‘Going Out’: An Embodied and Emplaced Practice of Citizenship for People Living with Dementia

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Declaration

I declare that this thesis has been composed by myself, that this work is my own, unless otherwise stated and that this work has not been submitted for any other degree or professional qualification.

Signed: Katie Gambier-Ross

Date: 08-10-2021

Abstract

The current estimate of people living with a diagnosis of dementia in the UK is 850,000 with over two-thirds living in the community. Supporting people to age in place is vital as formal care services will struggle to meet the needs of projected increasing numbers of people with dementia. However, there is a lack of evidence regarding how people living with dementia engage in their community. While being outdoors is an important part of living well and engaging with the community, people with dementia face increased risks when ‘going out’ compared to people without dementia. One of these is the increased risk of getting lost and/or being reported missing to police. Complex cases of people with dementia reported as missing have a high mortality rate, place a high burden on police resources and can result in immense stress for the individual and their family. Research on dementia-related missing incidents has explored newspaper reports, police records or conducted proxy tests. Whilst there is research on the lived experience of missing adults, people living with dementia have been excluded from these studies. Research to date related to lived experiences of people with dementia who live at home has focused on how they feel part of a local community or neighbourhood. Therefore, this research aimed to bridge the gaps across these two areas of research by examining the everyday practice of ‘going out’ for people with dementia and their care partners who live at home. It also aimed to consider how they can be better supported to maintain the everyday practice of ‘going out’.

This constructivist inquiry employed repeat walk-alongs, interviews and group discussions with 19 people with dementia and 19 care partners across Scotland. In this thesis, I present the data under four broad themes relating to participants’ experiences of ‘going out’: making adaptive decisions to maintain independence and control; relational agency; feeling part of a place; and challenges and coping strategies. In addition, I used thick descriptions to provide in-depth accounts of the walk-alongs with seven participants, highlighting how ‘going out’ is an embodied and emplaced practice for people with dementia.

Drawing on these findings, I developed the 3 P’s *(practices, people and places)* as a heuristic tool for understanding people’s motives and strategies for ‘going out’. The 3 P’s puts the person with dementia at the heart of decision-making in the context of ‘going out’. It considers the heterogeneity of experiences of dementia and can be used to inform prevention and response strategies in dementia-related missing incidents.

Empirically, this thesis contributes novel insights to the experience of ‘going out’ for people living with dementia, understood through practices, people and places. Therefore, I suggest a shift away from the categorisation and management of missing incidents for people living with dementia. Instead, when preventing and responding to missing incidents, we need to shift the focus away from their dementia specifically and onto the broader person through the *practices, people and places* they engage with. The 3 P’s can be used for future prevention and response strategies for people with dementia who are at risk of going missing. Theoretically and methodologically, this inquiry brings a social citizenship lens to the predominantly biomedical field of dementia and missing research. It also furthers the citizenship-in-and-as-practice approach in dementia studies through the application of an embodiment and emplacement lens to the practice of ‘going out’.

Lay Summary

Dementia is a term for several diseases affecting memory, language, problem-solving and other thinking abilities, and behaviours that can impact a person's daily life. Most people with dementia live at home so it is important that they feel safe and connected to their local communities. However, people with dementia are at an increased risk of getting lost or being reported missing to police when they are outside of their homes. When this happens, it can be stressful for the person who is lost and their family. To understand this better, previous research has focused on tracking the movements of people with dementia. There has been very little research to date that asks people with dementia about their experiences of 'going out' of their homes and finding their way around. Therefore, this study aimed to ask people living with dementia and their families about their experiences of 'going out'. To achieve this aim, I did walking interviews, regular interviews and group discussions with 19 people with dementia and 19 care partners across Scotland. When I analysed these conversations, I found that people with dementia made important decisions and were able to overcome challenges when 'going out'. I also found that each participant had a different experience of 'going out' depending on the place that they lived such as a busy city or quiet town. I also found that their body was important in their experience of 'going out'. For example, a person's physical fitness or other health conditions impacted their experiences. Finally, other factors such as their gender and their life history also impacted their experiences of 'going out'. Based on these findings, I developed a visual tool to help us to better understand the experience of 'going out' for people with dementia. In this visual tool, the person with dementia is in the centre (pictured as a woman walking her dog) to show that the person with dementia should be at the heart of making decisions. I argue that to understand people's hows and whys for 'going out', we must focus on the *places* they go, the *practices* they do in and the *people* they meet. This visual tool can be used by people with dementia and their families to support discussions and decisions about 'going out' as their dementia progresses. It can also be used for future prevention

and response strategies for people with dementia who are at risk of going missing. The main aim of this visual tool is to show that ‘going out’ is a practice of everyday citizenship. This means that people with dementia have rights and responsibilities. It also means that they can make decisions about how they live their lives and that they should be supported to do so.

The 3 P’s: A heuristic tool to understand motives and strategies for 'going out' for people living with dementia

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COVID turned our world upside down and without access to my beloved Buccleuch Place office, I had to learn how to recreate that work environment from home. Thank you to Rowena Murray for your Online Writing Courses and Retreats. You have created a wonderful counter-culture to the "publish or perish" nature of academia and help people to rediscover the joy in academic writing. It was on one of the virtual courses that I met Margot Leger, my real-life pen pal. Suddenly, it has been 18 months and we still meet on Zoom every week to write together in the early hours of the morning. Thank you for always being a tiny supportive face in the corner of my screen. I'll save my pennies to visit you for an in-person co-writing session in South Africa! When I moved to Ireland in the final months before submission, I again had to relearn how to create a working environment from my new home. Thanks to Cat Aitken and the Virtual Writing Retreat space for the peer support and for teaching me how to be self-compassionate (I'm still learning).

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Last but by no means least, the men and women who took part in this study. Thank you for allowing me into your homes, everyday lives and communities, and for taking a walk with me. Not only has this study added to the world of research but also has enriched my life experience. I dedicate this thesis to you.

Preface

I could not submit this thesis without acknowledging the impact of the COVID-19 global pandemic.

Since people with dementia make up the majority of care home residents in the UK, they suffered the most devastating consequences as a result of ill-preparation; a lack of staff, testing and PPE equipment; and a general lack of government support. Lockdown measures robbed people with dementia of their agency, which is key to maintaining the ability to live well with dementia. Quarantining measures have led to social isolation and a worsening of clinical symptoms of those who are living with dementia. In a survey published by the Alzheimer's Society UK in June 2020, people with dementia reported a loss of confidence in 'going out' since lockdown measures have lifted. It is without a doubt that the impact of paused health and social care services will be long-lasting and that governments around the world need to drastically improve how they fund social care and support their citizens who are living with dementia.

Although I completed the data generation phase of this study before the COVID-19 outbreak, it unquestionably impacted the lens through which I analysed the data. The quarantining measures suddenly placed a higher societal value on being outdoors. There was a time in 2020 in the UK when 'going out' for a daily walk within the confines of one's local authority was a collective daily highlight. Philosophers such as Thoreau, Nietzsche and Kant describe walking as an opportunity to escape and to think. To be robbed of this provided just a small insight into the daily injustices that people with dementia have faced for decades as their right to be outdoors and engage with a community is repeatedly denied. Hopefully this thesis, alongside learnings from the COVID-19 pandemic, contributes towards changing that.

"All truly great thoughts are conceived while walking."

— Friedrich Nietzsche, Twilight of the Idols

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Introduction

This introductory chapter sets the scene for the thesis beginning with a brief summary of how this thesis contributes to knowledge. Following this, I position myself in the inquiry, telling the story of how I arrived at this research and justifying my reflexive approach to this thesis. I then set the social and political context for this inquiry, providing a brief overview of the prevalence of dementia and missing persons and justifying the terminology used throughout this inquiry. I conclude this introductory chapter with an overview of the thesis.

Thesis summary

This thesis explores how people living with dementia experience ‘going out’, highlighting that they are not one homogenous group. This inquiry brings a broader sociocultural understanding of dementia to the predominantly biomedical field of literature that relates to dementia and missing, by applying a critical citizenship-in-and-as-practice lens to the everyday action of ‘going out’ for people with dementia who live at home.

Although the initial interest in this field was specifically in experiences of going missing, this soon broadened to experiences of ‘going out’. It became apparent that to understand why a person might become lost or missing, it is important to understand their motivations for leaving their home in the first place and the strategies they use to maintain an ability to get out and about. This inquiry used a constructivist methodology therefore, my voice is present in the thesis through frequent reflections on my role in the generation of knowledge. It also takes a critical stance by situating the findings of this inquiry within a wider socio-cultural context, critiquing how we view people living with dementia in current Western society.

Empirically, this thesis contributes novel insights to the experience of ‘going out’ for people living with dementia. Therefore, I suggest a shift away from the categorisation and management of missing incidents for people living with dementia. Instead, when preventing and responding to missing incidents, we need to shift the focus away from their dementia specifically and onto the individual person. I propose the 3 P's as a heuristic tool; to understand the motives and strategies for 'going out' through the lens of *practices, people and places* that people with dementia engage with. The 3 P's facilitates an understanding of people with dementia at the heart of decision-making practices in the context of 'going out'. Theoretically, this inquiry brings a social citizenship lens to the predominantly biomedical field of dementia and missing research. It also furthers the citizenship-in-and-as-practice approach in dementia studies through the application of a lens of embodiment and emplacement. Methodologically, this inquiry presents a novel embodied and emplaced analysis of walk-alongs with people living with dementia in Scotland.

Positionality statement - My background, social identity and reflexive approach

My motivation for undertaking this study comes from several influences. My primary influence was my mother, a gerontology nurse. As she focused from a general gerontology nurse to a dementia specialist, she undertook training in "Sonas" a sensory, therapeutic activity that engaged with people living with advanced dementia and completed an MSc in Dementia Studies at Trinity College Dublin. As a child, I frequently assisted her in activities that she had planned for residents at her work, witnessing how much joy and fulfilment that her work brought her. Interacting with people living with dementia has never been a challenge for me. It was always fun. Outside of my mother's work, I noticed that conversations regarding dementia were mostly negative. People called it a terrible disease, a curse, a burden and although I did not want to diminish the suffering of others, I simply did not see it that way. Later, I volunteered with my local primary care team on a pilot project that supported people living with dementia to live in the community using a range of resources including assistive technologies including GPS (Global Positioning System) tracking devices for those who left their homes alone and were at risk of getting lost. Therefore, I approach this inquiry with personal experience of interacting with people with dementia.

My second influence was my love of the outdoors. I was a competitive sailor for most of my childhood and was lucky enough to travel to various national and international competitions. So, in my late teens, I wanted to give back to the sport that had given me so much. I trained as a sailing instructor and started working at a local “Sail-ability” programme that aimed to make sailing accessible for people with disabilities. I taught children and adults living with physical and learning disabilities in specialised, accessible boats. I witnessed the joy that being out on the water brought to people. I got to share with students the incomparable feeling of wind on one’s face, sea air in one’s lungs and the sound of water sloshing against the boat. I saw first-hand, not just the therapeutic benefit that being outdoors brought to the students, but also the feeling of accomplishment, learning a new skill, pushing oneself to the limit and developing resilience (sitting on a small boat, in the pouring rain, in the middle of winter, when there is no wind to get you moving is a resilience-building exercise if ever I’ve heard one). From a young age, I valued the sense of freedom and connection to the outdoors that sailing afforded me. Therefore, I approach this inquiry valuing the importance of feeling connected to the outdoors.

My third influence was my undergraduate experience, undertaking a BSc Neuroscience with Psychology degree at the University of Aberdeen. My previous experiences volunteering with people living with dementia and working alongside people living with disabilities sparked an interest in learning more about the development and treatment of neurological diseases. However, as I sat in lecture theatres about the pathology of various neurological disorders, I soon felt disconnected from the people that I used to work with. I was frustrated by how far we seemed from any cure and how rarely we address the impact of living with these neurological conditions. I knew from my personal experience that people living with dementia and other disabilities could still lead rich and fulfilling lives; I had seen it first-hand. But that did not fit the narrative being taught in my undergraduate classroom which was one of loss and deterioration. I became more hopeful after completing an internship during the penultimate summer holiday of my degree. Working at the Health Service Research Unit at the University of Aberdeen opened my eyes to the vast field of health research that did not require me to be a clinician, or a lab scientist and the increasing value placed on researching people's lived experiences. Luckily, for our final year project, we were given the freedom to explore a wide range of topics. I knew I wanted to undertake qualitative research on lived experiences and particularly on tools used to self-manage health conditions. Far from exploring the experiences of a neurological disorder, and under the guidance of a multidisciplinary social scientist, I researched women's experiences using mobile fertility tracking applications. I enjoyed the research thoroughly and published my findings[1]. This confirmed to me that, although I had great respect for the researchers who spend their days at the bench studying neuropathology that was not where my passion lay. I wanted to take this knowledge that I had gained about researching lived experience and apply it to experiences of neurological impairment.

At that time, I saw an Alzheimer's Society PhD studentship advertised 'Staying Safe Going Out'. I had not considered undertaking a PhD before, but my previous research experience whetted my appetite and this project seemed serendipitous in how it brought together my personal and professional interests: researching the lived experiences of people living with neurological impairment and being outdoors. Thus, I began this PhD journey. It has been a steep learning curve as I transitioned from a predominantly biomedical academic background and immersed myself in social science literature. Although this proved challenging at times, it also allowed me to begin as a blank slate. This thesis is a reflection of how I went from that beginning to an original contribution to knowledge. With a background in

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[1] Gambier-Ross, K., McLernon, D. J. and Morgan, H. M. (2018) 'A mixed methods exploratory study of women's relationships with and uses of fertility tracking apps', *DIGITAL HEALTH*. doi: 10.1177/2055207618785077.

psychology, neuroscience, and health service research, my lack of disciplinary affiliation puts me in a unique generalist position and allows this thesis to be truly interdisciplinary, drawing on theories and methods across a range of social science disciplines.

On this PhD journey, I situate myself as a critical qualitative health researcher, interested in using innovative and creative methods to further our understanding of experiences of health, wellbeing, marginalisation and inequality and how these concepts intersect. Positionality is dynamic. Therefore, as my ontology and epistemology evolve and are shaped by my social and personal circumstances, the positionality that I have developed throughout this inquiry will continue to change throughout my research career. My life experiences prior to this PhD study have strongly informed my positionality. Positionality encompasses both the researcher’s worldview and the lens through which they undertake specific research (Darwin Holmes, 2020). It is informed by our social position in the world. One tool of a critical qualitative health researcher is to engage in a practice of self-critique and reflection on how we arrive at our researcher questions and how we influence the research process (Jacobson and Mustafa, 2019).

I do not use reflexivity to ‘bracket’ my experiences as is common in some phenomenological approaches (Crotty, 1996). Nor do I use it as a simple record of my own methodological and epistemological decisions. Instead, reflexivity is an integral part of my research process that allows me to embrace the broader social, political, and economic issues that may influence this study (Whitaker and Atkinson, 2019). Although I hope that this study provides a platform for the voices of people living with dementia, it must be noted that this is *my* interpretation of these voices and experiences. Therefore, I do not try to hide my voice and I share my thoughts, emotions and experiences throughout this thesis. Not only does my positionality influence the research process from fieldwork to analysis, but it also influences how the research is presented in this thesis and other published works that may arise out of this inquiry. For example, I have made decisions regarding whose stories and experiences to draw on when evidencing my analytical arguments.

In some fields, the concept of positionality is discussed in terms of insider or outsider status. According to Herr and Anderson's (2005) proposed continuum of insider and outsider relationships, I am an outsider working in collaboration with insiders (people with dementia) in non-equivalent relationships. Thus, this inquiry aligns with the participatory and reflexive nature of action research. I am not living with dementia therefore, I am an outsider, and my research approach does not allow participants and researchers to be co-inquirers with equal power. However, I have made methodological decisions that attempt to break down the power imbalance between researcher and participant and that foster a more collaborative approach to this inquiry.

Since criticality and reflexivity were important to me from the outset of this inquiry, I used a Social Identity Map (Jacobson and Mustafa, 2019). This is a reflexive tool developed to help novice, critical qualitative researchers, to practice positionality by mapping their social identities such as gender, citizenship status, age, sexual orientation, class and race. This tool highlights my privilege as a white, third-level educated, middle-class, able-bodied, heterosexual, young woman and how these experiences shape the lens through which I conduct this inquiry.

This thesis is a written representation of the journey that I have been on, starting as the daughter of a dementia specialist nurse assisting at my mother’s work, to an undergraduate neuroscience student with an interest in the ageing brain to finding my ‘home’ as a qualitative health researcher, interested in lived experience. Now that I have explained how I came to do this research and how I have evolved as a researcher throughout the process, I will provide background information on dementia and missing persons to provide context for the rest of the thesis.

Words matter

Before exploring the literature that frames this inquiry, it is worth noting that, in a world of seemingly increasing political polarisation, this attitude is also evident in the field of dementia research and advocacy. Although the dominant narrative is still one of disease and degeneration, which is not representative of all experiences, some scholars and advocates reject that stance so vehemently that the discussion becomes moralised. For some, the disease model of dementia is “bad”, and the personhood model is “good” or vice versa. This stance leaves little room for nuance. Similarly, using words such as “suffering” to describe people’s experiences is “bad” and “living well” is “good”. Although I acknowledge that everyone (especially researchers and people working with those who are living with dementia) should avoid stigmatising language, it is up to the person with the lived experiences as to how they wish to explain their experiences. Thus, although I do engage in an academic critique of the literature, I do not consider there to be a right or wrong way to view a person living with dementia. However, it is vital that the voices of those who are living with dementia are central to these discussions and that these discussions contribute to an overall improvement of quality of life and a supportive environment for people to age “authentically” and “resiliently” rather than “successfully” or “actively” (polarising terms that again, leave little room for nuance) (Harris, 2008).

In 2018, I attended two conferences that highlighted to me the importance of context as well as the use of language. At the first conference, one of the speakers was a man who cared for his mother-in-law who had advanced dementia. He referred to her experience as “suffering”. While it was incredibly brave of him to share his family’s most vulnerable moments, some people at my table winced upon hearing the word “suffering”. The person seated next to me whispered *‘oof…poor word choice’*. However, on reflection, the speaker did not refer to his mother as a dementia sufferer, he referred to moments where she, and the entire family, suffered as a result of her dementia. That was their experience and who are we to police that experience by telling him that he cannot use the word suffering? Several months later I attended the National Alzheimer's Society conference. Matt Hancock, the Secretary of State for Health and Social Care in the UK spoke to the attendees. In his speech, he referred to people living with dementia generally as "dementia sufferers". Eventually, one brave woman in the crowd stood up and interrupt his speech claiming that she was living with dementia, and she was not a "sufferer". In that context, that government official did not have the right to put the status of "suffering" on all people living with dementia.

"Wandering" is another divisive term that is more directly related to this thesis. In the summer of 2020, I hosted a webinar series for researchers, practitioners and people with lived experiences to discuss wayfinding and dementia. One presenter used the word "wandering" when sharing her research on the movements of people living with dementia who get lost. After the event, several attendees emailed the organising committee expressing their disappointment with the use of this term. We discussed this with the presenter, and she was unaware that the term could be perceived as pejorative. She viewed it as a medical label for a phenomenon. Although I understand that it is inappropriate to use the word as it assumes that people living with dementia have no understanding of where they are going and no intention behind their movement, this medicalisation and subsequent rejection of the word means that people who have dementia can no longer use the word "wander" in the same way that people without dementia use it. Personally, wandering conjures up warm memories for me, of being on holiday, exploring a new area at a slow and aimless pace. Do people with dementia not get to experience this joy of wandering? Perhaps. Several people living with dementia (including some who participated in this study) have reclaimed the word "wandering" and use it interchangeably with the word "exploring".

"Missing" is also a complex term that is hard to define because often the "missing" individual may or may not feel like they are lost. Despite it being a key issue of public concern, definitions of the term "missing" vary and lack clarity (Biehal, Mitchell and Wade, 2003). People who go missing intentionally often do not identify with the term because, although they may be absent from their daily life, they are present in time and space and thus, not “missing” in their own mind at all (Stevenson *et al.*, 2013). In this thesis, I use the term ‘going out’ when discussing people’s movements outside of their homes. Although it is a vague term, it encompasses a broad range of experiences. I do not focus on ‘going outdoors’ because leaving the home is not all about being outdoors. ‘Going out’ does not hold connotations and presumptions like words such as wandering and missing.

So as much as words matter, context also matters. Language is nuanced and it is often a grey area. However, we need to take time to understand and adapt it to ensure we are appropriately addressing people’s experiences. Perhaps in the future, people will look at this thesis and wince at my use of the word “dementia”. With the Latin roots of the word meaning ‘to lose one’s mind,’ there is a growing movement to reject the term (Trachtenberg and Trojanowski, 2008; Jellinger, 2010). In fact, in 2013, the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) was released replacing the word dementia with “major neurocognitive disorder” defined as ‘a decline in mental ability severe enough to interfere with independence and daily life’ (American Psychiatric Association, 2013). Although it is convenient for brevity, I try to avoid the acronym “PLWD” (people living with dementia) as it can be interpreted as dehumanising and degendering (Sandberg, 2018). All participants in this study were either men or women who had a diagnosis of dementia themselves or were family of those with a diagnosis. Therefore, I use pseudonyms to refer to individual participants. Where necessary, I distinguish between the care partner and the man or woman living with dementia. When pseudonyms are not appropriate, for example, when referring to groups of participants as a collective, I use the word “participants”.

Dementia context and policy

Dementia is an umbrella term for numerous diseases that affect the brain. Different diseases carry different symptoms, with Alzheimer's disease making up approximately 60%-70% of diagnoses globally (Alzheimer's Disease International, 2021; World Health Organization, 2021b). The World Health Organization (WHO) defines dementia as:

> *'a syndrome, usually of a chronic or progressive nature, caused by a variety of brain illnesses that affect memory, thinking, behaviour and the ability to perform everyday activities' (World Health Organization, 2021, para. 1).*

Dementia is understood differently depending on the historical and cultural context. For example, it can be explained as a consequence of normal ageing, as a spiritual experience, as a neuropsychiatric condition and as a dialectical process (Downs, Clare and Mackenzie, 2006). Although there has been a shift in recent years toward a person-centred understanding of dementia, in Western societies, dementia is primarily understood through a biomedical lens; a neurodegenerative disease with physical symptoms that can be targeted with medication. Thus, research on treatment, cure and prevention of dementia is of national and global priority (Department of Health, 2015; World Health Organization, 2017). Despite this, there is currently no known cure for dementia. With this emphasis on treatment and cure, research that explores experiences of dementia is often deprioritised.

Over 50 million people are currently living with dementia globally, and this figure is expected to rise to 152 million by 2050 (Alzheimer's Disease International, 2021). A recent Alzheimer's Society report found that approximately 850,000 people were living with dementia in the UK in 2015 and this is expected to increase to over two million by 2050 (Alzheimer's Society, 2014). Alzheimer's Disease International reports that the current global cost of dementia is US$ 818 billion, comparing it to the 18th largest economy in the world if it were a country (Alzheimer's Disease International, 2021). In the UK, the total estimated cost of dementia is £26.3 billion (Lewis *et al.*, 2014), with higher health and social care costs than cancer and chronic heart disease combined (Luengo-Fernandez, Leal and Gray, 2015) and an expected increase in cost to £55 billion by 2040 (Prince *et al.*, 2014). This increasing prevalence along with a lack of cure has resulted in dementia being recently identified as a global health priority by the WHO. As the global population ages and in response to this increasing prevalence, the WHO (2017) has published a Global Action Plan on the public health response to dementia 2017-2025 which provides a set of actions for countries to prevent dementia and support those who are living with dementia to lead meaningful lives. The global action plan recommends that each member state has a national dementia strategy.

Dementia was first identified as a priority by the Scottish Government in 2007 and Scotland's fourth National Dementia Strategy is currently under development and due to be launched in late 2021. Scotland's strategies take a rights-based approach to supporting people living with dementia. Scotland's third National Dementia Strategy 2017-2021, comprised 21 commitments that were developed in collaboration with people living with dementia, care partners and other stakeholders across Scotland. Of particular interest to this thesis is commitment 16: '*To consider the upcoming recommendations of Police Scotland Missing Persons report for the dementia client group'* (Scottish Government, 2017, pg. 23). In response to the crisis that the increasing prevalence of dementia poses, the UK Prime Minister set a challenge to improve dementia care and research (Department of Health, 2016). This challenge identified dementia-friendly communities as one of three priority areas. Central to this call for dementia-friendly communities is a need to advance our understanding of how people living with dementia experience being a part of these communities. More recently, the Annual World Alzheimer's Report published in 2020 addressed dementia-related design as a priority area (Zeisel, Bennett and Fleming, 2020). This report claimed that the built environment design for dementia is 30 years behind the physical disabilities movement and that having appropriate dementia design enables people with dementia to live in their homes and local communities for as long as possible. The 2020 report called for dementia to be recognised as a disability and for recognition of the environment's influence in contribution to that disability. Scotland is considered a global leader in dementia-related design with commitments in the 2017-2020 National Strategy to improve transport, dementia-friendly communities and supporting people to live safely and independently at home for as long as possible.

Although there has been a welcome push to support people living with dementia to live in communities, there is a lack of evidence regarding the impact of this and how best to support this. Though being outdoors is recognised as beneficial for people with dementia (Gibson *et al.*, 2007; Gilliard and Marshal, 2012; Bantry White and Montgomery, 2015; Mmako, Courtney-Pratt and Marsh, 2020), there is also a lack of research on how people with dementia interact with their environment as the focus of most research on the experience of dementia is on how they interact with formal care settings and institutions. When there is an emphasis on how people with dementia engage with public spaces, the focus is on design and accessibility rather than on how people with dementia move within and connect to their local areas or the impact of being at risk of being missing has on people's experience. A common symptom of dementia is confusion and becoming lost, even in familiar environments (World Health Organization, 2021b) and with two-thirds of people with dementia living in the community (Alzheimer's Society, 2013), the issue of being able to maintain a practice of 'going out' safely has enormous implications for the everyday lives of millions with dementia.

The intersection of dementia and missing

In the initial months of this inquiry, one of my supervisors introduced me to the Scottish Institute for Policing Research (SIPR). Through engagement with this network and several police forces across Scotland, it became apparent to me that police needed more research evidence in this field to assist them in search and rescue efforts in dementia-related missing incidents. In the UK, over 300,000 missing person incidents are reported annually to the police

(National Crime Agency, 2020), at an estimated cost of £750 million (Shalev Greene and Pakes, 2014). People with dementia make up approximately 4% of the missing person population (National Crime Agency, 2020). Police costs of missing person enquiries attributable to dementia range between 22.1 and 40.3 million pounds per year (Alzheimer's Society, 2014). In Scotland, over 40,000 people are reported missing each year with dementia-related incidents making up 2-3% of the reported missing population (Police Scotland, 2018). Although the majority of people living with dementia are found safe and well (Bantry White and Montgomery, 2015), figures from civilian specialist search teams (~15% of all police recorded missing person cases involve civilian search teams) indicate that there is an 18% mortality rate, 3% are not located at all and 16% are found with an injury (Perkins, Roberts and Feeney, 2011). Because of their high-risk status, these searches are given a high priority as it is imperative that people living with dementia are found as soon as possible. Searches for high-risk groups (which people living with dementia fall under) use considerable police and emergency services resources (Shalev Greene and Pakes, 2012). However, it is likely that reported missing figures do not represent the true prevalence of people with dementia who become lost. This is because it does not account for the number of people with dementia who get lost or become "missing" to their families and care partners but are not reported to the police. Therefore, the number of families who experience a missing event is assumed to be much higher. It is estimated that police are only aware of approximately 30% of missing cases (McShane *et al.*, 1998; Shalev Greene *et al.*, 2019).

The body of literature on missing adults remains underdeveloped (Stevenson *et al.*, 2013) and one of the biggest challenges in the field is identifying a common understanding of the terminology. For example, from a technical perspective, The College of Policing, a professional body for policing in England and Wales, define missing as '*anyone whose whereabouts cannot be established will be considered as missing until located, and their well-being or otherwise confirmed'* (College of Policing, 2016). Although similar, the Association of Chief Police Officers (now known as the National Police Chiefs Council) define a missing person as '*anyone whose whereabouts is unknown whatever the circumstances of disappearance. They will be considered missing until located and their well-being or otherwise established'* (Association of Chief Police Officers, 2010). Alternatively, Parr and Fyfe (2013) argue for a critical-social geography of missing people. They suggest that missing-ness is defined by the perspective of the person who is doing the reporting and that the absent individuals do not necessarily relate to the term "missing". They argue for *'a taking seriously of missing experience, missing voices, missing mobilities, absence-making and ambiguous loss*' (Parr and Fyfe, 2013, pg. 634). They also argue for the incorporation of the "unmissed missing", which they define as those who are noticed absent but who remain unreported. We could take this to mean people with dementia who get lost but are not reported missing, as previously mentioned. A clear definition is required to allow a shared understanding for future discussion and research. In a recent conceptual analysis of the use of the term "adult missing person" in professional and academic settings, Taylor, Woolnough and Dickens (2019) proposed the following definition:

> *'An individual, 18 years of age or older, whose whereabouts are unknown to members of their familial, social or professional networks and where there is concern for either their own safety and wellbeing or that of others. This may result in the initiation of a formal or informal search' (pg. 410).*

Missingness has also been conceptualised on a continuum from intentional to unintentional missing, with people with dementia fitting in the category of "unintentional missing" (Biehal, Mitchell and Wade, 2003) but this categorisation assumes that people living with dementia are only reported missing because they "wander" and get lost. This understanding is problematic as it does not allow for the potential that people with dementia can have other health conditions or life circumstances that mean they may go missing intentionally. People with dementia may also become missing due to wayfinding errors, forgetting where they were going, deciding to go somewhere else and not notifying their loved ones, feeling agitated and leaving a frustrating situation, or searching for places and people from the past. Empirical research that attempts to understand the behaviours and movements of people with dementia will be explored later in this thesis.

There have been several attempts on a national and international level to address dementia-related missing incidents. For example, in Scotland, the Purple Alert mobile application was launched by Alzheimer Scotland as a freely available smartphone application that alerts users if there is a missing person with dementia in their area (Alzheimer Scotland, 2017). This alert is initiated by the care partner and is intended as a community-based tool to accompany a missing persons report to the police. Purple Alert was designed in collaboration with Police Scotland, people living with dementia and their carers, Social Work, Dementia Friends Scotland, health and social care partnerships and telecare services. In this collaborative development process, staying safe and maintaining independence were identified as priorities for people with dementia and their carers. An additional tool promoted by police forces across the UK is the Herbert Protocol (Police Scotland, 2021). Originally developed by Norfolk Constabulary in collaboration with local health and social care agencies, the Herbert Protocol is a comprehensive form for people with dementia and their care partners to keep on record in advance of a missing episode. It records details such as places of importance, medications required and information on previous missing episodes. In the event of a missing report, the police can access this to inform rapid search strategies.

At a policy level, Scotland’s National Dementia Strategy 2017-2020 committed to considering the recommendation of a Police Scotland Missing Persons Report regarding people with dementia (Scottish Government, 2017b). This is the first national dementia framework to my knowledge that acknowledged missing as a priority. In addition, the Scottish Government also have a National Missing Persons Framework (2017a) which was developed under a multiagency consultation process and aims to prevent people from going missing and to limit harm to those who do go missing. This framework addressed people living with dementia specifically and acknowledged the importance of understanding why a person goes missing in preventing reoccurrence. Although this framework is welcome, it places people with dementia in the category of “unintentionally” missing, which risks not capturing the full experience of dementia and missing.

The risk of missing is given little consideration at an international dementia policy level. However, although the WHO Global Action Plan on Dementia 2017- 2025 does not address issues of wandering, going missing or becoming lost specifically, it proposed that all member states:

> *‘Support changing all aspects of the social and built environments, including the provision of amenities, goods and services, in order to make them more inclusive and age- and dementia friendly, promoting respect and acceptance in a manner that meets the needs of people with dementia and their carers and enables participation, safety and inclusion’* (World Health Organization, 2017, pg. 15).

Alzheimer’s Disease International reports that to date, 37 countries have developed National or Regional Dementia Strategies (Alzheimer’s Disease International, 2021). In an exploratory search of the current European National Strategies (Alzheimer Europe, 2021), I identified that only the Scotland and Flanders (a region in Belgium) National Dementia Strategies mention “going missing” as a specific area of concern and address collaboration with relevant police and social care services to address this. Although the risk of missing could be classified as a priority under the aforementioned statement from the World Health Organization, it could be argued that its absence from the narrative at an international level is reflected in an absence at national levels and thus, forcing community and grassroots initiatives to develop local solutions to the problem of dementia-related missing incidents. So, while progress has been made in supporting people living with dementia to live independently in the community and therefore, in preventing missing episodes, there is still a need to better understand the lived experiences of people who are living with dementia in the community.

Developing the research aims and questions

This introductory chapter provided an overview of this inquiry and background to my previous experiences that led me to this study. It set out the need for this research by reflecting on the socio-political context of dementia in Scotland, adding context to the overall aim of this inquiry. Based on my personal experiences and the social and political context set out in this introductory chapter, the broad aim of this inquiry is to explore how people living with dementia who live at home, interact with, connect to, and find their way around the world outside their homes with a specific interest in how people experience being lost or at risk of missing. To further develop specific research questions under this aim, identify gaps in the research and situate this research amongst existing theoretical perspectives, I embarked upon a thorough review of the theoretical and empirical literature, which is detailed in the following chapter.

The aims of this inquiry were three-fold:

1. To examine the everyday activity of ‘going out’ for people with dementia and their care partners who live at home.
2. To better understand experiences of navigation (including prevention or relocating when getting lost) and being at risk of missing whilst ‘going out’ for people with dementia.
3. To consider how people with dementia can be supported to maintain the everyday activity of ‘going out’.

Therefore, the following research questions were developed to guide this inquiry:

1. How is the experience of ‘going out’ for people with dementia and their care partners?

    a) How do people navigate when ‘going out’?
    b) How is the experience of being lost and or/ reported missing?
    c) How do people interact with the physical and social environment when ‘going out’?

2. How does ‘going out’ impact people with dementia’s sense of independence, agency and control over their lives?
3. How can we support people with dementia to maintain the everyday activity of ‘going out’?

The remainder of this thesis will detail how this inquiry achieved its aims and answered these research questions through a qualitative exploration of lived experiences of ‘going out’ for people with dementia and their care partners.

Overview of thesis structure

Chapter One, *Unfolding the Map*, sets the scene for this thesis. I begin by explaining how I arrived at this research topic and state my commitment to a reflexive approach. In reflecting on my positionality, I attempt to make my influence on the generation of data transparent. Next, this chapter discusses the importance of language and defines the key terms used in this thesis. Finally, I describe the social context and policy interests of dementia and missing persons in Scotland, highlighting how these intersect on both a national and international level and presenting the scope of the current problem in a global context with a specific focus on Scotland.

Chapter Two, *Signposting the Research* Landscape, continues to set the scene by exploring the research context for this inquiry. This chapter is split into two parts. Part A explores developments in the dementia studies literature from models of dementia to the citizenship lens which encompasses everyday experiences, critical approaches and person-place relations, therefore, justifying the examination of the everyday practice of ‘going out’ for people with dementia in this inquiry. In Part B, I review the cross-disciplinary literature relevant to dementia and wayfinding; wandering; getting lost; and missing incidents. By identifying the lack of integration in the dementia literature on person-place relations and navigation, getting lost and missing, the chapter provides justification for this inquiry to act as a bridge between these two fields of literature through the examination of the practice of ‘going out’ for people with dementia.

In Chapter Three, *Planning the Route*, I frame this study as an interpretive critical inquiry. I lay out how my epistemology, theoretical perspective, methodology and methods shape the research process for this inquiry. This chapter documents how the approach adopted in this inquiry facilitates the participation of people living with dementia and the recruitment procedures, data generation and data analysis methods adopted. Thirty-eight people living with dementia and care partners were recruited from across Scotland. Data were generated through several methods including repeated walk-along interviews with people living with dementia, traditional one-to-one interviews, dyadic interviews, group discussions and field notes. Data were interpreted using both reflexive thematic analysis and thick descriptions. In this chapter, I also discuss the importance of reflexivity, introduced in Chapter One, and make transparent how I adopted this approach throughout the study to ensure rigour and quality.

Chapter Four, *The Practice of ‘Going Out’*, presents the initial themes generated from this inquiry. Firstly, it highlights how decision-making in relation to ‘going out’ was a dynamic process that participants are capable of actively engaging with, providing examples and quotes from participants’ experiences. Secondly, it demonstrates how ‘going out’ was a relational practice for participants, describing how they reframed their perceived vulnerabilities as strengths and how they developed strategies in collaboration with their care partners and the wider community to maintain independence and control through a practice of ‘going out.’

Chapter Five, *'Going Out' in Place*, describes the themes generated in this inquiry that relate to place. Firstly, this chapter describes participants' experiences of feeling connected to their local community and how 'going out' is a practice to maintain their sense of belonging, purpose and routine. Secondly, this chapter presents the navigational challenges that participants faced when 'going out' and the strategies they developed to overcome these challenges.

Chapter Six, '*Going Out' as an Embodied and Emplaced Practice*, is the final findings chapter of this thesis. It deployed reflexive thick descriptions to present narrative snapshots from the walk-alongs conducted with seven participants living with dementia. These provide an in-depth supplementation to the themes highlighted in Chapters Four and Five. In doing this, participants are shown as whole people, not just data sources to support themes in my analysis. The seven narratives highlight how 'going out' is an embodied and emplaced practice for the participants. They also highlight underpinning themes of vulnerability, agency, belonging, connection, risk, decision-making and control.

Chapter Seven, *Where Do We Go from Here?*, brings this thesis to a close. In this chapter, I unveil the 3 Ps (practices, people and places) that I have developed as a heuristic tool to understand people's motives and strategies for 'going out'. The 3 P's frames the person with dementia at the heart of decision-making in the context of 'going out'. Importantly, it also considers the heterogeneity of experiences of dementia and can be used to inform prevention and response strategies for dementia-related missing incidents, contributing to the overall aim of this inquiry to support people with dementia to live at home in safe and supportive environments. After introducing the 3 P's, I discuss the novel contribution of bringing the lived experience of people with dementia into the evidence base in missing persons research. Next, I argue that 'going out' is an embodied and emplaced practice of everyday citizenship for people with dementia and thus, it is a practice that must be supported. I reflect on the methodological approach taken in this inquiry and the dissemination efforts I have made during this doctoral journey. Finally, I conclude this thesis by addressing the study limitations, making suggestions for future research and a closing reflection

Chapter Two – *Signposting the Research Landscape* – Literature Review

Introduction

The first chapter of this thesis set the social and political context for this inquiry. This chapter continues to set the scene by exploring the research context. This chapter is split into two parts. Part A explores developments in the dementia studies literature from models of dementia to the citizenship lens which encompasses everyday experiences, critical approaches and person-place relations. In doing so, I justify the examination of the everyday practice of 'going out' for people with dementia in this inquiry. In Part B, I review the cross-disciplinary literature relevant to dementia and wayfinding; wandering; getting lost; and missing incidents. In doing so, I justify the need for the inclusion of subjective experiences of people with dementia in the literature. As a whole, this chapter draws together several bodies of literature to identify a gap in the evidence base and to inform the development of the research questions that this thesis seeks to address.

Context of the literature review

This review takes a narrative and reflexive approach, offering the reader insight into how the literature shaped my decision-making for this inquiry. I began this doctoral journal by reading key authors in the dementia studies field (Kitwood, 1997a; Sabat, 2001; Hughes, Louw and Sabat, 2006; Bartlett and O'Connor, 2010; Hughes, 2011). Then, I set out to better understand the research landscape related to dementia and wayfinding; wandering; getting lost; and being missing. I conducted a primary exploratory search of the literature in late 2017. Sources were identified through electronic databases including CINAHL, Medline, PsychINFO, EMBASE, CINAHL, ASSIA, Web of Science and the online search engines PubMed, DiscoverEd and Google Scholar. While there was no date restriction applied when searching the literature, only sources written in English were included. Search terms used were dement(ia) OR Alzheimer('s), missing, 'going out', 'going missing', 'elop(-ement, -ing)', 'missing person(s)', 'missing people' wayfind(-ing), navigat(-ion), lost, wander(-ing), identity, control, purpose, experience(-s), subjective, perspective(-s), family, carer and caregiver. These terms were used in various combinations and additional sources were identified through reference lists of retrieved articles. Additionally, grey literature such as PhD theses, government reports, conference outputs, police outputs and key organisation's websites also informed the literature review. Since then, I have kept up to date with current literature through subscriptions to various journals, attending conferences, discussions with academic colleagues, Google Scholar alerts and Mendeley recommended papers and have updated this literature review accordingly.

As I immersed myself in the literature, I gained an understanding of the complexity in differentiating between navigation, wayfinding, wandering, getting lost, being missing, 'going out' etc. I identified the small and emerging body of literature on dementia and place that began to bridge the gap between examining the lived experiences of dementia and the practical relevance to dementia-related missing persons incidents. However, I identified a need to reinforce this bridge. Therefore, I broadened my inquiry from examining experiences of 'being missing' to examining 'going out' as a practice to encompass the contributions across disciplines. Rather than an exhaustive review of the various disciplinary perspectives, I highlight key contributions that provide the context and rationale for this inquiry. Although the interest of this study is in the experiences of people with dementia who live at home, some research conducted in residential care settings that had relevance to this study is included in this literature review.

Part A: Conceptualising dementia and examining emplaced and everyday practices

Dementia studies is both a multi- and interdisciplinary[2] field therefore, Part A of the literature review engages with theoretical and empirical contributions

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[2] Dementia studies consists of people from different disciplines working together, each drawing on their disciplinary knowledge (multidisciplinary) and it involves integrating knowledge and methods from different disciplines, using a synthesis of approaches (interdisciplinary).

across various disciplines in the field. This section summarises and critiques existing models of dementia, critical approaches in dementia studies and literature on dementia and place. In doing so, I situate this inquiry within the ‘fourth moment’ of dementia studies (Bartlett and O’Connor, 2010) and justify the examination of everyday lives of people with dementia and more specifically, the everyday practice of ‘going out’ that involves interaction with place.

Understanding dementia models

Since dementia has been studied from a range of different disciplinary approaches, several ‘models’ exist to explain the disease. These models can be considered heuristic tools that frame past, present and potential future theoretical understandings of dementia. Current societal perceptions of dementia are important to explore as these shape the experiences of those who are living with the disease. In exploring these models, I establish the historical context for examining lived experiences of ‘going out’ in this inquiry. Appropriate and inclusive understandings of dementia are necessary to better support people with dementia to remain a part of society and lead fulfilling lives. The purpose of this section is to present and critique the dominant models of dementia in Western society. For clarity, I present these models as separate constructs, however, I invite the reader to imagine them as overlapping and interrelated constructs that have differing relevance across periods of time, cultures, and contexts. Since dementia studies is such a multi- and inter-disciplinary field, several models are necessary, and we draw on all of them to form our understanding of dementia depending on the context (Hughes, Louw and Sabat, 2006).

The disease model

This section describes the disease model of dementia. This model has also been described as the biomedical, medical and neuropsychiatric model but for this thesis, I use the word “disease”. Like Hughes (2011), I use this language intentionally. Since the development of more social understandings of dementia, the disease model can be referred to pejoratively as “problematic” and “old-fashioned” by supporters of alternative models (Kitwood, 1997a). Simply put, the disease model considers dementia to be a result of abnormal biological processes and the degeneration of the brain. By framing dementia as a disease, it prioritises clinical research, symptom management and ultimately, the discovery of a cure. The disease model quickly replaced the “dementia as normal ageing” understanding in the 1970s and 1980s and is still the dominant model of dementia in Western culture. The disease model has been beneficial in developing our understandings of the neural mechanisms of dementia. It has improved diagnosis and medical interventions that can lead to increased post-diagnostic support services and therefore, improved quality of life for the people affected by dementia (Hughes, Louw and Sabat, 2006; Bartlett and O’Connor, 2010). This model has also developed our understanding of the different subtypes of dementia which has led to targeted interventions that can help people to manage some of the symptoms. For example, the identification of young-onset dementia subtypes, which provides evidence against the “dementia as normal ageing” theory. However, despite being useful in some clinical and scientific settings, the disease model is not an appropriate model for considering people with dementia as active agents and people who are engaged in society. This is because the disease model frames the person as passive, as a victim of their brain disease and as experiencing a loss of self (Downs, Clare and Mackenzie, 2006). Framing people with dementia as passive victims can feed the use of dehumanising language and thus increase the stigma associated with dementia (Swaffer, 2014). For example, people living with dementia are often depicted visually in stock images that are used by journalism sources as a puzzle shaped piece being removed from an older person’s head or an older person holding their head in pain. This negative imagery has the potential to permeate and shape cultural views of dementia (Harvey and Brookes, 2019).

The disease or medical model of dementia is the predominant model that frames our understanding of dementia in Western cultures, however, the tide is slowly changing. The main critique of the disease model is that it overlooks the social construction of dementia and the impact of the external environment such as social relationships on the construction of self in people living with dementia (Lyman, 1989; Kitwood, 1997a). In response to this, there have been shifts within biomedical paradigms to move the focus away from a disease model and towards a bio-psycho-social approach (Engel, 1977). Scholars have argued that an overreliance on the disease model of dementia disconnects neuropathology from philosophy (Davis, 2004; Thornton, 2007; Hughes, 2011). Davis justifies the importance of philosophical and sociological understandings of dementia by arguing that the vast philosophical history of examining what it is "to be" and the interrelation between being and thinking have shown that the human brain cannot be separated from the human mind and state of being (Davis, 2004). It is for this reason that philosophical, sociological, and cultural explanations of dementia must be pursued alongside biomedical approaches.

