Out and About: A Sensory Ethnographic Study of Therapeutic Landscape Experiences of People Living with Dementia in the Wider Community

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DECLARATION

I declare that this thesis is all my original work and I am the sole author. This work has not previously been published or presented for an award. All sources are acknowledged as References. It has been jointly funded by the Economics and Social Research Council and Age UK Lancaster.

ABSTRACT

Whilst ageing in place is considered important for a healthier and a better quality of life for older people, there is yet a dearth of evidence on how older people with dementia negotiate and experience the wider community. The aim of the present study is therefore to explore experiences of social and spatial engagement in the wider community for people living with dementia in order to advance understandings of how their interactions in and with community settings impact on their health and wellbeing. Drawing on the theoretical framework of therapeutic landscapes and a sensory ethnographic methodology, I provide social, embodied and symbolic accounts of people's everyday experiences and pursuits of health and wellbeing within their neighbourhood and beyond. An in-depth examination of socio-spatial interactions of nine people with dementia, seven of whom participated with family carers, is conducted by use of innovative interview methods (including photo-elicitation and walking interviews), participant observations and participant 'diaries' (kept for a period of four weeks).

The thesis presents three broad themes relating to participants' interactions with and experiences of places beyond the home- the diverse and changing nature of people's personal circumstances and conceptions of health and wellbeing; the interrelationship between people's changing health needs, lifestyle choices and geographical area of activities and finally the social, physical and symbolic processes through which people maintain a sense of normality and stay connected. Together these themes illustrate the significance of a variety of places to the lives of people with dementia. The 'shrinking world' analogy associated with experiences of dementia is thereby considered through a more focused discussion on the active role people with dementia play in shaping their life worlds and their everyday interactions to meet their health and wellbeing needs. Further, by applying the concept of therapeutic landscape to experiences of people with dementia in the wider community, this thesis makes an important contribution to dementia research whilst also suggesting new directions for the therapeutic landscape scholarship.

ACKNOWLEDGEMENTS

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CHAPTER ONE

Introduction

Feb 2014: while I read through the details of this PhD studentship advertisement I recall a conversation I recently had with an older patient. I have been working as a research assistant on a clinical trial involving patients with chronic kidney disease for the last couple of years, and have come across some people who have dementia. A few months earlier, this particular patient was keen to talk about his recent diagnosis of dementia, which in the end he summed up with: 'it's like having the lights on but there's nobody home'. I think about this statement in relation to the title of the research project 'The spatial and social dynamics of public inclusion for people with dementia'. Considering that the above patient questioned his very existence I wonder- so then to what extent does he still feel in touch with his surrounding? What does public inclusion mean to him? Is it important? Can the environment in which he lives his daily life support him to remain present in himself? If so how?

As a qualitative researcher, I have always been interested in people's stories of health and illness and the above questions formed the basis of my approach to this PhD undertaking. I was keen to further explore the internal and external dimensions of the existential situation people with dementia may deal with, through focusing on their social and spatial interactions in the wider community. I wanted to use my lack of knowledge and experience of working in the field of dementia to ask questions with an open mind. My PhD journey has in this way been one of asking many questions to and learning from a vast range of literature, people living with dementia, academics and those involved in the design and delivery of dementia care and practice. This thesis is thus a monograph of this journey, starting from an appreciation of the growing significance of dementia and how it has been addressed within policy and research to date.

1.1   Prevalence of dementia

The term dementia denotes a set of symptoms indicative of progressive cognitive decline, including memory loss, difficulties with language and problem-solving as well as changes in mood, personality and behaviour. Different sets of symptoms are attributed to different conditions of dementia. Alzheimer's disease is the most common cause of dementia, although other conditions such as vascular dementia and dementia with Lewy Bodies can often present

similar symptoms, affecting memory, perception and functional abilities. As the world's population continues to age, a growing number of people are diagnosed with dementia. The condition is presently incurable and affects around 6% of people aged 65 years and over, increasing to about 30% of people in their eighties (Luengo-Fernandez et al, 2010). In the UK, approximately 850,000 people are estimated to live with dementia and this number is predicted to rise to over a million by 2025 (Prince et al, 2014).

1.2   Dementia Policy

The growing incidence of dementia has significant implications for society, having become one of UK's main health priorities with major impact on its health and social care services (DH, 2009). There have been various policy initiatives and reports in recent years, aiming to address the challenges associated with the increasing prevalence of dementia. The 'Dementia: Out of the Shadows' report (Alzheimer's Society, 2008) published by the Alzheimer's Society and the subsequent National Dementia Strategy (DH, 2009) produced by the UK government were useful in setting out the responsibilities of health and social care services and providing a benchmark for quality service provision. Further, the drive away from institutional care for older people and the shift to ageing in place from the mid-1970s onwards has led to a rise of ideas around age friendly towns and cities, underpinning more recent ideas around dementia friendly spaces (Mitchell and Burton, 2010; Wiles, 2005). In March 2012, the British Prime Minister launched a personal challenge to move further and faster in driving improvements in dementia care, in which dementia friendly communities formed one of the three key areas of focus (DH, 2012). Key commitment number 6 within the Prime Minister's challenge aimed to target 20 cities, towns and villages to sign up to becoming more dementia friendly by 2015. The longer term policy ideals of dementia friendly communities was to support ageing in place for people with dementia, alluding to 'normalising' dementia (Innovations in Dementia, 2011) and facilitating its 'assimilation' into mainstream community life (Horner, 2013). It highlighted the need to improve accessibility and suitability of public transportation, local amenities and services as well as dementia awareness across all sections of the community. However, the impact of dementia friendly communities on the daily lives of people with dementia is not yet empirically documented.

1.3   Dementia Research

Existing dementia research also has yet to identify links between people with dementia's interactions with specific elements of the wider community and their experiences of health and wellbeing. Earliest examples of research on dementia and the environment focused on indoor spaces, proposing adaptation to home and institutional care settings in order to address challenging behaviour, impact of physical impairment or safety and security issues (Davis et al, 2009; Goldsmith, 1996; Mitchell, 2012; Sibley, 2001). Blackman et al (2003, p.361) argue that 'the public outdoor world is rarely conceived as a dementia setting' in such research and so the experience of people with dementia in public settings and its impact on their day to day living were categorically neglected. Gradually as policy developers, local planners and researchers began to acknowledge people living with dementia in the community, their research became overwhelmingly concerned with navigation and accessibility issues (Burton and Mitchell, 2006; Duggan et al, 2008; Mitchell, 2012; Mitchell et al, 2003; 2004(a); 2004(b)). The subjective experiences associated with 'citizenry' (Crampton et al, 2012) and being part of a community, as found within the work on dementia friendly communities is not captured by the above literature. These issues are yet to be brought together and fully explored within a socio-spatial context in dementia research.

1.4   Study summary

Taking the wider community as the primary setting in which I explore how people with dementia enact and experience health and wellbeing in their daily lives, I contribute to bridging the gap between dementia policy and research concerned with experiences of people with dementia living in the community and their implication on people's quality of life. I employ a sensory ethnographic methodology, involving innovative interviewing techniques and participant observations to capture people with dementia's experiences of engaging with places in the community. Furthermore, the concept of therapeutic landscapes is adopted as a lens for understanding how people with dementia's multi-faceted experiences of place are connected to their health and wellbeing (Gesler, 1992; 1993). Therapeutic landscape experiences are considered to be dependent upon physical, social and symbolic processes, in which case how people with dementia perceive and negotiate places in the locality is of particular focus.

1.5   Outline of chapters

This thesis comprises eight further chapters, presenting the theoretical, methodological and empirical work undertaken at different stages of the research process.

Chapter 2- Experiencing wellbeing with dementia

Engaging with existing dementia literature, this chapter considers the different ways in which health and wellbeing has been theorised and researched. It provides a discussion on the use of different models of dementia employed in research and practice, particularly the biomedical and social models, offering different perspectives on what it means to be well for a person with dementia. It is the latter approach that is of interest to this study, as it lends itself to a consideration of broader aspects of people's experiences of health and wellbeing, including its psycho-social and socio-cultural facets. Health and wellbeing is in this sense subjective, relating to people's sense of self, personalised interactions and individual response to dementia. These notions of health and wellbeing are then discussed in relation to the aims of the dementia friendly community policy directive.

Chapter 3- Emplacing health and wellbeing

This chapter draws on literature within health geography, illustrating the link between health and place. Different theorisations of place are considered and discussed in relation to what they contribute to understandings of people's experiences of health and wellbeing. A social constructionist view advocates that experiences of place are shaped by interplay of structural and individual factors. Place is, in this respect, mutually constitutive and relational, suggesting that experiences of place which lead to enhanced health and wellbeing can change and evolve with the onset and progression of dementia. The above discussion led to the question of how then to conceptually and empirically explore people with dementia's interactions with places in the wider community and their impact on health and wellbeing.

Chapter 4- Therapeutic landscape experiences in the wider community: A literature review

The concept of therapeutic landscapes provides a possible theoretical and analytic framework to guide an exploration of how people with dementia's interactions with places in the wider community shape their experiences of health and wellbeing. This chapter therefore considers the utility of the concept in the context of the present study, through conducting a scoping review of the literature on therapeutic landscapes in everyday settings. The review discusses themes entitled: conceptualising everyday places of wellbeing, therapeutic engagement and benefits and methodological innovations and implications. Findings from the review further informed the research aims and objectives, which are presented at the end of the chapter.

Chapter 5- Placing the senses: A sensory ethnographic study

This chapter provides an outline of the methodological approach adopted in the study, detailing the research process and explaining why it is most appropriate for exploring place-based experiences of people with dementia. Implications of using sensory ethnography are discussed in relation to the study objectives, making a case for understanding health and wellbeing priorities and engagement with place through the voices and experiences of people with dementia and their carers. Different interview techniques, participant observations and participant diaries are used with participants with dementia and their family carers to ascertain individual narratives on preferences for, and subjective experiences of, particular settings as well as capturing firsthand how they negotiate and interact with the different dimensions of place. In total nine participants with dementia and seven family carers participated in the research.

Chapter 6- Health and wellbeing: 'There's me and then there's my dementia'

This is the first of three chapters presenting findings relating to participants' engagement with places in the wider community. Chapter 6 presents pen portraits of four particular participants with dementia and their family carers to addresses the question: How do people with dementia and their family carers understand and seek experiences of health and wellbeing in place? Two underlying themes characterise the response to the above question first, seeking 'continuity of self' and second managing 'changing health and care needs', which are discussed in turn.

Chapter 7- Adaptive geography: 'Everything changes as you get older, you go with it'

The focus of this chapter is on how people have renegotiated their engagement with places and activities beyond the home since the onset and progression of dementia. This chapter is, in this case, concerned with answering the question: what are the places of interest/ importance to people with dementia in the wider community and how have they changed since the onset of dementia? The answer to this question is discussed under four subheadings: adaptive lifestyles; staying close to home; focusing on the mundane and 'doing the dementia stuff'.

Chapter 8- Places, routines and interactions for health and wellbeing

This chapter takes a closer look at participants' socio-spatial experiences in relation to their two overarching goals of everyday life in the wider community: maintaining a sense of normality and routine and staying connected to family, friends and the neighbourhood. Aspects of participants' interactions with everyday places pertinent to achieving these goals are discussed in terms of how they impact upon their experiences of health and wellbeing - particularly their sense of self, autonomy, personal responsibility, reciprocity, place identity and belonging.

Chapter 9- Discussion: From 'shrinking' to 'creation of adaptive' life worlds

In this chapter the empirical evidence presented in the previous chapters are discussed in relation to exiting literature, specifically addressing the notion of the 'shrinking world' of people with dementia. It summarises findings relating to particular settings, activities and practices which people with dementia are found to enact and experience as therapeutic landscapes. The chapter also highlights its contribution to both therapeutic landscapes and dementia research, followed by some methodological reflections and a consideration of study limitations.

Conclusion

The thesis concludes with a consideration of the implications of this research for dementia policy and research.

CHAPTER TWO

Experiencing health and wellbeing with dementia

2.1   Introduction

Each person's experience of dementia is unique, but invariably it challenges their ability to perform activities of daily living (Phinney, 2008). Whilst having dementia often means having higher support needs, about two thirds of people living with dementia choose to live at home (Alzheimer's Society UK, 2010). This has inevitably shifted the focus of care for older people from residential care settings to the home and the community (Kneale and Sinclair, 2011; Innes, 2009; Wiles, 2005). But, it is not only functional activities and self-care that people with dementia may struggle with; they also face a number of problems in terms of engaging with the wider community (Blackman et al, 2003; Duggan et al, 2008). Often problems of disorientation and confusion are compounded by the ways in which others respond to the behavioural and psychological changes precipitated by people's dementia. People with dementia describe experiences of exclusion and stigma, leading to feelings of being devalued, a loss of status and friends and consequently physical and social isolation (Alzheimer's Society 2008). Such experiences can impact upon people's quality of life, health and wellbeing (Katsuno, 2005).

This chapter will serve to embed the thesis within a wider context of dementia research and policy. The first section begins with some background about the different conceptual models of dementia which have informed the changing approaches to investigating dementia, and understandings of health and wellbeing within this context. It then introduces present discourses on experiences of dementia, namely the processes through which people with dementia understand, adapt to and manage their life, highlighting their position and engagement in society. Following this, the policy directive on dementia friendly communities is considered to explicate its vision for promoting the inclusion of people with dementia in community settings. The concluding section then brings together understandings of people with dementia's experiences of health and wellbeing with the aims of dementia friendly communities' policy, highlighting the need to fill the gap between the two with further consideration of literature on health and place.

2.2 Conceptualising Dementia

Prevailing understandings of dementia found within social science and wider health literature are underscored by a number of different conceptual models. These models have been the outcome of social processes propagating certain methods of investigation and theorisation of dementia at different time points since the mid 20th century. A succession of theoretical debates attempting to broaden the conceptualisation of dementia and its experiences have introduced a variety of ontological and epistemological approaches to dementia research. A critique of some of these key approaches will be presented in this section in order to explicate conceptions of health and wellbeing and its relation to the social and physical environment within extant theorisations of dementia.

2.2.1 Dementia as a disease or illness?

Biomedicine has been pivotal in raising the public awareness of dementia and has been influential in the development of dementia care policy and practice (DH, 2012). Pharmacological therapy is considered first line treatment for many of the behavioural and psychological symptoms of dementia and further biomedical research may well be the key to finding a possible cure (Schwarz et al, 2012). The biomedical construct of dementia gave it a disease category in the 'advent of rationalist modes of investigation' (Davis, 2004, p.372) in the mid 20th century and it remains a commonly employed definition by scientists, medical professionals, academics and those living with dementia. Concerned with neurobiology and neuropsychology, the ontological belief of biomedicine renders a person with dementia a disease entity, blighted by inevitable decline, deficiency and loss. Objectivist epistemologies of biomedicine, seeking causal relationships between symptoms of dementia and other objectively identified variables are widely evident within dementia research (Ashida, 2000; Ledger and Baker, 2007; Ridder et al, 2009). However, since the approach promotes knowledge of 'the disease the person has rather than the person that has the disease' (Sabat, 2011, p.97), it impedes any perspective embedded within the lived experiences of people with dementia, including their subjective health and wellbeing, or any concern for environmental factors which are external to the disease entity itself.

A health perspective instead separates the disease from health, suggesting that they can both coexist. The current definition of health established by the World Health Organisation (WHO) in 1948 is 'a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity' (WHO, 1948, p.100). The aligning of health with experiences of wellbeing

instead of disease is central to a de-medicalised notion of health, allowing the three key domains of human experiences - physical, mental and social - to become integral components of health research and interventions (Jadad, 2008). Health became conceptualised as a relational composition of an array of biological, psychological, social and environmental conditions and interactions (Engelhardt, 1981). According to Fleuret and Atkinson (2007, p.107) 'The broader lens that wellbeing brings to considerations of health opens up further arenas for geographers of health to explore in terms of the processes that promote, remedy or regenerate health and ill-health' (p.107). It was precisely this epistemological shift away from the disease-centred focus of biomedicine to a socio-cultural view of health which underpinned the emergence of health geography (Kearns, 1993; Kearns and Joseph, 1993).

With an ageing population and a rise in chronic illnesses, WHO's definition of health as 'a state of complete physical, mental and social wellbeing' would render many people as being unhealthy. In practice, health is still very much measured in terms of people's experiences of avoiding, managing or living with a disease (Bodenheimer et al, 2002; Potvin and Jones, 2011). Huber et al (2011) therefore suggest a 'formulation of health as the ability to adapt and to self manage' (p.3) rather than be free of the challenges of living with a debilitating condition. Further, according to the WHO constitution health is an umbrella term for the different dimensions of wellbeing, and whilst many scholars have attempted to define the concept of health and/or wellbeing they have often been treated as synonymous (De Chavez et al, 2005; Fleuret and Atkinson, 2007). Some however argue the need to assess health in relation to a set of objective measures for physical, mental and social state or capacity whilst considering wellbeing to be a set of subjective values relating to happiness and life satisfaction which are difficult to operationalise (Larson, 1991). The relationship between the two concepts is therefore the subject of an age-old debate and goes beyond the scope of this research. In either case health and wellbeing are interlinked and the term health is commonly coupled with the term wellbeing (Pretty et al, 2005). It would therefore be impossible to explore people's experiences of wellbeing without taking into account their health. Taking Huber's (2001) suggestion above, people's ability to live a healthy life with an illness depends on a whole range of lifestyle and environmental factors, in which case the WHO's broad definition of health and its linking of health to domains of wellbeing is important. Descriptions of wellbeing encompass all aspects of human experiences affecting how people feel, function and develop (Pollard and Lee, 2003; Ryan and Edward, 2001). Wellbeing is considered to be multi-dimensional and subjective, relating to resilience, autonomy, happiness, life satisfaction and ability to achieve personal goals (Diener, 2009; Armitage et al, 2012). So whilst a focus on wellbeing opens up the scope of research to physical, psychological, emotional, social and spiritual experiences contributing to

people's quality of life, taking Huber's (2011) suggestion above, a focus on health links it back to the idea of managing and living well with the symptomatic impact of dementia on people's lives.

By the mid 1980's, social theorists began to deconstruct the biomedical perspective of dementia (Davis, 2004; Gubrium, 1986; Lynott, 1983; Lyman, 1989). Researchers began to consider the biomedical rhetoric of loss and the binaries of ability/ deficiency and normality/ abnormality in real-life contexts in which they are enacted. Effectively, it legitimised the voices, including the impact the condition has on the emotional and social worlds, of the people affected by dementia. This brought to the fore an inclusive viewpoint and an 'illness narrative' of dementia (Innes, 2009; Kleinman, 1988, Wilkinson 2002). There is now a growing body of research on the illness experience of dementia, focusing on how people perceive and manage living with dementia in their everyday contexts (Harman and Clare, 2006; Steeman et al, 2006; Phinney and Chesla, 2003). They illustrate subjective meanings and experiences associated with living with dementia, and consider the impact of wider social structures on people's experiences of dementia. This narrative shifts the focus from clinical abnormalities to personal and social dimensions of people's experiences of living with the condition.

A narrative based on the interplay between subjective experiences and external relational implications of living with dementia is important for understanding the changes in and impact of people with dementia's everyday interactions with their social and physical environment in the wider community. Lyman's (1989) 'sociogenic model' of dementia which perceived people with dementia as 'social actors, who interact with others in a variety of socially structured environments...and shared knowledge of dementia is part of the socio-cultural world that is collectively defined, not a fixed biomedical reality' (1989, p.604). She was advocating a social constructionist lens on the experiences of people living with dementia, positing social discourse, interactions and relationships as central to the construction of their reality. Experiences of dementia are therefore contextualised as dynamic social processes whereby physical and social environments in the wider community are considered important facilitators of interactions and relationships which form different dementia experiences. This paradigm replaces the rhetoric of inevitable loss and decline with possibilities of transforming experiences of living with dementia, including enhancing the health and wellbeing of people with dementia, through socio-spatial means. There are two key approaches owing to social constructionism, that have made important contributions to dementia research, namely the psycho-social (Kitwood, 1997; Sabat and Harre, 1992) approach focusing on interpersonal interactions on the wellbeing of people with dementia and the more recent focus on socio-cultural contexts to define impact and experiences of dementia (Hulko, 2004; O'Connor et al, 2010).

2.2.2 Psycho-social Perspective

The psychosocial approach is concerned with meso-level social interactions and processes that mediate the influence of macro level social structures on individual level perceptions and psychology (Egan et al, 2008; Martikainen et al, 2002). A psychosocial focus has been widely employed in qualitative research exploring different social-psychological aspects of people's adjustment to living with dementia (Aggarwal et al, 2003; Gilmour and Huntington, 2005; Harman and Clare, 2006; Harris and Keady, 2004; Pearce et al, 2002; Holst and Hallberg, 2003; Werezak and Stewart, 2002). One of the first proponents of psychosocial approaches in dementia research was Thomas Kitwood (1990; 1997), who was concerned with improving the quality of care for people with dementia. Kitwood (1997) introduced the notion of personhood, 'a status or standing bestowed upon one human being by others in the context of social relationship and social being' (1997, p.8). His concept of personhood, links the health and wellbeing of a person with dementia to being recognised, respected and trusted as a social being by others he/ she interacts with (Kitwood, 1997). Conversely, social interactions which stifle personhood, leading to a further functional decline and reduced wellbeing, Kitwood (1997) called 'malignant social psychology'. Thereby, threats to independent living and autonomy, considered important features of personhood and wellbeing, are not only attributed to the disease itself but also to 'being accused, restricted, ignored or patronised by others' (Steeman et al, 2006, p.735). Dementia care and policy, adopting a psycho-social approach, have therefore slowly moved away from 'managing vulnerable people to managing vulnerable situations' (Bailey et al, 2013, p.392). The notion of 'risk' understood to reside in the person is in this case poised in harmful social interactions and environments which restrict self-expression, and autonomy (Adams, 2010; Robinson et al, 2007). The concept of personhood has been instrumental in making a case for person-centred approach to care, whereby the health and wellbeing of people with dementia is deemed to rest on the carers' willingness to explore and support their individuality and social values and roles (Buron, 2008).

However, whilst the notion of personhood has made great strides in establishing the importance of wellbeing and quality of life within dementia care and research, it has also been criticised for a number of shortcomings (Bartlett and O'Connor, 2007; Bond, 1999). Although it recognises the importance of individuality it does not recognise agency. Focusing on interpersonal interactions and the role of carers in maintaining the personhood of people with dementia, the concept does not acknowledge the capacity of people with dementia to determine what it means to live with the condition and how they respond to it (Dworkin, 1986; Kolanowski and Whall, 1996). Feelings of despair and fear are commonly associated with the challenges of living with the gradual loss of abilities, social status and relationships, indicating reduced health and

wellbeing (Gilmour and Huntington, 2005; Basting, 2003). However, often aware of such threats to their sense of self and wellbeing, people with dementia show resilience, asserting their self worth against societal perceptions of them as victims of dementia. McGowing (1993) in her biography on living with dementia writes:

'If I am no longer a woman, why do I still feel I'm one?... My every molecule seems to scream out that I do, indeed, exist, and that existence must be valued by someone' (p114).

Thus, contrary to Kitwood's understanding of malignant social psychology, many of the studies exploring self and identity allude to people with dementia's ability to be reflexive and thereby either accept or reject positions imposed on them (Beard, 2004; Beard and Fox, 2008; Ryan et al, 2009; Steeman et al, 2006). Also, aware of personal limitations, people with dementia often choose to adapt former roles and daily activities, taking control of their renewed sense of personhood and wellbeing (Steeman et al, 2006). Therefore, recognising people with dementia's capacity to demonstrate agency, resilience and self sufficiency, Bailey et al (2013) call for opportunities to let them 'build on a lifelong accumulation of social knowledge, psychological and material assets' (p.394).

Similarly, whilst Kitwood's (1997) conception of person-centred care promotes individuality and autonomy, proponents of a relationship-centred approach stress the importance of interconnectedness and social relationships (Nolan et al, 2004). For the latter, personhood and wellbeing are embedded within people's connection to one another based on mutual respect, reciprocity and interdependence. Supporting and valuing the contributions people with dementia can make within social relationships are therefore integral to improving care and enhancing the health and wellbeing of people with dementia. This leads to Bartlett and O'Connor's (2007) proposition to combine personhood with the notion of citizenship, in order to fully recognise the role of people with dementia within a wider socio-political context. Likewise, according to researchers interested in broader socio-cultural factors, differing experiences of dementia and conditions for malignant social psychology are underscored by people's age, gender, race, ethnicity, class and sexuality (Bender, 2003; Downs, 2000; O'Connor et al, 2010). These broader social contexts would then seem to also provide the precursor of what is meant by health and wellbeing and how it is affected in the context of dementia for people belonging to different groups.

2.2.3 *Socio-cultural context*

An emerging body of literature that is attempting to locate experiences of dementia within wider socio-cultural contexts, attributes subjective meanings and identity constructs associated with experiences of dementia to people's socio-cultural background (Hulko, 2004; Kontos, 2004; O'Connor et al, 2010). Prevalent social and political discourses on dementia are considered to be a reflection of an ageist society, perpetuating certain expectations and positions for older people (Gubrium and Holstein, 1999). Western social constructs of old age, beset with poor health and increased medical needs, are argued to have paved the way for medicalising dementia and propagating notions of decline and loss (Kauffman et al, 2004; Vincent, 2009). In this way, people with dementia signify two categories of negative cultural stereotypes: those associated with being old and those with having a cognitive impairment. This results in dual discrimination and negative constructs of self, impacting on people's sense and experiences of health and wellbeing.

People with dementia are far from a homogenous category, however. Researchers have found that the multiple and relational nature of people's identities influence their own perception of the condition and the response of others in complex ways (Hulko, 2009; O'Connor et al, 2010). Hulko (2009) suggests that each of the many social identities people manage provide them with a different degree of privilege or oppression, and together shape people's experience of living with dementia. She has found, whilst having dementia is described as 'hellish' by people of privileged socio-economic background, it is considered 'not a big deal' by those experiencing multiple socio-economic marginalisation (Hulko, 2009). Thus, subjective experiences of health and wellbeing are found to vary between people of different socio-economic backgrounds. Similarly, being young or homosexual can have a significant impact on access to appropriate care and support, presenting a different set of challenges to a person's experience of living with dementia (O'Connor et al, 2010). Opportunities to maintain health and wellbeing and a good quality of life are in this way inequitable for people belonging to different social categories. Also, different identities, such as being a female professional of a minority ethnic background, assumed by one person can work together and in opposition to one another, in which case their experience of dementia is constructed at the intersection of these identities (Hulko, 2009). Therefore, understanding the relationship between people's multiple positions in society and their experience of dementia could help to provide both a broader and a more nuanced understanding of their construct and experience of health and wellbeing (see McCall, 2008). If a person's socio-cultural position influences their own perception of living with dementia, as well as others' response to their illness, exploring how these influences manifest in their experiences of everyday environments in the wider community is important.

Both the psycho-social and socio-cultural perspectives have therefore helped to broaden the conceptualisation of dementia, highlighting the influence of both interpersonal interactions and wider socio-cultural backgrounds on people's experience of dementia, and therefore their health and wellbeing. However, also important to health and wellbeing for people with dementia, is the role of the body which neither of the above two perspectives discuss. Whilst the biomedical model frames dementia as the disease of the mind, rendering the body as a separate entity (Hughes et al, 2006), the psychosocial approach has 'inadvertently resulted in the privileging of the social over the corporeal with its focus on interactionist conceptions of self' (Kontos and Martin, 2013, p.2). Likewise, the socio-cultural perspective has only just touched on the body in the context of cultural stereotypes which link the aged body to disability, sickness and mortality, and subjects it to further social stigma when it is accompanied by dementia (Dein and Huline-Dickens 1997). Neither of these theoretical stances explains the active role of the body in the experience of dementia or health and wellbeing.

2.2.4   *The body*

In much of dementia literature, the loss of the person is ubiquitous with the loss of cognitive and intellectual abilities, despite the continuing presence and abilities of the physical body. Expressions such as an 'empty vessel' (Taylor, 2007, p.75) have been used to describe the existence of the body without the mind. The aged body therefore becomes insignificant beyond it displaying certain symptoms of dementia and being a symbol of loss and eventual death (Harding and Palfray, 1997; Kauffman et al, 2004). The theory of embodiment however rejects the duality between body/ mind, and instead introduces the body as central to shaping and enacting people's experiences, even for people living with dementia (Kontos, 2004; Kontos and Martin, 2013). So whilst the biomedical perspective presents a view of dementia and old age characterised by degeneration, an embodied perspective attests to a dementia discourse of retained bodily senses and capabilities. The body remains an important source for constructing experiences of dementia, including that of health and wellbeing. Health and wellbeing is in this sense plural and dynamic, whereby degeneration and disease in the course of ageing is a transitional process of the body to new norms (Davis, 2004).

According to the theory of embodiment, people's knowledge is constructed through embodied experiences and practices, since 'our first and foremost, most immediate and intimately felt geography is the body' (Davidson and Milligan, 2004, p.523). To understand people's experiences, it is therefore important to consider how they feel, think, learn and experience

through the body- with all of their senses (Harris, 2007). Embodiment has thus been a particular focus in ethnographic studies of various sports, highlighting the ways in which the body supports the participants to gauge and respond to the different elements of sporting activities and events (Wacquant, 2004; 2007). Literature in emotional geography places a similar emphasis on people as embodied beings, focusing on how the body perceives and relates to its environment. However, the concept of embodiment still remains rather ambiguous within research exploring experiences of space and place by people with dementia. Kontos (2004), Kontos and Martin (2013) and Phinney and Chesla (2003) have explicitly discussed the theory of embodiment in understanding people with dementia's relationship to, and engagement with, their surroundings. Whereas other studies highlighting the importance of physical and emotional familiarity with, and comfort in, particular settings for people with dementia do not necessarily link such phenomena to theories of embodiment (Brittain, et al, 2010; de Witt et al, 2009; Duggan et al, 2008). Theorising the body and embodied emotions and practices within psychosocial and socio-cultural perspectives can therefore help to expand understandings of dementia and how health and wellbeing is experienced.

So having outlined some of the conceptual debates surrounding research on experiences of dementia and how health and wellbeing is contextualised within each of these perspectives, the next section is intended to illustrate some empirical findings about how people with dementia understand and live with the condition. This will provide further insight to the application of some of the above theoretical thinking to the subjective construct and experience of health and wellbeing for people with dementia. By integrating both theoretical and empirical literature on experiences of dementia it may be possible to further understand implications for researching and understanding the role of community settings in supporting or hindering experiences of health and wellbeing for people affected by dementia.

2.3   Lived experiences of health and wellbeing

Subjective insights to people with dementia's experiences of health and wellbeing are overwhelmingly characterised by notions of loss. This body of literature extends understandings of loss from cognitive abilities to personal independence, relationships, professional roles and social status and activities (Basting, 2003; Robertson, 2014; Wolverson et al, 2010). It is not only the diminishing of a person's memory, but how it is perceived and accommodated by the wider society that impacts on a person's sense of loss and wellbeing. In a recent review of the subjective needs of people with dementia, quality of life related losses are

associated with self esteem, social contact, enjoyment of activities, being useful/ giving meaning to life, attachment, self determination and freedom, affect, physical and mental health and sense of aesthetic in living environments (van der Roest et al, 2007). Holst and Hallberg (2003) also, exploring the meaning of everyday life for people living with dementia, explicate three particular themes relating to loss: 1. losing the ability to reach out as a result of memory problems and unsympathetic treatment by others; 2. becoming a stranger in one's own life, described as a sense of emptiness; and 3. withdrawing from activities and significant interests due to personal and social restrictions. Their findings reveal a cyclical psychosocial process of loss; people's loss of abilities affect their ability to maintain relationships and manage their 'everyday life and leisure time activities, all of which threaten their sense of self and self esteem' (Holst and Hallberg, 2003, p.362).

The social and physical environments people with dementia encounter in the wider society therefore play an important role in either further perpetuating or instead redressing their cyclical experiences of loss. What also transpires from the above literature is that it is generally people's everyday settings and activities that define their individual characteristics and position in the world (Egan et al, 2006; Ohman and Nygard, 2005; Phinney et al, 2007; Robertson, 2014). From a social science perspective, 'it is the realm of everyday that brings the structure-agency knot directly into view…the immediacy and intensity of being in, and part of, social worlds' (Neal and Murji, 2015, p.813). It brings into focus the risks and triumphs inherent in mundane and routine encounters of daily living, which often go unnoticed (Back, 2015; Miller, 2008). Everyday settings of people with dementia are therefore key sites for enquiry into how place is implicated in their experience of self as well as of health and wellbeing. People's everyday interactions are found to shape their experiences of places they engage with and their sense of self, both of which are integral to their health and wellbeing. The following section will therefore explore further the centrality of people's sense of self in living well with dementia within the literature (Caddell and Clare, 2010; Cohen and Mansfield, 2006a; 2006b; Harman and Clare, 2006).

A conscious effort to maintain health and wellbeing despite experiences of loss with dementia is evident in people's attempt to balance their need for support with their desire to retain control (Gilmour and Huntington, 2004; von Kutzleben et al, 2012; Phinney, 1998, 2008).Whilst becoming increasingly dependent on others relinquishes people's sense of self and autonomy, maintaining some control gives them environmental mastery and purpose in life which is important for their health and wellbeing (Ryff, 1989). Pearce et al (2002), studying the coping process of 20 men with early stage Alzheimer's disease separate their findings into two main themes. Firstly, maintaining a sense of self and secondly, reappraising and reconstructing a

sense of self. Whilst efforts to maintain a sense of former self involved minimising the impact of dementia and normalising the symptoms, their efforts to reappraise and reconstruct a sense of self involved acknowledging loss, continual change and uncertainty. These processes are mechanisms for strengthening an individual's sense of health and wellbeing, when faced with the challenges posed by dementia.

As found in some literature, importance of different aspects of people's sense of self and identities change overtime, especially with the progression of dementia (Cohen and Mansfield, 2006a, Pesonen et al, 2014). So it is not the maintenance of a person's former sense of self, but rather a re-evaluation of values and the achievement of a new way of life that is attributed to successfully coping with dementia. Holst and Hallberg (2003) discuss the 'changeable inner story', suggesting that although a person's life story consists of facts, people's personal meanings and perceptions about these facts change throughout life and are apparent in the way that they 'story and restory' their life. Taking a social constructionist approach, the construction and reconstruction of personal preferences and aspirations is an ongoing process. Holst and Hallberg (2003) therefore consider the practice of storying through selective recall of likes, dislikes and experiences and emphasis on different aspects of life by people with dementia as well as the interpretation of these stories by others, to be essential in this process. Successful adaptation to life with dementia therefore impinges on the willingness of the person with dementia, and others, to together construct new and positive meanings to living with dementia, casting aside the fear, denial and resistance often evoked by its onset (Basting, 2003; McGowin, 1993).

Environments which are conducive to a positive affirmation of self, interests and aspirations are therefore important to maintaining and enhancing the health and wellbeing of people with dementia. It is important that they retain the ability to 'preserve independence and control in their lives' (Haggarty, 2013, p.4). But available evidence on subjective experiences of specific settings by people with dementia thus far overwhelmingly focus on two types of settings, health and care facilities (Caddell and Clare, 2010; Whear et al, 2014) and the home environment (Nygard, 2004; van Steenwinkel et al, 2014). For people with dementia who live at home, their home is typically considered the single most important setting for their health and wellbeing; it is a site for provision of care as well as maintaining personal interests and relationships (Gitlin et al, 2014; Samus et al, 2018). Much of the research maintains the narrative that people with dementia increasingly withdraw from activities beyond the home due to cognitive impairments and social stigma, acknowledging that this can also lead to experiences of isolation and loneliness (Gilmour and Huntington, 2005; Katsuno, 2005; Moyle et al, 2011, Robertson, 2014). But generally, experiences of health and wellbeing explored in relation to people with

dementia's identities have highlighted the role of relationships, social interactions and activities without taking into account the socio-spatial contexts in which they take place (Holst and Halberg, 2003; Hulko, 2009; Harman and Clare, 2006).

This body of literature has paid much less attention to people with dementia's motivations for and experiences of engaging with the wider community. Only a few studies have explicitly explored the role of places in the wider community in maintaining the health and wellbeing of people with dementia (Duggan et al, 2008; Olsson et al, 2013; Gibson et al, 2007; Keady et al, 2012). Olsson et al, (2013, p.793) describe people with dementia's experiences of outdoor activities as 'shifting between 'still being part of it all' and 'a sense of grief and loss', suggesting that the sensory stimuli, social interactions and sense of freedom people experience confirms their sense of self whilst their physical and cognitive impairments make certain desired activities difficult or impossible. The wider community is nevertheless considered important for maintaining health and wellbeing, whether it means having access to nature and opportunities for nature related activities (Gibson et al, 2007) or being able to socialise and carryout certain functional activities such as shopping (Duggan et al, 2008). But whilst dementia research is thus far only starting to acknowledge the importance of certain community environments and activities for the health and wellbeing of people with dementia, the dementia friendly communities' policy espouses a more ambitious and pragmatic approach to creating a dementia inclusive society.

2.4   The policy context

In March 2012, the British Prime Minister launched a personal challenge to move further and faster in driving improvements in dementia care, and the concept of dementia friendly communities formed one of the three key areas of focus (DH, 2012). Key commitment number 6 within the Prime Minister's challenge aimed to target 20 cities, towns and villages to sign up to becoming more dementia friendly by 2015. The ambition to create dementia friendly communities across the country stemmed from an acknowledgement that poor awareness and understanding of dementia in communities leads to stigma and social exclusion which has a 'fundamental impact on the health and wellbeing of people with dementia' (DH, 2012, p.13). The Alzheimer's Society defined DFCs as:

'A city, town or village where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia-friendly community people will be

aware of and understand dementia, and people with dementia will feel included and involved, and have choice and control over their day-to-day lives' (Alzheimer's Society, 2013a, p2).

Based on the above definition, the Alzheimer's Society has produced a code of practice for the recognition of dementia friendly communities (2015). This document provides recommendations, rather than a prescriptive checklist, for developing and assessing dementia friendly communities, allowing each town, city and village to determine their own priorities. Since research on the implementation and impact of dementia friendly communities is also still underdeveloped, how such concepts as 'respect, contribution, inclusion, choice and control' found within the above definition are interpreted and their impact on the health and wellbeing of people with dementia are however still unclear. Instead, for the purpose of this chapter, some policy focused journal articles (Pickup, 2012; Innes, 2013; Duffin, 2014), local authority strategy documents (Hampshire City Council, 2012; Horner, 2013) and reports from two leading dementia friendly communities programmes in York and Bradford (Crampton et al, 2012; Dean et al, 2015; Hare and Dean, 2015) have been drawn upon. Together, they bring forth several key themes, relating to ways in which dementia friendly communities are envisaged to enhance the health and wellbeing of people with dementia.

Dementia friendly communities affirm the right of people with dementia to 'remain independent for as long as possible and ... have choice and control over their lives through all stages of their dementia' (DH, 2012, p.12). Its emphasis on choice and control for strengthening wellbeing is consistent with the desires of people with dementia and their carers, to pursue hobbies and interests, simply go out, make more use of local services and help others in the community by volunteering (Innovations in Dementia, 2012). Built on the principles of ageing in place, the aim of dementia friendly communities is therefore to 'bring about a society where people with dementia can continue to engage in everyday activities ' (Innes, 2013, p1). Health and wellbeing is in this case entwined with the ability to carry out the everyday and mundane activities, which give people purpose and autonomy.

In this way, the concept of dementia friendly communities rests on an asset-based approach, seeking to support people's ability to demonstrate their full potential and live well (Nolan et al, 2006; Innes, 2013). Crampton et al (2012) describe dementia friendly communities as communities in which 'people with dementia and their carers are respected, empowered, engaged and embraced into the whole through encouraging them to network' (p.6). Recognising that it is important for people with dementia to contribute to the 'citizenry' (Crampton et al, 2012) of a place, not only are people with dementia encouraged to maintain

active participation in their community, but many have contributed to policy development and local practices relating to dementia friendly communities and health and social care (Dean et al, 2015; Hare and Dean 2015; Innovations in Dementia, 2011; Williamson, 2012).

An emphasis on enabling participation of people with dementia in the wider society has featured in dementia research for over a decade. Early efforts to make communities more accessible focused on physical characteristics of particular environments (Mitchell et al, 2004a, 2004b), whereas the notion of dementia friendly communities attends to both social and spatial barriers to engagement in the community for people with dementia (Alzheimer's Society, 2015). Such thinking is translated into actions varying from 'changing road layouts to training shop staff' (Duffin, 2014, p.16). Accordingly, the York's four corner stone model of dementia friendly communities focuses on the potential for making physical places and resources alongside people and networks more dementia friendly in its quest for realising the aims of dementia friendly communities (Innovations in Dementia, 2011, 2012; Crampton et al, 2012). An inclusive definition of dementia friendly communities, taking into account the physical, social and organisational aspects, therefore enables a more nuanced understanding of experiences of living with dementia and the complex ways in which people's health and wellbeing can either be threatened or improved by the environment.

Calling for a 'whole' community approach, an emphasis on civic responsibility in order to create a culture shift is at the heart of the drive for dementia friendly communities. Key commitment number 7 in the Prime Minister's challenge invites support from leading businesses and national organisations to consider 'how they and others can play a part in creating a more dementia friendly society and raising awareness of dementia' (DH, 2012, p.13). Alongside practical issues concerning transportation and orientation, people with dementia and their carers, stress the importance of dementia awareness across all sections of the community. Strategies for spearheading this cultural shift range from continued media attention and public awareness campaigns, to dementia friends training for local business employees including the police, public transport staff and also leaders in health and social care services. The ultimate goal is therefore to 'normalise' (Innovations in Dementia, 2011) dementia and facilitate the 'assimilation' (Horner, 2013) of people with dementia into mainstream community life. Health and wellbeing of people with dementia is in this sense considered to hinge on the wider community's ability to compensate the impact of dementia on individuals and make them feel part of the community.

2.5   Conclusion

Over the last two decades dementia research within social sciences has been effective in redressing the biomedical perspective of dementia with a 'sociogenic' view. Thus both the subjective and social dimensions of dementia and people's experiences of health and wellbeing were brought to the fore. Qualitative research, have been most instrumental in highlighting dementia as not simply a disease that 'happens' to an individual, rather the person and their environment play an important role in enacting individual experiences of it, including how they maintain their overall health and wellbeing. The epistemological and methodological shift within dementia research therefore allowed recognition of people with dementia as individuals with personal biographies and agency and also for their experiences to be understood through an examination of their socio-spatial world. But to date, individual agency and socio-spatial context of people's experiences have only been considered within private settings and interactions. There is a dearth of evidence on how people with dementia's engagement with the wider community influence their experience of health and wellbeing. Dementia studies that have considered people's experiences beyond the home lack any detailed examination of how people with dementia interact with different community settings or how their experiences change over time, in order to gain a nuanced understanding of the ways in which the wider community contribute to people's experiences of health and wellbeing.

On the other hand, improving participation of people with dementia in everyday activities beyond the home is central to the ambition of developing dementia friendly communities. Practical barriers to engaging in the wider community are considered in terms of environmental and transportation issues, whilst social inclusion of people with dementia is addressed through its commitment to provide community wide dementia awareness and training. However, although efforts are being made to make communities dementia friendly, both its empirical basis and evidence of its impact are rather scant. There is limited research on places and activities people with dementia like to engage with or their subjective experiences associated with 'citizenry' and being part of a community. Without such insight it is difficult to understand the complex ways in which environments can impact on people with dementia's experience of living in the community. To further understand how to effectively create dementia friendly communities, it is important to first develop a nuanced understanding of why and how people engage with different aspects of the wider community and their implications on people's ability to live well. It is therefore worthwhile to consider literature on health and place, as it offers insight on theorising and researching how environments which people engage with can contribute to their experiences of health and wellbei

<center>**CHAPTER THREE**</center>

<center>**Emplacing Health and Wellbeing**</center>

3.1　Introduction

The aim of this thesis is to advance understandings of the importance of community settings for the health and wellbeing of people living with dementia. The previous chapter outlined the context for the study, considering how UK policy on dementia friendly communities aims to address the health and wellbeing of people with dementia through adapting the environments in which they live. In so doing the chapter provided a prelude to the interconnection between environments and experiences of health and wellbeing. Dementia policy and research connecting experiences of health and wellbeing to people's environments are closely linked to the policy of 'ageing in place' and have been a particular focus for gerontologists and geographers alike. Much of this work promotes the view that ageing at home is important for a healthier and a better quality of life. However, experiences of dementia in community settings are yet to be fully explored and incorporated within theorisations of the link between older people, their environment and their health and wellbeing. It is thus worthwhile exploring some of the work underpinning discussions around 'ageing in place' in order to consider their relevance in the context of this study.

Moving the focus from understandings of health and wellbeing for people with dementia to how health and wellbeing is linked to environments, the aim of this chapter is to provide further theoretical context to the study. It will explore how the relationship between environments and experiences of health and wellbeing is conceptualised and investigated within health geography and wider social sciences. Section one considers place and relationality, foregrounding theoretical and operational implications of using the term 'place' in research. The second section takes an in-depth look at the complex and dynamic ways in which the relational place is linked to experiences of health and wellbeing within the literature. This is followed by a discussion of how experiences of place change over time, especially with the onset and progression of dementia, a how such changes impact on health and wellbeing, in section three. The chapter then concludes with a summary of the theorisation of health and place but more importantly highlights the need for a conceptual and analytic approach that will guide research on how people-place interactions can be experienced as or supported to be health enhancing.

3.2   Place and Relationality

Concepts of 'landscapes', 'space' and 'place' are used in literature to denote particular sets of ideas and experiences associated with specific settings. Landscapes often refer to the physical and visual features of areas of land, varying in size, shape and landforms. Also, although 'in most definitions of landscape the viewer is outside of it' (Cresswell, 2004, p.11), it is perceived and defined through the viewer's eyes. In this way landscapes are objective and subjective, since both imaginative and emotional work is normally involved on the part of the viewer (Gesler, 1992). Space is usually defined using 'universal and abstract ideas such as geometric distance', (Wiles, 2005, p.101) and considered in terms of 'areas and volume' (Cresswell, 2004, p.8). Unlike landscapes, space is not considered to be imbued with any meanings and instead 'becomes place as we get to know it better and endow it with value' (Cresswell, 2004, p.8). Place therefore is described as the setting which is directly experienced by those inhabiting it and which 'holds meaning for and social relations between people'(Wiles, 2005, p.101). Milligan (2003) in her work on the home as a setting for provision of care considers Marc Auge's (1995) distinction between the *anthropological place* which provides connection, memory and identity, and the *non-place* which lack any anthropological meaning. Here, a particular setting is simply bounded space unless it is imbued with anthropological significance, in which case it becomes a place. Place is distinguished from space on the basis that it signifies more subjective and experiential aspects of a setting, occurring through engagement and emotional attachment (Rose, 1995).

Place has been the subject of much theorisation by various scholars, including philosophers (Casey, 2001), geographers (Cresswell, 2008; Massey, 1992; Relph, 1976; Tuan, 1977) and gerontologists (Rowles and Bernard, 2013; Rubinstein and Parmelee, 1992). Reflecting 'a broader spatial turn in the applied social science' (Keady et al, 2012, p.160), the overarching goal has been to define what is meant by 'place' and how it can be used to understand human experiences, including experiences of health and wellbeing. Settings of interest to those concerned with the impact of place on health have therefore varied from the home to specific health care facilities, communities and neighbourhoods. However, there is inconsistency in the way in which the scope and nature of specific settings are defined and place is operationalised in research and practice. There are inherently irresolvable questions regarding whether to define the 'home' as a place where someone lives or a place where they feel they belong and 'at home' (Blunt and Dowling, 2006). Similarly, whilst policy makers are found to be concerned with administrative geographical boundaries when defining neighbourhoods, social scientists

have tried to define neighbourhoods in accordance to the area in which participants are physically and socially most active (Blackman, 2006; Keady et al, 2012). Whereas Blackman (2006) scaled down his definition of neighbourhood to the area with which people have direct contact, studies on neighbourhood effect on health risks have included nearby geographical areas with which people from the focal neighbourhood are connected through social processes (Chen and Wen, 2010; Cravey et al, 2001; Smith et al, 2001). They point to the importance of interactions along socio-spatial networks which are not contained within local geographical boundaries since neighbourhoods do not operate within a vacuum but are instead relational and influenced by their surroundings. Differences in the above perspectives therefore highlight epistemological debates about what constitutes place and how it impacts health; whether it is the physical and observable environment or the people and processes which constitute place and in turn its impact on health. These assumptions are fundamental to how the relationship between place and health is conceptualised and researched.

Social scientists, concerned with quantifying the effects of place on health, have traditionally been interested in quite a static and physical view of place (Pickett and Pearl, 2001). Structuralist theorists, and medical geographers, have tended to take the epistemological position of environmental determinism, articulating a cause-effect relationship between physical or structural characteristics of place and individual behaviours. The assumption that environmental characteristics are objectively experienced underscored the development and evaluation of earlier environmental interventions for wandering and disorientation in care settings (Calkins, 2001). This approach nullifies the subjective interaction between people and place, shaping the way in which people perceive and respond to their surroundings. Conversely, humanist researchers have taken an entirely subjective approach to understanding the diversity of experiences of health in specific places (Kearns, 1993). They are concerned with the phenomenological aspects of place, such as 'subjectivity, individuality, creativity, the importance of experience, meaning and value' (Gesler, 1992, p.737). Humanism is based on people's interpretation of their environment and situations, and place is perceived to exist in the meanings, value and significance people attach to them. Drawing on this approach, some researchers attribute health and wellbeing benefits of living at home for older people to the subjective values they associate with the home environment (Milligan, 2003; Rubinstein, 1989). Sense of ownership, independence and privacy are considered some of the positive features of the home, setting it apart from more public settings in which they may become less active and less in control with declining health. However, when the physical and social aspects of the home are reorganised to accommodate people's increased health and care needs it can blur the boundaries between the private and the public, changing how people feel in and about their

home (Milligan, 2000; 2003). Twigg (2000) describes care giving in the home as an 'intrusion in to the world, of values, rationalities and temporal structures that may belong to the formal world of service provision' (p.77). Here it is evident that there are perceived boundaries distinguishing one setting from another, but due to certain circumstances these boundaries are blurred, posing a strain on the way in which people understand and experience their home and the relationships shared within it.

