerged in different ways despite the organisational pressure of institutional-time. Hence agency is shown by the men when they do not comply with routines, and as Cohen's (2011) work shows, bodies are 'unpredictable' (p193). The men pushed against the atmospherics of the work-place time zones. Similarly to the work by Capstick and Chatwin (2016), discussed in Chapter 1, the men living with dementia found ways to perform a kind of temporal resistance to push against the restrictive temporalities of the care organisations. The men living with dementia were living different temporalities, and often appeared to live past and present simultaneously (May, 2016). This would give rise to atmospherics that challenged the here and now work-place culture of the care organisation. The atmospheric moments of temporal resistance, discussed in Chapter 7, provide an illustration of the men's lived realities of everyday life. This study builds on the notion of cultural resistance within care organisations and as I have

shown within the sensory and embodied narratives the men were often pushing against the structures imposed upon them by the care organisations.

8.7 From Resistance to restoration. A recognition of temporal difference

As discussed in the previous section dimensions of the care facilities give rise to resistive atmospherics. Resistance within care facilities has been discussed in other literature such as by McColgan (2005) who seeks to dispel the notion of passivity amongst residents in the nursing home where her study is based. McColgan's (2005) shows how residents living with dementia resisted the enforced structures and routines through 'feigning sleep' (p424). Residents who were self-mobile and able to choose where to sit themselves would claim space in the communal living area each day, trying to return to the same spots that they had previously sat in, similarly to Harry and Charlie in Lincoln Fields. Residents in McColgan's (2005) study would wear outdoor clothing signalling they were not at home and were ready to leave (for home) at any time. In Buse and Twigg's (2014) study female residents would carry handbags disrupting notions of home, or female residents would reapply lipstick in order to 'smarten' themselves up ready to make the journey back home (p84). This is notable in this study too, through the men wearing outdoor shoes, as if ready to leave and denoting the feeling that they are not at home. Harry as discussed would always wear his outdoor jacket carrying his necessary personal items of cigarettes, mints and a lighter. This was also present in the work by Chatterji (1998) where Mr Rijder attempted to escape the care organisation when no-one would listen to his pleas to go home, and when this resistance did not work, he undertook a quieter bodily resistance refusing to eat, or to get up in a morning. This was also similar to Don, on Sandbridge ward who began to get up later in a morning and refuse to change into night clothes when required. Or when Bryn found it laughable to be expected to choose lunch for the following day, when he was still having breakfast before he had even considered lunch that day, let alone the next.

Residents then were not passive, instead these residents were quietly resisting performing embodied and ritual expressions that pushed against the feelings of confinement brought about through the rigid and inflexible routines. In Wiersma's (2010) study exploring the experience of veterans living with dementia leaving their care home to attend a 'summer

camp' holiday experience. The men describe the freedom they feel outside of the care organisation, not only because they are outside and in the fresh air, but also because they are no longer confined by the 'hidden rules' of the care organisations (Wiersma, 2008, p792)

These studies have shown how through embodied selfhood the men (and other residents) living with dementia find ways to express themselves, and to articulate through their bodies resistance and symbolic acts of agency with relation to where they find themselves. Capstick and Chatwin's (2016) notions of cultural resistance suggest that where the psycho-social model might use malignant psychology as a lens through which to explore everyday challenges this becomes limited due to its focus on the response of staff to the person living with dementia. They suggest it is problematic because care staff are also struggling to have a voice 'the rights to self-determination of workers are frequently overlooked and traduced' (p25a). The notion of cultural resistance instead brings a focus to the complexity of relationships between people living with dementia and their relationships with staff in these environments.

I argue to develop this further that bringing an atmospheric lens to these environments allows the opportunity to see how resistance occurs within the everyday, whereby sometimes it is direct and loud and seeps out into the corridors and spaces of the care organisations producing affective atmospheres such as the through the sounds of distress when Bryn attempted to resist the bathing ordeal he endured. At other times resistive moments are quieter such as when Don rises later in the day and refuses to go to bed at scheduled times. Resistance also occurs through the lived temporalities of dementia, although the men appeared at times to be asleep they show that they are tuned in and within their own time will respond conversationally and sometimes through song, such as with Charlie, to the everyday happenings. Words and exclamations sometimes hung in the air, until picked up by another resident in the communal rooms who might respond on the same topic or even shout a shut up, but the response time would stretch because the reply came within a dementia time space; rather than the hurried sense of momentum created through the institutional framings of task-based temporalities. Another aspect of dementia time that resisted the normative organisation and structure of time, was the experience for the men of living simultaneously in past and present time. These lived experiences are resistant in as much as they push against the

continued normative expectations for the chronology of lived experience to be linear, and for the men this was not the case.

There is often overlap between resistance and restorative, in a moment a shift can occur that alters the feel of the care space. Time is key to these moments - having time and taking time. Residents present stories from their richly lived past experiences which provides evidence of the person they have been as a form of cultural resistance (Capstick and Chatwin, 2016). In Chapter 7 I note how despite some uncomfortable moments in the feminised communal living area for Samuel, there are other occasions where he 'holds court' as he talks about his life experiences such as living in India during his national service. I suggest that through telling these narratives, which work to uphold selfhood they would create restorative atmospheric moments where the men could feel recognised.

An atmospheric lens illustrates the movement within everyday life, from atmospheric moments of resistance to restorative moments (Sumartojo and Pink, 2018). Restorative atmospheric moments would occur sometimes between the residents as they sat passing time but they would also emerge between staff and the men, often at times when the staff were able to slow down and focus on them such as during hairdressing or shaving encounters, or at times when they were sat beside the men rather than moving through and past the spaces the men were in. As I have discussed previously staff were often aware of the divisions created through the dividing of spaces, through the wearing of uniforms and through the relentlessness of their task-based schedules, often exacerbated through staff shortages and the reality of unpredictable bodies, that cannot easily be scheduled. Staff at Lincoln Manor recognised that when outside of the institutional boundaries relationships had felt different and they noted the affinity between themselves and the men. Hence the need to create more opportunities for restorative atmospherics to occur.

8.8 Implications

8.8.1 Future research

- Key to this work is how an atmospheric lens provides support for more inclusive research with people living with dementia.

- There is more scope for using an atmospheric lens within other institutional settings in order to explore the context for everyday life and collective experiences of these places.
- This work built on earlier approaches to sensory and embodied narrative analysis (Lisahunter and Emerald, 2016) using atmosphere and affect to consider experiences of power and identity within care organisations; there are possibilities for developing the methodological innovation further.
- Atmospheres are helpful frameworks through which to think about both the small stories of everyday life in care and the big stories that relate to power structures, gender, and other aspects of identity. Further research is needed to consider the experience of atmosphere and atmospherics within dementia care in order to understand the experience of these places for a wider population of those working and residing within them.
- The development of critical thinking in dementia studies is expanding. Developing work that draws upon other disciplinary frameworks can provide useful insights through which to consider the experience of dementia in order to extend thinking in this field. New theoretical models need to be explored using empirical research in order to grapple with the reality of lived experience.

8.8.2 Education

- In order to progress understandings relating to dementia and gendered experiences it is important to ensure that there are more nuanced and complex readings of the gendered experience of living with dementia.
- Further to this there must be wider understandings of diversity and the lived experience of dementia.
- Environmental understandings of dementia care could take an approach that incorporated atmospherics. This would enable environments to be understood not as empty containers, but through lived experiences.
- This work offers opportunities to consider the collective experiences of living (and working) within care organisations. It draws attention to moments of reciprocity, compassion and affinity in everyday life in care organisations as well as the challenges. It is important to further understandings of lived experiences

within care organisations, and to consider what this means for developing care practice and policy.

8.8.3 Policy

- The findings from this study suggest value in bringing a gendered perspective to the experience of living with dementia. There has been a failure to date to explore the experiences of both women and men living with dementia, and instead there has been a continued focus on 'the person'. More recently a report exploring women's experience of dementia have made recommendations to address gender inequality in relation to dementia (Erol, Brooker and Price, 2015). However more needs to be done to ensure that gendered experience is looked at for men living with dementia too. Those living with dementia will have a range of backgrounds, social identities and living conditions and more needs to be done to ensure differences are taken into account in policy making.
- This study shows that it is not sufficient to focus on care environments, for example a focus on design and aesthetics does not provide a broad enough lens. Similarly a focus only on care practice is also too narrow. There is a need to develop understandings and policies that take a more holistic approach to considerations around the experience of collective care and of the experience of 'lived place' which an attunement to atmosphere can bring.

8.8.4 Practice

- There is a relentless dominance within practice that continues to develop task-based approaches to care-giving within dementia care institutions. However, this study shows how inadvertently a continued focus on this kind of care practice can lead to isolation and exclusion for people living with dementia. The experience of being abandoned to 'in between' time can incur further stresses to the experience of living with dementia. However, despite this, this research shows how the men living with dementia find ways to connect with each other through humour and friendship. There are experiences of restorative atmospherics that occur 'in the moment' and bring recognition to the men living with dementia. Supporting

opportunities for 'in the moment' restorative atmospherics will enhance a more facilitative and relational approach to care-giving.

- Policies around 'getting to know someone' have been pivotal in the development of life-story approaches in practice. Whilst it has been valuable to gather accounts of individuals, and to understand representations of their life experience, a focus on atmosphere has shown that it is also important to know someone 'in the moment'. Understanding lived experience and the shifting lived realities of the experience of dementia is essential in improving care practice.
- It is important to generate further understanding for care practice that the 'backdrop' of care facilities such as the soundscapes and other aspects of the sensory care environment have an integral role to play in how place is experienced by those within it. Bringing an atmospheric lens could be beneficial to thinking in a holistic way about care and care practice. In order to understand how to create care environments that provide more comfortable and inclusive experiences and thus enabling staff to be aware of atmospheric tensions.
- An atmospheric lens, that pays attention to the embodied, sensory and affective conditions of care can support staff to develop closer relationships with residents in order to support them in everyday activities and decision-making opportunities. Finding ways to create opportunities for belonging and togetherness in the day to day provision of care will enhance the experience of delivering care as much as for those in receipt of care.

8.9 Methodological reflections

In the early stages of the project, as I searched for an appropriate theoretical model for my study, I first needed to consider how theory operated in this context and secondly, consider if a single theory could explain the mass of complex data generated. Attempting to understand the complexities and messy reality of everyday life in fact required a number of ideas about the social world to develop the understandings that emerged from this data. To my mind 'theory' is a way to explain and help understand phenomena, following Madden's (2010) notion of theory as a 'thinking tool' (p18). I then followed a route through sociology, anthropology, human geography, dementia studies and cultural studies to create an interwoven disciplinary approach. Within these different disciplines there are nonetheless

shared and developing methodologies which are attempting to reach the essence of everyday life, and are interested in the material, the sensory and the embodied. They also raise questions of power and privilege and how these concerns manifest in everyday life. However, there are also sometimes contradictions found within these approaches, and sometimes I have mined the work of two theorists in order to extract the most useful insights, despite also being aware of differences, tensions or oppositions found within the rich seam of their work (Shildrick, 2009). Shildrick (2009) states that it is possible to do this if the theories are attended to with rigour, and there is an openness to moving beyond these theories.

In undertaking this study, there were methodological challenges in attuning to atmosphere and in considering ways to represent atmosphere. Critical accounts of this approach have noted it is difficult to engage with the notion of 'mystical [atmospheric] forces' that create emotional impact (Wetherill, 2012, p21). Yet 'atmosphere' is something recognised as existing as an experience of place, and it is widely noted by care organisations themselves. Tuning into atmosphere required an engagement with the material, sensory and bodily aspects of place. Sumartojo and Pink, (2018) argue that 'atmospheres cannot make people feel something, because it is what people feel that make atmospheres' (p5). This statement presents the difficulty that care organisations have in trying to intentionally create atmosphere because atmospheres are forever changing, merging and dissipating. Atmosphere is bound with the bodies that are both within them and in the making of them. Throughout this work I have presented scenes from the men's everyday lives that show how they are entwined with the atmospherics of place in the communal environments of the care organisations. Sumartojo and Pink, (2018) state that the conditions in which atmospheres occur are 'shot through with power' (p6-7) this is certainly the case within the confines of a dementia care organisation. Power and agency are at the core of everyday life in these settings. There are layers of power embedded in the relationships between those who are resident, and those who work within the organisations, and hierarchical levels within the staffing structures. The organisations are also subject to care policies that flow into the organisational places impacting on practice and feeding into the atmospherics.

In order to capture this, the study took an embodied and sensory approach to narrative analysis paying close attention to affect and atmosphere. Atmosphere emerged as an analytical lens through which to support the telling of embodied and sensory narratives. I

drew on the work of Lisahunter and Emerald (2016) and of Baldwin (2006) in order to tell the 'small stories' of everyday life which can ensure people living with dementia do not become 'narratively dispossessed' (p107). This approach allowed the data to be considered holistically and took account of the wider contexts within which the individual experiences of the men were situated (Mason, 2018b). I also drew on my own relationship with care and experience of dementia using a partial viewpoint that forms part of the narrative (Haraway, 1988). I have been careful to reflect on my position, and to take a reflexive approach to the work in particular during analysis. I will discuss the limitations to this work in the next section.

8.10 Limitations

Undertaking ethnographic work in which you are using your own body as a research tool in order to create interpretations has challenges and limitations within it (Madden, 2010; Coffey, 1999). These are subjective experiences and it is important to ask to what extent can I know these atmospheres? After all, I am not an older man living with dementia in a care organisation. Madden (2010) states 'good ethnographers will use their whole body as an organic recording device' (p19). I tried to attune my body to the atmospheres and to the sensory and embodied experiences of the men. Using a similar approach to the one taken up by Kontos and Naglie (2009) where they ask health and social care workers to engage with vignettes depicting care scenarios and ask them to consider how the person living with dementia might be feeling. I attempted to put myself in the shoes of the men living with dementia, and the care staff in order to understand their everyday experiences. I have attempted to engage with the sensory, embodied and materiality of the spaces in order to attune to atmosphere. In doing this it has been necessary to engage reflexively with the research process and my own position throughout all aspects of the work.

As already noted there are challenges in undertaking research exploring atmosphere and atmospherics. The study has sought to understand something that is intangible and cannot be seen, and that is ever shifting, always becoming; this is an inherent tension in the work. It is an on-going tension in the field of non-representational research, and those working within this field are critical of interpretation, and instead often attempt to describe their work through experimental forms of writing (Cadman, 2009). Hence this research might be

perceived as limited by non-representational theorists through its attempt to 'interpret', but also limited through the challenge of representation in order to present the everyday embodied and sensory narratives.

Similarly representing the sensory and embodied in text limits the scope of what can be seen and understood through these kinds of text representations (Lisahunter and Emerald, 2016). This feeds into the critique by Abram (1997) relating to a full-blooded approach, because in order to consider the sensory and embodied, I have needed to make them divisible, whereas the experience of being in the world is not divisible, rather perceiving and experiencing is through the senses working together as a whole. Visual ethnography and anthropology has looked to film-making in order to overcome some of these issues, however work of this nature has many layers of ethical considerations around capacity. Some filming was undertaken, but there were many stipulations around how this film could be used, and consent requirements were not always possible to obtain. Also filming could only take place in some areas and runs the risk of capturing non-participants. As already noted in the working methods chapter, a number of personal consultees felt that their relatives would not want to be captured on film – perceiving film as a more intrusive form of data generation. Hence these kinds of methodological and representational issues are on-going challenges for this type of work.

It must be also be acknowledged that a further limitation is that the men taking part in this research are all white and heterosexual, as far as is known, and although some of the men, at least, are known to come from working class backgrounds more work is needed to explore diverse experiences and to hear different kinds of voices within dementia studies.

8.11 Thesis Conclusion

This work has brought an atmospheric lens to the experience of living with dementia for men in a variety of care settings. I have taken this approach in order to explore the experience of place, and the role gender has in the everyday lives of men living with dementia. In order to do this I have used an ethnographic methodology that has drawn on sensory and critical approaches with the intention of interpreting the everyday embodied lives of the men who took part.

I carried out a sensory and embodied narrative approach to present the small stories of everyday life of the participants in this study, with the main focus on seven men living with dementia. The study has found that despite differences across the three fieldsites there were normative conditions and regulations that produced atmospherics and these are set out within four thematic headings: 1) the organisation and structure of time. 2) the tension of home-place versus work-place environments. 3) the management of men's bodies, and 4) the gendering of atmosphere. These conditions and regulations led to the production of resistive atmospherics that arose to create affective atmospheres within each of the care organisations through the experience of tensions, temporal and everyday resistance. These aspects of everyday life present experiences that are challenging and difficult for both residents and staff. The pressure of caring for a collective of residents gives rise to tensions that make it difficult for staff to provide person-centred care. However, the study has also shown how there are periods in the everyday where restorative atmospherics emerge, and that these bring harmony, connectivity and a sense of belonging and togetherness to the care organisations.

I argue that in order to provide care that enables more restorative atmospherics to emerge, there must be more attention given to relational aspects of care and to the sensory and material environments of care organisations. The study has provided some examples of how and when restorative atmospheric moments have emerged and exploring ways to extend these further within the everyday life of care organisations would enhance the experience of those who live and work there. I also have shown that more complex readings of identity are required in order to understand how aspects of identity are not fixed and are multi-dimensional and relational. This study has built on many of the studies that have already explored the everyday experiences of men living with dementia, and as revealed in Chapter 2 in this thesis, these experiences are not only of loss and decline. Despite the sometimes challenging aspects of life in care, the men living with dementia in this study have shown how they were able to develop and maintain relationships, support others and continue to bring aspects of their selfhood to the fore when given the opportunity.

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Appendix 1: The Hair and Care Study

'The Hair and Care project' was a 28-month study which set out to explore the role of appearance and identity in the lives of people living with dementia. The study sought to understand the importance of appearance to people living with dementia and looked in particular at hairdressing services in dementia care settings. Despite the importance of dignity in the lives of people living in care there is little policy guidance around appearance. Although the National Institute for Health and Care Excellence (NICE) and the Social Care institute for Excellence (SCIE) (2006) guidelines recognise that a person's ability to maintain personal care may be affected by their dementia they do not discuss personal grooming or maintenance of appearance with any of their references to supporting 'personhood'. The Nuffield Council for bioethics report on Dementia (2009) suggests that 'everyday' ethical encounters may be provoked through appearance-related work in care settings. The Hair and Care Project set out to investigate an area that was under-researched, with an absence of work in dementia research that considers the relationship between appearance and selfhood and also appearance from the perspectives of people living with dementia (Ward and Campbell, 2013).

The aims of the Hair and Care study were:

1) To capture the experience of receiving support with appearance maintenance and hairdressing across a number of different care settings and locations within an area in the North West.
2) To describe the experience of care-based hairdressers and care workers in these care contexts.
3) To scrutinise and document the different elements of the hairdressing experience.
4) To consider patterns of provision, access and affordability of hairdressing services for people living with dementia.

The study set out to achieve these aims through a series of objectives that guided the overall research strategy:

a) To map care-based hairdressing service provision across a specified region in the North West which would explore opportunity and access to care based hairdressing services.
b) To carry out on-site observations of the hairdressing facilities and appearance related activities provided in care settings. It would also carry out in-depth observations in other spaces within the care setting to understand the contexts in which care takes place.
c) To undertake filming to capture the embodied aspects of hairdressing practice. This also would enable an in-depth description of the processes involved in attending the care-based hair salon and the hairdressing experience.
d) To interview a number of key informants for the study: care-based and mobile hairdressers; people living with dementia; family carers; care workers and nursing staff; care managers, and other senior or policy focused leads within the care context.