The social constructionist model

As criticism of the disease model grew in the early 1990s, interest in dementia shifted from developing our understanding of the "dementia brain" to an interest in the social construction of dementia and the framing of people living with dementia as social actors who:

> *'live with impairment and interact with others in caregiving relationships, within a variety of socially structured environments such as long-term care facilities, daycare centres, and in families' (Lyman, 1989, pg. 602).*

This model of dementia was made popular by Tom Kitwood and Steven Sabat, two prominent scholars in the field of dementia studies who each proposed a social constructionist understanding of dementia by attending to concepts of personhood and selfhood. Psychologist Tom Kitwood challenged the disease model of dementia in his seminal publication; 'Dementia Reconsidered: The Person Comes First'. In this text, he proposed a model of personhood as a counterculture to the predominant biomedical model of dementia and carved the path for a new way of providing dementia care

(Kitwood, 1997a). Drawing on discourses of transcendence, ethics and social psychology, Kitwood defined personhood as:

> *'a standing or status that is bestowed upon one human being by others, in the context of relationship and social being. It implies recognition, respect and trust.'*
> *(Kitwood, 1997, pg. 8).*

Kitwood argued that a personhood lens enables us to '*recognise men and women who have dementia in their full humanity'* ((Kitwood, 1997, pg. 7) and to focus on the abilities that people with dementia maintain rather than those they might have lost. Kitwood adopted the term 'malignant social psychology' to describe the ways personhood was undermined in people with dementia, particularly when the impact of social relations were not considered. He proposed that inadequate care provision can erode an individual's sense of self or personhood and proposed the concept of person-centred care. Person-centred care is built on the principles that the "behaviours" of people living with dementia are a result of unmet needs and once we understand those unmet needs, we can better support that individual (Kitwood, 1997b). He theorised that people with dementia have five main psychological needs: comfort; attachment; identity; occupation; and activity (Kitwood, 1997b). Kitwood's work undoubtedly transformed dementia care practices and carved the path for alternative models to the dominant disease model of dementia however, it is still important to consider his contribution critically. Kitwood placed the personhood of an individual entirely on their relationships with others and did not address how people living with dementia maintain a sense of self outwith their relationships with other people. Kitwood shifted the narrative from biological factors of dementia to psychosocial factors but he failed to consider the body in his theories of personhood and person-centred care (Dewing, 2008). Additionally, his work on the physical environment and how people with dementia connect to 'place' was underdeveloped. Despite the welcome developments in our understanding of dementia that Kitwood's work provided, dementia is still a neurodegenerative condition, and his pejorative rejection of a biomedical model can be problematic for professionals in clinical practice (Hughes, 2011). Philosophical debates regarding personhood are rich and complex ones with no clear-cut answers. Despite this, Bartlett and O'Connor (2010) highlight three main limitations of the personhood model of dementia: that it does not promote the person living with dementia as an active agent; that it decontextualizes the dementia experience and lacks a critical lens and finally, that it does not address the political realm and therefore power dynamics involved in experiences of living with dementia. They suggest that a social citizenship model addresses these limitations and is thus more appropriate for achieving social and political change. Cahill contends this by arguing that, if Kitwood had framed the needs of people with dementia instead as rights, then he could have extended his work into the political realm, making it more appropriate for informing policy and legislative developments related to dementia (Cahill, 2018).

Like Kitwood, Sabat was critical of the disease model, arguing that it reduced a person to be '*defined principally in terms of his or her catalogued dysfunctions'* (Sabat, 2001 pg. 10). Also a psychologist his research interests are in the intact abilities of people with dementia, the subjective experience of dementia and enhancing communication between caregivers and people with dementia. Building on Kitwood, Sabat argues that the "malignant positioning" of a person with dementia as someone incapable and even unhuman can lead to a decreased ability for that person to have a good quality of life (Sabat, 2001). Drawing on his experience working with people with dementia and in-depth analyses of these conversations, he argues that selfhood can be achieved and maintained in the process of engaging in discourse. He claims that this is achieved because people with dementia are "semiotic subjects", which implies that they are still capable of conveying and understanding meaning despite their communication impairments (Sabat, 2001). Sabat encourages us to consider that a person with dementia has a history and that history is the context in which we must attempt to understand the person in order to afford them the opportunity for social inclusion. He argues that the loss of self in people with dementia is caused, not innately by the dementia, but by the lack of inclusive communication and interaction from others (Sabat, 2001). Like Kitwood, Sabat's work has made practical contributions to providing care for people living with dementia. His work encourages carers to focus on how people with dementia convey meaning rather than on the communication errors they might make. However, unlike Kitwood, Sabat has developed his work beyond the realm of psychosocial and recognises the necessity for a biopsychosocial approach in some areas of practice (Sabat, 2008).

Both Sabat and Kitwood challenged us to reconsider dementia and how we communicate with and provide person-centred formal care. Sabat paved the way for valuing lived experiences of people with dementia in research as he argued for a shift in focus from people with dementia as objects to study, to subjects, much like Kitwood suggested we view them as PEOPLE with dementia and not people with DEMENTIA (Kitwood, 1997a; Sabat, 2001). Although a focus on selfhood and personhood through psychosocial lenses have advanced understandings of the experience of dementia and have provided an alternative approach to the disease model, there is still room to examine the experience of dementia as one that is situated in a physical place and in-and-through a physical body.

Philosophical approaches to dementia

Dementia challenges the age-old philosophical question of existence and "Being-in-the-world" and therefore, scholars have drawn on a philosophical lens to propose ways of understanding dementia. Much of this work draws on 20th century, European philosophers; Heideggar (1962) and Merleau-Ponty (1962). Prior to their contributions, the dominant model of understanding human existence was the Cartesian model of mind-body dualism, which argued that the mind and body exist as separate entities and is often summarised by the Latin saying '*Cogito, ergo sum'* (I think, therefore I am). This understanding perpetuates dehumanising narratives of decay and the erosion of the self in dementia and therefore, a philosophical understanding that does not consider cognition as the root of selfhood is required.

Heidegger's alternative framework suggests that Being is not dependent on thought alone, nor is there a distinctive split between the subjective and objective (1962). Instead, he suggested that existence is maintained by Being-in-the-world, in relation to objects and other human beings. As human beings, we are born into a world already full of meaning and thus, we have a pre-ontological understanding that shapes how we live in the world. This approach decentres cognition and in the case of dementia, it means that no level of cognitive impairment can diminish our Being-in-the-world or selfhood.

Post, a bioethicist who examined the moral challenges that Alzheimer's disease posed, instead urged us to consider people with dementia as meaning-seeking people, as are all people (Post, 1995). He encourages us to reflect on the qualities that make people with dementia similar to those who live without it, rather than the qualities that set us apart. Post coined the term "hypercognitive" to describe the current culture that values cognitive capacity over all else, which can be detrimental for a person living with dementia because in a hypercognitive culture, as they lose cognitive capacity, they will lose their personhood (Post, 1995). Post suggests an approach of "being with" rather than "doing to" and taking inspiration from the work of Kitwood, Post rejects the notion of "I think, therefore I am" and embraces the notion of "I feel and relate, therefore I am" (Post, 2006). Swinton's examination of dementia through a spiritual and theological lens further supports Kitwood and Post's rejection of a hypercognitive culture, arguing that it contributes to the dehumanising and stigmatisation of people with dementia (Swinton, 2012). Although these scholars do not reference the work of Descartes or Heidegger directly, they demonstrate how these philosophical approaches play out in a practical sense in the context of dementia.

Merleau-Ponty took the ideas of Heidegger further by examining the role of perception in our experiences of the world and arguing that Being-in-the-world is an embodied experience that does not require cognitive consciousness (Merleau-Ponty, 1962). In other words, the body is our primary site of knowing the world and our vehicle for experiencing the world. This experience of Being-in-the-world does not cease to exist in the case of dementia and thus, embodied selfhood promotes a broader understanding of the experience of dementia (Kontos, 2004).

In his book, ‘Thinking Through Dementia’ (2011), Hughes, a psychiatrist and philosopher, brings a real-life lens to the philosophical and ethical dilemma of dementia by reflecting on examples of the ‘messy’ decision-making that he engages with in clinical practice. Hughes proposes that we view people with dementia as Situated Embodied Agents. Situatedness addresses the context and external factors, based on Heidegger's ‘Being-in-the-world’ (1962). Embodiment addresses both the pathological process of dementia as referred to in the disease model and the occupation of space and experiencing the world in and through the body, based on the philosophical contributions of Merleau-Ponty (1962). Finally, agency addresses intentionality and context. It cannot be separated from situatedness and embodiment. Hughes argues that, in addition to issues concerning personhood, a philosophical lens on dementia is also relevant to issues around citizenship, human rights, technology, capacity, diagnosis, treatment and our nature as human beings in the world (Hughes, 2013a). It supports the understanding of a person with dementia as a situated and embodied human being including psychosocial, socio-cultural and spiritual factors (Hughes, 2011, 2013a). Although Hughes argues for using philosophy to frame our understanding of dementia, he also calls for dementia to be treated as a political issue (Hughes, 2011). Thus, the remainder of this chapter will focus on understanding dementia within a wider social, political, and cultural context.

Beyond models

In recent years, the work of Kitwood and Sabat has been developed further into what Bartlett and O’Connor (2010) call the “fourth moment” in dementia studies. They explain this vision via two overarching themes: a recognition of reciprocal relationships and agency in people with dementia and *‘the* *importance of a more textured, multidimensional lens for contextualising the experience'* (2010, pg. 25). The remainder of this chapter explores recent contributions within the fourth moment in dementia studies thus carving the path for this inquiry.

Social citizenship

Despite recognising the value of a personhood lens, Nolan *et al.* (2004) raise some limitations of person-centred care, particularly in their critique of how UK policy has adopted an individualistic approach to person-centredness. Instead, they suggest that relationship-centred care in dementia would be a more useful tool in practice. Their approach frames relationships with people with dementia as reciprocal. It challenges the binary view that people with dementia are care receivers and others are care providers. This understanding is one of the building blocks for a citizenship model of dementia which argues for the treatment of people living with dementia as not just people who deserve care and compassion but to go further and argue that people with dementia deserve to be treated as equal citizens, with rights and responsibilities (Bartlett and O'Connor, 2010).

It should be noted at this point that personhood and citizenship models are not in competition with each other. Swinton supports the argument that both citizenship and personhood models are necessary in dementia studies (Swinton, 2021). Swinton critiques that political citizenship models alone do not force people to love and value each other and they do not address issues that come with degeneration and changing capacity (2021). Instead, Swinton draws on the work of Bartlett and O'Connor to suggest a social citizenship approach, in combination with philosophical models of personhood.

Bartlett and O'Connor extend the notion of traditional citizenship and put forward the idea of social citizenship defined as:

> *a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It*

> *involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level (Bartlett and O'Connor, 2010, p37).*

This definition goes beyond political rights and duties to include personhood and relationships. A social citizenship approach frames dementia through a rights-based lens, whereas personhood frames dementia through a needs-based lens. The issue with an entirely needs-based lens is that it does not address the structural impact of oppression, stigma, and discrimination on people's experiences of living with dementia (Bartlett and O'Connor, 2010).

In recent years, because of the advocacy work carried out by people with lived experience, the human rights of people living with dementia have moved up the political agenda. Although this is welcome, Bartlett and Nedlund suggest that a citizenship lens is more appropriate than a human rights approach to dementia because '*according to citizenship scholars, it is not possible to have human rights without first having citizenship'* (2017, pg. 50). They draw on Isin and Turner (2007) who suggest that citizenship should be regarded as a foundation for human rights and not a competitor. It is without a doubt that the issues of rights are central to how people living with dementia are treated in the world and that taking a human rights approach to dementia would align it with the mainstream disability rights movement (Shakespeare, Zeilig and Mittler, 2019). This gradual societal shift towards a citizenship and rights-based understanding of dementia has been supported by national and international legislation. For example, in 2009, a Charter of Rights for people with dementia and their carers was developed in Scotland. This charter reflects Human Rights standards set by the United Nations is at the centre of all campaigning activities in Scotland (Scottish Parliament's Cross-party Group on Alzheimer's, 2009).

Within the citizenship movement, the focus has shifted from citizenship as a status bestowed on people to citizenship as a practice that people do (Nedlund and Bartlett, 2017). One way that citizenship is practised by people living with dementia is through shaping and contributing to research that values their lived experience.

Valuing everyday lives in dementia research

In parallel with this theoretical development in the field of dementia studies, researchers were also beginning to examine the lived experience of people with dementia outside of a care context (Wilkinson, 2002b). When arguing why we should include the experiences of people living with dementia in research, Wilkinson (2002) gives two reasons: to shift power and to develop understanding. In exploring the experiences of ‘going out’ for people living with dementia, this thesis holds these two justifications at its core.

As well as gaining recognition in research, people who are living with dementia have built a growing global advocacy movement. Kate Swaffer, Wendy Mitchell and Christine Thelker are just a few examples of women who have written books about their experiences of living with dementia and in doing so have fought for their right to be treated as people who do not need to go home and “get their affairs in order” a process that Swaffer has coined as “Prescribed Disengagement” (Swaffer, 2015). Advocacy groups such as the Scottish Dementia Working Group and Dementia Alliance International were established by people living with dementia to represent, support and educate others. Today, people living with people not only participate in research as valuable knowledge sources, but they lead research practices. Dementia Enquirers was established by the Dementia Engagement and Empowerment Project in the UK to fund and conduct research led by people living with dementia based on the priorities they have set themselves.

This thesis takes up the call to be more inclusive of people living with dementia in research by taking a participatory approach as detailed in Chapter Four. I also draw on the aforementioned social citizenship lens and a valuing of lived experiences by focusing on the everyday lives of people living with dementia. Nedlund, Bartlett and Clarke consider activities of daily living such as ‘*finding one’s way around’* (2019, pg. 1) to be sites of citizenship in practice for people living with dementia, as it is a way for people with dementia to demonstrate '*agency and capacity to take control of one's life'* (Nedlund, Bartlett and Clarke, 2019, pg. 1-2). They argue that locating citizenship in the everyday is crucial because this is '*where lives are lived out and decisions are made*' (2019, pg. 3). Similarly, Spinney, Aldred and Brown, (2015) argue that citizenship is not a fixed status but is performed through everyday experiences of movement and mobility.

One way of examining citizenship in the everyday lives of people with dementia is through the lens of risk. Contemporary western societies view risk-taking behaviour as deviant and irresponsible (Lupton, 1999). The problem with this outlook is that it suppresses views that risks are a normal part of our everyday experiences (Manthorpe and Moriarty, 2010). Although risk management is central in professional dementia care practice, it is largely under-theorised in the everyday lives of people with dementia (Clarke *et al.*, 2010; Sandberg *et al.*, 2017). In a review of the studies that have examined everyday lives of dementia through the lens of risk, Bailey *et al.,* (2013) note a changing narrative from risk as '*a negative event to be avoided'* (pg. 391) to '*one in which the external situation in which people live poses threats to them and in which policy and practices are moving to a greater level of individual responsibility'* (pg. 391). Although this emerging narrative promotes positive risk-taking in dementia (Mapes, 2017), this is often undermined by a conflicting risk-averse culture stemming from professional care environments (Clarke and Heyman, 1998). Perceptions of risk can in the context of dementia vary across cultures, professions and individuals (Clarke *et al.*, 2009, 2010; Sandberg *et al.*, 2017). For example, in a survey of professionals working in dementia care, Clarke *et al*. (2009) identified a range of understandings of risk from avoidance of physical harm to a more positive engagement with risks to improve quality of life. In a follow-up study, Clarke *et al.* (2010), included the perspectives of people with dementia, family carers and practitioners and addressed the variability in perceptions of risk across these groups. They identified five contested territories of everyday living with risk: friendships; going out; smoking; domestic arrangements; and occupation and activity. This finding is crucial as it inspired the use of the term ‘going out’ for this thesis to encompass a broad range of lived experiences. In support of this, in interviews with 12 people with dementia who live at home, Sandberg *et al.* (2017), showed that perceived risks varied across individuals. They also identified leaving the home to be a risk-laden activity as participants reported that being in unfamiliar places was risky and that having wayfinding difficulties increased their risk of getting lost. Similarly, in a qualitative study of ten people who live at home alone with dementia, Gilmour, Gibson and Campbell (2003) identified getting lost as a main area of risk. Although people with dementia who live at home may not be aware of all of the risks that they face (Smebye, Kirkevold and Engedal, 2015), they are still capable of attempting to manage these risks (Bartlett and Brannelly, 2019). Additionally, Bailey *et al.*, (2013), identify the importance of understanding local context to support people living with dementia and identify a gap in the evidence base regarding the examination of risk and resilience through a person-environment lens. Taken together, these studies lay the foundation for a further examination of the everyday experiences of people with dementia, how they engage in risk management and their potential experiences of getting lost. The remainder of this section will briefly explore the literature related to the two relevant lenses through which we can examine this: critical and person-place relations in dementia studies.

Critical dementia studies

Since the influential work of Kitwood and Sabat, literature has begun to emerge in the field of dementia studies that address the limitations of psychosocial understanding of dementia by embracing critical theoretical and creative methodological approaches (Phinney and Chesla, 2003; Hulko, 2004; O’Connor, Phinney and Hulko, 2010; Kontos and Martin, 2013). This is achieved by situating the intersectional experiences of dementia in a wider socio-cultural context (Hulko, 2004). Socio-cultural factors such as gender, race, class, age and sexuality can vary hugely across people living with dementia and this has been shown to affect how people view dementia and thus, how they cope with it (Hulko, 2009; O’Connor, Phinney and Hulko, 2010). Building on the critical dementia studies discourse, Sandberg seeks to ‘*put gender on the dementia studies agenda*’ (2018, pg. 30). In a theoretical discussion paper, Sandberg argues that dehumanising and person-focused discourses frame people with dementia as one homogenous group leading to the de-gendering of people with dementia and the exclusion of non-normative gender expressions (Sandberg, 2018).

As previously mentioned, a criticism of the personhood model is that, by privileging the psychosocial experience of dementia, it fails to address the embodied nature of the experience of dementia (Kontos, 2004; Dewing, 2008; Kontos and Martin, 2013). The disease model of dementia also fails to address this as it privileges cognitive decline and has, therefore *‘resulted in a more disembodied approach*’ (Kontos and Martin, 2013, pg. 289). When the body is considered in biomedical and care contexts, it is only a focal point when it “fails” for example, when people with dementia go ‘wandering,’ are incontinent or become physically aggressive (Phinney and Chesla, 2003; Kontos and Martin, 2013). Embodiment theory rejects the mind-body dualism and frames the body as central to maintaining selfhood and language practices through Being-in-the-world (Kontos, 2004; Hughes, 2013b).

The role of the body has been shown to be significant in meaning-making processes for people with advanced dementia (Isene *et al.*, 2021) however, it has not been examined in people who are in earlier stages of dementia. When a person maintains the capacity to communicate verbally, this is often privileged. To maintain a practice of ‘going out’, people with dementia are dependent on their bodies as a medium through which they experience the world therefore, an embodied lens could reveal insights about this experience. Critical dementia scholars have called for further analysis of embodiment in the context of dementia through the use of creative research methods (Kontos and Martin, 2013). This small body of literature supports the pursuit of a more nuanced and intersectional understanding of the experience of dementia, which can, in turn, enable more appropriate facilitation of people with dementia to participate in everyday life.

So far, this section has outlined some of the conceptual debates that frame our understanding of dementia and has begun to situate this inquiry within a critical dementia studies approach. Having argued for the importance of positioning experiences of dementia in a wider socio-cultural context and examining the experiences of dementia through novel lenses such as embodiment, I now turn my attention to emplacing these experiences.

Emplacing dementia

Earlier in this chapter, I highlighted the recent turn in dementia studies towards examining the practice of citizenship in everyday lives. This has provided the rationale for this thesis to examine an everyday practice for people with dementia. But practices of everyday life cannot be accurately examined without the context in which they occur. One way to address this is to situate everyday life in the context of place (Pink, 2012).

Conceptualising place

Definitions, understandings and experiences of place have been of interest to scholars across the social science disciplines from geography to philosophy to anthropology to sociology. This section does not intend to review the entire cross-disciplinary literature on place. Instead, it intends to provide the reader with a broad overview of how place has been conceptualised by others thus framing my understanding of place for this inquiry. Conceptions of place can generally be split into two categories: place as an abstract concept and place as a physical locality. As an abstract concept, place is a ‘sense’ that people have. It defies geographical boundaries and enables the exploration of lived experience in a place. Massey (2005) is a geographer who suggests that places are dynamic. She argues that they have multiple rather than single identities, they are ongoing processes, not frozen in time and they have blurred boundaries. On the other hand, Casey (1996), a philosopher with an interest in the philosophy of space and place draws on Merleau-Ponty (1962) to suggest that we can only know and understand a place by being in it. Similar to this, Ingold (2007), a British anthropologist, draws on theories of philosophy and ecology to argue that place is something we are part of, not something we act on or in. In other words, humans create places through action and therefore, spaces are never neutral. They are a part of peoples' experiences of movement along and interactions with and in spaces (Ingold, 2007). At this point, it would be useful to distinguish between place and space. Although often used interchangeably, these terms are highly interrelated yet there are subtle differences. Cresswell defines space as '*a realm without meaning'* (2004, pg. 10) thus place is just space '*invested with meaning*' (2004, pg.12). Drawing on the contributions of Massey, Casey and Cresswell, I consider both abstract and physical elements of place to be relevant for this thesis.

Despite the vast majority of historical health research overlooking the role of place in human health, it is now a commonly held belief that people, and places are interwoven. Thus, in recent years, place has been put back on the health research agenda (Cummins *et al.*, 2007). However, there is no single theory that explains place and the nature of the relationships between people and places. In the context of later life, human-place relationships are examined through the notion of ageing-in-place. Although there are several interpretations and definitions of ageing-in-place (see Pani-Harreman *et al.*, 2021 for a comprehensive discussion), for the purpose of this thesis, the notion of ageing-in-place in the context of the United Kingdom is understood as a cost-effective solution to the problem of the ageing population and of benefit to the quality of life for older people by increasing their wellbeing, independence and social participation (Sixsmith and Sixsmith, 2008). Although ageing-in-place has become an important aspect of health and social care policy (Sixsmith and Sixsmith, 2008), experiences of how people with dementia engage with the places they live in are largely underexplored in research. This gap in the literature has been previously highlighted by Clarke and Bailey (2016) who argue for the need for place-centred as well as person-centred dementia policies in Scotland.

In response to the ageing population, initiatives such as dementia-friendly and ageing-friendly communities have become the focus of national and international policies (Alzheimer's Society, 2013; Alzheimer's Disease International, 2016; World Health Organization, 2017). The intended outcomes of these policies are to address concerns about the ageing population by reducing admission to formal care and to enable people with dementia to live in a supportive and enabling environment. A dementia-friendly community is defined as a community *'in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them'*. (Alzheimer's Society, 2013, pg. viii). This definition is based on a survey of 510 people with dementia in the UK. In addition, it is interesting that this survey found that one of the ten priority areas for a community to be considered dementia friendly is that it is *'easy to navigate'.* This is of particular interest when examining experiences of 'going out' for people with dementia and will be addressed in Part B of this literature review. These policy development have occurred in conjunction with an increased theoretical interest in how the outdoor and built environment intersects with the experience of living with dementia (Keady *et al.*, 2012). However, much of this literature is interested in designing accessible physical environments rather than the everyday and emplaced practices of people with dementia (Blackman *et al.*, 2003; Mitchell, Burton and Raman, 2004; Mitchell and Burton, 2006, 2010).

Emplaced experiences of dementia

Until recently, the public environment was a neglected space in dementia research with priority being given to formal care settings or the home environment (Brittain *et al.*, 2010). However, with the increasing interest in the everyday lives of people with dementia, there has been a turn towards how they engage with public spaces and places. Going outdoors is associated with freedom, independence and an opportunity to engage with the local community for people with dementia (Gibson *et al.*, 2007; Duggan *et al.*, 2008; Brittain *et al.*, 2010; Olsson *et al.*, 2013), However, it can also pose challenges such as the risk of temporal and spatial disorientation and fear of becoming lost (Duggan *et al.*, 2008; Brittain *et al.*, 2010; Olsson *et al.*, 2013;

Sandberg *et al.*, 2017). It has been suggested that these challenges lead to the shrinking of physical and social spaces and places for people with dementia (Duggan *et al.*, 2008). This has been contested by others who argue that the '"shrinking world" analogy does not foster a view of people with dementia as having agency (Odzakovic *et al.*, 2021; Ward *et al.*, 2021). Additionally, it has been highlighted that the design of public environments is not well suited for people with dementia (Brorsson *et al.*, 2016). Nevertheless, people with dementia have demonstrated coping strategies to mitigate some of the challenges faced such as using landmarks, asking for help and staying on familiar routes (Brittain *et al.*, 2010; Brorsson *et al.*, 2013; Olsson *et al.*, 2013). These studies provide the foundation for further exploring the experiences of people with dementia when 'going out'. The outside space has the potential to be an enabling place (Brittain *et al.*, 2010) and maintaining a connection to it through activities such as group walking have been shown to be practices of citizenship for people with dementia (Phinney *et al.*, 2016). Blackstoc*k et al*. (2006) noted an embodied relationship between participants and their physical landscape when examining the lived experiences of people with dementia and carers in rural Scotland. It is unsurprising that outdoor spaces and a connection with nature have been shown to have a positive impact on the health and well-being of people living with dementia (Gibson *et al.*, 2007; Gilliard and Marshal, 2012; Mapes, 2017; Mmako, Courtney-Pratt and Marsh, 2020). Although there is a small and emerging body of research that investigates the relational aspect of the neighbourhood and the accessibility of the built environment, the relationship between people with dementia and nature remains largely unexplored. This is supported by a mixed studies review on the impact of green spaces conducted by Mmako, Courtney-Pratt and Marsh (2020). They found that the voice of people with dementia is missing from the evidence base on dementia and green spaces.

Another lens through which the person-place relationship in dementia has been examined is that of the neighbourhood. This lens was employed by a longitudinal qualitative study entitled ‘Neighbourhoods and Dementia’[3] (2014-2019). Conducted across multiple sites in the UK and Sweden, this project aimed to understand how neighbourhoods and local communities support people living with dementia to remain socially and physically active. Contrary to previous research on the relationship between people with dementia and the built environment, this study emphasised the social and relational elements of the neighbourhood (Ward *et al.*, 2018; Clark *et al.*, 2020; Odzakovic *et al.*, 2021). Despite previous research arguing that most people with dementia are not meaningfully engaged in their local communities (Heward *et al.*, 2017), this study found that they have a desire for connection (Li, Keady and Ward, 2019). This suggests that the rights of people with dementia to access and belonging within their local communities are not being fulfilled. Akin to the aforementioned challenges with the definition of ‘place’, understandings and interpretations of ‘neighbourhood’ is also contested. Clark and colleagues argue that neighbourhoods are ‘*more than a walkable zone’* but not as large as ‘*a global sense of place’* (2020, pg. 6). They suggest that the concept of the neighbourhood does not map directly onto physical locality and instead is better considered in relational terms as a site for ‘*connection, engagement and social interaction’* (2020, pg. 1). For the purpose of this research, place is understood as both an abstract concept where people connect, interact and engage and as a physical landscape and a geographical location that people navigate. Drawing on Massey (2005), Casey (1996) and Ingold (2007), place is operationalised in this research as something dynamic, that we are a part of and can only understand by being in. Although I agree that neighbourhoods and communities are relational, I also consider the physical locality of the places where people conduct their everyday practices in to be of equal importance. This broad operationalisation of place enables the focus of this research to be inclusive of the diverse experiences of ‘going out’ for people living with dementia.

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[3] This project was funded by the Economic and Social Research Council and the National Institute for Health Research. The project consisted of 8 work packages across 7 universities in the UK and 1 in Sweden. https://sites.manchester.ac.uk/neighbourhoods-and-dementia/

Part A summary

This first section of the literature review has established the theoretical backdrop to this inquiry, situating in the field of dementia studies. It has drawn on the published thoughts of researchers across disciplines such as psychology, sociology, geography, philosophy, and health research. In this section, I have discussed how theoretical understandings of dementia have evolved. Consequently, I arrive at a similar conclusion to the scholars before me; despite the several models that exist to frame our understanding of dementia, the ultimate imperative is that we foreground the humanity of people living with dementia. I argue that one way to achieve this is through taking a critical approach to understanding the lived experiences of people living with dementia, specifically, concerning the body and place. In doing so, I have provided justification for exploring everyday lives in dementia and more specifically, how these interact with place. The focus of this inquiry is neither solely on how people navigate their local environment nor on how they connect to the neighbourhood. It is both. Thus, I justify the aim of this inquiry to examine the practice of ‘going out’. Some people may travel across the country, city or town whist others might be confined to their local park. Some might spend more time in the outdoor, natural environment whilst others might engage more with the built, public environment. ‘Going out’ occurs in indoor and outdoor; natural and built; rural and urban; familiar and unfamiliar; and public and private places and spaces. Therefore, it enables a richer understanding of people’s experiences. Now that I have explored the literature pertaining to the element of this inquiry that examines the lived experiences of people with dementia, in the following section I examine the literature pertaining to being lost and at risk of reported missing whilst ‘going out’ as previous studies identified this as a concern. In doing so, I highlight a further gap in the evidence base and consequently, hone the research questions that this inquiry aims to answer.

Part B: From finding one’s way to being found

Although getting lost is a common human experience, it is embedded in our cultural perception of dementia in Western societies that people with dementia are at a high of getting lost and experiencing harm when ‘going out’. Thus, in Part B of this literature review chapter I explore previous literature on the movements of people with dementia who live at home whilst ‘going out’ including how they navigate, the difference between wandering and going missing and the features of dementia-related missing incidents. In discussing this literature, I highlight a gap in the evidence base regarding lived experience knowledge in the context of people with dementia’s experiences of being lost and at risk of missing.

Navigation and wayfinding

Having identified that people with dementia may face increased risks whilst ‘going out’ in Part A, this section provides insight into how people with dementia navigate the environment outside their homes. This chapter will not engage in an in-depth critique of the neuroscientific literature about dementia and navigation because this inquiry is more interested in the experience of navigation rather than the neurological mechanisms. Although the terms wayfinding and navigation are often used interchangeably, they are distinct, yet closely related concepts. Wayfinding is defined as the broader ability of human beings to find their way, orient themselves and navigate whereas navigation is the actual practice of finding one’s way. Wayfinding is an active and dynamic process that requires planning and decision-making whereas navigation is a goal-oriented means of wayfinding (Dalton, Hölscher and Montello, 2019).

The neural mechanisms of spatial navigation involve a complex interaction of several different brain regions and cell groups. Our ability to navigate depends on the use of two integrated strategies: egocentric and allocentric navigation. Egocentric navigation is used independently of the environmental cues and relies more heavily on cognitive maps and proprioceptive information that allows an individual to orient themselves in space (Lester *et* *al.*, 2017). On the other hand, allocentric navigation depends on external cues such as landmarks and boundaries (Lithfous, Dufour and Després, 2013). Since dementia is related to changes in several neural mechanisms in the brain, it can result in an inability to switch between egocentric and allocentric navigation strategies and thus, a reduced ability to navigate (Serino and Riva, 2013). Virtual reality has proven useful for researching spatial navigation strategies and impairments in a controlled environment. Previous virtual reality studies have shown that landmark recognition is impaired in Alzheimer's Disease (Zakzanis *et al.*, 2009; Allison *et al.*, 2016; Caffò *et al.*, 2017). In virtual settings, a combination of geometry (the shape of the environment), as well as landmarks, assist spatial reorientation in people with probable dementia more so than landmarks alone (Caffò *et al.*, 2017). There have been a limited number of studies investigating the spatial navigation of people with dementia in real-world environments due to the difficulty in controlling external factors such as weather, noise levels, and other people in the environment. This lack of control makes real-world navigation studies difficult to replicate.

Now that I have provided a brief insight into the neural mechanisms of navigation, I will examine the literature on wayfinding strategies and challenges for people with dementia. To date, research on dementia and wayfinding has focused on indoor environments (Marquardt and Schmieg, 2009; Caspi, 2014). Arthur and Passini (1992) identify three key processes in wayfinding: decision making; decision executing; and information processing. Wayfinding is a spatial problem-solving task that requires spatial representations and spatial-cognitive operations to generate useful information (Passini *et al.*, 1995). When observed in both familiar and unfamiliar environments, people with dementia demonstrated wayfinding difficulties (Passini *et al.*, 1995; McShane *et al.*, 1998). Previous neuropsychological testing and caregiver reports suggest that these wayfinding difficulties are a result of visuospatial disorientation (Pai and Jacobs, 2004) and reduced executive functioning (Chiu *et al.*, 2005). When having difficulty wayfinding, people with mild dementia have been shown to use a less effective “trial and error” approach that appears to lack organisation in comparison to older people without dementia who use a plan-oriented approach (Passini *et al.*, 1995). This suggests that people with dementia are at an increased risk of experiencing wayfinding difficulties as a result of impairments in egocentric navigation and therefore, are at an increased risk of becoming lost. Impairments in allocentric navigation strategies can also lead to wayfinding difficulties for people with dementia. Recent research indicates that the complexity of a multi-layered situation, with multiple junctions, busy traffic and many pedestrians greatly exacerbates the difficulties for people with dementia in navigating an external environment (Brorsson *et al.*, 2016). In support of this, a retrospective analysis of missing persons reports for people with dementia concluded that people are at an increased risk of going missing in areas with more complex road structures (Puthusseryppady *et al.*, 2020). Most studies that examine the navigational abilities of people with dementia are based on neuropsychological tests and caregivers’ accounts rather than real-world events. Interestingly, it has been shown that caregivers underestimate the wayfinding capabilities of people with dementia (Chiu *et al.*, 2005) suggesting that caregiver reports do not provide accurate representations of the navigational abilities of people with dementia. Despite this, few studies have examined these challenges from the perspective of people with dementia. As a result, little is known about the decision-making practices that people with dementia engage in whilst they are experiencing navigational challenges.

Studies that examine wayfinding strategies of people with dementia have begun to emerge in real-world, outdoor environments using accompanied walks as one of a variety of data generation methods (Mitchell, Burton and Raman, 2004; Sheehan, Burton and Mitchell, 2006; Olsson, Skovdahl and Engström, 2019; Seetharaman, Shepley and Cheairs, 2021). Accompanied walks have identified that people with dementia use landmarks when in conjunction with various other strategies such as sticking to familiar routes, stopping and thinking, using signage and depending on cognitive maps (Mitchell, Burton and Raman, 2004; Sheehan, Burton and Mitchell, 2006;

Sandberg *et al.*, 2017; Olsson, Skovdahl and Engström, 2019; Seetharaman, Shepley and Cheairs, 2021). In contrast to previous reports of caregivers underestimating the navigational abilities of people with dementia (Chiu *et al.*, 2005), some people with dementia have been shown to overestimate their navigational abilities (Mitchell, Burton and Raman, 2004; Sandberg *et al.*, 2017). Weather conditions and seasonal changes posed specific challenges such as poor visibility and visual changes in the environment however it remains unclear if people with dementia were aware of the impact that these specific challenges had on their navigational abilities (Olsson, Skovdahl and Engström, 2019). Of the research evidence that aims to understand mechanisms and experiences of navigation and wayfinding for people with dementia, few have sought to support active wayfinding for people with dementia. Previous research has shown that people with dementia can still learn to navigate new environments with the support of accessible environments and visual cues (Davis and Weisbeck, 2017). One way to support wayfinding in outdoor environments could be using GPS devices. Typically, GPS-based interventions are used to track the movements of people with dementia in a passive way (Bulat *et al.*, 2016). However, GPS can be actively used by people with dementia to support wayfinding. In a simulated environment, people with mild dementia can use GPS to improve their driving (Yi *et al.*, 2015). In a real-world environment, walkers with mild dementia were able to use a GPS application on an iPhone to find their way and promote independence (Kwan, Cheung and Kor, 2018).

Taken together, these insights could be used to inform the design of dementia-friendly outdoor environments and to prevent people with dementia from getting lost in the community. However, there is still a gap in the literature regarding the subjective experience of navigation and wayfinding for people with dementia. In addition, although studies that investigate experiences of navigation for people with dementia mention the prevention of incidences of getting lost as an intended impact of the research, researchers rarely link to missing persons reports. Before examining the literature relevant to missing incidents of people with dementia, it is worth exploring the conceptual differences between wandering and being missing.

Conceptual differences between wandering and missing

Various terms are used in the literature to describe the movements of people with dementia when ‘going out’. Some of these terms included wandering; elopement; walking; getting lost; and missing. Although these terms have been used interchangeably in the past, distinctions are beginning to emerge. These distinctions and alternative perspectives are important to inform appropriate responses to support people with dementia to maintain a practice of ‘going out’.

Although wandering has been addressed extensively in the literature, there is little consensus regarding how to define or measure it (Price, Hermans and Grimley Evans, 2001). Reviewing the broad range of literature on wandering and dementia is beyond the scope of this inquiry. Instead, I will provide a brief overview of the wandering literature that is relevant to this research. This includes a discussion of the definition of wandering and how it differs from other terms used to describe the movements of people with dementia and management and prevention strategies for wandering in a community setting. In some countries including the United Kingdom, wandering is perceived as a pejorative term when used in the context of dementia. This has resulted in an attempt to replace the term with other words such as walking (Marshall and Allan, 2006). This has been contested by researchers who argue that, although wandering may be a type of walking, they are distinct forms of movement (Dewing and Wilkinson, 2010). Therefore, a shared understanding of wandering is important. In a review of 183 articles that describe and define wandering, Algase and colleagues refined the definition of dementia-related wandering to

> *‘A syndrome of dementia-related locomotion behaviour having a frequent, repetitive, temporally-disordered and/or spatially-disoriented nature that is manifested in lapping, random and/or pacing patterns, some of which*

> *are associated with eloping, eloping attempts or getting lost unless accompanied' (2007).*

This definition distinguishes wandering from getting lost thus supporting the argument that they are conceptually different (Rowe *et al.*, 2011). In developing a definition for wandering, researchers can distinguish between wandering versus exiting behaviour, elopement or getting lost which are considered to be potential consequences of wandering (Algase *et al.*, 2007). It also allows for accurate response strategies to wandering episodes. In dementia, wandering is typically examined from a biomedical perspective. Through this lens, wandering is framed as a behaviour to be managed and prevented, typically via social, environmental and technological interventions (Moore *et al.*, 2009; Petonito *et al.*, 2013; Neubauer *et al.*, 2018; MacAndrew, Brooks and Beattie, 2019). Some scholars have contested this approach, arguing for an alternative perspective on wandering as a positive, innately human act (Dewing, 2006; Solomon and Lawlor, 2018). In a critique of the narrative discourses, media portrayals and institutional perspectives on wandering in Alzheimer's Disease and Autism Spectrum Disorder, Solomon and Lawlor (2018), influenced by the work of phenomenologist Merleau-Ponty, argue that the current emphasis on management and prevention puts people with dementia at the risk of exclusion from everyday life by denying them the opportunity to "have a world". The benefits of this alternative perspective on wandering are fourfold. Firstly, it makes space for the enablement of safe wandering to replace traditional management and prevention strategies (Dewing and Wilkinson, 2010). Secondly, an enablement approach to wandering recognises the benefits of walking and being outdoors as ways for people with dementia to maintain a sense of purpose, belonging and agency (Marshall and Allan, 2006; Kelson, Phinney and Lowry, 2017; Mmako, Courtney-Pratt and Marsh, 2020). Thirdly, this approach contrasts the dominant narrative that wandering is negative and makes space for wandering to be considered a form of positive risk-taking (Mmako, Courtney-Pratt and Marsh, 2020). Finally, an enablement approach allows for the inclusion of the experiences of people with dementia, which has been largely excluded from the evidence base (Dewing, 2006; Robinson *et al.*, 2007).

As discussed in the introduction of this thesis, definitions of the term "missing" vary and lack clarity (Biehal, Mitchell and Wade, 2003). Put simply, a missing person is someone whose whereabouts are unknown however, people who go missing intentionally do not identify with the term because, although they may be absent from their daily life, they are present in time and space (Stevenson *et al.*, 2013). Both empirical and theoretical research on missing adults remains undeveloped (Stevenson *et al.*, 2013) with a dearth of literature on experiences of missing from the perspective of people with dementia. People with dementia are often categorised as "unintentionally missing" (Henderson, Henderson and Kiernan, 2000; Biehal, Mitchell and Wade, 2003). This is problematic because it assumes that people with dementia only go missing as a result of wandering behaviour or getting lost. As previously stated, contrary to these assumptions, research suggests that wandering and missing are conceptually separate (Rowe *et al.*, 2011; Solomon and Lawlor, 2018). Therefore, it has been argued that wandering management strategies are not appropriate for all dementia-related missing incidents (Rowe *et al.*, 2011). Despite their conceptual differences, both wandering and missing are considered to be potential outcomes of wayfinding errors (Algase *et al.*, 2004; Rowe *et al.*, 2011). Wandering is understood as a result of temporal and spatial disorientation whereas missing incidents are defined as:

> *'unpredictable, non-repetitive, temporally appropriate but spatially-disordered, and while using multiple means of movement (walking, car, public transportation)' (Rowe et al., 2011, pg.1).*

This definition attributes missing incidents to wayfinding errors rather than aimless movements however, it still assumes that people with dementia go missing unintentionally and do not consider that they might have to agency to go missing intentionally. As an alternative to considering missing as a result of wandering or on a continuum from intentional to unintentional, Rowe and colleagues developed a preliminary missing incidents model as a heuristic to encourage discussion and the development of prevention and response strategies (Rowe *et al.*, 2015). This model highlights the antecedents and consequences of a missing incident for people with dementia and their caregivers. Although it is a welcome development, this model is insufficient as it does not refer to lived experiences of being missing from the perspective of people with dementia. In suggesting surveillance-based prevention strategies, this model fails to consider people with dementia as having potential for agency. In addition, this model fails to consider how to support people with dementia to maintain a practice of ‘going out’ safely beyond using a GPS device to track their movements.

When people with dementia are reported missing

In a survey conducted by Alzheimer’s Society regarding dementia-friendly communities, 60% of people with dementia reported that they worry about being lost is a barrier to community engagement (2013). Missing incidents result in a high burden on police resources due to the high-risk nature of the episodes (Shalev Greene and Pakes, 2014) and distress for the person with dementia and their families (McShane *et al.*, 1998; Shalev Greene *et al.*, 2019). Measures taken to prevent future missing episodes can have negative consequences for the physical and mental wellbeing of people with dementia and often lead to earlier institutionalization (Balestreri, Grossberg and Grossberg, 2000). The remainder of this chapter will discuss the literature on dementia and being reported missing. This is split into three sub-sections: features of missing incidents; prevention strategies; and the impact of being missing.

Features of missing incidents

To date, the majority of research on dementia-related missing incidents is based on retrospective methods such as the analysis of the US Safe Return database, UK police databases or US and Australian media reports (Rowe and Glover, 2001; Rowe and Bennett, 2003; Gibb and Woolnough, 2007; Hunt, Brown and Gilman, 2010; Bowen *et al.*, 2011; MacAndrew *et al.*, 2018).

In support of the argument that wandering and missing are conceptually different, Rowe and colleagues suggest that antecedents to missing episodes need to be identified to prevent dementia-related missing incidents (Rowe and Glover, 2001; Bowen *et al.*, 2011; Rowe *et al.*, 2015). Due to their dementia-related impairments, people with dementia are at higher risk of going missing when compared with those without dementia (Biehal, Mitchell and Wade, 2003). Although people with dementia tend to go missing during routine daily activities (Bowen *et al.*, 2011; Rowe *et al.*, 2011), it is difficult to identify antecedents to missing incidents as they are usually unpredictable and unexpected (Rowe and Glover, 2001). However, mobility and 'hyperactivity' have been reported as behavioural predictors (McShane *et al.*, 1998; Hope *et al.*, 2001) as well as lapses in carer supervision (Bowen *et al.*, 2011) or failure of caregivers to recognise behavioural cues before elopement attempts (Chung and Lai, 2011). In addition, men are more likely than women to go missing (Gibb and Woolnough, 2007; Rowe, Greenblum and D'Aoust, 2012) although it is not speculated as to why this is the case. There has been no research on the association between dementia sub-type and risk of going missing (Rowe *et al.*, 2010) although it has been noted that people's motivations may differ depending on the stage of dementia (Gibb and Woolnough, 2007). Despite the cultural perception that people with dementia only go missing as a result of wandering, there is conflicting evidence on whether a history of "wandering behaviour" is a predictor of people with dementia becoming lost (Algase *et al.*, 2004; Aud, 2004; Chung and Lai, 2011). In fact, in a Missing People report examining fatal disappearances, two of the fifteen dementia-related missing incidents reported to the police were found to have died by suicide (Newiss, 2011). This is important because search guidelines for missing people who have dementia and missing people who are suspected to be suicidal can vary (Gibb and Woolnough, 2007).

When people with dementia are reported missing, harm is associated with older age and length of time missing (Bantry White and Montgomery, 2015). Previous research suggests that people are typically found alive in populated areas and are more likely to be found dead in natural and isolated areas (Rowe and Bennett, 2003; Newiss, 2011). In addition, males and people who are missing from residential homes are at a higher risk of death than females and people who live in their own homes (Rowe and Bennett, 2003). A retrospective analysis of an emergency services database in the US suggests that there is a higher chance of survival if found within 24 hours (Koester and Stooksbury, 1995) which was confirmed in a retrospective analysis of US newspaper analysis (Rowe, 2003). This evidence is supported in an analysis of police-held missing persons data in the UK, which concluded that over 90% of dementia-related missing persons reports were resolved within 24 hours (Gibb and Woolnough, 2007). This critical evidence opposes the commonly held and dangerous misconception that one must wait 24 hours before reporting a missing person to the police. One explanation for this relatively quick search time is that most people with dementia who go missing are usually found close to home or the place they were last seen (Koester and Stooksbury, 1995; Rowe and Glover, 2001; Rowe and Bennett, 2003). An alternative hypothesis could be that, due to their high-risk nature, dementia-related missing incidents are afforded more search and rescue resources in comparison to other groups who go missing. Although there is evidence that changes in the weather can impact wayfinding strategies used by people with dementia (Olsson, Skovdahl and Engström, 2019) this has not been examined in relation to missing incidents. One study found that people who are reported missing were more likely to be harmed in winter months when compared to the summer months but found no significant association with harm when comparing missing incidents that occurred during the day versus at night (Bantry White and Montgomery, 2015). Only two studies have examined lost and missing incidents in drivers with dementia with both concluding that people with dementia should not be allowed to drive because the risk of harm is too high (Hunt, Brown and Gilman, 2010; Rowe *et al.*, 2012). In an analysis of newspaper reports, Rowe and colleagues found that missing drivers have different characteristics to missing walkers, for example, they do not fit with the characteristics of wandering and they take longer to find in comparison to those found without a vehicle (2012).

A recent scoping review found that there is limited evidence regarding strategies to locate people with dementia who are reported missing (Neubauer *et al.*, 2018). Of the guidelines that did exist in the academic and grey literature, Neubauer and colleagues identified strategies including search perimeter and procedures; locating devices; and community engagement (2018). Although police and search and rescue agencies are the primary resource in a dementia-related missing incident, “Good Samaritans”; healthcare practitioners; security services; and social media have been identified as additional resources for locating a missing person with dementia (Aud, 2004; Rowe, Feinglass and Wiss, 2004; K. K. Tsoi *et al.*, 2018; K. Tsoi *et al.*, 2018). Search and rescue professionals are highly dependent on behavioural profiling studies to inform their search strategies (Koester and Stooksbury, 1995; Gibb and Woolnough, 2007). In the UK, based on a statistical analysis of previous incidents, the hugely impactful ‘Missing Persons: Understanding, Planning and Responding’ report (Gibb and Woolnough, 2007) advises that searches for people with dementia begin immediately due to the likelihood of death increasing significantly after 24 hours of being missing. In addition, it advises that searches begin close to home or the place last seen as 80% of missing people with dementia are found within 2km of where they were last seen (Gibb and Woolnough, 2007). The guidelines also acknowledge that people with dementia may have varying temporal and spatial understandings of the environment, differences in gender and differences in recommended search parameters based on whether the individual is suspected to be on foot or public transport (Gibb and Woolnough, 2007). This profiling has been replicated with similar results and a larger sample size across the UK in a report ‘iFind’ produced by the National Crime Agency Missing Persons Bureau (2016). In North America, search and rescue agencies are highly dependent on a single retrospective profiling study with a sample size of 42 people with suspected dementia in Virginia, USA (Koester and Stooksbury, 1995). These guidelines are similar to that of Gibb and Woolnough (2007). Although these studies have been invaluable in increasing the speed and effectiveness of search and rescue procedures, they are outdated and based on small sample sizes (Koester and Stooksbury, 1995; Gibb and Woolnough, 2007). This literature review did not find any evidence of dementia-related search and rescue procedures outside of the UK and North America.