Whereas structuralism is criticised for neglecting to consider the role of individuals and their agency in shaping place, humanism also fails to consider the structural constraints influencing individual thoughts and actions and in effect shaping their experience of place. Research on experiences of place finds that people's interactions with and interpretations of place occur within broader structural and socio-cultural processes (Freund, 2001; Phillipson, 2007; Pinfold, 2000; Wiles, 2005). Kitchin and Law's (2000) notions of 'geographies of disability' and 'geographies of non-disabled people' describes well the influence of structural factors on the different experiences of place by disabled and non-disabled people. Thus, according to some researchers, there is a sense of 'dualism that pervades and structures social space: ability-disability, independence-dependence, integration-isolation...' (Pinfold, 2000, p.202). These binary categories have socio-spatial implications for where illness and care are perceived to belong, whereby 'the public outdoor world is rarely conceived as a dementia setting' (Blackman et al, 2003 p.361). There is however also a strong case made for acknowledging the role of individuals in how a place is utilised and experienced, suggesting that a consideration of both structure and agency is necessary to advance understandings of the relationship between health and place (Cummins et al, 2007; Kearns, 1993; Valentine, 2001). Such a relational approach considers the link between place and health as the outcome of reciprocal interactions between individuals and their environment, combining both structuralism and humanism. Place is not only considered a physical setting defined by its structural features but interwoven with human activity. It is considered a 'set of social relations which interact in a particular location (Massey, 1992, p.12), bringing to the fore the importance of exploring the mechanisms through which the physical and social elements influence experiences of health and wellbeing.

This approach moves beyond a reductionist inquiry of the structuralist tradition to exploring context specific experiences of health in place, influenced by both individual agency and structural constraints. The distinction between place (context) and people (composition) as separate entities is thereby blurred, and the conceptualisation of place is 'neither subjective nor objective; it merges both sides of place by training attention on the action between elements sharing a locale' (Williams, 2002, p.145, see also Calkins, 2001; Cummins et al, 2007; Kearns, 1993). This is important in the context of this study, because whilst the physical environment

may remain unchanged the way in which people with dementia now perceive and interact with this environment may change, altering their overall experience of place. Thrift's concept of the 'ecology of place' (1998) is useful for understanding the relational encounter between a person and their environment, suggesting that place is a construct of the interactions which take place between people and their socio-spatial environment. He also, explains 'whilst places may be designed to elicit particular practices... all kinds of other practices may in fact be going on within them which they were never designed to admit' (Thrift, 1998; p.310–11). Therefore place is very much constructed in the actions and experiences of people within a setting rather than what can be deduced solely from its physical appearance or a set of rules prescribing its functions; it is according to Cresswell (2002) a 'practiced place'. This not only gives phenomenological concerns a substantial purchase in understanding people-place relationships but also attests to a notion of place which is unbounded, fluid and interconnected through human activities (Andrews et al, 2013; 2014; Conradson, 2005; Cummins et al, 2007; Duff, 2010; Jones, 2009; Parr, 2004). Moreoever, in considering people, particularly their actions and practices, as a constitutive component of place, researchers have been increasingly engaging with what Howes (2005, p.7) calls the 'emergent paradigm of emplacement'. The idea of emplacement suggests that people as embodied beings are firstly situated within and secondly shape the experience of place, alongside its other 'animate and inanimate entities' (Pink, 2008, p. 178). So individuals are considered as embodied, emplaced beings; their perceptions and experiences constructed through their participation in a particular 'gathering of things' constituting place (Casey, 1996, p.44).

Places are considered as 'constellations of connections' which are multiple, overlapping and span across varying spatial scales and time (Massey, 2005, p. 187). Places are thus conceptualised as 'nodes in networks' of numerous other nodes people engage and disengage with over time (Cummins et al, 2007). So returning to the earlier concern with defining neighbourhood boundaries, it is known that with the progression of dementia, the size of a person's geographical area of activity gets smaller and much more selective (Duggan et al, 2008; Rowles, 1978). Keady et al (2012) suggests a definition of neighbourhood which reflects the 'fluidity of the relationship people with dementia have with their localities' (p.160). However, a limitation of using even a flexible and fluid conceptualisation of neighbourhood, is that it is still concerned with proximity of places of interest to each other and the home and defining individual neighbourhood boundaries. For a person with dementia, places of significance may not necessarily relate to their rapidly decreasing everyday activities in the locality, they may instead be geographically unconnected and dispersed. In this case, drawing a boundary around a small cluster of places most frequently used would deem places that are geographically more

isolated, yet significant, less important. However, extending the boundary around the outliers would render individual neighbourhoods expansive and meaningless. Therefore, scaling down the analysis to specific community settings people with dementia interact with, whether they are within or across neighbourhoods, would not only highlight the influence of the 'flows of capital, culture and people between geographically distant places' (Cummins et al, 2007, p.1832) but also hone in on places that are subjective, lived and meaningful to each person.

3.3   Relationship between Health and Place

Place is linked to better health and wellbeing for older people when interactions between individuals and their physical and social environments are supportive of their ageing process. Research on ageing in place has highlighted the importance of the home and community settings for older people to maintain a good quality of life (Wiles et al, 2011). The role of the wider community in the prevention of illness and management of health and wellbeing has received significant attention in recent years (Abraham et al, 2010; Larson et al, 2006; Lopez and Hynes, 2006). For people with dementia too, engaging with the wider community is associated with opportunities for physical exercise, social interaction as well as psychological and emotional recuperation (Olsson et al, 2013; Keady et al, 2012). Duggan et al (2008, p.195) found that for older people with dementia:

'… *interaction with familiar people outdoors was a source of identity and social inclusion… Functional reasons for enjoying a walk outdoors included exercise and the benefits of breathing fresh air… emotional well-being (feeling 'great') that walking outdoors can bring. In the same vein, a sense of relief, escape and freedom were mentioned by other interviewees*'.

Whether it is the home or wider community settings, these places attend to a number of needs connected to people's health and wellbeing. As such, place is considered a multifaceted resource for health and wellbeing and it is useful to think about how the different facets interact with each other and influence individual health and wellbeing.

3.3.1   Socio-spatial dynamics of health and wellbeing

The relational configuration between social and spatial dimensions of place shape experiences of health and wellbeing for older people living at home. Wiles (2005) argues that the arrangement and provision of informal health care for older people is dependent upon both the

physical proximity of family/ lay carers and a multitude of social factors that have historically placed women in a more likely position than men to provide such support (see also Milligan and Wiles, 2010). Close social connections between people, including with healthcare professionals, can also compensate for the many physically distant and inaccessible formal healthcare facilities and spatial isolation in rural communities, ensuring that 'individuals... are imagined to be socially proximate but physically distant' (Blackstock et al, 2006, p.165). The physical environment is nonetheless an important moderator of social activities and processes which have implications for health and wellbeing. Moore (2004) claims there is always a 'hidden program' of place and no social activity or relation is independent of the physical setting in which they take place. For instance, 'everyday technologies' (Brittain et al, 2010) such as signage, crossings, entrances to building, which mediate people's engagement with the outside world are argued to have been developed for a 'hyper-cognitive society'(Post, 2000). These technologies espouse certain normative behaviours and social interactions which a person with cognitive impairments may find difficult to follow, contributing to their social isolation (Freund, 2001). Consequently, increased attention to environmental features such as signage, landmarks and other orientation cues have so far informed strategies to enable people with dementia to independently navigate their way around towns and cities and remain socially active (Blackman et al, 2003; Burton and Mitchell, 2006; Mitchell et al, 2004a).

However, whilst the physical characteristics of place may be important for managing certain symptoms of dementia and supporting navigation, the extent to which they promote activities and interactions beneficial for health and wellbeing is unclear. People's interactions in and with place often depend upon their interpretations of the physical environments. Environmental cues can be experienced as both assistive and restrictive of individual freedom, depending on how they are perceived in relation to a person's own ambitions for maintaining their quality of life. According to a relational perspective, people perceive and engage with place subjectively and in accordance to their personal/ social values and abilities. Thus, whilst social relationships may be a significant buffer to the distress and hopelessness people with dementia may feel about living with the condition, their ability and motivation to maintain social relationships and networks are affected by changes in their health status. Disorientation, confusion and memory loss can lead them to withdraw from settings and activities that are important to maintaining their social networks (Duggan et al, 2008). In this case, a number of researchers have drawn attention to the beneficial impact of short-term relationships and fleeting encounters people with dementia may engage in (Phillips and Evans, 2018). Socio-spatial impact of health and wellbeing is thus relative to individual circumstances and perceptions. Health and wellbeing

related experiences of place are shaped by subjective relationships people share with particular socio-spatial environments, highlighting the role of psycho-social interactions in place.

3.3.2   *Psycho-social implications of place*

People share a psychosocial relationship with place; their interactions with the social and physical elements of place are determined by, and experienced through, the subjective meanings and values they associate with them. The term 'sense of place', denotes the various social, psychological and environmental processes involved in establishing place attachment, rootedness, belonging and place identity, in order to affiliate a person to place (Eyles and Williams, 2008; Gesler, 1992, 1993; Williams and Stewart, 1998). These emotional responses to place are considered important mechanisms through which place affects health and wellbeing (Gesler, 1992; Williams, 1998; Williams et al, 1992). To think of the home as a place imbued with symbolic meanings; for many it is a manifestation of autonomy and power which they do not attribute to a residential care home or other institutional settings (Wiles, 2005). The symbolic and metaphoric qualities of place are also evident in less spatially tangible contexts, such as what Blackstock (2006, p.162) calls the 'universalising narratives about rurality and the rural idyll' having a positive impact on his participants' perceived quality of life. Similarly, for older people living with dementia, continued experience of place which hold meanings associated with their life history, personal identity and sense of belonging provides them with the 'one constant in an emotional world threatened by losses' (Fogel, 1992, p.16).

Place is thus important for health and wellbeing as a source of both personal and social identity (Goffman, 1963). Williams (2002) states: '... places, as bounded locales imbued with personal, social and cultural meanings provide a significant framework in which identity is constructed, maintained and transformed' (p.144). Also relevant here is Thrift's (1998) notion of the 'relational self', suggesting that the 'self' emerges within and through relations to other people and events within a given setting. In Blackstock's (2006) study, the rural landscape perpetuates a sense of personal identity and a distinctive lifestyle which the participants maintain through particular physical and social practices, which they consider to positively impact their health and wellbeing. Underlying this psychosocial relationship between people and place is the assumption that meanings of place are rooted in the history of interactions between people and their physical setting, where 'elements of biography are woven together with place(s)' (Hall, 2009, p.581). But whilst familiarity over time and a sense of personal history with a particular setting is important to establishing place identity and attachment, people's needs and perceptions change over time. In the case of dementia in particular, people often experience

disorientation in time and space causing them to sometimes feel out of place, and a sense of 'existential outsideness' (Relph, 1976). In such instances, there is a disconnect between time, place and identity (Steenwinkel et al, 2014). But according to a relational perspective, place is a process in which the relationship between people and their socio-spatial surroundings are dynamic (Massey, 1999). People's sense of self and meanings they associate with particular settings are in this regard mutually constitutive and changing.

3.4   Changing experiences of health and place

Dementia, precipitating changes to a person's life course including their social relationships, lifestyle and personal activities, is particularly likely to impel a renegotiation of their relationship with place. People become increasingly anxious and fearful of getting lost or of the negative reactions from others resulting in them withdrawing from the wider community (Blackman, 2003, p.362). The geographical area of day to day engagement and social networks, which are important to their health and wellbeing, draw in towards the home, resembling what is described as a 'shrinking world' (Duggan et al, 2008; Rowles, 1978). Familiarity, particularly their embodied knowledge of their surrounding, instead becomes crucial to a person with dementia's sense of wellbeing, and 'a source of security and social inclusion' (Duggan et al, 2008, p.195). But, since people's perceptions, emotions, memories and sense of place are unique to their physical experiences; becoming wheelchair bound or visually/ aurally impaired due to dementia can change how people interact with and experience familiar places (Merleau-Ponty, 1962). Familiar embodied connections to place become altered, such as when a person begins to lose some of his/ her faculties and they have to learn to reconnect with place in new ways, which can have a significant impact on their health and wellbeing.

People with dementia's connection to place are made difficult by physiological changes, and aspects of their environment and their behaviour become more evident in their efforts to engage with place. An interesting argument put forward by Brittain et al (2010) discussing the sometimes disabling impact of assistive technology in the home is relevant here, as they suggest that such technology is effective only when it conforms to a person's established way of life. But when it is unable to do so, or 'is broken or missing, its "phenomenological transparency" is changed and it can act as an opaque interference between the person and the world' (p. 274). To no longer be able to drive for instance thus poses similar obstacles to a person's taken for granted sense of self in relation to the way in which they have previously interacted with and experienced place. Following a relational view of place, Pink (2011) argues that 'the competing/performing body is part of an ecology of things in progress' (p.349). Similarly, Wylie

(2005) maintains a view of embodiment as a continual process; the body and environment continually 'enfold and unfold' (p.242) because they are never completely one. This view recognises that the body and environment are always changing and embodied connections are continuously negotiated, sometimes leading to disengagement:

'The same landscape offering comfort to those at an early stage become hazardous as disorientation and walking occur, until their weakened physical condition confine people with dementia indoors'. (Blackstock, 2006, p.171)

Moreover, in the context of dementia, the ill/well self is in regular negotiation determining how a person may relate to their physical and social surrounding on a day to day basis. The 'concern with the construction of self in the world and its connectedness to place' (Williams, 2002, p.145) therefore becomes most pronounced with the presence of dementia. To date much of the dementia research focuses on people with dementia's gradual socio-spatial and existential withdrawal from place, whereas there is evidence to suggest that people with dementia continue to engage in place-making processes despite their impairments and altered relationships to place (Steenwinkel et al, 2014; De Witt, 2009). In De Witt's (2009) study, the female participants' choice to continue living at home is associated with their desire to maintain control over their sense of self and relationship to place. The participants continually grapple with the tensions between being *here* (home), being *there* (nursing home) and being *out* in the community, resorting to 'living on the threshold'. De Witt's analogy of the 'threshold' describes how the women occupy a middle ground, protecting themselves from not only moving into residential care, but also from the isolation of the home space and the negative experiences out in the community. Whilst one participant expressed the importance of being close to local shops and amenities, another alluded to the need to retreat from unconstructive situations out in the community. The 'threshold' is their 'space for resistance' (Tulle-Winton, 2000) exemplifying their attempt to establish their own socio-spatial position, choosing what they must 'bring closer' and what they must keep at a distance to maintain their health and wellbeing. Whilst this is an example of how these women with dementia use their home as a place through which they renegotiate their sense of self and socio-spatial relationships, it is possible that people with dementia engage in similar place making processes in the wider community.

3.5   Conclusion

This chapter has brought together literature on theorisations of place, work linking place to experiences of health and wellbeing and evidence from dementia research discussing how the

relationship between health and place may change with the onset and progression of the disease. Together they provide a conceptual and empirical basis for thinking about how engagement with the wider community can promote or hinder the health and wellbeing of people with dementia and also how this may be investigated. A relational perspective of place is particularly useful for exploring the construction of place and its experiences, allowing a consideration of socio-spatial features of place and psycho-social processes through which place interact with health and wellbeing. The relationship between health and place is thus complex, involving interactions between spatial, social, cultural, psychological, embodied and emotional entities. It is through a close examination of these elements of health-place interactions that people's changing relationship to place, due to the onset and progression of dementia, and its impact on their health and wellbeing can be determined. Having identified key features of place and health and wellbeing related experiences of place then, the next step would be to conceptually account for the complex ways in which people interact with place and their impact on health and wellbeing. The concept of 'therapeutic landscapes, first introduced by Gesler (1992) offers a lens through which to theorise and explore how individual and external factors within particular settings, combine and interact to create experiences which promote health and wellbeing.

CHAPTER FOUR

The wider community as a therapeutic landscape: A literature review

4.1   Introduction

The previous two chapters have been concerned with setting the context of this thesis. Chapter two introduced the concept of health and wellbeing in relation to experiences of people with dementia whilst chapter three outlined conceptualisations of place, highlighting the complex ways in which people, including people with dementia, create and experience place. The latter chapter provides evidence from existing research on various health and wellbeing impacts of place, rendering it to be multifaceted and occurring along social, spatial, psychological and temporal dimensions. This highlighted the centrality of the processes through which place impacts health and wellbeing. Whilst it is apparent that place matters to the health and wellbeing of people with dementia, the mechanisms through which place helps to maintain and promote their physical, social, psychological and emotional health is still vague. If the aim of dementia friendly communities' policy is to enhance the health and wellbeing of people with dementia, it is important to unpack and socio-spatially contextualise notions of health and wellbeing and their experiences in relation to people with dementia.

The aim of this chapter is therefore shaped by the question of how to account for intricate interactions between people with dementia and place and their impact on experiences of health and wellbeing. The concept of therapeutic landscapes addresses how 'the healing process works itself out in place (situations, locales, settings and milieus)' (Gesler 1992, p.743). It draws attention to the way in which the physical, social and psychological environments work together to contribute to the healing and health promoting attributes of place (Kearns, 1993). The concept not only focuses on the geographical location and characteristics of space and place, but also the opportunities they provide for certain, potentially therapeutic, interactions and activities to take place within them. As such therapeutic landscapes provides a lens through which transactions between people and place, particularly the interactions and symbolic processes through which people perceive and experience place, can be understood (Andrews, 2004; Cutchin et al, 2010). Considering people with dementia are a heterogeneous group with differing health needs, functional abilities and lifestyles, the concept allows due attention to be paid to the interplay between structure and agency in the creation of therapeutic landscapes. Viewing inner thoughts and feelings as playing alongside material and discursive aspects of

place, therapeutic landscapes offers a holistic approach to conceptualising everyday places and experiences of people with dementia in the community.

In its initial conception, everyday environments were not conceived of as therapeutic landscapes, and the framework was applied to specific places of interest rather than specific populations. There are several developmental themes identified by Williams (2010) within the extant literature which illustrate the evolution of the concept and its application over time. Williams (2010) found that the therapeutic landscapes literature focused on three areas of research- (1) physical spaces with a reputation for healing such as hot springs and pilgrimage destinations, (2) created spaces of formal health care sites such as hospitals and (3) settings that have been negotiated by, and specific to, marginalised populations stretching from an alcohol self-help group (Wilton and De Verteuil, 2006) to a first nations community (Wilson, 2003). Although dementia research cuts across the latter two themes, therapeutic landscapes has had limited application in this field (McLean, 2007). Nonetheless, considering the theoretical and practical use of the framework in existing geographical, gerontological and wider work may also shed light on how experiences in the wider community are implicated in the health and wellbeing of people with dementia.

Following Williams (2010) work, a recent scoping review conducted by Bell et al (2018) illustrates ways in which the application of the therapeutic landscapes concept has expanded over the past decade. There is an increased focus on therapeutic materialities of macro-scale blue spaces as well as micro-scale environments such as allotments and community gardens, with sparse interest in the symbolic role arts and other cultural mediums play in shaping people's experience of place. The review explicates emerging nuances in terms of the creation of therapeutic landscapes: an emphasis on spatio-temporal nature of experiences; the liminality of therapeutic spaces combining both emotional retreat and everyday sociality; the prevalence of 'therapeutic encounters' counteracting the tension between social control and a secure space found in earlier work; and a more holistic approach to healing taken by pilgrims in spiritual sites. These trends identified within the current body of therapeutic landscapes literature, suggests that there is a growing diversity in terms of the settings in which the concept is applied and also the ways in which how landscapes contribute to health and wellbeing is understood.

Whilst the findings of the review highlight the extension of the concept to everyday landscapes, it did not aim to provide any focused attention on the specificity of settings, the population or mechanisms through which therapeutic experiences occur within those contexts. The purpose of this chapter is to therefore elucidate the breadth and variant utility of the therapeutic

landscapes concept through a review of literature focusing on the everyday. A scoping review was decided as the most appropriate approach as it is inclusive of both published and grey literature, allowing an exploratory approach to identifying and synthesising current knowledge on a broadly defined topic such as therapeutic landscapes (Arksey and O'Malley, 2005). The research question this review set out to address is therefore: *To what extent does the therapeutic landscapes literature inform understandings of everyday experiences in the wider community and their impact on the health and wellbeing of people with dementia?* Linked to this primary question are concerns around conceptual and methodological implications of applying therapeutic landscapes to the context of the present study. The following three objectives will therefore be addressed in the course of answering the review question:

a. What are the conceptualisations and characteristics of everyday places considered in therapeutic landscapes literature?

b. How are everyday places found to impact experiences of health and wellbeing for different populations?

c. What are the methodological approaches adopted to examine every day therapeutic landscape experiences and why?

4.2   Methods

In this scoping review of therapeutic landscapes literature, articles were searched and identified using the following databases: *Scopus*, *ProQuest*, *Pub Med and Web of Science*. The search term "Therapeutic landscape" was used to search for articles which included this term within their title, abstract or key words. Further articles were identified from reference lists of found articles, including relevant theses and review papers, as well as from hand searching the journals *Social Science and Medicine* and *Health and Place*. The internet search engine Google was also used to identify any grey literature on the topic. All articles and grey literature published since 1992, (the date of the initial introduction of the concept of therapeutic landscapes by Gesler) were searched. The initial search was conducted between February and March 2016 and repeated again in February 2018 to ensure the inclusion of more recent articles.

Only literature on therapeutic landscapes within health and social sciences were identified and included in the review. In medical science the term 'therapeutic landscapes' is used to denote pharmaceutical interventions; this body of literature is not relevant to the subject of this thesis and so results from biomedicine or related fields were excluded during the search process. A total of 620 articles were identified for initial screening of titles and abstracts, after which full

texts of 93 articles, which use therapeutic landscapes as a primary concept within their theoretical discussions or presentation of research findings, were retrieved. Collectively, the empirical studies espouse experiences of health and wellbeing in a wide range of settings, which I stratified into 3 broad categories: 1. *Clinical and health related settings*, 2. *Spiritual, healing or retreat sites*, 3. Ordinary everyday settings (see Table 1: Settings in TL studies). Unlike Williams' (2010) categorisation of the therapeutic landscapes literature which focused on themes, I separated the studies according to the types of settings they investigated since the focus of my review is on ordinary 'everyday' settings specifically. The first two of my categories almost resemble that of Williams, whilst the last category comprises studies on various community settings open to the general public, although sometimes examined from the perspective of a particular group. For the purpose of this review, only the 39 articles focusing on the latter category have been included, although references are also made to the wider body of therapeutic landscapes literature where relevant.

Table 1: Settings in TL studies

Settings		
Clinical and care settings	**Spiritual/ healing or retreat sites**	**Ordinary everyday settings**
Psychiatric unit Traditional healers Residential care for vulnerable adults/ older people. Hospice Youth Camp Rural respite care centre Drug and Alcohol recovery programmes Art therapy Maggie's Gilda's club, Toronto	Epidaurus, Greece Lourdes, France Wells, Ireland Roman-Irish Baths, Ireland St Anne de Beaupre, Canada Healing gardens, China Healing village of Bama, China Yoga and massage retreat	***Neighbourhood features/ facilities*** Churches and Mosques Supported housing Blue spaces (coast, island life, swimming 'spots', promenade) Green spaces (parks, walking trails) Woodlands and Edgelands Wildscapes in the work place Public libraries Neighbours/ neighbourhoods (urban and rural) ***Community Activities:*** communal gardening, The Shed project Local heritage group Walking groups Self-help group (informal support group)

4.3   Findings

The 39 studies included in the review have been published between 2003 and 2018, with 28 of them published since 2010. In terms of the countries in which the studies were undertaken, 14 were in the UK (two articles from same study), 10 in Canada, 5 in Australia, 1 in Germany (two articles from same study) and one each in Netherlands, Mexico, New Zealand and Denmark.

Table 2: Summary of studies included in the review

Author, Date, Type	Aim	Population	Setting	Methods
Agyekum and Newbold, 2016 Qualitative study	To explore whether immigrant places of worship are therapeutic places.	African immigrants- Ghanian Christians and Somali Muslims- in Canada	Churches and mosques Canada	24 in-depth interviews (as part of a larger mixed methods project)
Alaazi et al, 2015 Case study	To explore experiences of the AHCS project's indigenous participants- their sense of home and health and wellbeing.	First Nation mentally ill clients of a housing project	Accommodation for homeless people provided by AHCS project. Canada	14 in-depth interviews with housed participants
Bell et al, 2015 Qualitative study	To explore diverse coastal experiences which promote and preserve health and wellbeing	33 adult residents	Coast in Cornwall England	33 Geo-narrative interviews involving activity maps produced using GPS. 9 Go-along interviews with subset of sample
Bell et al, 2017 3 stage Interpretive geo-narrative study	To explore diverse temporalities of TL: different processes through which green and blue spaces become therapeutic or otherwise	33 adult residents (25-85yers old)	Green and blue spaces – Cornwall, England	33 Geo-narrative interviews involving activity maps produced using GPS. 9 Go-along interviews with subset of sample
Brewster, 2014 Qualitative study	To outline the role of the public library as a therapeutic landscape.	16 participants with mental health problems	Public Libraries (10) UK	Life course interviews as part of a larger project involving interviews, participant observations and use of secondary data sets.
Cattell et al, 2008 Ethnographic study	To explore interconnections between public open spaces, social relations, and people's sense of well-being	Local residents and community activists of East London 42	Everyday public spaces in East London UK	A scoping exercise, 7 discussion groups, 24 in-depth interviews.
Chakrabarti, 2010 Qualitative study	To elucidate link between place and participant's use of social networks in effort to live a healthy pregnancy.	Pregnant Bengali immigrant women	Local and transnational networks USA	In-depth interviews with 40 women

Coleman and Kearns, 2015 Phenomenological interpretive study	To investigate the impact of island life on experience of place and ageing.	28 participants (65-94 years old)	Bluespaces of Waiheke Island, New Zealand	28 In-depth interviews 11 participatory photo-elicitation
Colley et al, 2016 Case study	To address the question: Can green spaces at work promote wellbeing?	Employees	5 science parks, Scotland	Go-along interviews
Doughty, 2013 Qualitative ethnographic case study	To explore the affective potency of shared movement for producing therapeutic landscapes	Group walkers	Walking group in Hampshire, England UK	Mobile interviews- Talking to walkers whilst walking
English et al, 2008 Qualitative study	To explore importance of place for shaping health and healing among breast cancer survivors.	14 Female breast cancer survivors	Daily geographies- Everyday lives and settings Canada	In-depth interviews
Finlay et al, 2015 Qualitative study	To understand therapeutic qualities of everyday contact with nature for older participants.	27 Older adults (65-86yrs old)	Green and blue spaces in Vancouver, Canada	Sit-down interviews Walking interview
Finlay, 2018 Qualitative study	To characterize white space impacts on the perceived well-being of older adults.	Community residents	3 case study areas of Minneapolis metropolitan area USA	125 semi-structured interviews 12 months of PO
Foley, 2015 Qualitative study	To explore swimming as a healthy body-water encounter	Swimmers	Outdoor swimming spots Ireland	20 Interviews Participant observations
Fullagar and O'Brien, 2018	To offer a relational understanding of how	Women (self identified as recovering	Eastern Australia	16 Semi-structured interviews

	recovery from depression is produced through rural and gendered emplacement	from depression)	
Gastaldo et al, 2004 Qualitative narrative study	To concentrate on our own experience of migration and on how we, as immigrants, evoke places in everyday living.	Immigrant to Canada	Host country- Canada	Narratives
Houghton and Houghton, 2015 Qualitative study	To explore Edgelands as micro-therapeutic landscapes.	Richard Mabey's (2010) book The Unofficial Countryside (originally published in 1973)	London's Edgelands UK	Thematic analysis of the literature
Laws, 2009 Case study- Ethnographic study	To explore how the unconventional spaces of the group are not mere products of marginality but a serious aspect of mobilising the dissident and 'anti-psychiatric' recovery.	Members of an 'alternative' psychiatric survivor (self-help) group.	City park, north of England UK	Participant observations 20 unstructured interviews (in small groups and 1-to-1)
Liamputtong and Kurban, 2018 Qualitative study	To explore how young Middle-Eastern refugee individuals perceive their health and wellbeing and address barriers in their new homeland	10 young refugees	Melbourne Australia	In-depth interviews and mapping exercises.
Liamputtong and Suwankhong, 2015 Qualitative study	To explore the lived experience of breast cancer among women	20 women diagnosed with breast cancer	Southern Thailand	Interviews Drawing exercise (an image of personal meaning and experience of breast cancer)
Macpherson, 2017 Ethnographic study	To explore the experiences of members of specialist blind and visually impaired walking groups.	Six volunteer sighted guides 19 visually impaired members of a visually impaired walking group and a walking holiday group.	Peak District Lake district UK	Sit- down interviews Walking interviews Video Photographs
Marsh et al, 2017	To investigate if and how a community	Community members	Information evening, 4 weaving-	Creative consultations,

Qualitative Participatory Action Research	garden (largely run by volunteers) might play a useful and sustainable role in palliative and grief support	Project team members	conversation sessions and 1 day workshop Tasmania., Australia.	Participant observations 5 semi-structured interviews Focus group discussion
Masuda and Crabtree, 2010 Community based-Participatory research	To challenge the deficit-orientation of DTES by reporting the results of a research process in which DTES residents chronicled their impressions of the neighbourhood.	9 Residents	Down Town East Side neighbourhood, Canada	Group discussions and photography activities in the neighbourhood- to articulate suppressed therapeutic discourses
Meijering et al, 2016 Qualitative study	To explore how a therapeutic engagement with the rural landscape may change over time for individual stroke survivors.	19 stroke survivors	Rural areas of Northern Netherland	In-depth interviews
Milligan and Bingley, 2007 Qualitative study	To examine the extent to which childhood experiences of play in wooded landscapes may influence how woodland can become a life-long resource for health and wellbeing.	Young people aged 16-21 years	North of England	Interviews Group discussions Art workshops- (expression of memories and multisensory perception of landscape) Follow-up interviews
Milligan et al, 2004 Ethnographic study	To examine how communal gardening activity on allotments might contribute to the maintenance of health and well being amongst older people.	19 men and women aged over 65 years.	9 month community gardening projects Carlisle, north of England	Pre and post project: Focus groups Interviews Participant diaries Participant Observations
Milligan et al, 2015 Qualitative study	Drawing on research with 'Men in Sheds' pilot programme, this paper seeks to illustrate how everyday spaces within local communities might be designed to both promote and maintain the health and wellbeing of older men.	Male shed participants (isolated older men) and Shed coordinators.	Three men in Shed projects in the UK	Project monitoring information 24 semi-structured interviews with members Focus groups with 27 members Semi-structured interviews with project coordinators.

Piat et al, 2017 Qualitative study	To demonstrate how recovery is 'emplaced' (or materially and symbolically situated in time and space), and how places factor into the 'everyday work of recovery'	17 Tenants with serious mental illness	5 Supported housing projects in 4 Canadian cities	Respondent photographs (How does independent living affect recovery and community connections?) Respond controlled photo-elicitation interviews
Pitt, 2014 Ethnographic study	To develop the concept of therapeutic place experiences by considering the role of activity in community gardening	Visitors, volunteers and staff	3 Community gardens in Wales, UK	Participant observations 32 semi-structured interviews
Plane and Klodawsky, 2013 Qualitative study	To explore and discusses the links between access to nearby urban green space, feelings of well-being, and having a sense of belonging to the broader community for formerly homeless women living in supportive housing.	9 women living in supportive housing development	Ottawa, Ontario	Photo voice (photographs of healthy and unhealthy aspects of the neighbourhood) Interviews Participant Observations
Power and Smyth, 2016 Mixed methods study	This paper examines the personal motivations and impacts associated with people's growing interest in local heritage groups	Members of 32 HLF groups	East Anglia, UK	Questionnaires Interviews Conceptual mapping of routes
Sampson and Gifford, 2010 Qualitative data from a larger mixed methods study	To explore the relationship between place-making, well-being and settlement among recently arrived youth with refugee backgrounds	120 refugee youth (11-19 years) in their first year of arrival	Melbourne, Australia	Photo-novellas Neighbourhood maps/ drawings
Sanchez and Liamputtong, 2017 Qualitative study	To explore and discuss the health-related benefits of rural community gardens.	10 participants of a community garden project (aged 50-82 years)	Rural community garden in South Gippsland, Victoria, Australia	Semi-structured interviews Observation
Straughan, 2012	To examine how 'touch' works as a sense experienced through material engagement	1 instructor 5 trainee instructors		Photographic documentation of anything relating to touch and texture during

Qualitative study	with the aquatic world for both physical and metaphorical effect	1 drive master Own journal of driving instructor course.	participant's dive 4 Semi-structured interviews Participant Observations
Thomas, 2015 Qualitative study	To examine how experiences in different types of green and blue space provide important health and wellbeing benefits for women in Copenhagen	Women aged 18-60 years Policy makers	Copenhagen, Denmark	Semi-structured interviews Focus groups
Volker and Kistemann, 2013 Mixed methods study	To explore the beneficial health outcomes and wellbeing created by urban blue, using an innovative application of the concept of therapeutic landscapes.	42 participants (completed Questionnaires)	Promenades in Cologne and Dusseldorf, Germany	Pedestrian counting Field mapping Systematic non-standardised participant observation Qualitative questionnaires
Volker and Kistemann, 2015 Qualitative methods	To explore which differences in wellbeing occur when visiting urban green and blue spaces in high-density areas of the inner city		Dusseldorf and Cologne, Germany	Semi-structured interviews
Wakefield and McMullen, 2005 Case study	To explore the processes by which ordinary places are characterised as healthy or unhealthy and investigates how health-affirming and health denying places exist together in everyday life	36 -suburban residents 21-industrial area residents	Suburban and industrial parts of Hamilton, Ontario	In-depth interviews Newspapers and other reports Authors' own experiences as residents.
Wilson, 2003 Qualitative study	To broaden the analysis of TL by exploring their culturally specific dimensions in the context of everyday lives of 'Anishinabek' and thus contribute to a better understanding of First Nations peoples	15 community members 2 staff at the community health centre		17 in-depth interviews

4.3.1   Conceptualising everyday places of wellbeing

There are two subcategories of places and activities covered by the literature that I have included in the 'Ordinary everyday settings'. The subcategory of *local neighbourhood features and facilities* include places of worship (Agyekum and Newbold, 2016), public libraries (Brewster, 2014), the workplace (Colley et al, 2016) residential areas and neighbourhood amenities (Cattell et al, 2008; Wakefield and McMullen, 2005; Masuda and Crabtree, 2010; Wilson, 2003; Sampson and Gifford, 2010; Piat et al, 2017), and local green[1], blue[2] and white[3] spaces (Thomas, 2015; Coleman and Kearns, 2015; Volker and Kistemann, 2013; 2015; Plane and Klodawsky, 2013; Finlay et al, 2015; Finlay, 2018). These are generally public settings, involving contact with people from the wider community and which the participants in the respective studies routinely engage with. The focus of much of this research is on how everyday public places are experienced by particular populations: Socio-spatial interactions which support the integration and wellbeing of refugees and immigrants' in their host country (Agyekum and Newbold, 2016, Gastaldo et al, 2004; Liamputtong and Kurban, 2018; Sampson and Gifford, 2010); interconnection of everyday life with the cultural values and practices of First Nation's people (Wilson, 2003; Alaazi et al, 2015); the rehabilitative potential of having access to local amenities, including public libraries for people with mental health problems (Brewster, 2014; Piat et al, 2017); impact of green and blue spaces on older people's experience of ageing (Coleman and Kearns, 2015; Finlay et al, 2015); the role of everyday geographies in the recovery journey of women with breast cancer (English et al, 2008; Liamputtong and Suwankhong, 2015); the impact of rural life on experiences of stroke survivors (Meijering et al, 2016) and women with depression (Fullagar and O'Brien, 2018); factors influencing restorative use of woodlands by youths (Milligan and Bingley, 2007); aspects of local neighbourhoods which contribute to a sense of home for former homeless people (Plane and Klodawsy, 2013; Alaazi et al, 2015).

These studies shift the focus of therapeutic landscapes from specific places of health and healing to a wide range of ordinary places of everyday living. Although the studies are interested in everyday places within specific neighbourhood settings or those that serve a particular purpose such as aiding recovery from cancer (English et al, 2008; Liamputtong and Suwankong, 2015),

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[1] The term green space is commonly used in health promotion literature to refer to gardens, parks, forests and the countryside that are characterised by vegetations and considered to promote healthy behaviours (walking), relaxation and social capital (see English Nature, 2003; Swanwick et al, 2003)

[2] Blue spaces describe open spaces with water such as lakes, rivers, the sea and urban water features. Access to and benefits of such spaces are also addressed in a wide range of literature concerned with the therapeutic/ health promoting qualities of water (see Volker and Kistemann, 2011)

[3] The use of the term 'white' space is not found to be used in any other literature pertaining to health or geographical research and is used by Finlay (2018) to refer to spaces filled with snow and ice.

preserving the value system of a specific cultural group (Wilson, 2003; Alaazi et al, 2015) or providing contact with nature (Finlay et al, 2015, Thomas, 2015), they generally include landscapes of different scales and nature. In so doing, many of the studies lend themselves to a more inductive approach to identifying people's needs and preferences in terms of places they engage with and their therapeutic impact. By exploring experiences of place from the perspective of particular groups of people, the focus is less on the socio-spatial characteristics of a particular setting and more on where they intersect with the needs and abilities of individuals engaging with them. Therapeutic landscape literature on extraordinary places certainly give thought to the relationality between the physical, social and symbolic dimensions of such places as holy wells, pilgrimage sites and spa retreats as well as the practices that take place within them (Foley, 2011; 2013; Lea, 2008; Maddrell, 2013). But they lack an adequate account of personal health or socio-economic factors influencing how people engage with and benefit from place.

Therapeutic landscapes in ordinary places has by contrast been considered under a much more critical gaze, highlighting how gender, culture, age and health status are implicated in its production (Fullagar and O'Brien, 2018; Thomas, 2015; Plane and Klodawsky, 2013; Wilson, 2003; Alaazi et al, 2015; Chakrabarti, 2010; Coleman and Kearns, 2015; Meijering et al, 2016). As Coleman and Kearns (2015, p.206) point out in their study:

'A therapeutic landscape experience occurs as a result of interactions between seniors, the landscapes of everyday life, and the broader social contexts that shape these settings'.

The bidirectional nature of interactions between personal/cultural factors and people's surroundings is therefore most paramount in the literature on everyday places, thus portraying therapeutic landscapes as relational outcomes of such interactions (Conradson, 2005). Consequently, language barriers (Liamputtong and Kurban, 2018); lack of affordability (Finlay et al, 2015) and gendered norms (Fullagar and O'Brien, 2018) are found to restrict certain populations' access to everyday therapeutic landscapes. For the older participants in Finlay's (2018) study, their engagement with the neighbourhood is affected by seasonal changes, particularly snowfall and ice. Additionally, everyday landscapes that are considered positive for health and wellbeing by some people are experienced negatively by others. Milligan and Bingley (2007) contrast cultural constructs of woodlands as restorative with personal perceptions of danger, which deter some youths from engaging in local woodlands. Similarly the studies by Wakefield and McMullen (2005) and Masuda and Crabtree (2010, p656), both offer a 'paradoxical therapeutic response' by local residents to the wider social and political

stigmatisation of their neighbourhoods. Focusing on ordinary places, these studies have therefore sought to frame therapeutic landscapes within broader social, economic, cultural and personal circumstances affecting people's daily lives.

The other subcategory within ordinary and everyday settings, I call *community activities,* include walking groups (Doughty, 2013; Macpherson, 2017), an 'alternative' psychiatric survivor group (Laws, 2009), a local heritage group (Power and Smyth, 2016) and community gardening and similar projects (Milligan et al, 2004; Marsh et al, 2017; Pitt, 2014; Sanchez and Liamputtong, 2017; Milligan et al, 2015). These are activities usually designed and created for specific, often marginalised, groups such as older men and women and people with certain health impairments. In this respect, they are similar to drug and alcohol recovery programmes (Love et al, 2012; Wilton and de Verteuil, 2006), or youth camps (Dunkley, 2009), in that they are exclusive. But what distinguishes community activities from such interventions is that they are community based and focus on providing psycho-social benefits through participation in ordinary everyday activities and community networking. Most of the community activities studied therefore encourage ongoing attendance, providing a place for people to escape their daily pressures and tackle experiences of isolation at home or in wider aspects of community life.

A common theme within this literature is that ordinary everyday settings are considered as landscapes for *maintaining* wellbeing and a part of people's routine lifestyles. Neighbourhood environments, including green and blue spaces, are explored as sites where multiple aspects of wellbeing- physical, social, mental and spiritual- are continually negotiated and maintained by local residents (Bell et al, 2017; Coleman and Kearns, 2015; Cattell et al, 2008). Whilst they are not approached as special places providing 'healing', they are integral to feeling and functioning well and maintaining a 'healthy balance between met and unmet needs' (Cattell et al, 2008, p.545) in people's daily lives. In the studies exploring experiences of people who have been displaced through migration or have certain debilitating health conditions, therapeutic landscapes are often explored in relation to people's adjusted lifestyles. Local diasporic communities and transnational relations become important sources of support for pregnant Bangladeshi women living in New York (Chakrabarti, 2010), African immigrant's in Canada seek social and spiritual reassurance in places of worship (Agyekum and Newbold, 2016) whilst the body, home and the wider community turn into sites in which recovery and efforts to endorse a healthier lifestyle occurs for survivors of breast cancer (English et al, 2008). There is an emphasis on the rehabilitative potential of everyday landscapes, supporting people to adjust to their changing circumstances. But linked to this, there is also the idea, particularly in research

concerning people with enduring health conditions, that wellbeing experiences 'relate to improving the quality of life for people and their carers; that is, people may not necessarily be well, but they feel well' (Marsh et al, 2017, p.111). Learning to better self-manage their health (Brewster, 2014), finding a 'space in the world' (Laws, 2009) or feeling a sense of achievement (Meijering et al, 2016; Macpherson, 2017) are some of the many benefits people with a debilitating health condition gain from their everyday environments. A broader scope of restorative motives for and experiences of engaging with everyday landscapes by people with specific health conditions, than simply recovery, is therefore considered within this strand of therapeutic landscapes literature.

Additionally, the literature in this review is found to approach the ordinary and everyday in three quite distinct but interrelated ways. Most studies focus on specific settings such as public libraries, churches and mosques or particular green and blue spaces in the neighbourhood. In this case, therapeutic landscapes are examined in relation to the range of functions they serve in the daily lives of individuals, including the subjective meanings they hold for people. There is a smaller body of research which focus on place-based activities people engage in within and across settings such as walking (Doughty, 2013; Macpherson, 2017), swimming (Foley, 2015), diving (Straughan, 2012) and sharing of food and advice (Chakrabarti, 2010). These studies conceptualise therapeutic landscapes as occurring in and through the activities, referring to concepts of therapeutic 'mobilities' (Macpherson, 2017), 'assemblages' (Doughty, 2013) and 'networks' (Chakrabarti, 2010). This reflects trends in the wider therapeutic landscape literature, where place is increasingly rendered as fluid and continuously unfolding through interactive processes between human and non-human elements (Gatrell, 2013; Foley, t2011; 2014; Gorman, 2017; Plane and Klodawsky, 2013). The other particular perspective of therapeutic landscapes found amongst the extant literature, is that it can be intangible and difficult to attribute to the socio-spatial environment that 'exist in 'real' (linear) time and in physical space' (Andrews, 2004, p.309). Gastaldo (2004) discusses the therapeutic landscapes of the mind, whereby everyday experiences of the host country are shaped by and through the immigrant participants' memories and practices of their home country. Wakefield and McMullen (2005) also draw on the blurred nature of real and imagined characteristics of place determining whether they are considered as therapeutic or harmful by local residents and outsiders. Thus, Laws (2009) contrasts the general perception of a city park as dangerous and decrepit with the 'dissident connectedness' it provides a psychiatric survivor group. In this way, everyday settings are conceptualised as layered with both real and imagined landscapes, shaping their therapeutic experiences.

4.3.2 *Therapeutic engagements and benefits*

The literature on everyday therapeutic landscape experiences examines the processes through which routine interactions with and activities in ordinary settings become therapeutic, and in turn contribute to the maintenance of health and wellbeing for individuals. The studies in this review therefore, to a varying extent, attend to the three dimensions of people-place interactions (physical, social and symbolic) proposed by Gesler (1993) to illustrate the therapeutic qualities of participants' experiences in particular settings. In this section, I will briefly outline ways in which the physical, social and symbolic characteristics of everyday settings, particularly in terms of how they are constructed, perceived and engaged with, have been described to impact health and wellbeing within the literature.

Across the literature there is a common concern with the role of the physical environment in supporting health and wellbeing. Both aesthetically pleasant views and health promoting activities facilitated by the physical landscape are considered important for maintaining the health and wellbeing of people who participate in them. Direct physical engagement with the sea (Foley, 2015; Bell et al, 2015), countryside (Doughty, 2013; Bell et al, 2017; Macpherson, 2017; Houghton and Houghton, 2015), woodlands (Milligan and Bingley, 2007), community gardens (Sanchez and Liamputtong, 2017; Milligan et al, 2004; Marsh et al, 2017) or nearby parks and other facilities (Finlay et al, 2015; Thomas, 2015) are found to often involve activities that enhance physical health. Bell et al (2015) associate the range of activities allowed by the coast such as running, walking, sailing, kayaking, fishing or surfing, as integral to its therapeutic qualities. In addition to blue spaces, local green spaces are reported to similarly promote physical activity amongst older people through encouraging 'lower-impact walking and gardening, and also... hiking, bicycling and tennis for more mobile participants' (Finlay et al, 2015, p.100). People with reduced physical health are also able to continue using local blue and green spaces for leisure activities that are less challenging (Milligan et al, 2004; Doughty, 2013; Macpherson, 2017). Some studies in this case particularly focus on the habitual and rhythmic nature of walking and gardening, through which the landscapes are considered enabling and restorative (Gatrell et al, 2013; Pitt, 2014; Doughty, 2013). These activities therefore have clear physical health benefits, resulting in enhanced mobility and weight management. Also by offering people with reduced physical capacity the opportunity to engage in outdoor hobbies that are more suited to their needs, physical landscapes play an important role in addressing isolation and boredom amongst certain populations.

But whilst physical activity is an important means through which everyday landscapes are often linked to health and wellbeing, many of the studies highlight more passive ways in which people can benefit from their physical surrounding. Coleman and Kearns (2015, p.215), state that 'Given our cohort of 'older' seniors, participants' appreciation of such spaces was less connected with actively engaging with natural settings as it was with being in proximity to beaches, the sea, bush and hills'. Both Bell et al (2015) and Finlay et al (2015) emphasise the versatility of blue and green spaces, where specific physical activities as well as more general sensory immersion can be enjoyed. Much of the literature focusing on natural elements of everyday settings therefore draw attention to people's sensory and embodied restorative interactions with fresh air, water, trees, wildlife, plants, clouds in the sky, sunset and scenic views. These studies claim that the aesthetic beauty and slow pace of natural settings allowed 'connections that facilitated observation, contemplation and, ultimately, a contribution to wellbeing' (Coleman and Kearns, 2015, p.215 see also Bell et al, 2017; Houghton and Houghton, 2015). The restorative impact of nature is thus invariably linked to the micro-scale elements of smell, sight, textures, and sounds within these settings, rendering therapeutic landscape experiences as multisensory (Bell et al, 2015; Finlay et al, 2015; Milligan et al, 2004).

Collectively, natural physical features of everyday landscape are considered to evoke feelings of calmness, relaxation, reflection, freedom and emotional transitioning. There is a common theme of physical and emotional rejuvenation as a result of corporeal and mental engagement with such landscapes. But a similarly strong narrative of therapeutic multi-sensorial experiences is not apparent in studies concerned with more urban landscapes which include churches, mosques, public libraries, street markets and residential areas. In the urban context, proximity of local amenities (Piat et al, 2017; Plane and Klodawsky, 2013; Sampson and Gifford, 2010) or spatial features of particular built environments espousing a 'non-technical space' (Laws, 2009) or the 'freedom to tarry' (Brewster, 2014; Cattell et al, 2008) are associated with enhanced feelings of wellbeing. Whilst proximity to schools, shops and places of worship are important for carrying out daily activities, the non-purposive and dynamic nature of other everyday settings such as local parks and libraries are found to offer a sense of freedom and comfort. But much of the literature on urban settings nonetheless attributes the occurrence of therapeutic landscape experiences on the "coexistence of city and nature" (Volker and Kistemann, 2013, p.146). Coleman and Kearns (2015, p.215) conclude their article with 'seniors' opportunities for wellbeing are increased when there are local places where natural beauty can be enjoyed'. It is implied that the presence of nature is an important contributory factor to the aesthetic beauty and therapeutic landscape experiences of urban settings (Colley et al, 2016; Piat et al, 2017; Sampson and Gifford, 2010; Volker and Kistemann, 2013; 2015).

The impact of other physical or sensory features of urban landscapes on health and wellbeing, such as graffiti on walls (Masuda and Crabtree, 2010; Laws, 2009), smoking chimneys (Wakefield and McMullen, 2005), noise of human traffic (Volker and Kistemann, 2013) or a quiet and 'secluded spot on a housing estate' (Cattell et al, 2008, p. 552) is much more dubious within the literature. They are not discussed as being pleasant to the senses, but shown to have therapeutic impact because of the meanings or purpose they hold for certain people. The graffiti or artwork on the walls represents reclamation of a space by people who are otherwise marginalised. Similarly, an out of sight area on a council estate is a private space for a teenager to smoke and escape to (Cattell et al, 2008). Likewise, for immigrants their imagined sense of therapeutic landscapes is sustained through a variety of multisensory aspects of their everyday urban life such as music, food and art which are only meaningful to them (Gastaldo et al, 2004). In this way, people's experience of the physicality and sensorial nature of everyday urban landscapes is portrayed as much more diverse, relational and personal in comparison to blue and green spaces within the therapeutic landscapes literature.

The literature also draws links between physical and social environments, arguing that the two are intimately linked in the construction of therapeutic landscapes. Coleman and Kearn (2015) attribute islanders' sense of community to the physical isolation and boundedness of the island. Milligan et al (2004, p.1785), discussing people's engagement in communal gardening, claim that 'the aesthetics of a pleasing and tranquil environment form a significant element of the therapeutic qualities of the social encounter'. Similarly, rural village settings are seen as socially 'unthreatening' landscapes for stroke survivors who prefer social interactions from a distance (Meijering et al, 2016).   But, whilst most of the articles allude to a harmonious intertwining of the physical and social dimensions of place, studies focusing on unhealthy physical environments demonstrate the compensatory role social support play in such settings to generate therapeutic landscape experiences, (Laws, 2009; Masuda and Crabtree, 2010; Plane and Klodawsky, 2013). Despite the deprived socio-economic status of the neighbourhood, the local residents in Wakefield and McMullan's (2005) study emphasise strong social ties with their neighbours as a protective factor for their health and wellbeing. In this respect, social relations and interactions still remain emplaced, since the material deprivation of the neighbourhood has played a significant role in isolating the residents from neighbouring areas and instead bringing people within the neighbourhood closer together.