North West Region

The study was conducted within a metropolitan area within the North West composing of 10 metropolitan boroughs and one of the largest metropolitan areas in the UK; and the second most populated area in the UK. The research was conducted within three of the metropolitan boroughs which were three of the most deprived in the country. Although two were more deprived than one of the boroughs which also had an area known as 'stockbroker land' due to the wealth in the particular location.

There were many similarities between the locations, and although overall the North West has thriving multi-cultural communities, the boroughs in which the research took place had low minority ethnic populations. Two of the boroughs had significantly lower numbers of people from minority ethnic backgrounds. In addition to this, two of these boroughs also have increasing numbers of indices of poor health and only one of the boroughs, the least deprived, has improving health indices. In addition to this the North West region has the lowest life expectancy in the England (ONS Info graph: North West life expectancy). Despite this statistic all the three boroughs had a rising number of the oldest old (80+) in their boroughs. One of the included boroughs had the worst health in the whole of North West with relatively more people living in the borough with poor health than good.

In summary the boroughs included in this research reflect a rising older population in the UK, in particular of those over 80 years old. Alongside this these were regions in England where there were significant health and social deprivation issues which can lead to pressures upon health and social care services.

Fieldwork

Methods for undertaking the Hair and Care Study:

- Mapping Exercise and scoping: initial phase – telephone survey and informal discussions with a group of people living with dementia.
- Observations and filming (10 month period: 3 months initial site visits (October 2011-December 2011); 5 months observation (January 2012 – May 2012); Further 3 months (September 2013 – November 2013).
- 'In-situ interviews' were carried out during filming with hairdressers and people living with dementia. They were unstructured and were undertaken to capture experience in the moment rather than remembered experiences.
- Discussion groups with various groups of informants (see under participants).
- Interviews were held during the observation periods between October 2011 and November 2013. Interviews with hairdressers, health and social care staff, key informants and family carers were semi-structured. 'Appearance biographies' were held at the later stage of observation work. These were unstructured interviews which covered a range of topics and were undertaken using material objects as props such as family photograph albums, framed photographs and in one instance clothing and make-up.

Research Sites

A number of different research sites were recruited to take part in the study; these reflected a range of experiences for people living with dementia in the area. The variation in the care sites was not reflected geographically with the site locations having similar demographics which were typical of the region as already described.

Local Authority Day Service

The service initially offered places to around sixty service users through Monday to Friday. During the period that we were engaged with the day service, a number of changes to the service user clientele took place. These changes were due to new spending priorities for the local authority and the restructuring of provision. Service users offered places at the service were referred by social services and were available for individuals with high and complex needs. This led to much lower numbers attending on a daily basis with around twenty service users per day.

Care homes

The first care home which took part in the research was owned by a large private care provider which facilitated a residential and nursing home. The care home had three floors and one of the floors is a dedicated dementia unit which has locked door access. There were 24 en-suite bedrooms on this floor.

The second care home was a private family owned nursing and residential home which was purpose built in 1991. It had 26 single rooms, 3 shared rooms, 5 of which were en-suite. It was not a dementia specialist home.

The third home was owned and run by a charitable institution and focused on providing care facilities to ex-service personnel. The home had space for 50 residents and offered single and shared room occupancy. It was also dual registered to provide nursing and residential care for its residents; it was not a dementia specialist home. Until very recently the home had only male residents; at the time of data generation, there was one female resident living there.

Hospitals

There were two NHS hospital wards included in the study both in different parts of North West. The first was a mixed sex ward which was situated in a specialist dementia hospital that was purpose built around 23 years ago. The other hospital ward was situated in a mental health unit on the site of a general hospital. The ward was also a mixed sex ward.

Participants living at home

A voluntary sector respite organisation was recruited to the study to enable participants to be reached who were still living at home in the community. One family was recruited to the observation phase through the respite organisation. Another family also took part in a small number of observations and were recruited through one of the care-based and mobile hairdressers participating in the study.

Recruitment and Sampling

Recruitment to the study was purposive: for staff it was self-selective; and for people living with dementia it was, in the most part, through family members and on the advice of staff in the research sites. However, recruitment did take place differently according to the settings and the method which best suited the local site. There was always a lead contact for the study in each site who participated in identifying potential participants to the study. For the inclusion of people living with dementia in the study the majority of recruitment took place after meeting family members. There were only a couple of occasions where a participant was recruited to the study and the researcher had not met the family member, although they had spoken on the telephone. Thus indicating the value of the face to face contact for those supporting people living with dementia, and having the opportunity to discuss the issues and concerns about their relative being involved in a research study.

There were family members who decided after talking to the researcher and taking away the personal consultee information that they did not think their relative would wish to take part and in some cases carers agreed that their relative with dementia would wish to be involved but would not consent to being filmed. Two participants during the observation phase of the study did not require a personal consultee and were able to give informed consent to take part in the study themselves; however, one chose only to take part if their family member also

agreed and became a consultee because they themselves did not want to sign the consent form; this raises issues regarding writing and form filling for this particular cohort of participants. Some recruitment took place at a research site which did not continue in the study. This particular care home did not formally withdraw from the research but stopped responding to requests to visit.

At each site, information sessions were held with staff to inform them about the study, and participant information sheets and reply slips were distributed. Staff were self-selecting and returned reply slips if they wished to take part. Sometimes staff were asked by the researcher if they would like to take part in the study and, in one site, the manager distributed information to staff regarding the study.

Family carers were selected through the research sites or via carers groups within the geographical region. Additional people living with dementia were contacted about the study to take part in appearance biographies through user forums within the participating NHS Trust and other voluntary organisations.

Hairdressers were contacted through the care homes involved in the study and by sending out information to care homes in the region and requesting hairdressers to contact the researchers.

Participants

Participants took part in a number of ways in the study: observation; filming; interviews and discussion groups (some participants took part in more than one research activity).

- 108 participants consented to take part in the study overall.
- 27 were recruited through the NHS (1 withdrew)
- 85 were recruited through non-NHS settings
- 2 died during the research process

Interviews were undertaken with:

- Health and Social Care Staff n= 15
- Family Carers n= 9
- Hairdressers n= 10
- Key Informants (inc. senior health and social care staff; educators) n= 7

- Appearance biographies n= 13

Discussion groups:

- Hairdressers n= 1 group of 6 hairdressers
- Family carers n= 1 group of 14 family carers
- Health and Social Care Staff n= 4 – 2 groups of 2; 2 groups with 5 people.

Observations

- Filming: 48 hours of film was undertaken in salon settings.
- Ethnographic observations: around 300 hours of observation was undertaken for a period of 10 months (divided into an 8 month period and a later 2 month timeframe). For the observation phase of the study n=23 people living with dementia were recruited which was higher than the original target for recruitment to the study.
    - Day service n = 2 (female)
    - Care home 1 n = 6 (2 male; 4 female)
    - Care home 2 n = 2 (female)
    - Care home 3 n = 3 (men)
    - Care home (later withdrew) n = 1 (female)
    - Hospital 1 n = 4 (2 men; 2 female)
    - Hospital 2 n = 3 (female)
    - Living at home n = 2 (female)

Observation and visual data generation took place over 10 months. The initial three months began by spending time in each setting, getting to know the environments, meeting with staff and managers to present the study and get them on board and to begin recruitment as well as undertake early observations in the various settings. During this time it was clear that an intensive period in each of the settings would be required to undertake the detailed ethnographic observations necessary for the research questions, and to ensure that each participant was able to be visited on a number of occasions. For 5 months, observations took place in the care settings each day (Monday to Friday) for between 3 and 8 hours each day. The time was split into three months in three settings, two of them twice each week and one setting for either a half-day or day each week. The following two months continued with two

days in two settings and another day observing in a family home with a couple living with dementia receiving domiciliary care in the community. Another couple were recruited but were only visited on two occasions. Later in the study, a further care home was recruited to take part because of its unique demographic providing a home for mainly male residents. This site was visited for at least one day per week for two months observations and other data generation was undertaken (videography, informal conversations, discussion groups and interviews).

1.9 Ethics

The Hair and Care project with the inclusion of the doctoral study received NHS ethical approval in June 2011 after an application via the Integrated Research Application System (IRAS) was undertaken to a 'flagged' research ethics committee. The flagged committee held responsibilities for assessing studies that sought to work with people who might lack mental capacity to give informed consent to participate in the study. The study then applied for site specific approval via NHS Research and Development and three local authority sites.

1.10 DenDRon Network

The study was 'adopted' by the NIHR Dementias and Neurodegenerative Diseases Research Network which was established to support dementia and neurodegenerative disease research taking place in the NHS. The network believes that 'everyone has the right to take part in high quality research', recognising that it can be more difficult to take part in research if you do not have the mental capacity to give informed consent for yourself. DeNDron aims to support opportunities for people to take part in research that has the potential to improve lives. (http://www.dendron.nihr.ac.uk/).

For further information including findings:
http://www.thehairandcareproject.wordpress.com

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Office for National Statistics Regional Infographs: https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/labourproductivity/articles/regionalandsubregionalproductivityintheuk/february2018

Appendix 2: Search terms used in the review.

Search terms: (**Numbers outside brackets retained**)	Dementia AND Men AND Everyday	Dementia AND Male AND Experience	Dementia AND Masculinity	Dementia AND Gender AND experience
2013 : CINAHL PLUS, OVID, SCIENCE DIRECT, WEB OF KNOWLEDGE.	**3 (641)**	**5 (143)**	**11 (21)**	**23(239)**
2018 : CINAHL PLUS, OVID, SCIENCE DIRECT, WEB OF KNOWLEDGE	**0**	**1 (25)**	**6 (45)**	**10 (226)**
2013: Other sources: via bibliographies/key texts and academics/google	**9 (15)**			
2018: Other sources: via bibliographies/key texts and academics/google	**3**			

Appendix 3: Core literature table

No.	Study Reference	Aims	Sample	Methods	Methodology	Theoretical Frameworks
1	Archibald, C. (1998) Sexuality, dementia and residential care: managers' report and response. Health and Social Care in the Community. 6(2), 95-101.	To explore types and prevalence of sexual expression by people living with dementia in residential care and how managers respond to this. The paper in particular examines the role that gender plays in how sexual expression is understood and perceived.	Managers at 28 social work residential homes were contacted. 24 returned the questionnaire. One questionnaire was not included in the	Cross-sectional survey using a structured postal questionnaire that was developed by Holmes et al (1994). The questionnaire was separated into four sections: demographic information; checklist of behaviours usually described as sexual; a section focused on the sexual expression of people living with dementia using vignettes. Managers	Mixed methods qualitative study.	The study uses a 'gendered lens' through which to explore the responses from managers. (see column 2.)

			final data analysis.	were asked if the situations were acceptable or not, if similar situations had occurred in their homes and who was involved. Finally they were asked how the situations had occurred and how they had responded. Responses were measured using a five point scale: ignore, observe, observe then intervene, intervene immediately, and other.		
2	Archibald, C. (2003) Sexuality	The work explores the way that sexual	21 spousal couples took	Semi-structured interviews, observations and analysis of	This study is from the same wider study as above which	Not explicitly mentioned although a 'Foucauldian

	and Dementia: The role dementia plays when sexual expression becomes a component of residential care work. Caregiving challenges. 4(2):137-148.	expression is perceived and responded to by care workers in a residential home.	part in the research. 12 women and 9 men living with dementia alongside their heterosexual spouses.	documentation over a 12-month period.	uses a mixed methods qualitative methodology. The study employs what is called a 'triangulation state of mind' to make inferences from multiple data sources and methods to validate and check against itself.	notion of the 'whole' perspective of interaction' is mentioned for use in the study.
3	Boyle, G. (2013) Still a woman's job: the division of housework in couples living	The study explored the social process of everyday decision making in spousal relationships where one person has	21 spousal couples took part in the research. 12 women and 9	The study used creative methods including observation and interviewing which was undertaken with individuals within the couple.	Ethnographic study.	The work was informed by decision-making models prior to dementia and as current whilst living with dementia. Most decision making was

	with dementia. Families, Relationships and Societies Vol 2. No.1. p5.21. The policy press.	dementia. This paper focuses on these decision making aspects of the relationships regarding housework.	men living with dementia alongside their heterosexual spouses.	Observations were undertaken whilst couples were going about their household tasks. Photographs were used during fieldwork to act as visual memory aides.		defined as 'spousal dominated' and were often deemed to adhere to traditional gender roles. A small number were collaborative. Post dementia most decision making models were carer dominated.
4	Boyle,G. (2017). Revealing gendered identity and agency in dementia. Health and Social Care in the Community.	The study explored the social process of everyday decision making in spousal relationships where one person has dementia. This paper focuses how gendered	21 spousal couples took part in the research. 12 women and 9 men living with dementia	The study used creative methods including observation and interviewing which was undertaken with individuals within the couple. Observations were undertaken whilst couples	Ethnography	Gender identity and gender roles within households using sociological explanations for gender.

	25. John Wiley and Sons Ltd. pp1787-1793	identity plays a part in decision making.	alongside their heterosexual spouses.	were going about their household tasks. Photographs were used during fieldwork to act as visual memory aides.		
5	Barrett, C., Crameri, P., Lambourne, S., Latham, J, R., and Whyte, C., (2015) Understanding the experiences and needs of lesbian, gay, bisexual and trans Australians	The aim of the study was to document the experiences and needs of LGBT Australians living with dementia and their partners.	The paper draws on two empirical studies. 30 LGBT people were recruited. 9 of these were people living with dementia. 6 service	In-depth interviews were carried out. Most were face to face interviews (20). The paper doesn't say how the other interviews were carried out – not mentioning if by telephone or skype.	Both studies are described as qualitative studies. No specific methodology is mentioned.	No specific theory is mentioned.

	living with dementia, and their partners. Australiasian Journal on Ageing. Vol 34. Supplement 2. October 2015. pp34-38.		providers were also recruited.			
6	Bartlett, R. (2007) 'You can get in alright but you can't get out'. Social exclusion and men with	The paper is part of a wider study exploring issues concerned with social exclusion. The paper aims to explore how men with dementia	Purposive sampling with 12 residents included, 10 were female and 2 were	Interviews were undertaken with residents each time the home was visited and between one and four interviews were carried out with each participant.	The study combines a phenomenological methodology with an ethnographic approach. It has taken a 'case study' approach to enable an in-depth analysis	This case study takes a 'gendered lens' to explore the concept of 'social exclusion'. No theoretical framework is explicitly discussed.

	dementia in nursing homes: insights from a single case study. Quality in Ageing; Jun 2007; 8, 2; ProQuest Nursing and Allied Health Source pg. 16.	experience, and cope with nursing home life. The study focuses on one man who is a participant in the wider study. The study argues that men with dementia are more likely to experience social exclusion due to factors relating to age, gender, mental health status and the residential setting.	male. 4 followed up for detailed case study. Here the author focuses on one man for the purposes of the paper.		to be shown 'between human experience and societal factors'	
7	Buse, C., and Twigg, J. (2016) Clothing,	The aim of this study was to explore the significance of clothing and dress in	The sample included 32 people living	The study collected data using observations, qualitative interviews and	This was an ethnographic study with other qualitative	The paper presents work that has drawn from a range of sociological theoretical

	embodied identity and dementia: maintaining the self through dress. Ageing and Society 36. pp1115-1135	the everyday lives of people living with dementia, and their carers and care workers.	with dementia. This included 9 men and 23 women. 15 were living in their own home and 17 in care homes. 15 family carers of those living at home were involved. 14 relatives of care home residents and 28 care home workers	used 'wardrobe interviews' (Woodward 2007) asking participants about the clothes hanging in their wardrobe.	approaches including narrative approaches.	frameworks. Drawing on embodied and sensory experiences and on materiality and memory.

			from a variety of roles.			
8	Buse, C., and Twigg, J. (2015) Clothing, embodied identity and dementia: maintaining the self through dress. Age, Culture, Humanities.	The aim of this study was to explore the significance of clothing and dress in the everyday lives of people living with dementia, and their carers and care workers.	The sample included 32 people living with dementia. This included 9 men and 23 women. 15 were living in their own home and 17 in care homes. 15 family carers of those living at	The study collected data using observations, qualitative interviews and used 'wardrobe interviews' (Woodward 2007) asking participants about the clothes hanging in their wardrobe.		This paper presents ideas around the performance of identity through dress, and it explores notions of 'curation' of identity through dress. It also explores narrative and embodied performances and the tensions that can arise around the experience of dementia and identity through clothing.

			home were involved. 14 relatives of care home residents and 28 care home workers from a variety of roles.			
9	Capstick,A. and Clegg, D. (2013) Behind the Stiff Upper Lip: War Narratives of Older Men with Dementia. Journal	The study presents narratives from people living with dementia in order to argue that even those judged to be no longer capable of meaningful	Three men's narratives - taken from a wider study collating and collecting narratives from	The narratives examined are taken from a first-person biographical testimony collection. A series of arts projects carried out with people living with dementia (www.trebusprojects.org.uk).	Narrative methodology. (Secondary analysis of first-person testimonies). It takes a social constructionist approach.	Understandings from cultural theory and history are employed to explore the notion of memory as a social construct. The purpose of the study is to challenge stigma and influence social and

	of War and Cultural Studies. Vol 6. No. 3 August 2013, 239-254.	communication may be able to contribute to understandings of cultural history. The paper argues that the onset of dementia has a significant impact on the telling of cultural history that may allow for previously untold stories to come to the fore because narratives become less mediated by the position of the present as dementia allows individuals less of a linear	people living with dementia . Recruitment for this not described - only that these men's stories were analysed for a particular purpose/aim: Can the narratives of men with dementia contribute to	There is no account of why these men are selected. The narratives were collected starting with the initial statement 'Tell me about yourself'.		cultural viewpoints of people living with dementia and their contributions.

		overview of their life history.	cultural studies research?			
10	Carone,L., Tischler,V., and Dening,T. (2016) Football and dementia: A qualitative investigation of a community-based sports group of men with early onset dementia. Dementia. Vol. 15 (6). pp1358-1376.	The study is an investigation of a weekly community group providing sports and physical activities for men living with early onset dementia. The group has been established by Notts County Football Club.	20 participants were recruited to take part in the impact evaluation. This included 5 men with early onset dementia; 5 wives of people living with early onset dementia; 10 coaching staff	Interviews and focus groups were carried out. 5 interviews with the men with early onset dementia and focus groups with the staff and family members.	No specific methodology is named. It was a qualitative study, gathering evidence for impact of a non-pharmacological intervention. Used thematic analysis for the interview data.	Explores impact of a diagnosis of Early onset dementia on individuals and their families. No theories referenced.

			or other staff directly involved in delivering care to people living with early onset dementia.			
11	Cedervall.,Y. and Åberg.,A.C. (2010) Physical activity and implications on well-being in mild Alzheimer's disease: A	This study sought to understand the experience of people with mild Alzheimer's disease and their significant others related to the physical activity that the people living with dementia	The participants were two men with dementia and their wives. The inclusion criteria were that the	Interviews were undertaken with both the men with dementia on two occasions and their spouses only once. Each interview lasted between 45 minutes and one hour. Participant observations were also undertaken with	The study is a qualitative case study design.	Continuity theory.

	qualitative case study on two men with dementia and their spouses. Physiotherapy Theory and Practice 26(4):226-239	undertook and how important it was to them.	participants with dementia had to be considered to have mild dementia and as such their MMSE score should be around MMSE=20, normal cognition is rated between MMSE 25-30. The	each man on two different days during a physical activity. These observations lasted between 45 minutes and two hours. Analysis used a multiple triangulation strategy to look across all the data collected using a thematic strategy.		

			participants were recruited through their physicians who suggested two community dwelling man as meeting the inclusion criteria.			
12	Chatterji, R. (1998) Ethnography of Dementia. A case study of an	The aim of this study is to create ethnography of one man, Mr Rijder's, journey through the experience of dementia and moving into	Case study of one participant with dementia and the people that care for	The researcher uses observations, informal conversations, documentation. The researcher had a dual role as	Ethnographic case study. The author makes reference to discourse analysis but it not clear if this is used (describes influence of hermeneutics).	There are a number of theoretical underpinnings to the work: Habermas with relation to his theories of

	Alzheimer's Disease patient in the Netherlands. Culture, Medicine and Psychiatry 22; 355-382.	an institutional setting to his subsequent death. The researcher sets out to weave together the different narratives and stories that are presented describing this journey, including the man with dementia himself. The author argues that they are giving a 'voice' to someone whose voice becomes marginalised as they become ensconced in the care system due to	him: includes wife, social worker, carers and researcher.	researcher and trainee social worker.		communication, rationality and intersubjectivity.

		their diagnosis of dementia.				
13	Chisholm, R., and Bischoping, K. (2018) The narrative self in rural dementia: a case study from eastern Nova Scotia. Ageing and Society. Cambridge University Press. pp1-23.		The sample for the research is an extended family supporting a man living with dementia who is the 'patriarch' of the family. There were 13 adult members of the	Interviewing and observation work over three years with a man living with dementia and his extended family who live across 7 households.	This is ethnographic research with a small rural community. One of the researchers was a member of the family and took the role of family member-researcher.	The data is presented using a narrative framework. Alongside this the study takes an intersectional approach to explore the interconnections of rurality, gender and dementia in order to construct selfhood.

			household and 12 children. 10 adults were recruited for interview.			
14	Gleibs,I.H., Haslam,C., Jones,J.M., Haslam,.S.A., McNeill,J., and Connolly,H. (2011) No country for old men? The role of a 'Gentlemen's	This study sets out to explore whether the impact of same gender groups increases social identification and well-being. It was particularly interested in the impact on men due to the increased likelihood of social isolation for men living in	Six care homes were included in the study. There were initially 30 participants recruited for the study intervention but only 26	Participants were interviewed using a survey method which took 40-60 minutes to complete. There were two scales used to assess social identification with others in care and also personal identity strength.	Methodology not explicitly described.	The study uses a 'social identity approach to health' as the framework against which to analyse their findings.