Prevention strategies

This section reviews strategies to prevent a person with dementia from being reported missing. In a government report on missing persons in Australia, James, Putt and Anderson, (2008) call for the identification of strategies to prevent adults with dementia from going missing. Despite this, prevention strategies for missing episodes have developed at a slow pace over the past ten years. Current strategies are targeted as management and prevention strategies for wandering despite the evidence that wandering and missing are conceptually different and thus, require different responses. Strategies can be broadly categorised as restrictive or enabling. Restrictive measures such as locking doors; concealing exits; physical restraints; and sedative medications have been previously recommended to prevent wandering and getting lost for people with dementia who live in the community (McShane *et al.*, 1998; Hope *et al.*, 2001; Rowe and Glover, 2001; Lai and Arthur, 2003). These recommendations are based on the assumption that ‘going out’ is a dangerous activity for people with dementia that must be avoided. On the other hand, going outdoors has proven to be beneficial for the wellbeing of people with dementia and restricting this activity denies them the opportunity for enacting agency (Clarke *et al.*, 2010; Gilliard and Marshal, 2012; Bantry White and Montgomery, 2015; Mmako, Courtney-Pratt and Marsh, 2020). Psychosocial interventions such as walking activities and music therapy have been suggested as an alternative to restrictive interventions to prevent wandering (Robinson *et al.*, 2006). Community day-care and support services have also been suggested as opportunities for the person with dementia to exercise and respite opportunities for the caregiver (Rowe *et al.*, 2010). Although psychosocial interventions are preferred over pharmacological methods as a person-centred and enabling approach, evidence for their effectiveness is limited. Therefore, there has been an increased interest in technological interventions such as tracking devices to reduce unsafe wandering without restricting the movements of people with dementia (Robinson *et al.*, 2006; Bantry White, Montgomery and McShane, 2010). Tracking technologies have the potential to be both restrictive and enabling, depending on how they are used. A review of UK health and social care policy related to assistive technology and dementia identified the potential to support people with dementia to maintain independence when they are implemented appropriately (Woolham, Gibson and Clarke, 2006). However, there are concerns around the appropriateness; ethical implications; and cost-effectiveness of such devices (Woolham, Gibson and Clarke, 2006; Robinson *et al.*, 2007; Chung and Lai, 2011). In addition, care partner peace of mind is often reported as the main benefit of tracking technologies (Bantry White, Montgomery and McShane, 2010; Liu *et al.*, 2017; Shalev Greene and Collie, 2017) rather than benefits reported for people with dementia. Despite the ethical debates that tracking technologies raise, they have the potential to enable people with dementia to maintain participation in everyday life and thus maintain a practice of citizenship whilst staying safe and avoiding a missing episode (Bantry White, Montgomery and McShane, 2010). This has been evidenced in a study that demonstrated the capacity for people with dementia to use GPS applications on their smartphones to assist navigation in Hong Kong (Kwan, Cheung and Kor, 2018). To improve the uptake of technologies that assist outdoor navigation, Teipel and colleagues (2016) recommended that they are introduced to the person with dementia at the earliest possible stage of the disease when they have greater cognitive resources and are better coping with the stress induced by learning new ICT procedure. Another potential for including people with dementia is to involve them in the design process for tracking technologies like the work of the KITE project in the UK, which conducted focus groups with people with dementia and their carers to co-produce two devices that promoted the independence of people with dementia (Robinson *et al.*, 2009). The only known study to investigate technological prevention strategies for missing incidents independent of wandering is a pilot study in the UK that used tracking technologies to reduce repeat missing incidents and reduce the time taken to locate missing persons with dementia (Shalev Greene and Collie, 2017). Researchers found that tracking technologies reduced police search times and financial costs significantly. In addition, relatives of people with dementia reported that tracking devices gave them peace of mind and increased the confidence of the person living with dementia when ‘going out’ (as reported by relatives) (Shalev Greene and Collie, 2017). In conclusion, although there has been research on preventing wandering in dementia, few studies distinguish between prevention of wandering and the prevention of missing episodes. In addition, there is a paucity of evidence-based strategies that support a person to maintain a practice of ‘going out’ safely and no known research that investigates the impact of missing incidents from the perspective of people living with dementia.

The experience of being missing for people with dementia

This final section of the literature review highlights the absence of the voice of people with dementia in the evidence base regarding missing incidents. To date, the ‘Geographies of Missing People’ study has been the only research to investigate the lived experiences of adults who return from being missing (Stevens*on et al*., 2013). This research advanced practical and theoretical knowledge of “missing” and made a significant contribution to the Scottish Government National Missing Persons Strategy. However, people with dementia were excluded from the study so the particular issues concerning people with dementia remain unknown. Although not directly related to missing incidents, this literature review only found one study that included the perspective of people with dementia on wandering management strategies (Robinson *et al.*, 2007). In an informal focus group with six people with dementia, participants reported that they worry about the risk of getting lost yet they want to continue ‘going out’ alone to maintain their independence. The only known qualitative study to examine dementia-related missing incidents was an interview study with family carers in the UK (Shalev Gree*ne et al*>, 2019). Researchers found that, despite carers having valuable knowledge to inform search and rescue procedures, care partners under-report missing incidents to the police due to embarrassment and guilt; fear of disapproval or judgement by the police; distrust of the police; and a desire to protect their relative. This supports previous claims that missing cases are under-reported to police forces (McShane *et al.*, 1998). Several researchers have argued that first-hand accounts of wayfinding, wandering, getting lost and being missing from the perspective of people with dementia need to be included in the evidence base (Robinson *et al.*, 2007; Bantry White and Montgomery, 2016; O'Malley, Innes and Wiener, 2017; Neubauer *et al.*, 2019).

Part B summary

In summary, Part B of this literature review has provided context for the societal assumptions that are placed on the movements of people with dementia when they are 'going out'. In doing so, I have identified that the varied understanding and uses of terminology across research disciplines have resulted in a fractured evidence base and ineffective translation of relevant research into practice. For example, existing guidelines for missing people with dementia have been developed on the premise that all people with dementia who go missing are wandering. This results in the positioning of people with dementia as passive victims rather than active agents and the exclusion of their subjective experiences in the evidence base. This provides further justification for examining the practice of 'going out' in this inquiry rather than a particular phenomenon such as wandering or missing. In addition, to improve how agencies prevent and respond to missing occurrences and to better support people with dementia to maintain a practice of 'going out', we need to develop a better understanding of their experiences.

Conclusion

In this chapter, I have identified a lack of integration in the dementia literature discussed at the end of Part A on person-place relations and the literature discussed in this Part B on navigation, getting lost and missing. Therefore, this inquiry acts as a bridge between these two fields of literature, by examining the practice of ‘going out’ for people with dementia. The literature discussed in this chapter has shaped this inquiry by identifying the gaps in existing knowledge and, thus, leading to the development of the specific research questions that this inquiry has addressed. The following chapter will discuss the methodologic approach undertaken to answer the research questions and address the aim of this inquiry set out in the introduction to this thesis.

Chapter Three – *Choosing the Map and Planning the Route* – Research Approach

Introduction

Thus far, this thesis has set the scene for this study, positioning myself in the research and providing the political, theoretical and empirical background that has influenced the subject matter of this inquiry. This chapter details both the underpinning philosophical assumptions and the practical aspects of undertaking this research. The design of this inquiry was largely influenced by Guba and Lincoln's (2016) constructivist approach to qualitative inquiry. Crotty's 'The Foundations of Social Research' (1998) and Mason's 'Qualitative Researching' (2017) were additional key texts that guided the framework development for this inquiry. I begin this chapter by discussing my ontological and epistemological position: that knowledge is socially constructed. This chapter clarifies why I chose to frame this study as a constructivist, qualitative inquiry. Following this, I describe the research methods used to address the research aims within an interpretive critical paradigm. I begin by describing how I prepared for the process of generating and analysing the data. Then, I discuss the practicalities of gaining ethical approval, access and recruitment. Following that, I explain the data creation process from generation to analysis to theorisation. Consequently, this chapter can be viewed as an audit trail, detailing my decision-making process from the point of study conception to the writing up of this thesis. This chapter is grounded in the theoretical backdrop of previous chapters and informs the findings and discussion in proceeding chapters.

Deciding on a qualitative design

In the introduction of this thesis, I established the first phase of the research process: acknowledging the researcher (myself) as a multicultural subject (Denzin and Lincoln, 2013). I discussed the history underpinning this research and my concept of self. This should bring you, the reader, up to speed with the complex landscape that I enter as a social science researcher and how I attempt to position myself within it. To find the best-suited research approach for studying lived experiences of dementia, I explored various epistemological and methodological paradigms, learning which approaches best aligned with my ontology and the research in the field to date. I documented the process in my research diary and arrived at my own research paradigm of a constructivist approach. More specifically, I frame this study as an interpretive critical inquiry drawing on flexible and inclusive methodologies. When preparing for this research, I considered the following paradigm-defining questions posed in Guba and Lincoln (2016, pg. 37):

1. What is there that can be known (ontology)?
2. What is the relationship between the knower and the knowable (epistemology)?
3. How does one go about acquiring knowledge (theoretical perspective/paradigm/framework, methodology and method)?
4. Of all the knowledge available, which is the most valuable, the most truthful, the most beautiful, and the most life-enhancing (axiology)?

I encountered these questions in various forms during my training as a qualitative researcher (Denzin and Lincoln, 2013; Mason, 2017; Silverman, 2017; Creswell and Poth, 2018) but they were made clearest to me in Lincoln and Guba's Constructivist Credo (2016). Asking these questions of myself guided the research process. Epistemology is constrained by ontology and methodology is constrained by both ontology and epistemology (Crotty, 1998; Mason, 2017). Thus, questions one to three should be considered in chronological order (ontology → epistemology → methodology). I also considered these questions in reverse order. In this manner, I drew on Crotty's four elements of social research (see figure 1) as a heuristic tool to expand on the backwards and forwards process of designing this research (1998). As with most research, the starting point for this study was with a research question addressing a real-life problem and proposing a method to address it. Although this chapter presents the aspects of the research process in a linear fashion, in reality, when designing this research, I worked backwards and forwards along the continuum of deciding research method, methodology, theoretical perspective and epistemology, before beginning the data collection process.

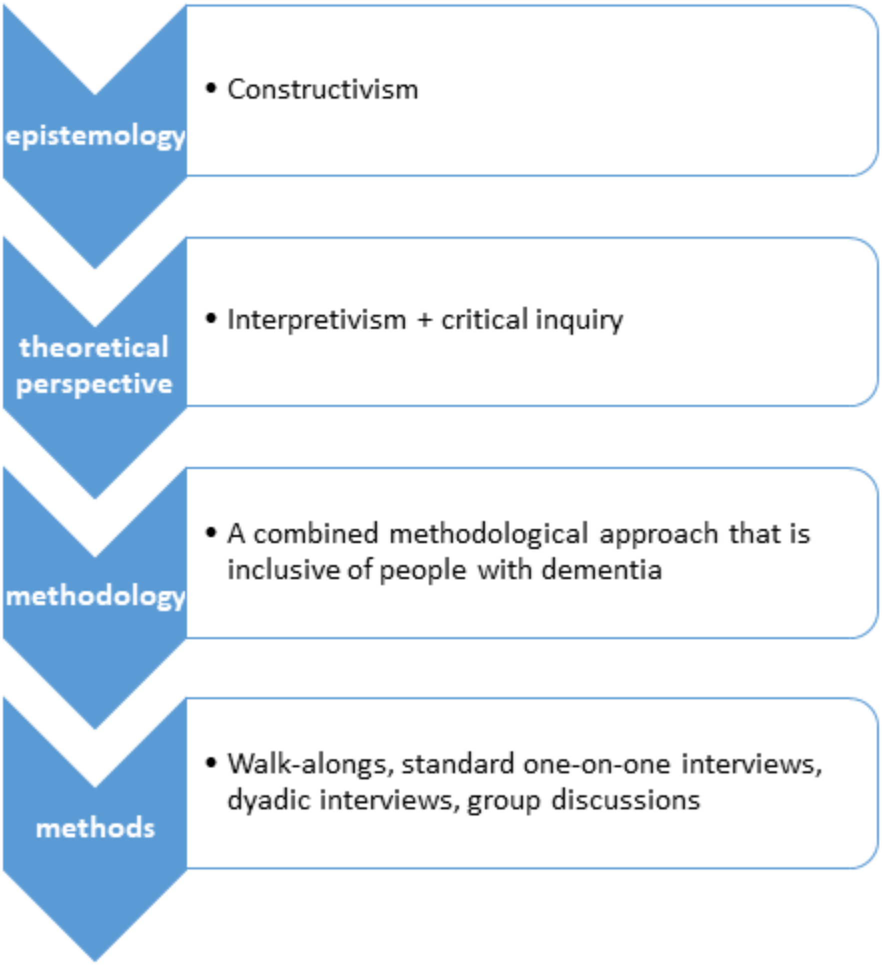

Figure 1. The four elements of this study (adapted from Crotty, 1998)

A note on ontology and axiology

Rather than addressing ontology and axiology as individual constructs, they are woven into each phase of the research process and are discussed throughout this thesis. For example, my positionality statement presented at the beginning of this thesis gave the first insight into how I view the world and the values that I hold. Put simply, ontology is the philosophical study of being and axiology is the philosophical study of values (Given, 2008).

I align myself with the ontological presupposition of relativism; that truth does not exist without meaning, that reality is context-bound and therefore, cannot be generalised (Given, 2008). I take the ontological stance that there is no absolute truth. Instead, truth is created through meanings and experiences. However, to be aligned with relativism does not mean that I oppose realism. I understand that both social and physical realities are equally relative and real. For example, a tree does not cease to exist without human beings imposing meaning on it. It is real regardless. However, by labelling it as a tree, human beings impose a particular meaning on the object. In this study, participants may hold different perspectives depending on their circumstances such as their dementia-related cognitive decline, socio-economic status, level of social support, other health conditions *etc*. One person's experience of living at home with dementia and engaging with 'going out' may be starkly different from another. Thus, the nature of an individual's social reality is time and context-specific. Therefore, this inquiry required an ontological position that acknowledges the equal value of each of these perspectives. People with dementia's ability to 'go out' may change over time, as they age, and as their social circumstances change. For example, retirement, deteriorating health, and moving to residential care will have major implications on a person's ability to 'go out'. Considering this, in order to explore people's experiences of 'going out' effectively, an epistemology that enables the development of a relationship between the researcher and participant was required to support the co-construction of knowledge.

My axiological stance is that individual values are honoured and negotiated among individuals. Although I recognise the value of an objectivist or positivist approach to answer certain research questions, I reject that approach when researching lived experience. Therefore, for this inquiry, I do not attempt to bracket my values from this research. Instead, I make my values as a researcher explicit through the process of reflexivity. I also acknowledge the values of the stakeholders in this research and their influence on the process of research design. For example, from the onset of this study, policing communities have expressed interest in the findings, suggesting that I produce an accessible guide to inform their professional practice of keeping people living with dementia safe. I also recognise that funding bodies place value on this research, as it has to be 'worth the investment'. This research was funded by Alzheimer's Society UK, a dementia charity that, rightly so, want to see results that will lead to better support for people living with dementia. Finally, I consider public engagement and dissemination efforts to be highly important, moral obligations for all researchers and therefore, I engage in these activities throughout the research process. These will be discussed further in the final chapter of this thesis. Taken together, this suggests that my own values and the values of project stakeholders are integral in this research process. Therefore, this study takes a value-laden and even value-informed approach.

A constructivist epistemology

I situate this study within a constructivist epistemology. Epistemology is how we know what we know (Crotty, 1998) or 'the relationship between the knower and the knowable' (Guba and Lincoln, 2016). Epistemology is strongly related to ontology. Broadly speaking, most studies take the epistemological stance of either objectivism, subjectivism, or constructivism. Objectivism is the epistemological stance that meaning exists separately from consciousness whereas subjectivism considers meaning to reside only in the mind and constructivism exists to fill the gap between objectivism and subjectivism (Crotty, 1998). Constructivists view meaning as something which is constructed as opposed to uncovered. It focuses on the interaction between the subjective and objective. In other words, knowledge is not sitting around "out there", waiting to be discovered. Instead, we build it with each other, with objects and with the collective knowledge that we already have, passed on across generations. Human beings do not merely experience events, instead, making sense of events is an act of construction. Sense-making is not achieved solely through cognitive processes and verbal communication. It is also an embodied and emplaced process. We do not create knowledge from nothing. We have something to work with, a world already there, that we impose meaning on (Merleau-Ponty, 1962).

In alignment with my own ontological position, Crotty claims that ‘social constructionism is at once relativist and realist’ (1998, pg. 63). In other words, just because reality is socially constructed, is not to say that it is not real. In a similar vein, constructivism and social constructionism do not give the researcher permission to decide that ‘anything goes’. I uphold standards through reflective practices and making my values apparent (Charmaz, 2006).

Considering my ontological position of relativism and my epistemological position of constructivism, I sought a methodological approach that delved into the minds of multiple knowers, attempted to understand their experiences and uncover the meaning behind their constructions of social reality. This required a hermeneutic process that explored phenomena in collaboration with knowers; working together to understand how they construct the world that they live in. As much as this inquiry is a co-construction of knowledge between the researcher and the participants, I also recognise that we each come to this research process with a unique set of expertise. I bring my moral values, my previous experiences and knowledge of dementia and my academic/research expertise. Participants bring their own set of expertise about their experiences, which I am seeking to understand. Therefore, as much as we are co-creating knowledge, we are also building on pre-existing knowledge. This aligns with my epistemological stance of constructivism, arguing that we are born into a world already full of experiences and constructs of meaning. The participants and I come to this inquiry already full of our own experiences, meanings and expertise.

An interpretive critical theoretical paradigm

Crotty defines theoretical perspective as *‘the philosophical stance lying behind a methodology’* (1998, pg. 66). A theoretical perspective is not a prescriptive set of instructions for how to do research that can be plucked off a shelf. Instead, researchers construct their theoretical perspective based on pre-existing paradigms and how they relate to an inquiry’s aims. Although it is common for certain disciplines to be affiliated to particular theoretical perspectives and therefore certain methodologies, any research can exist on the boundaries of these disciplines and therefore, with adequate explanation and justification, should be allowed to avail of the range of tools available to them from various disciplines and approaches (Denzin and Lincoln, 1994; Geertz, 2003). Therefore, considering my ontological position of relativism, my epistemological position of constructivism and my axiological position of being value-laden, I situate this study within an interpretive critical paradigm.

Interpretivism emerged as an alternative theoretical perspective to positivism, the dominant paradigm at the time in an attempt to understand and explain human behaviours, experiences and realities (Schwandt, 1996). Interpretivism is often linked to Max Weber's *Verstehen*, which means understanding and is built on the notion that reality is constructed through the interaction between human beings (Tucker, 1965). Therefore, the methodologies carried out within an interpretive paradigm are well-suited for understanding lived experiences.

Historically, interpretivism has taken many forms but can generally be split into three main paradigms: hermeneutics, phenomenology and symbolic interactionism/pragmatism. These three paradigms are overlapping and share numerous qualities. However, the main distinction between them is how they view culture. Symbolic interactionism explores culture as a system that guides how we live our lives and needs to be studied and unpicked whereas phenomenology approaches culture with '*a good measure of caution and suspicion'* (Crotty, 1998, pg. 71). Phenomenology requires the research to set aside their preconceived ideas and 'bracket' themselves (Zahavi, 2003). Although interpretations of phenomenology have evolved (particularly after it reached North America and informed symbolic interactionism), traditionally, phenomenology is uncritical and subjectivist in nature (Heidegger, 1962; Merleau-Ponty, 1962). I come to this research because of my previous experiences and to contribute to social change so adopting a phenomenological perspective was deemed unsuitable for this study. Although this study draws influence from all aspects of interpretivism, it best aligns with a hermeneutic paradigm. Hermeneutics is often used as a synonym for interpretation, to describe the research process (Denzin and Lincoln, 2013). Hermeneutics originated in studying biblical texts and spread across disciplines away from texts and into attempting to understand human practices (Crotty, 1998). In religious and legal hermeneutics, it is an applied form of inquiry, not just an academic endeavour. As a mode of understanding, hermeneutics assumes the paradoxical stance that there is both an affinity between researcher and object being studied whilst assuming a level of distance between the two. This approach has been carried over into modern hermeneutics and in current social science research practice. For example, in this study, I hold a certain level of knowledge and personal experience in the field of dementia thus having an affinity with my participants, however, there is a level of distance between my participants and me, as I do not live with a diagnosis of dementia myself.

Whilst interpretivism seeks to understand, critical inquiry seeks to challenge (Coghlan and Brydon-Miller, 2014). This inquiry seeks to challenge stigmatising views about people living with dementia including their ability to meaningfully contribute to research and to live at home, independently. Traditionally, interpretivism is an uncritical paradigm. Therefore, this study also drew on critical theory. Critical theory encourages researchers to approach research with an air of critical reflection on societal norms and a readiness to incite change (Hoy and McCarthy, 1994). It is a philosophical stance that originated in the Frankfurt School of Social Theory in the 1950s drawing on the ideas of scholars such as Karl Marx. Society has never lacked critical voices so to call Marx the “father of critical inquiry” would be unfair; however, one cannot deny the influence his work had on the development of modern thought.

Critical research is born out of the desire to not just comprehend, but to transform. Although it is perhaps an over-stretch to claim that this inquiry aimed to emancipate participants, my motivation was to create change. Namely, to foster a safe and supportive environment for people living with dementia to flourish. By giving a platform for the experiences of people living with dementia, I hope to change practice, particularly to encourage and inform person-centred search and rescue techniques. In undertaking this study, I considered myself accountable to people living with dementia, and specifically to my participants. This led me to consider how this research could improve their quality of life, even marginally. Axiologically, this means that this inquiry did not only consider the values of its stakeholders such as people affected by dementia, instead, it goes one step further: to be guided by them. As well as seeking to understand the experience of ‘going out’ for people living with dementia, I sought to uncover any injustices, stigmatisation and discrimination my participants faced and to contribute to changing that. Therefore, this inquiry is not neutral and critical theory is used as a framework for the inquiry as it provides a space to consider how participants’ everyday experiences of ‘going out’ are impacted by wider social, political, cultural and economic factors.

Considering my ontological and axiological position and the research questions posed in the introduction chapter of this thesis, I have chosen to frame it as an interpretive critical inquiry. Within a constructivist epistemology, this inquiry draws from both interpretive and critical paradigms. I draw on both paradigms because, although I seek to understand the experiences of people living with dementia, I seek to use these understandings to create social change. I want to challenge stigma and particularly views that people living with dementia are incapable of living independently. Having described my epistemological position and the theoretical stance behind this inquiry, the following section will describe the research strategy that links my epistemology and theoretical perspective to the research methods used.

A flexible and inclusive methodology

Methodology refers to the philosophies that guide how data should be gathered (Crotty, 1998; Denzin and Lincoln, 2013). Although several methodological frameworks exist for qualitative research, it is not as simple as “picking one off the shelf” (Mason, 2017) as ‘*there is rarely one ideal method - or methodology - for a research project’* (Braun and Clarke, 2021, pg. 2). This becomes even more important when working with people with dementia as pre-existing research methodologies need to be flexible enough to meet the needs and capabilities of people who may be excluded from traditional methods of data collection (Hubbard, Downs and Tester, 2003; Murphy *et al.*, 2015). Therefore, this inquiry draws on several different methodological approaches to enable the appropriate inclusion of people with dementia in the research process. In doing so, I consider myself a *bricoleur* described by Denzin and Lincoln as an inventor who ‘*recycle(s) old fabric’* to ‘*cobble together stories*’ (1994, pg. 584). I am also influenced by Mason who, suggests that qualitative research is in itself, a justifiable methodology if the researcher makes apparent the *‘essence of their enquiry’* (Mason, 2017, pg. 16) through an examination of their ontology, epistemology, research area, intellectual puzzle, research questions and your aims and purpose.

The most predominant methodological approach that underpins this inquiry is a participatory one. The fundamental premise of participatory approaches is that they provide *‘opportunities for individuals, groups and communities to actively participate and engage in the research process’* (Higginbottom and Liamputtong, 2015, pg. 2). This methodological approach is informed by the theoretical lens in critical dementia studies, which were addressed in Chapter Two of this thesis. Alongside the theoretical shift from people with dementia as biomedical subjects to be examiner to objective people whose experiences are valid, there has been more value placed on the experiences of people with dementia as evidence (Hubbard, Downs and Tester, 2002; Wilkinson, 2002a). However, the dominant narrative is still one of loss, degeneration and decline in the lives of people living with dementia. Therefore, there is a need to move away from traditional research approaches that are inflexible and risk the exclusion of people with dementia by denying them appropriate support (Brooks, Savitch and Gridley, 2016). One way to achieve this is to embrace more flexible and inclusive research frameworks (Hubbard, Downs and Tester, 2003; Nygård, 2006). To effectively give a platform for the experience of people living with dementia, the methodology employed in this study supported participants to engage with the research and allowed the development of authentic and meaningful connections (Bartlett and O'Connor, 2010). I do not consider myself to be a researcher who studies people living with dementia, doing research 'on' them. Instead, I consider myself someone who is learning from their lived experience, who is co-constructing knowledge with them, as per my constructivist epistemology. Only through this lens, could I form meaningful connections and attempt to understand people's experiences of 'going out'. Drawing on participatory principles fits within a critical theory paradigm as it offers an alternative innovative way to undertake social research, which enables emancipation and acts as a call for community action.

Core to the flexible and inclusive nature of this inquiry was the process of reflexivity, as made apparent in the introductory chapter of this thesis. By keeping a research diary and making my influence on this inquiry transparent, I hope to not just improve the rigour of this study, but also to provide a richer understanding of the research that was conducted (Dodgson, 2019) by thinking critically about what I am doing and why (Mason, 2017). In deciding a research methodology for this study, the need for a focus on the individuality and richness of each individual's experience clicked with me as I reflected on my own life experience. For example, I am often asked the question: "where are you from?" because of my accent that is difficult to pin to a particular dialect (or so I have been told). The answer to this question is not straightforward. It requires a deeper narrative. The easy answer would be "Scotland" because that is where I was born, however, that would not resolve a person's interest in my non-Scottish accent. The full story is that I was born in Scotland to a Scottish mother and an Irish father. Then, I was raised in Saudi Arabia where I attended an international school until I was seven years old. After that, my family moved to Ireland where I spent the rest of my childhood. At eighteen years old, I moved to Scotland to attend university and have been living in Scotland for the past ten years. Therefore, the answer to a seemingly straightforward question requires a narrative and after hearing this narrative, the person has a better understanding of my “mid-Atlantic” accent. I began to realise that this same logic could be applied to my overarching research question: “how do people living with dementia experience ‘going out’?” Akin to my own experience, the answer to this seemingly straightforward question requires a more in-depth narrative.

In addition to the influence of a participatory approach and a practice of reflexivity, this inquiry was also influenced by an ethnographic lens. Although I am careful not to frame this inquiry as a traditional ethnography (as I did not enter the field and immerse myself in a culture), the ethnographic approach was nonetheless, useful in informing the flexible and inclusive methodology of this inquiry. Ethnography is a research strategy, which cuts across philosophical paradigms (O’Reilly, 2014). Using ethnography as a guiding principle allowed me to enter “the field” without a fixed plan for how I would collect the data (Pink and Morgan, 2013; O’Reilly, 2014). This allowed me to build in flexibility from the outset for the research process. For example, participants could cancel if they were having a difficult day or could suggest a change in data collection methods depending on their circumstances. In addition, the notion of a “short/mini ethnography” did not require a prolonged and potentially intrusive amount of time spent with participants (Pink and Morgan, 2013). To understand the experience of ‘going out’ an everyday activity, immersing myself in that practice was important. Typically, ethnographic studies in dementia take place within a residential care setting where the researcher can be present for prolonged periods. This was not feasible for this study exploring the experiences of people who live at home as I felt that prolonged observations would be intrusive. I spent nine months in “the field”, but I was visiting different people, different environments, and my relationships with participants lasted from one visit on one occasion to five interactions over five months and everything in between. It is not ‘quick and dirty’ but it was also not a prolonged in-depth immersion into a culture.

Having provided the epistemological and methodological rationale for this inquiry, I will now discuss the research methods utilised to answer the research questions.

Research method

Until now, this chapter has discussed my philosophical assumptions, which frame how I value knowledge and how this shapes my approach to the research process. The rest of the chapter will discuss the specific methods used to answers the research questions posed in the Introduction Chapter of this thesis. The following section begins with an insight into how I designed this research project to align with my axiology, ontology and epistemology. Then, I describe the setting in which the research took place. Following this, I discuss the process of gaining access to participants, from ethical approval to recruitment. Next, I describe the data generation methods in detail and reflect on the ethical challenges faced throughout the data generation process. Finally, I explain how the data was analysed and how rigour and quality of the research process were addressed.

Designing a “dementia-friendly” study

In line with the principles of participatory research, I sought the opinion of people who were affected by dementia on the research design. As this project was funded by the Alzheimer’ Society UK, an advisory group of volunteers affected by dementia was established and we met annually throughout the project. During our meetings, I would update them on the progress of the project, and they would give feedback. For example, during one meeting, an attendee suggested I broaden the location of my recruitment from Lothian to across Scotland, capturing both rural and urban experiences of ‘going out’. In addition, as a member of the Edinburgh Centre for Research on the Experience of Dementia (ECRED), I presented my research plan at the meetings. Individuals who were living with dementia were present at these monthly meetings and they would give detailed feedback on ways that I could be more inclusive for people with dementia. For example, one individual cautioned me that people might become tired if I was to conduct walking interviews so advised me to offer my participants opportunities to take a break. As the project progressed, I sense-checked my “dementia-friendly” consent forms and information sheets as well as my interview guide with the people living with dementia who attended ECRED meetings. Finally, input on research design was also sought from Alzheimer Scotland as they assisted my participant recruitment. For example, the research officer advised that I take a “drip-feed” approach to recruitment, starting local and then slowly adding in more strategies such as advertising the study on Alzheimer Scotland’s social media platforms.

There must be careful epistemological and methodological consideration when designing a study of the everyday lives of people with dementia (Clarke and Keady, 2002; Wilkinson, 2002). Therefore, I followed criteria established by Clarke and Keady (2002) for developing appropriate qualitative methods for people with dementia:

1. **Develop a mutually trusting relationship:** I attended dementia cafes to introduce myself and promote the research, I met with participants on multiple occasions where possible, informed consent process was facilitated at a pace that suited each participant, and I developed a relationship with people living with dementia directly and not via their care partner.
2. **Sufficient engagement:** Where possible, I met with participants on more than one occasion.
3. **A collaborative approach with the person with dementia:** Participants guided what we did when we met and the length of time that we spent together. I shared emerging findings and summaries of previous discussions with participants to allow them to reflect and give feedback.
4. **Minimizing anxiety and tiredness by considering the pacing, duration and location of the data collection:** I was attentive to participant needs during data collection. I offered to meet in locations

familiar to participants and if participants appeared tired, I would suggest a refreshment break.

5. **Visual prompts and corroboration with the carer**: Walk-alongs enabled visual prompts in the physical environment. I used video clips as prompts in group discussions. I interviewed care partners following interviews with people with dementia when possible (data generation methods are discussed in full later in this chapter).
6. **Emotional engagement by the researcher**: I was attentive whilst in conversation with participants engaging in active listening. If participants became emotional or uncomfortable, I was supportive and did not probe or pressure them to continue.
7. **Attention to detail**: I relied on observations and field notes to collect data that audio recordings may not pick up such as body language and movement.

In addition, when designing the research method for this inquiry, I consulted ‘The Core Principles for Involving People with Dementia in Research’ developed by the Scottish Dementia Working Group Research Sub-Group UK (2014) and adhered to their recommendations, which includes keeping to ‘dementia time’, keeping the process simple, undertaking appropriated training and experience, conducting the research in a safe environment, valuing the lived experience and following up with participants. A large part of ensuring this study was flexible and inclusive required careful consideration of potential ethical issues.

Ethical considerations

This section highlights how I navigated the ethical landscape of this inquiry. Although this is a standalone section in the methodology chapter of this thesis, I reflected on ethics throughout the research process, from the ideation stage up until the writing up of this thesis. Ethics is far from a tick-box exercise and there is a delicate balance between abiding by the world of ethical regulations and recognising its constraints (Mason, 2017). There is a distinct difference between procedural ethics (such as obtaining approval from a research ethics committee) and ethics in practice (that unpins the entire study), with the former getting being privilege in qualitative work as the emphasis is placed on gaining approvals to go out into “the field” rather than conducting ethical research once out there (Guillemin and Gillam, 2004). The gap between these two elements of ethics can be bridged if the researcher takes a reflexive approach to the study (Guillemin and Gillam, 2004). This not only improves the rigour of the inquiry but also ensures the research is conducted in an ethical manner thus, being more inclusive of people with dementia.

Obtaining ethical approval

Alzheimer Scotland required me to become a member of Protecting Vulnerable Groups (PVG) Membership scheme, a programme managed by Disclosure Scotland, to recruit via their networks. Once this was in place, I obtained a letter of support from Alzheimer Scotland (to support my university ethics application and to take with me in the field to verify my approved status). Following this, ethical approval was granted by the Counselling, Psychotherapy and Applied Social Science Research Ethics Committee, School of Health in Social Science, University of Edinburgh on 12th November 2018 for twelve months. Mason (2017) warns qualitative researchers against putting too much emphasis on the process of obtaining institutional approval, claiming that this might distract the researcher from engaging with ethical thinking throughout the project. However, preparing documentation for university approval was a useful process as it required me to think through potential ethical dilemmas that I might face.

Establishing capacity and informed consent procedures

In Scotland, the Adults with Incapacity Act is a framework for safeguarding the welfare and finances of adults who lack capacity, including those living with dementia (Scottish Government, 2000). This legislation considers capacity as a binary concept, which is not reflective of the experiences of people living with dementia whose capacity can fluctuate. Previous research has identified criticisms of this legislation, with some people’s experiences being disempowerment and distress (Wilson, 2017). Although the inclusion criteria for this research clearly stated that only people who have the capacity to consent could participate, I recognised that levels of capacity can fluctuate in people with dementia therefore, I drew on a process consent approach (Dewing, 2007). This approach involved a subjective assessment of a person's willingness and ability to participate in the research and continuously checking that the participant understands the purpose of the research and is given the opportunity to decide whether they want to be involved (Dewing, 2007). I assured participants that declining to participate was permissible at any time and that the experience of participating should not bring them distress or harm. Full details of the inclusion and exclusion criteria are listed in Table 1.

Inclusion criteria:	**Exclusion criteria:**
People who have a diagnosis of dementia (or memory problems that are indicative of dementia) and their care partners	People who have a level of verbal communication or hearing loss that precludes interview-based data collection
People who have the capacity to provide informed consent	People who are in a state of distress or acute illness
People who live at home	
People who have the mobility to leave their own home (including those who use a mobility aid)	
People who are fluent in English	

Table 1. Inclusion and exclusion criteria

Along with using a process consent approach, I prepared 'dementia friendly' information sheets and consent forms (see appendices E, F, G and H). I consulted documentation that had been previously used by dementia researchers in my department. I also consulted Alzheimer Society UK’s guidelines for dementia-friendly documents (Alzheimer’s Society, 2017). I used contrasting colours, large print, and avoided jargon. Before submitting this documentation to the department ethics committee for approval, I sought feedback from two people living with dementia who were regular participants in research.

When possible, I sent a copy of the information sheet and consent form to participants in advance and would spend time reviewing them and supporting participants to sign consent forms at the beginning of our initial meeting. During this process, I observed that some participants found it to be a frustrating and stressful activity. Although participants were capable of understanding the research and engaging in relevant conversations, many of them had challenges with reading and writing because of their dementia (Cummings, Houlihan and Hill, 1986; O’Carroll *et al.*, 1995; Paque and Warrington, 1995). It could be argued that signing consent forms are not of benefit to the participant and instead, are intended to give more protection to the researcher than the participant (Murphy and Dingwall, 2007). When obtaining informed consent, I frequently faced ethical dilemmas regarding how I balance the institutional requirements with the best interests of the participants.

As I became comfortable in the research field, I learned to balance sticking to my research plan with “going with the flow” of participants’ lives. Many ethical questions arose where I had to make split-second decisions. I learned that human beings are not straightforward. They do not behave the way you expect them to. Although I was prepared, wrote risk assessments, and had strategies in place to ensure the safety of myself and the participant, when I went into “the field” with a participant, I often did not know where we were going, how long we were going for, or how the participant would handle the situation. Nevertheless, this is the strength of exploring the human experience and therefore, I highlight them by discussing the challenges that I faced as a researcher throughout this thesis.

Maintaining confidentiality and minimising harm

I used pseudonyms throughout this thesis and removed or changed specific details such as place names to safeguard the anonymity of participants. In the participatory spirit of this project, I gave participants the option to choose their desired pseudonym during the informed consent process. Given the nature of qualitative research and the thick descriptions used to articulate participants' experiences, anonymity is not guaranteed. Therefore, I ensured that participants were aware of this during the informed consent process.

An additional risk was the potential for discussing experiences related to dementia to be stressful. In asking participants about challenges that they faced while 'going out', I was potentially confronting them with issues that perhaps they had not considered before or that were distressing for them. My previous experience in volunteering with people living with dementia gave me the skills to be aware of signs of distress so I could change the topic or diffuse the situation. I also made participants aware of the details of support services included on the information sheet. Before entering "the field", I prepared risk assessments for any challenges that may arise during walk-alongs (see Appendix C) such as the participant falling. I also discussed with participants before our walk-along how they wanted to explain our relationship if we were to meet people they knew whilst out walking.

Preparation, professional support and adequate supervision were important factors in managing the risk of harm to myself as a qualitative researcher investigating potentially sensitive topics (Dickson-Swift *et al.*, 2009). In line with the University of Edinburgh lone working protocol, I notified a colleague or family member by text or call with details of where I was, what time I arrived at each location and how long I expected the interview to take. Following the interview, I would send a follow-up text or call notifying my contact that I had left the interview location. I also considered the potential emotional impact that conducting this type of research could have on me. As a lifelong journal-keeper, keeping a research diary was a cathartic process for me. It helped me to decompress, particularly after an interview where a participant became emotional. Colleagues with experience of conducting research with people living with dementia provided pastoral support and monthly meetings with my supervision team were a useful sounding board for ethical challenges or emotional situations that I had encountered.

Setting

The research setting is considered to be *'the physical, social, and cultural site in which the researcher conducts the study'* (Given, 2008, pg. 787). The physical site of this research was Scotland. Originally, the inquiry was designed to take place in the Lothian area but was expanded to all of Scotland after consultation with Alzheimer Scotland and project advisors. Scotland is an important place in the story of dementia research and advocacy work (Hare, 2020). It was the first country in the world to establish a working group of people living with dementia and to develop a charter of human rights for people living with dementia (Scottish Parliament's Cross-party Group on Alzheimer's, 2009). Although Scotland has a reputation for leading dementia policy and advocacy work on a global scale, I wanted to turn attention to the everyday lives of "normal" people living with dementia in Scotland. Therefore, my sampling units were people affected by dementia. I was interested in people's experiences in-situ, in the moment, and in context. Thus, I recruited from across the country from one of the Islands to the Highlands, to the major cities and several smaller towns. Recruiting participants from this variety of locations was important to compare participants' experiences depending on their geographical location (for example, in rural versus urban environments). To answer the research questions about 'going out' that this inquiry posed, the social and cultural sites of this research (also known as "the sample") were the everyday lives of people living with dementia who live at home.

Access and recruitment

Once I had established the setting of this study and that I wanted to conduct the research across Scotland, to gather as wide a breadth of experience as possible, I turned my attention to recruitment strategies. Having the support of Alzheimer Scotland was crucial in accessing potential participants (see Appendix A for a letter of support). After consultation with the Alzheimer Scotland Research Officer, we decided to first promote this study to dementia advisors. Dementia advisors are employed by Alzheimer Scotland across Scotland. Their role is to provide advice and support to people affected by dementia. I started to develop relationships with dementia advisors prior to recruitment so that they would know who I was when it came time to recruit. I presented my research plan at a dementia advisors training day in April 2018. Eight months later, when I obtained ethics approval for the research, I contacted the dementia advisors who were in attendance via email and phone. Initially, 36 dementia advisors across Scotland were sent study information via email and invited to engage. From there, advisors would either put in touch with a specific person; share my information with the people whom they supported; invite me to their local dementia café to recruit there; or assist me with setting up a group discussion. On three occasions, the dementia advisor would discuss my research with a weekly support group and if people were interested in taking part as a group, I was invited back to host a group discussion during one of their weekly support meetings. After a few months and as recruitment numbers waned, as per the advice of the Research Officer, the study recruitment flyer (see Appendix D) was shared on the Alzheimer Scotland internal staff newsletter and promoted via Alzheimer Scotland social media.

I visited thirteen different Alzheimer Scotland gatherings across Scotland. Most of these gatherings were informal cafes but some were support groups and formal meetings. These visits were an opportunity to meet potential participants; promote my study; gauge levels of interest (and capacity to consent); and invite people to participate. Most participants were recruited by myself directly at these Alzheimer Scotland gatherings, however, some dementia advisors put me in touch with potential participants directly. I also recruited two participants from a local research centre (see Tables 2 and 3 for further recruitment detail). In four cases, I had direct contact with the person living with dementia but for all other participants, contact was through their care partner (or dementia advisor on the three occasions that they set up a group discussion for me.

Deciding on sample size

For logistical reasons, I had to state my desired sample size in my university ethics applications. Therefore, I suggested that between seven and ten people with dementia plus their care partners would be recruited for interviews, meeting each individual on two or three occasions. This data was to be accompanied by six focus groups, each made up of approximately six participants (thirty-six group discussion participants in total). This decision was informed by previous research with people with dementia who found focus groups with three to six participants to be most suitable as it enabled the participants to be involved in the discussion (Rosenberg and Nygård, 2011; Rosenberg, Kottorp and Nygård, 2012). Therefore, I suggested a sample size as a rough estimate to ensure that I collected data that achieved adequate breadth and depth. In other words, data that was *'large enough to make meaningful comparisons that relate to your research questions but not so large as to become completely diffuse so that a detailed and nuanced focus on something, in particular, becomes impossible'* (Mason, 2018, pg. 71). With this principle driving my sampling decisions, it was hard to pin down a number. Practical constraints of time and finance mean the sample size of this study is relatively small, which is considered normal in qualitative research. My chosen sample size was also guided by my research strategy; I was interested in the 'why' and 'how' of 'going out', thus moving beyond a focus on sample size (Guetterman, 2015). I did not use data saturation (when no new knowledge "emerges" from the data) as this did not align with my constructivist epistemology and stance that new knowledge can always be generated from data depending on the lens of interpretation (Braun and Clarke, 2021b).

Data generation methods

The term "data collection" implies that the data are sitting "out there" waiting to be gathered whereas "data generation" implies that I, the researcher, had an active role in the construction of the findings of this thesis. This aligns with my ontological and epistemological perspectives and thus, I consider myself to be a co-creator of the data that was generated by this study. The data generation process occurred over ten months between December 2018 and September 2019. The methods of data generation used in this study were (1) walk-along interviews, (2) semi-structured one-to-one and dyadic interviews and (3) group discussions. These methods were conducted in parallel rather than sequentially. I kept field notes in a combination of handwritten notebooks, digital memos and audio-recorded reflections. I also collected some basic demographic information via a paper questionnaire. This included anonymous details such as age; gender; dementia diagnosis or care partner; living arrangements (alone or with someone); and living environment (countryside, town, city). These data are presented in Participant Tables 2 and 3 (see Appendix I for the demographic questionnaire). My choice of data generation methods was heavily influenced by the participatory principles underpinning this research. Using multiple methods enabled me to explore the research questions in different contexts. For example, walk-alongs generated contextually relevant, serendipitous data that traditional interviews did not. They also shed light on nonverbal communication and interaction with the physical environment whereas group discussions framed the data in a social context. Interviewing people living with dementia together with their care partners and apart enabled me to gather the differences in the shared and individual viewpoints. As a constructivist, I was particularly interested in how different social contexts such as the home, walking outside or indoor spaces outside the home, influenced my conversations with participants. In addition, meeting with participants over multiple occasions added a temporal element to the data. Not every method suited every participant and in order to be inclusive, I often had to adapt. For example, if a potential walk-along participant was having a bad day and did not want to go for a walk, I had to decide whether to reschedule the interview or to alter the data generation method. I would leave that decision up to the participants and they usually asked if we could carry out the interview indoors rather than reschedule. I learned early in the data generation process that participants were more responsive to a flexible and informal approach to the interviews. Over time, I became comfortable sharing my own stories and experiences, so the conversation was a genuine two-way experience.

Using topic guides

All methods of data generation were semi-structured. This allowed me to have a balance between being prepared for the data generation, as well as being able to 'go with the flow' during data generation. I developed a generic topic guide that was adapted for each interview and group discussion (see Appendix J for examples). Generally, I memorised the topic guide and would not need to consult it during interviews. Occasionally, I could sense that when taking field notes or consulting my topic guide, participants would appear uncomfortable, and the conversation would not flow naturally. If that happened, I would put them away and depend only on my audio recording and post-interview field notes. When conducting walk-alongs, I would carry the interview guide on a folded piece of paper in my pocket, but I rarely consulted it. One example of when I did consult it was when I would go to the bathroom whilst a participant and I were in a café. Meeting participants on multiple occasions eased my anxiety about forgetting to cover an important topic. If I did not have time to transcribe each interview before the following one, I would listen back to the audio and make note of any topics or questions, which I wanted to revisit or probe in the following interview. Therefore, I viewed topic guides as a flexible tool that was a key part of the iterative process of research.