Social integration facilitated through opportunities to interact with other people is a key therapeutic outcome of places studied in the review articles. Everyday settings and activities are essentially access points to either specific groups of interest (Agyekum and Newbold, 2016;

2016; Chakrabarti, 2010; Doughty, 2013; Marsh et al, 2017; Milligan et al, 2015) or the wider community (Cattell et al, 2008; Finlay, 2018; Masuda and Crabtree, 2010; Meijering et al, 2016; Piat et al, 2017; Plane and Klodawsky, 2013). Allotments in Milligan et al's (2004) study are considered as places which, through communal gardening, offer participants a means of 'combating social isolation and promoting the development of their social networks' (p.1790). Similar benefits are also found in more fleeting encounters between people at the beach, riverside or street markets, contributing to 'perceptions of inclusion and a sense of community' (Cattell et al, 2008, p.547, see also Meijering et al, 2016; Plane and Klodawsky, 2013). Providing a sense of belonging and shared identity, the social milieu in places of worship, parks, street markets, community gardens, promenades, walking groups or the local heritage group therefore fulfil an integral facet of health and wellbeing.

Many social landscapes are also found to be important for conferring people's self esteem and sense of self. Milligan et al (2015, p.135) in particular identify the familiarity and significance of communicating 'shoulder-to-shoulder' for the male participants in the 'Shed' project, allowing them to experience a continued sense of self and enhancing their ability to relate to their peers. Several of the studies also highlight that sharing of information and experiences 'acts as a buffer to alleviate distress and strengthen resilience for individuals who experience stressful life events' (Liamputtong and Suwankhong, 2015). Similarly, shared activities such as communal gardening and walking groups are found to encourage people to support one another in order to complete tasks (Macpherson, 2017; Milligan et al, 2004). The establishment of such reciprocal relationships are not only reported to contribute to the achievement of personal and group goals, but also lead to personal empowerment. In this way, parks and promenades used by people to spend time with family and friends have been discussed as therapeutic landscapes, since they provide opportunities to maintain meaningful relationships (Sampson and Gifford, 2010; Thomas, 2015; Volker and Kistemann, 2013).

The final dimension of people-place interaction impacting on experiences of health and wellbeing, as proposed by Gesler (1993; 1996) is symbolic. People's experiences of socio-spatial environments are mediated through the symbolic meanings that they are assigned by people. Places of worship represent a direct connection with the greater force, where people feel closeness to god and enhanced spirituality. Similarly, much of the therapeutic landscape literature involving everyday blue and green spaces attends to a 'symbolic construction of their scenic and picturesque beauty' (Macpherson, 2017, p.251). Therapeutic experiences are often described in terms of symbolic conceptions of feeling a sense of oneness with nature or a sense of renewal within it. But, in studies which focus on everyday environments that are not

characterised by nature or spirituality, examples of symbolism and its impact on experiences of health and wellbeing is much more complex and subtle. Local parks, libraries, shops and housing estates are not characterised by specific symbols as are extraordinary places of healing. Rather, in the context of everyday landscapes, as Volker and Kistemann (2013, p, 143) argue, 'emotions, identities or sense of place are included' within the range of symbolic experiences shaping people's daily lives.

The review literature often links experiences of health and wellbeing to experiences of one or more of the four dimensions of 'sense of place' outlined by Kyle et al (2004): place attachment involving affective emplacement (Coleman and Kearns, 2015; Milligan and Bingley, 2007; Piat et al, 2017), place bonding involving emplacement through shared experiences (Chakrabarti, 2010; Doughty, 2013), place dependence involving emplacement through particular behaviours and activities (Bell et al, 2015) or place identity involving the cognitive emplacement of self (Gastaldo et al, 2004; Laws, 2009). Food, music, language, cultural practices, images, memories of places and events, social norms, patriotism and collective identity of social and political marginalisation are some of the features of people's daily lives that are found to hold symbolic value. They permeate the physicality and sociality of landscapes discussed in the studies, influencing how people perceive and feel within place. Laws (2009, p.1830) describes 'a symbolic reclamation of the park from a discourse of unhealthiness to a symbolic landscape of recovery' referring to the dissident identity of the group. The group's alternative discourse of psychiatric survivorship as opposed to psychiatric therapy, is supported by the marginal social status of the members and the decrepit setting in which they meet. Thomas (2015) refers to the significance of socio-cultural identity in people's use of a particular park in Copenhagen:

'Kongens Have, for example, was a key destination space for most of the younger women interviewed, since it was considered a fashionable setting in which to socialise with others, to drink alcohol and to perform a public identity.' (p.190)

The park promotes a particular lifestyle and identity, defined by class, influencing the kind of people who experience and enact a sense of place within such a setting. Likewise, Milligan et al (2015) draw on the symbolic significance of the 'Shed' project, concluding that the resemblance of the shed environment and activities to male orientated work the participants have previously been familiar with supports the maintenance of their sense of self and place. The concept of 'ontological security' is in this case mentioned in a few of the articles, describing people's existential sense of comfort and security in particular settings. People are actively enrolled in the process of creating places and experiences of ontological security, whether they create a

garden as a 'retreat from the conflicts and perceived threats of the urban landscape' (Milligan et al, 2004, p.1786) or 'build and maintain a daily routine during retirement' in order to combat physical and social isolation (Finlay et al, 2015, p.100).

In a number of articles then symbolism is linked to people's perceptions of landscapes as a reflection of themselves. In Coleman and Kearns (2015) study, the older participants contemplate ideas of journeying and exile in respect to the island as symbolising their current stage in life where they have reached an end. Similarly both Milligan et al (2004) and Meijering (2016), bring attention to how unattended gardens can represent loss of skills and current state of incompetence amongst people who have been affected by physical ailments. However, for people who are blind or visually impaired, reaching a summit during their walking expeditions symbolises achievement (Macpherson, 2017). The symbolic meanings ascribed to the socio-spatial composition of and interactions with everyday settings, whether they are rooted in personal or collective values, therefore influence how people perceive and experience place. People's sense of place, which occurs through symbolic pathways, is in this respect considered an important mechanisms through which place effect health and wellbeing and therefore an important purchase in therapeutic landscape literature.

4.3.3   Methodological innovations and implications

In an effort to achieve a nuanced understanding of people-place interactions and processes linking health and wellbeing to experiences of everyday landscapes, all of the review studies are of a qualitative nature. They follow Gesler's conception of therapeutic landscapes, influenced by cultural geography which prioritises the need to seek subjective meanings and rich descriptions over other approaches (1992; 1993). Following a case study design, most take a specific site, type of environment and/ or population as their object of enquiry, and examine people's experiences of and meanings they attach to particular settings and activities within them. Some studies further align themselves with a specific qualitative approach, such as phenomenological interpretivism (Coleman and Kearns, 2015, Bell et al, 2015; 2017), ethnography (Cattell et al, 2008; Doughty, 2013; Laws, 2009; Macpherson, 2017; Milligan et al, 2004, Pitt, 2014) or community-based participatory research (Marsh et al, 2017; Masuda and Crabtree, 2010). Whilst these different approaches are tied to slightly different research aims and their epistemological stance is not necessarily alike, there are commonalities in the use of qualitative research tools across this body of work.

All studies are concerned with eliciting detailed accounts of participants' experiences of place, mainly by use of semi-structured or unstructured interviews. Gastaldo et al (2004) and Houghton and Houghton (2015), take a slightly different approach presenting authors' own written narratives on adjusting to life in Canada and an analysis of a reflecting literary piece on London's 'edgelands', respectively. Whilst these narratives are not data generated through interviewing, they are nonetheless personal accounts, revealing processes through which people understand and construct their landscapes of experience. They, along with the interview data are thus based on people's in-situ or post hoc reflection on how they negotiate and engage with different dimensions of place and their benefits. Some studies have also sought to add a longitudinal dimension to the interview data, linking people's personal motivations and preferences, integral to therapeutic landscapes, to past experiences. Brewster et al (2014) conduct life course interviews to place mentally ill participants' experiences of public libraries in the context of their individual biography and illness history. Milligan and Bingley (2007), Foley (2015) and Bell et al (2017) also explore participants' life histories, particularly their previous engagements with woodlands, 'swimming spots', and green and blue spaces, respectively, to understand their impact on participants' present day perceptions and use of such landscapes.

In a number of studies, the one to one interviews are accompanied by some form of a mapping exercise, producing a visual representation of places and activities people engage with. This is particularly appropriate in research exploring people's experiences of neighbourhoods, allowing research participants to identify and discuss places of varying importance and function in their neighbourhood (Bell et al, 2015; 2017; Liamputtong and Kurban, 2018; Power and Smyth, 2016; Sampson and Gifford, 2010). Participants in Sampson and Gifford's (2010) as well as Liamputtong and Kurban's (2018) studies, were asked to draw their neighbourhood, mapping out various features they engaged with as well as highlighting those they like and those they did not like. Liamputtong and Kurban (2018, p.101) who worked with Middle-eastern refugees now living in Australia noted that producing visual maps in this way 'is particularly useful when engaging with participants with linguistic and conceptual barriers'. The task of plotting and colour coding places on a map is in this way an effective method of eliciting complex relationships people have with different places. On the other hand, Bell et al (2015; 2017) have used GPS to track and map participants' movements in and around local green and blue spaces for a period of one week. The GPS provided instantaneous data of routes taken, amount of time spent at each location and how often certain places were frequented during the week, which were then used to produce personalised geo-narrative maps to aid participants' recollection of events during the interview.

Another visual aid commonly used in the studies is photo-elicitation, also described as photo-novellas and photo-voice. Participants in these studies took photographs of settings, objects and activities describing their experiences of place and then built their interview narratives around these images (Coleman and Kearns, 2015; Masuda and Crabtree, 2010; Piat et al, 2017; Plane and Klodawsky 2013; Sampson and Gifford, 2010). This is considered a participatory method, allowing participants greater control over how they construct their stories of therapeutic landscape experiences. In Masuda and Crabtree's (2010) 'community-based participatory research' such an approach was important for empowering and giving participants an active role in the data collection process. Thus, most of the studies use a semi-structured approach for guiding participants in taking photographs and discussing them in the interview. Plane and Klodawsky (2013, p.4) however, employed a more 'open-ended approach and simply asked the women to discuss the content of their photographs and the meanings behind each place, person or object depicted'. Likewise, in Coleman and Kearns (2015) study where the researcher took photographs at the participant's direction, they found that 'it was the act of taking photographs, rather than simply the photographs themselves, which enabled the interpretation of participants' experiences of aging-in-place' (p.209). The task of taking and presenting photographs is therefore found to be a useful 'ethnographic tool' (Sampson and Gifford, 2010, p.118).

To explore what participants know and can articulate about their emplaced experiences of health and wellbeing, as well as that which can be deduced from their interactions with and in place, many of the studies have adopted ethnographic methods of enquiry. For a number of researchers, this involved spending extended periods of time becoming familiar with the research participants, settings and practices. Cattell et al (2008) and Foley (2018) conducted observations of their research sites, whereas other studies have relied on more immersive practices. Macpherson (2017) volunteered as a sighted guide with the walking group, Doughty (2013) regularly walked with the ramblers she studied, Laws (2009) sat in the psychiatric survivor group meetings, Finlay (2018) accompanied her participants in their daily routines, Straughan (2012) undertook a diving instructor course, whilst Milligan et al (2004) and Pitt (2014) participated in communal gardening. Through participant observations the studies achieved rich context specific insight to people's experiences of health and wellbeing. Straughan (2012) and Doughty (2013) draw on their own sensorial and practical experiences of place suggesting the primacy of embodied and pre-reflective knowledge of place in the construction of therapeutic landscape experiences, which can only be appreciated through *doing*.

Mobile interviewing has in this case been a key ethnographic data collection tool to capture therapeutic landscape experiences as they are constructed. Generally referred to as 'go along interviews' (Colley et al, 2016; Macpherson, 2017), 'walking interviews' (Bell et al, 2015; 2017; Finlay et al, 2015), 'walking-whilst-talking' (Doughty, 2013), or 'accompanied outings' (Finlay, 2018; Plane and Klodawsky, 2013), they have been used in studies concerned with larger settings such as neighbourhoods and expansive green and blue spaces, involving movement of people. This method essentially allows both participant observation and in-situ interviewing to take place on the move, therefore revealing how people negotiate and interact with different aspects of place. It elicits people's cognitive and affective responses to their surrounding which are embedded in corporeal engagement and movement through place. Thus, Colley et al (2016, p.606) point out that 'The go-alongs revealed not only the ways in which outdoor breaks contributed to mental well-being, but also the particular places that these benefits were associated with'. The mobile nature of this interviewing technique therefore brings forth the different elements of place people encounter on route and how they contribute to or contest experiences of therapeutic landscape experiences.

4.4   Conclusion

So to conclude, this chapter considers the following two intertwining questions: how useful is the concept of therapeutic landscapes and its use in the extant literature in thinking about how to explore and understand experiences of people with dementia in the wider community? Also, what contribution can the present project aiming to apply therapeutic landscapes to the study of the daily lives of people affected by dementia make to dementia research? Based on this discussion, the overall aim of the study and a number of research objectives will be devised and presented.

A review of the literature reveals that therapeutic landscapes are not only places which heal but also places which attend to experiences of wellbeing and *wholeness* of person, which is particularly important in the case of people with dementia. The aim of the present study is not to explore experiences of healing and recovery but ways in which people with dementia's overall health and wellbeing is sustained, despite living with the condition. Whilst the physical and cognitive impact of dementia cannot be undone, it is held that people can be supported to live well with dementia. Recognising that the physiological and social challenges faced by people with dementia occur in geographical context, the goal of dementia friendly communities is to create public spaces in which they can fully and meaningfully participate. Thus, the therapeutic

landscapes concept facilitates a consideration of health and wellbeing in the context of socio-spatial interactions shaping how people with dementia perceive and experience their daily lives. Across all of the literature reviewed in this chapter, therapeutic landscapes are discussed in terms of enabling people to manage their own physical and mental health, to experience a connection to others and their physical surrounding, and to attain a sense of achievement. Directing the focus of my research to such health and wellbeing related impact, therapeutic landscapes offers an important lens for exploring how place can support and enhance the quality of life of people affected by dementia.

The review also illustrates application of the therapeutic landscapes concept to various ordinary settings recognised for their health promoting qualities, including everyday locales. These studies have successfully demonstrated that restorative landscapes are not restricted to extraordinary sites, but can be created and experienced in ordinary everyday places. As noted in the previous chapters, dementia research has to date mainly focused on people's experiences in the home and care settings, in which case exploring their therapeutic landscape experiences in community settings will expand current understandings of the lived experiences of people with dementia. Everyday settings in the therapeutic landscape literature represent places in which people are already embedded and which are part of their daily lives, therefore confirming my decision to explore the health and wellbeing impact of people with dementia's everyday geographies. For people with dementia, therapeutic landscapes may exist in a cafe, a local park, or the marketplace. But, therapeutic landscape studies have generally taken a deductive approach to examining therapeutic experiences in everyday settings, predefining their setting of interest in terms of its location or physical characteristics, such as local green and blue spaces, woodlands or gardens. To fully appreciate experiences of therapeutic landscapes for people with dementia in the wider community however, this study will take an inclusive approach considering all types of places and activities which the participants engage with beyond the home.

People with dementia are a population who are biographically diverse with different ideas about health and wellbeing and places and activities that are important to conserve their desired state of health and wellbeing. Whilst some scholars adopting the therapeutic landscapes concept have taken into account past experiences and socio-cultural factors influencing experiences of therapeutic landscapes, there is call for further examination of how people make choices about the places they engage with and those they do not, and the role such places play in people's daily lives (Bell et al, 2014; Thomas, 2015). I will therefore take people with dementia's daily routines as a starting point in order to understand where and how therapeutic

landscape experiences occur in their everyday context, potentially further expanding the range of therapeutic geographies found in existing literature. Also, focusing on the agency and biographical trajectories of people with dementia will not only bring to light their longstanding relationships to places but also the fluidity of such relationships precipitated by the onset and progression of dementia. People with dementia's changing engagement with settings in the wider community are intricately linked to shifting identities, values and wellbeing priorities. Certain everyday places may thus become more or less therapeutic for people with dementia, as their capacities and preferences change, which will further emphasise the temporal nature of therapeutic landscapes, yet only scarcely identified within the extant literature, and in turn facilitate a more critical examination of the concept.

The therapeutic landscape concept essentially allows a consideration of how people with dementia relate to and utilise the physical, social and symbolic elements of place, therefore turning attention to micro-scale interactions characterising people's daily routines and socio-spatial experiences. Thus, many of the studies have taken an ethnographic approach to obtain rich and nuanced accounts of such interactions. The use of some of the visual and mobile methods found in these studies will be of particular value in my study involving participants who may have difficulty recalling or verbally articulating aspects of their experiences. This will be a significant investment to the existing, relatively small, body of work within dementia research concerned with environmental features relating to issues of orientation and way finding in outdoor settings. With an emphasis on the detrimental impact dementia has on people's ability to access and engage in place, themes relating to socio-spatial encounters and the mutually constitutive and health enhancing elements of people- place interactions remain inadequately developed in such research.

To summarise how the review has informed and helped to further clarify my research aim; it has firstly highlighted the use and experience of a wide range of everyday environments in which therapeutic landscape experiences can occur. This includes '*community activities'* such as dementia groups which, although based on exclusive membership, promote regular engagement in the wider community and therefore an important part of people's everyday geography. Secondly, exploring therapeutic landscapes from a first-person perspective such experiences are considered to be relational. Therapeutic landscape experiences hinge on personal and socio-cultural factors, particularly in regards to access to and perceived health and wellbeing benefits of certain settings. They are in this respect fluid, whereby people's perspective and experience of places may change over time, especially with the onset and progression of dementia. Thirdly, the review studies draw attention to socio-spatial dimensions of people place interactions;

drawing attention to spatial features that promote health affirming physical activities as well as restorative mental immersion and social milieus that enable people to establish and maintain meaningful relationships. Underpinning these socio-spatial interactions are symbolic meanings and processes connecting particular settings and activities to people's self identities and sense of place.

The review also leads to many important questions about how might the therapeutic 'process work itself out in place' (Gesler, 1992, p.742) in the context of dementia. People affected by dementia are often physically and socially isolated, in which case for those individuals living in inner urban neighbourhoods how accessible are places of nature and aesthetic beauty found to be important for therapeutic landscape experiences in outdoor settings? Or are there alternative settings which they utilise for similar benefits? To what extent does their shrinking social networks and activities impact on their experience of belonging and engagement in the wider community? Or are such connections less important? For many people with dementia, visual and hearing deterioration along with cognitive changes causes their ability to understand the implications of sensory experiences to slowly diminish and their perceptions of their surroundings to become distorted. Their experience of disorientation in time and space also has an impact on their sense of self and place. So whilst concepts of place making and therapeutic landscapes of the mind are useful for understanding how individuals contribute to the construction of therapeutic landscapes, do experiences of dementia deem such processes to be much more complex than that documented within the therapeutic landscapes literature? All of these questions therefore inform this study's approach to examining how health and wellbeing is maintained and enhanced through people with dementia's engagement with the wider community. These questions also underscore the concern with adopting a methodological approach which will generate such data, whilst being suitable for use with people with dementia. The methodological choice, informed by the review, will however be discussed in the following chapter, though the research aims and objectives are outlined below.

Study aim and objectives

The overall aim of this study is to explore experiences of social and spatial engagement in the wider community for people living with dementia in order to advance understandings of their impact on health and wellbeing. This study is therefore concerned with addressing the following research question:

What type of community settings are now important to people with dementia and how do people's changing relationships to and everyday interactions with such places contribute to their perceptions and experiences of health and wellbeing.

The specific objectives of the research are to:

1. Describe people with dementia's experiences of engaging with community settings, from their perspectives and that of their carers.
2. Understand how people with dementia experience the link between engagement with place and health and wellbeing
3. Explore how family members/ carers understand and support engagement and experiences of health and wellbeing of people with dementia
4. Explore the dynamics between people with dementia's social networks/ practices and engagement within community settings.
5. Identify characteristics of place, interactions and processes which facilitate/inhibit engagement with place and experiences of health wellbeing for people with dementia

CHAPTER FIVE

Placing the senses: A sensory ethnographic study

5.1   Introduction

This chapter will discuss how the methodological design of the study supports its aim of exploring socio-spatial experiences of engaging with the wider community and their impact on the health and wellbeing of people living with dementia. As a CASE studentship, the broad aim of the study, along with some of its parameters which I will discuss in the course of this chapter, were predetermined by the PhD supervisors at Lancaster University and Age UK Lancaster. My role was to further articulate the research objectives and methodological approach for undertaking the research. Understandings of dementia and the relationship between health and place, considered in the previous chapters have thus been instrumental in my formulation of the research questions set out in chapter four. A critical appraisal of this research also provided foresight to possible ways of addressing these questions and in so doing lead me to consider sensory ethnography as my primary approach. Its ability to yield rich descriptive insights to the sensorial realities of settings and participants' experiences rendered it an apt and novel approach to understanding how people perceive, interact with and experience place. How I adopted this particular methodology within my study were however further clarified through consultations and piloting of the methods with people who are affected by dementia.

Methodological insights gained from the literature considered in the previous chapters will be discussed in the first section, followed by section two, providing a detailed account of sensory ethnography and the suitability of particular methods to the aims and objectives of the study. Section three discusses the role and input of a public involvement panel within the study, followed by a detailed account of the fieldwork process, including a description of the sample, recruitment strategy and data collection methods and my role within the research, in section four. In section five I detail the process of thematically analysing the qualitative data and then in section six I discuss some ethical issues pertinent to the research and how they have been addressed. The final section considers issues relating to research quality and rigour, followed by some concluding remarks.

5.2   Insights from existing literature

As I have noted in chapter two, there has been a growing interest in the lived experiences of people with dementia and their carers within dementia research. Describing experiences from the perspective of people with dementia through qualitative engagement was therefore one of the main stipulations set out by the supervisory team and forms a key objective (*objective 1*) in this study. Research *objectives 2 and 3* further augment the role of people with dementia and their family carers by allowing them to identify and define issues that are important to their experiences of health and wellbeing and of place, whether as research advisors or participants. Input from family carers became an important part of these objectives following a consideration of studies (Gilles, 2012) and conversations with people with dementia and their carers which highlighted the central role family carers play in ensuring that the places and activities the person with dementia engages with are supportive of their needs.

With the gradual diminishing of their cognitive and communicative abilities, engaging people with dementia in research is nonetheless without problems. A number of dementia studies acknowledge that people with dementia possess agency, but contrast language and reflective capacities, through which people express their views and experiences, with more embodied forms of agency people express through non-verbal gestures and behaviours (Kontos, 2004). There is thus a call for methods which enable rather than hinder people with dementia to meaningfully engage in and contribute to research despite their declining cognitive and verbal abilities (Bartlett, 2012). Linked to these developments within dementia research, psycho-social and socio-cultural theorists have made efforts to shift the focus of enquiry from the disease to social interactions and practices people with dementia engage in. Research *objective 4* of this study thus addresses the dynamics between people's experiences of health and wellbeing and their social networks/ practices in community settings.

Literature considered in chapter three and four has been most useful in providing both theoretical and methodological insights to understanding how experiences of place by people with dementia and their impact on health and wellbeing can be theorised and researched. The multi-faceted and relational perspective of place inherent within the therapeutic landscape framework has been significant in framing research *objective 5*. It adopts a view of place that is both holistic (social, physical and symbolic) and dynamic (in a constant state of *becoming*), suggesting the need to explore place as it is *done* and experienced (Creswell, 2004; Massey, 1999). The choice of methodology was therefore important for two specific reasons in this study, to firstly enable organic engagement of people with dementia in the research process and setting and to secondly examine place as a multidimensional experience. A methodology that

enables an exploration of people's cognitive and corporeal engagement with place to elicit how different components of people-place interactions combine and create certain experiences was required. It was also important to adopt a subjective-person-centred approach which could provide descriptive insights to the complex and changing nature of a person with dementia's embodied and emplaced interactions with place, linking the internal with the external and agency with structure. A sensory ethnographic approach was seen to potentially satisfy these criteria (Howes, 2005; Pink 2008, 2015).

5.3   Sensory Ethnography

Whilst previous research involving people with dementia have successfully used traditional ethnographic approaches, sensory ethnography was chosen in this study to offer a richer and more textured understanding of the embodied and emplaced world of participants (Hubbard et al, 2003; Kontos, 2004; McColgan, 2005). Sensory ethnography is the study of people's 'sensory, emotional and intellectual experiences' (Sunderland et al, 2012, p.1056), specifically explored through the ways in which their bodies interact and engage with their surroundings. It provides a nuanced approach to what Atkinson et al (2008) claim ethnography has always been in the business of doing: 'studying the 'social and cultural life with a proper regard to the many modalities of action and organization: sensory, discursive, spatial, temporal, and material' (p.2). The view that people's experiences of the world are multisensory, in which their sense of smell, touch, taste, hearing and sight are all intertwined, has seen a sensorial revolution in social research in recent years (Howes, 2005, 2006; Pink, 2008; Pink et al, 2013; Sunderland et al, 2012). Howes (2005), a proponent of sensory anthropology, highlights 'the sensuous interrelationship of body-mind-environment' (p.7) in his work. Senses play an important role in theories of embodiment and emplacement, as they seek to explain how place is constructed and experienced by people. Sensory ethnography has thus been used in a vast range of contexts exploring such issues as experiences of commuter cycling (Jones, 2012), to energy consumption in the home (Pink and Leder Mackley, 2012), place making by the researcher during an urban tour (Pink, 2008) and the social determinants of health in place (Sunderland et al, 2012).

Taking the body and embodied experiences as its primary focus, sensory ethnography sits within a constructionist paradigm, in that social phenomena are understood to be constructed through the actions and interpretations of human beings (Berger and Luckmann, 1991). For sensory ethnographers individual realities are the outcome of both cognitive and embodied systems of meaning making people engage in, in their everyday lives. The most appropriate way to understand particular phenomena or experiences is to observe them in their context, to

become familiar with the interactions and practices of those participating within a setting (Hammersley and Atkinson, 2007; Pink and Leder Mackley, 2012). Construction of therapeutic landscapes can therefore benefit from a sensory ethnographic exploration of the dynamic relations between social, spatial, temporal, psychological, and symbolic entities. This type of analysis considers the spatial characteristics, material objects, olfactory stimuli, soundscapes and aesthetics as more than a backdrop of experiences, and instead explores their role in constructing meanings through the way in which they are perceived and experienced by individuals. As a conceptual framework for understanding how place impacts health and wellbeing, exploring how people's perceptions and experiences of therapeutic landscapes are mediated through their body is key. As a researcher I would be attending to the sensoriality and materiality of my participants' therapeutic landscape experiences, to, if not perceive and appreciate such landscapes in the exact ways as them, at least see, feel and participate in the processes through which they are constructed.

Also important to note here is that a transaction of structure and agency is clearly at play in the configurations of place and people's experiences of them. Proponents of sensory ethnography have highlighted the socio-cultural conditioning of bodily senses and sensory experiences (Howes, 2005). Sunderland et al (2012) comments: 'The body as a medium for experience can be seen as a highly complex, dynamic, and interpretive filter on experience... the complex social settings and systems within which they are embedded throughout their lives' (p.1057). People's sense of self, social identity and cultural values are in this way important to how they perceive and experience their sensuous world. This alludes to a multi-method approach involving direct observations of people's physical interactions with place and interviews to explore the historical and socio-cultural contexts of their practices. Sensory ethnography was therefore employed in this study on the basis that both observations and interviews will be conducted with research participants. With a focus on the everyday life of people with dementia, there was also a need to supplement sensory experiences of *here and now* with more longitudinal data on where people go, what they do and how they feel in and about them on a day to day basis. Existing literature was vital for determining such methodological choices, but further ground work with people affected by dementia was necessary to appreciate the relevance and implications of conducting this study in this way.

5.4   Public Involvement Panel

With the support of Age UK Lancaster a public involvement panel of ten people with dementia and carers of people with dementia were recruited to provide advice on the design and process of the research. The initial meeting convened in January 2015 provided the panel members with further information about the study and their role as panel members. They shared their personal thoughts on issues they considered to be pertinent to the research topic and provided a number of suggestions on how I can capture people's experiences of living in and interacting with the community. Our discussion helped me to gain further insight to factors affecting the day to day lives of people with dementia and their ability to participate in this type of research. The second meeting held in April 2015, involved focused discussions on some of the study material (consent form and participant information sheet), prompting me to make some important decisions regarding the material and processes used for recruitment and data collection. One of the main outcomes from this meeting was the agreement that a study information leaflet needed to precede the use of a participant information sheet with prospective participants, which I discuss below. Four of the panel members (two persons with dementia supported by two family carers) also participated in the pilot study to test and provide feedback on the data collection process. As a result, I was able to better gauge the effectiveness of my chosen methods of data collection in engaging people with dementia and obtaining their experiences and thereby make some key modifications to how I use these methods in my study, which I also discuss below.

5.5   Fieldwork

Ethical approval for the inclusion of people with dementia in the study was granted by Lancaster University Research Ethics Committee in September 2015. The fieldwork commenced in October 2015 as I began to recruit and collect data for the pilot study. The pilot study took approximately 4 months to complete and included two persons with dementia and their family carers. A substantial amendment to the protocol was submitted during this time to include family carers in the study, since it became apparent during the pilot study that family carers were very much involved in the day to day lives of people with dementia and the latter expected a similar level of involvement from their family carers in the research. This amendment was approved by the ethics committee in February 2016. Recruitment for the full study began in April 2016 and data was collected up until March 2017.

5.5.1 Research settings

Participants were recruited from the North West of England, UK. Lancaster was the initial site for recruitment as Age UK Lancaster agreed to support the recruitment of participants from amongst their service users. As a local government district of Lancashire, Lancaster spreads out towards the north east coastline, comprising a number of towns and villages such as Morecambe, Heysham and Carnforth. The overall population of the district is over 140, 000 with 13% of its population aged 60-79 years and 5% aged 80-99 years (Lancaster City Council, July, 2013). The percentage of older people aged above 65 years in Lancaster is currently higher than the national average and recent estimated figures show that 2.17% (1,869) of the population in Lancaster, compared with 1.89% of the national population, live with dementia. Due to organisational changes that took place within Age UK Lancaster during early 2016 however, support with recruitment came to a halt. After approaching other dementia organisations within the district, with little success, I contacted dementia groups and services in Manchester. Manchester is a cosmopolitan and diverse city with over 530, 000 inhabitants. There are currently 49,774 (9% of total population) people aged 65 years and above living in Manchester, about half of whom are within the 65 to 74 years old age bracket (Manchester City Council, August 2016). The older population, especially those aged 75 years and over, are concentrated in outer suburban areas than the inner city centre. It was estimated in 2009 that almost 5,000 people (1.06% of total population) above the age of 65 years will be affected by dementia in Manchester by 2016 and more than half that population will be living in the community (Manchester City Council, May 2009).

5.5.2 Recruitment

Participants were recruited through community based organisations, projects and groups rather than National Health Service sites or other care settings (McColgan, 2005; Pesonen et al, 2014). Previous studies that have recruited some or all of their participants from the community have mentioned approaching wellbeing cafes and day centres (Boyle, 2014; Cohen-Mansfield et al, 2006a; 2006b); dementia resource centres (Bamford and Bruce, 2000), dementia care networks (Forbes et al, 2012), local Alzheimer's Society organisations (Gilmour and Huntington, 2005; Harman and Clare, 2006; Hulko, 2009; Sixsmith and Gibson, 2007) and care organisations (Sixsmith and Gibson, 2007). Many of these studies have focused on one particular community group/ service, although it has been noted in a recent article that it is advisable to engage with a wide range of community organisations to ensure that the sample is as representative as possible of the general dementia population (Cridland et al, 2016). I

therefore approached a number of local services and groups in both cities; some which were affiliated with national organisations such as Age UK and Alzheimer's Society and others which were much more informally structured and independent.

All persons with dementia, above the age of 65 years and live at home or sheltered accommodation in the community, were eligible to take part. The minimum age of 65 years was decided on the basis that dementia is most prevalent beyond this age. Although some people are diagnosed with dementia before the age of 65 years, they are considered to have early-onset dementia, the causes of which along with the life situation of these individuals can therefore be significantly different from that of older people with dementia. Participants were also required to be mobile outside of their home and have adequate verbal communication skills. Additionally, family members who are included in the study had to satisfy the criteria of being the primary carer of the person with dementia and providing support with activities beyond the home.

Information about the study and the eligibility criteria for participants was shared with staff and volunteers at these organisations and groups. I visited two dementia social groups in Lancaster as well as a dementia singing group and a walking group in Manchester on a weekly basis for a period of five to eight weeks. I supported staff members and volunteers with group activities and refreshments during the sessions, although I always identified myself as a student to the service users and was happy to talk to them about my research when they showed an interest. It was made clear that my research is independent of the services provided at the organisation/ group. Since the staff and volunteers were however much more familiar with the service users and vice versa, they were often better positioned to identify individuals with capacity to take part and who the research may appeal to. They were also able to introduce the research to the service users in a personable way, giving them the reassurance that it is safe to take part if they wished to do so. With certain groups, I arranged visits to introduce myself face to face and discuss the research. A reader friendly study leaflet, including pictures and non-technical language, was produced for prospective participants to provide them with an overview of the study. These were produced on the request of the public involvement panel who found the participant information sheet to be too lengthy and therefore potentially anxiety provoking. The leaflets, along with expression of interest forms were given out at every visit and emailed/ posted out to individuals and groups who could not be visited.

Expression of interest forms were usually handed in at the end of a visit when the family carer of the person with dementia was also present, as the decision of whether or not to take part was ultimately left to the family carer. In some cases where family carers of people who staff members thought would be interested in taking part and had capacity to do so were not present

during my visit, they contacted them separately. Some family carers therefore returned the expression of interest forms on behalf of the person with dementia by post using the prepaid envelops or by email. Once the person with dementia and their family carer agreed to take part, we arranged a time for the initial interview. Prospective participants were explained that the participant information sheet can be posted out to them before the interview if they wished, but as it is lengthy I could alternatively go through it with them at the beginning of the interview. All participants chose the latter option. At the initial interview, I verbally explained the detailed participant information sheet to them and allowed time for participants to ask questions. Family carers were requested to support the person with dementia to talk about their experiences as much as possible without talking on their behalf. Both the person with dementia and their family carer were then asked to sign separate consent forms before any data was collected. Thereafter, the method of process consent was adopted to determine if the participants with dementia were still aware of and happy to take part in the research at each point of data collection (Dewing, 2007).

5.5.3 Participants

A total of nine participants with dementia and seven family carers have participated in the research. Of the participants with dementia in the study, six are women and three are men. They are aged between 70 and 86 years and all but one live with a partner or family member. Five of the participants with dementia are from Lancaster and four from different suburban areas of Manchester. Whilst many of the participants have been living in the same area or house between 18 to 46 years, one participant moved to her present home in the last 18 months although has been living in the area for over 15 years. According to their self-rated state of health, two participant with dementia consider their overall health to be very good and seven to be good. Six people with dementia enlist the support of professional carers from once a week to twice a day, and three participants report having no professional support. In regards to participants' mobility outside of the home, it ranges from going out a couple of times a week to going out up to three times a day and they are all always accompanied by a family member or support worker during these occasions.

Four of the family carers are the spouses of the persons with dementia, two are adult children and one is a younger sibling. Apart from an adult child carer in the sample who lives apart from her mother with dementia, the other family carers live with the person with dementia. The spouses are aged between 75 and 82 years, the sibling is 67 years and the adult children are 65 and 55 years of age. In terms of their self rated health, three family carers claim their health to

be very good and four consider their health to be good. Most of the family carers think of their health status to be at par with the person they care for, with only two family carers feeling healthier and one feeling less healthy than the person with dementia.

Table 3: Profile of participants with dementia and family carers

Participant Pseudonym	Age	Diagnosis	General health	Care needs	Living arrangement	Occupation/ profession	Past interests	Places engaged with	Neighbourhood features
David	77	Vascular dementia 5 years	Good but has vertigo and requires wheelchair.	2 days at the day centre. 3 days sit-in service at home	Moved to current address 17 years ago after retirement, with wife Katherine.	Retired. After leaving the army worked as a mechanic for approx 30 years.	Dog racing Motorcycle racing Saxophone Brass bands Nature walks Bowling	Garden centres Parks/ coast/ country side Local cafe Supermarket Day centre	Park Countryside Quiet cul de sac
Katherine (Wife)	75	N/A	Very good. Keeps active.	N/A	Lives with David	Retired. Managed own B&B and then worked part-time in customer service.	Dancing Bowling	N/A	
Mary	82	Dementia 2 years	Good- but is partially blind and had a knee transplant.	1 day at the day centre	Moved to current address 19 years ago, after retirement, with husband John.	Retired Book keeper	Walking with ramblers Knitting Arts and crafts	Local restaurants/ cafes Day centre Age UK, Galloways, Royal Air Force Association	Fields A short drive to the bay
John (husband)	84	N/A	Good	N/A	Lives with wife Mary	Retired Sales executive, also	Walking Steam rallies	N/A	

						worked as electrician.			
Diana	84	Vascular dementia 5-6 years	Good- but has had falls and is incontinent.	3 days at the day centre. Support worker twice a day.	Have been living at current address for over 50 years.	Retired performer in theatre shows.	Dancing Theatre/ cinemas Social gatherings/ parties. Gardening. Holidays abroad	Pubs and cafes Garden centre Promenade Local shops Dementia groups Day centre Theatre Walking in neighbourhood	Sea/beach/ promenade Quiet streets Local shop/ news agent/ post office
Hannah (daughter)	66	N/A	Good- but has had knee transplant.	N/A	Moved in with mother Diana 18 months ago.	Retired Air steward.	Cinemas Meals out Holidays abroad	N/A	
Belinda	82	Alzheimer's Disease 4 years	Very good- only some muscle ache.	Only an AS companion 2hrs a week	Lived at current address almost 50 years	Retired customer service manager.	Walking/ hiking Social events Golf Bowling Meals out Holidays abroad	Pubs Local shops Cafes Park Dementia groups	Village shops, restaurants and cafes Local pubs
James (Husband)	82	N/A	Good- but has bad knees.	A housekeeper 2/3 times a week	Moved in with Belinda about 30 years ago.	Retired electrician and carpenter.	Golf Social events	N/A	
Alan	80	Alzheimer's Disease 2- 3 years	Good- but has a bad leg	Care worker once a day	Lived in current address for approximately 50	Retired owner of travel agent	Travelling abroad Meeting with friends at the pub	Pub Dementia walking group	Pubs Shops Busy roads

Name	Age	Diagnosis	Health	Care	Living situation	Occupation	Hobbies	Places	Area
					years		Watching sports (football and rugby)	Dementia arts and crafts group	
Ellen	81	Dementia 7 years	Good- dizziness sometimes	Care worker twice a week. Niece and Lucy visit rest of the week	Lived at current address for over 40 years	Retired care worker	Shopping Buying gifts housekeeping	Local charity shops Supermarkets Cafes Parks	Quiet residential area Local shops and post office
Lucy (daughter)	55	N/A	Very good	N/A	Lives on her own, but Ellen also stays over.	Community artist	Art Social events	N/A	
Emmeline	86	Dementia 4 years	Very good- some difficulty walking.	Carer does cleaning and shopping 2-3 times a week	Living at current address for 18 months. But have been living in the area over 15 years	Retired teacher	Volunteering Meals out Church Singing	Restaurants Cafes Park Church Local shops Dementia group (singing/ social)	High street Shops and banks Park a short drive away
Boris (Husband)	77	N/A	Very good	N/A	Lives with wife Emmeline	Retired church minister	Community work Meals out Walking		
Eric	70	Vascular dementia 3-4 years	Good- Leukaemia does not restrict daily life	None	Moved to current address 10 years ago, but has been living in the same town for almost 40 years	Retired newsagent/ chip shop owner	Going to music gigs/ concerts Walking the dogs	Cafes/ restaurants Local park, canal and streets.	Quiet cul de sac Canal Fields

Amelia	79	Alzheimer's Disease 5 years	Good- just some aches and pains	None	Moved to current address 26 years ago. But familiar with area from childhood.	Retired community nurse	Keeping dogs and cats Walking Meals out Theatre Football	Football matches Parks Camping sites Local meadows and canal City centre shops/ cafes Restaurants Dementia cafe/ singing group Day centre	Canal Meadows City centre Quiet housing estate
Muriel (Sister)	67	N/A	Good	N/A	Moved to current address 26 years ago. But familiar with area from childhood.	Retired nurse	Keeping dogs and cats Walking Meals out Theatre Football	N/A	

5.5.4   Data collection

There were three phases of data collection involving interviews, observations and participant 'diaries'. Each of the methods sit well within sensory ethnography, contributing to a rich understanding of experiences of people with dementia in the wider community and their impact on health and wellbeing. The table below unpicks each of the research questions by providing a description of their individual objectives and the methods through which they have been addressed.

Table 4: Linking Research questions with research methods

Research question	Objective	Method
How do people with dementia and their family cares understand and seek experiences of health and wellbeing	To elicit subjective meanings of health and wellbeing and experiences people associate with it.	Interview and observation
What are the places of interest/ importance to people with dementia and their family carers in the wider community? Why and how have they changed since the onset of dementia?	To explore changes in people's everyday environments, and its connection to dementia, people's sense of self and their perceptions of wellbeing	Interview and participant 'diary'
How is health and wellbeing maintained, enhanced or hindered through participants' interactions with particular settings?	To understand the purpose and characteristics of places and activities (social, physical and symbolic) which make them important for maintaining health and wellbeing. To understand cognitive and sensory experiences which hinder/ contribute to feelings of health and wellbeing	Interview and observation

5.5.5   Life history and illness experience interview

The life history and illness experience interviews were conducted to elicit a historical and socio-cultural context of why people with dementia engage with certain places or activities and not others, including their sentimental or practical value and if and how they are considered to benefit health and wellbeing. These interviews were conducted with both people with dementia and their family carers, lasting between 50 minutes to 1 hour 40 minutes. To maximise participants' comfort and sense of familiarity, the interviews were conducted at their home, with the exception of one participant who preferred to be interviewed at the place where he attended a dementia group (Elwood and Martin, 2000). Given the purpose of the interviews, conversational style semi-structured interviewing techniques comprising open-ended questions were used (Clarke and Keady, 2002; Moore and Hollet, 2003; Phinney, 1998). By using this style I was able to refrain from asking direct questions and thereby minimise instances where the

participants felt disempowered by their inability to recollect certain information or talk about experiences they found distressing. In turn participants felt comfortable to also ask me questions about myself, trying to find common grounds. Aware of our substantial age difference, participants with dementia were often keen to describe what life was like when they were younger. I therefore responded with several probing questions, encouraging them to tell their story in their own words, despite it often appearing incoherent and disjointed (Beuscher and Grando, 2009; Cridland et al, 2016). The pace of the interview was also tailored to each participant, allowing them to take as many breaks as they needed, especially since some participants with dementia struggled to concentrate for long. Similarly, with one set of participants the interview was conducted over two occasions to work around their daily routine. However because of the restriction of time, whenever I felt a participant was going off track I have had to interrupt their narrative and bring them back to talking about the topic at hand.

Physical aids used during the interview process were particularly important for encouraging reciprocal engagement and supporting participants to share their biographies. A visual timeline was produced, whilst talking to the participants about important life events and experiences during the interview (**see *Figure 1***). I plotted all of the information I considered to be important or I thought were perceived as significant by the participants, when producing the timelines.

Fig 1: A participant's timeline
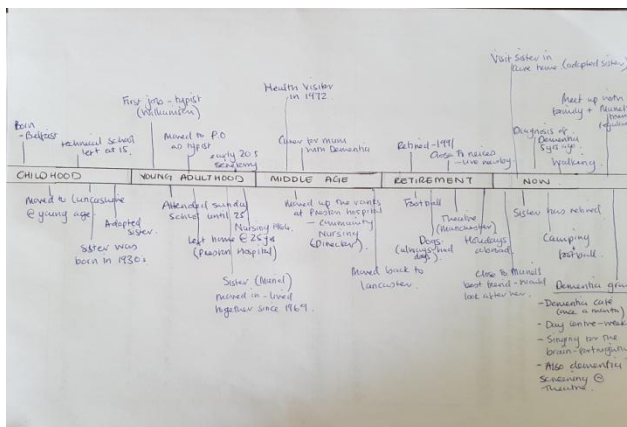
This was incorporated within the interview following feedback from the participants and my reflection on the interview process in the pilot study. A structured timeline helped to encourage and guide participants who struggled to recall and talk freely (Haak, 2003; Moore and Hollet, 2003). Participants were probed about their work, family and social life, their experience of receiving the diagnosis of dementia along with any perceived changes in their social networks, places of interest and overall health and wellbeing since having dementia. Whilst allowing

participants the opportunity to dwell on certain issues of importance to them, the use of a structured timeline assisted the process of covering various aspects of participants' life history and experience of living with dementia within a relatively short space of time. Participants were also encouraged to share personal photographs and artefacts as a way of using photo elicitation to facilitate the discussions (Clark-Ibanez, 2004; Mason and Davies, 2009). This particular technique has been utilised in previous research to aid memory of people with dementia about past events and their relationship to people and places (Boyle, 2014; Haak, 2003). The participants in this study thus often reflected on the internal narratives of an image or object, talking about their reasons for showing it or what it means to them. The method was adopted in different ways by each participant, some pre-selected photographs and other objects for the interview whilst others pointed to or brought them out as the interview progressed. Participants shared photographs of deceased family members, special events in their lives or places with particular memories, which we were able to see and talk about together allowing us to strengthen our researcher- participant relationship. The photographs and other artefacts therefore made participation in research more 'personal, human, and emotionally evocative than words alone' (Burles and Thomas, 2014, p.197).

The interviews helped orient me with participants' personal biographies and their personal perceptions and experiences of living with dementia. According to previous studies, people's sense of self and how they seek to either retain or adjust that sense of self in the face of dementia has significant implications for the places and activities they engage with (Pearce et al, 2002; Ryan et al, 2009; Steeman et al, 2006). Meanings people give to certain settings and situations are linked to their existential emplacement, shaped by their health status, cultural norms and values and ideas of wellbeing. Recognising the unbounded nature of place, tracing connections between places and activities along temporal and geographical dimensions of people's lifetime experiences was therefore an important aspect of understanding sensory experiences. Rich sensory insights to people's experiences of place emerged through their narratives since, as Mason and Davies (2009, p.595) state, 'Talking about and describing sensory things is part of everyday parlance and there is much evocative vocabulary available'. The participants also often narrated the extra-sensory aspects of being in certain places, such as their 'gut feelings' or the feeling of safety.

5.5.6   Walking interview

The second stage of data collection involved walking interviews with people with dementia, and their family carer, to a place of particular significance to them (Carpiano, 2009; Kusenbach,

2003; Sheehan et al, 2006). This method is also often referred to as 'go-alongs' or 'walk-along interviews' and has been used in studies with people with dementia (Olsson et al, 2013). Such a mobile method is considered to provide the researcher a privileged vantage point to observe the instantaneous embodied and sensory experiences of participants in their interactions with place. According to Adams (2001, p.188), 'To walk through a place is to become involved in that place with sight, hearing, touch, smell, . . . and even taste'. What people say and do and the meanings they make are understood in relation to the material and sensorial worlds they inhabit and engage with (Hurdley and Dicks, 2011). Observations of this kind can provide access to aspects of participants' embodied and emplaced experiences which they are either unaware of or feel uncomfortable to discuss (Briggs et al, 2003; Nygard, 2006). Additionally, walking interviews can evoke personal biographies, linking present experiences to more distant places and activities (Carpiano, 2009; Kusenbach, 2003). For people with dementia who often experience difficulty with memory and verbally expressing themselves, this method can be significantly enabling. A focus on embodiment shifts attention from knowledge expressed through language to that expressed through embodied practices. Also, by capturing both the sensory experience and the biography of the participants, walking interviews provides an enhanced and contextual approach to conducting sensory ethnographic research.

The participants were supported by their family carers to decide on the place to visit and the route to take. Whilst some participants invited me to join them on one of their usual outings (i.e. walking the dog, walking group or weekly walk into the village) others arranged a day and time to visit a place they considered appropriate for the walking interview (i.e. park). The latter participants were usually concerned about going to a place at a time when it would be quiet enough for them to walk and talk with me. Because walking can cause tiredness amongst older people, Kusenbach (2003) recommended up to 90 minutes as the length of time for the actual interview. Following my experience of conducting the walking interviews with the participants in the pilot study, I allocated up to 2.5 hour slots for each participant, which included time for a short brief at participants' home before the interview and then to bring the interview to a close when we returned to their home at the end. Depending on the setting, participants were encouraged to engage in conversations about their experiences and perceptions of places encountered en route, initiated with general warm up questions about the weather, the traffic, the scenery and so on. Participants were consulted before the interview about how they would like to explain their participation in the study to curious friends and acquaintances encountered during the walking interview. Most participants were happy for me to provide a short pre-prepared description of the study on their behalf, whilst others provided quite varied descriptions of the study to people who enquired- from 'I'm helping with a university project' to

'she wants to know about where we live'. The participants did not specifically mention or want to talk about the dementia aspect of the research in front of others.

I also gave participants the option of taking photographs of anything that they felt was important about the place or activity, using a digital camera. The purpose of taking the photographs was to help participants to talk about their subjective realities and allow us to critically examine what is captured together (Clarke-Ibanez, 2004). However, none of the participants wished to take photographs, either because they did not feel confident in undertaking the task or because they preferred not to attract attention from other people. Some participants did however point out places for me to take photographs of during our walk. Further, three of the walking interviews involved a short car journey, as this is their normal mode of transport to places they chose for the walking interview. In many cases we spent a considerable amount of time sat at a cafe, since that is also part of their normal routine. With some participants who were unable to partake in a walking interview or the final stage of data collection however, they preferred me to conduct participant observations at a place they regularly visit such as at a luncheon club, day centre or theatre (see *Table 5* below). To understand everyday life of people with dementia in the wider community, it was also necessary to collect information on their experiences of several different settings over a longer period of time. Longitudinal data in ethnographic research is often collected through prolonged engagement within a particular setting (Creswell and Miller, 2000). However, conducting more than one walking interview with each participant in this study was impractical. Instead participants were asked to produce a 'diary', documenting places and activities they engaged with and their experiences of them over a number week.

5.5.7   Participant 'diary'

Participants were asked to produce a written/ audio diary, scrapbook/ collage or a memory box illustrating places, people and experiences they have encountered over a period of between 2 to 4 weeks. The purpose of using the diary method was to enable people with dementia, with the support of family members/ carers, to map their spatial and social experiences longitudinally. Symptoms of dementia can fluctuate from one day to another and different surroundings and environmental factors can affect people with dementia in different ways (Blackman et al, 2003; Burton and Mitchell, 2006; Davis et al, 2009; van Hoof et al, 2010). Understanding experiences of people with dementia in different settings over time is thus important. The complexity of living with dementia, its impact on people's everyday life and the influence of broader contextual circumstances are most likely to transpire overtime, and a diary method offers such a

longitudinal lens (Bernays et al, 2014; Bolger et al, 2003; Milligan et al, 2005). As a collection of private accounts, diaries can provide access to participants' everyday experiences that are often unobservable or concealed from the public gaze (Bartlett, 2012; Bernays et al 2014; Milligan et al, 2005). Diary entries can often be both factual and reflective accounts of self, circumstances and events pertinent to a person's private world. The content is usually directed by the participants, with minimal guidance from the researcher, and completed in their own personal time and space.