	Club' in promoting social engagement and psychological well-being in residential care. Aging and Mental Health, 15:4, 456-466.	care organisations where there are reduced numbers of male residents and staff.	remained in the study due to ill-health. The final sample included 14 female and 12 male participants.			
15	Herron, R.V. and Rosenberg, M.W. (2017) "Not there yet": Examining community support from the	The study set out to examine the relationships that people living with dementia and their families had with their local communities and to	46 people living with dementia and 43 care partners were recruited in rural	The study employed a qualitative approach using semi-structured interviews with an interview guide. People living with dementia were asked if they would like	The study used a case study approach. The case studies took place in selected sites which were engaged due to information provided by service providers relating to	The study argues for a relational approach to consider dementia and community. It seeks to use this approach to bring together elements of

	perspective of people living with dementia and their partners in care. Social Science and Medicine. 173. Elsevier. pp81-87.	find out what they felt about community support in rural and small town settings.	Ontario, Canada. Sample was recruited through memory clinics and snowball sampling.	to have a partner present during the interview. Only two participants were interviewed alone, and these were participants who lived alone.	rural demographics and locations.	experience, place and practice.
16	Hulko, W. (2009) From 'not a big deal' to 'hellish': Experiences of older people living with dementia. Journal of Aging	The study was intent on exploring experiences of dementia and understanding these as they intersect with other aspects of identity such as: race; gender; ethnicity;	8 participants were recruited through hospital outreach programme and Alzheimer's	Data generation was undertaken using interviews and participant observation sessions over one to two months with each of the 8 participants with dementia. The observations were	The study used an exploratory qualitative methodological approach which was based on grounded theory and informed by feminist and	The study aims to connect the research methodology 'to theoretical concerns and political commitments. The study uses the theoretical framework of intersectionality to explore

	Studies. 23 (2009) 131-144.	and class. The study seeks to explore diversity in the experience of dementia and to locate the experience of dementia within a socio-cultural understanding.	Society. Participants were recruited to represent different levels of privilege and oppression and this was based on social class, race, ethnicity and gender. All the participants were diagnosed with dementia and all were over 65 years.	selected after undertaking some analysis and aimed to confirm or disconfirm the hypotheses. Photography and photo elicitation were used to prompt discussions as were objects from participants homes. 24 interviews were undertaken; 17 participant observation sessions; two focus groups with participants and significant others were held.	anti-oppression methodologies.	the 'corollary of interlocking oppressions.

			The degree of impairment ranged from mild to severe. All participants were community dwelling. Other participants included in the study were family members, neighbours,			

			service users, service providers, employees. No= 50.			
17	Kinney,J.M., Kart,C.S., and Reddecliff,L. (2011) 'That's me, the Goother's': Evaluation of a program for individuals with early-onset dementia.	This study is an evaluation of a service provided for individuals diagnosed with early on-set dementia. The programme offered weekly volunteer work in the community, which was supervised work at the local zoo. The	Purposive sampling. The participants were part of the GOOTH project. 6 white men attended the project and all agreed to be interviewed,	Semi-structured interviews were carried out with each of the men taking part in the programme. Interviews were guided by five organising prompts. Photographs taken whilst the men were involved in the volunteer work were also used to elicit responses.	Methodology not explicitly described.	The study takes a life course perspective that provides a framework for understanding the impact of Early Onset Dementia through its approach to locate experiences within the historical time and geographical location.

	Dementia. 10(3) 361-377.	individuals involved became known as 'Goother's' as the programme was called 'Get out of the house'. The evaluation carried out semi-structured interviews with the participants of the programme and a focus group with the participant's partners.	one man had recently stopped attending because of a decline in abilities and did not take part in the evaluation. All the participants' wives were involved as participants. The average			

			age of the men was 57.2 years.			
18	Koehn,S.D. Kozak,J-F. Drance,E. (2012) 'The problem with Leonard': A critical constructionist view of need-driven dementia compromised behaviours. Dementia. 11:725.	The paper aims to examine the experience of a man, Leonard, with a particular form of dementia, 'fronto-temporal dementia' and the relationships that he has with his co-residents and the environment he lives in, with staff and family carers. The paper takes a critical standpoint to ask what factors impact	Purposive sampling. Staff were recruited directly, residents via their families (proxy). Family members were also approached to take part.	Data was collected through observations, interviews and focus groups. Spouses were also present during interviews and occasionally helped with information. Field notes were taken during each interview recording body language and pauses and the interviews were tape-recorded. A focus group was carried out with the spouses and field-notes were also	The research takes a critical constructionist methodology which is interested in how individuals in a particular environment are engaged in the constructions of meaning and narrative. Alongside an ethnographic methodology. This paper focuses on case-study from the research.	It explores theories around social capital and psycho-social environments.

		on the experience of dementia for Leonard.		recorded during this for use in analysis.		
19	Kontos,P and Naglie,G. (2007) Bridging theory and practice Imagination, the body, and person-centred dementia care. Dementia. Vol 6. (4) pp 549-569.	A qualitative study which explores how an embodied notion of personhood could support better person-centred care.	The organisations that took part were recruited because they provide specialist services for people living with dementia. Purposive sampling was used to select	Focus groups were undertaken to collect data. 6-8 participants were included in each focus group. A total of n=43 practitioners were involved overall. The focus groups were audio-recorded and transcribed. The transcripts were analysed first using descriptive coding and then by grouping codes into broader topic categories to explain the data.	A qualitative research study (no deeper explanation of the methodology). It is a paper focused on a practice-development project. The project is based on wider study which Kontos has written from widely and this work is exploring how her original research can influence changes in practice.	Theories around the concept of 'moral imagination' and an 'epistemology of care'

			participants for the six focus groups. Health practitioners were included who had clinical expertise of working directly with people living with dementia and whose roles also provided a focus on ‘the			

			body'. Potential participants were identified by administrators within the facilities.			
20	Kontos,P. and Grigorovich,A. (2018) Rethinking musicality in dementia as embodied and relational. Journal	This paper aims to highlight musicality within people living with dementia and to use an embodied relational citizenship approach in order to do this. The work looks explicitly at the	The work is using secondary data to explore a theoretical framework for considering musicality and	Secondary analysis with a particular focus on understanding the musicality of persons living with dementia.	Taken from previous empirical research using an ethnographic methodology.	This study is employing a relational model of citizenship. It is using the theory of embodied selfhood (developed previously by Kontos 2004) as a key feature of citizenship here, and then a relational understanding of

	of Aging Studies. 45. pp39-4.	musicality of two care home residents and also draws on a study of elder-clowning.	draws on the experience of two individuals taken from a previously undertaken ethnographic study by Kontos, and also another study by Kontos on elder-clowning.			communication and interaction by person's living with dementia.
21	Milligan,C., Payne.S., Bingley.	This study presents data from a study of a pilot	Purposive sampling. n=62	It used semi-structured interviews and focus groups	The study was a qualitative study exploring a pilot	The theory driving the work is the concept 'therapeutic

	A., and Cockshott. Z. (2015) Place and Well-being: Shedding light on activity interventions for older men. Ageing and Society. Pp.1-26.	programme, 'Men in Sheds' ran by Age UK which sought to provide community opportunities for men. The aim of the study was to explore to what extent a gendered intervention was helpful in supporting and maintaining men's health and well-being.	participants took part overall. Interviews were conducted with: n=24 'shed members' and n=5 'shed' co-ordinators. n=4 focus groups were carried out with shed members. All data gathered by shed	which were recorded and transcribed. These were then thematically analysed using a framework approach. The other data gathered was also analysed using this approach.	programme involving three 'shed' projects. No methodological framework described. Though in essence the study is an evaluation – exploring impact and effectiveness of the 'Men in Shed's' programme.	landscapes'. It moves the focus of this framework to 'everyday spaces'. The study uses a gendered lens and more specifically explores masculinity.

			managers and co-ordinators was included in the study.			
22	Pearce,A. Clare,L. and Pistrang, N. (2002) Managing sense of self: Coping in the early stages of Alzheimer's disease. Dementia. 1:173.	This study sets out to explore the coping strategies and experiences of coming to terms with dementia for men in the early stages of the condition.	30 participants were approached and, 20 were recruited from seven memory clinics across London. The men included in the study were aged	Interviews were undertaken with each of the men and also their wives separately. Interviews were guided by a semi-structured interview schedule and lasted between 30 minutes and one hour. The interviews were all transcribed. The wives interviews were used as a 'credibility check'.	The study is undertaken with a social constructionist framework. It uses Interpretative Phenomenology Analysis framework.	Uses coping model frameworks and social constructionist theories exploring multiple selves/social selves. Also influenced by psychoanalytical approaches.

			between 60 and 85 years and met the diagnostic criteria for Alzheimer's Disease. Criteria were such that the men had been diagnosed at their local memory service and had mild impairment.			

			They were all living in the community with spouses and no other major mental health problem. They were all able to speak English and were able to give informed consent. The men's wives were also			

			recruited to the study.			
23	Phinney,A., Dahlke. S., and Purves.B. (2013) Shifting Patterns of Everyday Activity in Early Dementia: Experiences of men and their families. Journal of Family Nursing. 19:348.	This study is an in-depth phenomenological study. The data is taken from a larger study which examines the experiences of two men and their families as they adapt to a diagnosis of dementia. The study had a focus on gender and how personhood is supported through everyday activity	The participants were from two families which included in total n=5 participants. (There were n=9 participants in total in the wider study). Inclusion in the	Interview data was collected over a 3-4 month period, totalling 9 hours of interview data. The interviews were sometimes individual and sometimes in couples and on one occasion there was a group interview with one man and his three adult daughters. Field notes were also taken during observation periods which were carried out with both of the men with	Interpretive phenomenological study: seeking to explore the 'lived experience' of the study participants through a number of means for gathering data.	The study uses a number of relevant theoretical or conceptual frameworks to explain the data: 'personhood'; 'Family identity'; 'masculinity'. They explore these identities within 'historical and cultural' situatedness.

		and how gender influences this.	study meant that the diagnosis of dementia had to have been given within the last six months. This paper focuses on these two families because of the compelling data and the significance it drew to the	dementia undertaking everyday activities such as going for a walk; gardening; attending a baseball game. The data was analysed using interpretive strategies.		

			value of family connections.			
	Regan, J.L., (2016). Ethnic minority, young onset, rare dementia type, depression: A case study of a Muslim male accessing UK dementia health and social care services. Dementia. Vol 15 (4). pp. 702-720.	The study is investigating the experiences of one man, Mr Q, and is concerned with his choice to access UK health and social care services and his experiences of these services as a Muslim male living with dementia.	Based on the experience of one man living with dementia. Involved service providers and family in the case study approach.	A mixed-methods approach using a number of methods including interviews, observations, and formal discussions.	This study took a case study approach within a Critical Realist Grounded Theory study. It is also part of a PhD study that is investigating the impact of religion on accessing dementia care services and the experiences of the South Asian community, focusing on attitudes and perceptions of dementia. This case study is interested in the experience	The study does not state that it uses a specific theoretical framework though it is influenced by cultural understandings of dementia.

					of one person in a range of circumstances to explore why he sought help and what his experiences were of this.	
	Solari,C. and Solomons, L. (2011) The World Cup effect: Using football to engage men with dementia. *Dementia* September 2012 vol. 11 no. 5 699-702	This study was undertaken within a memory clinic and aimed to establish whether patients attending the memory clinic could be engaged by having a football based activity with the view to the establishment of a football reminiscence group.	A questionnaire was devised that was sent to all patients using the number was not reported). 29 questionnaires were returned. 21 returning the questionnaire	The questionnaires were analysed but although findings are presented there is no information presented relating to the analysis that was undertaken. The results are inconclusive as there were discrepancies between service user and carer responses and no follow up has been undertaken.	This is a quantitative study to explore an idea for engaging men with dementia. The survey is referred to as 'quick and dirty'.	No theoretical framework.

			were female and most were over 80 years of age.			
24	Tolhurst, E., and Weicht, B. (2017) Preserving personhood: The strategies of men negotiating the experience of dementia. Journal of Aging Studies. 40. pp 29-35.	The aim of the study was to gain understandings of the experience of men living with dementia and to consider their relationships within the family, including the spousal relationship as well as to gain more understanding of how they accessed service	The sample of the study is 14 men living with dementia and spousal carers. 13 of the spousal relationships were heterosexual with one same	The study uses semi-structured interviews which are carried out in together with the man living with dementia and his partner. The interviews were conducted using an interview schedule.	The methodology for the study is not mentioned. Although the study does describe drawing on narrative approaches to understand the data.	The data was considered through the lens of personhood and strategies for upholding personhood.

		provision and managed professional relationships.	sex male couple.			
25	Ward,R., Vass,A,A., Aggarwal, N., Garfield, Cybyk,B., (2005) A kiss is still a kiss?: The construction of sexuality in dementia care. Dementia 4:49.	The paper presents work exploring the experience of gender and sexuality in a number of units offering residential dementia care. The study aimed to find out what the views and perceptions were by staff of the sexuality of people living with dementia and also to consider what informed responses made by individual staff and the	Staff were self-selected after holding meetings about the research. Residents were randomly selected and families were approached for consent. Seventeen people living	A range of methods were used for gathering data such as interviews with care staff; analysis of the care home documentation alongside observations and diary keeping. The research took place in eight units over all the dementia care homes over six months. There was also video recording of a random selection of residents with a formal diagnosis of dementia.	This is a mixed methods qualitative research study. The methodology for the study is not described in this paper.	Exploration of identity – focus on sexuality and gender.

		wider management of the home towards sexual expressions made by people living with dementia. The paper sits within a wider study which was investigating communication and dementia care.	with dementia took part in the observations and video-filming for the study.			
26	Ward, R., Campbell,S., and Keady,J. (2014) 'Once I had money in my pocket, I was	The aim of this overall study was to explore appearance for people living with dementia through the lens of care-based hairdressing. As	The sample for this aspect of the study was 7 women and 5 men all living with dementia	Unstructured interviews were undertaken with the 12 participants asking them to share their 'hair stories' but also to tell us about appearance throughout their	The 'appearance biographies' were part of a wider study which was undertaking an ethnographic methodology. For this set of interviews a	The paper draws on a number of theoretical understandings for the work, using narrative citizenship (Baldwin 2008), embodied understandings and

	every colour under the sun': Using 'appearance biographies' to explore the meanings of appearance for people living with dementia . Journal of Aging Studies. 30. pp. 64-72.	part of the study, a series of 'appearance biographies' were undertaken in order to understand appearance throughout the life-course and its meanings for people.	and who were white-British and all their life histories indicating they had lived heterosexual lives.	life, and taking a loose chronological form, and on most occasions using family photograph albums to elicit the conversations.	'narrative approach' was undertaken.	drawing on body techniques (Crossley 2006).

Appendix 4: CASP Assessment tool

www.casp-uk.net
info@casp-uk.net
Summertown Pavilion, Middle Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a Qualitative research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

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CASP
Critical Appraisal Skills Programme

Paper for appraisal and reference: .....

Section A: Are the results valid?

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

Yes	
Can't Tell	
No	

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes	
Can't Tell	
No	

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

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

Yes	
Can't Tell	
No	

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

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

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

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

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:

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

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

CASP
Critical Appraisal Skills Programme

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

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Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix 5: NHS Research Ethics Committee Approval Letter

North Wales Research Ethics Committee (Central and East)
G1/G2 Croesnewydd Hall
Croesnewydd Road
Wrexham Technology Park
Wrexham
LL13 7YP

Tel: [redacted]

08 July 2011

[redacted]
Project Worker in Ageing and Mental Health
University of Manchester
School of Nursing, Midwifery and
Social Work,
University of Manchester
M13 9PL

Dear Dr Ward

Study title:	**Personal Identity and Dementia Care: Improving care practice by exploring the activities of hairdressing, hair care and personal grooming in the everyday lives of people with dementia using NHS and social care services**
REC reference:	**11/WA/0147**
Amendment number:	**AM01**
Amendment date:	**17 June 2011**

The above amendment was reviewed at the meeting of the Sub-Committee held on 08 July 2011.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	3	13 June 2011
Covering Letter		17 June 2011
Protocol	2	13 June 2011
Protocol	2	13 June 2011
Participant Consent Form: Service Users	4	13 June 2011
Participant Information Sheet: Service Users	4	13 June 2011

Participant Information Sheet: Service user accessible	4	13 June 2011
Letter of invitation to participant	1	13 June 2011
Participant Information Sheet: Nominated consultee information sheet & agreement	1	13 June 2011
Invitation to personal consultee	1	01 June 2011
Nominated consultee information sheet	1	06 June 2011
Personal Consultee declaration form	4	13 June 2011
Participant Consent Form: Relatives/next of kin	4	13 June 2011
Participant Consent Form: Care staff & hairdressers	4	13 June 2011
Participant Information Sheet: Relatives/next of kin	4	13 June 2011
Participant Information Sheet: Care staff & hairdressers	4	13 June 2011
Participant Information Sheet: Personal Consultee information sheet	2	13 June 2011
Notice of Substantial Amendment (non-CTIMPs)		17 June 2011

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

11/WA/0147:	**Please quote this number on all correspondence**

Yours sincerely

[redacted]

p.p. [redacted]

Chair

E-mail: [redacted]

Appendix 6: Example of personal consultee information sheet

(logos removed purpose of formatting in PhD)

The Hair and Care Project

Consultee Information Sheet

Research Ethics Committee Reference no: 11/WA/0147

Part 1

Why have I been approached?