Initial meeting

In my correspondence with participants prior to the first visit (via phone call, text or email), I made it clear that we could meet wherever they were most comfortable. I also clarified that the first interview would be an opportunity to get to know each other, discuss my research further and answer any questions they might have. All participants chose to conduct this initial meeting in their own home or a space that was familiar to them such as a local café or Alzheimer Scotland Resource Centre. This initial visit was crucial for building rapport. Typically, we would begin with getting to know each other over a cup of tea and would go through the informed consent process. On four occasions, the care partner was present and a part of this initial meeting. Some participants chose to go for a walk straight after this initial meeting but for some, we would agree to do it on a follow-up visit. Again, I left it up to the participants to make this decision.

Walk-alongs

As discussed in the literature review and earlier in this chapter, traditional qualitative methods do not always suit the needs of people with dementia and thus, creative approaches are required (Baldwin, 2008; Bartlett and O'Connor, 2010; Webb *et al.*, 2020). I addressed this by offering participants the opportunity to walk together outdoors in addition to (or instead of) a traditional interview. Walk-alongs (also known as walking interviews, mobile interviews, go-alongs) are a mobile method often used in geographical, place-based and neighbourhood research (Jones *et al.*, 2008).

Studies that employ walk-alongs with people with dementia have been emerging in recent years and have been reported as a positive experience for both participant and researcher, creating opportunities for the confirmation of self and acts of citizenship for people with dementia (Olsson *et al.*, 2013; Kullberg and Odzakovic, 2018; Bartlett and Brannelly, 2019; Brannelly and Bartlett, 2020). Therefore, I took up the recommendation of previous researchers to employ them as a data generation technique in this study (Brannelly and Bartlett, 2020). The rationale behind using walk-alongs in this study were multiple. Firstly, in the attempt to understand a person's lived experience, the researcher must put themselves in the shoes of the participants and experience life alongside them. Walk-alongs were an opportunity for me to immerse myself into the participants' experience of 'going out'. I also chose to conduct walk-alongs due to their contextual appropriateness (Clark and Emmel, 2010). Standard measures such as surveys and interviews are incapable of effectively measuring contextual relevance (Carpiano, 2009). The environment also provides conversational prompts to stimulate conversation and facilitate recall for people living with dementia (Ward *et al.*, 2018) as well as the opportunity to link *what* people say with not just *how* and *where* they say it thus enabling an embodied and emplaced lens. Fourthly, walking with participants allowed for serendipitous moments that would not be possible if using a traditional interviewing method. Although this lack of control over the environment came with certain risks such as the risk of harm to myself or the participant while out walking and the threat of weather conditions, it also facilitated positive risk-taking for participants (Mapes, 2017). It also enabled participants to guide the route, therefore, renegotiating the research/participant power structure. Occasionally, giving this decision-making authority to participants meant that walk-alongs were cut short or decided against due to weather conditions or how the participants felt on that particular day. Finally, walk-alongs employ a combination of interview and observation techniques which has been previously recommended as an approach to conducting qualitative research with people with dementia (Nygård, 2006). Following the advice of Bryman (2015), I tried to become an ethnographic observer-as-participant throughout this research. However, strict observational studies can be limited by the researcher’s interpretation skills (Carpiano, 2009) and they do not fully capture the participants’ experience (Kusenbach, 2003). Therefore, walk-alongs fit with my research approach as they are a more active ethnographic method (Kusenbach, 2003).

Walk-alongs ranged from a 20-minute walk around the local village to spending three hours together, hiking local trails, going to charity shops and stopping for lunch or coffee in local cafes. I conducted between one and three walk-alongs with each participant. Being flexible in my approach and undertaking these activities alongside participants, allowed for novel insights into people’s experiences without sacrificing the integrity of the research process. The recording of walk-alongs will be discussed later in this section.

Traditional interviews

As per my flexible and inclusive approach, I allowed the participant to decide the format of our interview. As a result, I conducted a combination of traditional one-to-one interviews with people with dementia, care partners and dyadic interviews with them as a pair if preferred. Details of how I engaged with each participant are recorded in the Participant Tables later in this chapter (see Tables 2 and 3). Interviews were semi-structured and conversations were guided by the use of a topic guide. This structure allows for probing questions to be asked and for the reframing of questions if they were not understood by the participant.

If a person with dementia is reported missing, care partners are an integral part of that experience. Thus, in addition to interviewing people living with dementia, I also interviewed their care partners to better understand how they support their loved ones to maintain ‘going out’. Not all care partners could engage in a one-on-one interview with me, so I made it clear that it was up to them whether they wanted to have a separate one-on-one interview with me or whether they were happy to go ahead with their partner present. Some care partners expressed that they could only be truly open and honest with me if their partners were not there, some felt that there was nothing that they would not say in front of their partner, and some would have liked to have a one-on-one discussion with me, but it was not possible because they could not leave their partner alone. In line with my commitment to participatory principles, I encouraged care partners to choose how they would like our interviews would be conducted. Some chose to meet me alone in a public space such as a café whilst others invited me to their home.

Group discussions

Focus groups can be particularly appropriate for people with limited power and influence (Morgan and Krueger, 1993). Sharing experiences may trigger recall of similar events and participants may feel empowered and supported in a group who share similar experiences (Kitzinger, 1995). Focus groups are social contexts for meaning-making. Therefore, observing participants in a group dynamic, I provided a space for participants to create shared meaning. Although focus groups have been successful with older people with dementia (Bamford and Bruce, 2000) in allowing participants to contribute to research in a supportive environment, they are not without their challenges. Drawing on the participatory principles that informed this inquiry, I chose to conduct group discussions rather than focus groups. Payne and Payne (2016, pg. 103) make the following distinction between group discussions and focus groups:

> *‘Group discussion is a means of collecting data in one go from several people (who usually share common experiences) and which concentrates on their shared meanings, whereas a focus group is a special type of group discussion with a narrowly focused topic discussed by group members of equal status who do not know one another.’*

Thus, the group discussions in this inquiry were conducted with people who already knew each other and were comfortable sharing personal experiences as they had already had this level of trust and intimacy with most members of the group. Group discussions also differ from group interviews. I did not pose a question and ask each member of the group to answer individually as is common in group interviews. Instead, I was interested in group interactions and social dynamics between participants. Achieving consensus or agreement was not the goal (Morgan and Krueger, 1993). Instead, facilitating group discussions provided insight into peer support and strategy sharing amongst participants.

Following advice from my Alzheimer’s Society advisory group, I held group discussions in familiar venues and at times that suited participants. For example, in the same building and at the same time as their weekly dementia café. I provided drinks and snacks for participants and offered to reimburse any travel costs they incurred to get to the group discussion venue (although the majority of participants declined to take me up on this as travelling to the location was an established part of their weekly routine). I gave participants dementia-friendly information sheets and consent forms. Typically, I would spend 15 minutes at the beginning of each group discussion answering questions about the research and supporting participants to review information sheets and sign consent forms. Group discussions sessions lasted from one to two hours including the time spent signing consent forms and taking breaks.

During group discussions, my role was to be a facilitator rather than an interviewer. I would start the discussion by asking a question from my topic guide or would ask participants to respond to the film sequence by asking *‘What did you think of that clip?’* I took part as an active observer, occasionally probing with follow-up questions or encouraging the more reserved participants to share their views. I had an assistant facilitator present at every group discussion. Twice, it was an undergraduate student interested in dementia research and on three occasions, it was an Alzheimer Scotland staff member. I briefed the assistant before each group discussion, giving them the agenda and topic guide to review. Their role was to assist participants with reading information sheets and signing consent forms, then to take on the role of the observer during the discussion. I asked them to make note of group dynamics and to be aware of participants showing signs of distress. If this occurred, we agreed that the assistant would raise their hand to alert me, and I would call a five-minute recess to resolve the issue. I also offered them the opportunity at the end of the discussion to ask the group any questions relevant to the research that I may have missed.

After the consent process and general introductions, I showed participants film segments to stimulate discussion (Harper, 2002) with the ultimate aim of enabling rich and meaningful connections to form in the group scenario (Bartlett and O’Connor, 2010). Segments from the film “Jack and Jill and the Red Postbox”[4] were shown. This film portrays a woman with dementia who becomes lost in her local town, capturing her response, the response of her

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[4] Originally a fictionalised play, written, performed and produced by Skimstone Arts, Newcastle, and inspired by findings from research undertaken by Edinburgh and Northumbria Universities.
https://vimeo.com/149265276

family and the responses of the people she encountered while lost. This elicited strong emotional responses from participants and lead to some engaging discussions. I selected sequences of the film to show participants based on my research questions.

Audio-recording

All interviews and group discussions were audio-recorded using the Olympus WS-853 digital voice recorder. For walk-alongs, I used a lapel microphone and wind muff, and I would wear the microphone myself rather than asking participants to wear it. The reasons for this were two-fold. Firstly, after piloting I considered the microphone of high enough quality to pick up both of our voices, regardless of who was wearing it, as long as the participant and I were within one-metre proximity of each other. Secondly, if I wore the microphone, then I could subtly check the recorder throughout the interview to confirm that it was still recording.

Reflexive field notes

My field notes were a key methodological tool and data source, capturing my reflections from the field, observations that I thought the audio recorder would not pick up and a record of my thoughts and feelings (see Appendix K for excerpts from my field notes). Whether I took field notes during interviews or after their completion, depended on the environment. For example, all group discussions took place around a table so having a notebook open in from of me to jot down observations was appropriate. Other interviews took place in people's living rooms, in public spaces such as cafes and walking outdoors where it would have broken the authenticity of the interaction. Regardless of whether I was able to take notes during meetings or not, I would find a calm environment to record my reflections after every interview. Occasionally, I would record verbal reflections with my audio recorder while out walking, which I would transcribe into written field notes later. If I were travelling home on public transport, I would spend the journey switching between audio reflections and written notes, trying to get every possible piece of information and observation out of my brain and onto the page or audio recorder. If I drove to the interview, I would find a safe place to park the car so I could audio-record and jot down my thoughts. In the days that followed, I would listen back to my audio reflections and update my field notes accordingly. My audio reflections comprised of a detailed recount of the interview interspersed with commentary on how I was feeling and what I was thinking throughout the process. I also recorded moments of the interview that I considered to be important in terms of body language or things that happened in the environment in which the audio recorded may not have picked up.

Participants

In total, I conducted walk-alongs with seven participants and interviews with their seven carer partners. I also conducted traditional one-to-one interviews with two people with dementia who opted not to walk. Walk-alongs took place from one to three visits and care partner interviews either took place as a one-on-one or a dyadic interview with their partners depending on participant availability and preference. Out of the seven walk-along participants, all of the care partners except one lived with the person they were supporting. In the case of the distant care partner, the people living with dementia lived alone and her daughter supported her from a distance. I also facilitated five group discussions. Two of these were with people with dementia only; two were made up of a mix of people with dementia and their care partners and one was with care partners only. See Tables 2 and 3 for full participant information.

Pseudonym	**Dementia diagnosis?**	**Relationship to person living with dementia**	**Approx. age**	**Sex**	**Ethnicity**	**Living circumstances**	**Living area**	**Took part in walking interview(s)?**	**Type of interview (walking, one-to-one, dyadic)**	**Approx. time spent with researcher**
Dyad 1										
Robert	Yes	-	70s	Male	White British	At home, with wife	City (suburb)	Yes	1 walking; 1 dyadic	3 hrs
Nicola	No	Wife	70s	Female	White British	At home, with husband	City (suburb)	No	1 dyadic	2 hrs
Dyad 2										
Philip	Yes	-	60s	Male	White British	At home, with wife	City	Yes	3 walking; 1 dyadic	5 hrs

Angela	No	Wife	60s	Female	White British	At home, with husband	City	No	1 dyadic; 1 one-to-one	2 hrs
Dyad 3										
John	Yes	-	60s	Male	White British	At home, with wife	Large town	Yes	3 walking	9 hrs
Claire	No	Wife	60s	Female	White British	At home, with husband	Large town	No	1 one-to-one	1 hr
Dyad 4										
Kevin	Yes	-	50s	Male	White British	At home, with wife	Town	Yes	2 dyadic; 1 walking	4 hrs
Joanne	No	Wife	50s	Female	White British	At home, with husband	Town	No	2 dyadic	3 hrs
Dyad 5										
Simon	Yes	-	60s	Male	White British	At home, with wife	Village	Yes	2 dyadic; 1 walking	3 hrs
Kim	No	Wife	60s	Female	White British	At home, with husband	Village	No	2 dyadic	2 hrs

Dyad 6										
Laurence	Yes	-	70s	Male	White British	At home, with family	City	Yes	3 walking; 1 dyadic	7 hrs
Mari	No	Wife	60s	Female	White British	At home, with family	City	No	1 dyadic; 1 one-to-one	2 hrs
Dyad 7										
Maria	Yes	-	70s	Female	White British	At home, alone	Town	Yes	1 walking; 1 dyadic	4 hrs
Laura	No	Daughter	40s	Female	White British	7 hr drive away from mother	Town	No	1 dyadic	1 hr
Individual 1										
Margaret	Yes	-	50s	Female	White British	At home, with family	City	No	2 one-to-ones	2 hrs

Individual 2										
Donald	Yes	-	50s	Male	White British	At home, alone	Town	No	1 one-to-one	1hr

Table 2. Participant interviews

Pseudonym	Dementia diagnosis	Relationship to person living with dementia	Approx. age	Sex	Ethnicity	Living circumstances	Living area
Group Discussion 1							
Drew	Yes	-	90s	Male	White British	At home, with wife	Town
Ethel (Drew's wife)	No	Wife	80s	Female	White British	At home, with husband	Town
Bella	Yes	-	80s	Female	White British	Sheltered housing	Town
Louise (Bella's daughter)	No	Daughter	50s	Female	White British	At home	Town
Charlie	No	Son (father deceased)	60s	Male	White British	At home	Town
Jim	No	Husband (wife deceased)	90s	Male	White British	At home	Town

Group Discussion 2							
Timmy	No	Husband (wife deceased)	80s	Male	White British	At home	Town
Shona	No	Wife	80s	Female	White British	At home, with husband	Town
Gerald	No	Husband	80s	Male	White British	At home, with wife	Town
Nora	No	Wife	70s	Female	White British	At home, with husband	Town
Rosie	No	Wife	70s	Female	White British	At home	Town
Group Discussion 3							
Ali	Yes	-	70s	Male	White British	At home, with wife	Town
Lizzy (Ali's wife)	No	Wife	60s	Female	White British	At home, with husband	Town

Andy	Yes	-	70s	Male	White British	At home, with wife	Town
Patricia (Andy's wife)	No	Wife (Husband deceased)	60s	Female	White British	At home	Town
Alex	No	Husband (wife deceased)	70s	Male	White British	At home	Town
Group Discussion 4							
Donald	Yes	-	50s	Male	White British	At home, with family	Town
Peter	Yes	-	80s	Male	White British	At home, with family	City
Jackie	Yes	-	70s	Female	White British	At home, alone	City
Group Discussion 5							
Jimmy	Yes	-	60s	Male	White British	At home, alone	City

Cindy	Yes	-	50s	Female	White British	At home, with family	City
Annie	Yes	-	60s	Female	White British	At home, with family	City

Table 3. Participant group discussions

Organising and analysing the data

This section details how I managed the physical and digital data generated in this inquiry. The purpose of this section is to act as an audit trail, explaining how I transformed the data generated into “findings”, which will be presented in subsequent chapters. The methodology guiding this inquiry also informed my approach to data analysis. Data analysis is an iterative process that can be simply defined as the researcher’s attempt to make sense of the data (Srivastava and Hopwood, 2009). It is an embedded part of the research process and is not an activity that is done solely upon the conclusion of data collection.

Data management

I prepared a Data Management Plan in preparation for conducting this study that guided how that data was identified, stored, shared and deleted (Appendix B). Digital data were stored on the University of Edinburgh secure server and physical files were stored in locked cabinets on University of Edinburgh premises. I uploaded the interview and field notes audio files from the recording device to the server as soon as possible following the interview. When transcribing the audio-recordings myself, I anonymised the data immediately. When sharing audio files with a transcription service, I uploaded them via a password-protected portal. The transcription service was a reputable business with experience of working with academic transcriptions and a privacy agreement was in place. Once the transcription service uploaded the completed file to the portal, I would download it, change any identifiable information immediately, save the new anonymised version to my university drive and delete the original. My physical research diary either was on my person or kept at home and I avoided writing any identifiable information in it. I used NVivo (Version 12), a qualitative data analysis software, as a tool to store transcriptions, record field notes and code data.

Transcribing

Once audio-recorded data were generated, they were transcribed verbatim within the days following the event. I sent half of my audio-recorded data to be transcribed by a professional service. Upon receipt of these transcripts, I would re-read them, line-by-line, whilst listening to the audio recording to ensure they were accurate. I made minor changes such as adding in details of body language and movement into the transcription. Transcriptions were completed in Microsoft Word and uploaded to NVivo for coding. I also printed all transcription on paper and hand-coded them, writing notes in the margins, and updating the codes in NVivo accordingly. Although I did not transcribe my audio-recorded reflections, I listened to them repeatedly, noting anything of importance in my Research Diary memo in NVivo and coding it accordingly. Occasionally, I listened to audio recordings whilst out walking or when I needed inspiration in the midst of writing up this thesis. I considered the act of transcribing and reviewing transcripts to be embedded in the data analysis process (Sandelowski, 1994; Tessier, 2012). Field notes (written and audio), transcripts and audio recordings were equally considered as data sources (Tessier, 2012).

Familiarisation, coding and generating themes

The data were then subject to content analysis to find patterns of meaning across the data. Initially, these data were coded and themed using Braun and Clarke's reflexive thematic analysis approach (Braun and Clarke, 2019). See Appendix L for data analysis excerpts. Although reflexive thematic analysis is popular due to its theoretical flexibility, it is not an atheoretical approach. This approach aligned with my epistemology of constructivism and my paradigm of interpretive critical inquiry. It also aligned with my epistemological stance that themes do not 'emerge' from the data. Patterns and meanings were not sitting in the data, waiting to be found. Instead, I imposed my subjective lens on the data to construct themes thus justifying my role in the data generation process. I also opted to follow Braun and Clarke's (2019) approach because it embeds reflection into the coding and theme generating process and emphasises the importance of writing up in the process of analysis. Braun and Clarke's (2019) six-phase approach to thematic analysis involves:

1. Familiarisation with the data

2. Coding
3. Generating initial themes
4. Reviewing themes
5. Defining and naming themes
6. Writing up

Through the process of organising and transcribing the data, I familiarised myself with the data and thus, began the process of coding and generating themes immediately (see Table 4 for examples of coding and theming segments of the data).

Transcription excerpt	**Initial code**	**Sub-theme**	**Theme**
'Oh, I meant to bring a bar of chocolate for this boy. He likes sweet things.'	Considering others	Relational support to enable 'going out'	The relational agency of 'going out'
'Well, I think originally it was always the benefits, now it's now slipping into risks, in my own mind.'	Risks vs benefits	Everyday decision-making	Making adaptive decisions to maintain independence and control in 'going out'

Table 4. Example journey from transcript to code to theme

The role of writing up will be discussed later in this chapter. Coding was a layered process. As I coded data, I grouped them into categories with some codes constantly shifting. Saldana describes coding as *'not a precise science, it is primarily an interpretive act*' (Saldaña, 2015, pg. 217). Coding the data was both an abductive and iterative process. It was abductive as I used a combination of semantic (descriptive and data-driven) and latent (concept and theory-driven) codes. Prior to data-generation, I had knowledge of existing models, theories, and concepts in the literature. This knowledge base, combined with participant-led experiences shared in the data generation process, informed my approach to coding. I took an iterative approach by reading data numerous times, each with a different strategy. For example, I read transcripts with my research questions to hand considering how the data fit with the wider literature and I read them whilst attempting to disregard my research questions and the wider literature. Therefore, some of the codes and themes that were generated in this inquiry were expected whereas others, were not (see Table 5).

Expected themes generated	**Unexpected themes generated**
Considering risks vs benefits of 'going out'	*Embracing vulnerability*
Being supported by care partners to maintain 'going out'	*Adapting to a life with dementia and demonstrating resilience*
'Going out' to maintain independence	*'Going out' to support others in the community*

Table 5. The abductive process. Expected vs unexpected themes generated

Theme generation was a process that shifted from within NVivo to using flip chart paper and post-it notes so I could visualise the movement of categories and relationships between themes. Thus, the data went through multiple variations of theme generation after initial coding. This experience was reflective of Saldana's words that "*data are not coded – they're recoded'* (Saldaña, 2015, pg. 88). For example, my first attempt at theme generation was to organise codes around themes of environment, self and other but there were too many 'cross-cutting' categories which I deemed too important to cut so I broke down the categories again and this reworked organisation of themes became the basis of the first draft of my findings chapters. I changed the organisation of the theme and rewrote the chapters two further times until I was satisfied that the thematic analysis was completed.

Using thick descriptions

As I progressed with the thematic analysis, I saw how it was not a well-suited method for language practice. Coffey and Atkinson describe the purpose of qualitative analysis to be *‘as much about how things are said as about what is said’* (Coffey and Atkinson, 1996, pg. 77). In the case of this inquiry, as well as an interest in *what* people said, I became increasingly interested in *how* and *where* people say things. My mind was drawn back to specific moments during the walk-alongs, when participants were engaging with the environment, which I considered important but were not represented adequately in my initial drafts. Although I coded the data “interacting with the environment”, it did not fit the story that I was generating from the thematic analysis. Exploring these interactions enabled a deeper engagement with the overarching aim of this inquiry and therefore, alternative analysis methods were required to show meaning beyond the themes identified. Therefore, I performed a second analysis on the walk-along interviews using “thick descriptions”, a method proposed by the anthropologist, Geertz (2001). I mapped out the journey of each walk-along and then selected key moments and themes that stood out to me. This allowed me to weave in temporal and situated context to the data that I couldn’t make fit with the thematic analysis. My use of thick descriptions attuned to context (Denzin and Lincoln, 2013). I introduce the participant to provide orientation, then focus on a key moment or event between the participant and myself, concluding with a reflection on the interaction. In addition, I was influenced by a walk-along study that focused their analysis on the co-constructed narrative including the silences that occurred during the walk-alongs (Stiegler, 2021). This led me to focus on what was *not said* as much as what was said in my data, which facilitated participants to be *‘narratively repossessed and thus become narrative citizens’* (Baldwin, 2008, pg. 223). This analytical approach aligned with the participatory principles that guided this inquiry.

Going beyond the data

I employed an abductive approach in this inquiry, moving backwards and forwards from the data, my own experiences and theory (Lipscomb, 2012). Writing up was a key technique in this abductive process. In his influential text, *Writing Up Qualitative Research*, Harry Wolcott proposes that '*writing is thinking'* (2009, pg. 18). In a similar vein, in his book, *Writing for Social Scientists*, Howard Becker states that the skill of writing is in fact, in *rewriting* (Becker, 2007). The progression of moving from data generation to completed thesis involved several iterations of drafting, receiving feedback, deconstructing, and redrafting. This facilitated new ways of seeing my data and contributed to the development of my thinking and analysis.

Other techniques employed to bring a new lens to the data was to consult "outsiders" to the project to act as a sounding board, particularly my mother, a retired dementia care nurse and fellow PhD students who asked the probing questions which challenged my thinking. Monthly discussions about the data with my supervision team, (who were not outsiders to the inquiry but had more distance than I) shaped how the data evolved. Presenting preliminary findings at conferences and seminars also allowed me to gauge outside interest in this inquiry and shaped how I returned to the draft chapters, often leading to edits in the framing of certain sections.

A theory is '*an idea about how other ideas can be related'* (Dey, 1993, pg. 51). I employed theory as a heuristic tool to develop ways of thinking with the data as '*the generation of ideas can never be dependent on the data alone'* (Coffey and Atkinson, 1996, pg. 153). The abductive approach consisted of constantly shifting from being embedded in the data to researching theories, which might offer a framework to explain that data. In this sense, theories were not considered at the end of the analysis process as a '*final gloss'* (Coffey and Atkinson, 1996, pg. 158). Instead, they were *'drawn on repeatedly as ideas or formulated, tried out, modified, rejected, or polished'* (Coffey and Atkinson, 1996, pg. 158). For example, I frequently returned to citizenship, risk and human rights theories that were relevant to the field of dementia, trying to find the theoretical lens that “best fit” with my data.

Although the data for this inquiry was generated in 2018 and 2019, the formal writing up of the thesis took place in 2020 in 2021 during the global COVID-19 pandemic. As most of the world was practising social distancing and were limited in their abilities to leave home, this undoubtedly had an impact on how I interpreted the data for this inquiry and provided another lens through which to consider this research. Although data analysis is never complete, there comes a point in all qualitative research when one has to bring the data analysis process to a close recognising that there are *‘always more ideas and more lines of inquiry open to us than we can ever hope to exhaust’* (Coffey and Atkinson, 1996, pg. 147). The process of writing and rewriting helped to draw the data analysis process for this thesis to a close.

Ensuring rigour and quality

This study demonstrates rigour and quality by drawing on principles of reflexivity and transparency throughout the research process. Quantitative measures of evaluation such as validity, generalisability and reliability are not appropriate measures for qualitative research (Seale, 1999). However, the principles that underline these measures need not be abandoned in qualitative research; they just need to be reimagined (Mason, 2017). Thus, the quality and credibility of qualitative research should be judged by the study methods and findings aligning with the researcher’s ontology, epistemology, axiology and methodology (Mason, 2017; Creswell and Poth, 2018). Qualitative researchers can make this apparent by adopting a reflective methodological process (Seale, 1999; Charmaz, 2006; Mason, 2017; Braun and Clarke, 2019). As highlighted throughout this thesis, I draw on reflexivity to ensure that this study is of high quality. As discussed earlier in this chapter, I reflected on my positionality and the lens through which I view this research; kept a research diary and checked preliminary findings with participants, other researcher and study advisors. Creswell and Poth (2018) use the word “validation” to describe quality in qualitative research and acknowledge that *'authors need to choose the types and terms with which they are comfortable*' (pg., 259). I have adapted their suggested validation strategies (highlighted in Table 6) to demonstrate to the reader how I employed these strategies, thus ensuring rigor and quality in this inquiry.

Validation strategies checklist		How I employed these strategies
Triangulation of sources and methods	✓	I employed multiple methods to generate data (walk-alongs, interviews and group discussions) and multiple methods to analyse data (reflexive thematic analysis and thick descriptions).
Prolonged engagement in the field	✓	Although it was not the case for every participant, I engaged with most participants on more than one occasion. Overall, data generation took place over nine months.
Peer reviewing and debriefing	✓	I had monthly supervision meetings and frequent discussions with fellow PhD students.
Clarifying researcher bias	✓	I address this in my reflexive approach throughout this thesis.
Member checking	✓	I conducted member reflections (Tracy, 2010) with several participants.
Using rich, thick descriptions	✓	I employed rich, thick descriptions in writing up this research.

Table 6. Quality checklist (adapted from Creswell and Poth, 2018)

Presentation of data in this thesis

The following three chapters report the findings of this inquiry. Chapters Four and Five present the findings that were generated from the reflexive thematic analysis. Chapter Six employs thick descriptions to show how participants experienced ‘going out’ as an embodied and emplaced practice. While the thematic analysis allows us to see patterns and commonalities across participants’ experiences of ‘going out’, the thick descriptions chapter provides a richer insight into these experiences, helping us to see that although ‘going out’ is a universal practice, it is also a unique practice, which holds different meanings across individuals. If a single data analysis method was used, we would be at risk of losing the nuanced and rich picture of the experience of ‘going out’. This decision to use two methods of analysis aligns with my critical epistemology and participatory methodology as this inquiry has broader aims to break down the stigma surrounding dementia by demonstrating how each individual has a different experience. Data excerpts are presented in a way that aligns with the participatory principles of this inquiry. Participant quotes are used frequently to prioritise the voice of participants and to allow the reader to see what participants said versus how I interpreted that. In addition, participants are referred to by their pseudonyms to avoid potential stigmatisation and labelling of “people living with dementia” as if they are one homogenous group.

Conclusion

This chapter has provided an exploration of the philosophical assumptions which underpinned this research. I justified why I chose to frame this study as a constructivist inquiry (specifically an interpretative critical inquiry), within a “dementia-friendly” methodology, drawing on participatory, reflexive, and ethnographic principles. I then provided a detailed explanation of the data generation methods used in this study including walk-alongs; semi-structured one-to-one and dyadic interviews; group discussions; and field notes. I employed a reflexive approach throughout this chapter (and continue to do so throughout this thesis) to unpick underlying tensions between balancing operating within a methodological and ethical framework with embracing the mess of the human experience and being guided by participatory principles. These tensions provided opportunities for me to reflect on the research process and in doing so, make this study more transparent and therefore more rigorous. The following three chapters will present the main findings of this thesis, teased out through the process of capturing, interpreting, writing, and rewriting people's experiences.

Chapter Four – *The Practice of 'Going Out'* – An Adaptive and Relational Pursuit of Agency

Introduction

The empirical findings from this inquiry are split across the following three chapters. These chapters draw on the walk-alongs, field notes, one-to-one interviews, dyadic interviews and group discussions to explore the motives and strategies regarding 'going out' for people with dementia who live at home. In order to understand these motives and strategies, together, these three chapters describe the *practices, people* and *places* participants engage with when 'going out'.

In Chapters Four and Five, I present these findings by drawing on direct participant quotes. My motivation for this was twofold; firstly, it aligns with participatory principles that aim to give a platform for the voices of people living with dementia. Secondly, I rely heavily on direct quotes to give the reader insight into what the participants said in comparison to my analytical lens applied to those words to arrive at a theme. Chapter Six employs reflexive thick descriptions to explain the embodied and emplaced experience of walking with participants.

This chapter presents two main themes: (a) making adaptive decisions to maintain independence and control in 'going out', and (b) the relational agency of 'going out'. Participants' pursuits of agency were upheld by the support of care partners and the wider community. This chapter also highlights how people living with dementia are not only recipients of support; they also support others and contribute to the local community. Together, these themes explain how participants 'go out' as a practice of everyday citizenship.

Making adaptive decisions to maintain independence and control in 'going out'

The theme explored in this section demonstrates how participants maintain 'going out' through engaging with dynamic decision-making practices. This theme indicates that participants are active agents in the practice of 'going out.' In other words, when people living with dementia 'go out,' they are continually making decisions and weighing up the risks versus benefits. As dementia is a fluctuating condition, people are constantly renegotiating what they are capable of on a daily and even moment-by-moment basis. My inquiry found that these decision-making practices occur at two levels: broader life decisions and everyday decision-making regarding 'going out'. These decisions are also made in collaboration with care partners.

Adapting to a life with dementia

Generally, the participants who maintained a routine of 'going out' were those who accepted the changes that accompany a dementia diagnosis and were able to adapt to those changes. Participants who had accepted that one consequence of living with dementia is that they can no longer do certain things often devised alternative ways to engage in activities that were meaningful to them. For example, Maria explained that she could no longer tolerate busy and loud environments such as live music concerts and Simon could no longer tolerate the sensory overload brought on by watching a film at the cinema, which they both used to love doing. Instead of focusing on what they could no longer do, they both focused on continuing to do the activities that they were capable of doing independently such as meeting friends for coffee or going to yoga class. Likewise, participants who could no longer drive learned to negotiate public transport or asked friends and family for lifts. John also embraced this attitude of "getting on with life". He articulated this by playing me his favourite Neil Diamond song "Hell Yeah" on his CD player at home before one of our walks. John explained that the song captures his attitude to life since his diagnosis:

> *'Having listened to the words of that song, and just*
> *saying to hell with that, let's get on with life and enjoy it.*
> *So that's it.'*

Once participants came to terms with their dementia, they did not accept that it meant that was the end of their life. They accepted that they had to make changes to continue to lead an independent life, but they demonstrated resilience in their ability to make those changes and to continue living their lives to the fullest. For example, after Kevin and Joanne told me the story of Kevin's diagnosis, Joanne summed up Kevin's outlook on life:

> *'He was never one who felt sorry for himself or had woes about anything.'*

This attitude of getting on with life was a viewpoint that participants who were living with dementia and their care partners both held. When Joanne discussed how she and Kevin coped since his diagnosis, she said:

> *'…we've been managing fine. It's just different wee things when they come up but we find our way around them. Just deal with it and get on with it.'*

This united front between care partner and person living with dementia enabled both parties to feel more confident in their decisions and actions.

However, adopting an attitude of "getting on with life" was not easy, for people living with dementia and care partners alike. It took time to come to terms with a dementia diagnosis. Mhairi reported how she coped with the changes in their life since Laurence's diagnosis:

> *'It doesn't bother me now. I mean it was hard at the start, you know, the earlier days, but I think it just becomes a way of life, you know, you just get used to it and you just do everything.'*

During a group discussion with care partners, George echoed this sentiment. After an emotional reflection on the challenges of adjusting to his wife's dementia diagnosis, through a teary smile, he concluded:

> *'…you just have to pick yourself up and get on with it.'*

One way that participants enacted this attitude of "getting on with life" was by striving to maintain a sense of independence. However, balancing this right to freedom and independence whilst recognising the risks they face underpinned every decision related to ‘going out’. Participants often had to depend on others to achieve this, which was not always easy to do. For example, Maria lived alone and therefore, did not have the everyday support of a care partner. In some ways, this simplified her decision-making practices because she did not have another person to consult however, this also complicated her decision-making because she had to depend on other people and strategies to ensure she was safe. When I asked whether having freedom was important to her, Maria responded:

> *‘I’ve been brought up in a free society, I’ve been brought up to believe it is our human right to be free, our human right to make choices. And if I want to go out I should have a right to be able to go out, but I also have as a human being...to do it...calculated...taking risk. So calculation is having a freedom to roam bracelet [GPS tracker] or a tracker and a Herbert Protocol*[5] *and things in place so that you’re doing it with safety in mind, but you still...if I want to go out, I don’t care how far on my dementia is, I have a right to go out, so it’s up to others to enable that to happen.’*

Maria chose to go out alone to maintain her sense of independence and in doing so, she argued for a shift in the decision-making responsibility regarding her safety from herself to *‘others’*.

Unlike Maria, who lived alone, Simon lived in a rural area with his wife, Kim. Simon experienced various sensory challenges, which made using public transport difficult for him. Therefore, Simon was dependent on his family to drive him anywhere he needed to go and although he was appreciative of their support, he felt guilt and frustration that he was dependent on that assistance:

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[5] The Herbert Protocol is an information gathering tool to assist the police to find a person living with dementia who has been reported missing as quickly as possible. The initiative was first developed by Norfolk Police. It is named after George Herbert, a war veteran of the Normandy landings, who lived with dementia.

> *‘You do feel you lose your independence a bit and your sense of pride probably. I feel less… Because I have to ask someone to take me somewhere.’*

Simon could no longer be spontaneous in his decision-making. For example, if he wanted to take the dogs for a run along the local beach, he had to coordinate with Kim regarding whether driving him to the beach fit into her schedule. Although Kim was committed to supporting Simon to do the activities that help him to maintain his sense of independence, she had the power to say no. Although this may be for valid reasons such as feeling unwell or having a prior commitment, the fact that Simon was dependent on her to go to certain places means that he felt a loss of agency as he was no longer able to make these decisions for himself.

Maintaining independence was a shared priority for those living with dementia and their care partners. Similar to Kim, Mhairi was committed to supporting her husband, Laurence to maintain his sense of independence. When reflecting on how she balanced Laurence’s safety with supporting him to maintain his sense of independence, Mhairi said:

> *‘… most cases it's worth taking the risk as long as you check it all out properly it's worth taking the risk for the happiness, you know, for their mental state it's well worth it. It's getting the balance.’*

One of the ways that Mhairi tried to maintain this balance was by using the Purple Alert app[6]. At a local coffee morning with Mari, Laurence and some of their friends, Mhairi showed me this app that she had recently downloaded and set up a profile for Laurence. However, this was the first Laurence had heard about it and he was upset that she did not ask his permission to create a profile of him. The next time I met Mhairi (without Laurence), I asked how she was getting on with the app. She replied:

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[6] Purple Alert is a mobile application developed by Alzheimer Scotland. It is a free, community-minded app to help finding people with dementia if they are missing. https://www.alzscot.org/purplealert

> *‘Well, I actually took it off my phone because Laurence didn't seem too happy about it. Although he never commented on it again, but I thought, I probably should have discussed it with him, but at the same time it was just it came into my head when I was sitting myself one day and I thought I should really have that on. I mean it's not something that you would need to use, but it's there if he went missing, I can alert and there is people would go out, you know, on the lookout. I actually think it is quite a good thing to have. So, I've still to broach the subject with him again about me putting it back on.’*

Although Mhairi downloaded the app with the intention of it supporting Laurence to maintain ‘going out’ safely, his dissatisfaction highlighted that she had not consulted him in the process. As a result of this, Mhairi deleted the app even if she thought having it reduced his risk of harm. This demonstrates how decisions relating to ‘going out’ are not set in stone. Embracing the “getting on with life” mindset whilst trying to manage risks is a complex and dynamic decision-making environment.

Everyday decision-making

Along with the broader decision-making practices regarding coping with and adapting to a life with dementia, participants also engaged in dynamic decision-making practices depending on their capabilities at the time. For example, when Kevin could no longer navigate to the local town that was a 20-minute walk away, he changed his daily walking route to something more local and familiar. Although it was different from what it once was, he maintained his ability to get out of the house each day:

> *Joanne: You used to walk up and down to (nearby town) but you can’t do that yourself now.*
>
> *Kevin: But I don’t really bother with it now because I’ve adapted to something else.*

Similar to John, Simon avoided busy city environments and stuck to quiet areas and Laurence only ventured to parts of the city that he was familiar with. In this vein, most participants demonstrated an ability to change their ‘going out’ practices depending on their abilities.

The use of transportation was a major change in most participants’ lives after a diagnosis of dementia. Most participants had to give up driving and adjust to using public transport or depend on friends and family to drive them to places. When public transport became challenging, several participants transitioned to using taxis more regularly. For example, during one group discussion, Jackie, who lives alone and cannot drive because of her dementia, shared that she now uses taxis instead of buses. She found bus journeys to be stressful and often dangerous, as the bus driver would regularly pull out of a stop before she had a chance to sit down. When someone else in the group discussion admitted that they also had these challenges with buses, she encouraged them to switch to taxis, claiming:

> *‘it’s a great safety.’*

Similarly, Joanne cannot drive so when Kevin had to give up driving due to his dementia, she set up an account with the local taxi firm so that they could both use taxis regularly. Simon also highlighted the benefit of using taxis. Because the nature of his dementia-related impairments made using public transport difficult for him, the local council gave him £5 vouchers to put towards taxi fares. This allowed him some freedom and reduced his dependence on his wife to drive him everywhere.

It is a common misconception that a diagnosis of dementia renders a person unfit to drive. Although some people decide to give up driving immediately after their diagnosis, this was not the case for every participant. For some, it was a crucial skill that they depended on to maintain a sense of independence after their diagnosis. However, those that still drove were aware of how their dementia affected their driving. For example, Donald lived in a rural area with limited public transport, so he still drove. However, he did not venture too far from his local area:

> *'I'm very aware that I need to be very careful.'*

Donald was aware of his impairments and was adamant that he did not want to pose a risk to others. He acknowledged that he may have to give up driving soon and then he will be dependent on his sisters to drive him to the places where he cannot walk. Like Donald, John still drives. However, he had recently decided to make changes such as switching from a manual to an automatic car and no longer driving at night or in bad weather. He also acknowledged that he would have to give up driving in the future, but he wanted to be in control of that decision:

> *'I would like to think that come the time when I don't think I'm up to it I would confess to that. And stop driving.'*

Several participants decided to give up driving when they were diagnosed. For example, Margaret chose to give it up voluntarily:

> *'I had kind of decided not to because I was quite happy taking public transport.'*

Regardless of when the decision was made, the important thing to note here is that Donald, John and Margaret felt that the decision was theirs to make. In contrast to this, Laurence and Simon shared upsetting stories about being told by the doctor that they were no longer allowed to drive when they were diagnosed. On the day of his diagnosis, Simon drove himself to the hospital and when the doctor confiscated his driving licence there and then, Simon was stranded at the hospital, without the means to get himself home. Although Laurence and Simon did not necessarily disagree with their respective doctor's decisions, they were frustrated with how these decisions were made without their consultation and that they were, therefore, denied agency in that impactful decision. Laurence suggested that he could have been supported to continue driving in a safe way such as on a restricted licence and avoiding certain roads. This frustration at decisions being made by others was echoed in group discussions. Frustrated at his experience of healthcare professionals making decisions for him, Peter proclaimed:

> *'all of a sudden, I'm not allowed to do anything now.'*

Taken together, these experiences can be used to support the argument that people living with dementia should be involved in the decision-making process that will impact their ability to maintain 'going out.'

Whilst walking with participants, I observed how they engaged with everyday decision-making practices by deciding which routes to take. Every walk-along participant took on the role of tour guide or lead navigator with pride. For example, Laurence guided me on and off several buses in a city that I was unfamiliar with, telling me where we will disembark with ample warning, what times the buses will arrive and what numbers will take us in which direction. When waiting at a bus stop, I asked Laurence which bus we were getting. He replied:

> *'The 3. That was a [different operator] 3 that came in but that doesn't take us to the door. And it might be bucketing down. That bus (point to bus that is pulling up) will take us near but not near enough.'*

By talking me through the potential buses that we could get, I suspected that Laurence was intentionally showing me how well he was able to navigate and how he was capable of changing his mind depending on the weather or how he was feeling on a given day.

Walking with participants also gave me insight into how they considered other people, including me, in their decision-making practices. For example, some participants chose walking routes based on what they thought I would enjoy most. Maria took me to her local loch for our walk-along because it was a quiet, safe, and picturesque location for our interview. Laurence quizzed me on what parts of the city I have been to so he could take me to his local haunts and areas in the city that I had not yet explored. Likewise, John chose to walk on routes that I might enjoy based on the scenery and landscapes. John also considered my safety. For example, he decided to walk on the more "dangerous" side of the path nearest a potential hazard such as the road or a river as we walked side-by-side. He explained this choice of positioning:

> *‘That’s why I always walk on the side of the water, because generally speaking, I’d hate to be the one that pushed somebody in the water. And somebody would have to be pretty big to push me in there really.’*

John also admitted that he was more cautious when walking with me compared to when he was walking alone:

> *‘Normally when I’m by myself I just jaywalk across these roads without any problem but now I’ve got somebody with me we’ll cross safely, because there’s an added burden of responsibility.’*

Unlike John, Maria chose to take my arm and suggested that we jaywalk telling me that if she were on her own, she would walk the extra distance to the crossing, but my presence provided her with more security. Although their justification for their actions differed these situations show that John and Maria could assess risks and make decisions based on this.

As I walked with participants, I observed how they embraced the role of navigator. Most participants seemed to give directions with ease and confidence:

> *‘go through this wee bit’ [Kevin]*
>
> *’go left here’ [John]*
>
> *‘we’ll go out past here then do a right turn’ [Laurence]*
>
> *’I think we’ll go up here’ [Philip]*

It is difficult to unpick how my presence changed participants’ experiences of ‘going out.’ I was surprised by how confident they were in their navigation skills. Perhaps this is because they felt safe with me, knowing we could work together to relocate ourselves if we got lost or perhaps, they would be this confident regardless of whether I was present or not. I reflected on this experience when walking with Robert in my field notes:

> *I'm not confident that Robert would be able to find his way home if I was not there but he seems eager to explore with me. I try not to take charge of the route, but he often gives me a choice e.g., 'we can go left or right here-which way do you want to go?' I try to let him decide. We are both deflecting the decision-making onto each other. I am deflecting onto him because I want to see how he copes with taking charge of the route and perhaps he is deflecting onto me because he does not want me to see that he is having difficulty with navigating… would he be able to find his way home without me? Nicola says that he doesn't go further than the local corner shop on his own now… He seems so confident! Is it a deflection?*

In addition to adapting to a life with dementia and considering other people, the final aspect of participants' everyday decision-making practices was their consideration of risks involved in 'going out'. Perceptions of risk differed from person to person. For example, during one group discussion, Bella did not consider 'going out' to be *'too risky'* because of the risk of getting lost but instead, she feared being taken advantage of by other people:

> *'And a lot of places that I now do that I have to be careful on some of the roads, because there's a lot of bad people.'*

In another group discussion for the risks versus benefits of 'going out,' Annie was adamant that it was simply not an option for perceived risks to obstruct her ability to go out:

> *'No, never, no, when I go out, no. I can ask people, I need to…I never…I'm not afraid of going out at all, no.'*

In contrast, in another group discussion on the topic of risk, Ali admits that potential risks are now at the forefront of his mind when 'going out':

> *'Well, I think originally it was always the benefits, now it's now slipping into risks, in my own mind.'*

Not only did people’s perceptions of risk change based on the individual, but they also changed based on the location. For example, Laurence considered himself to be more at risk in isolated areas:

> *‘Well, I think it’s too dangerous if it’s too isolated. I mean, I could go anywhere but you’ve got to think, if I collapse, who's going to find me?’*

Laurence’s bus pass gave him the freedom to travel anywhere in Scotland, but he could not go anywhere he wanted because he was concerned for his health. He decided that the safest way for him to maintain ‘going out’ was to stay within busy environments. That way, if he did collapse, someone would find him.

In summary, when adjusting to life after a dementia diagnosis and specifically when ‘going out,’ participants engage in dynamic and relational decision-making practices in order to maintain their sense of agency and independence. This dynamic process requires constant renegotiation depending on each individual’s limitations and capabilities and a careful balance of the risks versus benefits regarding ‘going out’. Although participants were vocal in advocating for their rights to independence and exercising agency, they acknowledged that for these rights to be fulfilled, they needed support from others. This will be discussed in the following section.

The relational agency of ‘going out’

The second theme of this chapter demonstrates how participants maintained ‘going out’ through engagement with other people. Building on the previous finding that people are capable of accepting and adapting to their dementia, they also embraced the vulnerabilities that came with this. This finding indicates that, for participants to be active agents in the practice of ‘going out’, they needed support from their care partners and to feel integrated into their wider community.