Bartlett (2012) used a combination of written and audio diaries in her study involving people with dementia. In the present study I offered participants the option of either keeping a written diary or sending diary entries by email on a daily/ weekly basis. Alternatively for participants who struggled to write, they were able to keep an audio diary (Alaszewski, 2006; Valimaki et al, 2007). The use of audio diaries can negate the effort of writing, whilst also facilitating deeper insights to participants' thoughts and feelings. Bernays et al (2014) found in their study that participants' '... audio diaries tended to produce more detailed reflections on their roles and relationships, whereas the written diaries read more like a log of facts and events with little affective commentary and few links to everyday life' (p.631). Similarly, Bartlett (2012) notes 'I could hear the participant's spouse call out the dates and names of places they had visited' (p.1721), providing further insight to aspects of people's lives and support network they may not necessarily discuss in their diary. The audio diary nonetheless requires the participants to be confident in their verbal communication skills and have a certain level of technical ability. Both written and audio diaries were perhaps undemanding for the participants in Bartlett's (2012) study as they had early stage dementia and were involved in social campaigning, therefore verbally articulate and already in the habit of keeping appointment diaries, which set them apart from the participants in this study. The third option participants in this study were therefore given was producing a scrapbook/ collage or a memory box, so to remove the emphasis from their written and verbal communication skills and provide them with opportunities to be creative in how they represented their daily life (Latham, 2003; Mannay, 2010).

The practice of keeping a 'diary' is considered to support people to 'rediscover their sense of self, to release complex emotions by naming them, and work their way through the many changes in their daily lives' (Ryan, 2006, p. 423). In Bartlett's (2012) study, it was the participants' roles as campaigners that were the focus of the study and keeping a diary on this aspect of their life helped some participants to positively change their outlook on life and give new meanings to everyday activities. However, keeping a 'diary' can also serve as a reminder of

people's diminishing physical and cognitive abilities and their existential sense of loss. Since this study focused on participants' personal lives beyond the home and it was apparent that some participants had very minimal contact with the wider community, the exercise of keeping a diary had the potential to exacerbate this realisation. The creative approaches to keeping a diary were therefore encouraged to remove the focus from the number and variety of places people engaged with to how they can convey the meanings and experiences of places important to them. But since almost all of the participants with dementia required extensive support from their family carers to complete any of the choices of 'diaries', the carers chose the most familiar and least time consuming option- the written diary. To clarify and explore some of the contents of their 'diary', a reflective interview was offered to each set of participants (person with dementia and carer) who kept a diary. This gave the participant with dementia and their family carer the opportunity to add further details to specific events and experiences they have recorded (Bartlett, 2012; Gibson et a, 2013). However, these interviews were optional to ensure that participants did not feel deterred from expressing their private views and experiences by the need to talk to me about them upon completing their 'diary'.

Table 5: Participant involvement in different stages of the research process

Participant pseudonym	Consent	Life history interview	Walking Interview	Participant observation	Diary
David	Theatre (June 2016)	Home (Aug 2016)	*NO- became too unwell*	Day centre/Theatre (June/July 2016)	*NO- moved into care home*
Mary	Home (July 2016)	Home (July 2016)	*NO- preferred observation at the luncheon club*	Luncheon group (Sept 2016)	*NO- she and husband did not have the time*
Diana	Home (Aug 2016)	Home (Aug 2016)	*NO- suggested observation at the theatre*	Theatre (Dec 2016)	*NO- she and daughter did not have the time*
Belinda	Home (Oct 2016)	Home (Nov 2016)	Park (Dec 2016)	Walking group (Jan 2017)	Written (Jan-Feb 2017)
Alan	Walking Group (Nov 2016)	Walking group (Nov 2016)	Park- walking group (Jan 2017)		*NO- felt it was too much*
Ellen	Home (Dec 2016)	Home (Dec 2016)	Village- shopping (Jan 2017)		*NO- did not manage to complete it*
Emmeline	Singing group (Dec 2016)	Home (Jan 2017)	Park (March 2017)	Singing group (Dec 2016)	Written (March-April 2017)
Eric	Home (Jan 2017)	Home (Jan 2017)	*NO- He cancelled 3 times*		*NO- Did not want to*
Amelia	Home (March 2017)	Home (March 2017)	Neighbourhood (April 2017)		Written (April-May 2017)

All of the life history and illness experience interviews were audio-recorded with participants' permission. During the walking interviews, it was only possible to obtain short audio clips of our conversations due to the impracticality of using a voice recorder in certain settings. Research field notes were written up at the end of all of the interviews and were particularly important for recording my recollection of conversations and events as well as my impressions of participants' attitudes and behaviours during the walking interview. Reflective interviews following the completion of participant diaries were also audio-recorded and supplemented the information within the written diaries.

5.6   Researcher Reflexivity

The notion of 'practiced place' by Cresswell (2002) defined the methodological premise of this study. But, whilst advocating an understanding of place rooted in people's practices, the idea of 'practiced place' also brings into question how experiences of place may be affected through the practice of research- for both the researcher and participant. Ethnographers play a critical role in the field, from deciding what position they will view a phenomenon to influencing how the phenomenon unfolds through simply being present in the space (Finlay and Gough, 2003). Reflexivity is therefore an integral part of conducting ethnographic research. For some, sensory ethnography requires researchers to produce and document sensory data through their own shared experiences of a particular place or activity with the participants (Pink, 2012). Echoing the mutually constitutive perspective of place, the sensory ethnographer is considered both a 'constituent and constitutor' of place (Pink, 2013, p.9). Bearing in mind that people's sensorial worlds are shaped by personal and socio-cultural factors, it was unlikely that my research participants and I perceived and experienced our shared space in the same way (Jones, 2012). A reflexive approach however leads the researcher to consider how they and the participants are collaboratively engaged in creating ethnographic knowledge and the role each of their subjectivities play in this process (Pink, 2015). By being aware of and reflecting on my own biographical background, thoughts, feelings, interactions and actions against that of the participants I was able to better understand and appreciate the subjective nature of the realities I sought to capture and represent through my research.

5.7   Thematic analysis

Data collection, transcribing and analysis took place simultaneously. All of the audio recorded interviews were transcribed verbatim using Microsoft Word by an independent typing service

provider, approved by Lancaster University. I however typed up all of my field notes on Microsoft Word to supplement the interview transcripts. The word documents of both interview transcripts and field notes were then uploaded on to Atlas.ti for analysis. Participant diaries remained in their original format to be analysed manually following the same analytic process used for the interviews and field notes. Photographs taken during the walking interviews, although useful for photo-elicitation when conducting follow-up conversations, were not the subject of analysis themselves. They are instead used illustratively when discussing some of the key findings from the study in this thesis.

Thematic analysis was considered most appropriate for exploring experiences of place from a social constructionist perspective as it provides a flexible approach to extracting, organising and interpreting the data (Braun and Clark, 2006). It is deemed to be most suitable for exploring 'the ways in which events, realities, meanings, experiences and so on are the effects of a range of discourses operating within society' (Braun and Clarke, 2006, p.9). In this way the approach allowed for the analytic framework of therapeutic landscapes to guide the extraction of data relating to physical, social and symbolic experiences of place. This provided a useful starting point although the analytic interest of this study was not restricted to a predefined framework and followed much more of an inductive approach to exploring the multifaceted concept of health and wellbeing and its relationship to place. Data were identified and extracted on the basis that they related to: 1. How people understand and experience health and wellbeing, 2. Subjective meanings of and interactions with places in the wider community and 3. Examples of where experiences of health and wellbeing and engagement with place intersect.

The data from the interviews and observations in this study comprised people's descriptions of particular events, settings and activities as well as their evaluation of their specific experiences of/ in them. Similarly, my observations captured both static aspects of place such as the physical features of a settings as well as its dynamic aspects manifest in the interactions that took place between participants and their socio-spatial surrounding. This range of data was therefore taken as a whole and a holistic approach was adopted to identify patterns in how participants perceived and experienced place, following the six-step model of conducting thematic analysis proposed by Braun and Clark (2006).

Step 1: To familiarise myself with the data I read and re-read all of the transcripts and field notes. This exercise helped identify repeated patterns relating to places, people and activities important to participants. I began formulating ideas for coding based on my initial impression of the general messages transpiring from this data.

Step 2: I then systematically worked through the data set to generate initial codes, highlighting all semantic and latent components of the data that appeared relevant to the analytic interest of this study as explained above. As a result, I compiled a list of 45 codes.

Step 3: I conducted an interpretive analysis of the data using a mind-map to organise different codes into themes and subthemes. Both the study supervisors and I examined and discussed the mind-map, resulting in some codes being developed into themes, whilst others were merged, discarded or used as subthemes.

Step 4: I subsequently reviewed the themes by examining their internal homogeneity and external heterogeneity in consultation with the supervisors. As a result some new subthemes were created and others merged. The thematic map, containing all the themes and subthemes were then considered in relation to the whole data set to ensure that it accurately represented it (**see figure??**). In total 6 themes and 21 subthemes addressing the research topic were finalised.

Step 5: To define and name each theme, I organised the extracts corresponding to the themes so to tell a story about each theme. This produced a brief description of each theme, capturing both its content and scope.

Table 6: Themes and sub-themes from data analysis

Main Themes	Subthemes
Impact of dementia	Behaviour and cognition/ awareness, Physical ability, Autonomy, Self/perception
Care needs	Supervision and support Companionship Decision making (role of the carer/ carer's needs)
Identity/ lifestyle	Personal/ professional achievements Past hobbies/ interests Likes/ dislikes Change in activities
Everyday places	Home and neighbourhood Cafes, pubs and shops Being outdoors Dementia groups

Place experience	Physical/ spatial characteristics (distance from home, atmosphere, pace, views, barriers)
	Social environment (being known, socio-cultural compatibility, intergenerational contact, place to meet)
	Engagement (passive/ active, embodied, conversations, walking)
Benefits/ challenges	Familiarity and Routine- confirmation of self, confident
	Filling the day-
	Staying connected- family, friends and neighbourhood

Step 6: The themes informed the content of the three substantive findings chapters; chapter six focusing on participant biographies and the impact dementia has had on their sense of self and abilities, chapter seven exploring participants' care needs and changes in the places and activities they engage with and chapter eight taking a closer look at people's experiences of place to explicate how they use everyday settings to maintain their health and wellbeing. Whilst some of the headings and subheadings within the chapters reflect the above themes, many of the themes and subthemes are discussed in more than one chapter. The writing of the chapters has involved balancing between focusing on experiences of specific participants and settings in a holistic way where a number of the above themes and subthemes are drawn up, whilst also developing some of these themes in their own right by exploring their relevance to experiences across various settings and situations. Findings are therefore discussed in this thesis in a way to both address the research questions set out in the previous chapter and to also remain true to the views and experiences of the participants.

5.8 Ethical consideration

Due to their cognitive impairment, people with dementia are considered a vulnerable group, whose right to participate in research is counterweighed against the fact that they are often unable to make decisions independently, understand the purpose of research or communicate coherently. However, over the last couple of decades, the view that research must also uphold an ethical duty to empower and actively include people with dementia in research, so that their perspectives receive unequivocal representation has been strong (Bamford & Bruce, 2000; Cottrell and Schultz, 1993; Hellstrom et al, 2007; Pritchard and Dewing, 2001). A number of ethical issues pertaining to working with people with dementia were therefore raised and addressed through consulting existing literature and the public involvement panel.

The first ethical issue considered was participants' capacity to provide consent. Usually, when a person with dementia is unable to satisfy the requirements of providing informed consent research has tended to rely on proxy consent. But there is increasing evidence that there are sometimes conflicting interests and views between the person with dementia and the proxy (Dresser, 1994; Hellstrom et al, 2007; Katsuno, 2005). It is therefore advised to initially assume that people with dementia have capacity to consent and that provisions are made to enable them to do so effectively (Sherratt, 2007; DH, 2005). According to Dewing (2002) 'the traditional approach and methods based on a universal system of ethics grounded in responsibilities and rights is not consistent with research that is said to be person-centred and that therefore values personhood' (p.158). For McCormack (2003) the five prerequisites for conducting person centred research are informed flexibility, sympathetic presence, negotiation, mutuality and transparency. This approach to obtaining consent requires that the needs and desires of a person with dementia, in the here and now, are acknowledged and used to understand their expressions of consent.

So whilst it is generally expected that the participant must have the capacity to understand all of the information provided about the study to provide informed consent, an alternative and flexible approach to this demand is that a person is able to at least understand and participate in what he or she is being asked to do (Hubbard et al, 2003). Therefore, one of the first steps taken to minimise the cognitively demanding task of reading and understanding the participant information sheets by people with dementia was to produce a reader-friendly leaflet. These leaflets provided all of the basic information about what the participants will be asked to do and why, whilst the more detailed participant information sheets were verbally explained to the participant before obtaining initial consent. As a result I was able to 'reach towards the person with dementia rather than the person with dementia having to reach into a cognitively demanding reality in which they become incapacitated' (Dewing, 2002, p.164). Similarly, Hellstrom et al (2007) claim that, 'for people with dementia, their capacity to understand is far greater when the focus is on feelings and experiences rather than on the recollection or manipulation of facts' (p.611). Thus, since the general focus of the present study was for participants to reflect on their experiences and share memories evoked by their sensorial surroundings, participants were only required to have an adequate level of verbal communication skills to take part.

Process consent was decided as the most appropriate approach for obtaining consent from participants, as it incorporates many of the principles for person-centred research. Paying close

attention to both verbal and non-verbal expressions, Dewing (2007, p.20) suggests that 'the researcher needs to assess if ongoing consent is provided consistent to the initial consent, and if the person wishes to continue or their feelings about participation have changed'. The use of process consent encourages a flexible and sympathetic approach to obtaining consent and conducting research, requiring the researcher to recognise and be responsive to the fluctuating nature of participants' moods and abilities. A strategy which helped me to become familiar with the participants was visiting the community groups from which the participants were recruited over a number of weeks before approaching them about taking part in the study. Also by liaising with staff and volunteers at these groups, I was able to gain better insight to the personalities and signs for agitation or confusion in prospective participants. I found that whilst many people with dementia are aware of their diagnosis and happy to discuss their condition, some are unclear of their diagnosis or in denial and prefer not to directly talk about it. Respecting the fact that this is an individual choice, I chose to refer to their condition as having a 'memory problem' and the term 'dementia' was used only after it was initiated by the participant. This approach to dealing with the disclosure of dementia was considered to further empower participants with dementia in a previous study (Hellstrom et al, 2007).

Despite making every effort to empower the person with dementia, for many people decisions are made jointly with family members/ carers. They rely on family carers to provide reassurance and support when making decisions and engaging in unfamiliar situations. To deny the involvement of family carers in the research process would have in this case been disempowering for the person with dementia. The involvement of family carers were therefore welcomed and resulted in a substantial amendment to the study protocol, reducing people's concerns around safety, comfort and ability to contribute to the research. The family carers were in this way able to step in to help persons with dementia recall specific experiences and events and in turn fill in the details (Beuscher and Grando, 2009). Of course when conducting joint interviews there is the risk of restricting each participant from expressing certain concerns in the presence of another or the carer's voice taking prominence over the voice of the person with dementia. But such compromises were seen to be offset by the importance of making the participants with dementia feel safe in the presence of a family member. I nonetheless also requested the family carers to allow and assist the person with dementia to tell their story as much as possible, at the beginning of each interview. Further, taking the view that how a person experiences living with dementia is shaped by how they and their family carer understand and respond to the changes caused by the condition, I wanted to create a space for them both to contribute to 'a shared meaning of living with dementia' (Pesonen, 2011, p.655).

5.9   Quality and Rigour

Terms such as generalisability, reliability and validity are typically employed within quantitative research when referring to the quality and rigour of a study. Ethnography however differs from quantitative research, and its contribution to social research is attributed to such differences. It offers rich detail and participant generated meanings whilst positioning the researcher within the context of the research. Nonetheless, maintaining research credibility whilst providing rich contextual insights to a phenomenon is an important concern amongst ethnographers and they therefore follow techniques that are more appropriate in qualitative research (Golafshani, 2003).

Most qualitative researchers dismiss the positivist notion of generalisability arguing that all experiences are context specific (Denzin, 1983; Lincoln and Guba, 1985). However, some are open to the possibility of analytic generalisation referring to the fact that often 'qualitative researchers develop conceptualizations of processes and human experiences through in-depth scrutiny and higher-order abstraction' (Polit and Beck, 2010, p.1453). This relates to what Lincoln and Guba (1985) consider as the transferability of research findings, whereby with detailed descriptions of the processes and the context of the study, as provided throughout this thesis, readers are enabled to make inferences about the applicability of the findings to a different population or setting. The present research therefore intends to be transferable and to contribute to other work exploring a similar topic, using similar methods or working with similar research participants by describing and reflecting on many aspects of the research process and empirical findings.

Similarly, the concept of reliability in qualitative research does not refer to its replicability as in quantitative studies, but to the trustworthiness of research (Lincon and Guba, 1985). Linked to the trustworthiness is the idea of transparency, which I have tried to maintain within the conduct and presentation of my research (Noble and Smith, 2015). The theoretical premise of my research along with my approach to collecting and analysing data are discussed in length within the thesis. Likewise, the findings chapters of this thesis draw on and present data from interviews and participant observations comprehensively, whilst my interpretation of the data have also been subject to peer examination. Further, I kept a reflective journal and made extensive field notes throughout the research project documenting details of research sites and recruitment strategy; my own role within each research site and my relationship with participants; demographic characteristics of participants; the different context and settings in which data was collected and my use of different props (i.e. photo-albums, camera, audio-

recorder). These are all contributory factors to the research findings and by identifying and highlighting them I have sought to further strengthen the credibility of my work.

The validity of qualitative research depends upon how accurately and authentically it has examined and presented a phenomenon (Davies and Dodd, 2002). Through continual engagement with research participants and data collection, ethnographers are usually able to assess and enhance the validity of their research on an ongoing basis. Thus having conducted the interviews and participant observations alongside analysis and interpretation of data I was able to continually evaluate my approach to data collection and my interpretation of participants' realities. The methodology adopted in this study was chosen on the basis of its appropriateness for exploring participants' lived experiences of places beyond the home. The interviewing techniques and focus of participant observations were thus carefully selected to enable people with dementia to talk about and enact their everyday life experiences in a natural manner. Using a triangulation of methods (interviews, observations, participant diary keeping) I have been able to capture different dimensions of participants' experiences and in so doing develop an understanding of a phenomenon that is holistic and as close as possible to the lived realities of the participants (Creswell and Miller, 2000). Used in conjunction with one another, the limitations of individual methods were therefore counterweighed and participants were better able to express their perceptions and experiences and in turn meaningfully contribute to the study findings. As for data extraction and analysis, several steps were taken to ensure the validity of my research conclusion. Coding of the data was conducted systematically and conferred with the academic supervisors.

Member validation is a useful approach for validating the researcher's interpretation of the data and exploring alternative interpretations from participants (Creswell and Miller, 2000). However, in the case of the present study, because many of the participants with dementia were no longer able to read and follow content-heavy documents, finding it an anxiety provoking task, this method was decided to be counterproductive. The family carers were offered the opportunity to check and comment on interview transcripts and a list of emerging themes from the overall data. The risk of doing that was that the participant with dementia's version of reality was allowed to be scrutinised and altered by the family carer. But due to other commitments, although two of the family carers requested interview transcripts none were able to provide any feedback. Much of the data collected from the walking interviews were my observation and interpretation of participants' experiences and I have often tried to confirm my understanding of what I observed with the participants and their carers through informal conversations in the field. The higher order abstraction of data that I conducted after the transcribing and coding phase was based on findings across all of the research data, in which

case any particular participant would have had difficulty relating it back to their individual experiences.

5.10   Conclusion

Addressing a research topic that is currently understudied, there is no methodological precedent on which to start thinking about how to explore experiences of people with dementia engaging with the wider community and their impact on health and wellbeing. By drawing on a range of methods, this research has taken the opportunity to inductively explore how to engage with the voices and experiences of people with dementia as well as capturing their interactions with place in its fullest sense. The sensory ethnographic approach is particularly conducive to understanding how participants' experiences of health and wellbeing is embedded within the socio-cultural, biographical, embodied, psycho-social and material contexts of the settings and activities they engage with. Maintaining the view that place is the nexus of human experiences, both shaping and shaped by what people do, feel and think, participants' emplacement is thus examined through their reflections of particular socio-spatial settings as well as through how they enact them in practice.

CHAPTER SIX

Health and wellbeing: 'There's me and then there's my dementia'

'We've got a life on the other side of that door – put to one side – because we don't think we can handle it on this side o' the door' (James)

6.1   Introduction

The empirical findings are organised into three chapters in this thesis. This chapter is the first of the three chapters and begins by exploring how people with dementia and their carers understand and seek experiences of health and wellbeing; taking participants' particular biographies, personal qualities and experiences of living with dementia as its central focus. The latter two empirical chapters move the discussion forward, considering health and wellbeing in the broader context of people's socio-spatial engagement and experiences in the wider community. Chapter seven explores the implications of participants' shifting health and wellbeing priorities on places they engage with beyond the home. It thus addresses the research question- What are the places of interest or importance to people with dementia in the wider community and how have they changed since the onset of dementia? Chapter 8 explores the question- How is health and wellbeing maintained, enhanced or hindered through people with dementia's interactions with particular settings? It focuses on the processes through which place impact health and wellbeing, paying particular attention to social, physical and symbolic dimensions of people-place relationships, as propagated within the therapeutic landscapes literature. Together the three chapters explicate personal, interpersonal and societal factors shaping where, when and how people with dementia maintain and experience health and wellbeing.

Understandings and practices relating to the maintenance of health and wellbeing amongst people with dementia are complex, subjective and multilayered, warranting grounded insight to people's biographical histories, socio-cultural emplacement and different life transitions. The aim of this chapter is to explore the unique configuration of these elements in the shaping of people's lived experiences of dementia, everyday activities and in turn their conceptions and experiences of health and wellbeing (Thomas and Milligan, 2015). This chapter opens with a quote by James, a carer to his wife Belinda, as he reflects on their quality of life. Behind the door, to which James points, is a spare bedroom now turned into a storage room for all of their formal attire and all of Belinda's jewellery from the days when they revelled in the company of dinner party guests and cruising in the Caribbean. Their sense of health and wellbeing hinges on how well they deal with the challenges of living with dementia in the here and now (this side of the

door) but which they nonetheless assess against the lives they lived there and then (the other side of the door). All participants are in this way found to evaluate their experiences of health and wellbeing through a complex web of associations between biographical and contextual factors. Exploring the life histories of the participants and their personal journeys of coming to terms with dementia, I have been privy to a room full of artefacts and stories from the past, the private space of the home where behind the scene aspects of daily life take place or people's inner sense of self and resilience that is often shrouded by the outward manifestation of dementia. These are all aspects of people's lives and factors shaping their health and wellbeing, which are not always readily palpable and therefore hidden on the other side of the door. To provide a comprehensive and subjective view of how people with dementia understand and seek to maintain their health and wellbeing, it is thus important to look past the door and consider experiences across people's past and present lives, private and public spaces as well as inner and outer identities.

A holistic lens to people's understandings and enactment of health and wellbeing is sought in the use of illustrative pen portraits in this chapter. Pen portraits are considered 'descriptive pictures' (Gadd, 2011, p.43), drawing together rich demographic and contextual data to portray a multidimensional perspective to people's experiences. To provide rich, elaborate descriptions of people, settings, situations and experiences, I inevitably focus on a small number of participants from the sample. The pen portraits are therefore based on four participants with dementia and their family carers, who have been selected for their varying background and experiences of living with dementia. Three of the pen portrait participants are female and one male, which is representative of the overall sample. Two of these participants live with their partners, whilst one lives with an adult child and another with a sibling. Their life histories reveal very different professions and past interests whilst their attitudes towards living with dementia are also quite diverse. The pen portraits provide a cumulative account of participants' lives, comprising a combination of data from interview transcripts, participant diaries and my own observations. All such data are subject to my interpretation, which I also put forward and discuss within the pen portraits. The chapter then concludes by unpicking some key themes emerging across the pen portraits around how the participants with dementia and their carers construct and reflect on their sense of health and wellbeing and the implications this has on the places they engage with, in the wider community.

6.2   Pen Portraits

6.2.1   David and Katherine

The second time I meet David, it is in the lounge of Hayfield Daycentre. He is picked up from home around 9am on Mondays and Thursdays each week by the centre minibus, to spend the day at the day centre and then dropped off at home again between 2.30pm and 3pm. I go along on a Thursday morning, at around 11am and find him sat up straight on the sofa with his hands clasped together in front. He is smartly dressed, still wearing his flat cap and scarf. Exchanging the odd glance with the other people in the room, David watches the staff as they walk in and out of the lounge trying to organise the furniture. I observe him for a short while:

I sit on the edge of a large sofa near the door as I enter the lounge…. There's a slight musty smell in the room. The deco and the silence amongst the people sat in their seats remind me of a care home I once visited. I feel sorry for them, but then wonder how they (people with dementia) feel about being here…. Sat on the sofa, David seems to be in waiting; patiently, silently, waiting for something to happen. One of the staff has come in to the lounge to ask 'Right so what shall we do first?' …. David, mischievously chimes in with 'Go to the pub'. The man with dementia sat next to him and the support worker both laugh out loud… This lifts my mood a bit.

He looks around the room as he makes that remark as though to see the reaction of others. I ask myself, was his intention to make others laugh or express his boredom? May be both? They play 'Who wants to be a Millionaire' for the next hour until lunch, and each time it is David's turn to answer a question, he wittingly defies with responses such as '*I don't know*' or '*Pass*' and laughs. Perhaps this is what he means upon reflecting on his experience of the day centre a few months later when he says:

> *'I have a laugh….you try to make your own way all the time'.*

He does not come across particularly jovial at the day centre, but intermittently turns to the person next to him or the two men sat opposite making a humorous comment or telling a joke. The day centre facilitator tells me that David usually sits amongst the other men with dementia at the day centre and 'enjoys the banter'. Stoic, self assured and sarcastic best describes my impression of David after spending some time with him at the day centre. As I later find out during the interview at his home, David served in the army during his early adulthood and then worked as a mechanic. In his younger days, he enjoyed going to motorcycle and dog races,

whilst he expresses a clear dislike for any housekeeping duties. David recalls the time he was required to help out at their family bed and breakfast:

> *'I was always up early in the morning and it was hard work... I hated it...If anybody didn't have something you had to, you got stuck ... you didn't know what you were doing'*

Asked if he enjoys gardening, as I point to their well kept garden out the window during the interview, '*Oh no, no... but I sit in it...sit in it and do my stuff*' he laughs. Katherine shakes her head in agreement, claiming '*He hates the gardening! No I do the gardening'*. Instead, Katherine and David proudly talk about his past mechanical skills, with Katherine reminding him:

> *'You kept all our cars going didn't you, all the family cars. That was your responsibility....A whack from a hammer would sort it out in your day.'*

David's line of work had always been male dominated and involved the use of physical strength and power. His admission to being averse to domestic work and preferring to leave the running of the household to Katherine is perhaps suggestive of his position on gender roles. After having met David a few times, I reflect on the issue further:

He seems to assume quite a traditional view of a male's role as he doesn't like cleaning, cooking, gardening or decorating. He suggests that he now sometimes helps Katherine in the kitchen, but 'you don't cook do you? You can't....' Katherine clarifies, claiming that 'he helps with the pots...I've got him a nice pair of yellow rubber gloves, he doesn't mind washing up'. David looks rather embarrassed by Katherine's disclosure and pulls a face. He then rolls his eyes as he tells me that he sometimes goes shopping with Katherine as though it isn't by choice. Could this be to do with his attitude towards what a man should and shouldn't do? Perhaps he considers certain places and activities as supporting his sense of self/ masculinity and others as contradicting it? Talking about some of the other men at the day centre, he says 'they're funny some of them, some of them used to just sit there, wouldn't talk or have a laugh or anything'. According to Katherine he recently refused to be supported by a male care worker, because he 'didn't care very much' for his homosexuality and had also complained about a female care worker for being 'too loud and bossy'.

After being diagnosed with vertigo some 25 years ago, David took early retirement and spent a lot of time at home. He describes giving up work as a forced decision, since he was no longer '*safe*' to carry out such work as welding. Shortly after, he and Katherine decided to sell their bed

and breakfast and move to their present address 30 miles away. They now live in a two bedroom bungalow in what Katherine describes as a quiet neighbourhood with easy access to local amenities. After moving to their present house, David taught himself to play the saxophone, often practicing in his bedroom, and then joined a local brass band. Music, along with dancing, was one of David's passions which he and Katherine talk about at length when recollecting their younger years:

Katherine: *We used to go to Hayworth, dancing in the Plaza. We met each other really, through dancing…Ball room dancing, a bit of a jive… you used to go to a class for ballroom dancing…*

David: *One and six…yeah.. well in them days a lot of people used to go dancing more often and we met wherever there was a dancehall within the distance, you know a bit of a jive, or ….*

Katherine: *… and it was bands then, wasn't it, it was a proper band.*

David: *Yeah…I only wish that I'd learnt more in the army about music….*

Realising that I live in the city where they grew up, David and Katherine try to recall all of the places they used to go dancing, noting that I may not have heard of many of them as the dance halls closed by the 1970's. As I explain what some of these places are now used as, David becomes rather nostalgic, 'yeah, it's all changed, nothing like the good old days, they were good'. Playing in the brass band in some respects reconnected David to music and its communal pleasures as they played '*gigs*' (David) at different local venues each week.

It is about five years ago that David was diagnosed with dementia and since then hallucinations, incontinence and memory loss are some of the issues he and Katherine have to manage on a daily basis. When we meet at a dementia film screening at a local theatre, he is wheeled in through a separate side entrance by Katherine. He is unable to walk for long and '*sometimes he can't walk at all, his brain doesn't get to his feet*' Katherine explains. When I introduce myself to him on this occasion, he cannot recollect having met me before and continues humming songs from the film 'Calamity Jane' (1953) which they have just watched. His speech is also very slurred, so Katherine intervenes to clarify what he is saying and sometimes resorts to responding to my questions on his behalf. David is very much dependent on Katherine, and because Katherine is sometimes overwhelmed by the extent of support David requires, she draws comfort from knowing that help is available if needed, at the dementia friendly film screenings. Similarly, she claims that she frequently enlists the support of their two daughters when taking David on holiday or to any place she is unfamiliar with, as he often becomes

restless and agitated in new settings. Katherine recounts his recent experience at the hospital after a stroke *'he thought he was on a plane, he thought he was on a boat'*, explaining that his hallucination often causes him to become perplexed and unsettled, which can be challenging for her to handle on her own.

But despite being dependent on Katherine, David is far from passive. When he complains during the interview that at the day centre '*They never let you go out...you might run away*', he expresses a desire for some degree of control and independence. It is still important for him to enjoy what he does, and he is able to clearly articulate what he likes:

> *'Just some countryside really, that's all we need. Just go and admire the beauty'*

By contrast, when he is accompanying Katherine to places like the supermarket or garden centre, which he is less interested in, Katherine says her biggest challenge is his:

> *'Boredom, he'd say "I'm fed up"... no, he doesn't like shopping, doesn't like gardening, he doesn't really like anything like that...never did'*.

David instead likes to visit his daughters, who live nearby, or go out for family meals with them. He is particularly close to his older daughter Julie and enjoys their regular days out together to the bay or the park, allowing Katherine some respite.

Over the past three to four years, with the progression of dementia, David gave up activities he used to enjoy. He stopped playing in the brass band because he did not want to rely on the other band members to pick him up from home. He now enjoys going to see a brass band at their local park during the summer months. David also gave up bowling a few years ago, which he light-heartedly attributes to '*I didn't like losing',* to which Katherine adds *'It was just getting too difficult for him, you know with the balls'*. Consequently, when Katherine now goes out to carry out her daily errands or hobbies, David is either at the day centre or has sit-in service at home. Katherine claims that '*...he likes to be at home'*, where he usually *'sits in his armchair by the window, and just stares at the hills and the sky for hours'* (Katherine). David agrees with Katherine, but also adds that it '*gets a bit lonely'*, which is why he looks forward to the day centre. It is still apparent however that David is much more relaxed within his home environment, which I note during our interview at his house:

He is sat back in his slippers with a table set up next to him holding the TV remote, a newspaper and his cup of tea. Seeing David relaxed and 'at home' in this way, makes me relax. I don't think about illness and suffering as I did when visiting the day centre. As I walk into the room, David

acknowledges me with a '*hello*' and points to the sofa near him, instructing me to take a seat. We are in a bright and airy space, surrounded by all normal things you will find in a home. There is also a certain enthusiasm in David's tone and unlike our previous encounters at the theatre and day centre, he is keen to know about me.

David seemingly deals with many situations and his increasing dependency with high spirits. Katherine's story about David's recent day out with his daughter Julie is a good illustration of him trying to have fun, despite being restricted by his impairments:

> '*Julie pushed you (in the wheelchair) and then you kept saying to her "Do you want a go?," he's always saying that, so she said "Yeah, I will," so she got in and David pushed her'.*

Further examples of him making light of circumstances made difficult by dementia are given by Katherine. When asked what he has eaten for lunch at the day centre, David always struggles to remember and so in jest claims to have had his favourite '*steak and kidney pie'*. Whilst Katherine recounts to me how worried she became that he was eating steak and kidney pie all the time as '*it's not good for his diabetes*' and so raised it with the staff who confirmed that it was not the case, David sits in his sofa chuckling. Similarly, with a smirk on his face he brings up his tendency to hallucinate during the interview,

> '*I see ghosts you know, have you ever seen a ghost?*' and quite quickly, perhaps appreciating my puzzled expression, reassures me with '*it's the illness'*.

The interview I conduct at David's home is the last time I meet David. Within a few weeks of our interview, he becomes unwell and unable to move. Katherine explains to me on the phone that she is no longer able to support him at home and so has had to arrange for him to go into residential care. David is unable to engage in the research after this point.

So what does the pen portrait reveal about David's health and wellbeing? Seeing David in his wheelchair with his slurred speech, his level of impairment and dependence is what strikes me at first, but the further I engage with him and Katherine the more the personal, social and emotional dimensions of his lived reality emerge. Taking a closer look at his subjective experience of dementia (on the other side of the door) it is clear that whilst the physical and cognitive impact of dementia has caused David to become more housebound and reliant on Katherine he continues to exercise agency and personal choice in his every day activities. Mid way through his account of how he feels '*dementia has crept upon*' him he tells me '*there's me and then there's my dementia'*, making a clear distinction between him as an individual and him as a person with dementia. His unrelenting humour and masculine identity, which are rooted in

his past sense of self strongly shape how he now adjusts to living with dementia, from the way he responds to certain losses to how he negotiates new situations and social relationships. He refuses to engage with settings or activities he has previously shown little interest in whilst being partial to those that have some connection to his past interests and hobbies. Although David feels most comfortable and in control at home, he considers it to be a lonely place and contrasts it with the male company he enjoys at the day centre. David is also averse to domineering care workers or being considered unsafe to go out into the garden at the day centre. Whereas Katherine is reassured by the fact that David is closely supervised at the day centre as she worries about his safety, for him such restrictive behaviour are at odds with his desire to retain a sense of independence. By contrast, instances where David is able to act on impulse, such as when pushing his daughter in his wheelchair, despite it involving a certain degree of risk, he considers as moments of freedom and 'fun'.

6.2.2   Diana and Hannah

Diana's story of living in the community, as narrated by her daughter Hannah, is predominantly characterised by her lifelong involvement in local theatre groups. When asked about Diana's past, Hannah replies with:

> *'She used to be an entertainer, her and my dad...mum's little shows were with her friend that did the Keep Fit recently, they did shows at Barton in the Women's Institute and things like that. But when she was going with dad, it was usually summer seasons, up and down the country...and they went to Germany entertaining the troops. '.*

Dancing and helping back stage, Diana travelled around the country quite often. Even after giving up working in the theatres in her late 50's, she and two other friends continued tap dancing with a local dance group up until a few years ago. Photographs mounted on the walls of Diana's living room and further photographs, newspaper cuttings as well as flyers, programmes and tickets contained within several of her photo albums, were remnants of almost seven decades of Diana's life in the entertainment business:

There are several photographs of Diana dotted around the house, some in colour and some black and white. On top of the sideboard, there's a framed black and white photograph of Diana in a sparkly dress. Trying to guess her mother's age and looking at the outfit, Hannah suggests it must have been taken at a show sometime in the late 1960's. Her hair was quite short, but with

volume and much more neatly styled than it is now. Other than the eyes it is quite difficult to see the resemblance between the slender figured lady with youthful skin in the photograph and the tiny lady hunching her shoulders as she sits in the armchair before me....There are other photographs on the wall and in the photo albums with 'entertainer' friends, at parties and social events. Diana is in a bottle green cocktail dress, a black gown, a yellow and white floral frock with a matching head band as well as a pale coloured jumpsuit (some of the descriptions of outfits) in these photographs. Today, she is in a cream knitted jumper and dark trousers with a drawstring waist.

Performing in theatre shows and competing in both local and national contests, formed an important part of Diana's self identity and personal achievements. She points herself out in the photographs in the albums she has out for me during the interview, as she sits in her arm chair which almost encases her now petite structure. She holds a newspaper cutting from 1996 when she competed in a national dance contest, on which Hannah elaborates *'they won the Dome (the dance hall where the first stage of competition took place) and went through to Southport for the second competition'.* Then Diana picks up a programme of a show she was in during the 1970's and she and Hannah begin to sing one of the songs together. Although she is now no longer able to perform, with the memorabilia displayed around her home there is an overwhelming presence of her former self. Keen to preserve that aspect of her mother's life, Hannah has recently been busy creating a scrapbook based on Diana's entertaining career which she says:

> *'Is really to talk to mum about the years ... and we would go through the programmes with the shows and things'.*

Realising that I am not familiar with any of the songs which Hannah and Diana name from the scrapbook, '*they were all well before your time, long before you were born probably*' Hannah laughs. But the changing fashion illustrated by the photos capture my attention and we thus find a common interest to talk at about as we briefly look through the scrapbook.

Diana's involvement with the theatre groups has also influenced her role in the community. Her and her husband knew many people and had a very active social life, as Hannah recalls:

> '*With me mum and dad knowing a lot of people, me mum's group, they always had dos together... and a lot of the ladies in the classes, any dos, they all, you know, went together...*

> *and Pauline (friend) always had Christmas dinner where all the families, we all went didn't we? 'Cause we used to go up to lunch there a lot'.*

Despite giving up dancing some years ago and losing contact with many of her acquaintances, Diana is still locally recognised for her dancing:

> *'… there's a lady in Boots, when I went in there last week, the week before, she was asking about me mum, "How's your mum? What she doing?" 'cause her friend was an entertainer you see',* Hannah explained.

Also, recently having joined an Alzheimer's Society dementia cafe, Diana has been approached by some service users who remember her from her entertaining days and as a result have become good friends. Thus, Diana's background very much influences her more recent interactions and activities. Going to the theatre was one of Diana's favourite activities, which she used to do with a friend who has now passed away. Since then, she and Hannah have been attending the creative workshops and '*old film*' screenings at the local theatre as part of their dementia friendly programme.

I meet with Diana and Hannah at one of the dementia friendly screenings on a cold December afternoon:

Walking in through the main doors of the theatre, I could hear the clinking of tea cups and people talking, laughing in the foyer. People are gathered around the bar and many sitting around the small tables draped in red and white gingham cloth with little flower vases placed in the middle. There is a warm and homely feel about the place with the table dressing and serving of homemade cakes. The older people, usually supported by a family member or support worker, slowly walk past making their way to an empty seat in the bistro or heading in the opposite direction towards the toilets. The volunteers, dressed in black, weave through the crowd, greeting people and making sure they are seated. There is still 40 minutes until the film starts. I spot Diana sat on her own at a table in the corner of the bistro, wrapped up in her sparkly hat and scarf. She is sat watching Hannah over at the bar ordering them some hot drinks.

Diana does not seem particularly alarmed by the noise or the crowd at the theatre. Diana and Hannah travelled to the theatre in a mini bus with a group of other Age UK service users and Hannah continues to chat to some of them over at the bar. Diana has her eyes fixed on Hannah and occasionally looks away and smiles at the other theatre goers and volunteers walking

around. In the earlier interview speaking about Diana in unfamiliar or busy environments Hannah said *'I don't think she'd be worried, because she's with me',* which explains Diana's calmness. When Hannah arrives to the table where Diana is sat, I ask about the film they have come to watch. Unable to remember the name of the film Diana pulled out from under her cup the flyer stating 'White Christmas' (1954). Diana does not say much, she smiles every time we make eye contact and continuously nods in agreement with Hannah who praises Age UK for organising their trip to the theatre and other events.

I get the feeling Hannah is very expressive in her approval of Age UK services because she either believes I am employed by Age UK or her views will be directly shared with them. This is understandable as I have been helping at many of the Age UK sessions. Note to self- need to explain to Hannah and Diana that I am conducting the research for my PhD, it is not an evaluation of any Age UK services and all data from participants will be anonymised, so will not be fed directly back to Age UK.

When a volunteer enters the bistro ringing a bell, Hannah stands up and ushers Diana towards the screen, following the rest of the crowd, Diana and Hannah sit in the middle, second row as the spaces at the front are reserved for people with wheelchairs and walking frames. As others join them, Diana simply gives them a nod of acknowledgement and smiles, whilst Hannah talks and laughs with the carers sitting around her. Diana watches the film attentively, with Hannah every so often leaning towards her mother pointing something out and making a comment, to which she simply nods and smiles.

Diana does not come across as the sociable lady Hannah describes her mother to have once been. She is quiet, although continuously smiling at people walking around the theatre. Diana was similarly quiet during the interview at her house, but at home, Diana was able to exude her presence and sense of agency through her personal belongings we were surrounded by. At the theatre however, it is difficult to infer from Diana's impassivity, any of her past connections to the setting or activity she is engaging in. She blends into the crowd of older people, who:

All seem preoccupied with the task in hand- finishing up their cup of tea, making it into their seat safely.... Neither Diana, nor the other people with dementia talk about the film they've come to see or their experience of the theatre. But talking about how much her mother enjoys coming to the dementia friendly screenings and workshops at the theatre Hannah says, 'Oh yeah, she

loves to come here. We both do... and when we get home, for days, we talk about the costumes and what we've seen'.

During the interval, sheets of paper with Christmas songs are passed around for the crowd to join in with the sing-along. As soon as the piano starts to play, Diana begins to sing. She holds the song words in her hand, but does not need them; she sings effortlessly remembering all the words.

After losing her husband 11 years ago, Diana became very lonely. Hannah claims:

> *'It could have been the start, because mum was so heartbroken and it could have been bringing it (dementia) on at the beginning'.*

With Hannah living in another city, Diana relied on the company of two close friends, who she went out to meals, the theatre and attended dance classes with. However, both of Diana's friends have since passed away, and her activities in the community gradually dwindled in that time. It has been six years since Diana was diagnosed with dementia, but she continued to live independently until 18 months ago when Hannah moved in. Diana now requires carers to support her with personal care in the morning and evening, whilst Hannah manages all other aspects of her care including the household shopping, financial matters and organising Diana's daily/ weekly routine. According to Hannah, Diana's cognitive decline has been very slow over the last couple of years but physically she has become very weak, having suffered a number of falls and becoming incontinent. Diana is accompanied at all times both at home and outside, as Hannah is afraid of her mother either having a fall or getting lost. Hannah therefore accompanies Diana when she goes out for a walk along the beach at the back of their house or around the cul-de-sac looking at the neighbours' gardens. Having lived in the area most of her life, Diana is very fond of her neighbourhood and had spent a lot of time either on the beach or working in her garden. No longer able to frequently or independently engage in such activities, Diana now spends a lot of her time sitting by her front window, watching and waving at the neighbours passing by or working in their gardens. Diana has also become increasingly engaged with dementia services over the past two years, spending a substantial proportion of her week at the day centre, and various other dementia groups.

Diana's story is based on her lifelong love for the stage, conserved through many of her present day activities and relationships and thereby an integral aspect of her overall sense of health and wellbeing. Entering through the door to her home, it is apparent that Diana's life in the entertainment business is an important part of her identity and celebrated everyday through the memorabilia displayed around the house and the scrapbook Hannah has laid out on the

dining room table. Over the past few years, deterioration in health and the loss of close friends have caused Diana to become lonely and much less active beyond the home, but her legacy remains an important source of self confidence, facilitating social interactions with people in the community. Despite her increased fragility and memory problems, Diana's achievements as an entertainer continue to define her present sense of self and how she is perceived by others. Diana and Hannah acknowledge the physiological and social challenges caused by dementia, but rather than express them in terms of *loss* Hannah describes them as 'gradual change'. Perhaps Diana still engaging in many activities and settings that are personally meaningful to her, including places in the neighbourhood and the theatre, is an important buffer to the sense of loss they would otherwise feel. Although Diana is engaging in such places in a much more passive way than before, since her cognitive decline has been very slow she is still able to link her present experiences to that from her past, therefore benefitting from an affirmation of self.

6.3.3   Emmeline and Boris

Emmeline and Boris have been married for 46 years and have three adopted children, the two sons live nearby and the daughter lives in London. Emmeline was a teacher by profession and having grown up in Yorkshire she moved away from home for work in her 20's. She worked at various schools across England as well as in Nigeria for a short period of time. Since retirement, Emmeline has volunteered in the prison service, Mission to Seafarers and more recently with a local charity providing support to older people. Emmeline has been a regular church goer from a young age and was very active at her local church, helping with organising events, until about three years ago. Talking about the Yorkshire town in which she grew up during the interview, Emmeline claims:

> '...somewhere like Huddersfield ... is not intended for someone like me ... em ... I know the place but I wouldn't want to live there... too small and nothing for me there...'

Emmeline explains that she refused to conform to her father's '*a bit strict'* expectations and the general way of life in the small community in which she lived, confirming that she has always been *'mmm, very independent....I am indeed'*.

Emmeline's sense of agency is still evident in her retained poise and effort to remain articulate during the interview, often berating Boris for speaking on her behalf and correcting her recollection of events. On one occasion when he tries to help her, she sarcastically remarks *'Well if you say so, right, yeah, anything you say'* and then later challenging the accuracy of the

information shared by Boris, she patronises him: *'Right?....yes Emmeline, no Emmeline?'*. She is similarly reluctant to simply go along with Boris' suggestions, especially when going out, in which case Boris has the task of motivating and 'bribing' her:

> **Diary entries by Boris:**
>
> <u>Wednesday 29th March 2016</u>
> *On way back from Joe's (son), Boris stopped at Aldi while Audrey sat in the car, she didn't want to come.*
>
> <u>Thursday 30th March 2016</u>
> *Coming home from church, Boris did some shopping at the CO-OP, Emmeline didn't want to come. She waited in the car.*
>
> <u>Monday 3rd April 2016</u>
> *Emmeline refused to go to the dementia group, didn't leave the flat at all.*
>
> <u>Thursday 6th April 2016</u>
> *9.30-10.30, Emmeline's hairdressing appointment at the salon, she didn't want to go, but Carol the hairdresser persuaded her to have a wash and blow dry.*

On my first visit to their house, Emmeline is lying on the sofa in the lounge whilst being asked several times by Boris to get up. She does not respond to his request immediately and seems more alert once she notices me standing by the door way. She eventually sits up combing her fingers through her hair and greets me with a smile. Whilst Boris tries to introduce me to her for the third time, she watches me intently and asks '*So what are you doing your research on, what's it for*?' She wants to speak to me directly, sidelining Boris' role as the mediator.

I feel coldness in Emmeline's tone, expecting her to interrogate me about my research and then decide she does not want to take part. I answer her questions, as simply and clearly as I can, but at the same time worry she might accuse me of being patronising. But she instead smiles and asks me to go ahead with my questions.... Reflecting on that segment of our interaction after finding out Emmeline used to be a teacher, I think about how I felt like a young girl summoned to the head teacher's office, slightly intimidated and unsure of how things will unfold... As the interview continues however, I could feel Emmeline letting her guard down and the conversation becomes much more fluid.

Despite Emmeline trying to take ownership of her narrative during the interview, she becomes confused and repeatedly talks about living near the 'hills' in both past and present tense,

whereas the landscape she is describing resembles the place where she grew up. At one point she is not able to recollect having any children, and when Boris tries to remind her she dismisses him, claiming:

'Well if you want to, but I don't know how much you know of my family'.

She is not willing to be corrected by Boris at that point. But whilst refusing to be spoken for by Boris, she later admits:

'I don't know, I get confused with who's who and where's where, so there's not much point in asking me is there'.

This is one of the few instances where she seems to forgo any attempt to retain a sense of her pre-dementia self and identity in my presence. She later also explains that she once used to 'be part of the process', suggesting a feeling of now being on the outside of everyday situations. Along with deterioration in her memory since her diagnosis of dementia five years ago Emmeline is also beginning to struggle to walk, which is further impacting on her sense of self. She does not like the wheelchair, as Boris informs me, and this is one of the main reasons why she refuses to now go out. Asked what it means to live with dementia, she points to the wheelchair across the room and says:

'It doesn't mean a great deal, because looking over there that wheelchair is a wheelchair'.

She uses the wheelchair to personify her experience of dementia, suggesting her imminent resignation to the physiological changes caused by the condition. Her frank expressions of vulnerability and hopelessness contrasted by the tone of condescension she uses to resist Boris' help, suggests that Emmeline is grappling with the tension between her former independent self and her present dependent self.

It has been almost 18 months since Emmeline and Boris moved into retirement housing. They decided to move into the one bedroom flat, as going up and down the stairs in their previous home became increasingly difficult for Emmeline. They both agree that they like the area in which they live and that moving into the flat close to their previous home of 15 years means they can maintain their routine of attending the local church and community groups as well as continuing to use the local shops. Whilst Emmeline seems indifferent to living in a communal environment, Boris feels happier to have the option of socialising with people of a similar age. Emmeline prefers to stay in her flat, usually looking out over the communal garden watching people entering and leaving the building:

'I watch people come through and it's only when, when the women, it was usually women, want to speak to you or want to do something that I, I move at all'

Emmeline therefore has not made any friends in the apartment complex as she usually avoids any interaction with the other residents. She considers the church as an important part of her life and she and Boris attend the Sunday service and other events at their local church every week. Other than the church, neither Emmeline nor Boris mentions previously having any particular hobbies or interests beyond the home. They spend a few afternoons a week with their grandchildren, which usually involve a trip to the park followed by a meal out. Once a month they also go out for a meal to a local restaurant with a couple of old friends. Since Emmeline has been diagnosed with dementia they have been engaging with local groups for people with dementia and their carers, such as a dementia singing/ social group on a Monday and a dementia social group for people with dementia and carers at their local church on a Friday.