As a relative of a (prospective) participant in the study, you will have an interest in the person's well-being and welfare. You may have been given a Lasting Power of Attorney to make personal welfare decisions on their behalf if they are unable to. You may be a deputy appointed by the Court of Protection. A 'personal consultee' is a partner, friend or relative of a prospective participant, who provides the project team with advice.

The project team would like to discuss with you whether you think that your relative would like to take part. As you have known them for some time, you may be aware of any views they may have about taking part in such a project or whether they have made an 'Advance Decision'. If your relative has made an 'Advance Decision' this is important as it shows that they have already made decisions for themselves. The project team would like to respect the person's wishes.

If you think that your relative may be interested in taking part in the project, you may be able to tell us about any possible difficulties they may have. You also may be able to tell us how they may communicate that they want to stop being involved. When thinking about the wishes and interests of your relative, it is important that you should set aside any of your own views about the project.

3) What do I have to do now?

If you think that your relative would be interested in taking part, please complete the invitation and the personal consultee declaration form and send this back to [redacted] using the stamped-addressed envelope provided.

If you think that your relative would not be interested in taking part, then it is important that you still complete the invitation and declaration form.

4) Will information that I give be kept confidential?

Information you have supplied about yourself, such as address and telephone number will only be available to members of the project team. This information will be locked in a secure filing cabinet.

5) What will happen to the forms when I have completed them?

Should you wish to be approached again a member of the project team will contact you using the contact details you have given in the personal consultee invitation. If you do not return the form, we shall assume that you do not wish to be contacted about the project.

6) Seeking Advice

If you are unsure about taking the role of consultee you may seek independent advice. You could speak to [redacted] who is Associate Director of Research at Greater Manchester West Mental Health NHS Foundation Trust. Her telephone number is: [redacted] and her e-mail address is: [redacted]. Or you could contact INVOLVE who are a national advisory group which supports greater public involvement in NHS, public health and social care research, their telephone number is [redacted] and their e-mail address is: [redacted].

We will understand if you do not wish to take on this responsibility.

The following information is the same as would have been provided to your relative/friend.

Please take the time to read the information carefully. Talk to others about the study if you wish.

Part 1 tells you the purpose of the study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study.

Please ask us if anything is not clear.

We would be happy to go through the information sheet with you and answer any questions that you may have. This would take about 30 minutes.

Contact details of researchers:

Project Lead: [redacted] – address details here

Researcher: [redacted] – address details here

What is the purpose of the study?

- The study wishes to find out about older people's experiences of receiving hairdressing services and help with the management and care of their hair and we are also interested in other aspects of support such as shaving and the maintenance of facial hair.
- The study wishes to examine what goes on when people visit the hairdresser or he/she receive help with their hair from care workers or nursing assistants
- The study also wishes to find out what having access to this service means to the people who use it and what are the outcomes of receiving this service.

The research project will do this by talking to service users, through talking to care staff and care-based hairdressers within the service and to the relatives and next of kin to service users.

The study will also look at care files and records kept by the service provider.

The research will provide recommendations for service improvement and also give examples of good practice where possible.

Why has your relative/friend been invited?

Your relative/friend has been invited to take part because they live in or attend the service we are carrying out our research in, and they regularly receive the kind of support that we are interested in.

Do they have to take part?

No.

It is up to you to advise as to your relative/friends likely view about whether or not they would wish to take part. You can go through this information sheet and ask us any questions that you may have. If you advise that they would like to take part, we will then ask you to sign a declaration form. Your relative/friend is free to withdraw at any time without giving a reason. This will not affect any future service provision, care or legal rights in any way.

<u>Part 2</u>

What will happen to your friend/relative if they take part?

Firstly we would like to observe and talk with your relative/friend whilst they visit the hairdressers. With your permission we will also take photographs and film this interaction. We may visit your friend/relative on 4 or 5 separate occasions. We will keep you informed of our research and visits all through the project. The observations and interviewing will last for as long as your relative/friend is at the hairdressers. We will also talk to the hairdresser at the same time.

Please think carefully about whether or not you think your friend would wish to be filmed/photographed whilst they are at the hairdressers.

During this time we will ask your relative/friend about their experience of visiting the hairdressers, the hairstyle they choose and more general questions about your appearance and presentation. We are interested to know how they feel when they visit the hairdressers and what it means to them. We will meet the cost of a visit to the hairdressers as a token of gratitude to them for taking part in the study.

We may also ask if we can observe and interview them during times when a carer or a nursing assistant is helping them with other aspects of personal grooming (not bathing or getting dressed), but for example, having a shave or having their hair brushed and styled.

During this time we will ask your relative/friend questions about their appearance and presentation and their experience of receiving help with personal grooming activities.

We will audio-record all the interviews with permission.

In the second stage of the research we will be asking a smaller number of people to take part in in-depth interviews. These will be held wherever is most convenient for the person and we will also audio-record these interviews. In these interviews we will ask more about your relative/friend's appearance and presentation thinking back in time to different points in their life. We may ask to see any photographs they have and we may replay the film or go through the photographs we took and ask you about them. At this interview your friend/relative can choose to have a relative or friend to join them for this interview. We will ask for you to sign another declaration form before we carry out the interview.

Information about the researchers
We can reassure you that the researchers are experienced in talking to older people who are service users, including people with memory problems and their carers.

Expenses and payments
If you or your relative/friend have any travel costs due to taking part in the study these will be reimbursed to you if you are able to provide a receipt.

There is no payment for taking part in this study. However for your relative/friend who is taking part in the study we will meet the cost of a visit to the hairdressers as a token of gratitude to them for taking part in the study.

Will taking part in the research be kept confidential?
Yes. All data generated by the research will be anonymised.

All the information that your friend/relative gives to us including the audio recordings of interviews film and photographs will be stored securely at the research site, (university) either in encrypted computer files or in locked storage cabinets accessible only by the Project team. Any photographs or film will be stored on secure university computers and only accessible by the project team.

Data will be held for at least 10 years after final publication of the study sufficient to allow reconstruction of the study for reanalysis and audit should that be required. Data will then be destroyed in accordance with the guidance and standards specified by the IT Security Coordinator. (see www.its.manchester.ac.uk/secure-it).

Reporting our findings
The experiences of your relative/friend will be pooled together with others that we speak to. No individual will be identifiable in any of the findings that are published from this study.

If we wanted to use any film or photographs for the presentation of our findings we would request your consent for this separately.

In the event that an experience of abuse or bad practice is disclosed to us then this information will be fed back to the service management to be dealt with through appropriate systems.

If information concerning criminal activity is disclosed to us then the research team are required to pass this information to the police.

What will happen when the research stops?
The research project is due to be completed in 2013.

The findings from the research will be written up into a short report that will be distributed to all participating organisations. It is likely that the research findings will also help develop training for care workers and care-based hairdressers

The research team will also submit papers about the research and findings to relevant research journals.

Part of this study is being used towards the writing of a PhD thesis.

What are the possible benefits of taking part?
The possible benefits of taking part are that your relative/friend will be inputting into the development and continuation of care practice and hairdressing services to people in care. You will be ensuring that any changes to existing provision will have taken into account your relative/friend's views.

What are the possible disadvantages and risks of taking part?
We do not anticipate any disadvantages or risks in being involved in this project. If however anyone has a complaint or suffers any unforeseen harm, this will be addressed as follows:

Complaints.
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator [redacted] or by email to [redacted]

Who is organising and funding the research project?
The research is being funded by the Economic and Social Research Council and it is being carried out by the University of Manchester.

Who has reviewed the research project?
The research has been given a favourable ethical opinion for conduct by North Wales Research Ethics committee (Central and East).

Appendix 7:

Example of staff information sheet

(logos removed purpose of formatting in PhD)

The Hair and Care Project

Participant Information Sheet

Health and Social Care Staff and Hairdressers

Research Ethics Committee Reference no: 11/WA/0147

Part 1

Invitation

We would like to invite you to take part in a research project. The study will investigate hairdressing services and hair care and other aspects of grooming support for men and women in receipt of care.

Before you decide whether you would like to take part or not, we would like you to understand why the research is being done and what it would involve for you.

Please take the time to read the information carefully. Talk to others about the study if you wish.

Part 1 tells you the purpose of the study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study.

Please ask us if anything is not clear.

We would be happy to go through the information sheet with you and answer any questions that you may have. This would take about 30 minutes.

What is the purpose of the study?

- The study wishes to find out about older people's experiences of receiving hairdressing services and help with the management and care of their hair and other aspects of grooming support
- The study wishes to examine what goes on when people visit the hairdresser or receive help with their hair from care workers or nursing assistants
- The study also wishes to find out what having access to this service means to the people who use it and what are the outcomes of receiving this service.

The research project will do this by talking to service users, talking to care staff and care-based hairdressers within the service and to the relatives and next of kin to service users.

The study will also look at care files and records kept by the service provider.

The research will provide recommendations for service improvement and also give examples of good practice where possible.

Why have I been invited?

You have been invited to take part either because you are a care-based hairdresser or a member of staff working in health and social care.

We would like to ask you to take part in a group discussion alongside other hairdressers/workers and following this we may ask to interview you. We may also ask to visit you at work to observe, interview and film you.

Do I have to take part?

No. It is up to you to decide whether or not to take part. We will describe the study and go through this information sheet. If you decide to take part, we will then ask you to sign a consent form. You are free to withdraw at any time without giving a reason. This will not affect any employment or legal rights in any way.

Part 2

What will happen to me if I take part?

Firstly we would like to ask you to take part in a group discussion with other health and social care workers/hairdressers. We will also ask some people to take part in a one-to-one interview. The group discussion and the interview will involve finding out about the work you do and your relationship with the people you support or provide a service to.

We will then ask a smaller number of people if we can observe and talk with you while you're at work. For hairdressers this will involve visiting you at the salon you work in or shadowing you while you make home visits. For care workers/nursing assistants this will involve visiting you in the home or ward that you work on. With your permission we will also take photographs and film you. We may do this on 4 or 5 separate occasions. We will also talk to the service user you are working with at the same time. We will ask you on each occasion if you still consent to taking part in the study.

For service managers and other key informants we will be asking you to take part on a one-off interview that will last no longer than 60 minutes.

Information about the researchers

We can reassure you that the researchers are experienced researchers in the area of dementia, and have experience in talking to people with memory problems and their carers.

After the research interview or discussion group

You will be given the opportunity to receive a full copy of the interview transcript.

Expenses and payments

There is no payment for taking part in this study.

Will my taking part in the research be kept confidential?

Yes. All the information that you give us, including the audio recordings, photographs and film will be stored securely at the research site, (university) either in secure computer files or in locked storage cabinets accessible only by the Project team.

Data will be held for at least 10 years after final publication of the study sufficient to allow reconstruction of the study for reanalysis and audit should that be required. Data will then be destroyed in accordance with the guidance and standards specified by the IT Security Coordinator. (see www.its.manchester.ac.uk/secure-it).

Reporting our findings

Your experiences will be pooled together with others that we speak to. No individual will be identifiable in any of the findings that are published from this study.

We will ask your permission separately if we wish to use a picture or image of you for publication. We will take steps to try to prevent anyone identifying you from your picture by using a pseudonym (false name) with the picture and by altering the name and details of the location that it was taken.

In the event that you disclose details of an experience of abuse or bad practice this information will be fed back to the service management to be dealt with through appropriate systems.

If you reveal details of any criminal activity the research team are required to pass this information to the police.

What will happen when the research stops?

The research project is due to be completed in 2013.

The findings from the research will be written up into a short report that will be distributed to all participating organisations. The findings of the research may also be used to develop training for care workers and hairdressers in care settings.

The research team will also submit papers about the research and findings to relevant research journals.

Some of the data generated by the study will be further analysed by the researcher in studying for a PhD.

What are the possible benefits of taking part?

The possible benefits of taking part are that you will be inputting into the development and continuation of care practice and hairdressing service to people in care. You will be ensuring that any changes to existing provision will have taken into account your views.

What are the possible disadvantages and risks of taking part?

We do not anticipate any disadvantages or risks in being involved in this project. If however anyone has a complaint or suffers any unforeseen harm, this will be addressed as follows:

Complaints.

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on [redacted] or by email to [redacted]

Who is organising and funding the research project?

The research is being funded by the Economic and Social Research Council and it is being carried out by researchers from the University of Manchester.

Who has reviewed the research project?

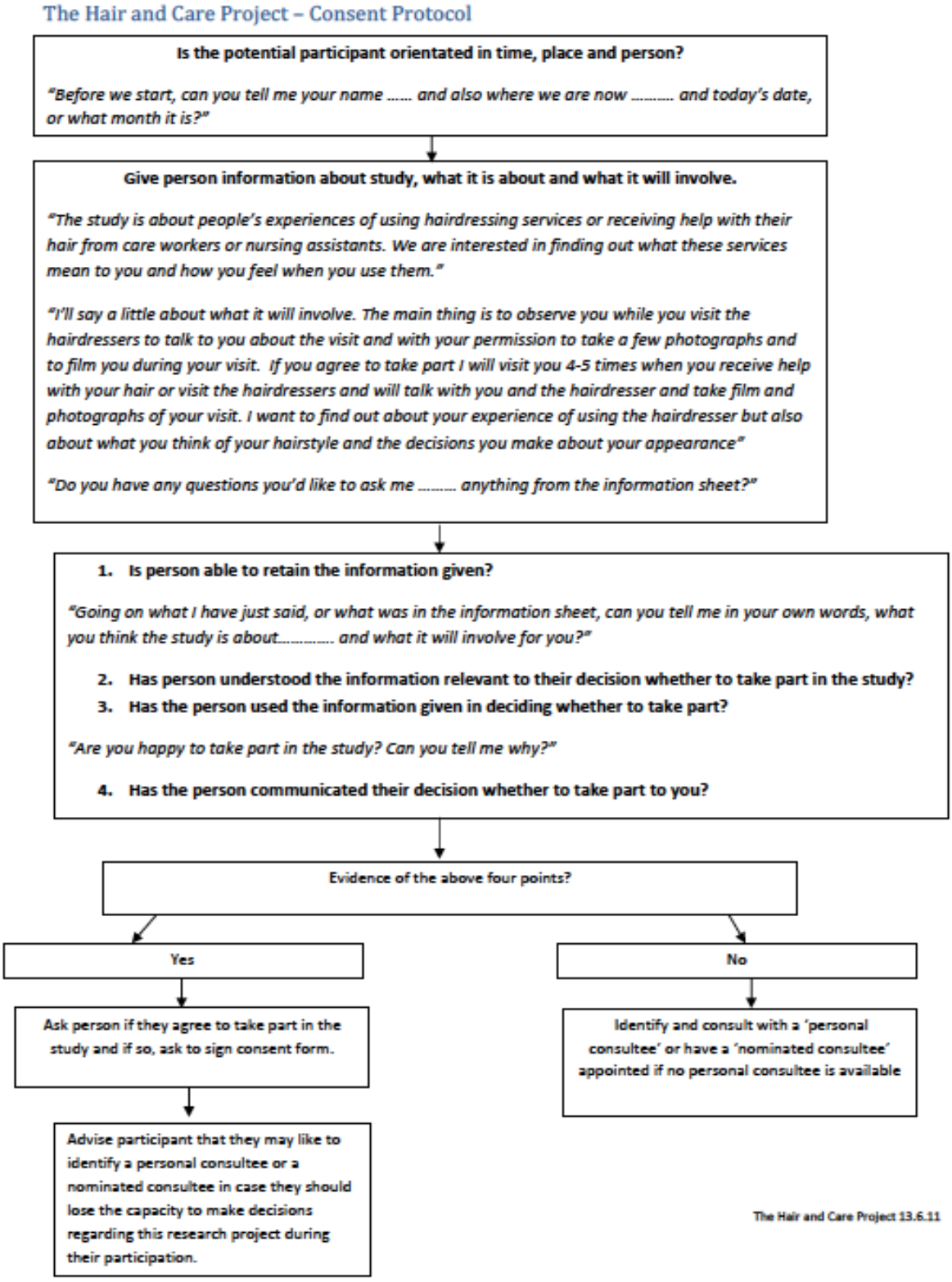
The research has been given a favourable ethical opinion for conduct by North Wales (Central and East) Research Ethics committee.

Contact details of researchers:

Project Lead: [redacted] – address details here

Researcher: [redacted] – address details here

Appendix 8: Mental Capacity Protocol



Appendix 9: Example of Consent for staff

(logos removed purpose of formatting in PhD)

Participant Consent Form for Health and Social Care staff and Hairdressers

Title of Project: The Hair and Care Project

Researchers: [redacted] and [redacted]

	Please initial:
I confirm that I have read and understood the information sheet version 4 dated 13.6.11 for the above study.	
I confirm that I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	
I agree to the interview / focus group / consultation being audio recorded	
I agree to being filmed and photographed while at work. (I understand that if the research team wish to use any pictures/images of me for published work they will seek my permission first)	
I agree to take part in the above study.	
I agree to the use of anonymised quotes in publications	

Name of participant Date Signature

_____ _____ _____

Name of Researcher Date Signature

Research Ethics Committee Reference number: [11/WA/0147]

Appendix 10: Example of consultee declaration form.

(logos removed purpose of formatting in PhD)

Consultee Declaration Form

Title of Project: The Hair and Care Project

Researchers: [redacted]

I, …… (name of personal consultee) have been consulted about …….(name of relative/friend) participation in this research project.

In my opinion he/she would have no objection to taking part in the above study.

I confirm that I have read and understood the information sheet version 2 dated 13.6.11 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that participation in the project is voluntary and that my relative/friend would be withdrawn if they do not wish to continue participating and without giving a reason. without his/her care or legal rights being affected.	
I understand that relevant sections of his/her care record may be looked at by responsible individuals from the University of Manchester where it is relevant to their taking part in the research.	
I understand that the interview and conversations with the researcher will be audio-recorded.	

I understand that my relative/friend will be filmed and photographed whilst receiving help from the hairdressers/care worker/nursing assistant and I confirm that in my opinion my friend/relative would be willing to consent to this. However I understand that if the research team wish to use any pictures/images for published work they will seek my opinion again.	
I understand that the anonymised quotes will be used in publications (this means that before anything that my relative/friend say is used in published work, it will be completely anonymised so that he/she will not be able to be identified) and in my opinion my friend or relative would be willing to consent to this.	
I am prepared to give a telephone number in order to receive a telephone call from the researcher if the researcher needs to discuss any aspect of the study with me.	

_____ _____ _____

Name of personal consultee Date Signature

_____ _____ _____

Name of Researcher Date Signature

Research Ethics Committee Reference number:11/WA/0147

Appendix 11: Research Protocol

Version 3: 13.6.11 (Research Protocol – not updated. As created in 2011, hence figures differ to main thesis text).

Personal Identity and Dementia Care: Improving care practice by exploring the activities of hairdressing, hair care and personal grooming in the everyday lives of people with dementia using NHS and social care services

Principle Investigator: [redacted]

Project Mentors: [redacted]

Researcher: [redacted]

Total duration: 28 months

Sponsor: University of Manchester

Funder: Economic and Social Research Council

Background

An estimated 750,000 people are currently living with dementia in the UK (Alzheimer's Society, 2011) of which approximately a third reside in long-stay care. Much of the care and support provided to people with dementia is by unpaid carers (usually family and friends), although as dementia progresses input from formal care providers tends to increase. People with dementia have access to a range of practitioners according to need but the largest proportion of day-to-day (formal) care is provided by social care workers whose work centres on the body and physical care tasks. However, while dementia care has been subject to intense

research scrutiny over the last twenty years, 'body work' (Wolkowitz, 2006) remains a neglected aspect of the support that is given to people with dementia.