Embracing vulnerability

A key element of relational agency and therefore, maintaining an ability to 'go out' for participants was in their attitudes towards vulnerability. In institutional settings, people living with dementia are often labelled as a "vulnerable group" and it is a commonly held misconception that vulnerability is synonymous with weakness. However, my understanding of vulnerability in terms of the human lived experience draws on the definition proposed by Brown, a grounded theory researcher at the University of Houston. Brown defines vulnerability as '*risk, uncertainty and emotional exposure*' (2010). Drawing on this definition, in this inquiry, participants' experiences of 'going out' represented how they embraced their vulnerabilities. For example, Maria recognised her vulnerability by highlighting the universality of human vulnerability during a discussion regarding the risks of 'going out'. She reflected that she did not consider herself uniquely vulnerable because of her dementia:

> *'…hey ho, we're all vulnerable, you know…. As a young woman we're vulnerable, as a young man, as an older...do you know what I mean. We've all got vulnerabilities at some point and there's dangers out there.'*

In acknowledging the universality of human vulnerability, Maria did not consider vulnerability to be the same as weakness. Instead, she considered embracing her vulnerabilities to be quite the opposite:

> *'...the longer I'm living with this condition I need to accept help and ask for help…And when you ask for help it's...and that's taken a lot of courage because I wasn't the kind of person who wanted to receive help.'*

Maria understood that, by recognising her vulnerabilities and accepting support, she was able to maintain independence and a sense of agency. John also acknowledged the universality of human vulnerability. He did not consider his dementia to be the only deciding factor in what gives him the status of "vulnerable". He frequently referred to his physical stature, pointing out that as a large male; he was less vulnerable than I was as a small woman:

> *'… but it's different for me, I'm 6'3.'*

Often, when I walked with participants, they would consider me more vulnerable than them. Every participant would ask if I got there safely and how I planned to get home. Laurence would walk me to the train station at the end of every visit to ensure I made my way home safely. John would insist on paying for my coffee or lunch when we stopped to refuel. Simon and Kim would insist that I have lunch with them before my long drive home and anyone I visited at home filled me up with tea and biscuits. In doing so, participants were attending to the vulnerabilities that they perceived me to have, my safety as a young woman, travelling alone and ensuring that I was well fed as a "poor student". This draws our attention to the fact that vulnerability is a universal feature of the human experience. It is evident that, although society may view people living with dementia as uniquely vulnerable, they do not always see themselves that way. Participants drew my attention to the vulnerabilities that we all have when 'going out' when they highlighted my own vulnerabilities as a young woman.

Participants also embraced their vulnerability by asking for help if they were lost when 'going out'. Most people did not consider this a moment of embarrassment. Instead, they considered it to be a strategy that enabled them to seek support whilst maintaining their sense of independence. Almost every participant carried a dementia ID card that they would show me during interviews and group discussions. Some considered revealing their diagnosis to strangers to be a risk, but that it was a risk worth taking if it meant they received the necessary support. For example, Philip said that he would be comfortable disclosing his diagnosis and asking a stranger for help if it was needed:

> *'Yes, if I was getting muddled. And I think people are reasonable.'*

John shared Philip’s outlook:

> *‘The short answer is I would ask for help, I've got my little dementia ticket on. And I wouldn't have any qualms about showing that and explaining the situation’.*

As did Kevin:

> *‘So, I don’t mind going up to a person, showing them [my dementia ID card] and asking, “excuse me, I’m a wee bit lost.”*

In contrast, Margaret was not as quick to resort to asking a stranger for help. As a confident iPhone user, she would first try to phone friends or family before revealing to a stranger that she has dementia and needed help. However, ultimately, she concluded that she was never too proud to resort to asking a stranger for help if necessary and that she had done so in the past.

When asked if there were particular people whom he would ask for help, Laurence explained that he used a combination of trusting his gut instinct and approaching figures of authority:

> *‘If they look reasonable. I'm not trying to say…because some people, you take an instant, what’s the word, awareness of them. There’s something not quite right. So obviously, the best thing is people in uniforms, like policemen, traffic wardens, ambulance men, or little old ladies.’*

Like Laurence, Maria revealed that she would trust figures of authority over members of the public if she were lost:

> *‘Because I trust the police more than I would trust volunteers.’*

During some group discussions, participants shared advice with each other regarding who the best people to ask for help are. One participant suggested that security guards are a good alternative to the police, and another suggested that staff in the retail and hospitality industries are the best people to ask for help as they often have special dementia training.

Relational support to enable ‘going out’

Building on their willingness to embrace vulnerability, participants also maintained ‘going out’ by accepting support from others. Other people play an important role in the practice of ‘going out’ for people living with dementia. In particular, the relationship between people living with dementia and their care partner was essential in enabling them to ‘go out’ safely and independently. Both care partners and people living with dementia acknowledged this increased dependence and those with a strong sense of unity were able to negotiate risks together to support the person living with dementia to ‘go out’. Although most care partners in this inquiry were the spouse of the person living with dementia and they typically live together at home, this was not the case for all. Maria, Donald, and several of the group discussion participants lived alone and depended on the support of their siblings, close friends, and children. In Maria’s case, her daughter, Laura was her primary care partner. Laura lived in England therefore they developed a communication system dependent on technology that allowed Maria’s daughter to support her remotely. Although participants would often go out alone to maintain a sense of independence, this was achieved with the support from other people. Thus, ‘going out’ was a relational practice.

All participants shared stories of how they depended on others to maintain ‘going out’. However, it was not always easy for them to do so. For example, Maria felt an internal conflict about being dependent on another person in certain circumstances. She highlighted this conflict when she spoke of travelling with her daughter:

> *‘Oh, it's great because then I don't think at all. I just leave it up to her. It's a much easier route of travel. And if I done that too often, I would lose my ability to wayfind and use my strategies. Because it's use it or lose it.’*

Maria acknowledged how much she enjoyed travelling with her daughter because she did not have to worry about the stresses of travelling, but she was aware that letting her daughter handle everything meant that she would struggle to make this trip alone in the future. She was aware that this convenience may make travelling easier at the time, but it could lead to a loss of independence in the future.

Similarly, as previously discussed, Simon was dependent on his wife, Kim to drive him everywhere. Although he felt guilty for this added burden on Kim, he was also envious of how easy it was for Kim to pop to the shops or to go to meet friends. Although Kim assured Simon that he was not a burden and that she was happy to take him wherever he wanted to go, it did not change the fact that their level of accessibility to do the activities that they wanted to do were different:

> *'I know they'll do it so I know I've got control in that sense but equally we have to coordinate so we have to decide what's more important you know what I want or sometimes we have to prioritise when we wouldn't have had to you know when I could say "I'll do it myself" so there is that and I feel- I just feel a bit bad asking. I know she'll do it, but I guess I do feel a bit- I don't know if you know if it's a lack of independence it's just a lot more to ask her.'*

Likewise, Kevin acknowledged how dependent he is on his wife:

> *'Yes, oh, Christ, I rely on Joanne. Yes, she does a hell of a lot for me.'*

However, unlike Simon, he did not appear to struggle with the associated guilt.

Robert also recognised that he had become more dependent on his wife, but he felt that they had a strong relationship where they could communicate with each other, so he did not consider this increased dependence to be a problem:

> *'I don't think I have got as much freedom but then we have a good relationship. If I'm going out, I will say, that's what I'm doing.'*

Regardless of the level of guilt, some participants felt about being dependent on another person to go out, they recognised the importance of not allowing this guilt to get in the way of their ability to go out. Maria grappled with getting this balance right and ultimately concluded that she was going to do what she wanted to do. She knew the risks in 'going out' alone and had regular conversations with her daughter, instructing her not to feel responsible for Maria's actions:

> *'…and I had said to [daughter] you have not to feel responsible. If I got lost and never survived that then [daughter] has not to say, "oh, my!" and don't take criticism off of people.'*

From a care partner perspective, Mhairi noticed that Laurence was becoming more dependent on her and wanted her to go with him more often when he was going out. Previously, he would insist on going alone but now he would ask her if she wanted to come. Even if she did not want to, she felt a responsibility to accompany him:

> *I think if he is not independent, I think that's him. I've got to try and keep him doing...so this going out with him, I mean people laugh when I say, they will say well what did you do? I say, oh, we did the charity shops, and they laugh, because they know I hate charity shops. But, I mean, I will just go and wander or I'll sit on a seat and wait till he's finished. But I would rather do that and let him have the freedom to wander and have time to do what he wants to do than say, oh well, not doing that because I don't like it. So, more often than not we do things that he would like to do just because he's got to be kept busy, and that's fine, that's fine, that's just the way it is.'*

Mhairi recognised that maintaining a sense of independence was crucial for Laurence's overall wellbeing, even if that came at the cost of her own independence.

Similarly, Angela discussed this sense of responsibility to accompany her partner, Philip when he left the house. She struggled to know when to show her support and accompany him, and when to encourage him to go out alone to maintain his independence:

> *'I try and…if he wants to do something, I feel I owe it to him to join him…If he's going out on his own to Tesco, which I will sometimes suggest that he does, just to…for him to get out.'*

Accepting this change in the dynamics of dependence was a struggle for both people living with dementia and their care partners. Regardless of this, participants demonstrated resilience and would find ways to continue to 'go out'. Although levels of dependence could be unbalanced between the care partner and person living with dementia, their approach to risk management was a joint venture. For example, Simon and Kim had discussed and had come to the joint decision that, although they both wanted Simon to maintain as much independence as possible, ultimately, Kim had the last say in whether he could go out:

> *Kim: I mean, we've gone through in great detail ourselves about all the things that could become contentious with regards moving about and such like you know do I have the right to actually say to him "no, you can't go out today"? So yeah, I've got to judge when the time comes- I've got to take control of that.*
>
> *Simon: Well, you do know sometimes. You know, when the weather is bad.*
>
> *Kim: Or when you're bad cause it's a variable type of condition he has as well.*

Another example of care partners and people living with dementia making decisions together was when Claire reflected on a holiday she went on with her husband, John a few months previously. They visited a local attraction and John wanted to go for a walk, but Claire wanted to stay and take pictures. They agreed that he would walk within the area where she could see him:

> *‘So, I can keep an eye on him, you know, without stopping him from enjoying himself.’*

It was important to Claire that John maintained his sense of independence. However, it was equally important that she knew John was safe. In contrast, John never doubted his safety as he viewed himself as a capable and independent person however, he hated that his actions might cause Claire stress and anxiety. Therefore, they came to an agreement where he could go exploring whilst she could have peace of mind.

Mhairi and Laurence used mobile phones to support Laurence to ‘go out’ alone. They had an agreement that he could call her whenever he was alone and facing a challenge. During a one-to-one interview with Mhairi in a local café, Laurence called her. He was on his way to meet us, but he got lost. Mhairi remained calm and helped him to reorient himself by encouraging him to look around for street names and key landmarks. Once she had an idea of where he was, she gave him clear instructions to navigate to the café. Mhairi was calm because she has an idea where Laurence was and knew he should have been able to find his way to us with her directions. He arrived ten minutes later.

Although people living with dementia acknowledged their increased dependence on their care partners, they considered themselves as equal decision-makers with their care partners. This was evident in John’s reference to teamwork:

> *‘So, we do help each other out when we get stuck. And we call ourselves Team [last name]. And no matter what happens we will help each other out to get through it…It's probably me really. Claire is more of a realist. But she shares it, and she shares the Team [last name] ethos.’*

Likewise, Maria told me that decisions about her care are made by herself, her husband, and her daughter collectively:

> *'And we don't mind having these put in place, if it means that we can still have freedom and [daughter] has the freedom of not being stressed. And that's as a family, and we're allowed to do that. As team [last name], this is what we've decided. We've had the hard decisions and we've both made these decisions.'*

Philip shared this attitude. When I praised him and his wife, Angela for finding ways to do activities that they both enjoy, he replied:

> *'Well, we're a good pair.'*

Support from care partners enabled people living with dementia to maintain the ability to 'go out'. This support came in many forms, but it was dependent on both parties accepting the shift in dependence dynamic between them. This acceptance allows for open communication and shared decision-making, which in turn supported people living with dementia to 'go out' independently and maintain a sense of agency.

Participants also maintained a practice of 'going out' in collaboration with neighbours and people who they knew in their local communities beyond their immediate care partners. The level of support that participants received from their local communities depended on what was available and how much participants chose to engage with them. This did not appear to differ whether the local community was urban or rural. Instead, individuals depended on the level of support that they were comfortable with drawing upon. For some this was a dependence on neighbours, for others it was dementia support groups or local shops, cafes, and community groups. For almost all participants there was a sense that their neighbours were looking out for them. During one group discussion, Jackie said:

> *'I'm so thankful for good neighbours...'*

And that it put her at ease to know that:

> *'there's people looking out for you a wee bit.'*

Care partners were also grateful for the support of neighbours. Philip's wife, Angela reported that their neighbours had "stepped up" since learning of Philip's dementia, offering to help with mowing the lawn, running errands, and making an extra effort to ensure Philip feels included at local social events. Similarly, Nicola said that, upon hearing about Robert's dementia, her next-door neighbour offered to tend to their garden and accompany Robert on local walks. Joanne worked full-time so Kevin was home alone during the week. Their neighbours knew this and kept an eye out for when Kevin left the house and returned home. Joanne was grateful for this extra support:

> *'Most of the neighbours around here are all very aware of what's going on with Kevin and I would say 100% they're looking out for us.'*

Not only did Kevin and Joanne have that support from their neighbours but they were also supported by their local services. Kevin attended various clubs or met with support workers most days. Joanne recalled a time when Kevin became lost whilst walking to his local gardening club. She could not accompany him on the trip because she was at work so the club organisers offered to collect Kevin from the house and drive him to the gardening club so he could still attend. The local taxi service also supported Joanne and Kevin. The local drivers knew about Kevin's dementia so if there was ever an issue, for example, if Kevin was not at home when they had arranged for him to be collected, the local taxi firm would call Joanne at work to let her know. In addition, they would never charge an extra fee if they had to wait. This reassurance that the community was supporting Kevin to maintain independence and an ability to 'go out' enabled Joanne to continue working full-time.

During a group discussion, Cindy shared that since learning about her dementia, her hairdresser now calls her the day before and on the morning of her appointment to remind her. Though these are seemingly small gestures, they can make a big difference to a person's experience:

> *'It's the little things.'*

All participants reflected on how other people in the community treated them. Participants appreciated and remembered when they were treated with empathy and kindness. Maria told a story of arriving at a city train station and there were repair works that had closed her usual exit route. She was confused and flustered. When she explained her challenge to a member of staff and asked for their help to get out of the station via the appropriate exit, they extended an arm and calmly said *‘I don’t know, follow me. We’ll get lost together.’* That response immediately diffused Maria’s building sense of panic.

Although participants shared examples of positive support, they also acknowledged that local communities and broader society must work harder to be more accommodating of people living with dementia. Participants shared stories of being treated with disrespect and made to feel incompetent. During group discussions, participants shared stories of rude staff in shops and impatient people in supermarket queues. Participants put these instances down to a lack of education and awareness about dementia.

Even though participants felt support from local communities and services, they often felt let down by wider systems and the lack of government support. During group discussions, people complained about the lack of funding that dementia services receive. Maria was angry at the lack of government financial support that she received considering the work that she has done to manage her dementia and raise awareness for the cause:

> *‘And that's why I get so annoyed and angry. We've hung on for so long, we've saved the government a fortune by doing all of this. We're not taking…we've never took from society. In fact, the opposite, we've given a lot freely of our time.’*

Similarly, Margaret was disgusted that she had to give up her job and “sign on” to claim benefits after her diagnosis. This was made worse by the challenges she faced when claiming benefits because her young age meant she did not qualify for dementia-related financial support. Margaret considered herself a hard-working citizen who had paid taxes and contributed to society her entire life. She was embarrassed to be claiming benefits and was horrified by how hard she had to fight to receive the financial support that she was entitled to. Laurence echoed the frustrations of Maria and Margaret. He worked tirelessly as an advocate for people living with dementia but now, as his ability declines, he felt as if he had been disposed of by the people and organisations that he worked for:

> *'Nobody ever comes and asks me for anything, now, or do things.'*

Although participants received support from others to 'go out', they would also 'go out' to *provide* support to others. Thus, they were not only 'going out' to fulfil their sense of freedom and independence but also to fulfil their civic duties as an active member of the community. For example, during one group discussion, Jimmy said that he volunteered at the local homeless shelter once a week. John also explained the responsibility he felt for his peers at his weekly dementia support group:

> *'I've got a pretty packed diary just by all these social things that I've taken on. And I feel a sort of responsibility to the other…. people, my colleagues as we refer to them. Just to keep an eye on them and see how they're doing, and if I can help out with them in any way.'*

Unlike John, Laurence did not like to attend dementia support groups. However, he was still an active member of his local community, and he fulfilled his civic duties in various ways. For example, he visited a local blind man for tea once a week and ran errands for him. Although Laurence did not consider himself a religious person and did not like to attend services, he volunteered for events at his wife's church regularly. He visited local charity shops daily, donating old books and purchasing new ones. He also carried snacks and dog treats to give to homeless people and their canine companions who he saw regularly. During one walk-along, Laurence spied a homeless man sitting outside of a shop ahead of us. He told me that he had forgotten to bring a treat to give to the man:

> *‘Oh, I meant to bring a bar of chocolate for this boy. He likes sweet things.’*

When I asked him why he spends so much time doing things for others, he responded:

> *Well, I like to do things for people. I think it’s because I come into contact with so many people with difficulties I thought well, I had an easy life for a while so it’s up to me to help them if I can.’*

The above example demonstrates how participants held valuable positions in the local communities. One of their motivations for ‘going out’ was to fulfil their responsibilities to other community members, contrasting the dominant narrative that people living with dementia are a burden to society.

Beyond the local community level, several participants considered participating in research to be a meaningful experience that allowed them to “give back” to society. They recognised that their participation might not help them directly but that it might help people with dementia in the future. During one walk-along with John, I reminded him that it was our last interview and John reflected that:

> *‘You've had a very big impact on me, anyway, just making me… It makes you realise that I've still got a contribution to make to someone.’*

Similarly, Simon also said that he was taking part in as much research and advocacy work as possible to raise awareness about the diversity in experiences of living with dementia. Laurence was also involved in advocacy work in the past. When I ask Laurence how involvement in these activities made him feel, he responded:

> *‘Well, it makes me feel good that I'm achieving something. And I don't have to look over my shoulder. That I can go ahead and do things.’*

Although this finding is not directly related to participants’ experiences of ‘going out’, it serves to put meat on the bones of the argument that people living with dementia are active and valuable members of their local communities and wider society.

Despite the importance of ‘going out’ for participants to receive and provide community support, participant motivations for ‘going out’ should not be reduced to a simple exchange of receiving support from and provide support to the local community. This inquiry highlights that participants also ‘go out’ for social interaction, health and wellbeing benefits and practical reasons such as doing the grocery shopping. This will be addressed in the following chapter through the lens of the role of place in participants’ experiences of ‘going out’.

Conclusion

This chapter demonstrates that people living with dementia engaged in the everyday practice of ‘going out’ to exercise agency. Participants achieved this by engaging in decision-making practices and by adapting to both broader life circumstances and everyday changes. When adjusting to life after a dementia diagnosis, participants were frequently making decisions to maintain their sense of agency and independence. This dynamic process required constant renegotiation depending on each individual’s limitations and capabilities and careful consideration of the risks versus benefits of ‘going out’. Although participants advocate for their rights to independence and to exercise agency, they acknowledged that for these rights to be fulfilled, support was required. Participants exercised their agency by receiving support from and providing support to other people. Support from care partners enabled participants to maintain the ability to ‘go out’. This support came in many forms, but it was dependent on both parties accepting the constant shift in the dependence dynamic between them. This acceptance allowed for shared decision-making and risk management, which in turn supported people with dementia to ‘go out’ independently and to exercise agency. The final sections of this chapter contrast the dominant narrative that people living with dementia are a burden on society. These findings show how participants added value to their local communities and therefore, should be supported to continue doing so through supporting their pursuit of agency.

Chapter Five – *‘Going Out’ in Place* – Belonging and Navigation

Introduction

In this chapter, I further address participant motives and strategies for ‘going out’ by highlighting the role of *place* in their experiences. I show this through two main themes: (a) feeling part of a place, and (b) challenges and coping strategies when ‘going out’. Together, these themes explain how participants connect to and engage with place. Place can be understood differently depending on the socio-cultural context or academic discipline. As described in Chapter Two of this thesis, for the purpose of this inquiry, I understand place as both an abstract concept and physical landscape. This chapter highlights the role of place for participants in the everyday practice of ‘going out’. Through exploring place as a physical environment, this chapter attempts to bridge the messy middle ground between participants’ experiences of ‘going out’, getting lost and being missing, highlighting how people living with dementia are active agents in the decision-making process regarding their navigation of the environment.

Feeling part of a place

The first theme explored in this chapter focuses on participant motives for ‘going out’. This inquiry found that participants ‘go out’ as a meaning-making practice to maintain a connection to nature and other people and a sense of belonging to a place. Additionally, participants ‘go out’ to fulfil a sense of purpose and routine and therefore, to remain active in the practice of everyday life.

‘Going out’ for connection and belonging

When walking with participants, they frequently expressed their appreciation for the physical environment. Since participants had control over where we went on our walk-alongs, they took this as an opportunity to show off their local area and our conversations were punctuated by moments of being brought to a standstill by the beautiful scenery. For example, John was in awe of the nature that existed just outside his front door. During our walks, we often stopped to observe the local wildlife. Once, we came across a man tending to a mare and her foal that had been born that morning. We stood in silence for several minutes, both watched in awe and John said:

> *'It's just a privilege to witness it…. there's just so much going on, and there's always something to see… it just puts the whole world straight.'*

Like John, Kevin felt connected to nature on his daily walks. During one walk-along, he drew my attention to the birdsong in the trees. He showed me how, when he whistled, they sang back to him. Even though he walked the same route three times per day, he never tired of the views:

> *'…it's a lovely wee path this, you know…. You get a good panorama.'*

Although Kevin and John lived in rural areas, showing appreciation for the local environment was also evident in city-dwellers. The division between nature and city is blurry. Nature is not only rolling hills or vast open beaches; it can be experienced in the centre of a city, in parks and gardens and urban spaces. As Philip and I walked through public gardens in the city, he claimed:

> *'This is lovely, you wouldn't think you were in a city.'*

Robert shared this appreciation for the city landscape:

> *'…having this, you know, on our doorstep [gesturing to the landscape], almost…what's not to like?'*

Similarly, Simon shared how much he valued walking his dogs in quiet rural areas and Maria drew my attention to the woodlands and birdsong as we walked together. All participants shared some insight into how 'going out' was an important practice for maintaining a relationship with the natural world.

In addition, all participants would 'go out' for social interaction. For example, Laurence no longer enjoyed dementia cafes because he was tired of everyone always talking about dementia. He enjoyed his local community coffee morning instead because people from all walks of life attended and the focus of the conversation was rarely on his dementia. Attending his local community coffee morning made Laurence feel valued:

> *'If you don't show up, they miss you, wondering if you're okay.'*

In contrast, Nicola and Robert enjoy attending their weekly dementia café together. They had always been socially active people, so they were shocked by the number of friends who withdrew from them since Robert's diagnosis. Since then, they enjoyed attending the local dementia café because it was both a form of social engagement and activity that filled the day and got them out of the house:

> *'But you see other friends say why on earth would you want to go to a dementia group? We say, you know, because it's fun. I said, it gets us out.'*

Similarly, when discussing the local Alzheimer Scotland support group that Kim and Simon attended together every week, Kim described it:

> *'...like a wee group cuddle'*

Participants valued the social interaction they got in both organised ways such as community coffee mornings and dementia support groups but also in more serendipitous ways when they were out walking. Walking the local area was a specific way for participants to engage in social interactions. Although participants did not necessarily go for a walk with the primary intention of meeting other people, it was often a pleasant consequence of walking in the local community. Whether it was a fleeting hello or to stop for a lengthy conversation, every participant told stories of interacting with people on the street, both strangers and familiar acquaintances alike. Even though Kevin walked the same route three times per day, he revelled in the moments where he could say hello to other locals:

> *'It's the same with the people round about here. We're all retired and doing the same walk and we're passing*

> *by each other all the time and on the way by we're blethering away.'*

Unlike Kevin who walked multiple times per day, John went for one long walk every morning trying to explore as many new areas as possible. Regardless of whether the walk was short and local or long and remote, John still reported that social interaction was a highlight of the walk:

> *'Even just for the moments where you'll see someone and say good morning.'*

Similarly, Donald used to be a postal worker so being active and interacting with people whilst out and about had always been an important part of his life. Since retiring he maintained this practice by 'going out' for daily walks.

Whether it was through the solitary act of walking or as part of a social group, 'going out' was a way for participants to feel a sense of belonging in their local communities. As I compared my experiences of walking with some participants and doing seated interviews with others, I discovered that being in a place and feeling a part of it was a particular way of knowing. Physical places could serve different purposes for participants such as to move, to rest, to eat, to drink, to shop and to socialise. Participants often took me to their favourite places so I could experience them. For example, John loved the local café where he had his weekly dementia café. He told me how friendly, accommodating, and hard-working the staff were and how tasty the food was. He tried to visit the café at least once a week outside of his weekly dementia meet up to '*pop in and say hello'* and to *'support the business'*. John took me to this café twice over our time together where I got to "feel" the welcoming atmosphere that he described. On a bigger scale, Philip felt this sense of belonging in the city that he lived in. It was the city that he and his wife had gone to university in and had only recently moved back to upon retirement. Therefore, the city was a sentimental place for Philip. As we walked the city together, landmarks and tourist attractions prompted him to tell stories from *'the good auld days'*. He reported knowing the city *'like the back of his hand'* and therefore, was confident in navigating it.

On an even bigger scale, some participants reported feeling a sense of pride and belonging in Scotland as a people, a nation and a physical place. For example, Kim and Simon returned home to Scotland after living in England for most of their life. They valued the natural landscape of their home in Scotland and Simon praises that *'the air up here is much cleaner'*. He also praised improved social support from health and social care services:

> *' …it's amazing the difference in care of dementia they have up here'.*

Likewise, John, Robert and Kevin all praised the unique beauty of the Scottish landscape while out walking.

This evidences that the places that participants engaged with whilst 'going out' were dynamic and unboundaried. Some participants travelled across the country on public transport regularly. Those who lived in cities were generally confident in their knowledge of the city and therefore their ability to be mobile within them. Some participants only went out in specific locations such as their local park. The participants who lived in towns and villages were often part of a close-knit community and almost all participants valued the unique natural landscape that Scotland had to offer. This evidences why individual experiences of 'going out' were so varied and dynamic.

'Going out' for routine and purpose

Besides maintaining a sense of connection and belonging to both the physical and social element of place, participants also reported 'going out' as a practice to fulfil purpose and maintain route. Keeping mentally and physically healthy was an important motive for participants to 'go out'. In the constitution of the World Health Organization, health is defined as '*a state of complete physical, mental and social wellbeing*' (World Health Organization, 2021a). Until now, these findings have mainly addressed the social wellbeing aspect of 'going out' but participants also associated the practice of 'going out' with maintaining their physical and mental health. For example, maintaining physical fitness was important to John to prevent poor health and he walked to stay *'out of falls.'* When he retired, he started a small exercise routine at home and although that kept him fit, he did not find it stimulating enough. He switched the exercises for longer daily walks in his local area instead. When discussing this change in routine, John said:

> *'That gets to be claustrophobic, and you're only wrapped up in your own thoughts. And you get out in the open air, and you can see that everybody's getting on with life. There's something different happening every day. You see deer about the place. You see different birds and things flying about. And you think that everything's really normal. So, there's nothing to worry about. You've just got to get out and enjoy… But it helps to put your mind straight.'*

Unlike the other walk-along participants who did most of their daily walks alone, Robert was less confident on his own. However, he still went for a daily walk with his wife, Nicola who reported that they both go mad if they are stuck in the house all day. Robert repeatedly mentioned how important it was for his health to go walking:

> *'We always liked to get out and get moving…I think walking gets you good. It's a good thing to be doing.'*

Walking, or simply getting out of the house, was an important practice for mental clarity. Although John had an extremely positive outlook on life since his dementia diagnosis, he occasionally got upset about the impact that dementia had on him. When he was down about something, he told me that walking was a way for him to work through that emotion:

> *'So, you just have to get it into perspective, but that's what walking does, it helps you get it into perspective.'*

Like Robert and Nicola, almost every participant related to the feeling of being trapped if they could not get out of the house. When I asked Kevin how he would feel about a hypothetical scenario of not being able to go out, for example, if he broke his leg, he physically recoiled and said:

> *'I don't know. I've no idea. I wouldn't like it anyway.'*

John also spoke about the negative impact of not being able to get out:

> *'If I get confined to a house for even just a day without getting out, I get stir crazy. So, I do have to make sure I get out every day.'*

All participants who had a diagnosis of dementia were retired and some mentioned the challenges that they faced when transitioning from working to retirement. When participants were not as busy as they once were, going for a walk became a crucial element of their daily routine:

> *'I've got something to do from the time I get out of bed, every time I go back to bed, I'm absolutely shattered… [walking] gives you something to talk about when you get home as well...' [John, walking interviewee]*
>
> *'If you're up at seven o'clock in the morning it's filling the day, so we try and get out every day, for a walk.' [Nicola, care partner]*
>
> *'See likes of when I get to the house and you… [deep exhale] oh, that was good.' [Kevin, walking interviewee]*

Going out gave people a sense of purpose and completing the task gave them a sense of accomplishment, which allowed them to feel like active citizens who were participating in the social economy.

As well as maintaining their social, physical, and mental health, the participants reported 'going out' to fulfil a practical purpose and to run errands such as grocery shopping and attending appointments. Participants completed these tasks using a range of means such as on foot, using public transport, driving themselves or being driven by others. Although these practices have a seemingly routine and mundane purpose, it could be argued that to identify a basic need, for example, the need for *'fresh air'* that several participants reported, then to fulfil that need independently by going for a walk maintains a person's sense of freedom, independence, and control and therefore their sense of agency. In this way, participants engaged in tasks and responsibilities no different from people without dementia. This is why it is important to consider these practices if a person is reported missing as it disproves the commonly held assumption that all people with dementia who ‘go out’ and are reported missing are wandering.

In summary, this theme highlights participants’ motives for ‘going out’ in relation to place. Although the specific motivations for ‘going out’ differed from person to person, there were patterns in the meanings behind these actions. This theme demonstrates how the desire to maintain a practice of ‘going out’ was underpinned by feeling part of a place. This included feeling a sense of connection and belonging to the people and places that participants engaged with. It also involved the maintenance of a sense of purpose and routine. Underpinned by concepts of freedom, independence and belonging, this theme further evidences how participants were active agents in the process of ‘going out’.

Challenges and coping strategies when ‘going out’

The first theme of this chapter, feeling part of a place, highlighted how participants would ‘go out’ to fulfil their needs for connection, belonging and purpose, explaining their motives for ‘going out’. This second theme addresses the challenges that participants faced and the navigational and other coping strategies they deployed for ‘going out’. This theme evidences how the physical environment presented both challenges and opportunities for participants to maintain agency whilst ‘going out’. Navigation became more complex when the environment changed or depending on how familiar it was. However, participants used features of the environment and place-based strategies to navigate and overcome these challenges. By examining participants’ experiences of navigation, I address the gap between ‘going out’ and being lost.

Challenges when ‘going out’

Participants’ experiences of ‘going out’ were impacted by challenges in the environment such as changes in weather, roadworks and construction, and the familiarity of the environment. These challenges could impair participants’ ability to navigate. For example, Robert told a story of when the canal overflowed, blocking his usual path, so he had to turn back. Laurence also shared examples of changes in the environment that could disorient him:

> *‘A change, any sort of change. Knock down a building, even knocking down a tree, I'm going along, and suddenly they’ve knocked the tree down overnight, it's changed the picture in your mind, you don't recognise it. So, and again, if they put up a, sometimes they can put up buildings within weeks, a new building appearing. So, you think to yourself, this isn't the road I'm going, this isn't where I should be.’*

Like Laurence, Maria explained her experiences of disorientation when the environment was changed:

> *‘It's easy to negotiate the station but it looks different because they've refurbished…it's when there's a change. An unexpected change, that's unexpected…as I said. When there's something that just happens, like there's a barrier that goes up or there's a diversion…’*

On another occasion, Laurence shared this experience of disorientation when his local train station was under construction:

> *‘Now this happened this morning at (city train station). They’re doing all the building work and they’ve moved it and shifted things and I’m beginning to think, you know, “Am I at the right place?” So eventually I walked up, and I went down, and I saw the sign so. But I did get slightly lost.’*

Similarly, Philip’s wife Angela reported that he was disorientated on one occasion when his usual bus routes were diverted.

Maria explained her challenges further by highlighting how seasonal changes also impaired her ability to locate herself in an outdoor environment:

> *‘What is important is the change of seasons. Because it does change. You're used to a tree, but the tree hasn't got leaves on it anymore, it doesn't look like a tree. You're looking… So, it looks different in the snow, it*

> *looks different…you know that yourself, in autumn than it does in the summer.'*

On the theme of weather, Laurence explained the challenges that the dark imposed for him:

> *'I'm more likely to get lost at night-time when it's dark because everything looks different. Sometimes landmarks are obscured, and everything looks changed even the way the streetlights make shadows, the shadows are different. It's very confusing.'*

Maria also experienced this challenge:

> *'Oh, the dark is a tremendous thing… No. And a lot of people with dementia don't go out in the dark because they can't find their landmarks. They can't locate themselves. It's not intuitive. It's not instinctive and they just don't…well, I don't feel safe, and I've heard people say they don't feel safe.'*

Perhaps these changes in the environment affected participants' ability to draw on their previous knowledge of a familiar environment, turning the familiar into unfamiliar. When a familiar environment became unfamiliar, participants felt less safe.

Unsurprisingly, the participants who lived in rural areas found cities difficult to navigate. To cope with this, Kevin avoided the city at all costs. He explained how overwhelming it was for him to cross a street in the city:

> *'Crossing all the streets and you've got to stop, cars stop, and you have to cross the road and they beep beep beep for you to go over. I just think forget it.'*

Simon shared this sense of overwhelm:

> *'Town is obviously the worst for this but the noise if there's noise as well as the vision. Again, I can't cope so that's the good thing about the village is that it's nice and quiet… usually… (Scottish city) would just throw me totally. I don't think I could even walk down (main street in city) now.'*

Both Simon and Kevin avoided city environments due to their dementia-related impairments. Kevin found the environment stressful due to the business, but Simon found it overwhelming because of the sensory overload that he experienced in the city. Avoiding the city could be interpreted as an enactment of agency: they both decided to stop going to locations that they did not enjoy; however, it could also be interpreted as an act of withdrawal that may lead to social isolation.

Interestingly, participants who currently or had previously lived in the city were used to that environment and did not appear to be overwhelmed by the hustle and bustle. As with the changes in the environment, this may indicate that familiarity with an environment is a more important factor in a person's ability to navigate than how loud, busy and overwhelming it is.

Despite the importance of familiarity of the environment, Laurence reminded me that he has also been lost in familiar places where they has been no changes in the environment:

> *'And I don't get lost all the time, but I've been lost a few times. And when I say lost, I might have been in a familiar place, but I didn't know where I was.'*

Although, participants reported getting lost in both familiar and unfamiliar environments, overall, they reported feeling more at ease in familiar locations. For example, Maria described how she seeks familiarity when she is in an unfamiliar place:

> *'I always make for Wetherspoons…. the staff chat to you.'*

Additionally, Maria's embodied way of navigating was an ability that she only had in places that she had been to before:

> *'I knew that my legs innately would know to navigate me as long as I didn't take me head into it'*

Perhaps finding familiarity in the unfamiliar made her feel more secure and confident as she reported feeling more anxious when she was alone, or when she was navigating unfamiliar environments in comparison to familiar ones:

> *I think one of the things I would say to that initially is when I'm somewhere familiar my tummy doesn't churn, right. When I'm doing the other ones, I'm in a state of anxiety, in a heightened state of alertness and the adrenalin's pumping and my tummy's butterflies and all the rest of it and... oh, yeah, that's the difference.'*

Robert was an outlier as he was the only participant who no longer went out alone. Therefore, familiarity of the environment did not appear to make a difference for Robert. His wife, Nicola reported that:

> *'…Robert's very familiar with the area but he doesn't tend to go out on his own.'*

Perhaps this was because he had several previous experiences of being lost and that had knocked his confidence in his ability to go out alone. On one occasion, Robert was reported missing to the police. Although he had only been lost in unfamiliar environments, this knock in confidence meant that he was hesitant to go out alone even in environments that were familiar to him.

Interestingly, some participants recalled times when they were not lost but had been reported missing to the police. This highlights that one of the challenges that participants faced when 'going out' was the assumptions that others put on their movements. For example, Maria recalled a time when she was reported missing to the police. She was visiting a friend in an unfamiliar environment and became disorientated. She could not find anyone to ask for directions:

> *'I was in a housing estate in the middle of the day so all the kids would have been at school and the parents at work.'*

Despite remaining calm and still knowing the general area she was in, Maria chose not to keep walking and risk getting lost further so she sat down and called her friend to explain the situation. However, when she told her friend that she was lost, he panicked and called the police. The police quickly located Maria and returned her home safely, however, Maria reported being embarrassed at the drama of the situation because, despite being lost, she knew the town that she was in, and she knew that she was safe. She felt that she would have been able to relocate herself without such a dramatic intervention:

> *'Imagine being taken to my sister's house in the back of a police car? She had to come home from work early. I was mortified! And my confidence took a big knock for months after that.'*

John has a similar experience of being reported missing without being lost. When out for a long cycle, John got a puncture. Embarrassed that he had forgotten his puncture repair kit and his mobile phone, he did not ask any passer-by for help. He knew the route home, so he decided to walk:

> *'I was too proud to ask anyone to use their phone so I just decided to walk my bike home along the canal.'*

This extended the length of time that John was gone, and his wife started to worry when he was not home by their agreed time. After he was gone for seven hours, she called the police. Fortunately, his daughter quickly located him on the bike path close to his home and the police search was called off. Importantly, this highlights that not all experiences of being 'missing' for people with dementia are a result of being lost.

Together, these findings suggest that changes in the environment could disorient participants and lead to a knock in confidence. Also, although participants got lost in both familiar and unfamiliar environments, the experience for each differed slightly. This might indicate that although navigating both familiar and unfamiliar environments could be stressful and anxiety-inducing for participants, being in an unfamiliar environment presented more negative risks for participants. This is supported by participants' accounts of using strategies such as staying in a safe zone and not going to unfamiliar places, which will be discussed later in this chapter.

Coping strategies

Participants were aware of how dementia-related impairments affected their ability to navigate an environment. This awareness meant that they employed a range of strategies to enable them to maintain 'going out' safely and independently. For clarity, these strategies are listed in Table 7. This section will discuss participants' experiences of some of these navigational strategies further.

Overview of navigational strategies shared by participants:

1. Stay within a "safety zone" or stick to familiar routes
2. Go out at quieter times of the day
3. Ask for help or how people dementia ID card if in need of assistance
4. Carry a small amount of emergency cash and written address for an emergency taxi home
5. Use landmarks and signage
6. Care partner timed walks on agreed routes
7. Carry a mobile phone to call for help if in trouble
8. iPhone users use Find my Friends app to track the location of their loved ones
9. Depend on the dog to navigate home
10. Use GPS tracking devices (note- this was discussed as an option and although the majority of participants were open to the idea and mentioned it as strategy that they would consider, not a single participant used them)
11. Use "inner maps" and embodied knowledge

Table 7. Summary of participant navigational strategies

The most common navigational strategy used by participants to negate dementia-related impairments when 'going out' was to stay in familiar places. For example, Simon said:

> *'I'll never take a route that I haven't done before on my own.'*

Similarly, Laurence shared his strategy for staying in familiar places:

> *'I've got my safety zone and I don't go outside it.'*

These strategies shared by Laurence and Simon support findings reported earlier in this chapter that familiar environments gave participants a stronger sense of safety and security.

Navigational strategies were also used by people with dementia in collaboration with their care partners. For example, Simon and Kim negotiated a compromise for him to continue 'going out' alone which involved Simon going on a pre-agreed route. Kim knew approximately how long it would take Simon to walk that route so she would time him. If Simon was gone more than fifteen minutes over the time limit, Kim would go to look for him. Although she has never had to go looking for him, having this strategy in place balanced Simon's right to independence with Kim's need to assure his safety. All participants with dementia who lived with their care partners deployed a similar strategy, several of which required the person with dementia to carry a mobile phone so their care partner could contact them.

Although using assistive technologies to support 'going out' was a frequently discussed topic amongst participants, and most participants reported a serious consideration of using tracking devices, levels of assistive technology usage varied greatly across individuals. Some participants with dementia did not use assistive technologies because they felt that they did not need them, some used them but felt that they were not needed and reported only using them to put their care partners at ease, and a small number of participants were dependent on them as a navigational aid:

> *'I wouldn't mind wearing it because as I said, I've been lost in the past' [Laurence]*

> *‘I would be quite willing to have a tracker put on me because then I know that if I got lost somebody would find me’ [Isobel, group discussion]*

> *‘I would use it for Laura (daughter) and me. I think it’s a two-way thing’ [Maria]*

> *‘I’m now tracking him which I feel very guilty about, but it’s quite good [Angela, care partner]*

> *‘As long as I knew and I’d given my permission it wouldn’t bother me’ [Simon]*

Although Margaret did not consider herself to need a tracking device, she was the only participant with dementia who reported using her smartphone to facilitate her practice of ‘going out’. She shared how she used a journey planner app to negotiate bus and train times.

Although most participants did not use assistive technologies to facilitate their ‘going out’, several participants had dogs and walking them was an important aspect of their ‘going out’ practice. When walking with Kevin and his dog, Cassie, he pointed to her and said:

> *‘See when I’m walking, Cassie [dog] is away in front of me and she’s taking me home. I’m not taking her. She’s in front all the time so she is actually taking me home.’*

Simon also shared this view that his dogs would assist him if he were to get lost:

> *‘I mean the dogs are very intelligent so I think that if I did get lost, they would take me home.’*

It could be argued that participants’ dogs were used as low-tech navigational aids to ease the anxiety of both care partners and people living with dementia and to support them to continue ‘going out’ independently.

Similar to how some participants had confidence in their dog’s innate ability to navigate, they also discussed their own “inner maps” of places. For example, during one group discussion on navigation, Annie mentioned her ability to follow the:

> *'… little map in your head.'*

Philip also referred to his "inner map". Philip had recently moved back to the city that he spend his student years in. When I asked him how he still knows the city so well after spending most of his life living elsewhere, he explained that a well-known place:

> *'… tattoos onto you.'*

Although participants discussed how they were dependent on their 'inner maps' to navigate, they also shared how these can be impaired by dementia. For example, Laurence compared it to an incomplete picture in his mind when he is lost:

> *'…you've got a picture and if that picture changes you start to doubt, am I where I think I am?... Now, I can only see where I am and where it is but not in between, not the way there.'*

Similarly, when Kevin highlighted his difficulty in navigating the local shopping centre, he said:

> *'I would walk in and wouldn't know which way to walk out. My compass doesn't work at all. I can't work out if I've to go there, stay there, go back that way.'*

Maria shared this challenge with her cognitive capacity:

> *'I can't be confident in my cognitive abilities because it is damaged.'*

During a group discussion, Jimmy also spoke about his loss of ability to use his 'inner map'. However, he had adapted to this by using a strategy:

> *'…. Tail End Charlie.'*

This strategy involved looking back at where he had been in an attempt to imprint it on his memory in case he became lost. He likened it to the military aircraft crewmember who operates a gun from the rear of the aircraft and is known in military slang as “Tail End Charlie”.

This “inner map” did not solely exist inside participants’ minds. Several participants shared that if they forgot where they were going, they would depend on their body to get them there. For example, Maria told a story about how she got on the wrong bus when she was returning home from the hospital. After a few stops, she realised that she was on an unfamiliar route, so she got off the bus. However, Maria was unable to figure out which bus she should get home and with nobody around to ask for help, she decided to walk home. She said she had to trust her body to take her home:

> *‘I knew that my legs innately would know to navigate me as long as I didn’t take my head into it.’*

Consequently, Maria demonstrated an embodied knowledge of her local environment.

The use of landmarks and signage was another strategy used by several participants. For example, Maria explained that when she is in Edinburgh city, she always looks for the castle. Edinburgh Castle is on a hill in the centre of the city and because of this, it can be seen from almost every street in the city. Maria explained that she looks for the castle so she can locate herself:

> *‘When we live alone, we rely on our own instincts and where are we? So, when we look, we look for a landmark. So, no matter what country we're in we look for something that will locate us where we are. So, like Edinburgh Castle's a good one.’*

Maria found comfort in knowing where Edinburgh Castle was because if she knew where the castle was, then she knew when she was in reference to it and she felt safer.

Similar to Maria’s experience with Edinburgh Castle, John lived in an area that had several key landmarks that are also tourist attractions. He highlighted how important these landmarks were for him as reassurance that he was on the correct route:

> *‘…so much of housing estates look like housing estates the whole world over… And even if you just around a corner 30 yards away from somewhere where you walk every day, if you can’t see some landmark that says that road up there, that’s the one that you should be on, then it could be distressing.’*

However, landmarks did not have to be as large and obvious as well-known tourist attractions for them to be useful for participants. For example, during a group discussion, Peter reported that he had started to forget street names. However, having travelled the bus around the city his entire life, he still knew the names of all the pubs on his regular bus routes. So, his new strategy when he was on a bus was to locate himself according to the passing pubs that he saw out of the window as opposed to the street names called out on the bus intercom. Jackie nodded in agreement with this story adding that, when approaching the local Alzheimer Scotland Dementia Resource Centre, she would:

> *‘... look out for the big purple sign.’*

Simon’s family, who live on the route of his daily walks around the village, created a landmark for the sole purpose of Simon to use as a navigational aid:

> *‘This house here with the flag is where my daughter and son-in-law live so it’s a sign I can…If I ever got lost, I know where the flag is to get to it.’*

This illustrates that both Simon and his family recognised the value of using landmarks to support Simon to maintain his independence through his daily walks around the village.

As previously mentioned, participants felt at risk of getting lost in both familiar and unfamiliar environments. Margaret explained that, when she is in an unfamiliar environment, she tries to identify somewhere familiar:

> *'If I'm going a place that I don't recognise as well as other places, I like to be able to find somewhere or a point that I do recognise. I feel safer that way.'*

Margaret explains that landmarks help her to locate herself when 'going out' in unfamiliar places, which makes her feel safe.

Similarly, Laurence's previous account of getting lost at his local train station illustrated his dependence on landmarks. Laurence could not identify the usual station entrance due to the construction work taking place:

> *'… my landmarks have been taken away.'*

Nicola also recalled a time when her husband Robert got lost whilst out walking in an unfamiliar place in poor weather conditions and was reported missing to the police:

> *'So, to cut a long story short he was missing for four or five hours. He'd got to the other side of [city] and I mean, he'd recognised the Tesco supermarket sign. He thought that was familiar. This is what he'd…and he'd gone in and said to them, I've got dementia. I don't know where I live. He said, I'm lost.'*

On that occasion, recognising the Tesco supermarket sign as a landmark in his physical environment and asking the staff for help could have saved his life. As a diabetic, spending hours walking alone in the cold and wet weather put him at a high risk of harm. The staff gave him tea and biscuits, and then called the police who returned Robert to his family.

In summary, regardless of whether they are large, obvious attractions such as the Edinburgh Castle or minor landmarks such as a local supermarket sign, participants reported using landmarks as a relocation tool when they were lost or as confirmation that they were on the correct route.