Whilst Emmeline appeared to have a good time at the singing group, she does not have much to say about it during the interview two weeks later. She has no recollection of the songs from the session before Christmas in which I took some notes:

Emmeline was sitting in the second row singing along to 'We'll meet again' (1939), 'White Cliffs of Dover' (1941) and 'I'll be seeing you' (1938) along with a few others. Emmeline knew all the words to the songs. The lady leading the group asked about the background of some of the songs and Emmeline shouted the answers out to quite a few. This impressed the other members in the group, the group leader exclaimed 'aren't you good'. Emmeline struck to me as very confident, as she then went on to request the pianist play 'On Ilkley Moor Baht' at'(Yorkshire folk song). It was difficult to tell to what extent dementia has impacted Emmeline's cognition or whether she was a person with dementia. She spoke very well.

During the interview when Boris and I remind her of the songs she sang at the group, Emmeline informs me that the song 'On Ilkley Moor Baht' at' originated in Yorkshire and then points out the strong Yorkshire dialect in the title:

> *'It means "On Ilkley Moor without your hat"..mmm, yeah...we managed to get by somehow'* she said sarcastically with a slight laugh.

Emmeline enjoys the singing, which enables her to connect with her past and aspects of her personal identity. Whilst explaining this particular song to me, she talks me through an imagined place:

'And down at the bottom, if I, if I left, if I left this place and went down … and round … then I, I could come across people who all knew the, the songs that we sang …'cause they didn't live with us, they lived somewhere else, my home is in Huddersfield'

Talking about the song takes her back to her childhood/ young adulthood, prompting images and memories of her former home town.

Another observation I make during the singing group is that Emmeline does not seem particularly interested in socialising with the other members during 'tea and chat' at the end of the session. She seems different to the person she described herself to be when younger, during the interview a couple of weeks later:

'I knew the people that were around me because that's the way I was brought up'

Sitting amongst four other women with dementia around a table in the cafe area, Emmeline focuses on dunking her biscuits in her tea. Her lack of interest in engaging with other people is something Boris is aware of and admits:

'I can stay with Emmeline, but I like to go for a walk or I go into a separate room so she isn't aware that I'm in fact there. Otherwise she doesn't get involved'.

She smiles with an air of confidence whenever she makes eye contact with someone, but she does not initiate conversation. Perhaps this is her public facade to mask the difficulties she would otherwise face if she was to engage in conversation. Her passivity is in this case an exercise of agency and an effort to give a desired impression of self.

Boris has gone out for a walk in the park on this particular occasion. As soon as he enters the cafe area of the community centre to pick up Emmeline, she stands up and walks towards him. They hold hands and walk over to the table where some of the staff members and volunteers are sitting. As Boris speaks to a staff member, Emmeline stands close by listening, smiling and also joining in the conversation. Although she does not say much, Emmeline seems much more confident in conversing with Boris by her side. I try to arrange a date for the interview with them before they leave:

Boris took out his diary, it's chock-a-block. They are busy with family and other events at the church the next couple of weeks. It's the Christmas period and their daughter is visiting from London he tells me. Watching Boris turning the pages in his diary, Emmeline instructs him to 'tell her when she can come round to our house to do this', she looks at me tut-tutting. Immediately

after, 'This is lovely' she comments looking at my scarf, she then asks me about where I live and about my family. I suspect she is curious about my ethnicity and faith, being a visibly Asian Muslim, but I start with telling her that I was born and raised in Yorkshire to which she perks up even more 'We have something in common, I'm from there too'. I ask her where and Boris joins our conversation at that point.

Emmeline appears much more engaged in her surrounding now and her tendency to take charge also surfaces during our brief encounter. She begins to talk to me, whereas she made very little eye contact and no attempt to engage in conversation with me before this point. Whilst Emmeline does not like Boris to speak for her, it is only in his presence that she tries to enact her confident and assertive self. As we talk, I find that Emmeline struggles to answer my questions as she responds with quite vague or unrelated answers, but she is insistent on satisfying her curiosity, enquiring about where I live, my ethnicity, what I am studying and so on. I allow her to ask the questions and I answer, which occasionally prompts her to reflect on her likes and dislikes or past experiences.

So the story which unfolds in Emmeline's case is underlined by her struggle to come to terms with the impact dementia has had on her abilities and how she is perceived by others. Emmeline's experience of living with dementia and how she now seeks to maintain her health and wellbeing become apparent when her interactions in both private and public settings and relationships are considered. Whilst Emmeline is aware of her reduced abilities, she struggles to accept and enact a sense of self that is now dependent and unable to hold conversations or carryout tasks with the same level of skilfulness as before. This leads her to sometimes display very assertive and other times quite reticent tendencies. Her unforthcoming attitude seems to be the result of her reduced confidence or an attempt to conceal her cognitive difficulties in social situations and the self-assured demeanour she presents in the presence of Boris, an over compensatory strategy for these difficulties. In both cases however, Emmeline is seen to be struggling with a sense of existential outsideness, of being on the other side of the door. Health and wellbeing for Emmeline therefore not only depend on opportunities to access places that are of importance but also on whether or not she is able to meaningfully engage with them and be 'part of the process'.

6.2.4 Amelia and Muriel

Amelia is an avid football fan, having been a supporter of 'Preston North End' for as long as she could remember. She recalls her and her sister Muriel being taken to football matches by their father from a young age:

> *'Well we've always been into football... oh yeah, 'cause me dad was keen. My dad always wanted a boy and failing having a boy, he took us'*

With season tickets, they make a three and a half hour trip, picking up a friend from another town, to continue to go watch their team play every fortnight. They also watch football on TV and listen to it on the radio. But Amelia now struggles to concentrate when watching TV, which is why she and Muriel have also stopped going to watch theatre shows, which was a regular activity until recently. They have instead started attending the dementia film screenings at the local theatre. Amelia also attends a dementia day centre one day a week and is a member of a monthly dementia cafe and a fortnightly dementia singing group. Although Amelia enjoys the company of other people at the day centre and dementia groups, having made some new friends there, she tells me she prefers to be outdoors with Muriel. She and Muriel are always out either taking their dogs for a walk or heading into town on foot. Muriel also mentions their new hobby, camping:

> *'We go and stay overnight in the camper. We only got it in June, but we went to....I think we have had about four or five overnights away last year'.*

Amelia is physically very fit and accompanies Muriel on the dog walks two to three times a day, which is one of her favourite activities. Asked where they would like to go for the walking interview, Amelia and Muriel both suggest going out for a walk with the dogs in the meadows near to their house. This they consider as their opportunity to show off their prized Papillons (dogs) and the local landscape, both of which they talk at length about during the interview. Amelia thinks taking me out on their dog walk to be a good idea because:

> *'You'll get to see why we love this place, and the boys (dogs) are so good. You'll get to see how much they enjoy it too.'*

On the day of the walking interview I meet Amelia and Muriel at their home in the afternoon:

Amelia and Muriel have been out in town in the morning, and got home after lunch time. Muriel had already reminded Amelia to get ready to go out, so I find her in the living room ready. She is wearing her quilted rainproof coat and walking shoes whilst trying to put both the dogs on a

leash. The dogs become exceptionally rowdy as I walk into the house and continue to bounce around taking no notice of Amelia's instructions. Amelia patiently perseveres, trying to gently stroke them into complying. She notices my uneasiness and reassures me 'Don't worry they won't do anything, they're just excited'. Finally Muriel enters the room and quietens them both with the firm tone in which she summons them to her, allowing Amelia to put a leash on one and she on the other.

Muriel suggests Amelia walk with me, while Muriel takes hold of both the dogs and walks ahead. She notices that Amelia is very much distracted by the dogs and presumes it would intervene with her participation in the walking interview. Amelia seems disappointed that she is unable to walk the dog on this occasion. She soon becomes engaged in conversations about the places we pass, regularly drawing my attention to the dogs as we walk closely behind them. She is clearly very attached to the dogs and both Amelia and Muriel explain how important their dogs are to them:

Muriel: *We've always had dogs, since we've been living in Preston (1970's), so most of our not-working time was taken up wi' them...at one stage we had 3 dogs and 6 cats '*

Amelia: *The dogs come with us wherever we go... when we go into town we take them, but of course I wait outside the shops with them while Muriel goes in to get the stuff...*

Muriel: *... we knew the walking area, that's why we wanted to come back here, weren't it?*

Amelia: *Yeah*

Muriel: *For the dogs, to be able to take them for a walk without having to use the car*

During the interview a few weeks earlier Amelia mentions how they have always tried to plan their activities around the dogs:

> *'We go to see whatever we like (at the theatre), but not so much wi' the boys you know, er, the dogs...the boys, the dogs,* [slight laugh] *eh you know as long as we can get back to them. Don't want to leave them for too long.'*

With Muriel adding:

> *'We sometimes go to Hebden Bridge, 'cause there's a dog cafe in Hebden Bridge. So we take the dogs there...they have 'pup cakes' as well as cupcakes'* [laughs]

Amelia and Muriel enjoy spending time with their dogs and try to ensure that their daily activities and the places they regularly engage with accommodate the needs of their dogs.

Their present neighbourhood is an area in which both Amelia and Muriel grew up, and after spending 30 years away, they decided to move back in 1991. Amelia's attachment to the neighbourhood is evident in her claim:

'Although it's different to what it used to be, it's very special'

To which Muriel also adds

'And we spend a lot of time, don't we, when we're out and about saying "we were so lucky to get back here" ...because that's how it feels'.

Amelia and Muriel enjoy taking long walks through the meadows and fields around their home with the dogs, in which case both the landscape and their dogs have become an important part of their present lifestyle. As we walk through the meadows, Amelia explains to me '*this is exactly where we want to be, not going anywhere from here now....this (a new community orchard) will be lovely in a few years time, will be lovely to sit under the trees* '. Amelia thus envisages herself ageing and changing with the local landscape, foreseeing the use of certain areas such as the orchard to sit and relax in when she is perhaps much more frail and unable to walk long distance.

I sit on a bench with Amelia in the orchard, whilst Muriel walks the dogs out towards the field to let them run around for a short while. I'm relieved to be at a safe distance from the dogs, feeling less worried about them jumping onto me... In early spring, the orchard is hardly in full bloom, the trees are still young and bare, but an air of serenity echoes around us as Amelia sits and takes a depth breath in. I do the same. There is a sense of stillness, the gentle breeze barely moving the leaves on the trees and the distant sounds making a faint rhythmic noise in the background.

Amelia was diagnosed with dementia five years ago, and now often becomes confused, forgetting information and words. She depends on Muriel to help her with her memory, claiming that

'I always say to her what do I say, what do I know... Without Muriel, I'd be dead! [laugh]. *No I couldn't... if Muriel had gone, eh, you know, for whatever reason, em I would, I would, I just wouldn't be able to do anything ...'*

Amelia considers herself to be a different person now than who she used to be, feeling much more insecure and fearful in unfamiliar situations:

> *'I would say anything that I needed to say, or do and I was alright then, but obviously now I, I depend on Muriel.'*

As two single women living together almost all of their adult life, they claim they have had to be head-strong. Before the first UK sex discrimination act came into force, Amelia talks about challenging rife gender inequality in the workplace and the problems she faced obtaining a mortgage as a single woman during the early 1970's. Muriel and Amelia agree with one another when describing their struggles as professional women during their early adult lives:

Amelia: *Oh, you've no idea what it used, it was like then*

Me: *I suppose ... it sounds like you had to be quite a strong woman in many ways*

Amelia: *It's the only way to do it*

Muriel: *We've had to be strong all the way through work, haven't we?* [slight laugh]

Amelia: [laughs]

Muriel: *'Cause you're al, always negotiating or arguing your way with people*

Amelia progressed in her career from starting as a health visitor in the 1960's to becoming the director of community nursing before she retired in 1996. She therefore reflects on her achievements during her work life as a way of presenting to me the other side to her, one that was once confident and resolute in her behaviour and actions.

Whilst Amelia enjoyed work, since retirement, particularly after Muriel also retired nearly 10 years ago, Muriel states *'We have a much bigger social life now than we've ever had'* and Amelia agrees:

> *'Yeah, we do, mind you we were always busy before and we're now, you know, it's ...its really nice'.*

With many family members, including nieces and nephews, as well as most of Muriel's friends living nearby, there are always social gatherings, meals out and day trips for Amelia to join. They also have a sister who has recently moved into a care home that they visit and spend an afternoon with every week. Amelia feels sad that her sister has had to go into a care home, but claims their weekly visits are important to '*keep her spirits up*'. In the same breathe she admits that she is *'lucky'* to have Muriel, as she would have otherwise been in the same predicament, to which Muriel reassures her '*Oh you're not going anywhere*'.

Amelia's story is about living an active life whilst also holding on to relationships that are meaningful to her, whether they are with family members, her pets or the local landscape. Because many of these everyday relationships are familiar and emotionally rewarding, her sense of health and wellbeing remains positive. Although Amelia worries that she is '*changing*' with the progression of dementia, her enthusiasm for life is endorsed through Muriel's determination to support her to do the things she enjoys whilst also introducing her to new opportunities and experiences. Positive health and wellbeing for Amelia is therefore attributed to both old and new relationships contributing to her sense of self, purpose and direction in life. Thus, camping, making more '*dementia friends*' to go out with and spending time in the local meadows and orchard with their dogs are important future goals Amelia and Muriel have been working towards. So whilst Amelia's past experiences are important for understanding how she perceives and negotiates her present circumstances, she also provides a glimpse to what lies behind the door to her future, her envision of leading a fulfilling life with dementia in the years to come.

The biographical stories presented in each of the pen portraits provide nuanced insights to participants' experiences of living with dementia and to the question- how do people with dementia and their carers understand and seek experiences of health and wellbeing? They are firstly testimonies to the diversity in understandings of what is important for health and wellbeing amongst the participants and how these conceptions change over time (Bell et al, 2015). Secondly what is most apparent within the pen portraits is that the participants with dementia and their family carers consistently subscribe to a notion of health and wellbeing which involves balancing the need to effectively manage changing health and care needs with the need to retain and develop a sense of self. Perceptions and experiences of health and wellbeing sit at the intersection of the two dialectical forces shaping how people construct and live their daily lives. The first and second point raised within the data will therefore now be explored.

Walking the dogs with Amelia and Muriel

Fig 2: Walking along the canal side

Fig 3: Path leading to the meadows

Fig 4: View of the old estate
(Amelia's childhood home)
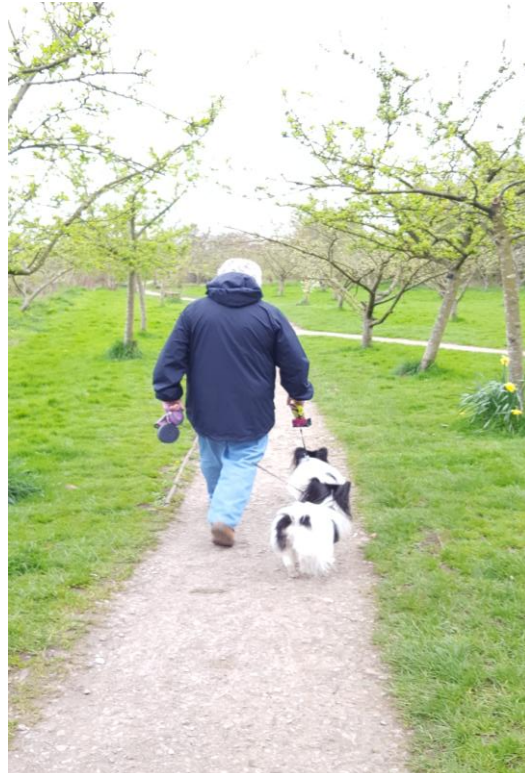

Fig 5: Resting by the canal (old
boat house)

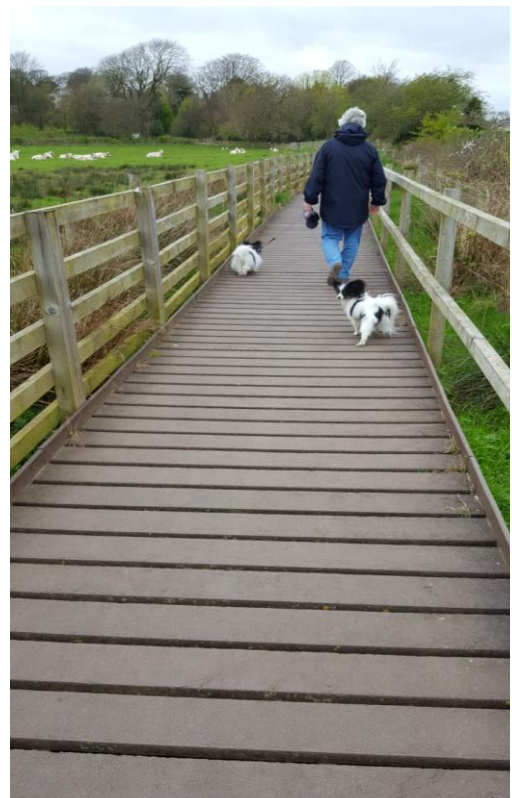Fig 6: Walking through the orchard

Fig 7: Bridge across the fields

6.3   Key Themes

6.3.1   *Diverse and changing conceptions of health and wellbeing*

The heterogeneity of participants' personal and cultural characteristics means that they have differing conceptions of health and wellbeing and how to maintain it. Whilst Emmeline is a private person who comes across quite reserved in the company of other people, David and Amelia enjoy the sociality of dementia groups and the day centre. Diana too consistently acknowledges people at the theatre although she now struggles to initiate or hold a conversation. Similarly, sitting by the window at home is a common occurrence for David, Emmeline and Diana, but the utility of this activity and the health and wellbeing benefits it yields varies for each participant. For Emmeline, looking out from her living room window is very much about surreptitiously watching the social activities outside whilst maintaining her privacy and distance. For Diana however, waving to her neighbours and watching them work in their gardens allows a continued sense of citizenship and belonging in the community. As for David, he achieves a sense of escapism from the quiet space of his home through focusing on the views of the sky and hills in the distance. Their focus on different aspects of the landscape reflects Gastaldo et al's (2004) discussion on therapeutic landscapes of the mind, which emphasises the point that even within a similar setting different people seek experiences of health and wellbeing from quite different perspectives. The contrasting social and emotional impact of sitting by the window is therefore relational to participants' personality and intentions for engaging in such an activity in the first place (Conradson, 2005).

David and Emmeline demonstrate quite different conceptions of what feeling good or functioning well means to them, which can be attributed to their socio-cultural emplacement. During her professional life as a teacher, Emmeline was respected for her intelligence and used her knowledge and experience to support others. She played a similar role in her work with the church and as a volunteer in the community. With her cognitive faculties compromised she feels she has lost her social value, which has had a negative impact on her sense of health and wellbeing. David on the other hand spent most of his adult life working as a mechanic before taking an early retirement, in which case he did not associate his social position or intellectual ability with his profession that has now ceased. So despite having to give up certain hobbies, dementia has not had the same devastating impact on David's sense of self or his overall health and wellbeing. This corresponds with Hulko's (2009, p.139) claim that 'The most privileged people in the sample had the luxury of being preoccupied with socio-emotional concerns, as instrumental preoccupations were rarely an issue'. Likewise, having led a busy work life, Diana emphasises keeping active as an important aspect of maintaining her quality of life. Since

retirement, Amelia replaced work with various recreational activities too, the up keep of which is one of Amelia's main priorities. For Diana, her social life was an integral aspect of her career, and when reflecting on the impact of ageing and dementia, she and Hannah stress the loss of friends and social activities. Diana's altered sense of health and wellbeing is in this case linked to changes in her social life rather than practical challenges she faces within the home and community.

Since the onset and progression of dementia, the home environment and family life has become important in participants' daily experiences of health and wellbeing. David and Diana now spend a considerable amount of time at home, which they describe as familiar and comfortable, echoing Milligan et al's (2004, p.1786) assertion that the home environment represents 'a place of ontological security' for older people. Diana draws on her personal belongings in her sitting room to articulate herself, appearing much more confident and engaged at home than at the theatre. David is also much more attentive and relaxed at home during the interview than he is during my observation at the day centre or theatre. Despite the fact that David likes being at home however, he is aware of his isolation. For Emmeline and Amelia in particular, the home has become a site for various negative emotions such as frustration, boredom and lack of productivity. At home Emmeline is assertive, and at times argumentative with Boris, whereas when out in the park or at the singing group she appears subdued. It seems that being at home contributes to Emmeline's spurts of frustration and being outside helps her to feel calmer. This is also true in Amelia's case, who feels irritable and without purpose if she is to spend longer than a day at home. Amelia instead relates the feeling of being at 'home' to when she is out in the neighbourhood.

As they began to give up many hobbies and other roles in the community family became important to participants' daily routine and self identity (Cohen and Mansfield; 2006a). Emmeline and Boris spend a lot of time with their grandchildren, eating out and going to the park together. David and Katherine also see their daughters who live nearby several times a week. Emotional connections and familiarity of one another are key contributing factors to participants' preference for spending time with family. The role that the participants play in their relationship with family members gives them a distinct purpose. For instance Emmeline claims she and Boris '*always look after the grandchildren*' after school. Likewise, Amelia, aggrieved by her sister recently going into a care home, explains that she and Muriel visit her each week to '*keep her spirits up*'. Amelia expresses a similar sense of responsibility towards her dogs who in turn give her a sense of joy, describing it as an interdependent relationship that she shares with them. David too, talks about one of his daughters enjoying his sense of humour and making her laugh on days when she is taking care of him. The sense of giving experienced in

such relationships further augments participants' contribution to personal relationships and activities of daily life. Family carers are in this way an important source of confidence to all of the participants, supporting them to navigate socio-spatial aspects of settings and activities that are vital to them feeling and functioning well.

All four participants with dementia describe and experience both physical and cognitive impairments, which cause them and their family carers to reprioritise their health and wellbeing goals. Their cognitive impairments have most commonly interfered with their memory, whereby they struggle to recollect people and places that are part of their everyday lives. Diana can no longer find her way to the local shops and back and Emmeline has in the past turned up to the shops in her area unsure of her whereabouts. This has resulted in a loss of autonomy and increased dependence on family carers having a negative impact on their self esteem and sense of self, as documented in previous studies (Fazio and Mitchell 2009; Harman & Clare, 2006; Holst and Halberg, 2003). David also experiences disturbed perceptions, including hallucination, which often causes him to become perplexed and agitated in unfamiliar settings or situations. So whilst the fear of getting lost, has meant that the participants with dementia are disallowed by family carers to leave the house unaccompanied, Katherine is also afraid of taking David anywhere different. The physical capabilities of the participants also vary; Amelia is still able to walk very well and does so often, Diana struggles to walk for long and David and Emmeline usually require the assistance of a wheelchair. Diana, David and Emmeline acknowledge that they no longer have the physical capacity to pursue activities they once enjoyed, such as dancing, going on nature walks or doing voluntary work, and have had to cut them out of their everyday life. This mirrors findings in Gilmour and Huntington's (2005) study, where people with dementia reduced their household and community activities as a way of managing stress associated with trying to complete tasks that were now too difficult. In turn, the authors claimed that the participants were able to retain a certain level of control and independence in their lives. For the participants in this study however, giving up of certain activities which previously defined their recreational interests, personal abilities and role in society are viewed with an overwhelming sense of loss.

Day centres and dementia groups are now an important lifeline for the participants with dementia in the pen portraits, offering much needed respite for the carers as well as social and recreational opportunities for the persons with dementia. The more advanced their dementia the more the participants engage with such services. Hannah and Katherine fear taking David and Diana out on their daily errands, claiming that shopping centres, busy car parks and heavily trafficked roads are becoming too difficult to navigate for them. David and Diana attend the day

centre three times a week, whilst Amelia is in the process of increasing her one day a week at the day centre to two days a week. Muriel is also compelled to increase Amelia's days at the day centre, as she is struggling to find some time for herself between her caring and housekeeping duties. Emmeline does not attend a day centre but frequents two different dementia groups each week. Participants with dementia's health and wellbeing is in this case increasingly governed by their experiences of dementia specific settings and services, as many everyday settings and activities in the community have become too demanding to negotiate (Blackman, 2003). Thus, for David and Diana their loss of friends and social opportunities have now been replaced with the social network and activities they now enjoy at the day centre. Amelia too mentions friends that she and Muriel have made at one of the dementia groups, who now join them on day trips and meals out.

6.3.2   Balancing health and care needs with trying to 'be me'

Previous dementia research have highlighted the primacy of a person's sense of self and identity in their perceived quality of life (Cohen-Mansfield, 2006b; Harman and Clare, 2006; Robertson, 2014). Whilst some of this work points to people's self identities being threatened by an increasing sense of loss and dependence caused by dementia, other work shows a more active role played by the person with dementia and their carer in renegotiating their identity as way of adapting to life with dementia. Likewise, in the present study the participants are found to continuously balance retaining aspects of their former sense of self with managing their changing health and care needs, which have implications on how they perceive and maintain their health and wellbeing.

Participants with dementia's sense of self is very much rooted in many of their past roles and experiences. Diana's history in the entertainment business has influenced her present engagement with the local theatre, whilst David previously playing in a brass band explains his desire to watch the brass band at his local park. Similarly, as a lifelong Preston North supporter, going to the football matches is one of the highlights of Amelia's week during the football season. Emmeline also unfalteringly attends the Sunday service at her local church, since it has been a routine part of her life from a young age. The participants attribute experiences of familiarity, belonging and emotional connections to these settings and activities, associating their state of health and wellbeing to a continued sense of self and place. The family carers in this case also often evaluate the person with dementia's quality of life against their ability to retain previous aspects of their lifestyle. Katherine for instance laments David giving up playing the saxophone and bowling as the dementia progressed, claiming it to be the main cause of his

loss of social network and purpose. Boris similarly alludes to Emmeline's loss of independence and ability to 'help' since giving up her voluntary work. Likewise it is very important to Hannah that she supports Diana to engage with the theatre and areas of the neighbourhood she has a special attachment to, without which she fears her mother's life would be much less fulfilling. Also, aware that Amelia enjoys the outdoors Muriel has decided to take up camping as a regular hobby and is committed to taking Amelia out for a walk every day.

With the progression of dementia, the family carers have become more involved in defining what is important for maintaining the health and wellbeing of the person with dementia. The family carers express their concern with participants' safety, comfort and personal dignity when assessing the appropriateness of particular settings and activities (van Gennip, 2014). Whilst David talks about the appeal of scenic views of the countryside, Katherine describes the strain of pushing David along uneven country paths and her fear of losing control of his wheelchair. Hannah explains that Diana would probably like to go into the city centre, but using public transport and busy spaces are no longer safe for her as she struggles to walk. Similarly, although Amelia claims she still enjoys going to the theatre Muriel reminds Amelia that she becomes restless after a while, and so they now only go to the dementia friendly film screenings. Additionally, Katherine and Hannah also have to ensure that appropriate bathroom facilities are available for David and Diana due to their problem with incontinence, influencing places they can engage with, in the wider community. As such the family carers admit that addressing the increasing care needs of the person with dementia takes precedence over pursuing activities which may resonate with their personal preferences or support their self growth. Participants' freedom to go out as and when they wish is necessarily curtailed by the need to have a chaperon to stop them from wandering or getting lost. Likewise, opportunities for them to engage in new activities and settings are assessed against how well they accommodate a person in a wheelchair or someone likely to suddenly become restless and agitated. Instead, the family carers often site provision of a safe space, healthy meals, self-care services and appropriate handling of behavioural problems at the day centre as integral to maintaining the health and wellbeing of participants with dementia.

Engagement with dementia groups and services vary amongst the participants, highlighting the fact that aspects of health and wellbeing people prioritise and ways they seek to maintain it in their daily lives are very personal. Emmeline is hesitant to leave her house and despite Boris' efforts at encouraging her to mingle with the other members of the dementia singing group, she usually keeps herself to herself. David on the other hand agrees with Katherine that the 'company' he enjoys at the day centre is crucial to his connection with the outside world. The 'laughs' David claims to have with other men at the day centre are important to his expression

of masculinity and sense of belonging whilst Emmeline's reluctance to interact at the dementia group helps her to avoid awkward social situations and thereby keep her social status intact. They both seek to protect and present a certain version of themselves, and the extent to which the socio-spatial environment allows them to do so determine how well they feel and function within a particular place. Health and wellbeing experiences are in this way constructed through a combination of individual and socio-spatial factors (Conradson, 2005; Finlay et al, 2015).

Participants with dementia's conceptions of health and wellbeing hinge on personal factors relating to their self identity, interests and abilities which shape how they engage with different settings and activities. Places which allow a continuity of self or a positive expression and development of participants' sense of self are actively sought. However, as the pen portraits also demonstrate, with the progression of dementia the participants have been struggling to meaningfully engage with and enjoy many settings and activities which were once characteristic of their socio-cultural position and personal goals and preferences. Consequently, participants have been increasingly engaging with alternative settings and activities, considered to be more suited to their changing needs. The socio-spatial contexts of participants' present lifestyle now define their sense of self and their place in the world and are as such responsible for their altered approach to maintaining their health and wellbeing. The participants now take pleasure in spending time in natural landscapes close to home, such as local parks, meadows or the beach, forgoing more formal or social roles in the wider community. They also make frequent use of dementia groups and services, forging friendships and finding safe ways to engage in activities of interest within those settings and networks. This reflects findings from previous research focusing on the impact of ageing on people's relationship to place, suggesting that people's experience of place along with their expectations of health and wellbeing change over time (Bell et al, 2015; Milligan et al, 2004). For the participants in the pen portraits, the diagnosis of dementia has had a significant impact on their self perception and how they manage their day to day life, precipitating changes in their expectations of health and wellbeing and the ways in which they seek to maintain it.

6.4   Conclusion

The pen portraits draw upon different occasions, environments, narratives and sources of information, which together provide rich and contextual insight to participants' lives. They demonstrate that people with dementia's conceptions of health and wellbeing are subjective, fluid and based on a complex concoction of past and present as well as personal and cultural factors and experiences. Their past interests, personalities and social aspirations are reflected in

their everyday practices, whilst their changing abilities and support needs compel them to adapt their lifestyles accordingly. Their perceptions and experiences of health and wellbeing are therefore underscored by how well they manage the impact of dementia whilst retaining aspects of their individual personality, personal relationships, social identity and previous interests.

The onset and progression of dementia signifies an important life transition, one that is on-going, precipitating a continuous reprioritisation of health and wellbeing and sense of self. The participants are essentially on a journey comprising various experiences of change, adaptation and *holding on.* Moore et al (2013) describes the journey undertaken by terminally ill patients, which involved three sequential existential modes of being- drifting, sheltering and venturing-each differently influencing people's experiences of the hospice. Emmeline is seemingly still at the 'drifting' stage characterised by feelings of alienation from her 'sense of self and... taken-for-granted life world' (Moore et al, 2013, p.154). David is much more comfortable with his condition and 'at home' in his new surroundings suggesting a sense of 'sheltering'. Diana finding a way to reconnect with the theatre through the dementia friendly programme and Amelia taking up camping with Muriel on the other hand are examples of 'venturing' where they, to some extent, have been able 'to find their bearings and move forward with their life' (p.156). Despite there being certain correlations between the experiences of the participants in this study and the terminally ill patients in Moore et al's (2013) research however, it would be too simplistic to assume such a linear transitioning of people with dementia's sense of health and wellbeing. As the pen portraits reveal, participants' conceptions and experiences of health and wellbeing do not shift in a linear fashion, they are constantly negotiated in light of a multitude of internal and external influences relating to participants' past experiences, present situations and opportunities as well as future goals. So taking the question 'What places are of importance to people with dementia and their carers in the wider community?' as its focus, chapter seven explores the physical and social significance of settings participants in the wider study are found to engage with. Underlying the issues covered, will be a consideration of how the places and activities participants engage with attend to their changing health and care needs as well as their sense of self.

CHAPTER SEVEN

Adaptive geography: 'Everything changes as you get older, you go with it'

'We don't have the freedom of confidence to do things, so necessarily we're very, very mundane now' (James)

7.1   Introduction

The progressive nature of dementia increasingly restricts people's roles, responsibilities and activities both within and outside of the home. According to existing research, people with dementia's reduced engagement in domestic and social life further compounds their decreased sense of health and wellbeing (Clare, 2003; Droes et al, 2006; Pearce et al, 2002; Phinney, 2008). Findings discussed in the previous chapter also illustrate participants' conceptions and experiences of health and wellbeing as being strongly characterised by a sense of loss relating to their reduced ability and opportunities to participate in former aspects of everyday life. Health and wellbeing is nonetheless continuously renegotiated and maintained by the participants, through every day practices and relationships. Moreover, ways in which they seek to achieve their health and wellbeing priorities in the context of living with dementia are reflected in their preferences for particular activities and environments. The aim of this chapter is therefore to draw on data from the entire sample to explore places in the wider community that are of interest/ importance to the participants and how these may have changed since the onset of their dementia. In so doing, factors influencing participants' changing geography and the implications they have on how participants' health and wellbeing is now maintained and enhanced is considered.

The chapter begins with a discussion of how the participants with dementia have adjusted their lifestyles in accordance with their emerging health and care needs and how this transpires in their engagement or disengagement with certain places. The subsequent sections will focus on three key features defining participants' adaptive geography overtime: keeping close to home; focusing on the mundane and everyday and doing the dementia stuff. Together these sections outline participants' everyday geographies, highlighting specific places they frequent and why they do so. The chapter then concludes with a summary of the findings and some final comments about how the above sections shed some important light on the role places play in the process of people adapting to living with dementia in the community and maintaining a positive sense of health and wellbeing.

7.2   Changing lifestyles

All of the participants have either given up or changed aspects of their lifestyle that were once an integral part of their life prior to being diagnosed with dementia. Having lived and worked in Spain when younger, Alan frequently visited friends in Spain over the last thirty years. Since his diagnosis however, Alan's children advised him against travelling abroad, which means that he has not been on holiday in the last four years and the only friends he is in regular contact with are two of his local childhood friends. Belinda and James were also accustomed to a particular holiday routine every year after their retirement:

> *"We used to cruise as well as go to, we always went to Scotland ... oh it was a rough life* [laugh]. *Scotland for the golf for a fortnight, American five to six weeks, either November, if it was cold enough, or if it was nice, February, because it's going to be cold then ... France ... for ten days to fill up with wine* [slight laugh]... *and now I'm kinda searching the Web for holidays that are tailor-made for people like this, who are lost".* (James)

Similarly, after retirement Diana began to go on holidays abroad and frequently holidayed in Spain and Greece with her daughter Hannah and husband, which she gave up after her husband's death over a decade ago. Hannah has recently been on holiday abroad, but without Diana claiming that 'it's just not possible any more in her state'. David too, recalls many caravan holidays in Wales with his family when younger, which he and his wife Katherine then continued up until a few years ago. Their more recent holidays, since David has had dementia, have been somewhat wearisome for the both of them:

> "*We're going to Ribby Hall, it's not far .... We went with the British Legion in a hotel in Southport, and that was lovely, but David had a bad turn there, didn't you? Mmm, it was a shame really, you didn't much care for it and then we went to Silverdale in the caravan with the girls ... that was a bit disastrous, he thought there was fellas there as well, but it's just one of those things, wasn't it*"

Although David and Katherine are due to go away again soon Katherine's last few experiences of being on holiday with David cast a shadow over her excitement.

Going on holiday, whether abroad or within the UK, is something that most of the participants with dementia and their carers now find increasingly difficult. Apprehensive about how they would manage long haul flights and complex security checks at the airports James and Hannah have suspended their holidays abroad. James, daunted by the possibility of missing their flight

or Belinda leaving things behind, has not considered going abroad since Belinda's diagnosis almost five years ago. They have instead recently been on a dementia holiday to a purpose built resort in the South of England, where James appreciated the additional support and dementia appropriate facilities, claiming that "*It is really for people like this, you know lost*". Belinda and James as well as Diana and Hannah also take short breaks to rural and coastal areas of the UK, such as the Lake District, Blackpool and Southport. Likewise, because of David's tendency to hallucinate and become disoriented David and Katherine now prefer day trips to places a short drive away from home such as the lake, the bay and the countryside:

> *"... It's on the sea side and that's quite nice to go, Fleetwood, you can see, from Knott End you can see Fleetwood over the ...over the bay. Lytham, we go to Lytham, Cleveleys, just like local places really... I drive and, or the girls come with me, or we all go and we push the, er, we go to places where it's easy to push the wheelchair, yeah."* (Katherine)

In the case of Amelia and Muriel, whilst having enjoyed holidays abroad together when younger, Muriel suggests they now prefer a '*hassle free*' life. Muriel has recently bought a camper van and they have been camping across England, Wales and Scotland and are eagerly waiting for the warmer weather again. The camper van affords them the flexibility of visiting different parts of the country as and when they wish, whilst also allowing them to take their dogs along with them.

The more regular hobbies the participants indulged in after retirement and which characterised their everyday life are now affected by their increasing frailty and cognitive difficulties. Eric, diagnosed with vascular dementia a few years ago has always enjoyed Jazz music and going to music events was one of Eric's most favoured activities from a young age:

> *"I used to read the music papers and if there was somebody on ...that I fancied going to see I went... and I didn't bother as to whether somebody wanted to come wi' me or I went on me own, you know, like I went because I wanted to see who it was ... what they were singing and all the rest of it, and I'd make me own mind up"*

Eric continued to travel to these events all across the North West of England and spent many hours a week in local record shops; he owns a large collection of what he calls *'weird and alternative'* music and has various other music merchandises displayed around the house. About five years ago when he gave up driving due to his dementia however, he became accustomed to searching for music on the internet at home. He now enjoys listening to and sharing his collection of music with his support worker. Similarly, David has always had a keen interest in

music, but although he can no longer play the saxophone Katherine and his daughters make an effort to take him to watch brass bands perform at their local park and other nearby venues. Likewise, two of Diana's much loved hobbies during her retirement were tap dancing with a local group as well as attending theatre shows with her friends. But as her friends have all passed away over the years and Diana herself has become unwell, it is now difficult for her to do these things. Recently however Diana has been able to revive her link with one of the local theatres through their dementia friendly events whilst also enjoying the occasional trips to the cinema and Christmas pantomime with a local dementia group.

When not on an extended holiday abroad, Belinda and James were fervent golfers after their retirement. James points out that:

> " *Belinda became quite proficient at it ...she won lots of prizes and I was also a member of three golf clubs...yeah, I was on the Committee at the golf clubs, so we were active in that direction"*

They gave up golfing a few years ago, since James started to find it difficult to stay standing for long and Belinda was becoming increasingly confused about how to play. James now considers taking up bowling:

> *"It's a much bigger job...there's a lot to playing golf ... more of an effort. Whereas bowling, just wander over there, yeah.. coincidentally my last six or seven years playing golf, we had a friend who had Alzheimer's and I used to make sure that he was with me, 'cause he would get lost, he'd only been a member 45 years, he'd get lost on the course..."*.

According to James, bowling is more appealing because it is cognitively less demanding than golfing and the bowling green is a short walk from home. Mary and John on the other hand attended steam rallies and air shows across the UK over the past 30 years and have a wide collection of model steam trains at home. Around the time of Mary's diagnosis of dementia, just over two years ago, she was becoming agitated by the noise at these events and so they instead started to visit steam train exhibitions at museums.

Mary and John were also keen ramblers for many years; they walked about "*a hundred miles or more a year*" (John). Mary explains that she walked with ramblers from a young age:

Mary: *I used to belong to a rambling club even before I met John. Of course there were walks every week, different leaders, different walk, and that was really good.*

John: *We can't now, Mary can't walk very far now... I'd go as far as to say she has a bit of difficulty walk...so we gave up about 4 years ago.*

Unable to walk long distance now, Mary and John enjoy their long drives to visit friends and family to different parts of the UK. Like Mary, Belinda used to also take pleasure in walking and often participated in nature walks and hiking trips to places like the Peak District and Derbyshire with James when younger. Whilst it is now difficult for both Belinda and James to go on such walking expeditions, Belinda continues to walk into the village several times a week with either James, Sheila her support worker or Pam her housekeeper. Belinda has been able to join a dementia walking group too, comprising people with dementia and volunteers who meet and take a walk in the local park once a week. Emmeline, during her retirement took up a different type of activity to keep herself occupied. She volunteered at various organisations over the last two and a half decades; one of the recent places she volunteered at is a local charity supporting older people in the community. Since Emmeline received her diagnosis of dementia, almost five years ago, she ceased her role as a volunteer and instead became a service user at this particular charity attending their social groups for people with dementia and their carers at a local church.

There is a clear shift in the places and activities participants with dementia now engage with. Holidays abroad and specific hobbies are replaced by short breaks and day trips to local destinations as well as activities that are considered physically and cognitively less demanding. Participants' changing geographies are therefore underscored by their efforts to adapt their lifestyles in ways that meet health and wellbeing needs that have been precipitated by the onset and progression of dementia. Three main themes characterising their changing geographies relate to- their reduced life space referred to as 'staying close to home'; the markedly 'ordinary and everyday' nature of settings and activities they now engage with beyond the home and the growing prominence of 'dementia stuff', particularly dementia groups and services in their day to day life. There is a mutually constitutive relationship between these important features of people with dementia's engagement with the wider community and their health and wellbeing goals and experiences. The following sections will in this case explore these aspects of participants' changing geography and their relationship to participants' ability to feel and function well.

7.3 Staying close to home

Alongside a withdrawal from participating in many of their former hobbies and leisure time activities, participants with dementia now commonly engage with places within the neighbourhood. Their adaptive lifestyles are manifest in their changing geographical area of activity. People with dementia's increasing tendency to draw in their day to day activities towards the home has been described in previous research using the analogy of the 'shrinking world' (Duggan et al, 2008). It is noted that the physiological impact of dementia causes people to limit both their level of activity and range of places they engage with outside of the home. A person with dementia's health and wellbeing is intimately connected to their recoiling life worlds, both as a reason for and consequence of their restricted geographical movements and activity. In the present study, I find several factors contributing to this phenomenon. In many cases it is to do with the person with dementia and their family carer exercising agency in redefining their engagement with and utility of the wider community, but quite often these efforts are underpinned by structural conditions making staying close to home more preferable and unproblematic than venturing further out into or beyond the neighbourhood.

With having to give up driving, many of the participants have lost the independence to travel to places they previously engaged with on their own. They now rely on either being driven or being accompanied on public transport by a family member or carer. Relying on family members and carers to drive has contributed to some of the participants becoming out of touch with distant places that were once important to them (Hedman et al, 2013). David used to be the main driver in his household before being affected by dementia as Katherine never enjoyed it. This was also the case with Belinda, where she drove James for many years until her diagnosis because he has a problem with one of his knees. Katherine and James have now taken over the driving, but whilst James struggles to drive long distance with his knee, Katherine fears driving on the motorway. David can no longer visit Wales or the Lake District on whim as Katherine keeps to places she can reach without going on the motorway. Katherine thereby appreciates the fact that they live close to the West coast which they visit often:

> *'I would drive there, yeah, I don't mind, you know, driving to places like that, it's just the motorway I don't like'*

Whereas Katherine lacks the confidence to drive on motorways, James' physical impairment restricts him from driving long distance, as he admits:

'It's six miles, quite difficult driving to the Golf Club, can't do it... Also, I used to always bring those lovely fruit tarts and pies... we nip out and, they're different prices now, but we nip out and just make a little sort of, there, you know ...just occasionally'

Although Belinda was beginning to struggle playing golf around the time of her diagnosis, it was not until she gave up driving about four years ago that James decided they would give up golfing too. Likewise, they no longer regularly travel out to places they used to eat at or spend their leisure time in, now making occasional trips to some of these places for old time sake. Eric's wife Irene however is a confident driver, but he does not expect her to drive him to music events he used to attend before giving up his licence, as she does not share the same interest. He usually only joins Irene on car journeys when she is heading to the city centre to shop or meet up with their daughters. By contrast Mary and John as well as Amelia and Muriel share mutual interests and continue to together participate in them; Mary and John both take pleasure in going on long drives and visiting family and friends who live some distance from them whilst Amelia and Muriel are both equally passionate about going to football matches and camping. Because Mary and Amelia's motivation for engaging with particular settings or activities beyond the neighbourhood are endorsed and shared by their family carers, who are also physically more able than them, they retain life spaces that are geographically much broader and more dispersed than that of David or Belinda.

Even though the participants can no longer drive, they seldom use public transport as a way of staying engaged with the wider community. Alan is an exception because since giving up driving he frequently travels by bus on his own. He cannot take a bus into the city centre as his children would not allow it due to their fear of him losing his way, but he now habitually travels by bus to the pubs that are more local, keeping to the routes he is familiar with. Belinda also occasionally uses the bus when she goes out shopping with her housekeeper, Pam, but this only involves a short trip into the village. James contemplates using public transport with Belinda too, but the idea so far remains dormant:

'we want to go on the tram … we've had a bus pass now, had it for about, I think I had the first one, it's in Roman numerals mine, and I've not used it, just that once from the pub, you know'

Although he does not particularly like driving, James feels becoming au fait with the local bus routes and timetable is a much harder task. According to Lucy, it is also '*just easier*' to take her mother, Ellen, in the car as she is not used to public transport herself. The carers often find it

easier to use their car because they do not consider public transport to be particularly accommodative of participants' physical impairments. With Mary's diminishing eye sight, John claims that:

> *'It's not safe to get on and off the train or the bus, she doesn't mind sitting in the car anyway'*

Issues relating to practicality and safety are also raised by Katherine and Boris who highlight the difficulty of travelling by bus when pushing a wheelchair. Similarly, Hannah believes crowded buses can be quite '*dangerous*' for Diana in her frail state and therefore only uses buses when she is travelling alone but relies on taxis when travelling with Diana. So although the use of public transport is a likely option for staying mobile and connected to places further away from home for people with dementia, they are considered unsuitable for independent travelling or for people who are relatively frail. Occasions when buses are used by participants it is for short journeys along familiar routes, in which case public transport seldom contribute to people with dementia's frequent engagement with places beyond the neighbourhood.

There are also cost and time implications to travelling out of the neighbourhood, dissuading the person with dementia and their family carer to do so. Hannah finds that it is expensive to use taxis in which case she is admittedly much more selective now about the places she and Diana visit. Also, previously having signed up to a dementia group that was at the opposite side of town, Hannah complains that they spent a considerable amount of time travelling to the venue and back, causing unanticipated disruption to their daily routine:

> *'We struggled a bit with that, you know how long and the transport getting to there; we've always found we've got there quickly but coming back at tea time ... it took quite a while, yes, so we've not done many of them.'*

The travel time, especially when travelling through dense city centre traffic is something that put off some of the family carers from taking longer journeys, even in the car. Katherine shakes her head at the prospect of driving into the city centre with David:

> *'Oh I wouldn't go into the city centre with David, it's too much stress for the both of us, I prefer to just drive down to the village... It's quiet and easy to find parking, we know what to expect.'*

Similarly, whilst Lucy does not mind driving she prefers to drive Ellen to a nearby retail park than into the city centre, as it means spending less time in the car and more time walking around the shops. There is thus a clear preference for staying close to home amongst people with dementia and their family carers.

Reflecting on their reduced life worlds, participants counterweigh the challenges they face in engaging with places beyond the vicinity of the home and neighbourhood with rationales for staying close to home. Talking about his locality, James says:

> '*There's a reason why we chose to stay and grow old here, we prefer this area... it suits us well, we can walk to the shops and the pub if we wanted to. We don't need to go into the city for anything anymore.*'

According to James, places and facilities available within their neighbourhood is sufficient for his and Belinda's needs, giving them little impetus to travel out of the area on a regular basis. Almost all of the participants share a similarly favourable view of their neighbourhood, discussing how particular places in the neighbourhood support their present lifestyle and day to day activities. Like James, Emmeline and Boris make a point of highlighting various functional and social places they have easy access to such as shops, restaurants, parks, a supermarket, a church, their doctors surgery and pharmacy. On a day to day basis, participants prefer to stay close to home unless it is necessary to travel out of the neighbourhood. According to Lucy, Ellen is much more relaxed when she is in the local village compared to places that are further away:

> '*It's familiar, she knows where she is. That's important.*' (Lucy)

Similarly, despite Amelia and Muriel taking regular trips out of the neighbourhood their daily practices are intertwined with the local landscape; as the canal and meadows near their home are important features of Amelia and Muriel's everyday geography. Eric talks about the convenience of living close to places that are important to his day to day life too:

> '*The hospital is just down the road, I walk there every week.... we have lots of places around here to take the dogs out... I usually go down by the canal, there's a gravel pit over there...*'

Hannah expresses a similar sentiment about her and Diana's neighbourhood, claiming that Diana is only able to regularly engage with the outside world by virtue of living a short walk from the beach and promenade as well as local shops and pubs.

Participants thus consider their respective neighbourhoods as being important for maintaining their health and wellbeing, despite having to give up certain activities which are not locally available. Their attachment to their home and neighbourhood is in this way stronger than their desire to engage with places that are new and/ or away from home. The participants with dementia increasingly appreciate the sense of familiarity and belonging they experience staying close to home, bringing into question the idea of distance and being 'away from home' as a precondition for therapeutic landscape experiences (Gesler, 1993; 1996). Instead participants are found to have steadily adjusted their lifestyle and health and wellbeing goals in accordance to what is available in the locality. In response to their reduced mobility and declining physical and cognitive health, they have begun to seek alternative opportunities within the neighbourhood through which they can maintain their health and wellbeing. Belinda and James are thinking of joining the bowling club near their home since they are no longer playing golf. Alan now frequents two particular pubs a short bus journey away from home rather than going to those in neighbouring areas as he once did. Also, Mary and John have become accustomed to taking a stroll along the quiet road adjacent to the fields near their home in the evenings since rambling has become physically too demanding for Mary.

Many of the participants have recently taken up walking in the neighbourhood for restorative purposes, echoing the recently emerging theme of movement and mobilities within the therapeutic landscapes literature (Gattrell, 2013; Macpherson, 2017). It is argued that the act of walking alongside the settings in which this takes place have a positive impact on the health and wellbeing of individuals (Doughty, 2013). Unable to drive or engage in previous hobbies, most of the participants now walk to and around local places; whilst having to walk contributes to participants' shrinking life spaces, walking has become their primary mode of engagement with the outside world. Eric and Amelia walk extensively as they walk their dogs a few times a day, but participants who have become more housebound now also engage in neighbourhood walking. James states:

> *'We go to Sainsbury's up that way, not for anything specific but because we like to walk on impetus....'*

Boris and Emmeline as well as Lucy and Ellen also mention frequently walking to the shops in the village as an excuse to get some fresh air. Similarly Diana and Hannah often walk to the local newsagent to buy some biscuits, the fields near their house to see the horses or around the cul-de-sac to look at neighbours' gardens whenever they are bored at home. Such examples of destination based walking suggest that walking is an integral aspect of people's daily activities

beyond the home, involving 'acts of self care' (Brewster, 2014). For many of the participants, neighbourhood walking is a way of keeping physically and mentally stimulated whilst also engaging in aspects of everyday life, primarily enabled by the functional or sensually pleasing qualities of local places.