Integral to body work in dementia care is the support given to service users concerning their appearance, presentation and grooming. Traditionally seen as outside of or peripheral to nursing practice much of this work is carried out by care assistants and peripatetic workers such as mobile hairdressers who commonly travel between care settings or homes providing a regular service to individuals who are unable to access such services within the community. This marginal or uncertain status for what is sometimes described as 'aesthetic labour' has meant that it has largely been neglected as a topic for research. Indeed, while hair care and hairdressing have a pervasive presence in dementia care settings there is currently no evidence base for this aspect of the support on offer to people with dementia. Consequently there is little understanding of good practice or the skills required for this work, let alone of the implications and outcomes for service users.

The backdrop to the study is a shifting pattern of provision to older people characterised by increasing efforts to personalise care through greater choice and control offered to service users (e.g. NSF for Older People 2001) but in a context of tightly defined and regulated task-based forms of support. A key challenge posed by this tension is how to enhance the relational, expressive and social dimension to routine care-based encounters (Ward et al, 2008).

Dignity in care

The challenge of upholding dignity in care has emerged as a key concern for nursing and care policy in recent years (RCN 2009). Building on high profile campaigns spearheaded by organisations working with and for older people, the significance of dignity to care practice is now widely recognised across health and social care services (SCIE 2006) and has particular resonance in relation to the care of vulnerable people (Alzheimer's Society, 2010). However, the task of defining dignity and translating it into concrete everyday care practice is not straightforward. Often, it has proven easier to identify the loss of dignity than to note its presence. And, despite findings to suggest that the denial of dignity is 'a major issue in the lives of older people across Europe' (Dignity and Older Europeans, 2004), research is

required into day-to-day dementia care practice to better understand the challenges associated with supporting dignity through care.

This research addresses the link between dignity and the appearance and presentation of people with dementia in care settings with a particular focus on hairdressing, hair care and grooming. Existing research shows that the body and the presentational work carried out upon it are central to what has been described as the 'dignity of personal identity' (Bayer et al 2005). Yet, little is currently known of how such issues are negotiated at the level of frontline care. The outcomes of this presentational work and their implications for body-image and the wellbeing of people with dementia will be a central consideration for the study. At the same time, the perspectives of and challenges faced by care-based hairdressers and care workers will be examined to support an understanding of good practice in relation to this currently under-researched aspect of dementia care. The findings will inform policy and practices in care and raise the profile of body-work that is fundamental to well-being and the avoidance of decline, depression and neglect.

Everyday ethical challenges in the delivery of dementia care

A key question for this study is the role played by body work in the maintenance and promotion of dignity in care for people with dementia. The perspectives and experiences of people with dementia are therefore central to the study and will be considered in the context of the challenges and dilemmas that arise for those who help and care for them. As dementia progresses both family and care workers can face ethical challenges in the support they provide:

> *"[For instance] difficulties may arise in helping a person with their choice of clothes: is the goal to make the person look normal or dress in their characteristic way, or to help them be comfortable, or to let them choose for themselves even at the risk that their choices may make them conspicuous or provoke criticism?"* (Nuffield Council for Bioethics, 2009).

Such dilemmas represent a commonplace feature of dementia care and can emerge as a source of tension between care providers and the families and friends of people with

dementia (Ward et al, 2008). Yet, little is currently known of how these challenges are resolved during the provision of care or the extent to which people with dementia are able to exercise agency in the context of sometimes competing interests and demands.

The Nuffield Council on Bioethics Report on Ethical Issues and Dementia (2009) draws particular attention to the importance of recognising such 'day-to-day' ethical dilemmas and the impact they can have over time upon those providing care. The report argues that 'all those involved in providing care (paid and unpaid) need much more support than is currently generally available in handling these difficult situations appropriately.' (pg. 2, 2009). The study will therefore provide an opportunity to critically examine how politically prominent notions of person-centred care and dignity are negotiated and upheld through the very concrete and grounded example of a consumer service in action within care settings.

Aims and Objectives

The main aim of the project is to improve current dementia care practice concerning the appearance-related and presentational support given to people with dementia. This will be achieved by developing an evidence base for hair care, hairdressing and personal grooming in dementia care settings, identifying examples of good practice and making recommendations for training and support.

To achieve this aim, the study will:

1) Scrutinise and document dementia care practice in relation to hairdressing, hair care and grooming;
2) Identify the outcomes of this work and explore the significance it holds for people with dementia;
3) Consider patterns of provision, access and affordability of hairdressing services to older service users;
4) And, provide resources and recommendations for workforce training

Plan of investigation

Mapping and access strand: The study will begin with a scoping exercise designed to map the context and patterns of provision across the areas covered by the study (Bolton, Salford and Trafford). This will involve telephoning dementia care providers in the GMW region. We will seek information on:

- Whether the setting has designated hairdressing facilities
- Who provides hairdressing and hair care support to service users
- How the service is financed and organised
- What services are offered and how frequently

Focus groups will be held with care workers, care-based hairdressers and with family/next-of-kin to people with dementia. Following this the researcher will spend time in a range of different dementia care settings, observing the provision of hair care and hairdressing services, interviewing staff and service users and with permission filming and photographing the care process. During this time one-to-one interviews with stakeholders will be carried out.

Settings and workforce strand: We will gather information on the physical spaces available for the provision of hairdressing and hair care to service users such as the size of salons, and the different equipment and facilities in use. Through observation and interviewing we will establish:

- How often hairdressers visit a particular setting
- The amount of time allocated to each client
- The cost to the client

Where permitted we will ask the host provider for information on the overall costs involved in providing a hairdressing service according to the nature of the service made available. This will support our intention to compare different types of service and settings. For example, the outcomes for service users of access to a subsidised hairdresser on a fixed contract may differ from settings where hairdressers are freelance or where hair care is undertaken solely by care workers.

Such information will form part of the contextualising account we provide of hairdressing services and the 'thick description' of settings that is integral to ethnographic research.

The final stage of the project will involve returning to a sub-set of participants to further discuss their experiences of body work in care and to explore issues of image and appearance in a biographical context.

Research sites

The research sites under investigation include care homes, hospitals and domestic homes (including sheltered housing facilities). The focus will be on settings that provide care to people with dementia and the spaces within them where hair care and hairdressing services are provided.

Participants

The study will invite the participation of up to 9 care workers/nursing assistants; 9 care-based hairdressers; 10 family/next-of-kin; 5-6 'key informants' such as managers, commissioners and hairdresser educators; and up to 20 people with dementia.

Inclusion criteria:

- The study will recruit a roughly equal number of men and women living with dementia.
- Presence of memory problems or a formal diagnosis of dementia. (Many people in settings such as care homes do not have a formal diagnosis of dementia. The study will seek to include people with memory problems as recognised by the host service provider as this will help to ensure that people in the earlier stages of dementia are not excluded from the study).
- Residing within the boroughs of Bolton, Salford or Trafford.

Exclusion criteria:

- Serious or critical health condition
- Unable to speak or understand English. (This reflects the limited size and resources available to the study however efforts will be made to explore issues relating to culture and diversity in the discussion groups and interviews).

Recruitment: Potential participants who meet the above criteria will be informed about the study by their care provider. If the person indicates they are interested in hearing further details they will be asked for consent to pass their contact details to the research team. The researcher, Sarah Campbell, will then contact the potential participant to provide further details on the research. If they remain in agreement information sheets will then be forwarded to them followed up by an appointment between them and the researcher (each participant will be given a minimum of 24 hours to consider the information). For individuals with

advanced dementia the recruitment process will be followed with the support and input of their next-of-kin or the person with primary responsibility such as an appointed guardian with power of attorney.

Consent protocol: The researcher will use a consent protocol to ensure that an individual is capable of providing informed consent and if they are not, will have recourse to a personal consultee, following the guidance of the BPS (2008). The consent protocol has been adapted from previous dementia-related research at the University of Manchester, and meets the requirements of the Mental Capacity Act. The researcher (Sarah Campbell) has prior experience in administering this consent protocol.

In order to support the participation of people with dementia in the study we propose to use a process model of consent (Dewing, 2007), this will include regular prompts and reminders regarding the research to participants and seeking assent at regular intervals.

Rationale for inclusion in the study of people with dementia who lack the capacity to consent

As the National Dementia Strategy (2009) makes clear the challenge to delivering personalised care lies in tailoring support to meet the needs of the individual. A central question for this research will therefore be to understand how hairdressing and grooming can be adapted to meet the needs of people at all stages of the condition.

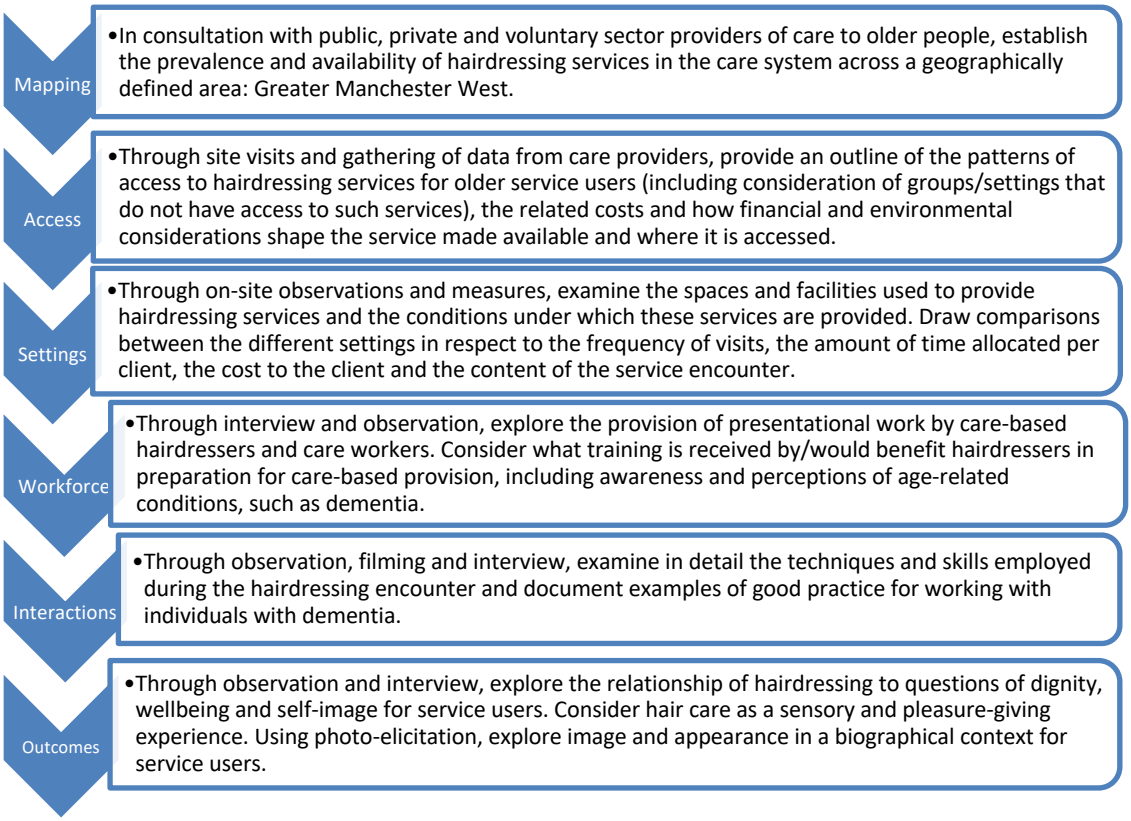
As indicated above, ethical dilemmas arise in the provision of body work to people in the later stages of dementia about which little is currently known and which are distinct from the challenges of working with people in the earlier stages of the condition.

Hairdressing and grooming involve a physical and sensory form of engagement. Workers use touch, massage, scented products, warm water and warm air in the hairdressing process and throughout this time are engaged in prolonged periods of one-to-one contact. This sensory dimension to the work holds particular potential for continued engagement with people in the later stages of dementia and the creation of a positive and pleasure-giving encounter that recognises the 'embodied selfhood' (Kontos, 2005) of such individuals. The intention is

therefore to seek to include people at different stages of dementia, including those with moderate-severe dementia, in order to better understand how such body work can be adapted to the widely varying needs and capacities likely to be encountered in dementia care settings. In particular, the research will help to understand how hairdressing and hair care practices can be used to maintain a connection with individuals in the later stages of dementia through physical and sensory engagement.

Methods

The study incorporates a mixed methodological approach. In the absence of existing research on this topic the design reflects the intention of mapping the context to this area of work; understanding the perspectives of key stakeholders and building a picture of what this area of work means to people with dementia at a personal level.



PhD element: The researcher appointed to the study ([redacted]) will use data generated for the main project in completion of a PhD. Permission to pursue a doctorate has been granted by the funder (ESRC). The PhD will focus on the experiences of the men involved in the study and consider broader questions of gender relations in dementia care.

Research process

Guidance: In addition to the input of two mentors, the research will be guided by a small network of experts in the form of an advisory group. The group will comprise service user representatives and a selection of 'key consultants'. The advisory group will: advise on the preparation of research tools; comment upon findings from the research and its relevance to different stakeholders; assist with recruitment; and support and participate in the dissemination of findings to aid in strengthening the overall impact of the study.

Focus Groups: These will be held with hairdressers, care workers and next-of -kin to people with dementia, both to inform development of research tools and as an open forum to explore certain questions that may prove difficult to fully address during fieldwork.

Interviews: Interviews will be conducted with care workers/nursing assistants; next-of-kin and care-based hairdressers. Semi-structured interview schedules will be developed and refined during the early stages of the research and tailored to each group. The interview schedules will provide a guiding structure to a full exploration of the issues that builds upon the multiple sources of data.

'In-situ' interviewing: During the visits to the different settings the researcher will observe and interview people with dementia while in receipt of help with hair care and grooming. This approach to interviewing 'in the moment' has been shown to support the participation of people with dementia in research as it does not rely upon recall (Bamford and Bruce, 2000).

Visual methods: Filming and photography will be used to support the involvement of people with dementia in the research process. Filming will only take place with the permission of the participant and worker concerned and after clearance by the host service provider. The main reasons for gathering filmed data are:

- Filming will support the inclusion of people with severe dementia. Where people are no longer able to communicate through speech it is important to pay close attention to non-verbal forms of self-expression as a means to understanding that persons experience of the care encounter. As previous research by the applicant (Ward et al 2008) has shown, having a real-time visual record supports close and repeated

scrutiny of a person's response to the care provided and enhances the opportunity for interpreting their interactions.

- The filmed data will also be played back to those participants that are asked to take part in the follow-up interviews. As well as enabling the researchers to confirm their initial interpretations with participants it will support recall by the person with dementia and help to overcome problems with short-term memory that might otherwise prove to be an obstacle to taking part in an interview.

- Filming will also help to capture the embodied and sensory aspects of the caring encounter as well as to provide a supporting record of the styles and presentation of participants that they will be talking about. Such a visual image provides a concise record of the outcome of the work undertaken that would be difficult to capture in words.

Biographical interviews: The researcher will return to a sub-set of participants to conduct a second round of interviews. This final stage will commence with a replaying of filmed data to elicit a commentary from the participant. Following this the interview will explore questions of image and appearance in a biographical context. The interview will include consideration of photographs and participants will be offered the option to be interviewed with the support of a family member or friend. One intention here is to develop an approach that might be replicated in practice.

Analysis

A central concern is to develop a situated understanding of the role that hairdressing and presentational care play in the lives of people with dementia with the intention of improving care practice. The analysis will draw upon multiple sources of data in order to support 'thick description' of this particular type of caring encounter and the context in which it takes place. Data will be collated using NVivo software for qualitative analysis.

The gathering of data from multiple sources will support a robust analysis through triangulation while revealing and helping to understand the contrasting perspectives of research participants. The reliability of interpretations will be supported by this triangulation of data sources alongside the use of 'member-checking', achieved by replaying and discussion of the filmed data with participants in the final stage of the research.

Data from the focus groups, semi-structured interviews and observations will be transcribed and thematically analysed. At the beginning of data analysis, a number of preliminary categories will be tentatively created in response to early data. These categories will then be refined as the data generation process continues. Data will be grouped and meta-themes identified. The purpose of the thematic analysis is to identify patterns and themes across the data and any salient contrasts according to the different sources and perspectives contributing to the study.

Central to the study will be the narratives elicited from people with dementia and those who provide care and support to them. Narrative analysis (Riessman, 2008) will be used as the primary analytical approach. Narrative inquiry takes narrative as the construction and performance of identity, an approach that supports the overall aim of the research in understanding and demonstrating the significance of aesthetic labour to the personal identity of the person with dementia. The device of eliciting a commentary on the visual data from participants in the second stage of the research will also help 'transform' visual data into narrative form.

A dialogic analytic approach to the narratives will be taken that recognises the co-constructed and intersubjective nature of the caring encounters and of the interviewing process. For people with advanced dementia, efforts will be made to co-construct narratives based upon close analysis of the filmed and observational data supported by contributions from next-of-kin and care workers (building on the applicant's earlier work with people with advanced dementia). [redacted] (mentor to the applicant), has extensive experience and expertise in narrative analysis in the field of dementia and will support the applicant throughout the project.

In order to promote good practice and support the development of training materials a case study approach will also be used during analysis, identifying and drawing out detailed and representative exemplars from the data that illustrate instances likely to be educative to practitioners.

The PhD element: The RA will use data generated for the main study as a basis for the analysis for the PhD but will develop her own theoretical and analytical framework to

support the consideration of men's experiences of body work and grooming and broader questions of gender relations in dementia care.

Main ethical considerations

Ethical issues in terms of voluntary participation, privacy and confidentiality and consent will be carefully considered throughout the research. Each participant will be asked to sign consent forms and at least 24 hours between agreeing to participate and data generation will be ensured. The study will involve individuals who may lack the capacity to consent to participate which raises on-going ethical considerations. The research will therefore be closely guided by the provisions of the Mental Capacity Act (the applicant and the RA appointed to the study have received recent training on the MCA).

Ethics protocol: The applicant has prior experience of conducting research with vulnerable individuals including people with advanced dementia, using multi-media methods and during this time collaborated in the development of an 'ethics protocol' (Vass et al, 2003). The protocol was used to support the recruitment process, the building of trust with stakeholders, and as a point of reference throughout fieldwork. An adapted and updated version of this protocol has been developed to guide the research and which takes into account the Mental Capacity Act; guidance from the British Psychological Society on working with Personal Consultees in research (BPS 2008); and the ethics framework for dementia detailed by the Nuffield Council on Bioethics (2009). The protocol will be used to structure the research process: supporting on-going monitoring of the wellbeing of participants; reminders to participants of their involvement in research and the right to withdraw at any time; and as a means of keeping a record of any ethical dilemmas and how they are addressed during the research process which can then support discussions in supervision. All identifying information in relation to the setting and the participants will be changed to ensure anonymity and protection of privacy in the subsequent writing-up of findings.

Mechanism for distressed participants: The wellbeing of participants will be monitored throughout their involvement in the research. Signs of distress and ill-being will lead to the postponement of the research and should these signs persist the individual concerned will be removed from the study.

If a participant shows signs of distress the researcher will seek to comfort and reassure them while taking steps to address the cause of the distress. The relevant individual (either key worker or next-of-kin) will be notified immediately and asked to further monitor the participant's condition following the departure of the researcher. The researcher will subsequently consult the participant concerned and their key worker/next-of-kin to discuss whether their continued participation in the study is appropriate.

Outputs and dissemination

The dissemination process will include an end of research event held in collaboration with the research participants that will address itself to national bodies in hairdresser education; care home management, user and carer networks and organisations, as well as care commissioners and local government policy representatives.