Although participants used the aforementioned navigational strategies to maintain ‘going out’ and to prevent getting lost, getting lost was still an unavoidable consequence for some people. Therefore, participants reported using a different set of strategies to relocate themselves when they were lost such as asking for help; turning around and retracing steps to safety; pausing to gather thoughts; and keep going in the hope that they would relocate themselves. For example, Maria, Kevin and Robert all reported using the strategy of going back the way they came when they were lost:

> *‘I look about to see what I can do and try to just get myself back to where I was meant to be. Leave where I was going, never mind that and just get back to the house.’ [Kevin]*
>
> *‘Retreat, so it’s like a battle plan, how do I get home to safety.’ [Maria]*
>
> *‘I would turn around and go back, I think.’ [Robert]*

An alternative strategy used by participants was to stay in place to gather their thoughts and blend in with society. John described his experiences with this when I asked what he would do if he was lost:

> *‘I'd find a quiet corner, sit down and just think things through, and come up with a solution. For instance, when I park my car, I frequently forget where I park my car. So, I have to sit down and think about it.’*

When asked the same question, Maria described what she might do:

> *‘You can sit, take a paper out, you don't need to read the paper. But you're just sitting and calmly looking… You're looking a part of society. I do mindful breathing, deep breaths and things like that. So that's good. So, it's putting strategies in that works for you and only you.’*

When discussing hypothetical scenarios of being lost during a group discussion, Jackie shared that she often stood at a bus stop if she was lost or just needed a minute to catch her breath:

> *'… because there is nothing strange about hanging around a bus stop.'*

These quotes indicate that participants were fearful of appearing disorientated or confused when 'going out'. Therefore, they made a conscious effort to "fit in" and appear as though everything was normal.

When sharing previous experiences of being lost, participants would either keep going with the hopes that they would recognise something or turn back to relocate themselves:

> *sometimes I can walk along and look up and think, where the hell am I, if I'm not concentrating, and then I've got to wait until I come across a landmark that I know and think, oh, that's where I am and sort of reboot.' [John]*
>
> *'I went up and took the wrong path and then I said "wait a minute"… so I just get myself back' [Kevin]*
>
> *'Once I got nearer the place I was going, my memory came ack' [Laurence]*
>
> *'I knew that if I kept walking I would find a place that I would know' [Maria]*

In summary, this theme demonstrates the challenges that participants faced when 'going out' and the strategies they deployed to overcome these challenges. Although the challenges posed a risk to the safety of participants, they also provided opportunities for participants to maintain agency whilst 'going out'. Participants reported that navigation became more complex when the environment changed or depending on how familiar it was. However, not all experiences of being missing were a result of being lost. This highlights the potential diversity in people with dementia's experiences of being missing. In addition, this theme shows how participants used features of the environment and place-based strategies to navigate and overcome the challenges faced to maintain a practice of 'going out'.

Conclusion

This chapter shows the role of place in participant experiences of ‘going out’. These findings show how place is an abstract concept that participants felt a part of and a geographical locality that presents navigational challenges and risks of getting lost but also opportunities for strategies to overcome these challenges. These actions are constantly being renegotiated and maintained through the practice of ‘going out’. The previous chapter discussed how people living with dementia maintain agency whilst ‘going out’ in relation to other people however, they also maintained agency in relation to the physical environment.

The findings chapters so far have presented themes from the data that provide insight into the everyday lived experiences of people living with dementia. These themes address participant motives and strategies for ‘going out’ in terms of the *practices, people and places* that participants engage in. The presentation of data in this thesis so far highlights the *practices, people and places* that participants engage with. The following and final findings chapter of this thesis presents co-constructed narratives from the seven participants who took part in walk-alongs for this inquiry. Although these narratives still address the *practices, people and places* that participants engage with, I employ reflexive thick descriptions to capture the embodied and emplaced nature of our shared experiences of ‘going out’ together.

Chapter Six – *'Going Out' as an Embodied and Emplaced Practice* – Walk-along Narratives

Introduction

Chapters Four and Five describe the main themes generated from the data, identifying the salient points across the breadth of data collected. However, this analysis highlighted a gap in the data that was unexplored: how participants interacted with their environment through their bodies. Therefore, this chapter employs reflexive thick descriptions to describe seven embodied narratives that were co-constructed by myself and each of the participants who took part in walk-alongs. These narratives highlight the role of the body as a medium for communication and experiencing the world. In addition, they explore how participants engaged with the physical environment, the sensory element of place and how our conversations were shaped and altered by the places we were in. This counteracts the narrative dispossession of people living with dementia that can be a consequence of traditional narrative approaches (Baldwin, 2008). Unlike the previous findings chapters that were written in the past tense, the narratives presented in this chapter are written in the present tense to give the reader a sense of being in the moment of the walk-along. Each narrative is titled with a direct quote from our walk-alongs, reflecting the overall theme of our interaction. First, I introduce the participant. Then, I offer an insight into some poignant moments from our time spent walking together. These narratives are not full accounts of the walk-alongs. They are stories that I have co-constructed from one or several specific moments on the walk-alongs, which capture how the participants interact with the environment. Finally, I conclude each narrative with a reflection on and interpretation of the meaning-making from each of the embodied moments.

Simon: 'Again, it's the sensory thing'

Introducing Simon (and a bump in the road)

Simon is a "what you see is what you get" type of person. He swears unabashedly. His humour is subtle, clever and sometimes dark. He is self-assured, articulate and is not afraid to speak his mind. I like him. Simon contacts me directly via email after seeing my recruitment flyer at his local Alzheimer Scotland Recourse Centre. He invites me to attend his upcoming monthly support meeting at the resource centre.

The first time we meet, I have a sit-down interview with Simon and his wife, Kim at the resource centre. Simon decides that he does not want to go for a walk as we are in a city, and he finds that environment to be overwhelming. Simon has young-onset Posterior Cortical Atrophy (PCA), and his primary symptoms manifest as sensory impairments. He is a passionate advocate for people living with PCA.

The second time we arrange to meet, I visit Simon in his home for a walk around his local village. We arrange to meet mid-morning and it is a long drive from where I live so I make the trip the night before and stay in a hotel to ensure I am well rested before the interview. However, my attempts are in vain because after a good sleep and hearty breakfast, I drive out of the tightly packed hotel car park and scratch another car. When I finally arrive, late and flustered, the weather has taken a turn. Eagar to get out before the rain, I go into the house to say a quick hello to Simon and Kim, then Simon and I swiftly don our raincoats and head out for our walk.

Walking with Simon

Simon and I set off on our walk but I am on edge after my experience in the car. I try to focus on the interview, but I am anxious about the long drive home, how much it will cost to fix my car and whether the owner of the car that I scratched and left a note on will call me. I am aware somewhat that Simon is also on edge, but my mind is occupied with my own worries, and I do not have the mental space to explore this with him. We have met before and get along well so rapport is not an issue. I worry that he is upset with me because I was late and feel guilty for offsetting his day. I fear that I have thrown off his routine, and now we are going for a walk in conditions that he would prefer not to go out in. I am also aware that in my anxious state, I am probably catastrophising. I try to push these worries to one side and focus on the interview, but I struggle to recall the questions from my topic guide. Fortunately, Simon takes control of our interaction and snaps me out of my thought spiral by directing me: *'we go down this way'*. Simon is taking me on the short walk to his local doctors. He tells me that he would not typically take the route that we are taking together but he wants to walk it with me to point out the challenges that he faces on it. Simon's first challenge is the bins sitting out on the footpath, waiting to be collected: *'today's a good day because bins are a hazard.'* He tells me: *'it's hard to judge. I was thinking about bringing the white stick because I have a white stick* *because I would use it to judge better.'* Simon explains that although the white stick would have been useful in this circumstance, he mostly uses it to let other people know that he has an impairment: *'I do have a white stick now, but I use it mainly…I use it in [local city] or [local town] normally as a warning sign, not for myself.'*

The weather is typical of a spring day in the Northeast of Scotland: intermittent showers and sunshine. This weather creates challenges for Simon. When I ask Simon how the rain affects him, he explains how the sunshine is reflecting off the wet ground and into his eyes: *'…the dampness, the wet on the ground, it's coming back at me because it's too bright'*. He squints and confesses: *'I didn't realise it was quite this bright. I have wrap-round shades... I should have worn them. I didn't realise it was quite this bright'*. It is challenging for Simon to walk in these conditions with his eyes barely open, he explains this to me: *'While I'm talking to you, I'm closing my eyes most of the time because I can't do both at once.'* A few minutes later, we face the next challenge in our environment: steps. Simon tells me: *'I've come this way because the steps are a problem because I can't really tell how deep they are'*. His primary strategy is to not use the steps telling me that he *'would usually avoid them'.* If he does come across them, his strategy is to use his stick as an aid, but he does not have it with him today: *'So the stick always goes down first, and I always go one at a time'*. As we descend the steps with caution, Simon tells me that his eyes are: *'fixed on the ground'*. His eyes are only slightly open, and he acknowledges: *'it is tiring on the eyes'.* Later, during our walk whilst reflecting on his vision impairment, Simon says: *'the harder I have to look, the worse the brain gets'.* With the steps behind us, Simon and I are back in our stride and approaching a main road. The doctor's surgery is on the other side of the road. Although it is a main road, we are in a quiet village and there is no pedestrian crossing. Simon does not seem worried by this and explains: *'I will always try and cross at crossings… They're not always available in the village but I think most people in the village know me, if only by sight'.* Before we cross the road, Simon takes his time looking left and right for oncoming traffic. He tells me that he is: *'actually taking more care today'.*

The final point of interest on my whistle-stop tour of Simon's walk around the village is his daughter's house. He points to the flag flying from a mast in the garden and tells me that it was put there as an aid for him: *'This house here with the flag is* *where my daughter and son-in-law live so it's a sign I can… If I ever got lost, I know where the flag is to get to it.'* As we come to the end of our short walk, the weather appears to be clearing up and I sense that the stress we were both feeling at the beginning of the walk has lifted as we fell into step with each other, mirroring each other's rhythm of walking. Before we return home, Simon takes one more opportunity to show me one of his sensory challenges, pointing to my car in his driveway and telling me: *'See, I can't read that number plate… It's just a blur'* and I am reminded again of the incident.

Reflecting on my experience of walking with Simon

Themes of control and agency underpin my time spend walking with Simon. The underlying tension during my walk-along with Simon is striking. We each have our own, individual reasons for this tension. From Simon's perspective, it seems to be a result of his discomfort with the weather conditions without the aid of his stick and glasses. From my perspective, it is created by my stress over the incident I had in my car on my way there.

In our first interview, Simon told me about the sensory challenges that he faced but walking with Simon is much more impactful as it allows me to experience them with him, physically. The weather conditions are a major factor in our experience together. For example, I observe the sunlight reflecting on the puddle, and squint myself when it shines into my eyes, something I had never noticed before. I observe Simon's lack of confidence in his restrained movements on the steps. Simon forgets his walking stick and glasses which makes it apparent how uncomfortable it is for him to walk in these weather conditions. I struggle with this because, although Simon was eager to participate in my research and was capable of making that decision for himself, I feel guilty that he is forcing himself to go for a difficult walk to show me his challenges. Although I struggle to accept this, I feel it would have been unethical for me to decide this walk was too challenging on Simon's behalf. Simon is the only participant who purposefully takes me on a route that was challenging for him so that he could show me the obstacles that he faced. For me to overrule that decision would be taking away his control and agency over our time spent together and what he thinks is important that I understand about his experience of 'going out'.

Having put a lot of work into the preparation and planning of this interview, my incident with the car on the way there knocks my confidence and puts me in a distracted and anxious state. This experience prompts me to reflect on research positionality and how I influence the data generation process. Considering the effort that I had made to get to this interview location, I am disappointed that our walk is so short and that I am distracted. It is difficult to ignore the voice in my head that is panicking over the damage I had done to the car and stressing over the cost of the repairs. I feel unprofessional for being late and embarrassed for the reason why. At the end of our walk-along, I forget to give Simon the thank you card that I had given all of my participants, seeing it sitting on the passenger seat as I drive home. I spend the long drive home feeling defeated and contemplate making the trip again, so I can have a do-over. However, the following day, I reflect on the walk-along with a fresh perspective. I realise that despite all of these challenges, the walk-along provided rich insight into the embodied and sensory nature of our shared experience of ‘going out’.

John: ‘It leaves a man’s sword-fighting hand free to deal with whatever happens’

Introducing John

I meet John at an Alzheimer Scotland weekly coffee morning in his local café. It is raining torrentially so I ordered a pot of tea to warm up accompanied by a traybake. When I sit next to John, he commends my choice of traybake and we immediately connect, bonding over our shared love of chocolate and all things sweet. John is relatively quiet in a group situation but chatty during our one-on-one conversations. I take his contact details and we agree to meet at his home the following week.

John is in his 60s and lives in a residential suburb of a small city in Scotland. He is retired and his wife, Claire works part-time. He was diagnosed with Alzheimer’s disease two years previously, shortly after he retired. John keeps to a regimented routine that he sets for himself. He gamifies everyday activities such as racing to prepare his breakfast while the kettle boils and keeping his brain active with daily exercises on the computer. John writes his weekly plan and to-do list on a whiteboard. It is important to John to have an activity scheduled that gets him out of the house every day whether it is a long walk on his own, golfing with a friend, doing the weekly shop or attending the local Alzheimer Scotland events such as the dementia café, dinner with friends or weekly bowling. John is a physically active and social person. He tells me that he is more social now, since his diagnosis, than he had ever been before.

When I first visit John in his home, he tells me that he had a long career in the military and emergency service planning. He does not divulge too much about his career, telling me that he would hate to become one of those old people who spends all his time reminiscing on the past claiming: *'I am actually human, I'm not just an ex-military person'.* This becomes a recurring theme during my time with John, he stresses that neither his career nor his diagnosis of dementia defines who he is as a person. Despite this, John recognises that his career has a major influence on his approach to life: *'the plans that I used to formulate before, for major incidents, I now regard myself as the major incident, and how do I fit in with civilisation if you like.'* It appears to me that John considers dementia to be both a wonderful and terrible thing that has happened to him and his family. On the one hand, he has *'never been happier'* as his diagnosis has opened up new social opportunities for him. On the other hand, he considers himself a "major incident" since his diagnosis and is acutely aware of (and frustrated by) the way people around him treat him differently as a result of this.

Despite this frustration at his deterioration, John is one of the most positive people I have ever met. Initially, I suspect it is a front, a cover-up for how he is actually feeling but over our time together I learn that taking a positive outlook on life is John's coping mechanism. It is genuine and infectious. I leave all our interactions with a smile on my face and a pep in my step. Humour is his forte; John cracks frequent jokes followed by a big bellowing laugh. When arranging our first walk John tells me to bring my hiking boots. I cannot tell if he is joking, but I bring them just in case and I am glad for it! On each of the three times we meet, we walk for at least two hours. Going for long, solo walks are a way for John to prove to himself, and others, that he is capable of 'going out' alone: *'just to make sure that I still can'* and to clear his head: *'it just puts the whole world straight'.*

Walking with John

On our first walk together, John and I are walking on a path alongside a river. We regularly bump shoulders. It is partially my fault as I am trying to walk particularly close to him. I am wearing a lapel microphone to record our conversation and I want to ensure that it picks up both of our voices. However, I am acutely aware that, although physically fit, John appears unsteady on his feet, and this is also why we keep bumping shoulders. I want to draw John's attention to this, but I do not want to offend John or bring his attention to a deficit he may not consider himself having. However, I need not have been worried because after it happens several times, John tells me: *'I'm not as agile as I used to be'.* He is aware that we keep bumping shoulders and that is why he chooses to walk on the side of the water, telling me he would hate to accidentally push me in. This is the first time I realise that John feels a sense of responsibility for me and, I must admit; I feel a sense of responsibility for him also. It is a genuine fear for John that he might accidentally knock me into the river. He is not fearful of any of the risks of harm that *he* faces himself but is hyper-aware of the risks of harm that he might impose on me. For example, when crossing the road: *'Normally when I'm by myself I just jaywalk across these roads without any problem but now I've got somebody with me we'll cross safely, because there's an added burden of responsibility',* or taking me on a slippery path: *'And now, we could go down those steps but having health and safety assessed, I'd hate us to slip down the steps, we'll just join the canal up there'.*

This comes up again later in our walk when John and I are waiting for the green light to cross the road. John is a fast walker. He tells me that he will set the pace and it is up to me to keep up. As John and I walk through the streets of his local town, we arrive at a pedestrian crossing where two boys are waiting for the green light. We also wait for the green light and once the boys are out of earshot, John expresses his irritation at having to wait but that he feels a sense of responsibility and civic duty to wait to cross the road when it is "safe":

> *John:* *That's one thing that irritates me is when you're standing at the traffic lights that I know that I'm okay to go but they have these little kids there and we're going to wait for this green man, so you think, do I just go and have their mum going, look at him, he's not going to survive until Christmas.*

> *Katie:* *Gosh, I don't think I've ever even thought about it like that now.*
>
> *John:* *It shows that I've still got a public conscience, even though I sometimes ignore it.*

A few moments later, John jaywalks, and I scurry after him. I notice that there is a car coming towards us, but we make it across the road before it poses a risk. Noticing that I speed up my pace to cross the road, he turns to me: *'I knew that car was coming'* to reassure me that I was in safe hands.

Although John has full confidence in his ability, I start to see little chinks in his armour. As we near the end of our first walk together, John casually directs us to cross the road. As he does this, he looks to see if any cars are coming and steps out on the road. I yelp because I check the road too, but I see a car coming towards us that he does not see. Luckily, the car is driving slowly, and John has time to step back onto the path. He explains to me that: '*I didn't see that car for a second because it didn't have its lights on, and it blended into the road'.* I sense that this is embarrassing for John. However, John does not consider his jaywalking to be a particularly risky action. He views jaywalking as a normal thing to do, especially because in most of the places we go walking, there are no pedestrian crossings.

Although John and I get on famously, there is an underlying tension between us because my microphone is clipped onto my left lapel therefore, I always try to ensure that I am walking on his right side. If I end up on his left side, I can switch the microphone over, but I would rather not touch it, aware that every time I do, I risk obstructing the audio quality. This becomes a point of tension between us because John makes it repeatedly clear that he wants to be the gentleman and always walk on the more "dangerous side" such as the side closest to the road or the water. At one point, we are walking on a narrow path alongside a busy road. The path is not wide enough for us to walk side-by-side in some sections so I stop to allow John to walk in front of me until it widens, and we can walk side-by-side again. I do this several times, thinking it is the polite thing to do, but John is sure to bring it to my attention. He calls me out, saying that, as the gentleman, he should have to step out on the road or fall in behind me. Although his tone is jovial, I can tell that this is something that frustrates John. This prompts a discussion regarding how John gets upset when his wife stands back and allows him to walk through doors before her. This upsets him for two reasons. Firstly, because he considers himself an independent individual and he does not relate to the role of care recipient, stating: *'I would hate to be in a condition where someone's helping me in and out of buildings and cars and things like that'.* Secondly, it annoys him because he feels like the chivalrous act is to allow the woman to go first and insisting that he should go ahead is an insult to his masculinity. John tells me that when he is out with his wife, he is: '*always on the right, probably because Claire carries her handbag in her left hand, or on her left shoulder but I like to think of it as it's hereditary because it leaves a man's sword-fighting hand free to deal with whatever happens.'* John does not identify with the care recipient status because, as a six-foot-three ex-military man, he is used to being the dominant person, the carer, the protector. When John questions why I repeatedly allow him to walk in front of me when the path narrows, I tell him that I am just being polite. In contrast to my perceived courteous behaviour, John views it as an act of overprotection. He does not like that I might think of him as someone "vulnerable" and assures me that he is still capable of risk assessment. John warns me that if these things are playing on people's minds: *'it will be straw that breaks the camel's back'.*

Reflecting on my experience of walking with John

Themes of vulnerability, control and agency underpin my time spent walking with John. John and I develop a connection quickly, so we do not have to spend time developing rapport. Of all the walk-alongs, my ones with John feel the most relaxed. Relaxed to the point where I frequently must remind myself that I am conducting a research interview and that we are not just two friends out for a walk and a chat. However, although we do not face the barriers that potential researcher/participant power imbalance imposes, I notice other tensions at play. John hates the thought of being viewed as someone vulnerable, who needs to be cared for. He hates the idea of his wife, son and daughter caring for him as he deteriorates. John recalls conversations he had with family during which he insisted on going into a home once living at home becomes too difficult for his wife to manage. He agreed with his son that if it ever came to the point that John was in a care home and John did not recognise his son, his son would stop visiting him as it was too distressing a thought to consider. Neither John nor his son could not face the pain of that circumstance.

Ironically, John is accepting of his dementia diagnosis, but he does everything in his power to delay his deterioration of basic capabilities. I sense that, on our walks, every action is a small protest against the perception that, as a person living with dementia, he is uniquely vulnerable. John uses our walks to show me that he is an active and engaged citizen who is in control. He insists on buying me lunch at his favourite café where the staff know him by name, he plans the route that we take, and he is assertive in his chivalry, always insisting that I walk ahead or on the safer side of the path. I believe that John is being genuine when he tells me he is the happiest he has ever been, but in trying to prove this to me he is hesitant to let me in on his struggles. In spending time with John, I get to peek behind the curtains and observe how he struggles to come to terms with his vulnerabilities. I do not believe I would have experienced these subtle tensions if we had been sitting together in a traditional interview format. John's upset when I step back and allow him to walk in front of me highlights the gender dynamics and further undercurrents of vulnerability, agency and responsibility that punctuate our time spent walking together.

Laurence: 'Watch the bike!'

Introducing Laurence

Laurence was diagnosed with dementia over twelve years ago. Since then, he has been an advocate for people living with dementia and has been involved in research for many years. We were in contact via email and although I explained that I was happy to come directly to his house, Laurence insists on meeting me at his local city train station. Every time we meet, he has a heavy backpack full of books or household items that he drops off to several local charity shops throughout our time together. Laurence is a considerate and caring person. As he takes me along on his daily ventures, I observe the rapport he has with people in his local community whether it is the staff at the café, the volunteers at the charity shop or the homeless people to whom he would drop off snacks. Laurence and I spend several hours together on multiple occasions. We travel across the city, jumping on and off buses using his bus pass that gives us both free travel. Laurence also takes me to a community café to meet his wife and friends, he takes me with him to run errands such as donating to local charity shops and popping into a local empowerment charity with whom he works. We also go to several of his favourite places for lunch or a coffee.

Walking with Laurence

Laurence as I draw our time together to a close with a walk back to the station. Laurence insists on seeing me back there safely every time we meet. We have already spent several hours together, and I sense that Laurence is tired. He does not tell me this outright, but I have learned how to read him. He told me previously that he goes home for a long nap after our walks together. I observe that his physical movements are slower and more laboured than when we met hours ago, and he has been carrying a heavy backpack all day.

As we walk the city streets, Laurence is recalling an occasion last week, when his wife did not listen to the directions he was giving to her in the car. He was getting passionate because, in Laurence's recollection of the story, he told his wife to turn right but she did not trust his directions and turned the car left, onto a dead end. Laurence is lost in the moment of telling the story. We approach a road and as Laurence glanced left and right hastily, then steps out onto the road. Although there is a pedestrian crossing at this road and every time I had been with Laurence previously, he has used it, this time, he does not wait for the green light to cross. Perhaps this is not a conscious decision because he is tired or lost in telling me a story. Luckily, I also glance left and right before crossing, and I see a bike speeding towards us. As Laurence steps onto the road, I jerk my arm out across him and shout: *'Watch the bike! Watch the bike!'* Laurence halts and claims that he did not see the bike: *'I was busy looking for cars.'*

Not wanting Laurence to feel embarrassed, and feeling slightly embarrassed by my own outburst, I quickly try to steer the conversation back to Laurence's story, but he says never mind and we amble along in silence for a few minutes. We start to make small talk about the street market that we are walking through, but it is as if neither of us is invested in the conversation. We are both digesting what just happened at the crossing. Laurence finally addresses the elephant in the room: *'I'll probably end up in a care home because I don't really look after myself'*. I am shocked. Laurence says this in a detached and matter-of-fact tone, but I sense his fragility and sadness. This was not the independent and confident man that I had come to know. I probe and Laurence responds with short, curt answers, which is not his usual manner. Taking on the role of the probing interviewer at this time feels invasive so I drop my line of questioning and embrace walking side-by-side in silence. A few minutes later, the smooth surface of the path turns to cobblestones and Laurence asks if he can take my arm. I offer it to him, and we walk, arm-in-arm until we reach the train station. I ask Laurence about his plans for tomorrow, and he tells me that he has several meetings related to his advocacy work. He is still flustered after the earlier event and struggles for the words to explain what the meetings are about. Sensing his frustration, I pat his hand reassuringly and smile. We do not exchange words, but I sense that we both know what each other is thinking. Laurence smiles back at me: *'I should have you all the time now. That's the station just there'* and he sends me on my way.

Reflecting on my experience of walking with Laurence

Themes of vulnerability, agency and belonging underpin my time spent walking with Laurence. He walks a fine line between asserting his independence and sense of control, with recognising how dementia makes him vulnerable and less capable of certain things. On each visit, Laurence insists on meeting me at the station and dropping me off there at the end of our time together, even though I assure him that I am capable of meeting him elsewhere. Laurence feels responsible for me, and by ensuring that I am safe, he fulfils that responsibility and maintains a sense of agency. He also asks me on every occasion, if my travel costs will be compensated by my university, as he hates the thought of me being out of pocket to visit him.

As Laurence takes me about the city on his daily activities, he explains to me all the ways that dementia has made life difficult for him and all of the struggles he has been through to fight for fair treatment and inclusion in the community. As I observe Laurence going about his daily activities, I see the value that he adds to other people's lives and the sense of fulfilment that this brings him. Laurence speaks passionately about his rights as a citizen, but through his actions, he also demonstrates his civic responsibilities. While walking with Laurence, I accompany him as he gives food to a local homeless person, checks in on his friend over a coffee and donates items to several of his local charity shops. We stop for lunch and coffee in small, independent, local cafes because he expresses that he would rather support them over large chains. Doing these activities with Laurence highlights how he is a valuable asset to his local community.

Walking with Laurence makes me aware of the physicality of our bodies, moving together through the busy city streets. When we are ‘going out’ together, he is chivalrous, like John, insisting that I get off the bus first and that I am served before him in the cafe. I consider this to be a protest again the potential perception of others that he is the person with a disability, and I am the young, able-bodied/non-dementia person looking after him. He is concerned for my safety and wellbeing asking if I feel safe with him and regularly asking if I am doing okay. Aware of his physical impairments, Laurence warns me that he is at risk of fainting and that he makes sure to let me know that he does not want me to feel the responsibility to care for him if that were to happen.

Laurence seems to take pride in looking after me but after the bike incident, I sense a shift. By asking if he can take my arm, he embraces his vulnerability and surrenders to his need for human connection. When Laurence asks for my arm, I sense the intimacy and vulnerability of that moment and choose not to probe with questions. It is a particularly special moment of genuine human connection and I do not think that it would have happened had we not been ‘going out’ walking together.

Maria: ‘Safety, safety, safety’

Introducing Maria

Maria is a petite woman with a big personality who exudes warmth and positivity. She worked as a nurse before retiring and has all the traits of a stereotypical nurse; stern but fair; kind but not a pushover; affectionate but still boundried. Maria was diagnosed with young-onset dementia over a decade ago and her impairments are primarily sensory-related. She is a fiercely independent woman who lives on her own and is passionate about self-managing her dementia. She leads a busy life and regularly travels around the UK on her own for dementia research and advocacy work. Although I have met Maria several times before and she insists that she is capable of travelling to the city to meet me, I ask her if I can go to her home to get to know her better in *her* local environment. We email back and forth to arrange a time that suits her, and she agrees to slot me in one afternoon between her morning with her support worker and evening yoga class.

When I first visit Maria, she waits for me at the local train station. We greet each other with a big hug, and she introduces me to her support worker, with whom she has been running errands. The support worker leaves, and Maria and I walk from the station to Maria’s house together. Maria assures me that it is only a brief ten-minute walk and that we will: *‘get ourselves warmed up with a cuppa’* when we get in. Maria knows what my research is about from our previous interactions, so as we walk home, without any prompting, she talks me through the challenges that she faces on the route. She draws my attention to the loud noise of passing traffic and the main road that she must cross without a pedestrian crossing. Maria proudly shows me around her house, particularly focusing on the adjustments she has made to allow her to live at home, independently. Once we finish our cup of tea at Maria’s house, I ask whether she would like to go for a walk together. It is a relatively warm day in late spring, but the dark clouds and the threat of rain outside are not inviting for Maria. She decides against going outside because she does not want to go out in the rain and risk becoming ill.

Walking with Maria

The second time Maria and I meet, her daughter, Laura is in town. The weather is beautiful, and Maria has already planned where we will go for our walk-along: a pedestrianised path around the perimeter of the loch. After the three of us chat over tea for an hour, Laura drives us to a local loch where Maria and I can do our walk-along. Maria tells me that we can walk home after. The walk to the loch, around the loch and home again is slightly too long for Maria and although she knows she is physically capable of it, she also knows that it will exhaust her.

The walk is a popular one and today it is busy. As we set off, Maria explains to me how important it is for her not to be isolated at home. She believes that people with dementia are not given the support that they need to live happy, independent lives. To illustrate this point, when a family with a child in an electric wheelchair pass us, she gestures to them:

> *‘So, when you look, when we're doing this walk around about you, how they're supporting people with severe learning disabilities, severe physical disabilities, and you see them out and about in ordinary society. Dementia is behind the times at the moment and we need to start saying how can we make it safe for people with dementia who live alone to still get out and about?’*

This is the first of many times that Maria refers to safety throughout our time together.

Maria explains to me that her daughter bought her ear defenders to use when she is in a busy, city environment. She tells me that this strategy is useful, but it has its downsides:

> *'It takes all the noise out. And that's good at some points. But you can't use that all the time or you would become isolated. You can't hear the birds [Maria points to the nearby trees to bring my attention to the birdsong in the background].'*

Hyperacusis is one of Maria's symptoms of dementia, which gives her a heightened sensitivity to sound. Noisy environments can be a site of '*sensory overload'* for her. She tells me that her best strategy is to stay away from noisy environments, which also has its downsides:

> *'Oh yeah. I don't go to the cinema, for the noise…. I wouldn't go to big concerts or anything like that. So yes, I'm isolated socially in as much as what can you do? Dementia does prevent me from a lot of things'.*

Maria concludes her point by ending on a positive note: *'see, this is beautiful. It's busy but it's not overly noisy.'* She brings us back to the present moment and gestures to our current, quiet environment. Maria is proud to show off her loch area and draws my attention to *'look at all the* swans' in the water.

Maria and I walk three-quarters of the way around the loch and then she directs us away from the loch and onto a woodland trail that will take us back to her house. The trail opens up to a minor road, which is being used by cars and several other pedestrians. As a car drives towards us, Maria has difficulty figuring out which side of the road we should be walking on:

> *Maria:* *We're on the wrong side*
>
> *Katie:* *Oh really?*
>
> *Maria:* *We don't know the…I don't know the right way to walk. You're supposed to walk…*

Katie: *Against the oncoming, aren't you?*

Maria: *Aha. So, this is the way you have to walk. That's coming that way and we're walking that way, so they can see it. We're not walking in the… I think. I don't know [throws up her hands and laughs].*

Maria gets slightly flustered during this moment of problem-solving. She carefully considers the safest way for us to walk along a road with cars passing us intermittently. We walk along the road for short time before re-joining a pedestrianised path and the problem is solved for us. I notice that Maria is immediately calmer. I tell Maria that it was a lovely walk, and she responds: *'Wasn't it? Just nice for you to get your interview, walking and what have you, done in a safe way.'*

As we near the end of our walk, Maria tells me that although she advocates strongly to be able to self-manage and be supported to live independently, she also recognises the importance of knowing when to ask for help: *'I want people to see me as independent…. But it's good for me to acknowledge the vulnerable side of that'.* To demonstrate her point, as we approach a road that we must cross, she takes my arm. Maria explains this action: '*This is a busy road. So, I'm not supposed to cross it unless I'm with someone.'* The road is indeed a busy one and there are no nearby pedestrian crossings, so Maria and I check for oncoming traffic then dash across the road, arm-in-arm. We both know that we are not supposed to cross unless there is a pedestrian crossing, but we do it in the safest way we can, given the circumstances.

Reflecting on my experience of walking with Maria

Themes of risk, agency, decision-making and control underpin my time spent with Maria. I gain insight into the careful planning that goes into the simple act of going for a walk. As with all my participants, I want Maria to feel in control and an active participant in our walk-alongs. When we first met, although I would have gone for a walk, Maria decides it is too risky and it is important to me that she maintains control over this aspect of the decision-making process. Maria enacts her agency again when she decides that we will do our walk-along in a 'safe place'. Not only is Maria concerned for her safety, but she is also concerned for mine. Maria felts a sense of responsibility for me and if she is going to take me out for a walk, then she is going to do it in the safest way possible for the both of us. In addition, although the weather could be considered as a barrier as it prevented us from going for our first walk-along, this experience allowed me insight into how Maria manages her risk and makes decisions based on this.

During our initial sit-down interview, Maria told me that one of the symptoms of her dementia was hyperacusis, which she likened to an auditory ‘sensory overload’. This knowledge means that I tune in to the auditory environment when walking with Maria. As we walk together along a quiet loch and a busy road and Maria brings my attention to the stark auditory contrast of the two environments. Walking with Maria also heightens my awareness of our physical bodies moving in space. Maria is an affectionate person who hugs me at every hello and goodbye. She is also a tactile person who frequently places a hand on my arm and stops to look at me during our walk. I have an urge to link arms with her, as I would do with female family and friends. Maria is the only participant who I am physically bigger than; she is also the only female participant in the walk-alongs. Ironically, I never question my own or our collective safety when walking with Maria. Perhaps this is because she is a woman, and I feel safer in the company of women or perhaps it is because Maria has already put in the risk-management work to consider how we can do our walk-along safely.

Kevin: ‘You hang about down here and blether away’

Introducing Kevin

I am introduced to Kevin’s wife, Joanne by their dementia advisor and Joanne invites me to meet her and Kevin in their home. Kevin is in his late 50s, fit and loves to walk. Joanne works full-time and Kevin is retired so he is home alone from Monday to Friday. Regular walks with his dog, Cassie, punctuate Kevin’s days. They walk “the loop” in the local area at least three times per day. Twice per week, a support worker accompanies Kevin on a long walk and once per week, he attends a local gardening club. Kevin loves to be outdoors regardless of the weather conditions. He lives in a small town close to where he grew up on the edge of a National Park. Kevin is not confident using public transport on his own and the services are not great in their semi-rural town, so his main mode of transport is on foot.

I first meet Kevin on a frosty, January morning. I am an hour late because the railway was closed due to the weather conditions. Kevin and Joanne meet me at the train station and accompany me in a taxi for the 5-minute drive back to their house. It is freezing outside; there is visible frost on the ground and a cutting wind is blowing. I am open to the idea of doing a walk-along with Kevin if he wants to, but Joanne insists that conditions are too poor, so we sit in the living room for our first interview, warmed up with tea and biscuits. Our second meeting is in March. The weather has warmed up enough for Kevin and me to go for a walk, so we set off on a walk with his dog, Cassie.

Walking with Kevin

Kevin and I are barely out of the door of his house when he tells me: *'it's a lovey wee walk'.* The visibility was so poor on my previous visit, and I did not realise that such beautiful scenes were just around the corner. I stop in my tracks and gasp in awe of the view, I say nothing, but I look at Kevin with wide eyes. Kevin smiles and acknowledges this: '*yes, you get a good panorama'*. I am not pandering to Kevin. The location of our walk is genuinely beautiful with rolling green hills in almost every direction. On my previous visit to Kevin and Joanne, Joanne spoke most of the time and there was barely a moment of silence. Initially, when I am alone with Kevin, I feel the need to fill our silences with running commentary but as we fall into a rhythm of walking alongside each other, I feel myself relax. It is as if, by showing my appreciation for the local area, there is a subtle, deeper connection between Kevin and myself. We embrace the silences together, letting the calming effect of being in nature take over. During our previous interview, Kevin told me that he struggled with anxiety since his diagnosis. After our initial prolonged silence, I bring it up again, on our walk, to see how he is coping a few months later. He explains how he has overcome it with strategies that his doctor has taught him including a gratitude practice: *'I feel myself grateful for - see what I've got now [sweeping gesture to surrounding environment]- I feel that this is my world now and I think it's brilliant. I think it's really good'*. It becomes evident to me that 'going out' and walking 'the loop' several times per day is crucial for Kevin to lead the life that he wants to live. Kevin is physically fit and walks without any mobility issues. As he directs us on our walk: '*we're going through this wee bit [gesturing to a gate that leads to the local park]'*, I notice his chest puffs with confidence, taking control and setting the tone for the rest of our walk. Kevin is in control. He is the tour guide and I allow myself to be guided. Kevin is proud to show off his local area. We walk through the gate, and as we stroll through the park, we pass several fellow walkers. Kevin either says hello or initiates small talk with every passer-by, explaining to me after several of these interactions: '*you get to know your neighbours and that as well… because they go down with their dogs and all that and sometimes you hang about down here and blether away'*.' Not only is it clear that Kevin engages in social interaction during our walk, but he interacts with the natural environment too. After we walk through the wide expanse of the local park, we arrive at a more secluded, riverside trail. This time, Kevin is the one to break our silence, telling me: *'I kind of like to have a whistle myself'*. Kevin then whistles a tune and then cups his ear: *'that's me and the birds start, see'* beckoning me to listen in. The walk is a circular route and as we start to turn back towards where I think the house to be, I ask if we are starting to loop back. Kevin appears happy that I am *'keeping up'* and gestures to the local park: '*yes… all this area here*… *I'm quite genned up with all this. I know all this, these people'*. To prove his point, as we pass the local mechanic further down the road, Kevin lingers, hoping that the mechanic will come out and say hello. After realising that he is not there, we walk on, and Kevin tells me: '*he stops every now and again and takes us in for a cuppa'.*

At the end of our walk, Kevin draws our time together to a close: *'that's more or less it… it's quite a good wee walk'.* I thank him for showing me around his local area and he concludes by telling me that he enjoys the social interaction on his local walks: *'you go down there and you're just blethering'.*

Reflecting on my experience of walking with Kevin

Themes of social engagement and connection to place underpin my time spent walking with Kevin. The act of shifting the environment from a stagnant indoor environment to something outdoors and more fluid allows Kevin and myself to feel more in sync. When we are sitting in the house, Kevin is limited to verbal communication but out on our walk, he can use the surroundings to support his communication by pointing out features of the environment. These environmental cues also stimulate conversation between us, for example when Kevin whistles to the birds and we both pause to hear them sing back, we start talking about feeling connected to nature. These shared experiences break down the researcher/ participant power dynamic and enable Kevin to take more control.

Kevin is determined to show me that he is fit, healthy and happy despite his diagnosis. The walk-along is an opportunity for him to embody this, to show me how physically capable he is and to give me an insight into the everyday life that he is so content with. While walking with Kevin, I gain insight into how he uses frequent daily walks in his local area to maintain a sense of connection to the fellow walkers and the physical environment. As a retiree, whose physical and social world may be shrinking, and with a wife who still works full-time, walking the dog is a vital part of Kevin's daily routine. The dog also provides Kevin with reassurance and security. If he gets lost on a route, he is confident that she will guide him home. Although the purpose of walking the dog is important for the health and well-being of the dog, it is as important for the health and well-being of Kevin. Walking with Kevin and observing him saying hello to passers-by and whistling with the birds demonstrates how 'going out' to walk the dog gives Kevin a sense of purpose and enriches his day by provide an opportunity for social interaction.

Philip: 'A tour of the city'

Introducing Philip

I meet Philip and his wife, Angela at a local Alzheimer Scotland dementia café where Angela tells me that she hopes Philip will take part in this study because she noticed on a recent holiday that Philip had difficulty navigating certain unfamiliar areas. Philip is an avid walker and often ventures into the city alone to explore. Philip is retired and during our walks he reminisces on his career frequently. It is apparent that he loved his career, the people he met through it, and the opportunities that it afforded him. Angela and Philip met in the city whilst they were at university, and both hold cherished memories of it. They moved away upon graduating but recently moved back upon retirement. Philip now spends his days exploring the city where he was once a student, reliving those cherished memories.

I contact Angela after the dementia café, and we arrange for me to visit them in their home. The first visit involves getting to know them as a couple, establishing rapport and going through consent procedures. Philip and I meet for our walk-alongs on two consecutive weeks after that. Philip has language challenges because of his Alzheimer's disease. I learn that this is difficult for him to come to terms with because he is quite the intellect. Philip has a wealth of knowledge about the city, which he imparts on me over the duration of our walks.

Walking with Philip

My first walk with Philip is a stroll around public gardens in the city. As I get to know him and ask questions about his past, he frequently interrupts the conversation to educate me on the surrounding plant life and to recall stories from his past. Our second walk is around the streets of the city. As we set off, Philip tells me about the rough plan for the route we will take, naming streets with confidence. As we are discussing some of the difficulties that he has when navigating, Philip interrupts the conversation to stop and point at a plaque on a building: *'Chopin!'* he exclaims proudly. I skim read the sign; Chopin stayed in the building when he played in Edinburgh. Philip follows up: *'Yeah, only for one night. But he was playing here. On the 4th of October, which is my father, that was his birth, well his birthday, he wasn't that old.'* This is the first of many instances on our walk where takes on the role of tour guide. Later in the walk, he does the same thing:

> *Philip:* *…And now, just a moment, here we go. In this hall, Robert Louis Stevenson went…*
>
> *Katie:* *He went to school? [Reading the plaque]*
>
> *Philip:* *…he went to here, and it was a school.*
>
> *Katie:* *I'm getting a history lesson!*

A few minutes later, he points to another house:

> *'And this is a genius… This is James Clark Maxwell; this was his home. Although, this was, the house was their parents, and things like that. But they kept going back to Galloway, because they had a sort of small castle. Because he was not a great lord, or anything, but he had a little bit of, quite good, doing that.'*

Not only does Philip give me a tour of the historical points of interest along our walk, but he is also confident in giving directions and demonstrating his knowledge of the city:

> *Philip:* *…We come down there [points to nearby walking path], there's a great, it was Stockbridge Railway Line, it took all the marshalling yard, in Stockbridge. It's now a park, and it's really nice, and that's my grandson's, on all the… [points to park]*
>
> *Katie:* *Oh, that's his stomping ground, is it?*
>
> *Philip:* *Oh, yeah, it's great. And from there, just in there, it goes into a tunnel, and it comes out at Tesco, further on.*

Although Philip is confident in his navigation and in taking on the role of tour guide, I notice that he has difficulty maintaining conversation whilst undertaking more cognitively challenging tasks such as crossing the road. As we approach a pedestrian crossing, I ask Philip whether he faced any challenges on his recent holiday. Philip looks left and right. I do the same and there are no oncoming cars. I assume he is deciding whether to jaywalk or to wait for the green light. As he is doing all of this, he responds to my question: *'Erm…oops. Erm, let me think. It was, I did quite well, that, erm…yeah'.* There is a lot to process, and I reassure Philip that we will cross the road first. I repeat my question after we have crossed. Philip is more relaxed and able to answer my question once the road crossing is behind us.

Philip navigates around the city with ease explaining to me that even if he gets lost, he doesn't panic because the layout of the streets in his local area makes it easy for him to navigate: *'One of the things, this grid makes it fairly easy, you can zigzag a bit…So, I'll try to get down to something else, shortly.'* He gives directions with confidence and although he has challenges with certain words, street names do not seem to be a challenge for him: *'Oh, we must go up [street name], this is…'* It is as if he is showing off his knowledge of this city to me. For example, when I ask Philip if he uses the buses, he responds: *'Yeah, yeah. Well, we've got quite good ones, there's only three going past, but that's not bad. And the eight goes to the Infirmary, and then, the east side. The 27 turns off into Gilmore Place after the Cameo. And the 23 goes up Morningside.'* I get the impression that Philip is proving to me how well he knows the city.

In walking the city together, I observe how Philip takes control of the route, taking on the role of tour guide and navigator. Although I live in the same city, he takes me to places that I have never been to before. There are times where I am a bit lost or confused as to where we are, but Philip maintains his confidence:

> *Katie:* *Are we at a dead end?*
>
> *Philip:* *No.*
>
> *Katie:* *Oh no, you can go down this way.*
>
> *Philip:* *I wouldn't take you to a dead end. Yes, here.*

Philip delights in the idea that he has taken me to places that I have never been. When I tell him it is a new place for me, he tries to orient me:

> *Katie:* *I've never been to this part of the path network before.*
>
> *Philip:* *Uh-huh, well this is Piccadilly Circus at this bit, there's five ways… That one, goes just a little bit, and then there's another one. And then, that one goes down there. That goes up there, and it ends up, and that's a big, long one that curves, and it goes to Murrayfield.*

Our historical walking tour of the city continues and during our three walks, Philip shows me several corners of the city that I never knew existed, from the platform of an old railway line to a pier used for whale hauling. He maintains the control of our navigational decisions, guiding me seamlessly: *'I think we might go into that street'*. He is constantly drawing our attention to the environment from the *'nice wee ducks, mallards'* to the children playing outside a school at break time: *'Oh, a primary school. And they're out.'* Philip has a wealth of knowledge about this city, and he is proud to show it off.

As we near the end of our final walk together, Philip's ability to articulate his knowledge of the city is challenged when a tourist asks for directions to a well-known attraction. The attraction is right next to Philip's home, and he knows exactly where it is but his ability to communicate that verbally is another matter. The tourist has limited English, so Philip's first attempt is to tell her to *'come with us'* as we are heading in that direction. After a few steps, he tries again to direct her saying: *'it's* *very easy'* and points in the direction we are walking. She thanks us and walks on, and we carry on with our conversation. A few minutes later, Philip and I are about to turn off the path to go back to his house. We observe the tourist in the distance who turns back to us and shrugs when she arrives at a fork in the path. The tourist is within eyesight but too far away to shout directions at so Philip points to the right and says under his breath: *'just turn in there'.* The tourist nods at us but takes the left fork in the path. Philip notices this and is frustrated: *'she's gone a wee bit far…she should come back'.* I reassure him that she will ask someone else for help, but I sense that Philip is deflated. Despite his best efforts, it is as if he feels that his inability to communicate clear directions were the problem telling me: *'I thought that was the reasonable thing'.*

Reflecting on my experience of walking with Philip

Themes of control, agency and connection to place underpin my time spent walking with Philip. I gain insight into how the city is an important place for Philip. His admiration for it is infectious and gives me a fresh sense of appreciation to be living there. Certain features of the physical environment would prompt memories about his student days and long retellings of the boisterous activities he would get up to in the city. Philip has a vast amount of knowledge about his city which he demonstrates frequently by taking me to lesser-known places of interest.