It is also noted that although the participants prefer to stay close to home, they do not necessarily want to stay within the home; they seek places that are familiar but offering more varied social, mental and physical stimuli compared to that within the home environment. The changing lifestyles of participants due to declining mobility, cognitive ability and confidence caused by dementia and other co-morbidities has meant a reduction in their geographical area of activity and also social and recreational opportunities, but they have not become inactive. In this way, the reduced life spaces of the participants in this study is not necessarily synonymous with what Rowles (1978) describes as the phenomenon of becoming 'prisoners of space'. Aware of the challenges of participating in settings and activities away from home, the participants have established new routines and everyday practices they can maintain closer to home. People with dementia and their family carers are therefore actively enrolled in creatively utilising their reduced life spaces to accommodate their adaptive lifestyles; many have moved to particular neighbourhoods after retirement pre-empting the need for easy access to certain environments and amenities as they grow older whilst others are beginning to identify and engage in activities within the neighbourhood they hope to sustain through declining physical and cognitive health in the future. With the intensification of people's activities within the neighbourhood however there is also an overwhelming sense of *mundane-ness* about their daily lives. Places close to home frequented by the participants are characteristically ordinary, everyday.

7.4   Focusing on the everyday and mundane

Ellen cannot recall ever having any hobbies, as her home life was most important to her when younger and she invested herself in taking care of her home and family. Lucy recalls her parent's younger lives:

> *'My dad would be into lots of things … he liked his motorcycles and his cars and everything, you name it … and me mum tended to look after everything else, the home … and shopping and making sure people got cards, presents … you know, that sort of role …'*

Doing the household shopping was Ellen's main role, but by the time she received a diagnosis of dementia seven years ago Ellen became very forgetful and unable to independently carry out basic daily chores. Ellen's friend Audrey who she usually '*went into town*' with also became

housebound due to ill health during this period, which further exacerbated Ellen's reliance on Lucy whenever she wanted to go out.

Ellen: *I like to do me own shopping 'cause you know what you're doing, Oh yeah, I've always done me own shopping love, haven't I Lucy, more or less?*

Lucy: *More or less …yeah*

Ellen: *Yeah*

Me: *Is it important being able to do your own shopping? What if you had to give it up?*

Ellen: *Yeah…I'd be sad, yeah*

Lucy: *We'd never give it up now mam…. We never order anything off the internet…. I mean it's important, mum comes to the shop, selects some things … We like to have a look at the second-hand shops, don't we, and have a rummage round… mum likes her skirts and blouses. You like shoes too.*

With Lucy's support, shopping remains one of Ellen's most favourite and frequent activities, as Lucy makes weekly meal plans with Ellen and they go together to the supermarket to buy the necessary ingredients. They often also go to a local retail park or to the charity shops in the village, engaging in some window shopping before stopping at a cafe for a cup of tea.

Ellen requires supervision when out shopping, but it is nonetheless an important activity to her, giving her a sense of independence and normality. Going shopping is a common activity amongst most of the other participants too. Although his children do the supermarket shopping each week, Alan takes a trip up to the high street once or twice a week to buy a bottle of wine. Whilst he does not have any involvement in the shopping done by his children, he likes to choose his wine:

'They said "no dad, no, we'll do it" … you know, they force themselves on me and who am I to complain about that. They get food for me, they tend to know what to get… Well I go to the shops two or three times a week, I get my own wine, I've got used to wine since my time in Spain you see.'

Similarly, despite Hannah and Diana's shopping being done by a care service, they often walk to the local shops to pick up small items. Hannah explains that it allows Diana to '*get out the house*

and see the girls working there', highlighting the sociality of shopping which Diana now feels the loss of. Boris and Emmeline also try to go out to buy fruit and vegetable from the local shops each week, as this is a routine they kept up for many years since moving to the neighbourhood and involves a walk around the area where they previously lived. Similarly, Amelia also accompanies Muriel into town to do their shopping, claiming that although she often stays outside with the dogs whilst Muriel goes in to the shops, she enjoys these trips as they have always done it together. Going shopping is usually a joint ritual which the family carer and the person with dementia seek to maintain, despite the person with dementia having lost the capacity to be actively involved in the task. As John explains;

John: *Since we've been married we very seldom went off on our own ...so she comes shopping with me.*

Me: *How do you find that Mary? Do you like to do the shopping?*

Mary: *It's alright, I get out.*

John: *Not r-e-a-l-l-y, because you can't really see.*

James' account of his shopping trips to the supermarket with Belinda, resembles that of John and Mary, especially as James claims:

> *'It's just me in charge, very acquiescent, Belinda, it's like taking sheep in, you know.'*

Both Belinda and Mary, whilst accompanying their husbands to the supermarket, are now considered to be passively involved. It is in main the familiar and ritualistic nature of shopping, as well as an opportunity to 'get out', contributing to its favourability amongst the participants.

The activity of shopping is essentially both reflective and a perpetuation of participants' self identities. It is something Belinda was in charge of before she was affected by dementia, so asked whether she still enjoys shopping, she replies '*Yes, yes I do, we go together',* without any indication of the reticence disclosed by James. Like Ellen, Belinda particularly enjoyed shopping for clothes, but going shopping now usually involves a trip to the supermarket or local grocery shops with either James or Pam. Shopping for clothes and accessories is one of the things James refers to when reflecting on activities he is unable to support Belinda with:

> *'There are things that I can't give Belinda, she's forgotten everything she knew if you like...I find the only way she will do something is if she watches and follows me, but I can't teach her to apply her makeup in the morning, so she doesn't do that anymore... so that's where Pam or Sheila come in.'*

Belinda would therefore sometimes have a *"wonder around the shops with Sheila"* looking at clothes, when they go out for a walk into the village. But for someone like Emmeline, shopping for clothes and accessories is not important, as she admits:

> *'I never cared for clothes... not a great deal no, because ... because I couldn't see the point, if I had it, if I had enough clothes to wear ...then that would be sufficient.'*

Boris and Emmeline seldom venture out to the city centre or any other shopping centres nearby. Ellen and Amelia on the other hand regularly go into high street fashion outlets, department stores and local charity shops in the town centre and in local retail parks. This is a frequent activity for Amelia and Muriel as well as Ellen and Lucy, and it is not necessarily because they intend to buy something, as they are often simply window shopping. Shopping is more than a functional act of buying, to some of the participants it is a much more holistic experience involving customary social and sensual engagement with place. However, due to reduced physical and cognitive abilities, not all participants are able to continue to regularly participate in such everyday experiences. For Diana a trip into the town centre is now very rare:

> *'Now and again we do go Harley's (shopping centre), if we're getting her some shoes or something in there. I wouldn't say I wouldn't go in them, but I would probably go more myself.'* (Hannah)

Although all of the participants with dementia, apart from David, mention enjoying shopping, whether for the opportunity to get out of the house, spend time with family members, see people, 'look around' or buy items of their choice, the family carers generally prefer to do the shopping and banking on their own. John tells me that Mary often stays in the car once they arrive at the supermarket because she finds it too crowded, which is also something that Emmeline has also started to do according to Boris. Although Belinda likes to accompany James into the supermarket, he worries about losing her or guiding her through the car park whilst pushing a trolley. In this way, Lucy avoids taking Ellen shopping in to the village or elsewhere on weekends because it is '*simply too busy*' (Lucy). The family carers are thus deterred by the challenges of ensuring the safety and comfort of the person with dementia whilst shopping at the supermarket or walking along a busy high street.

Other places in the wider community frequented by the participants are local pubs, cafes and restaurants. Many of the participants talk of a favourite cafe or pub where they go between once to several times a week. Ellen and Lucy have a number of cafes they usually call at when out and about. Stopping at a cafe is an important aspect of their trips outside, providing a pit stop, whether they are out shopping or on a leisurely walk:

Lucy: *There's a fantastic place up in the Salisbury retail park, you know the coffee shop? And great, 'cause we love to go in it, it's the Costa.... ... you drink cappuccino, don't you?*

Ellen: *Mmm, something like that, yeah, I don't know half of the names ...*

Lucy: *Yeah, we get a large cappuccino.... Dunham Massey, places like that, we might go to... We might see a stately home with a coffee shop ... oh there's always a coffee shop ... has to be...*

Similarly, Amelia and Muriel talk about the convenience of often having their lunch at a cafe or restaurant in town when they are out. Belinda and Sheila also always stop at a cafe in the village in the middle of their walk every Tuesday. During my walking interview with them, Sheila chooses one of their preferred cafes when we get to the main street in the village:

> *'This one specialises in tea... we'll go in all of them and see what they're like, 'cause we have been in one or two that are a little bit strange ...'* (Sheila)

This street, dotted with a number of cafes, is their usual destination during their walk; they spend about half an hour having a drink and taking a rest at one of the cafes before heading back home. Boris also mentions preferring to take Emmeline for a walk to a local park where there is a cafe inside. As Emmeline is normally quick to refuse Boris' suggestion to go for a walk in the park, the cafe is an incentive for her to do so. David is in the same way convinced to accompany Katherine to the garden centres with the prospect of having lunch at the cafe there at the end of their shopping. Katherine provides an account of their typical trip to the garden centre:

> *'I drag you around the garden centre don't I? "shall we go to Atherton?" [mimics David groaning]... But you like going for something to eat after... he just doesn't like the garden centre bit.'*

David and Katherine are also very fond of a local cafe, a short drive from their home, which Katherine describes as:

> *'It's cheap and cheerful, two for the price of one... It's not far, you can see it on the way out of this area...we like it there, we went there for our birthdays, didn't we? And father's day, with the girls...lately we've gone a bit more, it's just that it's ideal for us.'*

Likewise, John talks highly of a local restaurant where he and Mary often go for lunch.

> *'We go to the Brewer's Fayre quite frequently…it varies but we've been there 3 or 4 times a month…We go into other places at times, but nowhere specific or on a regular basis… We go to the Brewer's Fayre on a regular basis if you like, we know the food's good and the service is good.'*

So whilst cafes provide a place to take a short break and eat when out and about for some participants, it is the main reason for going out for others. Cafes are in this case ideal places for encouraging destination based walkers and people seeking purposeful activities to stay connected with the wider community.

Moreover, cafes, restaurants and pubs are places where the participants spend time with friends and family. David and Katherine often go to their favourite cafe with their daughters. Emmeline and Boris eat out at one of the local restaurants with either their family or two of their old friends at least a couple of times a month, as do Amelia and Muriel. Belinda and James once had a '*vigorously active social life*' (James) attending social events and dinner parties, but they now only eat out on special occasions. Instead, James claims they now spend up to three evenings a week at a local pub where they meet up with a regular group of friends:

> *'Oh it's set in stone; we go on Mondays, sometimes on Fridays, and on Saturdays because the same people are there…'*

This is also true for Alan, who goes to a pub near his home during the week but takes a bus to a pub further away to meet up with two of his childhood friends. He says:

> *'I've two pals, they're both 80-years-old and we meet once a week… we just turn up at the pub, you know, we often go to the one in Drayton… I've known them since we were 14 or something, we're all 80 now…'*

Hannah and Diana frequent a couple of pubs in their local village too where they enjoy the food and the company of other local residents:

Hannah: *When we've been going into the …*

Diana: *Yes*

Hannah: *the pub for the, they do the two meals for £10 ….. we haven't been as much this year, but we do go in there quite a bit…*

Diana: *Yes, we do*

Hannah: *and we always see somebody when we're up there …*

Local cafes and pubs therefore serve both a functional purpose in terms of providing a place to rest, eat and drink and a social purpose in regards to offering a place where the participants are able to meet with family, friends and neighbours. Participants' engagement with cafes and pubs are thereby driven by both reasons of practicality and sociality. They are in this case the most frequented places in the neighbourhood amongst the participants, sometimes providing stand alone experiences and other times interwoven with other settings and activities people engage with on a regular basis.

Cafes, restaurants, pubs, along with shops and supermarkets are a routine part of participants' daily lives, acting as an interface between persons with dementia and the wider community. These places of everyday 'occupations' (Cutchin et al, 2010) facilitate the enactment of identities, maintenance of personal and social relations as well as organisation of daily and weekly activities, assuming an inherent position in the shaping of health and wellbeing experiences for people with dementia. Whilst engagement with many everyday settings and activities are considered to support participants' ability to actively and meaningfully participate in community life, some are now less conducive to participants' health and wellbeing. Busy city centre locations and supermarkets are in particular discussed as becoming challenging to negotiate for participants with deteriorating physical and cognitive abilities, causing them to increasingly withdraw from these settings. People with dementia thus share a fluid relationship with everyday places; certain setting and activities which were once important to their health and wellbeing are now considered inappropriate and therefore less significant in their daily lives. Moreover, since the onset of their dementia, many of the participants have begun to engage with various dementia groups and services, adding a third dimension to their changing everyday geography.

7.5   Doing the dementia stuff

All of the participants in the study engage with a dementia group or service. These are settings and/ or activities specifically tailored to the needs of people with dementia and often supplement their declining participation in the home and neighbourhood. Listing the activities Belinda participates in on a day to day basis, James says:

> *'We nip out to Sainsburys… we go to the pub on them days as you know, she sometimes helps me get the dinner on…Oh and she does her dementia stuff too of course'.*

Belinda attends two local dementia groups, one where she participates in group walking at a local park and another which takes place at a community venue once a week offering different

activities such singing, gentle exercise as well as quizzes and games. Belinda is also offered befriending support through the local Alzheimer's Society branch, whereby once a week she goes out for a walk with her befriender, Sheila, for a couple of hours. The 'dementia stuff' which Belinda participates in are in addition to her life in the community with James. But they are important for reengaging Belinda with people and settings beyond the home, since her and James' social life has come to a standstill over the years. For other participants such as Amelia and Muriel however, the 'dementia stuff' is still quite new and they are still in the process of giving up or adjusting certain of their activities in the wider community to accommodate for the dementia specific activities. Muriel claims:

> *'I mean sometimes we'll have em, a season ticket at The Picture House (theatre) if we want to see everything ... although we are less likely to do that now because Amelia will soon be going to a day centre twice a week.'*

The dementia settings and provisions that the participants engage with vary in terms of the kinds of activities they promote and where they take place. They can be broadly grouped into three categories: dementia specific settings; dementia specific activities and ordinary settings and activities adapted for dementia.

7.5.1   Dementia specific settings

The day centres fall into the first category, as they are dementia specific settings focusing on providing supervision and care. Four of the participants, David, Diana, Mary and Amelia, attend a day centre during the week. The three day centres that are used by the participants in the study are local to them; two are within community health centres and another is a large re-purposed house used to provide day care for older people and people with other ailments. The participants spend from morning up until late afternoon at the day centres, partaking in specific activities such as arts and crafts, knitting and board games as well as eating lunch and socialising with other people with dementia. Additional services such as hairdressing, massage and nail cutting are also offered at two of the centres. David and Diana use day centre services the most, attending up to three to four times a week, since they require more support with all aspects of their day to day life and are much less mobile compared to Mary and Amelia. When Diana is not at the day centre she is only able to engage with places within a walking distance from home. Hannah therefore often arranges for a friend to sit in with Diana while she is out or respite care for when she is away for more than a day. Similarly, David has a sit-in service to

provide supervision and help him with personal care when Katherine is not at home. Discussing the day centre attended by David, he and Katherine therefore highlight its significance for countering social isolation:

David: *It's excellent, that*

Katherine: *Yeah, companionship really, isn't it …*

David: *Yeah… Other than that I'd be stuck in my chair … all day and all night*

Katherine: *He doesn't like to go out much otherwise you see.*

The day centre offers a place for David to go and be amongst other people, since he is unable and usually unwilling to go out with Katherine. Likewise, Hannah appreciates the opportunities Diana has at the day centre to engage in different activities:

> *'Mum is picked up outside her door with transport to take her there on the transport little bus… and that's three times a week. She has lunch there, a proper lunch, pudding and everything, err… she has gentle exercises, quite a few, in the morning… They do all sorts from singing, reminiscing, watching a video…'*

Without such services provided by the day centre, Hannah believes her mother would have a much more of a monotonous week at home. She will also miss out on seeing people on a regular basis, especially her childhood friend she has recently met at the day centre and likes to spend time with.

Mary and Amelia on the other hand, who still regularly accompany their family carers in their daily lives in the wider community, only attend the day centre once a week. But like David and Diana they also talk about the social benefits of attending the day centre. Amelia claims she can relate better to the people at the day centre who have dementia than those who do not have the condition:

> *'I feel like the other people there… I don't have a problem chatting to them.'*

Whilst Amelia finds herself increasingly withdrawing from conversations with family and friends, she appreciates being able to connect with people at the day centre. Mary used to attend a knitting group at the local church which she had to stop due to her diminishing eye sight and problems with memory. She therefore particularly enjoys the 'knit and natter' session at the day centre as they use larger needles, combining one of her favourite pastimes with the opportunity to engage in small talk. The day centre is therefore a place for people with dementia to find

companionship and participate in various activities of interest, but unlike places in the wider community it is far removed from everyday experiences in the community, as its premise is to provide care and keep people safe:

> *'He likes it, they're really nice there, they know what to do and how to handle him...so I don't worry when he's there.'* (Katherine)

So whilst David, as mentioned in the previous chapter, is disapproving of the fact that he is not allowed to step outside of the day centre, Katherine is thankful to be able to leave him in safe hands. Despite rejoicing in the company of other people, David thus claims the day centre required *'some getting used to'*, in terms both adapting to its rules and the different personalities of people there, bringing to light the less voluntary circumstances and contested nature of places in which therapeutic landscape experiences are constructed (Finlay, 2018; Love et al, 2012).

7.5.2   Dementia specific activities

The second category comprises singing groups, social clubs, creative workshops, luncheon clubs and dementia cafes. These are groups exclusively for people with dementia and sometimes their family carers too. The groups usually take place in community settings such as local church halls, libraries and community centres, with one of the luncheon clubs and two of the dementia cafes mentioned in this study being held at nearby hotels. The sessions last between two to three hours, and whilst many of the singing groups and social clubs take place weekly, the dementia cafes and some of the luncheon clubs are less frequent, running either on a fortnightly or monthly basis. All of the groups follow a similar format; there is a set activity (singing, art and craft, game, exercise, lunch), followed by refreshments, some time for socialising and sometimes a speaker to provide information on dementia or related issues. All of the participants with dementia, other than Ellen and Eric, and many of the carers too, engage with at least one of these groups. Emmeline is dropped off at a singing group near her home once a week by Boris, but Muriel always joins Amelia at the singing group she goes to. Boris and Emmeline however go along together to a social group for people with dementia and their carers once a week, which Boris describes as:

> *'A group for carers to get together really, but there's things to do for Emmeline too... It's divided into three parts, so there's a sort of, get round and have a cup of tea and chatter first of all, then in the middle there's some sort of activity which varies, it could be crafts, it*

could be music, it could be bingo, that sort of thing, and then they do a, for the third part, armchair exercises.'

Many of the family carers also accompany the person with dementia to the luncheon clubs and dementia cafes, as they provide opportunities for the carers to share their experiences and benefit from advice and support from specialist services. Katherine enjoys going along to the dementia cafe with David once a month, explaining that:

'We go to that for a cup of tea and biscuits, they have different things, sometimes it's about reminiscing... if we needed information about something, usually somebody will help.'

Emphasising the support and advice she benefits from at the dementia cafe, Hannah also claims:

'Well its tea and biscuit, and they always have a talk, so we've had safety, we've had auxiliary nurses, we've had gadgets and aids for people... and then we have a chat... everybody has a chat.'

These groups, regularly attended by the participants with dementia and their family carers are important for social interaction and making friends:

Amelia: *Yes we've made some really nice friends there.*

Muriel: *They're very new friends, whilst it feels as if they're going to be quite close eventually... It's obviously early stages yet.*

Amelia: *Yeah, we're planning on having days out in the camper*

Hannah, John and Boris also mention carers they have got to know quite well through attending the dementia groups, divulging into aspects of the other carers' personal lives and commenting on their particular personalities as though they are friends or close acquaintances.

7.5.3   Ordinary places adapted for dementia

The final category of dementia groups and services comprise the dementia friendly cinema events, walking group in the park and day trips organised by dementia services. These are everyday activities in everyday settings that are in some way adapted to meet the needs of people with dementia. The dementia friendly cinema events are held at a local theatre inviting people with dementia, their carers and the general public for the screening of mid 20th Century films. Whilst the films are selected to appeal to a particular age group, the events are not for

Walking group attended by Alan

Fig 8: Path in the park

Fig 9: Lake in the park

Fig 10: volunteers and walkers

Fig 11: Drinking tea and playing dominoes in the cafe

Fig 12: Walking in pairs

Fig 13: Feeding the ducks and swans in the lake

older people or people with dementia exclusively. The venue is adapted to meet the needs of people with dementia, through the use of brighter lighting, clear signposting, careful sound control and removal of objects which can be misperceived by people with cognitive problems. Additional touches contributing to a welcoming atmosphere for an older population are traditional table dressing in the bistro area. There are also volunteers available at the event to assist people with dementia to the toilets and to their seats inside the theatre. Although such measures are taken to ensure that people with dementia would have a pleasurable experience at the theatre, these events aim to provide an authentic cinema/ theatre experience for the participants.

David, Diana, Mary and Amelia all attend the dementia friendly cinema events, and they, along with their carers, report to enjoy them. They no longer generally go to the cinema or theatre and have started to attend these events because they are dementia friendly. Hannah says:

> 'It's just knowing that I can pop out with mum to get some air or to take her to the toilet. It makes a difference.'

Similarly, Katherine comments:

> 'Sometimes he's there muttering away, but good thing about this is that nobody tells you to shush.... They all understand, you know.'

The dementia friendly cinema events essentially enable the participants with dementia and their family carers to participate in a place and an activity they used to previously enjoy. The walking group at the park offers a similar opportunity for Belinda who is a keen walker. The group walk to some extent, although necessarily in a much smaller and manageable context, imitates Belinda's previous experience of nature walks in the peak district. The natural backdrop of the park is provided by the trees, the lake and presence of ducks, squirrels and birds whilst its accessibility to the general public allows the group to come into regular contact with people of all ages and background. The socio-spatial setting of the park therefore remains unaltered for the dementia group, and only to ensure their safety each walker is paired up with a volunteer to support them along the trail.

The opportunity to engage with places and people in the wider community is one of the main features of this type of dementia service. Hannah talks about the numerous day trips she and Diana have been on through one of the dementia social clubs they are members of:

> 'I mean we've done quite a few things really, like at the Christmas we went to Holton, to the pantomime... We also had a Christmas meal at Torrisholme, nice restaurant there ... then

last year we had a trip to 'Riverdance'. We've been twice to the Lakes ...once across on the boat and once around the Lakes. We've been to Hayes Garden Centre, we've been to Oswaldtwistle Mill ...'

All of the places mentioned by Hannah, the theatre, restaurants, garden centre and national parks are places in the wider community which the participants with dementia admit to frequenting much less since the onset of dementia. But through the support of the dementia social club Hannah and Diana are able to still regularly participate in such settings. By arranging appropriate transportation and supervision, the dementia groups make these everyday settings and activities suitable for the engagement of people with dementia.

7.6   Conclusion

This chapter draws out a significant shift in places of importance to the participants as they undergo changing lifestyle activities and health and wellbeing needs with the onset and progression of dementia. Due to the physical and cognitive difficulties they now experience, the participants with dementia and their carers have given up holidaying abroad and many of their former hobbies and interests such as golfing, dancing, playing in or attending music events and volunteering. This 'shrinking world' phenomenon experienced by people with dementia as has been documented in past research, is usually perceived under the gaze of a loss of activity, relationships and control over a person's own health and wellbeing (Blackman et al, 2003; Duggan et al, 2008; Forsund et al, 2018; Phinney, 2006). But countering this perspective, the present chapter illuminates everyday activities the participants consistently and actively still engage in within their reduced life spaces, such as shopping, eating and drinking out and also walking in the neighbourhood, which are integral to their health and wellbeing. Despite the physiological impact of dementia restricting participants' mobility and interaction with varied geographical spaces, their engagement in mundane everyday activities is an example of retaining some degree of agency in their daily lives and actively participating in the wider community. However, the changing and adaptive lifestyle activities accompanying people's 'shrinking worlds' are generally overlooked within the existing literature.

The participants have adapted their daily pursuits in accordance to their present health and wellbeing needs by engaging in settings and activities that are physically and cognitively less demanding, still familiar whilst also personally and socially rewarding. This adaptive tendency amongst people with dementia in terms of their everyday activities has been recognised in previous dementia studies, but there still remains a lack of consideration of the implications of

such adaptive strategies on the size and characteristics of people's life spaces (Gilmour and Huntington, 2005). This chapter on the other hand demonstrates that people with dementia's adaptive lifestyles and their shrinking geographies go hand in hand, hence the coining of the term 'adaptive geographies'. Participants' everyday geographies are shaped by activities and practices they now engage in, in response to their changing health and wellbeing needs, leading them to establish new or reinforce pre-existing relationships with particular places within the neighbourhood whilst disengaging with others (Bell et al, 2017). Most of the participants who frequently walk in the neighbourhood now engage with settings which were much less a part of their everyday lives before being diagnosed with dementia, either because they did not walk often or they walked in more urban settings or places that are further away from home. Likewise, participants' adaptive behaviours are also influenced by the characteristics of their respective neighbourhoods. Almost all of the participants have continued with or taken up walking, despite their cognitive difficulties, because their suburban neighbourhoods and village towns provide them with relatively quiet streets and nearby natural environments which they find conducive to walking. So to paraphrase Gesler (1992, p.74) 'structure and agency might be blended in the creation of therapeutic landscapes', people with dementia's adaptive geographies are determined by a combination of personal preferences and abilities as well as physical and social features of neighbourhoods in which they are embedded.

Moreover, as participants became less able to carry on with many of their roles and responsibilities in the wider community due to the impact of dementia, they became more involved with dementia groups and services. Such settings are therefore a significant part of many of the participants' everyday geography, with some participants spending more time at the day centre than any other setting in the community. This is interesting in respect to existing therapeutic landscapes literature where health care sites are commonly considered outside of the realm of the ordinary and everyday (Smyth, 2005). In this chapter I make a distinction between three types of dementia groups and services which the participants engage with. Day centres fall into the category of health care sites found within the therapeutic landscapes literature, because whilst providing a dementia appropriate environment, they are considered to be removed from mainstream community life. Yet, there are other dementia groups and services which seem to sit in between the home and neighbourhood, encouraging people to engage with local everyday settings or activities. Many dementia specific activities, such as the dementia cafe and dementia singing group, often take place in the community, bringing dementia care and support out of health related settings and into ordinary everyday environments. The dementia film screenings at the theatre or the local park facilitating a dementia walking group are examples of further progressive attempts to embed the facilitation

of people with dementia's health and wellbeing within ordinary everyday settings and practices. They not only encourage people with dementia to interact with community settings but also participate in aspects of everyday life they are familiar with.

Finally, all participants and their carers talk about their motivations for engaging or in some cases disengaging with certain places and activities. Their experiences allude to how they perceive and interact with different aspects of place, and their impact on participants' overall health and wellbeing. For instance, shopping is more of a symbolic task for some of the participants affirming their sense of self and normality, which involves places they recognise but now unable to negotiate on their own. For others the motivation for going shopping is to be outside and engage in some physical activity. Likewise, dementia groups are appreciated for different reasons by different participants, whilst for some it is the appeal of certain activities, such as singing or walking, for others it is very much their affordance of companionship. Places people with dementia consider important to their ability to live well with dementia, and how they engage with them very much depend on their health and wellbeing priorities. Chapter eight will therefore draw on participants' socio-spatial experiences in the wider community to further explore their relationship to participants' expectations for and experiences of health and wellbeing.

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CHAPTER EIGHT

Places, routines and interactions for health and wellbeing

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8.1   Introduction

The purpose of this chapter is to provide a closer examination of participants' socio-spatial interactions with places identified in chapter seven to further understand how health and wellbeing is maintained, enhanced or hindered through participants' interactions with particular settings and activities. Throughout the thesis I propose that health and wellbeing is a subjective concept and for people with dementia it relates to experiences of autonomy and self-worth, feeling comfortable and being able to achieve personal goals. These aspects of health and wellbeing as noted in chapter six are inherently linked to how the participants negotiate between ensuring a 'continuity of self' and managing their 'changing circumstances'. Prioritising their physical and cognitive needs, many participants have reconsidered their expectations and pursuit for health and wellbeing, leading to, as illustrated in chapter seven, changes to the kinds of places they now engage with and how they do so. This then brings into question how such place based experiences contribute to participant's ability to feel and function well. To respond to this question, the physical, social and symbolic dimensions of people-place relationships along which therapeutic landscape experiences are constructed, as presented in chapter four, are drawn upon.

Aspects of the therapeutic landscapes concept and contributions from its empirical use are woven into the discussion of findings rather than using the concept to frame the contents of the chapter from the outset. This is done, firstly because it is counterproductive to maintain a strict structure of presenting and discussing the physical, social and symbolic components of therapeutic landscapes separately when experiences of them are often interlinked. Secondly, it is important to illustrate that therapeutic landscape experiences are relational, occurring in relation to people's wider life experiences and expectations; for therapeutic landscape experiences are not inherent to a particular environment or location, but constructed through what people do within them and why they do so (William, 1998). The chapter is therefore structured around two overarching goals of everyday life held by the participants, according to which they usually assess and describe their experiences of health and wellbeing in place: 1. maintaining normality and routine and 2. staying connected with family, friends and neighbourhood. The first section, addressing participants' concern with maintaining a sense of normality and routine, explores how their daily place based roles and experiences work to

support or contradict their sense of self and place. Section two looking at settings and practices relevant to staying connected with family, friends and the neighbourhood, examine how place support participants to situate their *self* in wider socio-spatial contexts. The chapter then concludes with a summary of the findings.

8.2 Maintaining normality and routine

In the previous chapter I discuss participants' withdrawal from many everyday places in the community after the onset and progression of dementia, which in effect disrupts their daily routine and over all sense of normality. However, key to adapting to life with dementia for all of the participants to a varying degree is their ability to renegotiate a sense of normalcy in their everyday life, underpinned by regular patterns of engagement with different settings and activities in the wider community. The participants' sense of normality, and in turn their health and wellbeing, is therefore closely tied to the socio-spatial context of their day to day routines. Whilst their continuing interactions with places form their sense of normality, their conception of normality is also responsible for how they view and engage with place. For some participants, dementia settings do not have the same semblance of normality as ordinary places in the wider community. Sharing his reasons for not wanting to continue with a dementia group after a few weeks, Eric talks about the insincerity of making '*small talk*' and participating in activities which seldom resonated with his personal interests :

> '*I had to listen to rubbish music for starters [laugh]....They did quizzes, card making... it just wasn't me, I, not the sociable type, I don't normally bother with small talk you see and there, you're sat with them for a good few hours, so it was a bit awkward, too much hard work'.*

The socio-spatial environment and activities of the dementia group provided a break from Eric's usual routine, shifting him out of his comfort zone and habitual behaviours. This 'thrown-ness' after a certain degree of adjustment, Lea (2008) argues, can become an important element of therapeutic landscape experiences, prompting opportunities for self development. However, in Eric's case his preference for situations and experiences he is accustomed to surpassed his openness to new opportunities and ways of being.

The socio-spatial remoteness of certain dementia places, such as the day centre, to everyday life is often deemed to restrict rather than facilitate self development, putting off some participants and their family carers from engaging with such places. James believes Belinda's unfamiliarity with the setting and routines of day care or residential care facilities will contribute to a '*shorter*

lifespan'. Likewise, Ellen considers the day centre to be for people who have '*got no other choice but to go sit there*', connecting engagement with such places with a sedentary lifestyle and sense of rejection from the wider community. Lucy claims, Ellen would instead be willing to meet up with a group of older people, with or without dementia, in a more public setting:

> '*I can see loads of potential going forward... there's no reason we couldn't use the high street for meeting places ... if someone said "Oh let's all meet up somewhere", you know-it's warm, it's sheltered, it's vibrant, there's young people, there's older people ... you'd go...*'

The appeal of local cafes or precincts is their openness to people of different backgrounds and ages, which is in stark contrast to the extraordinary and exclusionary nature of many dementia settings (Glover et al, 2013). The social vibrancy of public places Ellen routinely encounters beyond the home, is in this case important to her sense of place and normality.

Many of the participants' familiar routines in the community involve socio-spatial environments that are dynamic:

> '*We do different things, things we like, like shopping and taking this one (dog) out... we don't do an awful lot, but it's nice with just us two (her and Lucy), always nice to bump into people, some are a bit annoying, but we don't mind 'em*' (Ellen)

It is the varied and serendipitous encounters in the wider community which provide the context for continued *normal* social engagement beyond the home, for Ellen and Eric. Whilst Eric talks about the awkwardness of *'making small talk'* at the dementia group, he appears much more convivial in his account of being out in the neighbourhood:

> '*Yeah, people around here are nice. I stop when out with the dogs, we chat, you know as you do. We just talk about stuff, nothing specific'.*

Similarly, although Belinda is relatively quiet at the dementia groups, James describes her to relish the bustling social atmosphere of the pub:

> '*The amazing continuity that Belinda enjoys - without realising she is- there... she joins in the conversations as much as she can... "Hello" here, "Hi" there to so and so, you know, she's different there... That's why it's all the more important for us to make the effort....'.* (James)

This echoes Moyle et al's (2011, p.1448) argument that care facilities are unlikely places for people with dementia to enjoy 'familiar human contact', the exclusive and unusual socio-spatial

environment of such settings hinder ordinary processes through which people connect with one another in their everyday life. However, participants like David and Amelia who see the day centre and other dementia groups as part of what has become their new *normality,* have adapted to their socio-spatial arrangements well and describe social connections they experience in such settings as vital for their overall quality of life.

Participants' sense of normality is closely tied to their sense of place, which is recognised to play an important role in how place influences health and wellbeing (Eyles and Williams, 2008). Since sense of place is developed through regular interactions with everyday settings, places for health promotion are often built upon familiar everyday environments and activities to invoke a sense of place amongst people who engage with them (Doughty, 2013; Eyles and Williams, 2008; Milligan et al, 2004; Milligan et al, 2015; Sanchez and Liamputtong, 2017). The day centre attended by David is designed to provide a home-like feel with its traditionally furnished lounge area and dining room (although I think of a care home as I initially walk in). The luncheon club Mary and John regularly attend at a hotel, provides a more *away from home* but nonetheless a familiarly pleasant dining out experience, with the formal table setting, three course meal and food served by waiters. A number of dementia activities are in this way provided in everyday environments. The creative workshops attended by Diana are held in a theatre, reminiscence scrapbooking activities Alan attends take place at a local library and a walking group which Belinda is a member of meets in a local park every week. The congruity between the nature of the activities and the settings in which they take place gives the dementia interventions a feel of ordinariness.

However, some participants and their family carers highlight how the sense of normality espoused within place is impeded by dissonance between its social, spatial and organisational aspects. The home-like feel of David's day centre is juxtaposed by the discouragement of free movement amongst people with dementia, which is often the cause of David's frustration. They are instead moved as a group from one room to another in accordance to a daily schedule of different activities, with the staff controlling when and how the different areas of the centre is used (Heggestad et al, 2013). Likewise, sharing his impression of the dementia arts and crafts group attended by Belinda, James claims *"It is very good, although they treat them like children".* Comparing the word games, colouring activities and '*doing stuff with plasticine, which is a bit child-like*', to the adult interactions Belinda is accustomed to, James questions their impact on her sense of self:

> *'It's just the way they communicate; they don't have many expectations of them. She's had an excellent career, she was a manager at a big firm and I think there is a lot more going*

on in there then she lets on. That's why I think the conversations with our friends at the pub are so valuable'.

James also describes how the facilitator of the group, upon finding out about Belinda's past hobbies, requested that she takes her golf clubs to the group, but much to James' disappointment they have turned it into 'child-like' play using a net.

'She [Belinda] finds it funny, doesn't really get in to it, it's not playing golf is it... but it's something to do I suppose.'

Playing golf using a net is accommodative of people with varying health needs, but it does not provide the same golfing experience for Belinda. James therefore attributes Belinda's child-like experience at the dementia arts and crafts group to its careful tailoring of space, activities and communication style between staff and people with dementia, which removes much of its feel of normality. The socio-spatial milieu and activity of walking involved in the dementia walking group however is subject to much less tailoring and Belinda appears to talk much more enthusiastically about her experience of it:

Belinda: *Yeah we go in the park, lots of us together.... I love to walk anyway, it's beautiful there, yeah*

James: *They have a walk around, her and Sheila with the rest of the group, may be about 14-16 of them.*

Belinda: *Yeah, they're very good.*

James: *You have a catch up with Sheila don't you*

Belinda: *Yeah [laugh]*

Belinda's participation in the activity of group walking along with the setting in which it takes place resonate with her past experiences, enabling her to participate in social interactions, appreciate the physical surrounding and connect with her sense of self. This is similar to how findings by Milligan et al (2015) who claim that the shed space and activities precipitated certain behaviours and interaction amongst older men. The physical, social and symbolic dimensions of group walking in the park in this way work together, contributing to the creation of therapeutic landscape for Belinda.

In the wider community, it is participation in routine activities within ordinary everyday settings that provides the context for normality, sense of place and in turn therapeutic

landscape experiences. This is most apparent with Ellen who continues to go shopping several times a week with Lucy, insisting *"I've always done my own shopping..."* The field notes taken during the walking interview provides a snapshot of Ellen and Lucy's shopping expedition:

As we enter the supermarket, Lucy takes a basket, and walks ahead knowing that I am walking behind with Ellen. Lucy stops at the toiletries section and Ellen stops a couple of yards away, looking at the bottles of shampoo– "Do you want this love, look how lovely her hair is?" She shouts at Lucy and without waiting for a response grabs a bottle and places it in Lucy's basket. Lucy smiles at me and when Ellen turns her back to her, she places the bottle back on the shelf.... Ellen stops by the cakes, "Would you like some of that love?" she asks Lucy holding a packet of scones, to which Lucy replies "It's too much sugar darling, not good for you?". Ellen screws up her face mimicking Lucy and puts the packet back down. The toy section in the aisle behind us has now caught Ellen's eye and off she goes. We stand for a while looking at the dolls, Ellen comments on their outfits and hair. Each time a tannoy announcement is made Ellen stops and listens, "Are they calling us?" she asks me several times. She often gets in the way of trolleys, but with a subtle nudge from me, she moves apologising to the customers. As Ellen and I walk together, Lucy uses this opportunity to quickly search through the other aisles for what she needs. I assume it usually takes much longer for Lucy if she has to keep an eye on Ellen.

Whilst Ellen's cognitive impairment hinders her from searching for specific items or considering why she might need something she continues to engage with and appreciate the shopping experience through her sensory faculties, constantly looking at and picking up items that catch her attention. Lucy claims that Ellen does not care to buy much, but likes to *"go out and see things.... skirts, bags, shoes"*, suggesting that it is the mere fact of being present within what Bell et al (2017, p.94) call the 'ordinary everyday assemblage' of shopping that is important to Ellen's therapeutic landscape experience.

Shopping is thus more than a functional activity; it is symbolic, speaking to people's sense of self and continued involvement in ordinary aspects of daily life. At the charity shop Ellen picks out clothing and accessories and brings it over to Lucy to see, often looking at the price tag and commenting on how expensive it is:

'£8.50? I can buy four of these tops with that money!'

Ellen seems to be in her element. Katherine similarly talks about David when they go out shopping:

> *'He's always asking "How much was that?" he always likes to know how much things are.'*

Whilst David begrudgingly goes along shopping with Katherine, the familiarity of the settings and the routine nature of shopping helps him to step into his old self and find his sense of agency. According to Katherine he is always probing her about the price of items and the amount of money she is spending. Belinda too, although quite passive when shopping with James, is much more alert when she is out shopping with Pam, the housekeeper:

> '*Here's the good news, when she goes with Pam, Pam will take an order of what I want and what I need, and for instance, grated cheese, you go and pick up some grated cheese and Belinda will say "Oh no Pam, that's not the right one … that's the one". So she can do it'.*

Going shopping allows Belinda and the other participants to resume a sense of responsibility, whether it is through taking charge or supporting the carer with the task.

However, everyday places in the wider community such as supermarkets, shops, cafes, pubs and restaurants, which are important to participants' engagement in routine activities and therefore maintenance of normality, are often busy and fast paced, becoming difficult for some to now negotiate. Supermarkets are particularly overwhelming for some participants; James recalls a time when he let Belinda take the trolley back, as she always used to, and she did not return to the car:

> '*...fear, and I sat in the car and I thought God almighty, she's a long time, so I looked back, couldn't see her, got out, and she wasn't there … so panic really hit, and I'm running into the car parks, and then I thought I'll go back into the supermarket, and Belinda was [slight laugh] … it could be funny though, it could make a good film: 'Carry On Being Demented,' with her trolley in this bloody great long queue, everybody piled up, with nothing in it … so she knew that was the way out …"What the hell are you doing in there?," you know. So there's that now'.*

Belinda is now accompanied by James at all times in the supermarket. Similarly, accompanying John to the supermarket is one of the few occasions when Mary engages in an aspect of everyday life beyond the home, but John admits:

> *'Yeah, mostly she comes, walks round with me but sometimes she'll just wait in the car … she doesn't like going places where there's a lot of crowds'.*

A busy supermarket is counterproductive for Mary, in terms of feeling safe and confident; she instead looses focus and becomes anxious in such situations. As a result when they do need to go shopping, Mary says they have to "*pick a quiet time*". Similarly, Lucy makes an effort to take Ellen out shopping during the week when it is not as busy, explaining:

> *'There's certain places that I wouldn't take me mum to 'cause they're just too busy, too frenetic with everything else … if they're noisy I know mum won't like that… it's best to go early or … a bit later … and I wouldn't go at the weekends'.*

Worried that Ellen would lose her way or would get in the way of other people, Lucy keeps Ellen by her side whenever they are out.

Various aspects of everyday places which the participants were once able to effortlessly navigate are now distractive. Meijering et al (2016), exploring people's changing experiences of rural life post stroke describe an increased sensitivity to material obstacles when undertaking certain activities, turning their enjoyment of the rural landscape into wariness and fear. When we are at the supermarket, Ellen is distracted by the tannoy announcements and struggles to swerve between trolleys without Lucy's help. Then with a queue forming behind us at the till, and Ellen unsure of which way to place the pack of kitchen towels in her bag, Lucy has to step in and help her. There is a sense of everything moving too fast and the need to constantly overcome obtrusive sounds and objects for Ellen to fully savour the experience of shopping at the supermarket. The slowness of the mind causes slowness of the body, where Ellen is now 'unable to engage in the easy habits of everyday living' (Phinney and Chesla, 2003, p289).

I feel Ellen's need for reassurance by the way she tightly grips my arm when we walk along the busy high street, cross the road or try to pass a queue of people at the check-out. I walk closer to Ellen, so she does not let go of my arm; her holding on to me provokes a sense of protectiveness in me, reminding me of my six year old daughter in such circumstances.

Like Ellen, Emmeline also becomes confused and indecisive about what to do in certain situations. During our walking interview we visit a cafe and the following excerpt from my field notes illustrates what Emmeline has to contend with in a normal everyday situation:

Emmeline is stood by the cake display, reading the names of each. Noticing the cards and sweets on the side of the counter, she walks over leaving Boris' side. Meanwhile, Boris has ordered his drink and tries to direct Emmeline's attention to the list of hot beverages on the wall. Emmeline begins to read the list from the very top, as I order my drink. Emmeline still has not decided, she continues to read the list without showing any indication of she wants from it. So Boris suggests ''Do you want to get a pot of tea?'' to which she agrees. Boris apologises to the barista and places the order. The barista politely says ''Not a problem, take your time''. The barista also notices that Emmeline is eyeing the colourful marshmallow and rice crispy cakes on the counter and asks if she'd like a piece. Emmeline smiles and says ''Yes I think I might''.

Emmeline is slow in deciding what to order because she reads the list of hot beverage off the menu on the wall several times without cognitively processing the information. The items on and around the counter also act as a distraction, although she is quicker at pointing out the cake she wants from the display than finding a drink on the menu, suggesting that she engages better with visual items. However, unlike previous occasions when Boris claims they had been hurried by waiters to order their food at restaurants, the barista at this particular cafe is very patient and assistive. Emmeline is allowed time to look at the menu and display of cakes, although she is not able to make her choice without some support.

Contrasting Ellen's experience at the supermarket, the slower pace and spaced out arrangement of the charity shop we visit next allow both Ellen and Lucy to be much more relaxed, as they take their time to look around:

As we step into the shop, Ellen lets go of my arm... Without the tall shelves and long aisles in the charity shop, Ellen and Lucy wander around the shop on their own, as they are able to see each other at all times. Ellen stops and looks through a book of British landscape images, she then walks over to a large dolls' house, kneeling down to open the door and admire the miniature furniture placed inside. There is not a trolley insight for Ellen to obstruct. There is soft music playing in the background and the three other customers in the shop are also quietly walking around.

The display of different and unique items on the shelves, walls, tables and clothes rails around the charity shop and the ample space in between each display are inviting of people to stop and muse over the items. The mellow background music is in stark contrast to the upbeat music and

constant sounding of the tannoy at the supermarket, setting the pace for the slow movement of customers. The more fluid arrangement of the charity shop, compared to the supermarket, also allows space for Ellen to follow her instinct and freely move around the shop floor. This particular charity shop is not unusual or specifically adapted for people with dementia, yet its spatial layout and atmosphere are much more accommodative of Ellen's needs than that of the supermarket.

Efforts to adapt everyday places to create a more pleasant and enabling everyday experience for people with dementia are also noted by some participants in respect to different community settings. Boris mentions that the church he and Emmeline attend has recently made their Sunday service "*dementia friendly*", with a place reserved at the front of the church for people with dementia or other disabilities, allowing wheelchair access and space to stand and walk during the service. In addition to this spatial adaptation, Boris says:

> *'There's a, there's a sympathy and acceptance that goes beyond that in a congregation...They understand it.'*

Following a number of sermons on dementia at the church, people have become much more aware of the condition and are more appreciative of people with dementia's experiences. Boris claims the extra attention they receive from others attending the church helps him and Emmeline to feel accepted and part of the congregation. Katherine makes a similar point about the importance of receiving a personable service and feeling valued in public places:

> *'They're [cafe] dementia friendly, I didn't notice the badge they have until the other day. But the lady who owns it is really nice, she always makes sure we get a quiet spot near the back. She knows about David you see. But it made sense when I saw the badge.'*

It is essentially a sense of social acceptance of and an attitude of care towards people with dementia that both Boris and Katherine relate the dementia friendliness of the church and cafe to. They consider people's willingness to adapt to a slightly different way of using the physical space of the church or cafe as profoundly enabling. Lucy's account of times when she and Ellen have had bad experiences at some of their local cafes on the other hand throws light on the detrimental impact a lack of diligence and care by staff members can have on the person with dementia's ability to enjoy such settings:

> *'... just putting the chairs back or tidying up the pots and the glasses, they just throw them around.. and of course that, really like, takes all the enjoyment out of it... I mean I've raised*

Shopping with Ellen and Lucy

Fig 14: Walking along the high street

Fig 15: In the supermarket

Fig 16: Ellen picks out some earrings

Fig 17: Ellen's enjoys looking at fashion accessories at the charity shop

Fig 18: Looking at household items in the charity shop

In the Park with Emmeline and Boris

Fig 19: Emmeline stands by the raised flower beds in the park

Fig 20: Flowers on the side of the path catches Emmeline's eye

Fig 21: Path through the park

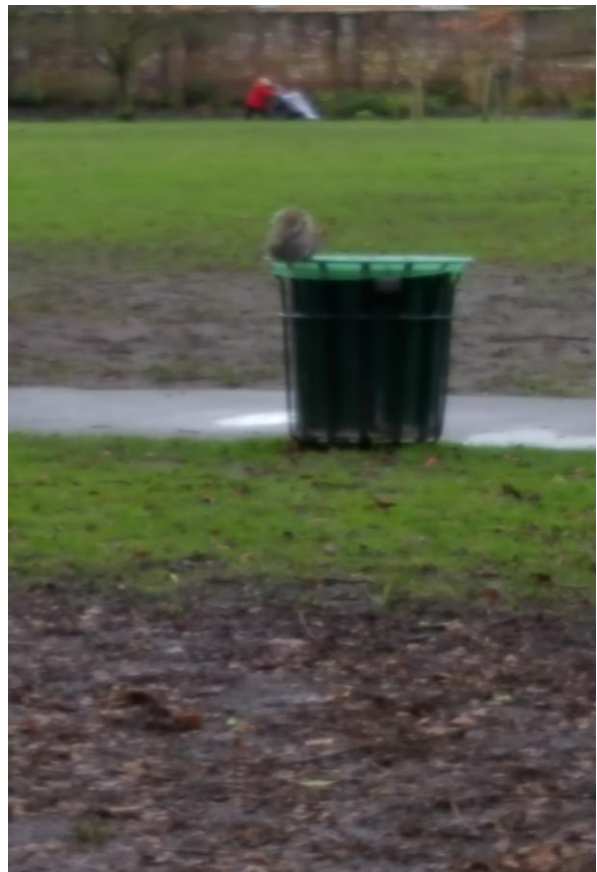Fig 22: Emmeline watches the child splashing in the puddle

Fig 23: A squirrel in the distance catches Emmeline's attention.

it once or twice... they're a bit like "Yeah, yeah, we kinda get it," but then "Oh well, there's nothing we can do about other customers," but actually it's not the other customers often, it's them.'

Whilst Katherine praises the lady at their local cafe for always seating her and David in a quiet area of the cafe, Lucy describes a situation where staff members fail to make such consolation due to a lack of awareness of the how different environmental factors may affect a person with dementia. Referring to their disappointing experiences at local cafes, Lucy suggests:

'I don't know about whether it's acceptable that people create environments for people who've got a condition, or whether... everybody should be just a bit more kind of... you know, why wouldn't you just go to a coffee shop and have the coffee shop sensitive to a level of things that we're all attuned to, like too much noise, too much of this ... you know, where you place the doors, where you place the draughts, cold..'