The applicant will use the findings from the research to develop training materials both for care-based hairdressers and for care workers and will work collaboratively with hairdressing educators to integrate findings into the training offered to hairdressers, including the development of web-based resources for mobile workers. Findings from the research will also inform teaching and training offered to dementia practitioners by the University of Manchester.

Given the potentially ethically sensitive nature of using visual data gathered from individuals with dementia the dissemination process will require consideration of creative opportunities for engaging a wider audience. For instance, by using ethno-drama methods (Kontos and Naglie, 2006) and other more experiential forms of knowledge transfer. A web-based presence will be developed for the research in order to engage with an international audience.

Benefits of the research to the NHS and Social Care Services

This project will inform the evidence base for dementia care with a particular contribution to understanding the role and outcomes of hairdressing services and hair care in dementia care settings. The findings will help to inform an on-going debate concerning dignity in care by making a contribution to the currently limited evidence available from clinical settings.

Specifically, the results will have significant benefit to people with dementia in receipt of high levels of care both at home and in institutional settings through improvements to care practice and a better understanding of good practice and the skills required to support personalised care for people at all stages of the condition. The research will make a contribution to the currently under-researched area of engagement and support to people with advanced dementia and understanding of the value of embodied practices to engagement and wellbeing.

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Appendix 12: Storage and handling of data

Essential to the confidentiality of participants was the storage and handling of data. This paragraph accounts for this.

The study held most of the data collected from participants on secure university systems. After audio recorded interviews the digital sound files were uploaded to the university systems and then sent to an approved transcribing service. The transcripts were then downloaded to the university systems.

For any publications or presentations data has been anonymised.

Film data were uploaded onto the University secure network in a purchased space for The Hair and Care project. They were also saved onto encrypted hard drives. One of these is stored in the University of Manchester in a locked cupboard in a locked room. The second is stored in a locked cabinet at the University of Stirling.

The film data was uploaded within a few hours of being recorded on each occasion. The film data was recorded onto memory cards and I would carry these separately to the camera before they were uploaded to the secure systems. Observations were recorded into handwritten notepads, which were carried with me until completed and then they were stored in a locked cupboard at university. Some notes were transcribed, and these were stored on university systems and were often anonymised at the transcription stage.

Appendix 13: Signage for filming – example situated poster

Appendix 14: Example of ethics protocol developed for the PhD and The Hair and Care Project

Ethics Protocol

Researchers: [redacted]

Project summary:

Much of the help and support provided to older people in care has the body as its focus. Assistance with eating, using the toilet, walking, dressing and grooming are all forms of 'body work' that are vital to everyday living and the wellbeing of service users. The aim of this study is to examine the role that body work plays in the lives of people living with dementia who are high level users of health and social care services. We will focus particularly upon hairdressing and hair care as an example of the body work undertaken in different types of care setting. Maintaining appearance and self-presentation are key considerations in upholding dignity and a sense of self-worth in care settings and this research will help to understand how this is achieved and where it may be possible to improve and enhance current practice.

The research will use a mix of methods including interviewing, filming and observation and we hope to draw on input from care workers/nursing assistants, care-based hairdressers, relatives/informal carers and people living with dementia . Our decision to include people living with dementia who lack capacity to give informed consent is because it has been shown that they have distinct needs in relation to body work and that those who provide this support often face particular challenges (e.g. around communication) about which little is currently known. In short, this research will contribute to an evidence base that will inform good practice and help us to better understand the role of body work in the promotion of wellbeing and the safeguarding of dignity in care.

About this document: This ethics protocol is designed to provide a clear statement on ethics for the 'hair and care project' and is intended for project participants and stakeholders; service users and their significant others, care workers and hairdressers as well as service providers and managers. The protocol includes details of: how the team will respond to ethical issues as and when they arise during the life of the study; the procedures put in place to ensure ethical compliance according to our proposed working standards and how these will be implemented and upheld. The document has been developed with reference to the Mental Capacity Act (2005); the Nuffield Council on Bioethics (2009) Report on Dementia and Ethical Issues (2009) and the British Psychological Society Guidance for Researchers on Conducting Research with People Not Having the Capacity to Consent to Their Participation (2008).

- In Part One we outline possible areas where ethical issues may arise and say how we, the research team, intend to respond to or handle these situations.
- In Part Two we set out how we intend to uphold our ethical commitment and ensure that the research is consistent in how we address ethical issues.
- Finally, in Part Three we explain how we will monitor the handling of ethical issues and make ourselves accountable for this.

We would welcome feedback and suggestions for any additions or amendments to this document.

Part One: Anticipated issues and proposed actions by the research team

Anticipated issues and the context in which they may arise	**Proposed action by the team**
Wellbeing of participants – including people living with dementia	

The nature/content of the research methods, including filming, observation and interviewing may prove distressing to a participant	Throughout the research participants will be monitored by the researchers (who have experience of working with vulnerable adults). Signs of anxiety or distress will lead to the postponement of that person's involvement. If, following a second attempt at involvement signs of anxiety persist, the person will be withdrawn from the study. The researcher will seek to comfort and reassure the participant while taking steps to try and address the cause of distress. The relevant individual (key worker or next-of-kin) will be notified immediately. The researcher will later consult the participant and/or their key worker/NoK to discuss whether their continued participation in the study is appropriate.
<u>Sharing of information</u> To engage participants and others in the research settings throughout the research and alleviate any personal anxieties about the purpose of the research	The team will introduce the research to staff and service users each time they enter a new setting and will offer opportunities for one-to-one meetings with anyone seeking further information on the research. In all stages of the project the team will seek feedback and advice from

The need for openness and communication with all participants	participants. Notices will be displayed to indicate when research is underway in a particular setting and the researcher(s) will offer verbal reminders and explanations.
<u>Gathering consent</u> The need to ensure that appropriate consent is given by participants and that this consent is maintained throughout their involvement. The health of the participant may worsen during the research and they may no longer be able to give informed consent to being involved in the study.	The team will seek signed consent from all participants. In the event that a person lacks the capacity to give informed consent we will approach someone close to them (e.g. personal consultee) and draw upon their knowledge of that individual in making a decision on involvement. The participant with capacity will be asked when they give consent if they would like to identify a personal consultee or nominated consultee with whom they may share information regarding their decisions to withdraw or remain in the study should they no longer have the capacity to consent for themselves. If the participant is no longer able to give consent for themselves and they did not give an advance decision agreeing to remain in the study they will be

	withdrawn at this stage without consequence and only their data gathered to this point in the study will be used. To take account of memory problems the team will use a 'process consent' model, offering regular reminders to participants of their right to withdraw from the study or to postpone involvement. The staff, service users and their significant others will be given a written guarantee that only members of the research team will have access to the data generated by the project
<u>Confidentiality</u> Access to data generated throughout the study	Publication of materials for their use for training purposes will protect anonymity but where individuals or settings may be recognised permission will be sought prior to presentation. Filming and photography is being used primarily to assist with detailed analysis of events and interactions and will be played back to participants to support further discussion of their experiences.
Usage of data following completion of the project	Only the research team and project participants will have access to this material.

Use of visual data	In the event that the team wish to use an image or excerpt of film for disseminating the findings of the project or in training materials then the individual(s) in that image will be asked to give signed consent to its use and will be shown the image concerned. Personal consultees or nominated consultees will be given advice to consider whether or not they think that their friend/relative/person they are consulting for would have found being filmed or photographed at the hairdresser when they had dementia embarrassing or degrading. They will be asked to give advice on whether or not their friend/relative would have given consent to this aspect of the research. If the person is giving information about their relative/friend who now lacks mental capacity to consent to the sharing of information themselves it is vital that the relative is mindful of whether or not their relative would have objected to the sharing of information. The researcher may need to refer to the advice of the personal consultees
Visual data: Dignity of participants who lack capacity to consent for themselves taking part in the research process	During fieldwork or analysis stages of the project any act, gesture, or verbal exchange deemed by the research team to constitute abuse will be acted upon by the

	team. The incident and any associated evidence will be handed to the management of the host organisation to be dealt with in accordance with their stated policy on abuse and anti-discrimination practice.
Confidentiality issues raised by the interviews with relatives and next of kin.	The researcher(s) will not enter any private or domestic spaces belonging to participants without their prior agreement and will not seek to observe or be present during the provision of intimate care such as (un)dressing or assistance in using the toilet Cameras will only be used in communal areas in care settings; no filming will take place in private areas in care settings without the permission of the participants concerned. The siting of cameras will take place under consultation with staff and service users and with the full knowledge of the setting manager. During home visits the workers and service users will be informed of the right to switch off the camera under circumstances in which they deem filming inappropriate.
Grounds on which code of confidentiality may be superseded - abuse	Researchers will download films/photographs to secure computers

	within 2 hours of a filming session being completed to ensure that the recorded data is protected securely as soon as is possible after each of these sessions.
<u>Privacy of participants</u> The need to protect the privacy and dignity of project participants at all times during the research The usage of video cameras may infringe upon the privacy of project participants	Posters will be strategically placed in each care setting to inform and remind people of the project and give contact details should they wish to raise any concerns Care will be taken to focus filming and photographing on participants (the researchers have both received training in using filming for research purposes). In the event that a third party is caught on camera for an image that we wish to use for dissemination purposes it will be anonymised using photo-cropping or pixilation. The research team will not entertain nor will they act as witnesses to any industrial dispute, differences of opinion or any other direct or indirect disputes of a personal, interpersonal or inter-group

	nature between employees, service users and employer/organisation The researchers are present in care settings for research purposes only. At no times are they able to assist in care (including observation of service users in the absence of staff) or offer support to service users that falls outside of the research role. The researcher is not able to hold documentation or information relating to service users or to pass on information on behalf of staff or service users.
<u>Implications for staff, service users and relatives not selected for the project</u> Non-participants may forget, be unaware or have concerns regarding the project and its intentions Those not participating in the research may be caught on camera during fieldwork	

<u>Whose side are we on?</u> In the event of an internal dispute within a care home or similar establishment Role of the researcher	

Part Two: Actions taken by the research team to ensure compliance with the stated ethical considerations

Wellbeing of participants – including people living with dementia

- Keeping a diary of events that is open to the scrutiny of the research team
- Through observation and monitoring by member(s) of the research team
- Liaison with staff, particularly with keyworkers of the people concerned
- Communication with the relatives of the individual(s) participating in the study where appropriate

Sharing of information

- Feedback will be obtained regarding the information distributed about the project when the team enter each setting and the most useful way to disseminate findings
- The team will invite feedback from representatives of service users, workers and host organisations and will meet with them to discuss any concerns or queries about the project

Gathering consent

- The team will keep a signed record of consent for all project participants
- The researcher(s) will follow an agreed protocol for assessing capacity to give informed consent

Confidentiality

- All confidential material – for example consent forms, video and audio data – will be locked away securely and access restricted to members of the research team
- No data will be shared beyond the team where it is possible to identify project participants without specific permission from the individuals concerned (see below)
- The researcher(s) will seek signed consent to use a particular image or excerpt of film (e.g. for inclusion in training resources or dissemination of findings) from the individual(s) concerned who will be shown the image and given an explanation of how it will be used. Steps will be taken (such as cropping pictures or pixilating images) to ensure that no other individuals are identifiable in such images.
- The team will not use or disseminate images of individuals who lack the capacity to give informed consent.

Privacy of participants

- This will be monitored throughout the study through liaison with staff, service users and relatives

Implications for staff, service users and relatives not selected for the project

- The team will invite feedback from representatives of the host organisations and will address any concerns regarding the impact of the project upon individuals not participating in the study

Whose side are we on?

- Monitoring by the team to ensure inappropriate information is not divulged
- Reading diaries kept by the researcher(s) and discussing in supervision any complaints about researcher behaviour and its relation to service user wellbeing

Part Three: Accountability

The study will be supported by an advisory group that will include academics involved in the field of ageing and social care, hairdresser representatives and user and carer representatives. At the advisory group meetings the research team will give a brief report on 'ethics' including what, if any, action has been taken to ensure compliance.

Using an agreed format the researchers will also keep a record of any ethical issues that arise during the life of the project and this record will be shared during supervision in order to further discuss and explore any dilemmas or concerns. The record will include details of

a) the event/action and its context;
b) any intervention or actions taken by the researcher at the time; and
c) the outcome or results.

By keeping such a record the project will be open to scrutiny, for example from the University of Manchester or host organisations regarding the way that ethical issues and dilemmas are handled on an on-going basis throughout the life of the project.

The project leader ([redacted] and Researcher [redacted] will also receive supervision from two project mentors who are senior academics in the field of dementia care and ageing: [redacted] (University of Manchester) and [redacted] (Open University).

Both the project lead and the researcher have undergone training in the Mental Capacity Act and in Good Clinical Practice in Research and will update and attend further training to enhance ethical practice as appropriate throughout the research.

Appendix 15: Further information relating to the fieldsites.

Neighbourhood Locations

All three sites were set apart from the neighbourhoods where they were located. Both Old Bay Hospital, where Sandbridge ward was set, and Lincoln Manor were in similar types of locations within the region. Both locations had high levels of deprivation. Forest Fields is situated in an area described as a market town and is set within a significantly more affluent residential district than the other two settings. This can be discerned immediately from the tree-lined avenue where Forest Fields is located. The residential area has large, gated houses with long driveways and Forest Fields is situated at the end of a tree-lined road of exclusive houses. The houses along this road are valued at over a million pounds. However, similarly to the other two places, there are rarely any members of the public walking along the pavements. Forest Fields has a car park and landscaping at the front of the building and is hidden from view of the road, behind a row of mature trees. It is not obvious to anyone who does not know, that it is there. Similarly, Old Bay hospital is a purpose-built one level NHS dementia hospital, which is also situated in its own grounds with an often-full car-park area at both front and back. It has some surrounding woodland separating it from a housing estate. Lincoln Manor is situated in a similar neighbourhood to the hospital and the local authority area has a higher than average older population. The Victorian building is accessed through a large stone gateway, via a long drive which leads into the gardens and grounds. It is situated in a residential area, set apart from the surrounding area in extensive grounds.

Care provision

Forest Fields is a residential and nursing home that aims to provide care for those who are no longer able to be cared for at home. Forest Fields is owned by an international health care group and service provider and opened as a care facility more than 20 years earlier. It provides care to residents with a range of health concerns that includes dementia. At the time of the fieldwork, it had a specialist dementia unit on the first floor, called Primrose residential dementia unit. Residents who live there are required to pay for the services. Fees are set by the health care group and costs will depend on the care required by the resident.

Funding residential and nursing care is complex and the costs can be met through personal finance, and or with the help of local authority funding and sometimes with support through the National Health Service (https://www.ageuk.org.uk/information-advice/care/care-homes/paying-for-a-care-home/). Care organisations set their own funding charges, and these vary depending on the type of organisation, care provision and also geographical location (Laing, 2004).

Lincoln Manor was home to Charlie, Harry and Bert and like Forest Fields, this organisation aimed to provide care for those no longer able to live in their own homes. Care was delivered through a charity, with a board of trustees who oversaw the work of the chief executive, and a medical advisory board which offered expert advice on the delivery of care. At the time of my observations, all the residents were male except for one female resident. There was a rich history to the building and organisation. The Victorian home had been purchased with monies raised in a charitable appeal during World War I (WWI) in order to provide hospital care to injured service men returning from the frontline. Many of these men remained in the hospital, making it their long-term home.

Old Bay hospital is run by the National Health Service (NHS) and is part of a Foundation Trust. It had a different function to the two long-term residential care organisations and provides both specialist in-patient and out-patient care, as a memory clinic and a specialist dementia hospital serving a large geographical area. There had been two ward spaces, one of which had closed not long before the field work began. This closed ward had worked specifically and exclusively with men who had been diagnosed to have challenging behaviours as a symptom of their dementia. The men placed on this ward were felt to present a heightened risk to themselves or others. At the time of the fieldwork, the Trust had decided to close the ward and the male residents were transferred to the mixed male and female ward, Sandbridge ward. This change to Sandbridge ward meant that during the three months fieldwork on the ward, there were higher numbers of men on the mixed ward than previously. At one point, there were 11 men on the ward and three female residents. There were also a high number of Sandbridge residents described as having challenging behaviours and complex needs during this time. Sandbridge was closed to any new admissions, during the fieldwork period.

Patients are generally admitted to the ward when they have had some kind of crisis in the community or their residential care facilities. The admission would often be made using Mental Health Act 1983 powers (Department of Health, 2015). Residents were admitted to hospital in order to consider the most appropriate treatments and to reassess their living arrangements. Admission to Sandbridge ward is a difficult time for most residents and their families because of the distress of the liberty-limiting consequences of being detained under the Mental Health Act 1983 (Department of Health, 2015). As admission to Sandbridge ward is often made under the Mental Health Act 1983 (Department of Health, 2015) the family also will be unclear as to how long their relative will be detained on the ward. Families have to adapt to a new location to visit their relative, with will be living amongst other residents who are also presenting difficult behaviours and who may not appear well.

The material environments

The three buildings were quite different from each other, Old Bay hospital is a purpose-built single-story building, Forest Fields a mock Tudor residential home and Lincoln Manor is a Victorian manor house that had been extended in the 1980s to manage its growth as a care facility. Both Sandbridge ward and Primrose residential dementia unit are restrictive settings, where those living with dementia are separated from others and were held within locked units. In Lincoln Manor, residents were not separated by their condition, and those living with dementia were alongside those living without dementia. Access to outside spaces was also possible through unlocked patio doors, although the main entrance and back entrance to the property required staff permission.

There is a main communal area in each setting. Sandbridge ward is open plan room separated into different spaces by partitions and furniture. In each setting there are spaces designated as communal living areas (or certainly seating areas) for people to sit during the day, as well as separate dining areas for those able to sit around tables to eat. The spaces are organised to reflect the structure of the days such that Primrose residential dementia unit had a large communal ‘day’ room, which is divided also into two sections: a seating area and a dining area and corridors with bedrooms off them. Similarly, on the Old Bay hospital ward, an area is partitioned off as a dining area. Lincoln Manor is a larger property which allows for more areas in which to sit.

The main communal area within Lincoln Manor was a multi-space room used as the dining hall, a sometimes ballroom and a bar area. The bar opened several nights each week, and each week day, one end of the bar would be set up as a shop for the men to purchase cigarettes, sweets, and soft drinks. There are also quite large grounds with a patio just outside the main building where some men went to smoke. In the main, Lincoln Manor residents who used the communal areas were mobile; this includes some self-mobile wheelchair-using residents.

The material environment of Lincoln Manor is quite different to the other two settings. Although decoration in the main communal area was fairly sparse, this was not so for other communal spaces within the home. Reception staff were based in the main entrance hall behind a glass partition, which sealed of the reception area completely. The entrance hall was a grand, tiled space, highly decorative with military service memorabilia. It features display cases containing military medals, commemorative plaques, displayed on walls and in cabinets, which refer to particular troops, as well as other memorials around. It also shows the staircase to the upper floor, where the staff areas and a small museum are situated. From the reception area there was an open doorway giving access to a corridor via which residents' bedrooms can be accessed. This image also shows that the paint work at Lincoln Manor was quite tired, in contrast to the grandeur of the military decoration and the building's high ceilings and grand staircase. The nurses' office - which is a glass-walled room – can also be found along this same corridor. The corridor also led to a number of day rooms, one of which is designated a smoking room. It is permissible to provide indoor smoking space in residential care, if required by residents (http://www.dbfiresafety.co.uk/2016/06/20/law-smoking-care-workers/; accessed 23 September 2018).