Walking with Philip shows me how he can take control and give me a tour of the city, despite his impairments. Philip treats the walk as an opportunity for him to take on the role of tour guide, pointing out various historical points of interest. He also takes on the responsibility of the navigator role, maintaining confidence in his ability to get us both around the city safely. I observe how he handles everyday situations such as giving directions to a tourist; a situation, which would not have arisen if we were not out walking together. This is a difficult situation that challenged Philip's seemingly unwavering confidence. Interestingly, Philip does not doubt his own knowledge in this situation. Instead, he appears frustrated by his inability to articulate his knowledge and give clear instructions.

Philip's language impairments force me to turn my attention to the role of our bodies during our time spent together. I observed how Philip becomes distressed when trying to engage in conversation whilst doing a cognitively challenging task such as crossing the road, his movements becoming staccato and hesitant. Philip frequently stops in his tracks when he is answering my questions or telling a story. Perhaps this is because he finds it challenging to walk and talk at the same time. In these moments, I feel guilt, questioning whether the walk-along method was too challenging for Philip. In contrast, when Philip feels in control, his movements are confident and rhythmic. When he reveals each historic point of interest to me, he gestures to them like a ringmaster of a circus introducing the next act. Philip's enthusiastic interaction with the physical landscape forces me to attend to features of the city that I had previously overlooked. Although Philip loves to walk and moving through the landscape is an important element of our time spent together, perhaps the more poignant moments are when we stop in our tracks, an action initiated by Philip. In doing so, he draws me in to focus on a feature of the environment so I can fully absorb what he is telling me.

Robert: 'I think walking gets you good'

Introducing Robert

I meet Robert and his wife, Nicola at a local community café. Robert is a gentle and quiet man, and they are both open to discussing his dementia with anyone, believing that the more people who know about it, the better. Robert lives life in the present moment. He was not always that way, but it has become a strategy for him to manage living with dementia as his memory deteriorates. When I meet Robert and Nicola in their home, Nicola tells me that although Robert's speech is still good, his ability to engage in conversation is not. He uses *'filler sentences'* and *'parrots'* what others say as a masking technique. Ironically, Robert nods along with what she is saying, shrugging with a bashful smile.

Robert and Nicola have experienced a change in their life circumstances since his diagnosis, a formerly active and social couple, they now lead a quieter life and struggle to hold on to that former identity. They have lost many of their previous friendships as people slowly pulled away because they did not know how to engage with Robert. They now attend regular coffee morning and music groups for solidarity and social engagement, but they often struggle to fill the day with stimulating activities. Robert is happy with the life he leads, stressing that the most important thing to him is to be able to get outdoors.

Robert is the only participant in this study who does not leave the house on his own anymore. Up until this point, Nicola has been a part of our conversations. Of all my participants, Robert has the most obvious communication deficits. I worry that this will make the walk-along challenging for me.

Walking with Robert

Robert and I walk along the canal on a cold, but sunny spring morning. Although Robert rarely goes out walking on his own anymore, he still goes out regularly. He is the type of person who cannot sit in the house all day. At the beginning of our walk, Robert tells me: *'we like walking, so, we always like to get out and get moving.'* When I probe to get him to elaborate on why this is the case, he responds with the succinct point: *'I think walking gets you good.'* Robert walks a slightly different variation of the same walk each day. He frequently uses 'we' when talking about his experiences. I assume this is because he is always with his wife: *'And although we're walking down here now, like this, sometimes, we cross over, just to see what's happening over there [points to the path on the opposite side of the canal].'*

Robert is aware of everything that is happening around us and there are several ways in which Robert draws our attention to the beautiful scenery and other people in our surroundings. Robert uses this awareness of what is happening in our immediate surroundings as a way of taking control. Although comical, an example of this is when he points to the ground in front of me and cautions: *'there's a big dog poo'* and I swerve to avoid it. Later in our walk, we are walking along a muddy trail, and he warns me to: *'watch for any slide-ey bits [wipes his foot back and forth along the ground to demonstrate the hazard]'*. Towards the end of our walk, the path becomes busy with other walkers and cyclists and again, Robert warns me: *'watch out for the… [cyclist]'* and *'Give this guy a chance to get past… [waves hello to overtaking walker]'*. Robert is alert to potential hazards in our immediate surroundings but also in the distance pointing and alerting me: *'there's somebody on a bike coming, I can see them'*. Robert has warned me enough times now for me to know that he is not simply drawing my attention to them; he is alerting me to them so when they come closer, I am prepared to step out of the way. Robert uses the environment to show me the challenges that he faces when he does not have the language skills to tell me about them verbally. For example, he points to the uneven ground underfoot: *'this bit is, you know, not so good'*. As well as being aware of potential hazards in the environment, Robert demonstrates a focused level of awareness of our own bodies and mobility. He asks me multiple times if the pace is okay for me: *'how're your legs doing?'* reassuring me*: 'we can just turn around and go back'.*

Robert acknowledges how beautiful the local scenery is and how fortunate he is to live where he does: *'Yeah, we're pretty lucky, I think, where we are…. Just for the views.*' He draws my attention to scenery right in front of us and in the distance: *'You see this, just have a look at that, all that there [pointing to a garden full of flowers] ….And then, you've got all the rest of this bit here [pointing to the hills in the distance]'.* What Robert may lack in verbal language skills; he makes up for with his body language. When he wants to draw my attention to the rowers in the canal next to us, he points: *'There's some rowers. Hands on'* and makes the motion of rowing with imaginary oars.

Although Robert is constantly looking out for me and has an air of confidence about him in this environment, at the beginning of our walk, he deflects navigational decision-making back to me at every opportunity: *'Which way do you want to go? Through this way?'* However, as we relax into our walk, Robert shifts from deflecting decision-making on me to expressing an inquisitive nature: *'We can do, let's have a try…. I'm not sure where this will take us'* and encouraging me to follow suit: *'Come on, let's have a look'*. Even though Robert is alert to what is happening in the environment, he is equally relaxed and at ease. He is not afraid to wander off the beaten path and investigate things in the environment that he doesn't recognise: *'What's this, here, actually? [gestures to a plaque on a park bench] Oh, it's installed by (local) Community Council, there you go.'*

Robert concludes our walk on the same positive note that he began. As we reach the top of the hill, looking down over the canal that we just walked along, he brings us back to the present moment. He stops in his tracks, and I do the same. Breathing in deeply, he says: '*this is nice, just this air, now, isn't it?'* I take in a big breath with him and nod. He smiles at me and shrugs, concluding: *'But it's just good getting out….And having this, you know, on our doorstep, almost…what's not to like?'*

Reflecting on my experience of walking with Robert

Themes of control, independence and decision-making underpin my time spent with Robert. Walking and talking with Robert is initially challenging for me as a researcher, as our conversation does not flow easily due to Robert's language impairments. Robert gives short answers to my questions, rarely expanding on his response or engaging in a fluid dialogue. This forces me to turn my attention to observing how Robert physically interacts with his environment. Unsurprisingly, it is through this embodied lens that I discover a wealth of information. In setting the pace that we walk at, Robert takes control of our interaction. He is able to adapt; despite lacking the language skills to tell me about certain challenges that he faces, he is capable of using his body and interacting with the environment to demonstrate them to me. This is exemplified when he slides his foot in the mud to highlight the danger of slipping. I don't think he would have been able to articulate that verbally in a sit-down interview if I had asked him what challenges he faced whilst 'going out.

Initially, I am stressed about Robert's language difficulties and what kind of 'data' this might generate but the act of walking side-by-side has a soothing effect on me. Learning from my experiences of walking with Kevin, I challenge myself to embrace the silences with Robert as opposed to filling them. Doing this opens an opportunity for Robert to initiate conversation, often with a comment of appreciation for the local environment.

Whilst walking with Robert, I feel a sense of responsibility that I did not feel with other participants. Perhaps this is because he is the only participant who no longer goes out on his own. Therefore, I assume that he would be dependent on me to make decisions during our walk. At first, Robert verifies my assumption but as we get into the rhythm and flow of walking together, Robert's confidence increases, and he takes control of our interactions. He decides the pace, he makes navigational decisions, and he shows consideration for my well-being. Robert is the only participant who suggests that we walk on paths that are unknown to him, encouraging me to explore. This is interesting because he is also the only participant who no longer goes out on his own. Perhaps this is because he feels safe with me and trusts that together, we will be able to find our way.

Conclusion

The purpose of this chapter was to provide an in-depth supplementation to the themes highlighted in Chapters Four and Five. In doing this, participants are shown as whole people, not just data sources to support themes in my analysis. The seven narratives demonstrate how participants were active in their engagement with the process of ‘going out’. Walking with John and Simon highlights my role in the co-construction of the data and the underlying dynamics and tensions at play. Walking with Laurence and Philip demonstrated how unplanned situations in the environment can expose vulnerabilities and lead to intimate human connection. Walking with Maria evidences the careful decision-making practices around ‘going out’. When walking with Kevin and Robert, I observed how they connect to the local community and geographical landscape through the body, even when they lacked the language skills to articulate it. Although the themes presented in the previous chapters are useful to see patterns across accounts, these reflexive narratives give rich insight into the differences between individual participants’ experiences and their encounters with ‘going out’. These stories highlight how ‘going out’ is an embodied and emplaced practice for the participants. They also highlight underpinning themes of vulnerability, agency, belonging, connection, risk, decision-making and control. This is in contrast to the commonly held assumption that people with dementia lack agency and provides evidence for how they are active social agents (Bartlett and O’Connor, 2010). How these stories fit into the broader debate is discussed in the next chapter.

Chapter Seven – *Where Do We Go from Here?* – Discussion and Conclusion

Introduction

This final chapter draws this thesis to a close by pulling together the various threads discussed thus far. At the beginning of this thesis, I stated that ‘going out’ and being at risk of going missing, from the perspective of people living with dementia, was underexplored. Therefore, this study aimed to explore how people living with dementia who live at home, interact with, connect to, and find their way around the world outside their homes. The study had a specific interest in how people experience being lost or at risk of missing. In this chapter, I draw on the findings of the previous three chapters to propose the 3 P’s: a new approach to understanding ‘going out’ for people living with dementia. This approach makes novel contributions to the missing persons and dementia studies literature, while also informing prevention and search strategies for people with dementia who are at risk of going missing. After introducing the 3 P’s, I discuss the novel contribution of bringing the lived experience of people with dementia into the evidence base in missing persons research. Next, I argue that ‘going out’ is an embodied and emplaced practice of everyday citizenship for people with dementia and thus, it is a practice that must be supported. I reflect on my methodological approach and the dissemination efforts I have made during this doctoral journey. Finally, I conclude this thesis by addressing the study limitations, making suggestions for future research and with a final reflection on the study.

The 3 P’s: A heuristic tool to understand the motives and strategies of ‘going out’ for people living with dementia

In the introduction to this thesis, I posed the research question: “How do people with dementia and their care partners experience ‘going out’?” Drawing on the findings of this inquiry, I answer that question by developing the 3 P’s: A heuristic tool to understand the motives and strategies of ‘going out’ for people living with dementia. This is visually represented in Figure 2. This study found that when ‘going out’, participants were active agents in decision-making practices. ‘Going out’ was also found to be a relational, embodied, and emplaced practice. Therefore, ‘going out’ can be interpreted as a practice of everyday citizenship for people living with dementia. This study also found that people with dementia are a heterogeneous group and that each individual’s experience of ‘going out’ depends on broader sociocultural factors such as level of community cohesion and individual factors such as gender and levels of mobility. Therefore, to understand experiences of ‘going out’, the findings of this study can be broadly categorised into *why* people go out (motives) and *how* people go out (strategies). Other common themes in the experiences of participants are the *practices* that a person engages in; the *places* that they go; and the *people* that they engage with (which can be shortened to the 3 P’s). In other words, the 3 P’s draws our attention to people’s motives and strategies for ’going out’. Thus, to understand the experience of ’going out’ for people with dementia, we must ask the questions “why do people living with dementia go out?” and “how do people with dementia go out?” To focus these questions further, we can examine the person’s practices and routines, the places they go and the people they engage with to add an individualised context to their experience of ‘going out’.

The central premise of the 3 P’s is that the *person* living with dementia should be at the heart of decision-making regarding ‘going out’. This is represented visually by a picture of a woman walking her dog in the centre of the diagram. The use of a graphic illustration to represent the 3 P’s was carefully considered to portray ‘going out’ as a practice that is done via the body. This enables the framing of ‘going out’ as a practice of citizenship (Bartlett and O’Connor, 2010). Practically, this diagram could be used by people with dementia and their families in advanced care planning, and as a self-management tool to prevent potential missing incidents. It could also be used by search and rescue teams to guide search strategies by the collection of appropriate background information when a person with dementia is reported missing. It is especially useful in the latter context as it shifts the narrative away from labelling people with dementia as one homogenous group whose movements can be categorised, towards a person-centred approach where an individual’s motives and strategies are understood in the context of sociocultural factors.

Figure 2. The 3 P's: A heuristic tool to understand 'going out' for people living with dementia

Valuing the lived experience of people with dementia

This constructivist inquiry provides crucial insight into subjective experiences of navigation for people with dementia. Amongst other strategies, participants reported a dependence on landmarks to aid navigation. Previous observational research has shown that people with dementia use landmarks to navigate (Sheehan, Burton and Mitchell, 2006; Olsson, Skovdahl and Engström, 2019; Seetharaman, Shepley and

Cheairs, 2021). This study supports these findings in Scottish contexts and various urban, semi-rural and rural environments. Participants in this study shared navigational strategies with each other during group discussion, such as resting at a bus stop or suggesting key landmarks to look out for. This self-awareness and consideration for one’s safety demonstrate how participants are active agents in the decision-making process of ‘going out’.

This study found that people’s ability to navigate urban or rural environments depended on what was familiar to them. Participants who lived in urban environments were not fazed by the hustle and bustle of the city, whereas those who were used to quieter towns found the city to be overwhelming and a difficult place to navigate. This supports previous investigations that the familiarity of an environment is an important factor reported by people with dementia (Brittain *et al.*, 2010) and in the use of cognitive maps in people with early Alzheimer disease (Jheng and Pai, 2009). Participants also shared how they developed strategies that involved their care partners such as timed walks and staying within a pre-agreed boundary, which evidences that navigation is not an individual phenomenon. In fact, it is an example of relational agency as participants demonstrate interdependence, vulnerability and reflexivity in this context (Burkitt, 2016). Although participants demonstrated an ability to use landmarks, some shared that they were unable to map specific landmarks to certain routes. This supports previous findings that people with Alzheimer’s disease and mild cognitive impairments recognised landmarks but could not locate them on maps or recall their order (deIpolyi *et al.*, 2007). However, by using strategies such as asking for help and sticking to familiar routes, participants were able to overcome these navigational impairments. This has also been evidenced in interviews with people with early stage dementia in Sweden (Olsson *et al.*, 2013). By understanding how people with dementia use these strategies means they can be better supported to continue using them and therefore, can be involved in the self-management of their dementia. This requires a shift in focus away from the cognitive deficits caused by dementia and onto the barriers of a public environment that is not inclusive for people living with a disability.

Despite using these navigational strategies, participants still reported experiences of getting lost or becoming disorientated when ‘going out’. However, these occurred predominantly as a result of changes in the physical environment such as road works, scaffolding on a building, the weather and season changes, which are largely overlooked in the academic literature and subsequently, in search and rescue guidelines. When ‘going out’ most participants tried to keep to routes and areas that they were already familiar with. Thus, environmental changes impacted their ability to draw on their previous knowledge of the area. These findings suggest the importance of people with dementia’s experience of using environmental cues when navigating an outdoor environment. This offers an alternative explanation for why people with dementia become lost to the predominant narrative that getting lost occurs as a result of deficits in working memory (Yatawara *et al.*, 2017). The UK Missing Persons Unit’s iFind search tool reports that people with mild dementia ‘*typically engage in goal-driven behaviours’* and ‘*may get lost whilst trying to reach this goa*l’ (NCA UK Missing Persons Bureau, 2016, pg. 56). The findings from this study could add further detail to these search guidelines by offering a further explanation as to why a person with mild dementia might get lost. These findings can also provide insight into how they might try to relocate themselves.

Although previous attempts have been made to profile the behaviours of missing persons, there is limited evidence to explain why people might go missing in the first instance or what their experiences of missing are (Parr and Fyfe, 2013). The Geographies of Missing People was a landmark study that aimed to address this gap (Stevenson *et al.*, 2013) however, the perspectives of people living with dementia were excluded from the study. Therefore, this inquiry builds on the Geographies of Missing People study by including the perspectives of people living with dementia to address this crucial gap. This research differs slightly in its aims by exploring experiences of ‘going out’ instead of experiences of missing. However, this study’s findings remain relevant to missing persons literature as it still provides insight into people’s experiences of being lost and reported missing. Interestingly, several participants in this inquiry reported instances of being lost yet few of the escalated to being reported missing. This supports the hypothesis that the rate of dementia-related missing incidents is that that what is formally reported to the police (Shalev Greene *et al.*, 2019)This study also reveals a varied understanding of ‘going out’. Specifically, this research positions people with dementia as active agents in a practice of ‘going out’ as opposed to passive victims of wandering behaviour. This evidences that each individual has a different experience. For example, Maria highlighted the additional safety concerns she had as a woman on top of the concerns she had as a person with dementia. This suggests the need for adaptable, person-centred prevention and response strategies that see beyond the dementia.

In order to inform prevention and search strategies, there have been attempts in the literature to develop models to explain missing incidents and wandering behaviour for people with dementia (Moore *et al.*, 2009; Rowe *et al.*, 2015). These models are framed within a biomedical understanding of dementia, framing any attempt to leave the home by a person with dementia as a 'symptom' or 'behaviour' that can be 'managed'. This language feeds the public discourse that people with dementia only exist as care recipients (Nedlund and Bartlett, 2017) and therefore, it is not applicable for every individual who has vastly different experiences. This is because dementia is not one disease with one set of symptoms. While I recognise that developing a shared understanding of terminology is valuable in both applied practice and academic discourses, I argue that by shifting attention away from trying to define the 'problem' of missing, getting lost or wandering in dementia and onto understanding people's motives and strategies for 'going out', we can view people with dementia as active agents who make decisions rather than a problem or behaviour to be managed. This approach is aligned with the aim of this research to support people with dementia to live in a safe and supportive environment where they can maintain a practice of 'going out' and therefore a practice of citizenship.

Previous attempts to profile the behaviours of missing persons with dementia have been based on statistical analyses of previous missing persons reports in the USA and UK (Koester and Stooksbury, 1995; Gibb and Woolnough, 2007). However, these guidelines are based on small sample sizes and there is a risk that search and rescue agencies are over-dependent on these resources as they have limited evidence-based strategies to assist them when locating missing persons with dementia (Neubauer *et al.*, 2019). Therefore, additional research has called for the inclusion of the subjective experience of people living with dementia in research involving 'wandering' and connection to place (Kullberg and Odzakovic, 2018; Neubauer and Liu, 2020). This study responds to that call by drawing on people's experiences of 'going out'. In doing so, this study proposes the 3 P's as a person and place-centred visual aid that can be adapted to frame our understanding of every individual living with dementia who may be at risk of missing whilst ‘going out’. The 3 P’s could be considered as an alternative heuristic tool to Rowe’s model of missing incidents and as a supplementary search tool to behaviour profiles. Broadening the scope of this inquiry to experiences of ‘going out’ allows the 3 P’s to be useful in both prevention and response to missing incidents and can be used to inform discussions and as part of advanced care planning by people with dementia themselves, their families, formal care workers and police or search and rescue services if the individual is reported missing.

As well as having implications in search and rescue practices and missing persons literature, the findings of this study also suggest that careful consideration should be given when designing an environment to be accessible or when changing an environment for essential construction works. Town planners should consider which landmarks might be obstructed and how to provide clear alternative signage and routes. For a community to be dementia-friendly, previous design guidelines and people with dementia themselves should be consulted to create inclusive and accessible public spaces (Blackman *et al.*, 2003; Mitchell, Burton and Raman, 2004; Mitchell and Burton, 2006, 2010). Understanding lived experiences of navigation for people with dementia are a useful evidence base for policies and initiatives that aim to make environments dementia-friendly. This is important because of the increasing prevalence of dementia in our ageing population of people living in the community.

‘Going out’ – a practice of everyday citizenship

This study contributes valuable empirical and theoretical knowledge that broadens our understanding of how people with dementia experience ‘going out’. Specifically, this study has demonstrated that ‘going out’ is a practice of everyday citizenship. The examination of everyday practices and routines is a well-established route of inquiry in sociological research. In ‘The Practice of Everyday Life’ DeCerteau (1998) frames everyday life as an act of resistance of the individual, whereas Bourdieu’s Theory of Practice (1977) argues that daily practices are relational and cannot be separated from the wider social context. Influenced by Pink’s interdisciplinary approach in ‘Situating Everyday Life’, I consider practices of the quotidian to be both normative and resistant (2012). Maintaining a practice of ‘going out’ can be considered as routine and mundane for a person living with dementia as a person without dementia. However, it can also be considered a political act of resistance; resisting the common narrative that people with dementia are passive care recipients and instead, frames them as active social agents (Bartlett and O'Connor, 2010). By examining this aspect of people's lived experiences, elements of citizenship such as purpose, independence, control, agency were explored (Nedlund, Bartlett and Clarke, 2019). These elements can be understood by examining the practice of 'going out' through the lens of adaptive and relational decision-making; risk and resilience; and embodiment and emplacement.

'Going out' – An adaptive and relational decision-making practice

Bartlett and O'Connor's conceptual framework for social citizenship in dementia argues for a shift from including people with dementia in decision-making regarding their care, to supporting people with dementia to actively participate in decision-making regarding their care (Bartlett and O'Connor, 2010). In this thesis, participants were active agents who participated in decision-making regarding the practice of 'going out'. Importantly, these decisions were not made in the context of care, but rather in the context of social participation. For example, several participants adapted their practice of 'going out' depending on their fluctuating capacities. When a city environment became overwhelming for Simon and John, they stuck to quieter walking routes. This allowed them to maintain a sense of routine and purpose by getting out of the house each day and to maintain a connection to nature and the people they would meet whilst out walking. Those who still drove adapted their driving practices by avoiding driving in bad weather or the dark. They still drove during off-peak times of the day to go shopping or meet friends. An alternative example of taking control and making a decision was when Maria decided that we would not go for our walk-along interview as had previously been arranged. The weather was poor, and she did not want to risk becoming ill. In making this decision, Maria exercised her agency. These examples of adapting to changing circumstances provide further evidence towards the argument that people with dementia have a desire to remain central to the decision-making process (Fetherstonhaugh, Tarzia and Nay, 2013) and have the capacity for agency (Boyle, 2014).

This study advances arguments that agency is a relational rather than an individual phenomenon (Burkitt, 2016). Participants made collaborative decisions with their care partners in the context of ‘going out’. This was evident in this study when Simon acknowledged his dependency on his wife to drive him when he wanted to go somewhere and when Robert and Nicola decided that he would only walk pre-agreed routes alone. Both people with dementia and care partners reported that making shared decisions made them both feel more at ease. This aligns with previous qualitative studies that demonstrate the ability of people with dementia to engage relationally and that people with dementia and care partners value interdependency (Boyle, 2014; Keyes, Clarke and Gibb, 2019).

It has been suggested that people with dementia have the potential to influence their wider social environment (O’Connor *et al.*, 2007). This study evidenced this by examining the roles that participants had in their local communities. For example, John felt a responsibility to support fellow people with dementia at his local dementia support group, Jimmy volunteered at a local homeless shelter and Laurence donated items regularly to local charity shops. These actions evidence reciprocal relationships between people with dementia and other citizens in their communities. Since citizenship is a relational concept (Wiener, 1998), these actions also provide evidence of how citizenship is a practice that people with dementia are actively engaged in (Nedlund and Bartlett, 2017). Taken together, these examples of adaptive and relational agency challenge the narrative that people with dementia only exist in a care-receiver capacity and suggest that they are active agents in society (Bartlett and O’Connor, 2010).

‘Going out’ – The intersection of risk and resilience

Risk and resilience are central concepts to the citizenship in practice approach (Clarke, Schwannauer and Taylor, 2017). This is illustrated when participants showed consideration for the risks involved in ‘going out’. Risk is defined as the probability of an adverse or an advantageous event, leading to harm or leading to improved quality of life (Clarke *et al.*, 2018). Participants demonstrated awareness of both positive and negative risks involved in ‘going out’. For example, they referred to the health benefits involved in ‘going out’ walking and the social benefits of being involved in the community. Positive risk-taking is an inherent part of being outdoors

(Mapes, 2017). In a dementia care context, professionals tend the emphasise negative risks and thus frame dementia as a behaviour to be managed (Clarke, 2000; Gilmour, Gibson and Campbell, 2003). Consideration is rarely given to people with dementia's capacity to consider risks and participate in decisions in the context of going out. This is representative of the risk-averse culture in wider health and social care (Titterton, 2005). 'Going out' has been shown to be a contentious action between people with dementia, care partners and practitioners with each having different understanding of what was risky (Clarke *et al.*, 2011). Despite cultural perceptions that getting lost is the biggest risk associated with 'going out' (Bartlett, 2017), it was not the only negative risk that people with dementia faced in this research. Some participants reported a fear of being taken advantage of by other people due to their old age and frailty. Although dementia made people fear getting lost, other health conditions such as diabetes made them more fearful of their risk of harm if they did become lost. If participants did get lost, they had strategies to reduce their risk of harm such as sitting at a bus stop or going to a café to gather their thoughts. This was carefully considered as neither of these activities were 'suspicious' or could indicate to other people that they are lost.

It has previously been reported that risk-taking behaviour generates concern in carers (Mmako, Courtney-Pratt and Marsh, 2020). Although this may be true, most care partners in this study encouraged positive risk-taking as they acknowledge the physical, social and emotional benefits that 'going out' independently had for their loved ones. However, each individual in this study had a different outlook on what activities were deemed risky and which risks were worth taking. For example, John left the house alone multiple times per day and still drove his car, but he placed restrictions on himself such as no driving at night or in bad weather. In the absence of John, his wife expressed concern about his ability to continue driving but she supported him in his decision to continue driving in a modified way. In contrast, Robert gave up driving immediately upon his diagnosis and he rarely left the house alone. His wife tried to encourage him to make small trips out to the local shop and post office alone to maintain a sense of independence but after getting lost several times, Robert considered 'going out' alone too risky. Risk is dependent on social environments and risk assessment differs from persons with dementia to family carers to professionals (Clarke, 2000). This suggests that risk management practices have to be adapted depending on the individual (Mapes, 2017). Risk-taking is a fundamental human behaviour (Mohun, 2016). However, when a person is diagnosed with dementia, more emphasis is placed on the potential negative outcomes of risky behaviour, rather than positive outcomes (Manthorpe and Moriarty, 2010). People with dementia who live at home have demonstrated the capacity to manage risks in their daily lives (Sandberg *et al.*, 2017). In the context of going out, this project found risk management to be an opportunity for people with dementia to make decisions and demonstrate the capacity for agency. This suggests, in line with previous guidance, that people with dementia must be supported to remain active in their risk management (Manthorpe and Moriarty, 2010).

Previous research has shown that people with dementia have an awareness of their vulnerability when outdoors (Bartlett and Brannelly, 2019)**.** In line with this, when assessing and managing the risks involved in ‘going out’, participants also demonstrated an awareness of their increased vulnerabilities. For example, Laurence showed vulnerability when he asked to take my arm after he nearly walked in the path of an oncoming bike. He acknowledged that he was becoming more dependent on others as his dementia progressed. Interestingly, some participants considered themselves vulnerable, not as a result of their dementia, but as a result of other factors such as old age, frailty and gender. They also highlighted how they were not the only people who should be considered vulnerable. Several participants alluded to my (the researcher’s) vulnerability as a young woman. Participants showed concern about my travelling to and from interviews alone and my financial ability to go out for lunch and coffee with them as a “poor student”. For these reasons, certain participants even positioned me as more vulnerable than themselves. This research provides empirical evidence for the intersectionality of the experience of dementia, specifically the intersection of gender and dementia, which has been notably absent from the dementia studies literature to date (Bartlett *et al.*, 2016; Sandberg, 2018; Bartlett and Brannelly, 2019; Odzakovic *et al.*, 2021). This inquiry also evidences the universality of human vulnerability as theorised in feminist social science literature (Fineman, 2008).

Since they were aware of the risks they faced and their vulnerabilities, participants in this study demonstrated capacity for resilience. This was demonstrated by using strategies such as keeping to familiar places when ‘going out’. This finding supports previous research, which has shown that people with dementia show characteristics of resilience and have coping strategies when they do not feel safe (Harris, 2008). Although they acknowledged that dementia limited their ability to do certain things, participants were determined to “get on with life” and found other ways to maintain independence, such as using public transport and taxi services if they could no longer drive. They also reorganised their social lives as several participants got value from attending dementia support services such as cafes, support groups and organised activities. Maintaining a practice of ‘going out’ was a way in which participants maintained a sense of purpose and therefore, it could be examined as part of an intervention to foster resilience in people with dementia (Whelan, Teahan and Casey, 2020).

It has been suggested in the literature that tracking technology is a potential intervention to prevent negative outcomes when people with dementia become lost (Bartlett, 2017). However, despite welcoming tracking technologies as a potential aid, none of the participants in this study used them regularly. This suggests that research is not translating into practice and, therefore, the barriers to the uptake of tracking technology must be further explored. Most participants reported that they would consider using a tracking device “when the time came”. However, it was not a device that they felt was necessary at present. During one of our walk-alongs, John told me that the next time I see him, he will probably have *‘one of those trackers around my neck’* however, that never came to fruition. His main reasoning for having it was for the peace of mind it would bring his wife. He did not consider how it might be a tool to help him. Maria also considered them a sensible intervention, but she did not want to wear something obvious or unfashionable. She suggested that she might instead wear a fashionable ring or bracelet with a hidden tracker. In line with previous findings, care partners in this study who had trialled tracking devices or used in-built smartphone trackers for their spouses grappled with the guilt associated with invading their loved one's privacy (Robinson *et al.*, 2007). Most literature concerning the use of tracking technology considers people with dementia in a passive way; as wanderers to be managed, rather than as active agents in their navigation (Robinson *et al.*, 2007; MacAndrew, Brooks and Beattie, 2019). John highlighted this when he struggled to understand how a tracking device would be able to assist him to relocate himself if he got lost. People with dementia have been shown to be capable of using smartphones for wayfinding (Kwan, Cheung and Kor, 2018). This was confirmed in this research as the small number of participants who did use smartphones, relied heavily on map and transportation applications. Although it has been previously recommended that further research explores the privacy versus safety debate regarding the use of locating devices, it has not been suggested that people with dementia themselves should be involved in this discussion (Neubauer *et al.*, 2018). This study demonstrates the potential that the experiences of people with dementia could bring to this debate. Specifically, it aligns with previous research demonstrating how current tracking technologies are more concerned with the needs of care partners and that little consideration is given to how people with dementia might feel about using these devices (Robinson *et al.*, 2009). Tracking and navigational assistance technologies have the potential to enable positive risk-taking and thus, promote citizenship in people with dementia (Bartlett, 2017).

‘Going out’ – An embodied and emplaced practice

In this section, I establish the importance of using an embodied and emplaced lens to effectively understand the citizenship practice and status for people with dementia. Citizenship studies tend to privilege language as a route to examining agency, which can exclude people with dementia who are known to have language and communication impairments (Baldwin, 2008). To overcome this, I adopted an embodied and emplaced lens to decentre verbal communication as the predominant mode of connection to people and places. An embodied lens considers knowledge and experience to be situated in the body as well as in the mind, therefore, this feature of experience must be examined. An emplaced lens adds the additional layer of the environment and how that interacts with the body. ‘Going out’ is a practice that cannot be examined in isolation from firstly, the body that it is experienced through and secondly, the environment it is experienced in. This outlook enables a critical approach, which considers the role of factors such as gender, disability, and the wider socio-political context.

In dementia studies, biomedical approaches are concerned with ‘the brain’ and the psychosocial approaches are concerned with ‘the self’. However, these are both disembodied approaches. When attention is paid to the body in dementia, the focus is on the failing and disintegration of the body and bodily functions in the context of care. Thus, this thesis argues for an alternative focus on the body: for the body to be considered both a source of experience and a vehicle through which people living with dementia experience the world. My understanding of embodiment is informed by Kontos’ critical theoretical contribution of embodied selfhood in dementia studies (Kontos, 2004). Kontos was influenced by a combination of Merleau-Ponty’s phenomenological understanding of the lived body (1962) and Bourdieu’s sociological concept of habitus, which considers social and cultural influences on the nature of the body and our physical behaviours (1977). Therefore, Kontos (2004) posits that selfhood in dementia has foundations in both the corporeal and the socio-cultural.

Walking with people with dementia provided insight into *how* they experience ‘going out’ as I experienced the action in situ. I observed how some participants stuck to specific routes whilst others took me across the city. I observed whom they engaged with and got a sense of their daily routines. I observed how they overcame challenges in the environment. This type of knowledge differed from the knowledge generated in traditional interviews. By focusing on the embodied element of people’s experiences, I facilitated those who have language difficulties and thus might have struggled to communicate an answer to the request “tell me how you experience navigation”. For example, Robert contributed very little to the conversation during my initial sit-down interview with him and his wife but during our walk-alongs he was very expressive via his body by drawing our attention to features of the environment, physically demonstrating certain challenges and ushering me out of the way of obstacles. People with dementia are often referred to as “already in the house of the dead” (Post, 1995, pg. 136) or emphasis is placed on what they used to be like before their dementia onset. Attending to the body enables a focus on what people with dementia can still do rather than what they can no longer do. As people with dementia experience cognitive decline, familiarity may still be held in the body. This was demonstrated when Maria discussed her stomach churning when she was in an unfamiliar place. Participants demonstrated this embodied knowledge when they struggled to tell me how they would navigate from point A to B, but they could show me by walking together or explained the knowledge as something within, that cannot be articulated. In addition, several participants referred to their body or legs as knowing where to take them when they were lost and having to trust their body to know what to do in unknown scenarios.

In line with my ontological and epistemological stance, I position myself within this thesis as a co-constructor of knowledge and, therefore, I must consider the role of my body in my interactions with participants. As a young, petite woman, I influenced the bodily dispositions of participants. Maria, the only woman I walked with found solidarity in our shared experiences as small women. These shared elements of our lived experiences enabled her to initiate physical contact with me to demonstrate affection (such as a hug when we greeted each other) or to show vulnerability (such as taking my arm when we crossed the road together). Our shared gender experience meant that I understood Maria's reference to the unique vulnerabilities that she experienced because of being a woman without the need to ask her to expand further. In contrast, my physical presence with the six men with dementia whom I walked with influenced them to take on the role of 'the protector' or the 'tour guide'. We settled into stereotypical and gendered roles where I was positioned as the naïve learner. This is exemplified by John insisting that he walk on the 'more dangerous' side as he considered me to be under his care and therefore it was his responsibility to ensure my safety. I did not resist this role; attending to the embodied interaction between myself and participants enabled an understanding of how 'going out' was a practice in which social factors influenced the bodily dispositions of the participants (Bourdieu, 1977). More broadly, I observed participants' embodied interactions with other people whilst 'going out', from waving hello to passers-by, making small talk with neighbours, offering directions to tourists, interacting with café staff or meeting with friends. Leaving the body out of the analysis is an extension of the cognitive nature of knowledge and experience, which can exclude people with dementia from sharing their experiences (Hydén, 2016). Therefore, I have included the body in my analysis evidenced in the reflexive narratives of Chapter Six. By doing so, I have shown that, regardless of a dementia diagnosis, the body is '*our general medium for having a world*' (Merleau-Ponty, 1962, pg. 146). By situating the experience of dementia as an intercorporeal one, people with dementia are positioned as active agents who maintain a sense of self through their relationships with others. ‘Going out’ is a practice that enables them to achieve this.

Although I agree with Kontos’ rooting of the experience of dementia in the corporeal and socio-cultural, I argue for an additional consideration to be given to the role of place. In recent years, there has been an increase in research on the human-nature relationship (Seymour, 2016). This is also the case for the relationship between people living with dementia and the natural environment (Gilliard and Marshal, 2012). However, most research on the experience of dementia is conducted in a care setting and little attention is given to how people with dementia interact with public outdoor spaces (Blackman *et al.*, 2003). When attention is paid to public outdoor spaces, it often focuses on accessibility, design and tracking people’s movements. Researchers have previously highlighted the need for attending to place in the everyday lives of people with dementia (Keady *et al.*, 2012; Clarke and Bailey, 2016). My understanding of place draws on Casey's (1993) philosophical interpretation of place as a humanised space as opposed to a geographical area with boundaries, as well as Ingold's (2000) anthropological framing of place as something that human beings produce and are a part of. Both Ingold and Casey attribute their understanding of place to Merleau-Ponty’s (1962) contribution that puts human perception at the core of how we experience place. Thus, places are not only lived in but they are created and made meaningful by our everyday practices. They are abstract concepts and are not confined by physical locality. Although previous studies that examine the relationship between people with dementia and place have used the term ‘neighbourhood’ to describe similar experiences, I refrain from using this term, as in my experience, it does not translate over to search and rescue contexts. Neighbourhoods have been shown to be a site of citizenship for people with dementia (Clark *et al.*, 2020). In contrast to this, I suggest that ‘going out’ is a practice of everyday citizenship that is not confined to a site and thus, has no geographical bounds. This is evidenced in the diversity of experiences of ‘going out’ for participants. For example, when ‘going out’ alone, Maria frequently travelled across the UK, Philip and Laurence explored every corner of the cities that they live in and Kevin stuck to a strict walking route of his local park. Contrary to previous suggestions that people with dementia experience a “shrinking world” (Duggan *et al.*, 2008), this research argues that they instead experience a “changing world”. For some participants, the geographical boundaries of their physical worlds did indeed shrink, however, a dementia diagnosis also had the potential to broaden their social worlds. In the case of some participants, engaging with local advocacy and support groups led to a growing world comprising of travel and new relationships. Like embodiment, places are continuous and dynamic processes (Petteway, Mujahid and Allen, 2019) therefore, dynamic methods are required to understand peoples’ experiences through these lenses.

Pink argues that ‘*research findings that are based solely on participants verbally reported practices cannot facilitate an analysis of their actual practices and of how these are performed, experienced and involve specific ways of knowing in practice’* (2012, pg. 41). Therefore, this inquiry was informed by Pink’s (2012) call to understand practice and place through movement. This provided three key insights. Firstly, it enabled me to attune to the sensory element of ‘going out’. Sensory interactions with place enable alternative forms of connection between participants and myself and between us and place. This unspoken connection was often formed through a shared, silent appreciation of the scenic views, through breathing in the fresh air together, through listening to the birdsong and observing deer running across a field. This connection was evidence of belonging, not only to a social community but to a place providing evidence for the role that place plays in supporting people with dementia to live independently at home. Keady *et al.,* (2012) recommend that practitioners pay attention to the person-in-place. Drawing on the findings of this study, I extend this notion to the person-and-body-in-place. Secondly, movement is active. Simply being in motion and by deciding the route of our walk-alongs, participants were positioned as active agents in society who had tasks to complete, responsibilities to uphold and thus a sense of purpose as opposed to passive recipients of care. Participants used walk-alongs to show me their world. This enabled me to reflect on their social and cultural positionings and locations throughout the research process. Thirdly, as advised by Stiegler, walking together allowed me to keep ‘*analytical lenses on the experiences that transpired during the go-alongs beyond just the words spoken during the go-along’* (2021, pg. 364). The presentation of the walk-alongs as a series of reflexive narratives in Chapter Six evidence these co-constructed experiences. In highlighting this aspect of the study, I demonstrate the value in attending to how people with dementia physically move in their bodies and across places, which could be useful in developing future dementia-friendly community initiatives.

In conclusion, this inquiry has extended the social citizenship approach in dementia studies by using a lens of embodiment and emplacement to understand experiences of 'going out' for people with dementia. An embodied and emplaced lens is critical for seeing the participants as *full people* who engage with the world (Cummins *et al.*, 2007). Through this lens, and through examining the everyday practice of 'going out' I have evidenced that people with dementia are relational beings who have civic, political and social rights; as people who should have access to participate in a community; and as people who belong to a community (Wiener, 1998).

Methodological reflections – An inclusive research approach

This section reflects on my methodological approach and how this relates to the wider methodological and theoretical literature in dementia studies. I use the CORTE guidelines as a framework to structure this methodological discussion (Murphy *et al.*, 2015). Developed as a result of analysing the inclusion of people with dementia in previous qualitative research, the CORTE guidelines are intended to be a guide for researchers to report on their research strategies. They involve four main areas: gaining **CO**nsent, maximizing **R**esponses, **T**elling the story, and **E**nding on a high. In doing this, this section builds on knowledge regarding the inclusion of people with dementia in the research process by being transparent about strategies used and challenges faced. Through describing walk-alongs in particular, I argue for the value of using mobile methods with people with dementia to enable contextually relevant interactions, an embodied and emplaced lens and therefore, in-depth insight into people's lived experiences.

Gaining COnsent

As previously mentioned in Chapter Three, I adopted Dewing's (2007) process consent as a method of gaining and maintaining informed consent from participants. Process consent requires a degree of knowing the participant as you must pay attention to their physical as well as verbal responses when engaging with them. Therefore, building rapport and developing trusting relationships with participants is a priority. In this study, I did not use a screening tool to assess capacity levels, nor did I seek medical confirmation of their dementia diagnosis as it has been suggested that these measures do not predict capacity accurately and therefore, could lead to the exclusion of people with dementia (Murphy *et al.*, 2015). The use of process consent was enhanced by meeting with participants on multiple occasions. This allowed for relationships to develop, to develop a degree of knowledge and to allow multiple opportunities to ’check-in’ that the participant still consented.

In preparing for this research, I developed ‘dementia friendly’ study documentation by adapting documentation used in previous research with people with dementia and by consulting two people living with dementia who acted as informal study advisors before submitting the documentation to an ethics committee. They advised that I make minor edits to the text and increase the font size. Although this documentation was approved by both a university ethics committee and people with lived experience, when I began using them with study participants, I realised how inaccessible they were for some people. For example, after one group discussion, I was approached by a participant who told me that although her mother had the capacity to consent, written consent forms were overwhelming and distressing for her. I observed this first-hand in several of the group discussions. Often, I could sense an air of stress and it would take ten minutes of informal conversation for that feeling to dissipate. Where possible, I sent the written study documentation to participants ahead of our first interview and on reflection, this reduced stress and allowed them time to digest the materials. Dementia can impact reading and writing abilities (Banovic, Zunic and Sinanovic, 2018) therefore, in hindsight, it might have been more accessible to create a video to accompany the information sheet and consent form. This could have been sent to participants ahead of time for them to review. Then, where appropriate, recorded verbal consent could be obtained in place of written consent, which may have made the research process more inclusive for people with dementia.

Maximising the Responses of people living with dementia

Mason (2017, pg. 164) invites researchers to *‘nurture your own creative energies in how you design a study and generate data’*. Taking a participatory and reflexive approach enabled me to embrace this sentiment, to allow sufficient time to build trust and rapport and to be flexible whilst undertaking this research, factors that have been identified as crucial when involving people living with dementia (Hubbard, Downs and Tester, 2003; Nygård, 2006; Hellström *et al.*, 2007). As discussed in Chapter Three, I prepared for data generation at length, by piloting the methods, consulting previous literature, and being advised by people with lived experience to ensure I was maximizing the responses of people living with dementia. In addition, I followed guidelines for doing research produced by the Scottish Dementia Working Group (Scottish Dementia Working Group Research Sub-Group UK, 2014). Central to this approach was adopting a degree of openness and to be guided by the participants. For example, two participants living with dementia were keen walkers but did not want to do a walking interview. Although they were physically capable, they stated that they would simply rather sit down and have the interview over a cup of tea. On one occasion, Maria did not want to go for a walk as the grey sky threatened rain, so we had a traditional interview in the kitchen instead. I supported participants' agency to make decisions such as these and in doing so, I attempted to shift power dynamic and maximise participation through techniques led by my participatory and reflexive approach (van der Riet and Boettiger, 2009). Researcher-participant relationships were also supported by repeating interviews. This removed pressure on both parties and allowed for a more authentic relationship to be developed. For example, if I forgot to ask a question or probe on a certain topic, I could revisit it in the follow-up meeting. Likewise, if a participant was having a bad day or forgot to tell me something, they had further opportunities to share their experiences. When I met participants on more than one occasion, I would begin each subsequent meeting by sharing my reflections on our previous interview and offering them time to feedback. I also contacted participants within a week of our final interview to share my initial reflections on our time spent together and gave participants the opportunity to agree or disagree with my reflections, and to offer any additional information (Tracy, 2010). Furthermore, I maximised responses by being flexible in my approach to data analysis. By conducting two modes of analysis, I highlighted the patterns of meaning across all the data generated as well as in-depth insights into individual experiences. Research funding bodies and ethics committees need to be aware of this level of flexibility that is required to support people with dementia to participate in research (Webb *et al.*, 2020).

Although this inquiry was not a traditional co-production study where people with dementia were involved as co-researchers, I tried to ensure that relationships between researcher and participant were as equal as possible. For example, as advised by Braun and Clarke (2019), I do not refer to data as being "collected" in this thesis, as if it was sitting waiting to be found, instead, I refer to data as being "generated", acknowledging that myself and the participants were co-constructors of knowledge. This aligns with my epistemological position of constructivism. To maximize responses and ensure this research was inclusive, people living with dementia and care partners were consulted at several stages of this research. Before my involvement, when the supervision team wrote the original research proposal, they consulted several patient and public involvement groups and the Scottish Dementia Working Group who gave feedback and supported this proposal. When the funding was awarded by the Alzheimer's Society, this study was allocated two research advisors who had lived experience of caring for people living with dementia. As a team, we met on an annual basis to discuss and shape the development of this research project. For example, at one research advisory meeting, it was decided to extend the study beyond the Lothian area to include more variety in experiences of living in rural and urban environments. I also maximised responses by developing trust and rapport with local support services. I visited thirteen different dementia cafes and support groups across Scotland. Although these visits did not always result in the recruitment of a participant, they were important to from relationship with Alzheimer Scotland staff who were present and would recommend that I attend another group or would put me in touch with a particular individual. The Alzheimer Scotland Research Officer also supported me to develop a phased recruitment strategy to maximise the responses of people with dementia.

One particular ethical dilemma that arose for me was the blurred lines when developing relationships with participants. Authentic relationships led to richer data being generated. Mason argues that you cannot assume a neutral stance in relationships (Mason, 2017). It is human nature to initially click with some people in comparison to others (Parkinson, Kleinbaum and Wheatley, 2018). I found developing relationships to be a time-consuming (yet undoubtedly worthwhile) endeavour as multiple visits were required to develop strong bonds with participants.