Instead of restricting efforts to meet the needs of people with dementia to certain spaces or occasions, Lucy calls for systemic changes to what is accepted as normal in everyday community settings. She considers a shift in societal norms to accommodate subtle socio-spatial adjustments that would preserve rather than disrupt people with dementia's daily routines and therefore sense of place as vital. Currently, Lucy describes how she and Ellen have to instead adapt their normal routine, choosing to go shopping or out for a meal to certain places and at certain times to avoid the hustle and bustle in public spaces. Nonetheless, Ellen and other participants with dementia work hard to maintain a temporal routine of daily activities involving interaction with people and settings in the wider community, as staying connected with family, friends and the neighbourhood is an important aspect of their experience of living in the community and maintaining their overall health and wellbeing.

8.3   Staying connected with family friends and neighbourhood

Spending time with family and friends in community settings is a common feature of participants' daily lives. With the support of family carers many of the participants have continued to enjoy mutual experiences and relationships beyond the home, with three particular settings found to be most important for maintaining participants' connection with family, friends and neighbours: the pub, dementia settings and the neighbourhood.

8.3.1   Down at the Pub

Pubs are an important social setting for some participants and their family carers, particularly to keep in touch with friends and acquaintances. Alan frequents a couple of the pubs he is able to walk to within his neighbourhood during the week, whilst he takes a bus to a pub further away to meet with two of his old friends on a Friday. Alan usually makes his way to the pubs on his own and asserts a sense of independence when he admits that he decides to do so against the will of his children. Belinda and James also go to two particular pubs in their neighbourhood. They started going to the pub closest to their home about a year ago and have become familiar to some of the regulars there. James reflects on a recent incident:

> 'We walked in and there's a chap, I still don't know his name, had already got the drinks for us … he saw us walking down the street, he knew what we drank and he got it.'

James appreciates the friendly gestures from some of the customers at this pub, but two to three evenings a week he and Belinda prefer to meet with some of their old friends at a pub a mile or so from their home. Similarly, Diana and Hannah take a trip down to a pub in the village some evenings:

Hannah: *We haven't been as much this year, but we do go in there quite a bit… we always see somebody when we're up there …*

Diana: *Yes we do, always.*

Hannah: *… always, even the chap that owns the Post Office, he's retired: "How's your mum?," When he finished work he'd have a pint, he would always come over to talk to me mum …*

There, reflecting James and Belinda's experience of impromptu conversations with customers at their local pub, Diana and Hannah enjoy the company of local villagers.

In discussing the role of the different pubs, the participants allude to quite distinct socio-spatial interactions that are constitutive of therapeutic landscape experiences. Pubs serve two similar but different purposes for the participants, Belinda, James and Alan have a pub where they meet with friends and a pub where they enjoy the social milieu through much less personal interactions. When Alan meets with his friends at the pub, he sits with them in a quiet area of the pub and they talk between themselves:

> 'We're the same… they're both 80 years old too…The three of us get together and we can chat…we talk to each other and we laugh with each other'. (Alan)

Separating themselves from the conversations and activities around them, the group of friends talk and listen to each other. There is a sense of togetherness emphasised in Alan's description of his interactions with his friends and also his active involvement in the social exchanges that occur. At the local pubs Alan goes to during the rest of the week however, he usually sits on his own by the bar, on the periphery of social exchanges between the other customers.

> *'I'm happy enough, I sit on my own and people often come and sit around me...and they're chatting to each other...make jokes... Our humour is not the same humour... they're younger than I am you see, so they happily chat away.'*

Alan attributes his differing ability to connect with the two groups to socio-demographic factors. Although proximally Alan sits near the younger men in the pub and is able to hear their conversations, socially he feels a clear discordance between himself and his fellow customers. Whereas a sense of being the *same* gives Alan equal status and confidence when in the company of his friends, feeling older than the other customers at the pubs he visits near his home restricts him from engaging in any meaningful dialogue with them.

James makes a similar distinction between the two pubs he and Belinda regularly visit. Belinda and James make special arrangements to continue meeting with their friends at the pub furthest from their home, because as James explains:

> *'There we're with likeminded people...It's set in stone; we go on Mondays, sometimes on Fridays, and on Saturdays because the same people are there ...The conversation is so valuable with our friends, I don't want to leave.'*

Not only does James stress the indispensability of the social connection he and Belinda share with their group of friends at this pub, but referring to the '*likeminded*' nature of the people there, he distinguishes it from the other pub they usually call in at by the socio-demographic disparities of their customer base. Speaking of the other pub, James says:

> *'It is a rough place, they're a bit rough there... they're not officer material, they're not our type... the landlord had a bit of a clear out recently though.'*

Calling the pub a '*rough place*' that has required a '*clear out*', James uses language pertaining to the physicality of a place to refer to the social characteristics and treatment of the people who frequent there. He is quite honest about his disregard for the mannerism and world view of the other customers and admits that he and Belinda consider the people they talk to as '*acquaintances*' instead of friends and would only engage in '*small talk*' there. So whilst the physical environments of the different pubs Alan, James and Belinda often visit are perhaps

comparable, the participants are seen to adapt their behaviours and interactions in view of their distinctive social composition.

However, the different ways in which the participants engage with the social aspect of place in each of the pubs are equally therapeutic. Making small talk at the pub near their home supplements Belinda and James' lack of social contact on days when they are not scheduled to meet their friends at the other pub:

> *'When we're bored and fancy a walk, we go to the Eagle Inn, it's easy to walk there....you need a reason for living.'* (James)

Despite acknowledging that he and Belinda are unable to engross themselves in conversations on topics of mutual interest, James mentions the '*invigorating benefits'* of being amusingly intrigued by the kinds of conversations that take place there. Likewise, without Alan's daily trips to one of the local pubs during the week, his day to day life would be rather lonely. Despite sitting alone at the pub, he claims:

> *'I prefer to go to the pub than sit at home and watch TV...'*

Rather than conveying a sense of loneliness, Alan is content in passively watching and listening to the conversations taking place around him. Even whilst sitting outside of the conversations or engaging in no more than 'small talk', the participants benefit from a sense of social connection and togetherness within the pub environment.

Hannah also describes quite short and serendipitous encounters with people she and Diana meet at their local pub, which she considers to be important for maintaining their connection with the local community. Hannah claims that it is nice for her mother to see people from the village, as she has now lost many of her close friends. Diana has a shared history of living in the village with many of the locals and their conversations are usually about people, places and past events in the village. According to Hannah, their '*chats*' in the pub often prompt Diana to candidly reminisce and sometimes share common experiences with people they sit with:

> *'He [post master] remembers dad, we always talk about him.... It's amazing some things mum would remember when we're talking sometimes, especially about things that happened around here.'*

These conversations are important for rekindling Diana's sense of attachment to the local community. Also, having recently moved back to the village to look after Diana, Hannah is out of touch with people she used to know in the village whilst unable to regularly leave Diana and visit friends in her previous home town. Thus, through the informal and personable interactions

with other locals in the pub, Hannah is also able to develop an affinity to the village and overcome her social isolation. Therapeutic experiences the participants construct within pubs are connected to their affordance of providing experiences that straddle both the private and public, similar to that which Warner et al (2012, p.309) describe in regards to cafes:

> '*The cafe is a private and protective space compared with the world around it, but it is also a public space when compared with the home spaces of its customers*.'

For the participants in this study the pub is simultaneously a place to escape the loneliness of the home environment and feel part of the wider community and a place where they can benefit from intimate and friendly interactions they may not experience in most other public settings.

It is the background hustle and bustle of the pub setting that most resonates with Alan and which he seeks to be close to. He says:

> '*It's easy enough... You order a drink and sit down, there's people laughing and joking...*'

Simply sitting down with his drink in the midst of people Alan becomes part of place, quietly enjoying the jokes and laughter around him. This in some ways echoes Amelia's preference for restaurants which are busy:

Amelia:	*I like places where there is a buzz, where there's life...everyone's loud (laugh)*
Muriel:	*Yeah and we can be loud... But we love people watching sometimes don't we, sat at the bar? Especially you...*
Amelia:	*(laughing) Yeah I do... right nosey we are.*

Amelia considers the exuberance of people talking and moving around in restaurants to bring the physical environment to '*life*'. She admits that she can sometimes be quite '*loud*' and high spirited and having become more self-conscious since the progression of her dementia, she finds it easier to deflect unsolicited attention and blend in, in busy restaurants. Also when Amelia withdraws from conversations around the table, as she often does, she is able to keep herself occupied watching the activities around her. This is in contrast to Ellen and David's preference for quiet cafe environments, although details of what Ellen finds off putting as shared by Lucy is the noise of furniture being moved on the shop floor and dishes being handled by staff in the kitchen rather than customers interacting around her. Also some family carers, such as Lucy, John and Hannah discuss the challenges of moving through spaces with high volume of human traffic such as the supermarket and busy high streets with the person with

dementia, whereas Amelia and Alan do not comment on how their dementia affects their ability to negotiate crowded spaces. Disparities found between participants' preferences for different environments are therefore perhaps due to one or more of the following factors. Whilst some preferences are expressed by the participants with dementia, others are relayed by the family carer; the participants represent a diversity of personality types and also participants use different coping strategies in which case some may be more effective than others in managing common challenges relating to environmental factors, leaving these participants less deterred by noise or crowdedness.

Whilst Amelia and Alan enjoy vibrant places, they like to watch and listen to the customers from the comfort of their seat, where they retain a safe distance without feeling obliged to interact with others. Amelia reflects on how she manages her social insecurities in places where she is in less familiar company:

> *'I'm more interested in what people are saying now, even if I've forgotten it after... If there's anyone that I'm not quite sure about I'd, I, I tend to be not myself, I go quieter.'*

Hannah makes a similar observation of her mother Diana at the pub:

> *'Mum always says hello and smiles at people. She likes it when they come over, but she doesn't say much, we talk and she's listening, yeah'.*

Like Alan and Amelia, Diana's participation at the pub is often as a passive onlooker. This reflects Meijering et al's (2016), observation of how older people after experiencing stroke chose to greet neighbours from a distance where a wave was suffice, as they lacked the confidence to engage in conversations. However, although Belinda is often quite reticent in social situations, James claims she has a tendency to impetuously join in conversations at the pub. This is captured in one of James' diary entries:

> MONDAY: *A good night - met with a few friends at the pub. Belinda engaged in conversations in a minimal way... A friend was telling a story, Belinda said 'Oh yeah, I remember that' but she wasn't there and she's not heard it before. She does that when we are in our group.*

James later elaborates on this, explaining that Belinda habitually reconfirms what he says with "*Yeah, yeah*", "*I know*" or by repeating what he says; all words and phrases being neutral but affirmative of what James is saying. This is perhaps Belinda's mechanism for engaging herself in conversations despite struggling to grasp the subject matter or the context in which it is being discussed by others. Mirroring other people's reactions is also observed with Mary at the

dementia luncheon club, as she smiles, laughs, nods and sighs in synchrony with others. Both Belinda and Mary therefore observe and imitate the verbal and non-verbal expressions of others during a steady flow of exchanges as a way of being part of the conversations without being impeded by their tendency to lose track of conversations or toil with finding the right words. Whether the participants prefer to maintain their position as a quiet bystander or participate in conversations through imitating others in social situations, they seem to seek undemanding connections with people around them, where they can passively enjoy a positive social atmosphere without the pressure of cognitively engaging with it.

8.3.2   At the Dementia Group

Whilst the pub is usually a place to meet old friends or make small talk with customers from all walks of life, dementia groups are settings where people with dementia are able to meet and socialise with people who share similar experiences of living with dementia. Often, dementia groups provide the only opportunity for a person with dementia to connect with people outside of their family or those involved in their care. As demonstrated in the previous chapter such places have now become an integral part of their everyday geography. David is grateful for the companionship he enjoys at the day centre, claiming that:

> *'I know what it's like sometimes to be stuck in one place, and don't have anybody to talk to… I'm looking forward to seeing those friends on Wednesday.'*

Through prolonged engagement with services such as the day centre, people are able to form new friendships. For David, they are the only friends he meets on a regular basis and are integral to his quality of life, because between his diagnosis and coming to the day centre he became very isolated at home, feeling incapable of continuing with most of his activities in the community. Like Alan, who meets his old friends at the pub every week, David looks forward to seeing his friends at the day centre. Whilst the two friendships are founded on quite different terms and their lengths vary considerably, they play a similar role in both Alan and David's lives. Amelia similarly, talks fondly of the people she has met at the day centre, particularly the close bond she shares with them:

> *'I feel like other people that are there…it's just like old friends.'*

Amelia is able to be herself amongst people she considers to be like her, and although she has known them for a relatively short time the closeness she feels to them bestows them the status of 'old friends'. Diana on the other hand has met a friend from her childhood at the day centre:

> *'Mum always sits next to Audrey, her friend I told you about, who's 94, They sit together and hold hands, put their arms around each other.'* (Hannah)

Having lost most of her old friends in recent years, Diana values the friendship she has formed with Audrey. It is this companionship, the opportunity to socialise and make friends that is often expressed as the primary motivation for engaging with dementia groups by both participants and their family carers. Hannah who often accompanies her mother to the dementia groups, insists that it gives her "*a big circle of friends*". Likewise, Boris feels one of the main advantage of attending groups is the opportunity to talk to other people. James also hopes to make friends through the dementia groups:

> *'Our little circle of friends at the pub needs expanding and it does need renewing... You get old and other people don't get old with you, so we have to find other ways to make new friends.'*

Recognising that his and Belinda's needs and abilities are changing over time, James anticipates having to give up their routine of meeting with friends at the pub in the near future. They are therefore relying on the dementia groups and services to meet people who are in a similar situation.

So to consider how the design of dementia spaces and activities support people with dementia to find companionship, an excerpt from the field notes illustrates a typical Thursday morning for David at the day centre:

He's sitting in the lounge with the usual five other people with dementia... The two women share one sofa and the men take up the other large sofa and armchairs next to it. They always stick to the same seating plan and communication takes place amongst people sitting closest to one another according to the support worker. After a round of tea and biscuits they play a question and answer game; a member of staff asks the questions and the people with dementia try to come up with the answers... At lunch time everyone is escorted into an adjacent room where they eat their meal sitting around a large dining table. After some rest they do some light afternoon exercise in a room down the corridor. They then return to the lounge for some refreshment before the end of day.

All people with dementia at the day centre eat together, sit together and exercise together. They occupy the same space and participate in the same activities. When they are not participating in

a specific activity, they sit in close proximity to one another and either bide this time in silence or use it as an opportunity to socialise.

Although, as discussed already, not all occasions when people with dementia are placed together stimulate feelings of solidarity or encourage social interactions, there are numerous occasions when people do make social connections. Diana who seems to be a quiet person by nature and now struggles with verbal communication does not engage in conversations with the rest of the group at her day centre. Instead Diana sits in silence with her friend Audrey:

> '... Always hugging, holding hands and fixing each other's scarves and hair... and this Friday they're having their haircut there with the hairdresser'. (Hannah)

Diana's friendship with Audrey is maintained through one to one expressions of affection through non-verbal gestures, which is enabled by the fact that they sit together, whereby the spatial and the social work hand in hand to facilitate a sense of connectedness. Mutual activities such as having their haircut together also resonate with experiences friends often share with one another in the wider community, further consolidating Diana and Audrey's friendship, albeit within a dementia setting. Unlike friendships forged in dementia settings by other participants in this study, Diana and Audrey's friendship is based on their shared history in the wider community rather than their common experience of living with dementia. The opportunity to situate their relationship in activities of daily life is thus significant in enabling a sense of continuity in their friendship.

Amelia on the other hand talks with various people at the day centre as well as at the dementia singing group and dementia cafe that she attends. In these places Amelia feels unrestricted by the expectation of social conformity that she now grapples with in the wider community:

> 'There you can just say what's in your head ....we're all the same in a way, I think being the same, and with one of your own... I've never felt anybody say "oh it's that silly woman", we're all trying to say nice things to each other'.

The connection Amelia shares with the other people at the day centre is based on mutual experiences. Whilst I earlier argue that the exclusivity and socio-spatial remoteness of dementia settings from everyday life in the community discourages some participants from engaging with them, here these two characteristics of dementia settings contribute to Amelia's ability to construct a positive self identity and sense of belonging. Coleman and Kearns (2015) similarly highlight 'isolation' and 'boundedness' of island life to be key to the construction of therapeutic landscapes by the older population of Weiheke Island. Because everyone at the day centre or dementia group has dementia, Amelia finds that they are less judgemental and more supportive

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of one another's needs. Whereas Amelia indicates feeling out of place during family gatherings, as she cannot follow conversations and so resorts to playing with the children, she attests to feeling empowered in the company of other people with dementia. David expresses a similar relationship with the other men at the day centre, where they have connected with one another based on their shared identities, experiences and sense of place.

The seating plan at David's day centre reveals something interesting about how that particular group of people with dementia relate to one another. People arrange themselves to be in close proximity to people they share certain similarities with, in this case their gender appearing to be the primary identifier. Similarly, when Alan is observed at the dementia walking group, the male and female members of the group divide themselves into two separate sub-groups:

The five men with dementia sit on one end of the large table and the four women with dementia sit on another. The volunteers place themselves in between the group members, the male volunteers sit with the men and the female volunteers stay with the women. The men decide to play dominoes and the women, as usual, play cards. As they play, the men share stories from their past. Alan talks about friends in Spain and a particular card game that was popular amongst them. Alan's mention of playing cards outside on the terrace triggers the man from the Caribbean to recall his homeland and how he struggled to acclimatise to the weather when he first arrived to England. This leads to discussions about past holidays and their favourite food. The conversation remains on this end of the table, whilst the women chat amongst themselves.

Alan joins the men in the cafe at the end of their walk since they, as he describes, "*like to joke and have a laugh*". Alan's description of the relationship he shares with the male members of the group bears a striking resemblance to the kind of relationship he maintains with his old friends at the pub. He claims that he and his friends do not talk about problems in their lives, they '*just have a laugh'*. Sitting in a cafe drinking tea and playing dominoes or card games with the male members of the group, perhaps resembles Alan's experience of being at the pub with his friends. David, also talks about his interactions with the other men at the day centre in a similar vein, placing an emphasis on having '*a laugh'*. So whilst for Alan, his interactions with the men at the walking group is an extension of the type of company he enjoys at the pub, for David the friendships he has formed with other men at the day centre substitutes the lack of male company in his personal life. For both Alan and David, their interactions in these dementia settings provide the kind of companionship they would normally seek in the wider community

and in so doing provide an important buffer to the isolation they experience in their day to day life.

By contrast both Diana and Amelia have developed friendships with other women at the dementia groups which they hope would be long lasting. Hannah reveals her and Diana's plan to invite Audrey and her daughter to their house:

'We want to invite them over for dinner one day, and may be we'll go out as well. It will be nice for mum and Audrey. Her daughter is really nice too, we're about the same age'

Amelia and Muriel are also planning to invite friends they have made at the dementia groups to join them in activities they enjoy in their spare time:

Muriel: *We've got two new ones that we're developing friendships with, haven't we? These are new friends, but we're going to the cinema on Monday.*

Amelia: *Oh are we?*

Muriel: *Yeah... em and they've been here for a meal, and we're going to go to them... and we've said we'll have days out in the camper.*

Amelia: *Yeah, we do alright (laughs). I'm looking forward to that.*

In both cases, friendships that have developed in dementia groups are hoped to be further developed in everyday community settings (Sanchez and Liamputtong, 2017). Also, whilst socialising with specific groups of friends and acquaintances in settings such as pubs and dementia groups are essential to participants' ability to meet and connect with other people, they also share the importance of a more general sense of connection to their neighbourhood.

8.3.3   *Out in the neighbourhood*

Areas of participants' neighbourhood which they regularly engage with vary in size and shape, sometimes representing nothing more than open space to an outsider, such as the meadows and fields, although meaningful places to the participants. Participants' fleeting interactions with people in the neighbourhood and its physical environment are integral to their experiences of living in the community. Most notably, Diana, Ellen and Amelia's long standing relationship with their respective neighbourhoods shapes their day to day interactions beyond the home. Having lived in the area almost all her life, Diana is well known by the neighbours and other people in and around the village. The neighbours quite often make an effort to call in on special occasions

or to simply check up on Diana. Hannah and Diana also regularly enjoy a walk around the area in which they live and talking to the neighbours:

> *'If it's a pleasant day we do like to walk even just local, have a look in the gardens … my mum's friend lives round the corner and her husband's just done the garden, we have a nosey in the gardens and say hello...'* (Hannah)

Similarly Ellen, whose favourite activity outside of the home is shopping, prefers the shops near her home. Ellen has lived in her house for over 40 years and has memories of working and spending time with family and friends in the neighbourhood. Her daughter Lucy believes Ellen likes to shop locally because *"It feels like home… a real community"* which she goes on to attribute to the warmth and concern shown by staff in the local shops and post office. Emphasising the importance of feeling a historical connection with the people and space in the neighbourhood, Lucy attests to the intertwining of the physical and social dimensions of place. Although Ellen is now unable to recognise many of the people they meet when out in the village, Lucy says:

> *'She is different when she's around here...she likes it when people come up to us and she will talk to people even though I'm not sure if she remembers who they are.'*

By virtue of being in a place she has a deep rooted connection to Ellen demonstrates what Dinnie et al (2013, p.5), describe as 'a very particular kind of knowing others, facilitated by the specificities of place'. The familiarity of the neighbourhood setting and her regular practice of carrying out daily errands within it provide Ellen with the feeling of being at *home* and an important part of that sense of home is its socially binding dimension, her affinity with people she may not personally know or recognise.

Amelia and Muriel's connection to their neighbourhood is also maintained through their regular encounters with people from the area when out walking the dogs. During the walking interview with Amelia and Muriel, they consistently greet the passers-by; Amelia would often smile and say hello to people she *knows* to be from the neighbourhood and they would reciprocate. Asked if she often saw these people on her walks Amelia replies:

> *'I think so, I don't really know. But we're all local people.'*

Again, being amongst people from the local neighbourhood provides a sense of connection for Amelia that does not need to be qualified by her cognitive capacity to recall any specific details

about the person or their previous encounters. Eric also describes similar encounters with local dog owners when he is out with his dogs:

> '*We'd say hello, wave or what have you… we just talk about our dogs, that's it.*'

Whilst Eric admits he is not one to "*bother making friends*", by walking the dogs on a regular basis, he has become accustomed to talking with other dog owners in the neighbourhood, highlighting the sociality of dog walking. Amelia also describes similar experiences of dog walking:

> '*Well I like anywhere where I can get out and see people … and with the dogs, because, you know, we go and, and you, you see people that say "Oh, what kind of dog's that?," you know*'

Her interactions with people from the neighbourhood are often centred around her dogs, with the dogs becoming key to facilitating conversations between them (Bell et al, 2015; Gorman, 2017a). According to Eric their interactions are uniform and impersonal, so he does not know or remember the names of the people he often sees and talks to. These exchanges have nonetheless become part of Eric's and Amelia's practice of walking the dogs, contributing to how they utilise and engage with the neighbourhood in their daily lives.

By contrast, Mary and John do not share the sense of attachment found in Ellen, Diana and Amelia's stories of living in the neighbourhood. They moved here 20 years ago without any pre-existing connections to the area and do not utilise any aspect of their neighbourhood enough for it to become an important part of their daily lives as is the case for Eric. Mary and John have mainly isolated themselves from the neighbourhood, spending mos t of their time either at home or, when they are out, beyond their immediate neighbourhood. Whereas the participants who express a sense of familiarity and belonging to their neighbourhood spend much more time engaged in activities within the neighbourhood. Sometimes participants attribute their allegiance to a small area within the neighbourhood, based on specific commonalities. Alan and Emmeline in particular talk about the demographic characteristics of different parts of their neighbourhoods, influencing their perception of where they belong and who they can relate to. As we drive down the winding street which Alan lives on, he tells me:

> '*This is where all the posh people live… so they say. But I'm not like that, can you tell?*'

Asked if he knows any of his '*posh*' neighbours he swiftly replies "*Oh no, no…no*", stressing the absurdity of my question with the repetition of his non affirmative response. Alan then mentions an old neighbour called Jim and another couple who live opposite him who have been living on the street for many years and are "*not posh*" like himself. The posh residents are

mainly younger people who have been moving into the area over the past decade and a half. I then experience an almost identical conversation with Emmeline on our way to the local park. As we drive out of the area in which she lives, she points ahead towards the row of Edwardian houses:

> *'Now this is the posh end, too posh for the likes of us'* (laughs)

Although Emmeline and Boris live less than a mile or so down the road and often drive past this area on their way to the park, Emmeline's awareness of the marked socio-economic affluence of the residents of this area conjures up the feeling of being an outsider here. Boris and Emmeline rarely come to any of the restaurants or the boutiques that are dotted along the main road on this end of the neighbourhood. It is a place they pass through, not where they expect to socialise and make friends with local people. The social reputation of place can therefore serve to invoke a sense of belonging among people of a certain socio-economic background whilst alienating others, shaping where and how the participants construct therapeutic landscape experiences within their respective neighbourhoods.

Whilst social connections are a prominent characteristic of neighbourhood engagement, participants' physical and embodied connections have also emerged as an important dimension of their experiences of the neighbourhood. Diana and Hannah's physical engagement with the neighbourhood occurs through walking around a defined area along a set route. The area within which they take their regular stroll is the part of the neighbourhood that they have formed a physical connection to, reflecting Gatrell's (2013) argument that movement of people in and through place is an important facet of place making. Amelia and Muriel's sense of belonging and connection to the neighbourhood is also largely attributed to its physical landscape. Although Amelia is aware of the changes the area has undergone over the last 50 years, as she mentions the demolition of the old school and building of new housing estates, Amelia insists that the neighbourhood still retains its essence, something she struggles to put into words:

> *'Although it is very different to what it used to be, it's still got a very special... Oh it's lovely, dead easy here... there's some lovely walks... we knew the area very well, all the walks, that's why we wanted to come back'.* (Amelia)

The local meadows and the canal are particular aspects of the neighbourhood Amelia engages with on a daily basis, defining her geographical area of familiarity within it. She provides a guided tour of the area during the walking interview and my field notes reflect both her familiarity and sensorial engagement with the landscape.

Hearing the cows mooing in the adjacent field Amelia laughs and points to them asking me "Can you hear them?" She recalls the house she grew up in, which was on the other side of that field. She notices that I'm not too keen on the smell of the dung and says 'It doesn't always smell like this, but that's what you get in places like this, we don't mind' ... We walk up to a ditch and Amelia tells me to walk around it behind her saying "It's just muddy now, but it's dangerous in icy weather', she then quickly adds "but that never stops us from coming out". Amelia systematically points to different aspects of the landscape– the sheep in fields, the ducks in the canal and the trees in the orchard– suggesting I take photographs of them. She tells me how juicy the apples are on one of the trees in the orchard...

Many of the places we pass during our walking interview hold sentimental significance for Amelia, in which case her relationship with the physical landscape is not only defined by its present day utility but also the history she shares with it. Similarly, although Alan has a good grasp of time and space, his perceptions of local places are often expressed through his earlier memories of them. Walking in the park, Alan talks about his experience of the walking group but intercepting these experiences are his memories of playing football on the grounds across the road as a young man, the friends who lived in the housing estate nearby or riding on the school bus which used to travel past the park. They therefore both use their memory as a way of retaining their connection to the physical landscape, which is a commonplace strategy amongst people with dementia as their socio-spatial surrounding and their engagement with it change overtime (Duane et al, 2011).

Even so, Amelia claims walking through the meadows and along the canal is '*dead easy*', referring to its openness and the simplicity of the route. Amelia knows exactly what is coming up ahead, and often forewarns me of such things as the nettles on the side of the path ahead and the canal across the road we are approaching. Acting as my guide, Amelia reassures me of how familiar she is with the surrounding; she is not put off by the smell, the ditch or the cold weather as she is almost at one with the landscape. An embodied connection with the local area is also evident in Belinda, Emmeline, Alan and Eric's interaction with their surroundings. Emmeline equates her embodied familiarity with the local area with feeling at 'home':

> *'I just know where I'm going when I'm here...It feels like home'.*

Despite being unable to recall the name of the park we are heading to during the walking interview, Emmeline gives Boris directions to the park, as though it is a route she has internalised. Eric also alludes to an embodied knowledge of the neighbourhood, when he says:

> *'I just walk and take different routes...it could be anywhere around here, I just walk and let it take me wherever, I don't plan it or anything, and I alway+s end up finding my way home'.*

Walking around his neighbourhood is almost second nature to Eric; he does not need to think about where he is or where he is going, he simply allows his body to "*take*" him. Eric thus feels a sense of confidence and autonomy when out in his neighbourhood which he lacks in places further away and which he frequents much less. For Belinda too, her familiarity with the local area is seen to afford her a certain level of mastery when she is out. An excerpt from the field notes captures how Belinda negotiates her way through the neighbourhood during the walking interview:

Belinda walks ahead, up the road from the house and around the bend. She stops at the cross road, standing on the edge. Sheila increases her pace to join Belinda and without any deliberation they cross over. I realise that Belinda always stops at the edge of the road when Sheila is not beside her, not because she requires direction but because she needs help crossing the road. I ask if they normally take this route and Belinda answers '*Yes*'...perhaps that is why the route is so familiar to her.... There are a lot of wet leaves on the ground and Belinda tries to avoid them pushing them aside with her feet when she can, '*Be careful, they're slippery*' she warns me. We walk past some houses, Belinda tells me '*This used to be a big house*' pointing to a detached building, which now seems to have been converted into offices... Belinda slows down as we approach a long row of houses with large gardens at the front, she stops every so often looking over the hedges. She is no longer focusing on the ground as she did along the main road. Sheila tells me they always peer in, many of the houses are undergoing renovation work....

Belinda is very much in tune with her surrounding as we walk through the quiet roads of her neighbourhood, focusing her attention on the leaves along the side of the pavements, the trees, the gardens and buildings. The embodied connection Belinda has to the neighbourhood is essential to her ability to orient herself in time and space and therefore an anchor to her existential confidence. However since all of the participants in this study have lived in their respective neighbourhoods for a considerable length of time, it is difficult to determine whether people with dementia who may have moved to a new area after the onset of dementia establish a similar embodied connection with their new environment and how these processes play out.

Another defining characteristic of participants' relationship with the neighbourhood is their use and appreciation of particular environments within it. As note/d in the previous chapter most of the participants engage with places within a walking distance or a short drive from home. Often other than local pubs, cafes and shops they may frequent in the locality they identify a number of natural features of the neighbourhood they regularly engage with. Mary and John, David and Katherine as well as Boris and Emmeline enjoy walking in places which are open and green, such as local fields and parks. Many of the participants also like to be near the water, whilst some talk about a walk along the canal, other participants, who live near the coast, spend a lot of time at the bay. Looking into the neighbours' gardens and watching the trees and plants change through the seasons is something which according to Hannah, '*brings such joy*' for both Diana and herself. Diana and Hannah also often walk along the promenade at the back of their house, the easy access to which is one of the reasons why Diana would not want to move elsewhere. Hannah claims her mother likes to watch the sea, stroke and feed the ponies and sit under the sun, providing a list of sensory experiences through which Diana connects with the physical landscape. Through walking and sitting on the promenade, Diana engages with several sensorial aspects of the neighbourhood, the sea, sand, grass, trees and animals. Whereas Diana has become quite passive in social situations, she is much more receptive to the physical elements of the neighbourhood.

> '*There are the horses with the young ponies in there at the moment and this one (Diana) feeds them, we've taken apples off the tree ... carrots ... She just puts her hand out and they just come up... she loves it'.* (Hannah)

The slow pace rhythm of her neighbourhood is accommodative of her physical inability to move fast, for which reason the city centre has now become too hazardous a place for Diana. Diana's neighbourhood on the other hand offers opportunities for her to experience a sense of physical and mental stillness; a 'change in pace and perspective' (Maybey, 2010, p.64) from other aspects of everyday life is required when appreciating the flowers in neighbours' gardens or watching the sunset. Similarly, whilst Emmeline struggles to talk about places and activities she enjoys outside of the home during the initial interview, when walking in the park she enthusiastically asserts:

> '*I like to come here, look at the daffodils there... This is my favourite season.'*

As we continue to walk through the park, Emmeline stops several times to watch the squirrels scurrying from one tree to another. She notices a bird sitting on the rails and spends a while trying to remember what type of bird it is, slowly walking up towards it to inspect it more

closely. The presence of flowers and animals in the park cause Emmeline to react spontaneously to her surrounding as she recalls and expresses the joy she feels coming to her local park, which Boris could not bring her to recognise and articulate during the interview at their home six weeks earlier.

Nearby fields, the meadow and canal are some of the places Eric and Amelia most often frequent to maintain their purposeful routine of taking the dogs out for a walk every day. Eric says:

> *'Yeah, I love a walk down the canal, yeah, I love a walk anyway… you know, it's … it's cheap … and it, it gives me a lot of pleasure, you know, to walk with the dog …'*

Whilst participants' direct interaction with the natural elements of place are experienced as restorative, allowing them to fully engage with their surrounding, for dog owners their engagement with such settings is interrelated to their relationship with their dogs. For Amelia the proximity of her home to nearby walking trails across the meadows and the canal is mainly significant because she can continue to take the dogs out for a walk. It is therefore being *with* the dogs as much as being *in* such an environment that contributes to their appreciation of place, reflecting the argument that pets and animals play an important role in the establishment of emotional connections between people and place (Gorman, 2017a). Likewise, Eric also mentions a nearby gravel pit which he has grown fond of over time, as he often takes his dogs there:

> *'They love it there, I watch them run around…. it's good, a good place to clear your mind actually.'*

His dogs are therefore important in the way in which Eric appropriates and uses local spaces for mental and emotional restoration.

8.4   Conclusion

It is clear that place is intimately linked to people with dementia's experiences of health and wellbeing. The two key themes relating to participants' daily life goals- *maintaining normality and routine* and *staying connected* - that posit experiences of health and wellbeing to everyday places involve different socio-spatial contexts, both in the wider community and within dementia specific settings. The participants with dementia seek out and enact therapeutic landscape experiences through place-making activities and subjective experiences as they

continuously negotiate the physical and social environments of places that are familiar and those that are new. Whilst place may offer a wide range of therapeutic landscapes prospects, for the participants with dementia they are relative to their efforts to maintain a sense of normality and routine and/ or stay connected to people and settings that are of importance, despite their reduced cognitive and physical capacities.

Participants' experiences of normality is constructed through regular and routine interactions with particular settings, whilst their continued efforts to maintain this sense of normality and routine during a time of transitioning renders some places to be more appealing than others. Typically, everyday places in the wider community that are important to participants' sense of normality are characterised by socio-spatial vibrancy, serendipitous encounters, sentimental/ historical attachment, functional activities and a degree of embodied pre-reflective engagement. Experiences of normality, underscoring therapeutic landscapes in community settings, are thus maintained through social, physical and symbolic aspects of people-place interactions. These places of normality are not restricted to a particular type of environment in the community either, as they include shops, supermarkets, cafes, pubs, parks, fields and even the local gravel pit, corroborating the point that therapeutic qualities of place are not inherent but constructed through mutually constitutive relationships between people and place. In this case, participants' routine activities being a key contributing factor to the creation of therapeutic landscapes, since participants' interactions with these settings are determined by the activities, such as shopping, meeting friends or dog walking, they engage in within them.

Based on their preoccupation with retaining a sense of normality, some participants have written of dementia settings as being counterproductive to their health and wellbeing because their spatial, social and organisational characteristics lack any semblance of normal everyday life. Others find inconsistencies between how the different elements of place within dementia settings contribute to the promotion of normality. However, participants who are open to adapting their sense of normality and routine are able to construct therapeutic landscape experiences through their socio-spatial engagement with dementia settings. Thus, people's sense of normality or the places where they experience normality are not static, much like therapeutic landscapes. As discussed in the previous chapter, whilst some places that have been a routine aspect of participants' daily lives before dementia are now less routine, since becoming difficult to navigate, participants have also adopted new routines involving different settings and activities in the community. What has perhaps remained more constant about their daily routines and activities, and which they find most therapeutic, is that these routine places are socio-spatially familiar and they resonate with personal interests and sense of self. The

primary role people's sense of normality plays in terms of ensuring their positive experiences of health and wellbeing in specific settings is that it endows them with a sense of control over their environment and activity (Wilton and Devereuil, 2006).

In regards to participants' ambition to stay connected with family, friends and neighbourhood, there are three particular settings that I discuss in this chapter. Regular visits to the local pub or walks around the neighbourhood are occasions for preserving existing social and spatial connections, whereas dementia groups and settings offer participants opportunities to make new friends and familiarise themselves with new places. While they actively engage in social interactions in some settings, they are found to play a more passive role in other social settings. The participants allude to the benefits of both types of social participation, although confirm that their ability to participate in conversations depends upon their relationship with the people within these settings and their familiarity to the situation. What the data discussed in this chapter demonstrates therefore, is that there are a number of nuances involved in the ways in which the participants engage with their socio-spatial surrounding and in turn how these interactions contribute to their health and wellbeing. The social vibe, spatial layout of a setting, socio-cultural context, social norms, the pace at which things happen, familiarity to the surrounding and tasks and visual stimuli, all have an impact on how well a person with dementia is able to engage with place. Whilst many of these factors are discussed in terms of enabling aspects of place for people with dementia, they are also experienced as barriers in certain contexts. In this respect it is perhaps inappropriate to try and devise a list of dementia friendly characteristics of place, which have no connection to the wider needs and circumstances of individual persons. In the next chapter I thus discuss and summarise insights to engagement and experiences of people with dementia in the wider community a subjective approach brings to light in this thesis.

CHAPTER NINE

Discussion: From 'shrinking' to 'creation of adaptive' life worlds

9.1 Introduction

In this thesis I have presented conceptual, empirical and methodological arguments pertinent to the research aim of: exploring how people with dementia experience and benefit from engagement with the wider community. The communities in which older people live have become a focus in research, policy and practice, as either non-institutional sites for providing health and social care or as places where older people can potentially benefit from experiences of familiarity, independence and continuity of personal history and social networks (Davies and James, 2011; Wiles et al, 2012). The present research sits somewhere in between. Focusing on the organic relationships between people with dementia and place and how they facilitate meaningful engagement in the wider community, I also consider how people's everyday practices in the community have shifted to accommodate their changing health and social care needs. This is a useful and timely approach for considering the diverse and multi-faceted role the wider community can play in maintaining the health and wellbeing of the increasing number of people living with dementia. Insights to how people with dementia interact with different places in the community and their perceived benefits can advance current understandings of and programmes of work falling under the dementia friendly communities' movement.

Engaging with literature within health geography and more specifically on therapeutic landscapes, the previous three chapters have sequentially addressed questions of: how people with dementia and their family carers understand and seek experiences of health and wellbeing; places of interest/ importance to them and how have they changed since the onset of dementia and also how health and wellbeing are maintained, enhanced or hindered through participants' interactions with these settings. In addressing these questions with the support of empirical findings the chapters have collectively sought to;

1. Describe people with dementia's experiences of engaging with community settings, from the perspectives of people with dementia and their carers.
2. Understand how people with dementia experience the link between engagement with place and health and wellbeing
3. Explore how family members/ carers understand and support people with dementia's experiences of health and wellbeing in the wider community

4. Explain the dynamics between people with dementia's social networks/ practices and engagement with specific community settings.

5. Identify characteristics of place, interactions and processes which facilitate/inhibit engagement with place and experiences of health wellbeing for people with dementia

In this chapter I will further reflect on the empirical evidence relating to each of the research objectives, as part of a broader discussion on the scholarly contribution of this thesis. As the thesis engages with issues pertinent within dementia research, the theoretical and empirical use of therapeutic landscapes and debates around methodological approaches for examining experiences of place, particularly of people with dementia, it offers some important contributions within these fields. The first section discusses how this thesis contributes to existing literature on experiences of people with dementia, particularly in regards to the prevalent assumption of their 'shrinking' life worlds. This is followed by a reflection on how the focus of this research and its findings can be aligned with the therapeutic landscapes scholarship, discussing its contribution to the conceptualisation and use of the concept. I then discuss the methodological contributions of my research, followed by a consideration of the study limitations.

9.2   A subjective examination of the shrinking life worlds of people with dementia

Drawing on the theoretical stance of social constructivism and a social model of dementia, this research forgoes the biomedical narrative of loss and abnormalities to a more subjective and nuanced view of how people understand and experience living with dementia. I engage with ideas around embodiment and emplacement to provide an alternative view of how people construct and experience their present life worlds. Seeking to elucidate the relational and multi-sensory relationships the participants share with the wider community, the empirical findings therefore challenge the phenomenon of the shrinking life worlds of people with dementia previously documented within dementia research.

9.2.1   Seeking a 'sense of home' when the home is a place of isolation

The literature on ageing and experiences of people with dementia emphasise the growing significance of the home, to the extent that the home is sometimes posited as a source of 'ontological security' (Milligan et al, 2004, Williams, 2010, 2014). The empirical data in this

research also attests to people with dementia spending more time at home with the decline of their physical and cognitive abilities. But whilst the participants allude to a sense of comfort and embodied attunement to the home space, the data also reveals experiences of physical, social and existential isolation within it. The home is often associated with inactivity and boredom by the participants in this study. This discrepancy is perhaps due to the participants in this study being less engaged in household chores in comparison to older people without dementia, or those participants with dementia in previous studies who were found to be still actively involved in housework (Gilmour and Huntington, 2005; Harman and Clare, 2006; van Steenwinkel et al, 2014). Indeed, the domestic chores which people undertake in their daily lives are considered important place-making activities, providing a sense of engagement, control and continuity as well as a structure to their day (Cutchin et al, 2010; Dinnie et al, 2013; Duane et al, 2011; Percival, 2002). With the diminishing of participants' domestic role then their ability to enjoy and feel an attachment to the home is threatened, much in the same way the introduction of home care provisions or a family member taking on the role of a carer can negatively impact on the subjective and embodied experiences of the home space of those involved (Milligan, 2003; Williams, 2002).

Rather than using the home as a place to retreat from the outside world, the participants are found to share a desire to see, hear, feel and be part of what is outside. At home, they sit by the window as a way of opening up the domestic space and 'inviting the outside into the home' (Duane et al, 2011, p.129). For Emmeline, the window which separates the home from direct contact with the wider community allows her to live on what de Witt et al (2009) call the 'threshold', therefore benefiting from both the socio-spatial security of her personal space and the social and aesthetic vibrancy of the outside. Other participants seek regular opportunities to be outside, claiming that the outdoor offers them a sense of physical and existential freedom, even if it means sitting in the car outside the supermarket. They appreciate being able to directly experience the varied physical and social environments the home setting lacks. The idea of the home as a 'safe haven' is thus challenged with concerns about its limitations in facilitating physical activity and social and mental stimulation that are important for people with dementia to live and function well (Martin et al, 2005). The empirical data from my research in turn suggests that whilst the participants wish to live at home, as opposed to moving into residential care, their sense of home expands beyond the house in which they live. The wider community in which they are situated plays an important role in the maintenance of their health and wellbeing; in many cases the wider community acts as a buffer to the loss of social contact, active engagement and emotional attachment in the home space.

9.2.2 From prisoners to creators of space

The 'shrinking world' analogy used by Duggan et al (2008) echoes the rhetoric of reduced activity, opportunities and control amongst people with dementia, which currently prevails within the extant literature (Forsund et al, 2018). The preceding empirical chapters corroborate the view that people with dementia are less mobile and therefore less likely to engage in settings and activities beyond the neighbourhood. In gerontological work, it is held that older people undergo 'fragmentation between physical environment, social relations and trajectories of ageing' (Wiles et al, 2009, p.665). But it is evident in my research that with ageing and the onset of dementia, as people withdraw from certain places that were once important, they become more involved in daily activities and settings within the immediate neighbourhood. Adopting a life course perspective which suggests people's everyday geographies to be in a continuous state of change throughout their life therefore offers a more positive narrative of dementia, replacing the discourse of loss with one of transitioning. During early adulthood, work was a prominent feature of people's daily lives, whilst leisure time was very structured involving activities with family and annual holidays. During retirement, people took up activities to fill their spare time and so enjoyed regular golf, bowling, hiking, volunteering and day trips with family and friends. As they grew older, developed dementia and other co-morbidity, along with losing their close friends and spouse, many of these places became a lesser part of participants' everyday life. These findings therefore support a view of emplacement which recognises that the body and its environment change and transition in tandem (Pink, 2011)

Instead of passively retreating to the local community, the participants are found to exercise personal choice and agency in how they use and engage with the setting and activities that are more accessible and appropriate than those they were once used to. No longer able to join a rambling group or go hiking, they have sought out areas within the neighbourhood where they can take regular strolls. Having no friends to go shopping or out for a drink with, they savour their interactions with neighbours, local dog walkers and customers when they are out in the neighbourhood. They have thus adapted their lifestyles to incorporate new sets of spatial practices and engagements that meet their new circumstances, whilst still retaining many connections between their past and present experiences. So whilst people with dementia's relationship with places beyond the neighbourhood have fragmented, their socio-spatial relationship with places within the neighbourhood is reinforced. Despite the uncertainty and progressive nature of dementia, people with dementia and their family carers seek to secure some sense of stability and quality of life through increased participation in places and activities

within the neighbourhood. Their connection with the wider community is now primarily maintained through a small number of mundane pursuits, providing a sense of routine and normality to their daily lives. Similar to the idea of people with dementia creating manageable 'little worlds' within the home space, as reported by van Steenwinkel et al (2014, p.1027), people in this study have constructed manageable little worlds in the local community through their routine use of certain settings such as shops, pubs, cafes, parks, canal and nearby fields.

9.2.3 Making place matter for health and wellbeing

Applying the concept of therapeutic landscapes, this thesis further illustrates different strategies which people with dementia employ to address their health and wellbeing needs within their reduced geographical area of activities. They have specific routines and settings or activities of interest in the wider community, which through social, physical and symbolic processes, assume a meaningful and therapeutic role in their lives. Shopping is one of the most common forms of activity through which many people with dementia retain and enact their sense of place. Whilst the participants with dementia no longer manage their money or choose when or where to go shopping, they find the practice of going shopping to simply browse personally symbolic. It relates to ideas of independence, normality and occupation which all of the participants emphasise as being vital to their quality of life. These concepts of health and wellbeing are indeed linked to how people with dementia interact with the physical and social aspect of shopping. A distinctive feature of shopping is its sociality; enabled by a strong sense of knowing and being known by others as people with dementia routinely engage in serendipitous conversations with other customers and staff. These regular encounters, albeit brief, help people with dementia to benefit from a wider social network comprising people of different backgrounds compared to that within the home (Blackstock et al, 2006; Duane et al, 2011). Their embodied knowledge of and multi-sensory interactions with the physical environment are also important to their ability to connect with the shopping experience, despite their cognitive difficulties.

Many of the people in this research have taken up or increased their participation in walking as part of becoming accustomed to living their life at a local level. Whilst some claim to enjoy walking, referring to the physical, mental and emotional benefits of moving and being in specific outdoor settings, others allude to only engaging in destination based walking, where they find a specific place of functional or recreational purpose to walk to. In both cases however, their practice of walking has shaped the places they regularly interact with in the neighbourhood. People with dementia and their carers describe the importance of walking in terms of providing

a change of scenery, which they describe to improve their mood, alertness and engagement. They thus refer to taking a 'stroll' or 'stretching our legs', reflecting a somewhat slow rhythm of activity. As pointed out by Gatrell et al (2013, p.102) 'The virtue of this type of walk is its very slowness', as its relaxed nature enhances people's firsthand experience of their surrounding. The empirical evidence in this thesis indicates that people with dementia look for quiet streets, dropped pavements and familiar landmarks in the neighbourhood to ensure they can navigate their physical surrounding with ease and without much cognitive deliberation or physical challenges. As a result, they are able to focus their attention on the more pleasant aspects of their surrounding such as the architecture, flowers, trees, birds and distant views, thereby achieving a 'therapeutic configuration' of the body, mind and environment (Lea, 2008). The moderate complexity of natural settings described within the therapeutic landscape literature is also found to be relevant in neighbourhood contexts, as people with dementia seek both local natural and built environments that are legible to the senses, enabling regular experiences of relaxation and composure.

Although some people prefer to walk alone, associating it with a retained sense of independence and 'personal space', most people use neighbourhood walking as a social opportunity. Almost all of the participants report enjoying greeting or engaging in conversations with people they transiently meet along the way. As Eriksson and Emmelin (2013) have found in their study, the 'Hi factor' is a human symbolic element of neighbourhoods, signifying an inclusive environment. Thus, engaging in social interactions and shared activities during the walk provides people with dementia with a reassuring sense of belonging and existence within time and space. The impromptu conversations with people in the neighbourhood and regular, fleeting, encounters with spaces, buildings and animals are significant to people's perception of living in and being part of the community (Cattell and Evans, 1999; Cattell and Herring, 2002). Quite often they use aspects of the environment such as the flower beds, trees, birds, squirrels and dogs as a point of conversation with others, therefore reflecting Milligan et al's (2004, p.1785) claim that 'the aesthetics of a pleasing and tranquil environment form a significant element of the therapeutic qualities of the social encounter'. Equally, when an environment is too busy, such as in busy pubs and restaurants, some people with dementia gain pleasure in observing the social activities around them as mere onlookers. They therefore seek and negotiate specific activities and settings in the community in ways that will meet their health and wellbeing needs.

9.2.4 Using the body to navigate and experience place

Alongside people with dementia's reduced life worlds, they are described to become increasingly passive in the way that they engage with the spaces and places relevant to their everyday life (Holthe et al, 2007). Without an awareness or memory of meanings they associate with self and their life world, people with dementia are argued to be no longer able to conceptualise the world around them and maintain an affective existence (Davis, 2004). Resultantly, empirical studies exploring experiences of people living with dementia allude to a sense of existential loss with the severing of affective ties to people and places caused by memory problems (Holst and Hallberg, 2003). The role of the body, as the primary interface between a person and the world around them, with the ability to sense, register and act upon it, is often overlooked within dementia research. However, taking a sensory ethnographic approach to conducting my research I have drawn on the physical and embodied relationship people share with place, demonstrating its contribution to the construct of therapeutic landscape experiences. Embodiment considers knowledge to not only reside in the mind but in embodied practices too, whilst the idea of emplacement goes further in bringing attention to how the body interacts with and even transforms in relation to the diverse elements of its environment. I have found it useful to engage with both concepts, without treating them as being mutually exclusive; embodiment helped me to focus on the individual and their retained capabilities whilst emplacement allowed me to take a more nuanced approach to exploring how people's embodied practices contribute to the creation and experience of therapeutic landscapes.

Although physical frailty has meant that people with dementia's interactions with place typically involve sitting and watching- in a cafe, in the garden, on the beach or at the local pub- they are nonetheless engaged with the physical and sensory aspects of place. Quite often, people express their appreciation of being out in the neighbourhood drawing on their sensual experience of attractive surroundings, the fresh air and visual stimuli. They describe intangible features of place such as the openness of meadows, parks and coastal areas which they find calming whilst the expansive and busy environment of city centres is something they consider to be daunting and anxiety provoking. Also whilst cafes, pubs and restaurants lack the physical and sensory qualities of nature to promote contemplative practices, they are ideal for 'people watching'. People with dementia sit in these places whilst observing and listening into conversations between other people, much in the same way natural landscapes allow people to watch and listen to birds and other animals (Gorman 2017a; 2017b). The odd smile, eye contact or a friendly gesture from staff and other customers are instances of passive but positive human connection.