Primrose residential dementia unit was centred around the main communal living area, off which two corridors led to bedrooms. The communal area was divided into two sections: approximately two thirds of the room had arm-chair seating around the room-edges, whilst the remainder was given over to dining tables, covered with table cloths. The windows looked out on to trees and the garden area below. The room was decorated with pictures, vases with artificial flowers and other ornaments. Positioned on a wall at the end of the room in the dining section was a large flat screen television. Close by, positioned against an

opposite wall, was a cabinet and book shelf and some further seating to the side, angled away from the television.

There were a greater number of residents with dementia who had mobility challenges on Primrose residential dementia unit than was in case in Lincoln Manor. Many Primrose residential dementia unit residents were brought into the room in wheelchairs, or lounge chairs with wheels, and positioned in the same place for what seemed long periods of time - certainly for as many hours as my observations took, anything up to 5 hours at a time (possibly longer). In the corridor, there was a seat next to the nurses' station. The nurses' station was a desk area, behind which were notices and posters about risk, mental capacity, work schedules, information about who to complain to and other notices such as health messages about the importance of hand washing. Next to the desk there was a cupboard where staff stored their bags and the desk itself had files on it, a telephone that would sometimes be heard ringing and there were filing cabinets behind the desk. There were two bedrooms off to the side behind the nurses' area. There was no other seating along the corridor, which was fairly narrow. It was wide enough for wheelchairs to be brought through, but seating in the corridors would have obstructed access.

The corridor view shown in the image below is a photograph I took during an observation session; it shows the hand rails which act as an aid to walking. They also are a symbol that mobility may be difficult for the people living here. There is a 'fire exit' sign that can be seen, which notes the need to adhere to fire regulations in a building that is not a domestic home. There are no legal requirements for domestic homes to have 'fire exit' signs (Health and Safety Regulations 1996). This sits in contrast to the pictures on the walls which might be seen as decoration used to create a homely appeal. The corridors have dim lighting and long corridors leading only to dead ends. The corridors on Primrose residential dementia unit had been decorated not long before the fieldwork began, the current lead nurse had led the redecoration which were stick on images of butterflies, flowers and trees, as well as framed pictures. Each room had a memory box next to the door, containing photographs of the residents usually and sometimes other memorabilia, from earlier times in their lives.

At the far end of one of the Primrose residential dementia unit corridors there was another living room area, smaller than the main room. This room did not appear to be in frequent use,

similarly to other areas. For example, on each of the three floors in Forest Fields there were small kitchenettes which did not appear to be used regularly. It was common in all the participating sites that there were rooms that appeared under-used, in Lincoln Manor there was a library room that seemed to be rarely used. The extensive and grand reception area and hallway was mostly empty, and the meeting rooms on the first floor did not appear to be used a great deal.

Sandbridge ward also had unused rooms, despite there being limited space on the ward. As well as the living and dining sections there were rooms off to the side of this area. One of the side rooms was labelled a 'quiet room' and another was the 'ladies; lounge' and neither appeared in much use. During time observing on the ward I saw the rooms used for handovers, a meeting with residents' family members and on one occasion one room was set up for a sensory session with one of the ward residents.

There are a number of places for patients to sit on the ward, and again, the space is divided by function and an understanding of what a living environment might look like. As such there is the 'living room area' as mentioned, where seating is arranged to enable residents to view the wall mounted television. There were glass panel walls that separated the living room from the dining area. However, those seated in the dining area would still be able to hear the television even if they couldn't see it. The glass panels were not floor to ceiling, nor were they wall-to-wall. Chairs were placed against these panels. These faced out onto the ward, and towards the lounge area and television. It was possible to sit here, outside of the television zone, although there was nothing to insulate residents using this area from the sound of the television. None of the distinct spaces prevented sensory overspill. There were more seats that faced towards the walkway with double doors to the bedroom area were. Again, this provided a space for pausing en-route to and from the bedrooms and bedroom corridor.

Sandbridge ward was within a hospital built around a central courtyard. The hospital also housed a community mental health team and also, as mentioned, the out-patient memory service. There was a purpose-built hair salon for hospital residents, a large kitchen area - separate from the wards - for providing meals to those living on the wards. There was also a staff room, which included a kitchen. Alongside these there were a number of meeting rooms and offices for senior staff.

In a number of ways, Sandbridge ward had more in common with Lincoln Manor than Primrose residential dementia unit, Sandbridge ward operated as a functional space and had not been decorated to appear 'home-like'. Lincoln Manor had previously been a hospital and having the same institutional origins could account for both Sandbridge ward and Lincoln Manor featuring similar furnishings and layout, and neither had been updated for some time.

Access to outside space differed in each setting. On Sandbridge ward, doors opened onto a secure outside space, enclosed on all sides by hospital buildings. The secure nature of the garden meant residents were able to access the outside space without staff supervision if they wished. A gazebo had been erected in the garden, providing some shelter. Some table and chairs had also been placed in the garden. However the garden area appeared under used, although observations took place during winter months. Primrose residential dementia unit was part of a care organisation, Forest Fields, there were garden areas here, however, the dementia unit was on the second floor and the garden was not accessible without accompaniment and the unit was locked so no-one could leave without accompaniment. There were large unsecured grounds at Lincoln Manor, including a patio area where men could smoke, however I was not aware of men using the grounds.

Staff

In all three settings most staff wore uniforms. For example, staff on Primrose residential dementia unit and on Sandbridge ward wore different coloured uniforms indicating their roles: nurse; care worker or nursing assistant; domestic staff; kitchen staff. Staff with regular everyday contact with residents were required to wear uniforms. However there were staff on Sandbridge ward who did have regular contact with residents and did not wear uniform these were members of the therapeutic teams such as the Occupational therapy team and the Psychology team. Uniforms were also not worn by either managerial or administrative staff at any of the sites. The majority of the work carried out by care workers and nursing assistants was bodily work, such as morning routines of getting people up and out of bed; dressing, bathing and providing meals. These staff were also responsible ensuring that residents were taken to the toilet when needed as well as scheduled toilet breaks and incontinence pad changes. Whilst uniforms were worn by all care staff across all sites, this wasn't the case for activity workers. The activity worker at Forest Fields who provided

activities throughout the home, including on Primrose did not wear a uniform. In contrast, the activity workers at Lincoln Manor did wear uniforms. This may have been because they were both sometimes also involved in care work.

Everyday work at Lincoln Manor was led by the Matron who was a nurse by profession. He was supported by a lead nurse who worked out of the nurses' office on the ground floor. Both wore uniforms. At Lincoln Manor there were also maintenance and ground workers on site every day. I often observed these staff walking through the main communal area, sometimes chatting to the men. The Chief Executive of Lincoln Manor worked on the upper floor and was rarely seen on the ground floor with residents. The charity also led by a board of trustees and a medical committee who would attend meetings and events at the home but I do not know how much time they spent with residents. A number of volunteers worked at the home, supporting the delivery of events and activities. Similarly to Forest Fields, staff who worked directly with residents wore uniforms, whilst office-based staff did not. As already noted the Matron wore a uniform despite his role being mainly office-based. His responsibilities were to the staff working directly with residents, and his uniform denoted his status of trained nurse.

There was always a qualified nurse in charge on Primrose residential dementia unit who was responsible for the overall management of the unit and compliance with legal requirements. As mentioned above, there were was a range staff alongside the qualified nurse and care staff. These staff would enter Primrose residential dementia unit to carry out specific tasks: domestic staff for cleaning; kitchen and dining staff who were responsible for laying tables, providing refreshments at morning and afternoon tea times, provision of other meals and delivering these to Primrose. A part-time self-employed hairdresser, who worked in the Salon on the second floor of Forest Fields, visited Primrose to ask if residents wanted to have their hair done and she also wore a uniform. There was also a clinical service lead who could be available on Primrose residential dementia unit if more nursing help was needed.
In addition to the permanent staff, agency staff were frequently booked to work on the dementia unit, to accommodate staff shortages.

The ratio of staff to residents on Sandbridge was much higher than in both the other care organisations. This was due to higher safeguarding thresholds. In addition, there were a

number of specialist staff working on Sandbridge. Many of the staff were qualified nurses. Regular student nurse placements were accommodated on the ward. The ward was headed up by a matron, a senior nurse in charge of the work on the ward, but not based on the ward. The Matron had her own office in another part of the hospital. Staff could also access an on-site, but off-ward psychiatrist and an Advanced Nurse Practitioner if a required by a resident. In addition to the other staff already mentioned, nursing assistants were on-ward performing similar roles to those carried out by care staff in Forest Fields and Lincoln Manor. There was also an occupational health team who would assess and support patients through the use of activities on the ward. Alongside all these staff were domestic staff, laundry staff and kitchen staff.

Appendix 16: Participant Pen Portraits of men living with dementia

This appendix provides pen portraits of the men living with dementia who took part in the study. The men's background stories were revealed to me through interviews, conversations, and observations or were left unknown. I was keen for my understandings about the men to develop organically and within the everyday contexts in which they were living at the time of the fieldwork. All participants were identified as having some form of dementia by staff or were living in specialist dementia settings.

1. Samuel

Samuel was 85 at the time of the study and had lived on Primrose residential dementia unit in Forest Fields care home for around a year. Samuel was a wheelchair user and his wife told me that he was prone to falls, which was why he now used a wheelchair permanently. Samuel's appearance was a balding man, with hair on the sides and back of his head, which was kept neatly trimmed. He did not see the hairdresser at the home (who his wife said had cut his hair too short) and she arranged for someone to come in to do his hair instead. Samuel was usually smartly dressed in a shirt, jumper or cardigan and trousers. He was always clean shaven. Samuel needed support to bathe and groom and to get dressed in a morning. He was an early riser, and often would be dressed and shaved by the time I arrived at the care home, usually between 8.30am and 9am on a weekday.

Prior to living at Forest Fields, Samuel had lived at home with his wife who was then his main carer. However, due to a number of difficulties with his physical health and dementia, and a stay in hospital, health and social care workers had expressed concern regarding his wife continuing to care for Samuel at home. She was advised that Samuel needed more support than health professionals determined she was able to provide. Samuel was not considered to have the capacity to make decisions about his future or where he should live and reluctantly his wife, Maisie agreed to Samuel moving into long-term residential care:

> *'But the social worker and the medical staff at Wythenshawe said the nurses were struggling to hold him up and they didn't think I would be able to…But I mean I used to do everything for him, shower him, dress him, undress him, do everything for him really for quite a while, a number of years really. And I would've carried on doing it,*

but when we had this best interests meeting, the family were there and you've got to stop and think what was best for Samuel really, for his safety…' (Maisie, Wife to Samuel, 23rd February 2012).

Samuel was from the North West and had been married to his wife for 60 years. He had undertaken national service in the army and this had taken him to India. His time doing national service was a formative experience and one that Samuel referred often during the time I spent with him. After his return from India to Britain, he worked firstly for the electricity board and then for many years as a sales representative for a company that sold edible oils. This company was taken over by a large US corporation and he decided to change careers. He opened a hardware shop, which his wife told me was something of a dream for him. He carried on in this independent business whilst his children grew up, but eventually sold it. Samuel then changed direction again and became a tutor within the probation service, teaching joinery skills to ex-offenders. According to his wife, he had a fulfilling life and was interested in a great many things. Their shared home (which I visited to conduct an interview with Maisie, Samuel's wife) was full of objects and furniture crafted by Samuel, alongside his collections of steam trains that were also on display. The family home still held much of Samuel's presence through these objects, which were of great significance to him and his identity. In his bedroom at the care home there were few of these biographical objects, although there were a number of photographs on a dressing table, including a framed photograph of him and his wife from a newspaper article about the celebration of their 60 years of marriage and one steam train. There were other family members also in photographs, children and grandchildren. His room included an en-suite shower room and toilet which he needed support to use. He also had a single bed, so there was no option for his wife to stay in the room overnight with him. There was also an armchair in his room and a chest of drawers. The room had a window that looked out to the garden area.

During my interactions with Samuel he was mostly upbeat, and keen to engage in conversation, often using humour in these interactions. He referred on a number of occasions to his time in military service. On one occasion in the communal living area he joked with me 'was I writing my life story?' I replied that I was sort of writing about his, and he said he would tell me it. It was easy to engage Samuel in conversation, yet despite his sociability, I rarely saw Samuel in the main communal area during the three-month period I observed on

Primrose residential dementia unit. On the occasions when he was there, he was engaged with conversation or tried to be and he joined in any activity. However, for the most part over the three months that I spent visiting Primrose residential dementia unit Samuel was mainly in his bedroom. He ate his meals in his bedroom which meant that Samuel, who seemed to enjoy a friendly jovial atmosphere, was often alone in his room, except for when his wife visited, which was most afternoons. Samuel may well have made the decision to stay in his room, but if he changed his mind, would be difficult to get help to move later on, particularly during morning routines when the care staff on the residential dementia unit were busy getting other residents up and ready for breakfast.

2. Bryn

Bryn lived on Primrose residential dementia unit, at Forest Fields and similarly to Samuel, he was a wheelchair user. Bryn was a large man, who often looked cross. His interactions sounded gruff, but this could have been because he found speaking difficult. I did also know from his wife that he had not settled well into life on Primrose residential dementia unit. As a couple they had not adapted to life in care, and now his wife was planning for him to return to their home. Bryn was rarely seen in the communal area on Primrose residential dementia unit. On the few occasions that he was there, he seemed to respond grumpily to the general hubbub of the noise, shouting back to people. At other times he when in a better mood whilst in the communal area he would try and have chats with Samuel if he was sat nearby. As with Samuel, Bryn may not have chosen to spend as much time in his room, had he been able to manoeuvre himself. Or it may have been because he was unhappy at the care home he preferred to be in his own room. I did not see Bryn's bedroom, and on the two occasions I was given the opportunity to observe Bryn being supported to have a shave, they took place in other rooms. The first time was in a communal bathroom, and the second time, he was in the communal living area. Both these observations are described in the main thesis document.

I did not interview Bryn's wife, it appeared to be stressful and time-consuming time trying to organise the care required for Bryn to move home. Like Samuel, Bryn's body and his care were now under the jurisdiction of health and social care. It was not possible to take him home without an approved care plan, and the material products of care that would be needed, such as hoists, to have him back home. These were taking time and cost to organise and Bryn

could not simply be taken home, as he was no longer considered to have mental capacity for decision-making (Department for Constitutional Affairs, 2007). Hence the decision about where he should be cared for, and the care required, was subject to a legal process. From my own experience of spending time with Bryn, although he had not been able to give informed consent himself to take part in the study and his wife had acted as his personal consultee, agreeing she thought he would want to be part of the study, he was still able to give clear decisions about some matters. On one occasion I asked Bryn if I could observe him being shaved and he was extremely clear that he did not want to be observed. Hence, there were decisions and choices that Bryn was able to make and be involved in. I felt that Bryn was at least trying to assert some power over his body in circumstances where he had very little individual agency.

3. Larry

Larry was a resident on Sandbridge ward in Old Bay NHS Dementia Hospital. Larry's daughter had acted as his personal consultee to support Larry to become part of the study. Although I later found out that Larry also had at least one other child, I did not see him with a spouse. Larry had been living in care prior to being admitted to the in-patient unit. He was an affable and well-mannered man and during the times that I saw him he was always polite with staff. Sometimes he would speak in an exaggerated 'posh voice' to deliver his 'thank you' or greetings. He also appeared popular with other patients who would choose to sit near him or engage in conversation with him. Larry would joke, laugh and converse with patients and staff. He was always smartly dressed in casual clothing such as polo shirts and smart straight jeans. He had a thick shock of white hair which was combed back and he was clean shaven, although his skin regularly appeared red and dry. His daughter had expressed concern over his skin, and how sensitive it looked, when she discussed Larry becoming involved in the research study.

Larry would usually be up when I arrived on the ward, and he would be in the breakfast area, or ready to have a shave and get dressed. He would move around quite a bit during the day. In particular he liked to sit outside of the main ward area in a seating area on the bedroom corridor. Although Larry was sociable with other patients, he would choose this quieter spot. It was away from the television and general hustle and bustle of the ward. It seemed he wanted to stay out of the way and perhaps also not be any bother. He also often appeared to

be passing time as he would shift and move positions in his seat, tapping the chair, or rubbing his chin and cheek. However, if someone sat down next to him, and talked, he would join in and at other times he would close his eyes, passing time by dozing. Larry could also express his boredom, or confusion from time to time at activities presented to him on the ward.

4. Don

Don was joined into the study through his wife who acted as his personal consultee. He had been admitted to Sandbridge ward shortly before the observations began in December 2012. Don had fine, thinning white hair and he wore glasses. He too was clothed in casual smart clothes which were usually a polo shirt, smart jeans and a cardigan. Don's wife came to visit him most days and would arrive at the hospital sometimes with another patient's wife that she had become friends with. She was concerned about Don and would regularly talk to staff about how he was doing during her visits. I learned that Don was admitted to the hospital after becoming anxious and aggressive. Don had hit someone at the day centre he had been attending, hence being admitted to hospital to undergo assessment and a review of his medication regime.

During the time I observed Don on the ward, his moods would change, however I did not see him behave aggressively. His face would light up when his wife arrived and often when her visit ended, Don would spend time standing by the exit door, or walking around the ward, and returning to the ward exit sporadically. Don would move slowly around the ward, his gait a kind of shuffle that was familiar in some of the other residents too. There was hesitancy in his walking and he didn't lift his feet far off the floor before stepping forward. At other times on the ward, Don would sit at the dining tables, and regularly appeared to be sleeping, with his head in his hands. When he woke he was restless and moved around the ward to find a new place to sit. On occasion he would engage with other patients, with his rhythmic style conversations and mumbled unclear words. He would gesticulate and appear as if he was imparting information, or he would smile and nod throughout his story.

Over the time I observed on the ward, I would note that Don began to get up later in the mornings. He would not rise from bed before 11am. This may have been a way of shortening the day or limiting his time on the ward. He would get dressed by himself, although staff would lay out clothes for him. Don was also able to shave himself, but would only do this if

encouraged by and with the guidance and support of staff. I observed Don shaving on a couple of occasions. Similarly to Larry, Don's skin suffered during his time on the ward, and he regularly looked like he had a red shaving rash. His skin looked sore and sensitive. Although Don's clothing still looked smart-casual and he was always clean, his hair sometimes looked a little dishevelled. I learned that combs were not always available on the ward as I had observed a staff member looking for a misplaced comb. During my observations on Sandbridge ward I filmed Don's visit, supported by an occupational therapist (OT), to the hairdressers. He appeared to enjoy the time off the ward, and chatted easily to the hairdresser and OT assistant, although even on the film it is difficult to hear Don's words. I discuss this experience in the main body of the thesis.

5. Charlie

Charlie lived in Lincoln Manor and was from the same area in which the care home was situated. At age 93 he was the oldest participant in the study, and like one of the other men (Bert) he had served during WWII. He was from a 'traditional working-class family'. His father had been a dock worker and his mother had been a housewife and had also worked in a shoe shop. He had one brother who was two years younger who was also still alive but did not live close by. Charlie had worked as a bus conductor and, like his father, had also worked as a dock worker. Charlie was the father of five children: four boys and one girl. His daughter revealed they had lived in a 'two up, two down' and there wasn't much room or money. Charlie's wife had died nine years earlier.

Charlie had joined up for military service in 1938 because 'he knew war was coming'. His daughter told me this proudly to give me a sense of the kind of man Charlie was, a brave man who did 'the right thing'. This was shown visually in his bedroom in photographs on display of Charlie in military uniform and wearing the many medals he had been awarded for his service during the war. During the interview that I carried out with Charlie and his daughter, he regularly broke into song, just as he did when seated in the communal areas of the care home.