However, placing an emphasis on the mind over the body, place attachment, which is recognised as a key contributing factor to older people's feeling of confidence and being in control in certain places, is also usually linked to psychosocial transactions or socio-cultural embeddedness (Wiles, 2009). Here, I argue that people with dementia seek and experience place attachment through regular physical contact with the neighbourhood; through emplacement. Routine engagement with particular settings and activities are found to facilitate an embodied connection to place (Kontos, 2004). The familiarity with which many people with dementia negotiate everyday places in the neighbourhood is in this way often embodied, rather than retained in the mind, enabling them to retain a degree of control and mastery over their surrounding, despite their cognitive difficulties. Particular smells, views and sounds are found to evoke a sense of connection to place, with their physical engagement in such activities as walking the dogs or shopping further augmenting their sense of belonging and purpose within it. The physical and sensory interactions between people with dementia and place, whether it is at the supermarket, the park or local streets, are therefore important for both experiences of familiarity and a positive sense of self. Personhood is in this way implicated within the body and bodily actions. Just as psycho-social experiences can either enhance or hinder personhood, the body's ability to recognise and positively relate to its physical surrounding is a fundamental prerequisite for maintaining personhood. Different activities of the body which people undertake- sitting by the window, walking along the meadows, watching the sunset, drinking at the pub, or pushing the trolley at the supermarket- are all examples of body work connected to the enactment of self (Ward and Campbell, 2013).

Moreover, the concept of the 'habitus', by Bourdieu (1977) posits behaviours and habits of the body as embodied social and cultural practices, giving the body and how people use it a much broader and interminable significance. Thus people's preferred physical proximity to others in certain settings is an interesting manifestation of embodied socio-cultural practices, giving rise to different experiences of place. Whereas sitting close to one another at the dementia group is too invasive for Eric who prefers more momentary contact with people he does not personally know, David enjoys sitting amongst the other men at the day centre and partaking in male banter, despite not being able to recall their names, whilst Diana savours the opportunity to sit and hold hands with the school friend she meets at her day centre. People's physical engagement with place and its contribution to therapeutic landscape experiences are thus very personal and culturally influenced. Similarly, sitting at the bar alongside other customers rather than around a table engaged in intimate conversation is a common practice amongst Alan as well as Belinda and James when engaging in small talk with or listening into conversations amongst people they do not have any personal connection to, indicating how people use their

body to direct how they engage with the social space. So whilst people with dementia's life worlds have significantly reduced, and they may appear somewhat inactive, taking a sensory ethnographic approach sheds light on imperceptible experiences of place that are valuable to people's sense of self and place. Through sensory ethnography, I present the sensuous experiencing and performing bodies of the participants, in order to understand the embodied and emplaced dimensions of therapeutic landscapes. Consequently, this thesis provides a more holistic understanding of how people with dementia experience and benefit from engagement with the wider community, than has so far been considered within existing dementia research.

9.3   Expanding the Concept and Utility of Therapeutic Landscapes

According to Williams (2010), there are three categories of landscapes the therapeutic landscape literature is concerned with: locations with a reputation for healing, formal health care sites and places that are specific to a particular or marginalised population. Focusing on everyday geographies of people with dementia, comprising public places of different characteristics in the wider community as well as settings and services specifically tailored to the needs of people with dementia, this thesis, to a varying degree, engages with all three areas of therapeutic landscape research. In so doing, it aligns itself more with the area of research Smyth (2005) considers to be concerned with therapeutic 'networks', the 'less formalized arrangements of support and care that often exist outside (or in parallel to) the traditions of biomedicine' (p.492). It is essentially the network of multiple settings and activities within which people with dementia's everyday geographies are embedded that provide the context for an exploration of therapeutic landscapes in this study.

9.3.1   Everyday geographies

According to some researchers, there is currently a dearth in literature exploring everyday geographies as therapeutic landscapes (Plane and Klodawsky, 2013). But those studies that do focus on the everyday, take quite a restrictive approach to what is defined as 'everyday geographies'. Firstly, although they are concerned with therapeutic landscape experiences which occur in people's daily lives, with the exception of a few studies (i.e. Cattell et al, 2008; English et al; 2008; Finlay, 2018; Masuda and Crabtree, 2010; Piat et al, 2017; Wakefield and McMullen, 2005) most studies focus on a specified setting. Secondly, everyday geographies are typically found to be synonymous with either the neighbourhoods in which people live their

daily lives (e.g. Masuda and Crabtree, 2010; Wakefield and McMullen, 2005) or places in the locality such as parks, schools, libraries etc, that are used on a day to day basis by people of different backgrounds (Liamputtong and Kurban, 2018; Sampson and Gifford, 2010). To understand therapeutic landscape experiences in the context of everyday lives people with dementia construct and maintain in the wider community, I have necessarily broadened my focus of enquiry to incorporate a wide range of settings. The theatre, shops, cafes, pubs, local streets, church, parks, canal, nearby meadows and coastal areas are all examples of community-based settings found to be important to the health and wellbeing of participants in this research. Everyday geographies considered here are therefore not distinguished by their particular location, physical characteristics or functional purpose; rather they are based on participants' daily routines beyond the home. Their everyday geographies are taken as a culmination of varied settings they engage with and which in turn have an impact on their overall sense of health and wellbeing. As Thomas (2015, p.188) argues in her study of the use of natural spaces in the everyday lives of women in Copenhagen:

'People do not experience spaces in a vacuum... such spaces form part of an embedded and interconnected matrix of settings through which people move and experience daily lives'

Also, whilst ordinary everyday places provided a starting point for understanding the therapeutic qualities of people's daily experiences in the wider community, people's use of local natural environments and dementia specific places emerged as important themes within their everyday geographies. Consequently, the present thesis not only contributes to the currently scant evidence base for how everyday geographies are utilised in therapeutic landscape experiences, it also arrives at a new way of identifying and defining everyday geographies, suggesting a more inclusive and inductive approach.

In taking into account different and diverse everyday settings constituting people's everyday geographies as a whole, I seek to highlight the interconnection between them and how therapeutic landscapes are constructed on the basis of how they relate to one another. The home is where the participants admittedly feel most calm, comfortable and in control, but they venture out into the wider community in search of physical activities, social connections and sensory stimulation the home space cannot offer. Participants' motivations for and experiences of engaging with community settings are therefore offset by the isolation and socio-spatial restrictiveness they experience at home. People are found to gain different benefits from different places in the community. Whilst they often frequent local natural sites such as parks, canals, meadows and coastal areas for mental and emotional relaxation, their social wellbeing

hinges on opportunities to spend time with family and friends and engage in social interactions at local pubs, restaurants or even dementia groups. People who are less involved in social activities in the community have in fact become more engaged with dementia groups and services for reasons of finding companionship. Also, not all people have easy access to places or choose to regularly engage with what are commonly referred to as *green* (i.e. country side) or *blue (i.e. coast, river)* spaces, known for their restorative qualities, in existing therapeutic landscape literature (Finlay et al, 2015; Volker and Kistemann, 2013; 2015). Their everyday geographies nonetheless bring to light alternative places of 'escape' such as quiet areas of the neighbourhood, streets with interesting architectural design, neighbours' landscaped gardens or a nearby gravel pit. In relation to the surrounding built up areas and busy roads, these quieter areas of the neighbourhood offer psychological distancing from the clutter of domestic settings and in turn an opportunity for physical exercise and emotional reflection (Cattell et al, 2008; Colley et al, 2016). A person's everyday geography is therefore not a mere coincidental assemblage of different settings, it is a network of 'nodes' arranged and maintained in ways that meet people's overall health and wellbeing needs (Duff, 2011). Everyday geographies are therefore closely linked to people's personal wellbeing priorities and the importance of different settings lie in their relational ability to meet these priorities.

9.3.2 Question of specificity, scale and temporality

People's therapeutic landscape experiences within their everyday geographies are characterised by an overlapping of many places and settings which vary in nature, scale and temporality. Often people, sequentially or at one time, engage with two or more different types of settings in the wider community. The conviviality of the pub environment is found to be important for providing people with a sense of inclusion and belonging to the community, however this experience is augmented by the routine and familiar journey people take through characteristically unique areas of the neighbourhood in order to arrive at the pub. Similarly, for participants who like to visit a cafe located within a park, their experience of the relatively intimate socio-spatial environment of the cafe is enhanced by their stroll through the open space of the park and their continued view of it from the cafe. This then raises the question of when the therapeutic landscape experience actually begins, is it as they enter the park or the moment they leave their house and cross various different socio-spatial environments along the way? As some researchers inclined towards the mobilities turn within health geography would argue, the route people take to a certain place of interest is of as much interest in terms of its contribution to the therapeutic landscape experiences as is the final destination (Thomas, 2015;

Miaux et al, 2010; Doughty, 2013; Gatrell, 2011; 2013). By following people's movement to and between everyday settings it is also possible to see the 'fluid and interconnected' relationship between natural and built spaces and how they work in relation to one another to form therapeutic landscape experiences (Thomas, 2015, p.192). The creative integration of natural and built spaces in everyday context is a phenomenon that has only recently been highlighted by Thomas (2015) and some of the examples within this thesis provide further evidence of how people with dementia incorporate landscapes of different characteristics within their everyday practices.

A longstanding criticism of therapeutic landscape literature is that it fails to clarify the scales of places in which therapeutic landscape experiences take place (Wilson, 2001; Milligan et al, 2004; Gastaldo et al, 2004). Although many recent therapeutic landscape studies have dealt with landscapes of different scales, they do not openly address the issue of scale. Perhaps, as Houghton and Houghton (2015, p.282) point out, 'It is inappropriate to be prescriptive about the size of such environments given the relational aspect of environmental experience'. In the context of this research, physical places that participants consider to be meaningful and important to their quality of life range from a particular spot in the lounge of the day centre, to the football stadium in which they watch their favourite team play, to the nearby coastline with its open sky and view of the sea and beyond. Thus, although the physical space a person with dementia occupies is easy to define, social and symbolic place-making processes through which it has become a meaningful place extend beyond the physical space. When considering the symbolic pathways through which sitting by the window has become a meaningful activity for some of the participants for instance, as noted in chapter six, defining the physical features or boundaries of that space becomes irrelevant. Each participant is found to mentally reduce or expands their view of the setting, working with a much smaller or broader space to construct their therapeutic landscape experiences.

Quite often, it is an object or a specific spot or activity within a larger space that is the focus of people's therapeutic landscape construct. For instance, David's therapeutic landscape experience at the day centre is restricted to a small socio-spatial area of the lounge where he enjoys the company of other men. This is set against instances of non-therapeutic experiences in other areas of the day centre, such as when he attempts to but is denied access to the garden area. Similarly, many participants focus on 'micro-scale' features of their everyday settings and activities, such as feeding the ponies in the fields or watching the flowers bloom in neighbours' gardens as defining aspects of their experience of place (Finlay, 2015). In this way a number of people with dementia focus on micro-scale barriers, which they experience in particular settings. Their struggle to use the stairs in public places, the cold draught coming in through the

cafe doors or the illegibility of small print menus at the restaurant are described to hinder their ability to meaningfully engage with place, and therefore negatively contribute to construction of therapeutic landscapes. When participants do focus out from the micro-scale features of place to the wider environment of town centres, theatres, parks, football stadiums, meadows and coastal areas however, these settings are usually discussed in terms of their social and symbolic significance. Even the attraction of local *green* spaces is often attributed to emotional symbolism- '*a special place*' (Amelia) or cultural symbolism- '*the beauty of the countryside*' (David), rather than their specific spatial characteristics per se. Experiences are also sometimes difficult to pin down to a single temporal place, as people, particularly people with dementia, often combine 'imagined landscapes' from another time and/ or setting to make sense of their present setting (Gastaldo et al, 2004). This was evident with some participants, as being in a particular setting or discussing their life history prompted them to mentally take themselves to and describe experiences of a place from their past. The idea that meanings, imageries and memories from the past can stimulate certain emotional responses and support therapeutic landscape experiences in the present has been a focal theme in research exploring the role of 'mindscapes' in order to cope with change (Andrews, 2004; Gastaldo et al, 2004; Rose, 2012; Rose and Lonsdale, 2016). Findings from the present study therefore further confirm its relevance to everyday context, especially for people with dementia who often experience a disorientation of time and space.

9.3.3   Therapeutic landscapes and the dementia self

Perceptions and experiences of settings pertaining to participants' everyday geographies are unique to each participant, and cannot be objectively defined in terms of their scale, nature or temporality. The dynamic and multi-layered nature of everyday geographies maintained by people with dementia reveals something of a very complex relationality between people and place. In exploring participants' everyday geographies, I came to appreciate their tapestries of everyday biographies. Participants' everyday geographies are inscribed with past experiences and personal values and preferences, thereby corroborating the now common view that therapeutic landscapes are created and experienced differently by different people (Bell et al, 2017). Taking a closer look at how their everyday geographies have evolved over time, particularly since developing dementia has allowed therapeutic landscapes to be viewed within a broader context of people's changing life worlds and in relation to their efforts to control their biographical narrative. People with dementia and their family carers participate in activities and settings that cohere with who they are, as the places they engage with and how they do so are

integral to their reproduction of self. Thus, people's everyday geographies do not only describe what they do in the wider community, but who they are, whether that is a dog owner, a former entertainer or a Christian.

Negotiation of self identities, including that of dementia, is embedded in the daily work of people with dementia (Caddell and Clare, 2010; Cohen-Mansfield et al, 2006a). Conradson's (2005) use of the 'relational self' in his work on therapeutic landscapes, is therefore perhaps ever more relevant in regards to place based experiences of the participants in this study. The extent to which the participants pursue and experience a particular setting and activity as therapeutic, depends upon how it relates to their conception of self and self development. It is on this basis that some of the participants in this study are divided on their perceptions of the therapeutic qualities of dementia specific places. For some people dementia groups and settings are an important outlet for sharing experiences, engaging in mutual support and experiencing a sense of belonging. These people with dementia have embraced their dementia identity and its impact on their biographical narrative, utilising dementia specific provisions to be able to live well with the condition. For others, dementia constitutes a negative social identity and is disruptive to their desired way of life. The performances that are carried out in and with place in regards to dementia settings and services are in this case perceived negatively by these participants (Wood at al, 2013). Instead of places of cohesion and positive engagement, they are perceived as places forestalling organic experiences of social inclusion and self-development and therefore unlikely landscapes for therapeutic experiences.

Societal expectations that people with dementia will engage with and benefit from dementia specific provisions are in this way challenged by people with dementia who refuse their self identity and place in the world to be defined by their condition. However, taking the view that the meanings people associate with dementia and therapeutic landscapes are socially constructed, there is perhaps more work to be done in terms of redressing the negative connotations associated with dementia and in so doing reinvent the therapeutic appeal and qualities of dementia places (Smyth, 2005). It is the aim of dementia friendly communities' policy to create a more positive view of dementia, by breaking down negative stereotypes and empowering people affected by it to live a full and active life (Phillipson et al, 2018). The application of therapeutic landscapes to people with dementia's everyday experiences beyond the home may in this case serve well to further understand how dementia friendly communities can optimise meaningful engagement of people affected by dementia and in turn support their health and wellbeing. Such policy implications of the present thesis will be considered in the concluding chapter.

9.4 Methodological Reflections

The methodological stance adopted within in this study has been informed through engagement with two separate bodies of literature: illness experiences within dementia research and therapeutic landscapes within health geography. Although, both areas of work are complimentary in that they both endorse a subjectivist view of reality and thereby focus on interactions and experiences that impact on people's health and wellbeing, to date the relevance of one in the work of the other has not been explored. This thesis sets a precedent by combining theoretical and methodological approaches deriving from these two distinct scholarships, to address its research aim.

From the outset there were two key implications of applying the concept of therapeutic landscapes to experiences of people with dementia. First, since the person engaging with place is posited as an active agent in the construction of therapeutic landscapes, the application of the concept in this study endowed the person with dementia with agency (Gesler, 2003). Second, social and physiological factors shaping experiences of people with dementia place them in a unique position, offering new insights to current understandings of where and how therapeutic landscapes are constructed. Sensory ethnography was chosen as the primary methodological approach as it plays well to the multi-dimensional notion of place endorsed by the concept of therapeutic landscapes and its methods provide scope to ensure meaningful engagement of people with dementia in research (Dewing, 2002; Moore and Hollett, 2003). In this section I will specifically outline two methodological insights from my thesis- one regarding the use of mobile/ walking interviews to substitute a currently restrictive repertoire of qualitative tools used in dementia research, and another regarding the use of a life course perspective to further enhance the study of therapeutic landscapes.

9.4.1 Walking with the person with dementia

Walking interviews is a mobile sensory ethnographic method of data collection, commonly used in therapeutic landscapes studies exploring experiences of the neighbourhood or outdoor settings more generally (Bell et al, 2015; Colley et al, 2016; Doughty, 2013; Finlay, 2018; Finlay et al 2015). Dementia research on the other hand have seldom tackled people's experiences in and of the wider community and are heavily reliant on the use of sit-down interviews followed by a lesser use of participant observations (Aggarwal et al, 2003; Boyle, 2014; Kontos, 2004; Phinney and Chesla, 2003). However there is now greater call for research on people with dementia's participation in the community, paralleled with concerns about the disempowering

emphasis certain research methods, including interviews, place on people's cognitive ability to recall and verbally articulate their experiences (Moore and Hollett, 2005). I was interested in their embodied practices and experiences of emplacement, which cannot always be expressed in words. The walking interview as a sensory ethnographic method in this case worked well in allowing my participants and me to perceive and experience the environments simultaneously. For some participants they considered the walking interview as an opportunity to share their knowledge and views of the neighbourhood, both through their actions and narratives. Whilst I asked all participants to 'carry on as usual', they chose routes and activities which would take us to places they like, with the walking interviews resembling something of a guided tour. It also initiated conversations about past events and practices in these settings, their history of living in the area and appreciation of certain neighbourhood features, bringing their biography into their experience of place which I, as the researcher, could not relate to. Walking interviews can perhaps become a method of choice in future dementia research, as its focus on corporal engagement is effective in evoking and making visible people's dynamic and embodied attachment and memories to place (Stevenson, 2014). Below I provide a brief summary of how dementia research can benefit from and adapt the use of walking interviews.

Being outside in the wider community provided a different setting to that of the home, where the initial interview was conducted with the participants. Effectively, it enabled participants to show and talk about a different side to them, one which was seen in the process of participants negotiating with elements of places beyond the home. Their experiences of emplacement were most apparent in such context. Whilst Olsson et al (2013, p.795) claim 'Outdoor activities as a confirmation of self through being and doing', it is also true that people's activities and interactions with places beyond the home can reveal a version of the self that is less apparent in their narratives during sit-down interviews. I found that the participants often adopted a different role in places in the wider community compared to that at home, surrounded by different people and different sets of challenges and facilitators. I was able to see them in the broader context of the community in which they live; both in terms of how they forge a sense of belonging through greeting neighbours and fellow dog walkers as well as their vulnerability to the presence of traffic and noise. Nygard (2006) discussing research with people with dementia highlights the significance of unexpected occurrences during observations which prompt spontaneous reactions and reflections in people. This is much more likely during walking interviews; it was only when we entered the park that one participant's delight of being in nature or as we walked through the neighbourhood that the aesthetic element for another participant's walking itinerary became apparent. All participants thus demonstrated greater engagement and ability to be present in their space.

The primary focus of walking interviews is the act of walking or at least moving. According to Dourish 'It is through our actions in the world – through the ways in which we move through the world, react to it, turn it to our needs... – that the meaning that the world has for us is revealed' (2001, p. 237). The idea is to capture the construction of place through movement of self and others and the goings on between different elements of and across settings. Taking this dynamic view of the construction of place, I came to understand how participants' experiences of the supermarket, the cafe or the park, were not only shaped by the environment contained within these settings but also by their journey there. Their experience of getting ready to go out, negotiating the traffic, conversations with their partner, encounters with other people and animals as well as the different landscapes they pass along the way, were all part of their experience of place. However, it is also important to recognise that movement can often become somewhat difficult for older people with dementia and they spend more time sitting and watching than moving. I have thus conducted walking interviews with participants where we spent a considerable length of time in the car, whilst in transit, where neither they nor I were engaged in any specific actions. Considering these participants were once drivers, the 'ride-alongs' were insightful in that they allowed me to observe how the participants adjusted to the role of being a passenger (Carpiano, 2009). Further, where participants stopped or sat and how and why they did so during the walking interview were just as important for understanding their relationship with place and its contribution to their health and wellbeing. Bissell (2008) writing about the sedentary body, states 'much of our everyday routine is spent in a relatively inert and sedentary configuration....these events of bodily statis...are a specific kind of relation-to-the world...' (p.1699). By being still the body is still engaged in place making, as has been found in a study of people with dementia by McColgan (2005). Stillness can be just as important as walking and moving when exploring experiences of place for people with dementia, particularly in the context of sensory ethnography as people are still utilising and engaging with their senses, and should therefore be incorporated within the walking interview method.

The walking interview method however raised certain concerns about the safety and privacy of participants in open public spaces, which should be taken into account. For participants who were less confident to go out of the house on their own, having a family member or carer present was important to ensure that they felt safe and supported (Sixsmith and Gibson, 2007; van Gennip et al, 2014). In addition, one participant was unable to participate in a walking interview with consistently poor weather during the winter months, whilst another participant's health had deteriorated significantly by the time he reached the second stage of data collection and was no longer able to go out. Another couple did not feel comfortable with the idea of being observed when they are out in the neighbourhood and so refused to

participate in a walking interview. Also, the use of props such as a camera or an audio-recorder during the waking interviews depended on the nature of the places engaged with and how the participant felt about the attention these props sometimes attracted from others. Many of the participants felt much more relaxed conversing with me without the presence of an audio-recorder in enclosed spaces such as a shop or a cafe, and were similarly more engaged in taking photographs when outside than when inside. It was therefore only possible to conduct brief audio-recorded interviews with participants, where it was deemed appropriate.

9.4.2   Adding a life course perspective to the study of therapeutic landscapes

Sensory ethnography is very much about capturing the configurations of objects, activities, and feelings that make up the sensorial place, although it does recognise that embodied experiences are always emplaced (Sunderland et al, 2012). Walking interviews and other forms of observation however, although provide in-depth first-hand insight to how people construct particular experiences in place, do not lend themselves to an examination of the biographical conditioning of the senses and behaviours through which people construct these experiences (Howes, 2005). A personhood perspective advocates that people with dementia's interactions with their socio-spatial surroundings be viewed in relation to their life histories and thereby people's habituated and embodied behaviours recognised as retained agentic capacity (Boyle, 2014; Holst and Halberg, 2003). Similarly, a socio-cultural perspective suggests that people's engagement with and experiences of place are the outcome and perpetuation of on-going socio cultural processes (Hulko, 2009). The therapeutic landscapes concept is also based on a cultural conception with Gesler (2003) arguing for 'healthy places' to be viewed as more than physical, to take into account the sense of place that is 'built up through lived experiences and involves the transference of moral, value and aesthetic judgements to a site' (Butterfield and martin, 2016, p.699). However, existing literature with one exception (Milligan and Bingley, 2007), despite using mobile methods, provide 'freeze-frame' accounts of therapeutic landscapes, making interactions between a person and place within a certain time point and context their focus of analysis. They tell you little about how these places are intertwined with people's personal biographies, previous social connections and their wider circumstances.

In this thesis I address this gap within the therapeutic landscapes literatures by examining participants' life histories and illness experiences alongside how they engage with and experience specific places in the community. Impact of factors such as people's health status, cultural norms and values, perceptions of health and wellbeing and previous lifestyles, which are pertinent to experience of place, are allowed to emerge through participant narratives. I

therefore begin my empirical chapters in this thesis with pen portraits of participants to provide a broader context of their life, needs and inclinations. Participants' experiences in and of the wider community are found to be reflective of past social roles and relationships as well as their current response to living with dementia, which in turn impact on where and how they construct therapeutic landscapes. The need to maintain coherence in terms of the settings and activities engaged with amongst people with dementia, has as a result, emerged as a key theme. They are found to assess their present lifestyle choices and opportunities in relation to how they support their sense of self, social identity and ability to live a life that they consider to be *normal* (Robertson, 2014). Eliciting a historical and socio-cultural context of why people with dementia engage with certain places or activities and not others and their sentimental or practical value, is an important contribution this thesis makes to the therapeutic landscape field of research (Thomas, 2015).

Acknowledging that the breadth of the data can be further enhanced through a more longitudinal approach, a diary method was also incorporated. Although diaries have been used in two particular therapeutic landscape studies, they were focused around a particular therapeutic activity or setting (Milligan et al, 2004; Rose and Lonsdale, 2015). Information on different settings people engage with over a long period of time in the community can instead provide further insight to people's efforts to maintain coherence between past and present and how people's relationship to certain places, and therefore their experience of therapeutic landscapes, in the community may have changed over time. Only three sets of participants agreed to keep a diary, for four weeks. As for the other participants, the demand of completing a diary was too burdensome for the person with dementia and their family carer. Feedback from the family carers who did keep a diary suggests that the family members with dementia made very little contribution to the diaries, and it was the family carers who took the responsibility of deciding what is recorded and when. All of the participants with dementia were said to struggle with talking about where they have been and how they felt once they reached home. This is not to say however that the method cannot be used with other populations in therapeutic landscapes research, in order to gain a better understanding of how people seek and maintain therapeutic landscape experiences in settings which they frequent on a regular basis, over time (Willis, 2009).

9.4.3 *Embodied interactions between researcher and researched*

Whilst illustrating how the participants experience and negotiate places through their bodily senses and actions, I have also on several occasions written my own body in, drawing on my

own embodied or emotional reactions to particular situations or settings. I consider the latter to have been an integral part of the research process and of the knowledge that has been constructed as a result (Malacrida, 2007). Sharma et al (2009), reflecting on their role as embodied researcher's in an ethnographic study of health care settings, discuss two particular themes '*Emotional and bodily ways of knowing*' and '*Being aware of and experiencing difference through the body*'. In this section I will briefly discuss both these aspects of my embodied engagement and influence on my work, as a way of engaging in some critical reflexivity.

My embodied presence in the field, whilst conducting the interviews and participant observations, played an important part in making sense of my interactions with the participants, their actions and our surroundings. I felt rather uncomfortable and subdued walking into the day centre in which I observed David, having had minimum contact with older people with advanced care needs up to this point and with the deco reminding me of a care home I once visited. Engaging in the conversations, games and laughter which followed however, lifted my spirit. Reflecting on the contrast of emotions I felt between walking in and walking out of the day centre, I could appreciate how such interactions would bring joy to David and other people at the day centre. Similarly, despite my initial uneasiness around Amelia's dogs during our walking interview, walking through the meadows, I soon found my attention drifting away from the dogs to the distant views. With my mind wandering I felt absorbed into the tranquillity of the surrounding, escaping from my fear of the dogs and later realising this is perhaps what Amelia means when she talks about how 'special' this place is. Thus, having taken some photographs of the walking interview with Amelia, I was able to relive and incorporate into my analysis, my emotional reaction to the physicality of the landscape and my encounter with it.

In this way my embodied experiences of my interactions with the research participants have also influenced how I have perceived and engaged with them during the research process and in turn my portrayal of them in the thesis. John, Mary's husband, came across particularly apathetic during the initial interview, which I sensed from his body language (arms folded, looking away) and short (often snappy) responses to questions. I continued with the interview to the end, since neither John nor Mary suggested otherwise. However I found the experience of probing them, as Mary struggled to answer the questions on her own, whilst being careful not to come across as prying, exhausting. I left the interview feeling rather deflated, especially as I could not understand John's sudden change of mood. Weeks later when I returned to my field notes, I realised I did not write anything about my impression of John and Mary or our conversation prior to the interview, as I have done with other participants; instead my notes were my analysis of John's behaviour during the latter part of the interview and how it made me

feel. In trying to suspend such emotional influences during the writing phase however, I found myself writing about John and Mary in a matter of fact way.

Being aware of my physical presence and the role that my embodied identities played in my relationship with the participants, the settings and situations was also important. Being much younger and of a different racial/ ethnic background to the participants, I was aware of possible challenges that this may present in building a rapport with them. Whilst many of the family carers and some participants with dementia have highlighted the fact that I am much younger than them at some point, I did not feel it was done to build a barrier between us. I often used our age difference to probe them to talk about aspects of their former life in more detail rather than let them assume I understand what they mean when they talked about certain events and experiences from their past. Also, some participants sought to find commonalities between us, in which case finding out that I am a mother, I was born in Yorkshire or that I live in Manchester spurred them to share certain information and relate to me in a way that may not have been possible without such exchanges. As for being a person of Asian-Muslim background, I found that whilst this aspect of my identity was not directly brought up or discussed by the participants, I was conscious of the attention I might be drawing to myself and the participants during the walking interviews. I felt as though I could blend in whilst walking in the park with the participants in Manchester where there is a visible presence of people of diverse ethnic and racial backgrounds and where the participants and I benefitted from a certain sense of anonymity. However, walking through a predominantly white neighbourhood in Lancaster, where the participants are known to many of the neighbours, I felt more aware of curious looks and the impact this may have on the participants.

9.5   Study Limitations

All participants in this study are of white British background, this is perhaps due to a couple of factors. Firstly one of the two cities from which participants were recruited has a predominantly white population. Secondly, participants were recruited through voluntary and community sector organisations which are claimed to be underutilised by people with dementia from certain ethnic groups due to various cultural barriers.

Socio-economic status of participants was not sought before or during the research. Details of their life histories reveal that their past occupations vary considerably, although their current lifestyles are very similar. Further, they are all home owners, living in similar neighbourhoods, suggesting a lack of socio-economic diversity amongst the participants.

Most of the participants in the study had relatively high support needs and were unable to provide consent or take part in the research without the input of their family carer. This may have been because the community groups and organisations from which I recruited my study participants attracted people who were now largely disengaged from community settings due to the limiting impact of their dementia.

Not all of the participants were able to complete all stages of data collection. Due to the fluctuating and progressive nature of the condition, it was difficult for participants to engage in all aspects of the research process, despite my efforts to be as flexible as possible and reduce the burden on participants.

9.6   Conclusion

So although the 'shrinking world' analogy used in previous research is a good descriptor for the phenomenon observed amongst participants' daily activities in this study, I would contest the assumption that they become 'prisoners of space' as a result. The idea of becoming 'prisoners of space' would suggest experiences of involuntary isolation, lack of self growth and feeling of apathy towards a monotonous everyday setting. But for most of the participants in this study, their neighbourhood plays a protective role offering a 'safe' and familiar environment, local amenities within walking distance, opportunities to socialise with the neighbours and access to places in which they can relax. In this way the local neighbourhoods shelter the participants from busy shopping centres, roads with high volume of traffic and restaurants where staff are unfamiliar to their needs, beyond the neighbourhood. In essence, participants experience a sense of 'ontological security', engaging in places within the neighbourhood. Their neighbourhoods allow for them to bracket out aspects of life they have now lost the ability to negotiate such as working and holidaying and in turn regain confidence and feel comfortable engaging in everyday routines closer to home. This sense of ontological security, impacting participants' health and wellbeing is achieved through a renegotiation of their everyday geographies by participants and also the amenability of socio-spatial aspects of the neighbourhood to participants' changing needs, thus reflecting an interplay between individual agency and societal structure.

Places in the neighbourhood have in this case become focal settings in which people with dementia and their family carers actively construct a sense of security, identity and self worth. Amidst changes in their health related circumstances as well as both personal and social relationships, participants' familiarity to the socio-spatial surrounding of the neighbourhood is an important anchor to their identity. People in this study allude to deep social, emotional and

embodied connections to where they live. For some the social connection is expressed through regular contact with neighbours on the streets, in the pub and local shops. For others, it is a more subtle sense of belonging and shared identity maintained through the spatialisation of socio-economic divisions in the neighbourhood, in terms of where the residents live, socialise and carry out their daily activities.

CONCLUSION

With an increasing number of people diagnosed with dementia who live at home, understanding and addressing how they experience the lived spaces of their daily lives in the community is important. Existing research elucidates a number of personal (disorientation, forgetfulness and frailty), social and physical barriers people with dementia face in outdoor environments, causing them to become largely excluded from mainstream society (de Boer et al, 2007; Duggan et al, 2008; Hulme et al, 2010; Mitchell et al, 2004). Efforts to design dementia friendly environments have in this case gradually shifted their focus from housing and residential care settings to public buildings and spaces (Bennett, 2015; Mitchell and Burton, 2010). However, the overall emphasis of the evidence base remains on physical and environmental barriers rather than the subjective choices and interactions constituting people's experiences of the wider community. A detailed examination of day to day settings and activities people with dementia engage with, their nuanced experiences and their relationship to people's sense of health and wellbeing is so far lacking within the literature. This presents a problem of disconnect between existing dementia literature and dementia policy, as the recent UK dementia friendly communities' policy takes a much more holistic view of how to support people affected by dementia in all aspects of life (Alzheimer's Society, 2013b). While identifying accessibility and way finding issues are important for encouraging participation of people with dementia in the wider community, there is also a need to explore their motivations for and benefits of engaging with certain places and how they can be maintained.

Summary of Research

Building on the work of Duggan et al (2008), who report on the reasons for and perceived benefits of using outdoor settings by use of semi-structured interviews with people with dementia, this thesis takes a sensory ethnographic approach combined with a life course perspective to further explore how people with dementia negotiate and experience places beyond the home. It demonstrates the importance of the wider community to the daily lives of people with dementia, albeit their reduced number and geographical area of activities. Offering a counter perspective to the notion of the 'shrinking world' commonly associated with the socio-spatial life worlds of people with dementia, the thesis employs the concept of therapeutic landscapes, highlighting the role particular settings and activities people engage with play in maintaining their health and wellbeing. Local cafes, pubs, parks, canal, meadows, fields and

shops are some of the places most commonly frequented and used to maintain health and wellbeing by people with dementia and their family carers. These places allow people to escape the isolation of the home space, succeed in self-care efforts, participate in activities that are personally meaningful, retain a sense of routine and normality, maintain connections with friends and neighbours as well as reaffirm their attachment to the physical and aesthetic landscape of the neighbourhood. Mapping the evolution of everyday geographies of individual participants, a growing importance of dementia groups and services in the lives of many people with dementia is also brought to attention. I suggest viewing dementia groups, settings and activities as part of people's everyday geography and perhaps in this way bring it into the discussion of what a dementia friendly community should look like and how different areas of dementia work contribute to the dementia friendly communities' overall policy ambition.

Policy Implications

The dementia friendly communities' policy is an important and pragmatic step towards tackling the ever growing prevalence of dementia in society and ensuring that people who are affected by the condition can live a good quality of life. Its overall ambition is claimed to be 'diverse, differing in size and ways of working' (Buckner et al, 2018, p.1). At the heart of the policy however are firstly increasing awareness of dementia to foster a culture of respect and understanding across society and secondly supporting people with dementia to live an active and independent life in the community. The present research can therefore shed some light on and further inform the aims and reported implementation efforts of dementia friendly communities.

The present thesis illustrates that people with dementia have different personalities, life experiences, personal preferences and health and wellbeing expectations, leading them to construct everyday geographies that are unique to their individual needs. Using the therapeutic landscapes concept a broad and personal conception of context is offered, taking into account daily routines, subjective meanings and historical connections which are found to mediate people's relationship with the wider community. The banner of dementia friendly communities on the other hand, as a population level response, places an emphasis on the 'dementia', doing away with the idiosyncrasies defining how people relate to and engage with place, regardless of their dementia (Rahman and Swaffer, 2018). While this approach is useful in identifying and addressing commonalities in people's experiences of social and practical barriers, it can serve to further segregate those affected by the disease. Dementia cafes, dementia singing groups, or

dementia luncheon groups are prime examples of dementia friendly communities' projects that aim to create communities of interest as opposed to integrating people with dementia within the wider geographical communities in which they live. They can empower and provide social stimulation, as a number of people with dementia in this study report experiences of shared identity and camaraderie in such settings while their family carers take comfort in knowing that their socio-spatial environments and activities are safe and tailored to the needs of people with dementia. For most people however, who are either still coming to terms with their dementia identity, or reject it altogether, their sense of place is connected to roles and routine practices they are used to performing in the community. They instead point to the social vibrancy of public settings and opportunities to encounter people of different backgrounds as being important. The wider community as a therapeutic landscape for people with dementia is therefore understood in terms of its ability to attend to the needs of the 'whole-person'. Dementia friendly communities would perhaps in this case be most effective in nurturing people's exiting daily routines, social connections and use of particular setting in the neighbourhood, instead of creating spaces and activities that are new and unfamiliar.

There is then a need for dementia friendly communities to begin with a focus on the everyday lives and health and wellbeing priorities of people with dementia as opposed to taking an environmentally deterministic perspective and starting with the environmental characteristics of place (Dinnie et al, 2013). This will help to understand the reasons why and processes through which different settings and activities in the community become a part of people's daily routines and how they contribute to people's quality of life (Bell et al, 2014). The present thesis demonstrates an intertwining of biographical and geographic shifts in people's construction of therapeutic landscapes over time, particularly since the onset of their dementia. As they withdrew from settings and activities that were once an important part of their lifestyle and sense of self, they sought to (re)establish a sense of place in more local contexts. Dementia friendly communities can therefore play a pivotal role in recognising and ensuring meaningful links between places people leave behind and places which they engage in building new connections with. The application of therapeutic landscapes offers various perspectives as how to facilitate experiences that are beneficial to the health and wellbeing of people with dementia-from visualisation or mentalisation of therapeutic landscapes linked to symbolic engagement with place (Gastaldo et al, 2004; Rose, 2012) to enactment of therapeutic landscapes through bodily movements associated with physical contact between person and their surrounding (Doughty, 2013; Gatrell, 2013).

Ordinary places in the community have in this way the potential to provide daily and sustained experiences of positive health and wellbeing in an organic manner, as the thesis demonstrates, as long as they are able to sustain the interest and engagement of people with dementia. A combination of natural and built environments within the community are frequently accessed and used by people with dementia, for maintaining physical activity, socialising, engaging in functional tasks or mental and emotional restoration. In this way they are both a constant part of everyday life, while at the same time providing retreat like experiences away from the home space (Evered, 2016). There is therefore perhaps some benefit in directing the attention of dementia friendly communities in facilitating 'everyday places of contrast, and lifestyles allowing time in diverse environments' (Pitt, 2014, p.88). The importance of adequate awareness and understanding of dementia amongst staff in different ordinary everyday places is also noted by a number of family carers, which can be crucial to people with dementia's ability to meaningfully engage in and enjoy their experience of the wider community. Availability of places which both the person with dementia and their family carers can enjoy, friendliness of staff in local shops and cafes, roads that are appropriate for wheelchair use, walking trails in the meadows and dispersion of benches at the beach, are some of the varied factors influencing if and how people with dementia engage with places within their neighbourhood and the extent to which they become part of their daily routine. For dementia friendly communities to ensure on-going positive impact on the quality of life of people with dementia, it is therefore important that its efforts focus on settings and activities which are embedded within people's everyday lives. Places of everyday use, as has been found in this study, can greatly benefit from increased awareness of dementia through the 'dementia friends' training and focused attention on how certain aspects of the physical and social environment act as barriers to engagement by people with physical and cognitive impairment.

Future Research

As a result of conducting this research, three further areas of research that can contribute to advancing understandings around health and wellbeing experiences of people with dementia in the wider community are identified. Firstly, this thesis illustrates the shifting nature of people's everyday geographies along with their personal conceptions of health and wellbeing. A longitudinal approach is necessary to provide detailed accounts of how people with dementia manage their changing circumstances and increasing support needs due to the progression of dementia against their desire to live in and engage with the wider community. This thesis adopts a longitudinal approach by use of the 'diary' method, but this approach could be further utilised for a much longer period. However, the extent to which persons with dementia will be

able to complete a diary over several weeks/ months as their condition progresses is uncertain and alternative options of recoding their day to day activities may have to be considered. Secondly, this thesis provides a brief summary of different approaches to reducing isolation amongst people with dementia-dementia specific settings, dementia specific activities and ordinary places adapted for dementia. It was beyond the scope of this research, but these dementia groups, settings and services can benefit from further examination of how the differences between them are experienced and perceived to contribute to individual health and wellbeing priorities by people with dementia. Finally, although this thesis uses the concept of therapeutic landscapes to highlight the agentic engagement and construction of place by people with dementia, it also alludes to experiences of contested spaces where there is an imbalance of power. A more critical examination of therapeutic landscapes in such context can further inform understandings of how people with dementia negotiate and experience places of daily life which they have less control over.

Concluding Remarks

By exploring in-depth, therapeutic experiences of everyday geographies of a diverse group of people with dementia, this thesis exemplifies the interconnection between people's experiences in the wider community and their experiences of health and wellbeing. According to Peace et al (2011), place and people's ability to establish an appropriate sense of place becomes significant for health and wellbeing as people grow older. This is particularly true for older people with dementia, as establishing and retaining place based activities and practices that provide meaning and structure to their daily lives is seen to be an important strategy for managing 'a process of ever changing subjectivity' (Gastaldo et al, 2004, p.160). In the context of dementia, therapeutic landscape experiences are viewed largely in relation to people's efforts to perform the *normal* and *mundane* aspects of life, suggesting the important role of anchoring therapeutic landscapes play in the daily lives of people with dementia. The therapeutic landscape concept also elicits different modes of engagement with place- social, physical and symbolic- which people with dementia employ in their everyday interactions in the wider community, thereby positioning them as individuals with agency, negotiating the social, physical and political structures within which their experiences are embedded. In adopting the therapeutic landscapes concept to frame the findings of this research this thesis highlights the need to view people with dementia as actively involved in constructing their experiences of place and also health and wellbeing as well as to further expand the concept and current understanding of therapeutic landscapes to embrace their connection to broader socio-spatial contexts of people's everyday geographies and experiences of living with dementia.

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APPENDICES

PARTICIPANT INFORMATION SHEET   (version 2, 1 Feb 2016)

Out and About: Living with memory problems in the community

My name is Rahena Mossabir and I am conducting this research as a PhD student in the Faculty of Health and Medicine at Lancaster University, Lancaster, United Kingdom. This research is jointly funded by the Economics and Social Research Council (ESRC) and Age UK Lancashire.

What is this study about?

Over 750,000 older people live with dementia in the UK and many live at home, in the community. This study aims to learn about experiences of general day to day activities of people living with memory problems in the community. It is particularly interested in exploring their experiences of engaging in the community and how that may impact on their wellbeing. If you are a person with memory problems or care for someone who has memory problems, please take a moment to read this information sheet before making up your mind about whether or not to take part in the study.

Do I have to take part?

Your participation is voluntary. If you do not wish to take part, you do not have to do anything in response to this invitation. You are being invited to take part because:

- As a person with memory problems, your experiences of living in the community will be valuable to this study. OR
- As a carer, your knowledge and ability to support the person you care for to share their experiences can make an important contribution to the study.

What will I be asked to do if I do take part?

If you decide to take part, you will need to contact Rahena by telephone or complete the Expression of Interest form and return it to her in the prepaid envelope. Once Rahena receives this, she will contact you to discuss and confirm your participation in the study. The study will be completed in 3 stages:

Stage 1: Interview on life history and experience of living with memory problems

The interview will be conducted with the person with memory problems and (if they wish) their carer. It will be audio recorded and participants will be asked to share relevant personal photographs and items if they wish.

Stage 2: Walking interview in the community and a sit-down reflective interview

The walking interview will be conducted with the person with memory problems and (if they wish) their carer. It will be audio recorded with some photographs taken en route. Researcher will visit the participant(s) again a few days later to reflect on the walk. At the end of the visit the researcher will provide participant(s) with a tailor made

Stage 3: Participant scrapbook and reflective interview

Participants with memory problems (with the support of their carer) will keep a record of their outside activities for a month with weekly telephone guidance by the researcher. At the end of the month the researcher will visit the participants to collect and discuss the information and material in the scrapbook.

Will my data be Identifiable?

The information you provide is confidential. The data collected for this study will be stored securely and only the researcher conducting this study will have access to this data:

- o Audio recordings will be deleted once the project has been examined.
- o Hard copies of questionnaires will be kept in a locked cabinet. At the end of the study, hard copies of questionnaires will be kept securely in a locked cabinet for ten years. At the end of this period, they will be destroyed.
- o The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
- o The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
- o All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

What will happen to the information obtained in the research study?

The information from the study will be used to write up a PhD thesis and academics publications as well as for presentations at conferences. The findings will also be made available to people living with dementia in appropriate formats.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher, who will try to address your concerns and if necessary give you details of appropriate support.

What are the possible benefits of taking part?

Whilst there may be no personal benefits to your participation in this study, you may find it interesting and the information you provide will be valuable to the study.

Who has reviewed the project?

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, you can contact the following individuals :

1. Rahena Mossabir (PhD student, Lancaster University)

Telephone: 01524 594959

Email:r.mossabir@lancaster.ac.uk

2. Diane Armstrong, (Dementia Support Coordinator, Age UK Lancashire)

Telephone: 01524 387843

Email:D.Armstong@ageuklancashire.org.uk

3. Professor Katherine Froggatt, (Research Supervisor, Lancaster University)

Telephone: 01524 XXXXXX

Email: k.froggatt@lancaster.ac.uk

4. Professor Christine Milligan, (Research Supervisor, Lancaster University)

Telephone: 01524 XXXXXX

Email: c.milligan@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Steve Jones (Research Director)
Faculty of Health and Medicine
Division of Health Research
Lancaster University
Lancaster
LA1 4YG
Tel: 01524 593382
Email: s.jones7@lancaster.ac.uk

If you wish to speak to someone outside of the Division of Health Research Doctorate Programme, you may also contact:

Professor Roger Pickup (Associate Dean for Research)
Faculty of Health and Medicine
Division of Biomedical and Life Sciences
Lancaster University
Lancaster
LA1 4YG
Tel: 01524 593746
Email: r.pickup@lancaster.ac.uk
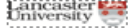
Thank you for taking the time to read this information sheet.

Appendix 2: Participant Leaflet

Who is doing the research?

This research is being undertaken by Rahena Mossabir, a PhD student at Lancaster University. She is being supervised by Professor Katherine Froggatt and Professor Christine Milligan. The PhD is jointly funded by the Economic and Social Research Council (ESRC) and Age UK Lancashire.

Contacts

For more information about the study, please contact:

Rahena Mossabir	**Dianne Armstrong**
PhD student	Dementia Support Coordinator
Faculty of Health & Medicine	Age UK Lancashire
Furness Building, Room C85	7-11 Chapel Street
Lancaster University	Lancaster
Lancaster	LA1 1NZ
LA1 4YG	
Tel: 01524 594959	Tel: 01524 387843
r.mossabir@lancaster.ac.uk	DArmstrong@ageuklancs.org.uk

Complaints

If you wish to make a complaint or raise any concerns please speak to the researcher or contact:
Steve Jones (Research director)
Division of Health Research
Lancaster University.
Tel: 01524 593382 / email: s.jones7 @lancaster.ac.uk

Out & About

Living with memory problems in the community

PARTICIPANT INFORMATION

What is this research about?

Over 750,000 older people live with dementia in the UK and many live at home, in the community. This study aims to learn about the experiences of general day to day activities of people living with memory problems in the community. It is particularly interested in exploring their experiences of engaging in the community and how that may impact on their wellbeing.

Do I have to take part?

Your participation is voluntary. You are being invited to take part, because your experiences of living in the community can make a valuable contribution to this study. If you wish, you are also able to have a family member/ carer accompany you in the research process.

What are the risks and benefits?

You may find it interesting and the information you provide will be valuable to the study. There are no risks anticipated with participating in this study, but if you do experience any distress following participation you are encouraged to inform the researcher

What do I have to do?

Once you have completed and returned your expression of interest form, the researcher will contact you to discuss you participation in the following 3 stages of the project:

Stage 1: Sit-down interview about your life and experience of living with memory problems.

Stage 2: Walking interview to a place of your choosing in the community. Followed by a reflective interview.

Stage 3: A scrapbook produced by you with the help of your family/ carer showing your activities and experiences outside of the home for a month. Followed by a reflective interview

Will my data be identifiable?

The information collected for this study will be anonymised and stored securely so only the researcher conducting this study will have access to it. All electronic information will be encrypted and stored in password protected computers. Hardcopies of information will be kept in locked cabinets.

CONSENT FORM-Person with memory problems   (version 2, 1 Feb 2016)

Out and About: Living with memory problems in the community.

You are being invited to take part in a research project aiming to explore experiences of people living with memory problems in the community.

Before you consent to participating in the study we ask that you allow the researcher to read and explain the participant information sheet to you. You or the researcher can tick each box below if you agree. If you have any questions or queries before signing the consent form please speak to the researcher.

1. I have read and/ or been verbally explained by the researcher the information sheet and I fully understand what is expected of me in the study.

2. I confirm that I have had the opportunity to consider the information, ask questions and have them answered.

3. I understand that the research will be done in 3 stages, involving sit-down and walking interviews and a scrapbook which I will produce over a month.

4. I understand that the interviews will be audio recorded and then made into anonymised written transcripts. The researcher will also collect and use photographs, written material and other items I provide during the research with my permission.

5. I understand that audio recordings will be kept until the research project has been examined.

6. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. This will not affect my medical care or legal rights.

7. I understand that any information I provide can only be taken out of the study within 2 weeks of providing it, even if I choose to withdraw from the study.

8. I understand that the information from my interview will be anonymised and discussed with the researcher supervisors. ☐

9. I consent to information and quotations from my interview being used in the researcher's PhD thesis, reports, conferences and training events. ☐

10. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐

11. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the researcher will need to share the information with her supervisors. ☐

12. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐

13. I wish for my carer/ family member to participate with me ☐

14. I agree to take part in the above study ☐

_____   _____   _____
Name of participant   Date   Signature

_____   _____   _____
Name of researcher   Date   Signature

_____   _____   _____
Name of Witness   Date   Signature

Appendix 4: Ethics Letter

Research and Enterprise
Services Division

Lancaster
University

Applicant: Rahena Mossabir
Supervisor: Prof Katherine Froggatt
Department: DHR
UREC Ref: RS2014/137

03 September 2015

Dear Rahena and Katherine,

Re: An exploration of social and spatial dynamics of engagement with space and place for people living with dementia in the community

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;

- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);

- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, Debbie Knight (01542 592605 ethics@lancaster.ac.uk) if you have any queries or require further information.

Yours sincerely,

S.C. Taylor

Sarah Taylor
Secretary, University Research Ethics Committee

Cc Fiona Aiken, University Secretary, Professor Roger Pickup (Chair, FHMREC); Prof Stephen Decent (Chair, UREC).