Charlie needed support to get dressed in the morning, but he walked without a stick, although slowly and sometimes hesitantly. Once dressed, he would move to sit in the same seating area

looking on to the dining hall each day and he wouldn't move much during the day. He would though take himself to his dining table at meal times and to the toilet as needed. Charlie always wore a white flat cap; it was part of his signature style. According to his daughter, appearance was something that had always been important to Charlie and this seemed to still be the case in the care home. He liked to be clean-shaven, and wore a button-down shirt. Since moving into the care home, he usually wore trousers with an elasticated waist, which presumably made getting dressed, undressed and toileting easier. Once after going to the toilet, Charlie showed me the front of his trousers and asked 'am I alright?' in case he had wet his trousers in the process. He was concerned about being presentable and clean, he had said in an interview 'I like to be turned out clean'.

Charlie spent a lot of his day with his eyes shut but would be roused by meal times and on occasion by the conversation around him. He would break into song or shout something out, joining in momentarily with what was going on around him. He was regularly visited by members of his family, who would join in the chatter with the men sitting around Charlie. Charlie seemed amiable when engaged in conversation, though he sometimes appeared anxious. Charlie shared a bedroom with another participant in the study, Harry, and there were often tensions at night between them. Sometimes Harry would get up in the night to use the toilet and would mistakenly try to get into Charlie's bed. This would lead to a fight between Charlie and Harry. On one occasion when I observed at the home, Charlie had a black eye as a result of a fight with Harry.

The room that Charlie lived in was divided by a curtain that could be drawn across to separate his half of the room from Harry's. He had a narrow single bed, beside which was a dressing table. The room also contained a chest of drawers with many photos and memorabilia displayed on it. There were photos of Charlie and his family, including his grandchildren, depicting Charlie as part of a family.

6. Bert

Bert lived at Lincoln Manor and was 88 years old. I interviewed him alongside his brother and nephew. He was from a city in the North West, close to the location of the care home. He was one of 10 children and he said his mother was 'the best mother in the world and his father was a so and so'. Bert and his family had grown up with very little money, although

Bert's brother explained during an interview that during the war everyone was better off because there were more jobs. They both described a 'tough childhood' where three siblings died young, and their father was an alcoholic. They said they often had to move homes as young children because their mother needed to do 'moonlight flits' because she was unable to pay rent due.

Bert served during the WWII in the Navy. He was stationed in Norway and told me about bombing ships with fighter planes on them. The bombing campaign Bert referred to was well-known bombing campaign resulted in the death of a large number of men. (http://www.bbc.co.uk/history/worldwars/wwtwo/norway_campaign_01.shtml). Bert was discharged from the Navy when the war ended. When he returned to civilian life, he got a job in a women's clothing factory 'on the press'. Bert said that it was 'piece work', that is, he was paid per item he ironed. His brother said that Bert was very fast at this task and usually earned double what most were paid and so he was (relatively) well off. Bert enjoyed ballroom dancing and gave lessons in his spare time. He met his wife through dancing. I asked Bert about dancing, and he responded by counting a dance beat 'a one, two three, a one two three'. Bert's brother says that his wife was 'posh compared to us'. Bert was married for 50 years before his wife died. They did not have children.

Bert rarely spent time sitting in the communal areas of the care home during the day, although I was told that he spent time in the bar area at night. The bar and evening social time may have appeared more familiar to him. Bert would also emerge from his room, and arrive in the dining hall area at meal times, signalled by the smells and sounds of meal times. He would make his way over to the same table each meal, where he sat with Harry and two other men. I didn't notice them talk much to each other. Sometimes Bert would pause to have a chat with men sitting by the exit on his way back to his bedroom. There were other occasions that I saw him come into the communal area, such as when the hairdresser came to the home, and he would have a haircut. I observed him one day having his haircut and he was able to tell the hairdresser with a few words and through actions with his hands, how he wanted his hair cut to be. Appearance continued to matter for Bert, as it had throughout his life. He was always clean-shaven. He shaved himself using an electric shaver. He got himself dressed and ready each day, without support from staff. He was smartly dressed, and wore shoes, despite spending much of his time in his bedroom. This appearance of Bert's clothing choices

signalled a tension, as he spent most time in his private bedroom, yet still seemed to be not quite at home, as his decision to wear outdoor footwear suggests (Buse and Twigg, 2014b).

7. Harry

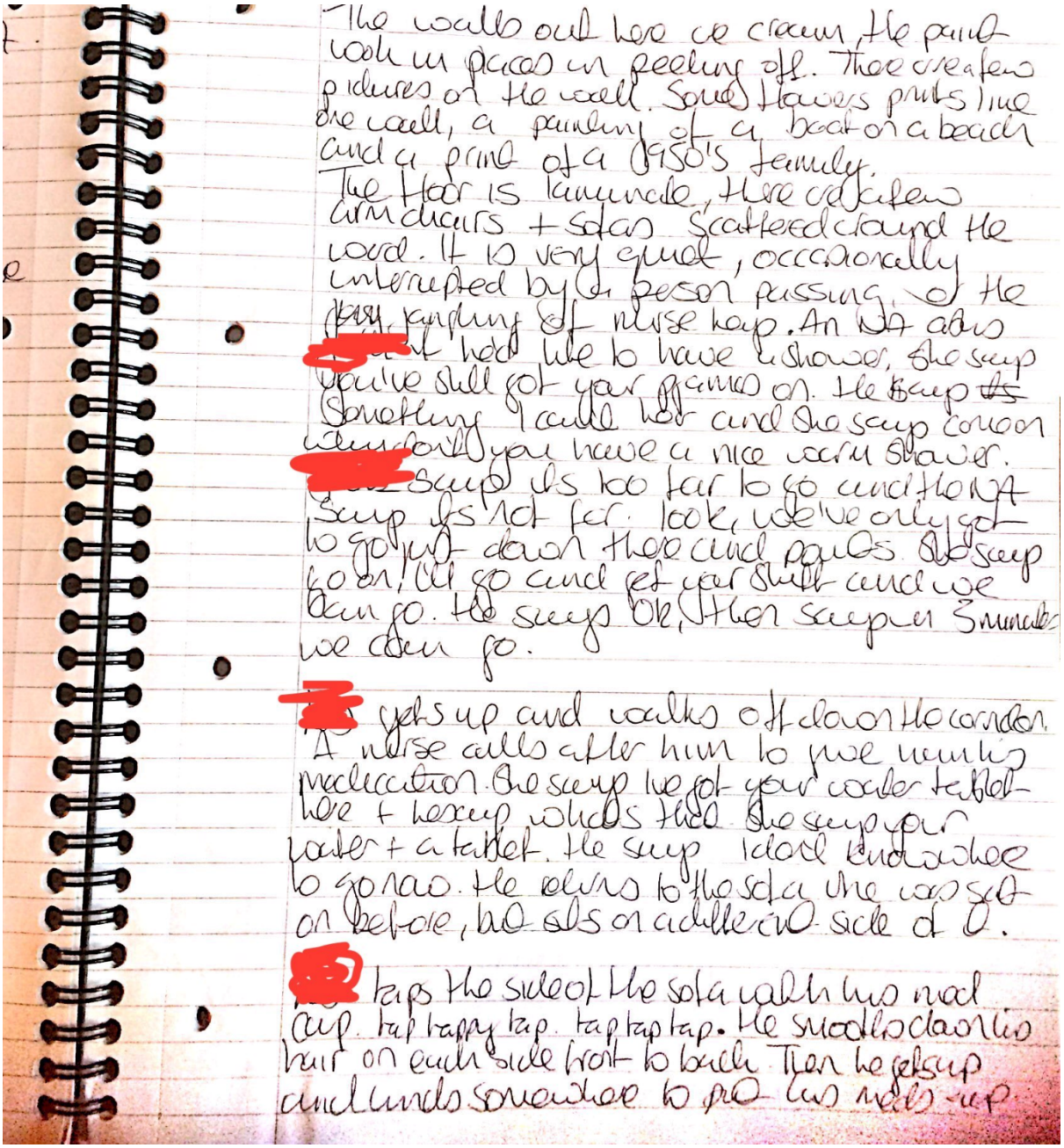
Harry also lived in Lincoln Manor and was the youngest of the participants. He grew up in the area in the area that the care home was located in. Harry chatted a lot about his past telling me about different life events. He said that when was in his teens, his mum left home to be with another man. Around the age of 17 Harry had joined the army after meeting a man who had been a Coldstream guard at the raincoat factory where he worked. Harry told me that up until that point in his life he had been a bit of 'a waster'. Harry's daughter told me in an interview that, without the army her dad may have ended up in prison, and the army had 'sorted him out'. Harry's dad died whilst he was away in the army yet no-one had told him - he came home on leave to discover his father was dead. This seemed a significant life event, and one that Harry remembered clearly, along with his mother leaving home.

Harry had been married and had two daughters. He was now divorced from his wife and he was in touch with both his daughters. He had served in the army for around 20 years. He then had worked in the building trade and developed an occupation linked to occupational health and safety although I was not quite clear what the role had been. He told me he was a 'professor' and that he told me he sorted out all the work contracts. He also told me that he 'earned plenty of money'. However, sometimes, he would get up from his seat and would go off for a 'walky' and then, on his return, he would choose a seat away from me. This seemed to signal that he no longer wanted to talk. Once he said to me 'I'm just going for a little chill, I'm not leaving you or anything I will come back'.

Harry smoked, in fact smoking was very important to him. It was through smoking that Harry would bring some structure to his day. He had smoked since childhood, once telling me that he'd smoked since he was 'knee high'; he showed me this by holding his hands to just below his waist. Smoking was an occupation he used for passing time, and Harry would disappear for walks and cigarette breaks throughout the day. I would see him outside on the patio having a cigarette and chatting to someone or standing alone. He chose to go outside and smoke rather than sit in the smoking lounge. He would arrive back at the row of seats where we all sat, smelling of cigarettes and mints. Harry carried cigarettes and a lighter in his jacket

pockets and always had a packet of mints. He would eat some mints after each cigarette break. . He told me that sometimes he stored his cigarettes in the reception area with the receptionist to stop himself from smoking them too quickly.

Appendix 17: Example of ethnographic fieldnotes



The walls out here are cream, the paint look in places in peeling off. There are a few pictures on the wall. Some flowers prints line one wall, a painting of a boat on a beach and a print of a 1950's family.
The floor is laminate, there are a few arm chairs + sofas scattered around the ward. It is very quiet, occasionally interrupted by a person passing, or the jangling of nurse keys. An NA asks [redacted] he'd like to have a shower, she says you've still got your pyjamas on. He says ~~its~~ something I can't hear and she says come on when don't you have a nice warm shower. [redacted] says its too far to go and the NA says its not far. look, we've only got to go just down there and points. She says go on, I'll go and get your shift and we can go. He says OK, then says in 3 minutes we can go.

[redacted] gets up and walks off down the corridor. A nurse calls after him to give him his medication. She says I've got your water tablet here + he says what's that. She says your water + a tablet. He says I don't know where to go now. He returns to the sofa the was sat on before, but sits on a different side of it.

[redacted] taps the side of the sofa with his med cup. tap tappy tap. tap tap tap. He smooths down his hair on each side front to back. Then he gets up and winds somewhere to put his meds up.

Appendix 18: Analysis example

Extract of Fieldnotes, Lincoln Manor

Harry and Charlie have been up for more than 2 and ½ hours now, they have had breakfast and are back on the row. The man next to me gets the channel changed to ITV, it is Jeremey Kyle. The Care worker who changes the channel says 'you don't want to watch this do you?' and the man replies that he's after what's on next. Another man complains to anyone who will listen about how dreadful Jeremey Kyle is and how it is on every day. One man appears to be listening to him. The man who has complained stands up and leaves. Harry watches him go, another man has fallen asleep, another is sitting in what looks like an uncomfortable position, both these men are wearing outside jackets. There is a smell of cleaning product. The man who left returns and says I'm going for a fag, I'll be back in a bit. There is shouting erupting from the TV. Harry looks at me and laughs, and then he says, 'it does get boring sometimes'. Charlie mutters something, the sleeping man coughs in his sleep and lifts a handkerchief to his mouth whilst he does so.

In order to explore narratives, the approach I have taken is to read the fieldnotes and for each section of text, or period of time during the occurrence of a happening or event. I would explore the fieldnotes for sensory and bodily knowledge. For example, in the extract here, I would refer to the reference to time and space in the first two sentences. This would lead to further questions about the relevance of time. Is this a long period for the men to be in this seating area? Is this usual? Also the notes include elements of how the men are utilising and moving in space.

Using this analytical approach, I would consider questions in relation to 'place' and the context for the notes, and there are a number of elements that I would return to consider:

- What is happening around the men?
- How does the sound from the television impact on them?
- What emotions are being shared?

In considering the fieldnotes and the questions above, there is emotion shown in the extract about the television programme, and from Harry that refers to the impact of time passing for him. There are a number of aspects from the text that are relative to the spatiality and materiality of the environment, as the television features, as well as the particular seating location and what the men are wearing. There are also a number of turning points, as people move in and out of the scenario.

Appendix 19: Related contributions:

Publications:

Campbell, S., and Ward, R., (2017). Video and observation data as a method to document practice and performances of gender in the dementia care-based hair salon in (eds) Keady, J., Hydén, L-C., Johnson, A., Swarbrick, C. (2017). *Social Research Methods in Dementia Studies: Inclusion and Innovation*. Routledge.

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Ward, R and **Campbell**, S. (2013). Mixing methods to explore appearance in dementia care. *Dementia*. Sage. First published on-line 23 February 2013.

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Campbell, S. Ward, R., Haughain, B.; Parker,M. (2012). Introducing the Hair and Care Project: Sharing good practice on appearance-related support for people living with dementia. *Journal of Dementia Care*. Nov/Dec 2012.

Conferences:

September 2018 Campbell, S., Ward, R., Keady, J. (2018). *Atmospheres of Dementia Care: Embodied Narratives within an ethnographic study of the everyday lives of men living with dementia*. Ageing in Europe: Agency, Citizenship and the Dynamics of Power. Research Network on Ageing in Europe. European Sociology Association.

April 2017 Campbell, S. and Sandberg, L. (2017): *Troubling corporeality and gender*. Presented at Aging Graz 2017, an international conference, Graz, Austria. 28th April.

July 2016 Campbell, S. (2016) *'Embodied Narratives' within an ethnographic study of everyday embodied lives of men living with dementia in care*. British Society of Gerontology Annual Conference. Stirling University.

February 2016 '*Embodied Narratives' within an ethnographic study of everyday embodied lives of men living with dementia in care*. Paper presented at the BSA Ageing, Body and Society Study Group annual conference. The University of Manchester

November 2015 '*Embodying Life Story work: 'Multi-sensory appearance biographies'*. Symposium 'Social Well-Being in Dementia Care: Using Creative Expression to Connect the Past, Present, and Future' at the Gerontological Society of America's 68th Annual Scientific Meeting, Orlando, Florida. USA.

July 2015 *'What does it feel like to live here? The Sensescapes of Dementia Care'*. Morgan Centre for Research into Everyday Lives bi-annual conference 'Atmospheres'. The University of Manchester.

November 2014 *'Embodying Life Story work: 'Multi-sensory appearance biographies'. Methodologies from research to practice*. Paper presented at a Seminar held by the Centre for Biographical and Ageing Studies, The Open University 'Researching with people living with dementia'. London.

October 2014 '*Embodying Life Story work: 'Multi-sensory appearance biographies'*. Paper presented at Life with Dementia: Relations conference. CEDAR, Linkőpping University. Sweden.

July 2013 *'A Sensory encounter: 'A Close Shave'*.
The Morgan Centre for the Study of Relationships and Personal Life, The University of Manchester. Encounters Conference

April 2013 '*Appearance isn't only skin deep: embodiment, masculinity and everyday grooming practices in dementia care'*. The Hair and Care Project conference ('Ageing, Appearance and the Lifecourse'. University of Manchester.

February 2013 '*Everyday Ethical Encounters: A Close Shave; masculinity and dementia care at Dementia, Embodiment and Body Work'*. 'Ethics, Opportunities and Dilemmas in Research and Practice'. University of Stirling.

November 2012 *'Researching the Care-based Hair Salon Experience: Developing a Full-bodied Approach to Dementia Care'*. Poster presented at The Gerontological Society of America Annual Conference. San Diego, USA.

July 2012 *'Experiencing the Care-Based Hair Salon': A Mixed Methods approach*. Paper presented at BSA Ageing, Body and Society STUDY GROUP 5TH ANNUAL CONFERENCE: Critical Perspectives, Future Challenges.

September 2011 *'Masculinity, embodiment and bodywork in dementia care'*. 'Gender, Sex and Sexualities': a day of provocations. University of Durham. Centre for Medical Humanities.

September 2011 '*The Hair and Care Project'*. Paper presented with Dr. Richard Ward at BSA Ageing, Body and Society Study Group 2011 Conference: Body Work in Health and Social Care.

Media:

2016: Radio 4 Thinking Allowed. Dementia and Hair Care: https://www.bbc.co.uk/programmes/b0832rjb

2016: Radio 4 You and Yours. Dementia and Care based Hairdressing.

Awards:

2013 ESRC Transformative Research Prize

Award of £8000 given by the ESRC Fostering and encouraging transformative research within the social sciences Seed Corn Funding for a study titled: 'Bridging the divide: the development of 'multi-sensory appearance biographies' in dementia care practice using multi-sensorial methodologies. The project sought to use a multi-sensorial research methodology to adapt and extend methods developed for gaining research evidence for use in care settings.

2012 Arts Methods Manchester Award

Award of £500 for facilitating an event for post graduate researchers and early career researchers: An Atelier with Sarah Pink 'Researching Everyday Life'. This event was held on 9th August 2013.

Appendix 20: Training and seminars undertaken during PhD studies:

December 2014 – January 2015 The University of Manchester– online training
Updated training on Good Clinical Practice in Research; Information Governance; Diversity Training.

July 2014 Creative Methods. The Morgan Centre, The University of Manchester. Summer School. A week long training on using creative social research methods within sociology and anthropology.

March 2013 Mental Capacity Act Training, Salford NHS Foundation Trust. Training for undertaking mental capacity assessments when undertaking informed consent working with people living with dementia.

December 2014 NIHR Information Governance
Online training in research information governance.

December 2014 NIHR Good Clinical Practice in Research
Online training regularly updated in good clinical research practice.

February 2013 Studies of ageing masculinities: still in their infancy?
Centre for Policy on Ageing and Centre for Ageing and Biographical Studies Seminar 15 in the Representation of Older People in Ageing Research Series,

January 2013 MODE: Introduction to Multimodal Methods for Researching Digital Data, University of London, Institute of Education.
Training for working with visual data held at The University of Manchester.

October 2011- July 2012 Masters/PhD/MPhil Research training programme
Required training for undertaking doctoral studies: Research Design; Qualitative Research Design and Analysis; Critical Appraisal; and Transferable Research skills.

May – June 2012 Granada Centre for Visual Anthropology: Film-making for Fieldwork. The University of Manchester. I undertook an intensive weekend film-making workshop during which we were taught film-making and film-editing skills.

December 2012 University of East London**:** BSA Bourdieu Study Group event: Gender and Bourdieu, 'Is doing gender unavoidable?'

November 2012 The Morgan Centre, University of Manchester: Material Culture Seminar.

March 2012 Methods North-West: Researching for a Literature Review Clinic.

March 2011 Manchester City Council: Mental Capacity Act Training

2011-2012 University of Manchester Training and Development
I have undertaken a number of courses provided through the training and development unit at The University of Manchester: Academic Writing; Effective Presentation Skills; Communicate with Confidence; Advanced Endnote; Literature Review; Critical Analysis of Research Papers;

October 2009 Introduction to NVivo 8. QSR.
I have undertaken training in NVivo 8 and this was updated in 2011 to NVivo 9. Currently working on NVivo 12.