Although I valued the formation of building trusting relationships, I was often aware of the fine line between authentic research relationships and developing friendships that could be perceived as inauthentic. At times, the naturally developed friendship that I had built with participants felt intrusive when I reflected on the premise of our interaction; I was involved in the relationship with the main goal of conducting research. This ethical dilemma came to light when John and I went for lunch after a long walk. Before we had even set out on our walk, John insisted that he wanted to treat me to lunch in his favourite café. I was conflicted because I did not want John to feel obliged to pay for my meal. We argued playfully back and forth as I stood my ground that I would pay for myself until John said he would be offended if I did not let him pay. I was in an ethical dilemma. I did not want to offend him so I reluctantly agreed, making a mental note that I would give John a small gift alongside his thank you card at our final meeting. Although allowing a participant to pay for my lunch may not be the best practice in terms of research ethics, when I reflect on my time spent with John, being chivalrous and gentlemanly was a large part of his identity. In accepting his offer to pay for my lunch, I was enabling him to enact that part of his identity. Considering my axiological stance that this research was to be value-laden and value-led, by forming these authentic relationships within the confines of a researcher-participant dynamic, I supported people with dementia to share their experiences.

Another way I maximised responses and supported people with dementia to be active participants in the research process was to allow them to decide which style of interview we would conduct. If they agreed to a walk-along, I would encourage them to choose the route. However, this attempt to be inclusive and break down power dynamics raised other ethical dilemmas. For example, Simon was the only participant who chose to take me on a route that he would typically avoid as he wanted to show me the challenges that he faced. Without a doubt it was an invaluable experience to witness these challenges, however, I felt guilty that he had put himself in such an uncomfortable position for the purpose of this research. As we walked together and I observed his struggling, I was frantically thinking of an excuse to cut the interview, secretly hoping it would rain so we could turn around and go home. However, on reflection, although Simon had put himself in an uncomfortable position for the purpose of this inquiry, it was his choice to do so, and I did not want to deny him that agency. In reflection, despite how uncomfortable it made me at the time, in walking with Simon on this challenging route, I was supporting and facilitating his agency (Boyle, 2014).

The lines between protection, paternalism and care are often blurred in qualitative research. At times when walking with participants, it was challenging to balance my sense of responsibility to ensure they were safe whilst taking part in the research, with supporting their sense of agency and autonomy in accordance with a social citizenship approach. I found it helpful to explain the relationship dynamic with participants using the analogy that they were the tour guides, and I was the “tourist”, learning about their everyday experiences. However, one key moment where that relationship dynamic could change whilst walking with participants was when we crossed a road. My reflection of walking with Laurence in Chapter Six discusses in-depth the ethical dilemma faced when he almost walked onto the road in front of a speeding bike. Following that event, I chose not to probe with questions in the final ten minutes of our walk. It could be argued that I took a “light paternalism” approach, which is justified if this approached within an ethics of care framework (Smebye, Kirkevold and Engedal, 2015).

Supporting people living with dementia to tell their story

Another feature of this inquiry that was central to my participatory approach, was the decision to use multiple methods such as interviews, walk-alongs and group discussions, and to engage with several participants on more than one occasion as suggested by Lloyd, Gatherer and Kalsy (2006) and Nygård (2006). This approach was also extended to data analysis and interpretation as can be seen in the two styles of presentation across Chapters Four, Five and Six of this thesis. Shifting focus away from the verbal dialogue and towards an embodied and emplaced lens maximised participant responses by supporting the narrative agency of participants (Baldwin, 2008). A particular strength of the group discussions was that they were all conducted with people who already knew each other and would meet regularly. Therefore, trust and rapport were already developed between group members, and they were comfortable engaging with each other. However, from a facilitation perspective, running group discussions was challenging. At times, it was difficult to steer the conversation back on to the research topic and during two of the five group discussions, there was one individual in each who dominated the conversation. In these cases, it was challenging to ensure all participants got equal opportunities to share their experiences. Despite these facilitation challenges, the group discussions were valuable for two main reasons. First, the two groups discussions that consisted solely of care partners reminded me of the dilemmas that care partners faced when trying to balance supporting the rights of their loved ones with keeping them safe. Second, group discussions were an opportunity to witness how participants shared strategies for 'going out' with each other, trading tips and discussing the similarities and differences in their experiences. For example, during one group discussion, Drew showed the group his dementia I.D. card and encouraged others to carry one. In another group, Jackie encouraged others to use her strategy of sitting at a bus stop when feeling disorientated or overwhelmed whilst 'going out'.

This inquiry adopted a flexible approach to data generation using multiple methods of engagement to ensure participants were supported to share their experiences in a way that they were comfortable with. Using walk-alongs and combining participant observations with interview techniques was an effective method to explore people with dementia's experiences of 'going out'. Bartlett *et al*. argue for *'place to be privileged in the quest to involve more people with dementia in research and knowledge production'* (2015, pg. 797). Through the use of walk-alongs and a focus on the embodied and emplacement lens, this inquiry took them up on that challenge. Building on previous studies that have used walk-along as methods to engage with people with dementia (Mossabir, 2019; Odzakovic *et al.*, 2019; Brannelly and Bartlett, 2020; Seetharaman, Shepley and Cheairs, 2021), this inquiry found that walk-alongs were an appropriate method of engagement as they were inclusive, contextually relevant, broke down the researcher-participant power dynamic and they allowed for serendipitous moments. Taken together, these factors allowed for the generation of rich data. Walking with participants highlighted the embodied and emplaced elements of their experiences of 'going out'. Previous research argues for the use of innovative and inclusive data collection methods when conducting research with persons living with dementia (Webb *et al.*, 2020) however, the richness of these innovative methods is at risk of being lost when 'data' is analysed traditionally. This inquiry supported participants to tell their stories, for example, Robert's story, as presented in Chapter Six, would not have had the same depth to it had I only done a thematic analysis of our interview transcript. It should be noted that walk-alongs may not be effective for all people with dementia such as those who do not have the mobility to do a walk-along, those who are not confident being in outdoor spaces or those who may find talking and walking overwhelming. Although there is no one-size-fits-all approach to maximize the inclusion of people living with dementia in research and supporting them to tell their story, embracing a participatory approach in this inquiry allowed for flexibility and for the voice of participants to be heard.

Ending participant relationships on a high

Several studies that involve people with dementia have highlighted the importance of leaving participants with a sense that they have made a positive contribution at the end of research interviews (Lloyd, Gatherer and Kalsy, 2006; Hellström *et al.*, 2007). Therefore, since I paid special attention to forming relationships with participants to develop trust and build rapport, I gave equal consideration to the ending of those relationships, particularly with those whom I met on multiple occasions over several months. One way of signalling that the research relationship had concluded was to offer a small token such as a handwritten thank you card so participants had a memento of our time spent together. I also kept participants up to date with emerging findings by sending biannual update emails either directly to participants or via dementia advisors who facilitated their local dementia café. I intended to revisit the dementia cafés where I had recruited from to informally feedback to participants however, this was never carried out due to the COVID-19 pandemic. As my relationships with participants ended, I witnessed how contributing could be a cathartic and empowering experience for participants (Hutchinson, Wilson and Wilson, 1994). During group discussions, I observed how participants benefitted by sharing coping strategies for ‘going out’ and how they took comfort in discovering that their peers encountered similar challenges. At the end of the interviews, participants often commented that it was therapeutic to share their stories or that they hoped that their experiences would help me with my research. One participant even remarked that taking part in this research made him realise that he has *‘still got a contribution to make to someone’* and that it had made him *‘feel important’*.

Another ethical challenge in this inquiry was considering the impact that building and ending relationships with participants had on me, the researcher. As this constructivist inquiry makes transparent my role in the research, this is an important element of the researcher-participant relationship to examine. It has been shown the researchers undertake emotional work when doing qualitative research and that the interview is an opportunity to be a therapeutic space for participants (Birch and Miller, 2000; Dickson-Swift *et al.*, 2009). Therefore, as researchers, we need to support the emotional well-being of our participants and in turn, funders and employers have a responsibility to support the emotional well-being of researchers (Mitchell and Irvine, 2008). Approaching this inquiry with an acknowledgement of vulnerabilities and interdependencies shared by myself and participants facilitated me to come to terms with these ethical challenges and to challenge assumptions of traditional ‘carer’ and ‘cared for’ binaries (Tronto, 1993). Writing a research diary helped me to accept that the authentic relationships that I had built with participants had come to an end but that I would hold on to the memories through the impact this research will have.

Knowledge mobilisation

Knowledge mobilisation is defined as ‘*a process, encompassing the co-production and channelling of knowledge’* (Bannister and O’Sullivan, 2013, pg. 249). Rather than focusing on translating academic research into practice, knowledge mobilisation focuses on the flow of accessible knowledge from academia to policy, industry and community and vice versa. It supports dissemination activities prior to the production of research outcomes to improve impact (Phipps *et al.*, 2016). The principles of knowledge mobilisation are at the heart of the participatory approach and thus, have been central to this inquiry. Although the COVID-19 pandemic and various lockdowns have posed challenges to effective knowledge mobilisation work, it has also created unique opportunities in the online space. Due to the interdisciplinary nature of this research, its findings have relevance across several academic disciplines and professional practices. Specifically, this thesis contributes knowledge to the fields of dementia studies and missing persons research and investigations. In this section of the thesis, I first highlight the traditional knowledge translation and public engagement activities that I have undertaken on this doctoral journey. Then I discuss the International Consortium for Dementia and Wayfinding, a platform that I co-founded during this research project. Finally, I discuss the practical and policy implications of the study.

Throughout this doctoral journey, I have presented elements of this inquiry both within and out with academic circles. In line with a social citizenship approach, I frame people living with dementia as experts of their own experiences and as active co-producers of knowledge. I do not consider myself to be an expert who should impart my knowledge to others. Instead, I view knowledge exchange as a reciprocal interaction of social learning in line with Freire's critical pedagogy (Freire, 1985). When discussing my research informally, I have always been met by the same response; genuine intrigue followed by a story about how their personal lives have been impacted by dementia and reassurance that my research would be important. Every doctoral student hopes to hear these words beyond their immediate research networks and I was fortunate enough to hear them frequently. However, with that privilege comes responsibility. A responsibility to the participants of this study is that the findings will be shared more widely than in this written thesis. Participating in science communication and public engagement events have been a way for me to fulfil this responsibility. It is easy to take for granted that I work in a field that supports people living with dementia to have their voices heard. I was reminded of this when I took part in Soapbox Science in 2019, a public outreach platform that promotes women and non-binary scientists and the science that they do. As I stood on my soapbox, telling members of the public about my research, I was met with questions of genuine interest (you've just said intrigue above) regarding how it is possible to gain reliable information through interviews with people living with dementia. Experiences such as this highlighted to me that, alongside my research interests in this field, I also have a moral duty to educate and reduce the stigma surrounding living with dementia.

This thesis also demonstrates how taking part can have lasting impacts on the people who engaged with the inquiry directly. For example, John and Simon both shared that taking part in research made them feel valued and that they still had something to give back to society. In taking part in this research, participants were supported to embrace their roles as active citizens. Simon shared that he was trying to engage with as much research as possible whilst he still had the capacity to do so, knowing that although it may not change his experiences of dementia, the knowledge generated may be helpful for *'the next lot'*. This study also enabled knowledge to be exchanged through dialogue amongst participants. Although I felt conflicted about how effective group discussions were in answering my own research aims, I observed how focused group discussions were embraced by participants as spaces to share their strategies for 'going out' with each other. Another way that knowledge was exchanged amongst participants was through me as a 'medium', when people asked me what I was learning from others. For example, Nicola asked me if other participants had reported a shrinking of old friendships and when I confirmed that was true for many people, she admitted that it provided her with some relief to know that she was not the only person whose friends had withdrawn since her husband's diagnosis. However, I was also able to reassure Nicola that several participants had reported a blossoming of new friendships through involvement in support groups and that encouraged her to reflect on her new friendships.

Whilst conducting the scoping literature review for this study, I identified relevant bodies of academic literature and practical guidelines pertaining to this field. As the risk of people with dementia going missing is of interest to a range of different organisations, I was surprised by the lack of shared resources across agencies and disciplines. To rectify this, I set out to create a platform where these resources could be shared. In 2018, I co-founded the International Consortium for Dementia and Wayfinding (ICDW)[7] with Noelannah Neubauer, a fellow doctoral student at the University of Alberta, Canada who I met via online networking on Twitter. This consortium is a global network of researchers, police, community organisations and people with lived experience. The ICDW aims to support people living with dementia to go out and about safely in their communities without fear of stigma or harm from getting lost. Since its inception, there are over 80 members from 10 countries, and we are continually growing. We have hosted symposiums in Calgary, Canada and Edinburgh, Scotland in 2019 and since COVID-19 we have adapted our face-to-face events to a webinar series that aimed to share multiple perspectives including that of people living with dementia, supporting individuals to have an online space to

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[7] https://icdwcontact.wordpress.com/

advocate for themselves and a facilitated online dialogue. This network has also been a platform to share preliminary findings with an international and multi-disciplinary audience, who have provided feedback at several stages of the inquiry. Through open dialogue and a collaborative approach, the ICDW has enabled relationships across disciplines and agencies. For example, through interaction with the ICDW network, a care home manager in Alberta, Canada became aware of the Herbert Protocol, originally developed by West Yorkshire Police in England[8]. She then adapted the protocol and implemented it locally. Most importantly, people living with dementia and care partners are members and board members of the ICDW. This is in line with a social citizenship approach, as the ICDW strives to challenge stereotypes and break down power imbalances between research, policing, third sectors, community organisations and people living with dementia. For example, at an ICDW event, I presented preliminary findings of this inquiry alongside an advocate and man living with dementia to a multi-disciplinary audience of academics, police, and charity and community organisations. Following the event, this police officer, who regularly conducted searches for people with dementia who were reported missing, shared that he had never heard a person with dementia speak candidly about the challenges that they faced whilst ‘going out’ before and that he would be sharing these learnings with his team and implementing them in his practice. As a member and former student representative of the Scottish Institute of Policing Research, I developed relationships with policing communities and used every interaction with them as an opportunity to educate professionals on the diversity of experiences of living with dementia. In 2019, I presented preliminary findings relevant to policing and search and rescue audiences at the International Law Enforcement and Public Health Conference and the International Conference for Missing Adults and Children. I was also invited to present at a College of Policing search advisor training event in 2020. I typically presented case studies from the participants that challenged perceptions that people living with dementia go missing because they forget where they are going and wander aimlessly. Following the completion of this thesis, I intend to produce guidelines for Police Search Advisors

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[8] The Herbert Protocol is an initiative introduced by West Yorkshire Police and other agencies which encourages carers to compile useful information which could be used in the event of a vulnerable person going missing. https://www.westyorkshire.police.uk/advice/personal-safety-and-possessions/dementia-awareness/dementia-awareness/herbert-protocol-missing-person-incident-form

and investigation officers and other search and rescue agencies, using the experiences shared by participants and the 3 P's as an evidence base for informing person-centred search and rescue practices. As a result of the aforementioned knowledge mobilisation, I was awarded runner-up in the Scottish Graduate School of Social Science Research Knowledge Exchange and Impact Award in April 2019.

In November 2019, I took a three-month interruption of studies to conduct an internship at the Scottish Government within the Primary Care Policy Team. My role during this internship was to conduct a stakeholder map in remote and rural primary care in Scotland. Although the internship was not directly relevant to dementia, the experience allowed me to establish contacts within the Scottish Government Policy Team and developed my understanding of how policy operates at a practical level. Given the critical nature of this study, this first-hand insight into the socio-political landscape in Scotland encouraged me to reflect on how the findings of this inquiry can have an impact at a policy level. In January 2020, I attended a Scottish Government Community Consultation Event to inform their upcoming Dementia Strategy. From the roundtable discussion at that event, it was obvious that the desire for the upcoming strategy was not to make several new commitments but instead to reflect on previous strategies and to ensure that progress was being made on previous commitments. As highlighted in the introduction chapter of this thesis, Scotland's National Dementia Strategy 2017-2020 committed to following up on the findings of a Police Scotland pilot project regarding people with dementia who go missing from care. Therefore, this research is timely as it provides evidence that this commitment should be taken further and expanded to consider working with non-government partners and prioritising the voices of people living with dementia to ensure they are adequately supported to live independently at home. In addition to my communication with the Scottish Government's Dementia Policy Team, I have also been in discussion with the National Coordinator of Missing People in Scotland about how this research could impact the upcoming review of Scotland's National Missing Persons Framework. In line with the framework's aim to prevent missing episodes, this study provides evidence for the need to (a) acknowledge people living with dementia as a unique (but not homogenous) group who are impacted by missing incidents and (b) to support and value research that platforms the voices of those who are impacted by missing. The findings of this inquiry support the shift in dementia policy focus towards an early diagnosis, a focus on prevention and supporting person-centred care. However, this thesis argues for wider consideration in a policy context of aspects of living with dementia that goes beyond cure, diagnosis and formal care. By developing a better understanding of the practices of daily life for people with dementia and the places in which they are carried out, people living with dementia can be better supported to remain integrated within their local communities.

Limitations

I have reflected on my research approach at length earlier in this chapter, weighing up what I considered to be successful and what I would do differently. Through conducting this research, it became evident to me that not all people with dementia shared the same challenges concerning ‘going out’ therefore, it is difficult to generalise the findings. However, generalisability is not the aim of most constructivist research. In fact, I reject the notion that qualitative research should be judged by similar criteria to quantitative research as there is no single qualitative research paradigm (Rolfe, 2006). Instead, by employing a reflexive approach and making my role in the data generation process transparent, I demonstrate the rigour of this research so the reader can verify the research process and come to their own conclusions (Sandelowski, 1993). The richness of a constructivist inquiry is a product of its interpretivist nature and although I do not consider this to be a limitation, it must be stated that the findings of this research were co-created by myself and the participants, yet they were interpreted by myself and were guided by my chosen theoretical lens. Although I attempted to address this by conducting member checking to ensure that my interpretation of the data was in line with the participants’ experiences, if another person were to conduct this study, they may generate different results.

The main limitation of this research is the lack of diversity in socioeconomic status, gender, and ethnicity in the participants. I did not generate any data regarding participants’ socioeconomic status however, I did gain a general understanding of this as I got to know participants, which revealed to me the lack of socio-economic diversity amongst the participants. In addition, across all participants, 53% self-reported as female (14 as care partners; 6 as living with dementia) and 47% self-reported as male (5 as care partners; 12 as living with dementia). No participant self-reported as ‘specified other’. Of the people with dementia who participated in the walk-alongs, there was only one woman and six men. I noted differences in the lived experiences between Maria and the six men who I walked with but it would have been interesting to see if other accounts from walking with women with dementia were similar to Maria, since gender impacts on the lived experience of dementia (Bartlett *et al.*, 2016). Finally, all participants were White and British. I suspect this lack of diversisty was due to my recruitment strategy, as I relied predominantly on local dementia cafes as recruitment sites. These are under-utilised by minority ethnic groups in the UK due to social and cultural barriers (Mukadam, Cooper and Livingston, 2013).

Future research

Dementia prevalence is increasing globally and subsequently more people living at home. Therefore, it is important to further explore how people living with dementia engage with their local communities using critical and inclusive approaches. In consideration of the limitations of this inquiry, the following approaches should be applied to this area of future research:

1. Longitudinal studies that explore how a person’s relationship with their local environment changes as their dementia progresses. However, it will have to be considered how to approach these studies methodologically if a person’s capacity diminished over time or their dementia symptoms prevent them from participating. Flexible approaches that acknowledge communication beyond the verbal will be key in furthering this knowledge.
2. This thesis highlights how people living with dementia are a heterogeneous group and that each individual may have different challenges and therefore different experiences of ‘going out’. These experiences are influenced not only by their dementia symptoms but by other health conditions, gender, ethnicity, socio-economic status and the wider socio-political context. Future research should explore how these experiences differ depending on aspects of their lived experience beyond their dementia. For example, we do not understand enough about the experience of living with dementia and other mental health issues and how that impacts their risk of going missing.

3. Whilst conducting this inquiry, I was involved in a pilot project that explored police-held data on people with dementia who have been reported missing. A wealth of data is available in police forces across the UK which could be analysed using quantitative methods. In addition to this quantitative approach, we need to further develop our understanding of police and search and rescue experiences to identify their needs and to highlight tools that might better support them.
4. It would be foolish not to address the impact that the COVID-19 pandemic has had on how people with dementia experience ‘going out’ or indeed, what the impact of not ‘going out’ during COVID has had on people with dementia and their families. Future research should explore this.
5. Finally, although this research employed a participatory approach and methods that addressed the power imbalance between researcher and participants, this could be extended further in future research to include people with dementia as authentic co-researchers. Dementia advocates have identified their priority areas for future research[9]. These suggestions for future research need to be considered alongside recommendations that are made by academic research.

Summary of the key contributions to knowledge

In summary, this constructivist inquiry has drawn on participatory principles to explore how people with dementia engage with ‘going out’. This thesis makes empirical, theoretical and methodological contributions to knowledge. Empirically, this thesis has shown that four themes can be used to describe participants’ experiences of 'going out’: decision-making; relational agency; feeling part of a place; and navigational challenges and strategies. The findings presented in this thesis make visible the active role that people living with dementia have in the practice of ‘going out’. It has also shown that ‘going out’ is an embodied and emplaced practice of everyday citizenship. Finally, this study has highlighted that each individual has a different experience of ‘going out’ depending on both personal and wider socio-cultural factors. Drawing on these novel insights, I propose that the 3 P’s can be used as a heuristic tool to understand the motives and strategies of ‘going out’ for

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[9] These resources are available on the Dementia Exchange and Empowerment Project website https://www.dementiavoices.org.uk/

people living with dementia. In order to understand experiences of ‘going out’, the findings of this inquiry can be broadly categorised into *why* people go out (strategies) and *how* people go out (motives). Other common themes in the experiences of participants are the *practices* that a person engages in; the *places* that they go; and the *people* that they engage with. This thesis makes novel contributions to the missing persons and dementia studies literature, whilst also having practical implications by informing prevention and search strategies for people with dementia who are at risk of going missing. Theoretically, this thesis is the first to bring a citizenship-in-and-as-practice lens to the field of literature pertaining to dementia and missing persons. In addition, it furthers the social citizenship approach in dementia studies by arguing for the inclusion of an embodied and emplaced focus on the lived experiences of people with dementia. Methodologically, this thesis contributes a novel embodied and emplaced analysis of walk-alongs with people living with dementia in Scotland. This final chapter has situated the findings of this inquiry in the wider literature. It has achieved this through consideration of the wider socio-cultural environment and the practical implications of this research to policy, practice and research. Finally, I draw this thesis to a close with some final reflections.

Concluding remarks

At the beginning of this thesis, I claimed that the experience of ‘going out’ and being at risk of becoming lost or missing for people living with dementia was poorly understood. The work of this thesis allows us to frame ‘going out’ as an embodied and emplaced practice of everyday citizenship. By analysing my interactions with people with dementia, I developed a heuristic tool to understand people’s motives and strategies for ‘going out’ that frames the person at the heart of decision-making in the context of ‘going out’. Importantly, it also considers the heterogeneity of experiences of dementia and can be used to inform prevention and response strategies, contributing to the overall aim of this inquiry to support people with dementia to live at home in safe and supportive environments. In closing this thesis, I reflect on four quotes that have resonated with me throughout this PhD journey. In doing so, I attempt to summarise the life lessons that I have learned from undertaken this research; lessons that I hope to carry with me in my personal and professional life going forward.

'If you've met one person with dementia, you've met one person with dementia.'

- Tom Kitwood

A well-known quote in the dementia studies field and for good reason. This study has taught me that experiences of living with dementia vary drastically from person to person. Therefore, we cannot assume that people with dementia will behave or move in a particular way when they are reported missing. More broadly, we ought to be careful when categorising any person according to one element of their lived experience. For example, when we classify individuals as 'people who go missing' or 'people with disabilities' or 'people with mental health problems', we risk reducing them to that identity and thus ignoring the intersectionality of lived experience and other elements of their identity. Before beginning this PhD journey, I saw the world in black and white. Now, I only see grey. Although challenging to research, the multiple identities that people hold, and how these intersect, are the elements of lived experience that we must strive to understand better.

'Not all those who wander are lost'

- J. R. R. Tolkien

A universally known quote written by Tolkien in his Lord of the Rings trilogy and shared with me by Christine Thelker, a Canadian dementia advocate who has claimed this quote as her life motto. I have since borrowed it as my own life motto. Specifically, in relation to this study, this quote also reminds me that not all people with dementia who get lost are 'wandering' and therefore, we should refrain from using this stigmatising language. It is also hypocritical that to wander without dementia is seen as an enjoyable and leisurely activity but to wander with dementia is a high-risk behaviour that must be managed. To wander, without being lost, is also a good metaphor for research that explores lived experiences.

'We're all vulnerable, you know'

- Maria (study participant)

Maria said this to me on one of our walk-alongs and it has remained firmly imprinted on my mind ever since. In saying this, she encouraged me to always consider the wider socio-cultural and political lens on certain issues, taking inspiration from the feminist mantra; *‘the personal is political’*. The years 2020 and 2021 have been tumultuous years. We have experienced life-altering events such as the COVID-19 pandemic, Black Lives Matter protests, and a furthering political divide to name a few. During each of these events and news headlines, I have turned Maria’s quote over and over in my mind, reflecting on how we treat the “most vulnerable” of our society. The COVID-19 pandemic, in particular, has highlighted how we are failing to meet the basic human rights of people in care homes; the devastating impact that social isolation has had on older people; and the sheer neglect of social care during this crisis. In the final months of writing up this thesis, I have become more familiar with Tronto’s ethics of care theory, and the potential we now have to rebuild our society post-pandemic, away from the Global North’s focus on capitalism and consumerism and towards a caring society that recognises the universality of human vulnerability, as Maria reminded us.

> *‘Being dementia-friendly is actually about being inclusive to everyone’*
>
> - Laurence (study participant)

Finally, a wise reminder from Laurence. The ageing population and the increasing prevalence of dementia may indeed be a ‘wicked problem’, but it is also a bountiful opportunity. It is an opportunity to build a more inclusive society and people living with dementia have a lot to teach us about this. Small, inclusive changes need to be made at a local level alongside a reframing of outdated wider societal attitudes that people with dementia are a ‘burden’ on society or a ‘drain’ on government spending. Instead, we must consider people with dementia as the valuable assets that they are. I hope that this inquiry has helped to further this notion. There is a wealth of knowledge to be gained from marginalised voices; we would do well to listen.

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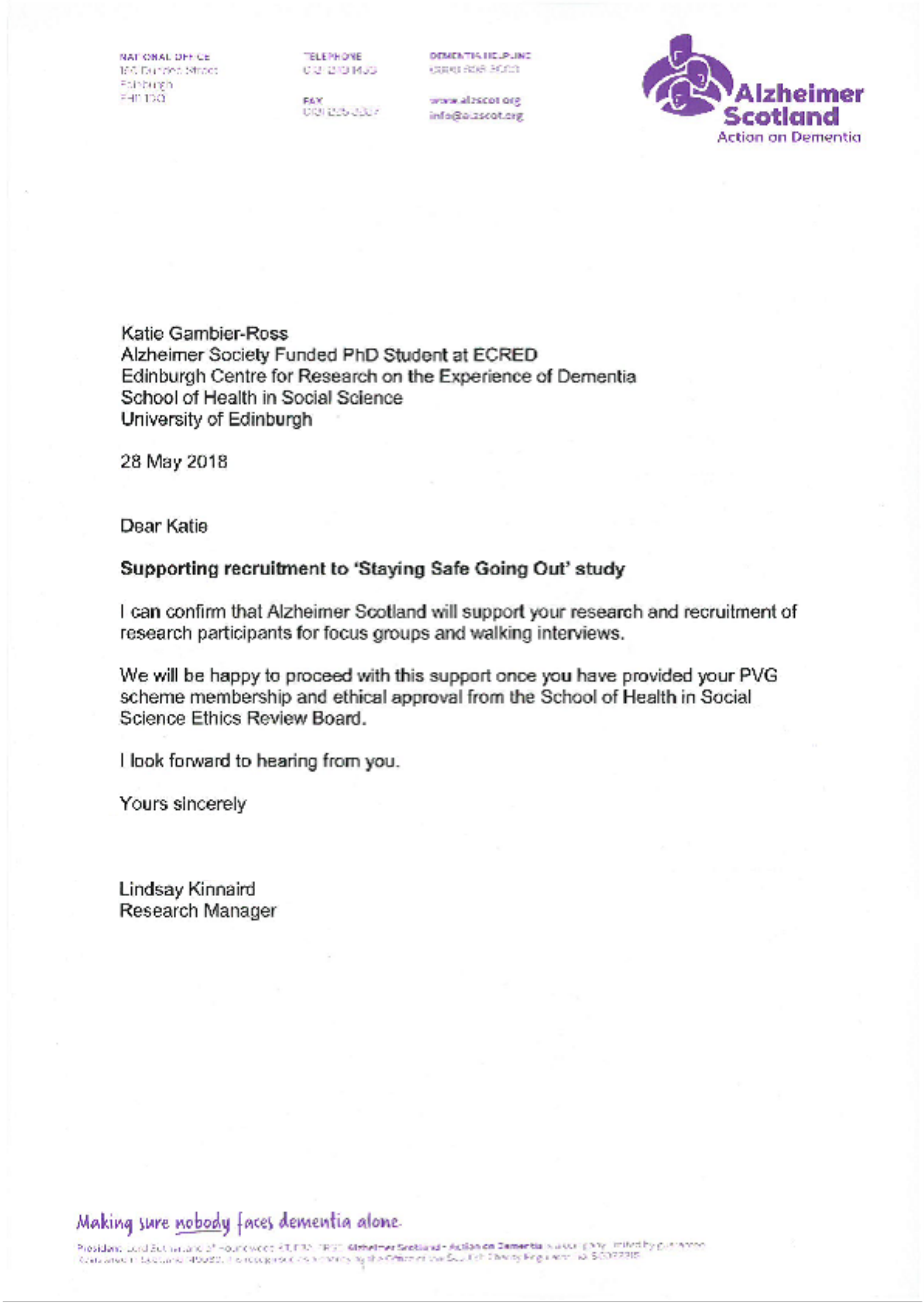
Appendices

Appendix A - Alzheimer Scotland Letter of Support



NATIONAL OFFICE
Edinburgh

TELEPHONE

FAX

DEMENTIA HELPLINE

www.alzscot.org
info@alzscot.org

Alzheimer Scotland
Action on Dementia

Katie Gambier-Ross
Alzheimer Society Funded PhD Student at ECRED
Edinburgh Centre for Research on the Experience of Dementia
School of Health in Social Science
University of Edinburgh

28 May 2018

Dear Katie

Supporting recruitment to 'Staying Safe Going Out' study

I can confirm that Alzheimer Scotland will support your research and recruitment of research participants for focus groups and walking interviews.

We will be happy to proceed with this support once you have provided your PVG scheme membership and ethical approval from the School of Health in Social Science Ethics Review Board.

I look forward to hearing from you.

Yours sincerely

Lindsay Kinnaird
Research Manager

Making sure nobody faces dementia alone.

Appendix B - Data Management Plan

This DMP is based on the University of Edinburgh Research Data Management Policy (http://www.ed.ac.uk/is/research-data-policy).

Project Name: Staying Safe 'Going Out'- The experience of going out at risk of being missing for people wit dementia and their carers.

PhD Student: Katie Gambier-Ross

Supervision Team: Professor Charlotte Clarke, Professor Heather Wilkinson and Dr Penny Woolnough

Institution: School of Health in Social Science, University of Edinburgh

Funding: Alzheimer's Society

Description: This research project aims to explore the experience of 'going out' for people with dementia and their carers. It aims to address how

1. Data Capture

What data will be generated or reused in this research?

This research project will be conducted in two phases. Phases one will involve focus groups and phase two will involve 'go-along' interviews. Focus group data will be recorded on an approved digital recorder purchased by the researcher with funding from the Alzheimer's Society. Interview data will also be recorded on this device but there may be certain circumstances where the recorder is not used. In which case, the researcher will use the recorder to provide a detailed account of what happened immediately after the interview. The researcher may also obtain visual data in the form of photographs. Data will be sent to an external professional transcription service and will be analysed using NVivo.

The researcher will also keep reflective diary to record their thoughts and opinions throughout the research process. It is a commonly used technique in qualitative research. The diary is mainly for the researcher, to help them make sense of their decision-making processes, as well as allowing them an outlet to reflect on their position within the research process and how it might impact on data collection and analysis.

Electronic data will be saved in the following format, as per UK Data Archive guidelines (please see https://www.ukdataservice.ac.uk/manage-data/format)

- Digital recordings .WAV or .mp3
- Interview transcriptions .rtf or .pdf
- Image data JPEG
- Project documentation (protocol, consent form etc.) .rtf or .pdf
- Project write-ups .rtf or .pdf

This project does not plan on using any third party data.

How much data will be generated?

- 500 GB – 2 TB

It is difficult to answer this due to the nature of qualitative focus groups and interviews. The project aims to hold 6 focus groups and up to 60 interviews. For every focus group and most interviews there will be the digital recording and transcript. The University has committed 500 GB of high quality storage with guaranteed backup and resilience to every active researcher. It is not intended to exceed this limit.

2. Data Management

How will the data be documented to ensure it can be understood?

To help make data easily understood, the following will be adopted;

Participant pseudonym

On entering this study, each participant will be given a pseudonym to ensure anonymity.

Version control

A Microsoft Excel spreadsheet will be kept for each project document, detailing the document version, the date amended and a brief note of any changes made. All versions of documents will be kept and stored for the duration of the project.

File names

Files relating to the project will be labelled as per the following examples;

Document	File name format

Interview transcript	InterviewTranscript_ParticipantPseudonym_YYYYMMDD_v1
Interview audio	InterviewAudio_Participant_YYYYMMDD_v1
Consent form	ConsentForm_YYYYMMDD_v1

Directory

Documents will be saved in the following directory system;

U:\Datastore\CHSS\hiss\s1226363\

Files will be arranged into folders, according to data type and will adopt the following structure;

U:\Datastore\CHSS\hiss\s1226363\PhDProject**InterviewTranscripts**

U:\Datastore\CHSS\hiss\s1226363\PhDProject**InterviewAudio**

U:\Datastore\CHSS\hiss\s1226363\PhDProject**ProjectDocuments**

U:\Datastore\CHSS\hiss\s1226363\PhDProject**DataAnalysis**

U:\Datastore\CHSS\hiss\s1226363\PhDProject**WriteUps**

Where will the data be stored and backed-up?

A) Paper records: Consent forms and reflexive diary will be stored in a locket filling cabinet that can only be accessed by Katie Gambier-Ross. This cabinet is located in the

Postgraduate Research Student office in the School of Health in Social Science, Teviot Place. Entry to this room is restricted via 'swipe access'.

B) Digital and electronic records: audio recordings and transcripts will be stored on DataStore. This is University of Edinburgh's high quality, enterprise-class storage with guaranteed backup and resilience. The data is automatically replicated to an off-site disaster facility and also backed up with a 60-day retention period, with 10 days of file history visible online. All digital files will be encrypted as per University of Edinburgh guidelines and files will be password protected.

3. Integrity

How will you quality assure your data?

This project will use reflexivity as a way of ensuring quality. This involves the researcher exploring the subjective nature of the study and their own influence on the process. These reflections will be recorded in a diary which should assist the researcher in viewing situations from different perspectives. Reflections will also include the researcher's own ambitions in the research agenda as well as identifying any power imbalances in the relationships. The diary will be sharing during supervision meetings throughout the data collection process.

4. Confidentiality

How will you manage any ethical and IPR issues?

Ethical approval will be approved by the School of Health in Social Science ethics board before starting data collection. Consent forms will be signed by participants and verbal consent will be audio recorded. Some individuals may be reluctant to have their data shared. Such concerns will be resolved for the interviews and focus groups by ensuring all transcripts are anonymous and identifying detail are removed or given pseudonyms in the transcript. Participants are free to withdraw from the study at any time and this will be explaining during recruitment.

5. Retention and Preservation

Which data do you plan to keep and for how long?

Data will be stored for a minimum of three years after completion of the study. This is in accordance with the UK Research Integrity Office code of practice which has been adopted by the University of Edinburgh (please see http://ukrio.org/publications/code-of-practice-for-research/).

How will the data be preserved?

Edinburgh DataShare is an online digital repository of multi-disciplinary research datasets produced at the University of Edinburgh, hosted by the Data Library in Information Services. It acts as a trusted repository, ensuring that research data will be preserved.

6. Sharing and Publication

Which data will be shared and how?

Data will only be shared with the supervision team. Since one member of the supervision team is outside of University of Edinburgh, anonymised data will be shared via email or via DataSync if it is not anonymised. Audio data will also be shared with an external university-trusted professional transcription service. Participants will be informed of this as it can potentially compromise data security and participant privacy.

Are any restrictions on data sharing required?

No data will be made available on an open basis. Prior to dissemination in peer-reviewed journals or conference papers, any identifiers will be removed from the data to protect the identity of the participants.

Appendix C - Risk Assessment

DEPARTMENT/SCHOOL/UNIT	*Social and Health in Social Science*	REF NO.	N/A
TASK/OPERATION BEING ASSESSED	Interviews and focus groups with people with dementia and their family/carers to discussion their experience of 'going out'.		

PURPOSE/METHOD OF WORK
Purpose The focus of this research is on the everyday lives of people with dementia and the decision-making they (and others) go through when 'going out' and during the potential or actual experiences of being missing. We do not know, for example, how people with dementia re-locate themselves if they feel 'lost'. I will explore these experiences and how they affect people's sense of identity, purpose, control over their own lives, independence and safety. Focus groups and go-along interviews will be conducted with people with dementia and their family members/carers to investigate how they engage with 'going out' and prevent being missing. It is hoped that this research will provide key information that could aid future search strategies when people with dementia are reported missing. Method

Stage 1 – Focus groups with people with dementia and their families/carers

Individuals will be recruited with the support of Alzheimer Scotland. Focus groups will begin with the showing of excerpts from the film ‘Jack and Jill and the Red Postbox’ following with a discussion of how it makes participants feel and how it relates to their own personal experiences. A schedule has been drawn up and can be found in the appendices.

Stage 2 – A series of up to three ‘go-along’ interviews with people with dementia and a follow-up interview with their family/carers

Individuals will be recruited with the support of Alzheimer Scotland, following which in-depth interviews will be conducted to provide critical insights into the experience of ‘going out’ from the perspective of people with dementia and their family/carers. An interview schedule has been drawn up and can be found in the appendices.

SPECIFIC LEGISLATIVE REQUIREMENTS		LEVEL OF SKILL/TRAINING REQUIRED
N/A		N/A

CHEMICALS/MATERIALS INVOLVED	HSC NO.	ASSESSMENT DATE		SPECIFIC WORK EQUIPMENT PROVIDED
N/A	N/A	N/A		N/A

MAIN HAZARDS IDENTIFIED	WHO WILL BE AFFECTED	CONTROL MEASURES TO REDUCE THE RISK
Some interview questions may cause distress to the participant, as they will recall their experience of dementia and potential challenges that they have	Interview and focus group participants	The researcher will be alert to participants showing signs of discomfort and will attempt to diffuse the situation by giving them a break or changing the topic of discussion. The

faced, which they may find hard to discuss.		participants will be fully informed of their right to stop the interview at any time without having to give a reason. In addition, contact details for the Alzheimer Scotland charity will be provided to all participants should they wish to access any additional support or help after the interview has ended.
‘Go-along’ interviews pose risks related to being outdoors such as falling, meeting members of the public	‘go-along’ interview participants	If the researcher meets someone she knows she will give a curt ‘hello’ but will not stop to talk. Prior to the interview, the researcher and participant will discuss what do to if they bump into someone the participant knows. It will be up to the participant whether they want to introduce the researcher, talk about the research etc.

		The risk of tripping and falling during a 'go-along' interview is no greater than during the participants' everyday life. The researcher will try to be alert to the participants' need e.g. suggest a coffee break if the participant appears tired, offer an arm if they are limping, suggest they wrap up the interview if they feel the participant is too tired to continue. If a participant falls or is injured during the go-along interview, the researcher will end the interview and support the participant to get home, contact their significant other and even contact medical services depending on the gravity of the injury. This will have to be dealt with on a case-by-case basis.
Some interviews may be conducted in the participants' own home.	Researcher	The research team will assess each case individually for any potential risks that may be

		present. This will be conducted by using various protocols, which have been adapted from lone working policy documents (NHS and the Social Research Association). Before any decision is made regarding each interview the research team will log any potential risks. An initial meeting or telephone call prior to the beginning of the study will provide the researcher an opportunity to assess the respondent and their circumstances. In addition, the researcher will not enter properties with lone men and will look into issues such as local tensions that they may need to be aware of such as strong cultural, religious or racial divisions. Contacting respondents in advance to ask about preferences and expectations may help

		avoid risk situations of these kinds. The researcher will not attend any interviews alone if she feels uncomfortable doing so or if the research team do not believe it to be a safe environment. In these situations she will take another person with her or arrange an alternative interview location. The researcher will also have the ability to cancel any interviews at her discretion should she feel unsafe for any reason (examples may include no mobile phone reception or a home address in a remote location). Should the researcher feel safe enough to continue with the interview, strict plans will be put in place to ensure the safety of the researcher. If worrying characteristics, such as a

		history of violent behaviour are known beforehand, the researcher will not enter into this individual’s home alone. If in the light of prior information there is any doubt about personal safety, a co-researcher will accompany them inside or wait in the dwelling or in a visible position outside. If waiting outside, a system for communicating will be arranged in advance. The researcher may also carry an alarm or device to attract attention in an emergency. There will be an appointed contact (most likely a supervisor) that will externally monitor the situation and follow a pre-arranged protocol. They will call regularly and take further action from their end if the researcher has not contacted them after an agreed period of time.

		They will call the pre-arranged number prior to entering the property and will also arrange a time to call back after leaving the property. There will be a set procedure if the researcher does not call within the specified time and if at any point during the interview, the investigator feels unsafe; they will excuse themselves, go to another room, and call for assistance using a code word for distress. The appointed contact will be aware of the following details prior to every interview: • Name, address and telephone contact of interviewee(s)/destination • Investigator's mobile telephone number.

		• Time of leaving the office. • Method of transport to interview location (car registration if appropriate). • Time of interview and expected duration of visit. Strategies for leaving may include arranging for a taxi to collect the researcher or having a personal vehicle outside to leave as quickly as possible.
Data may be leaked	Researcher & Participants	All data that is obtained as part of this study will be stored securely on a password protected computer or laptop within an encrypted file. Only the research team will have access to these files. In addition, no personal

		information will be stored with data in order to preserve the identity of participants.

MANUAL HANDLING RISK		PERSONAL PROTECTIVE EQUIPMENT REQUIRED
Has a manual handling risk been identified? NO Is the risk considered to be High / Medium / Low Is a further detailed assessment required? NO		NONE
If the answer to the above question is YES a separate manual handling assessment will be required to fulfil the requirements of the Manual Handling Operations Regulations 1992.		Is training and instruction required YES/NO Is there need for special accommodation YES/NO

		Is there need for test/examination YES/NO Is all P. P. E. compatible YES/NO N/A

FREQUENCY OF MONITORING						ASSESSMENT REVIEW PERIOD				
N/A	3 Months	6 Months	1 Year	> 1 Year		< 1	2 Years	3 Years	4 Years	> 4
x						x				

Print Name: KATIE GAMBIER-ROSS Post/Title: PhD

Appendix D - Recruitment Flyer

Would you like to help us find out more about the experience of 'going out' for people with dementia/memory problems?

We want to hear your views!

You may be able to take part if you are:

- Living in Scotland
- Have experience of memory problems, of dementia or as a carer/ family member
- Have the mobility to leave your home
- Are able to take part in a group discussion lasting approx. 2 hours or a series of individual interviews
- Are fluent in English

Please contact the research team for additional information if you think you can help us with this important research.

Contact Katie Gambier-Ross via email:

Alzheimer Scotland
Action on Dementia

Alzheimer's Society
United Against Dementia

THE UNIVERSITY *of* EDINBURGH
School of Health in Social Science

Abertay University

Appendix E - Group Discussion Participant Information Sheet

Research Title: **The experience of 'going out' for people with dementia/ memory problems and their family/carers**

Dear Study Volunteer,

You are being invited to take part in a research project about your experiences of 'going out'. Before you decided whether to take part, it is important to understand what the research is for and what you will be asked to do. Please read the following information and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part.

About the project

Going out is important for everyone to maintain good health. However, one consequence of dementia/ memory problems can be impaired navigational skills and as a result of this, people with dementia are at risk of getting lost and even being reported missing. For many, the worry about getting lost can lead to avoiding 'going out' and therefore can have a negative cost to people's quality of life. This research project is part of a PhD study which aims to understand this experience of 'going out', the challenges people face and how they cope with these challenges. By identifying these challenges and coping strategies, we can improve search strategies if people with dementia do go missing and we can support people with dementia to live in a safe and supportive environment.

As a person with dementia/ memory problems or a carer/ partner you are the expert of your own experience and can provide valuable information on how you experience 'going

Who is involved?

The research will be conducted by **Katie Gambier-Ross**, a PhD student at the School of Health in Social Science at the University of Edinburgh. The research will be supervised by Professor Charlotte Clarke, Head of School of Health in Social Science at University of Edinburgh; Professor Heather Wilkinson, ECRED director at University of Edinburgh; and Dr. Penny Woolnough, Senior Lecturer in Forensic Psychology at Abertay University. The project is funded by Alzheimer's Society UK.

The project has been reviewed by the School of Health in Social Science Research Ethics Committee. ***pending approval- link to email***

Why have I been invited to take part?

As a person with experience of dementia/ memory problems, or as a carer/partner, you are in a valuable position to share your experience to help us to experiences of living with dementia/ memory problems. By participating, you will contributing to wider learning which could help improve the lives of people with dementia.

Do I have to take part?

No. You are under no obligation to participate in the project. Taking part is voluntary and will not make any difference to services you may receive now or in the future.

What will happen if I do decide to take part?

If you decide to take part, you will be provided with information on the project and given the opportunity to ask questions and find out more. Then, we will arrange a date for a focus group discussion with you and other participants.

For the focus group, we will meet for approximately two hours. Refreshments and your travel costs will be provided on arrival. We will begin by discussing the study and taking signed consent from every participant. You will be asked to fill in a very short background questionnaire that will ask you for some information e.g. Do you live at home? Do you live alone? Do you live in a rural/urban environment? Etc. We will view clips from a short film about a woman's experience of going out and getting lost in her local town. We will then ask the group a range of questions in relation to your own experiences of going out, navigating and perhaps getting lost. We particularly want to understand more about what challenges you might face when ‘going out’ and how you overcome these. There are no right or wrong answers, we want to understand your own thoughts and experiences.

You are free to withdraw from the study at any stage and you do not have to give a reason for doing so. Any data collected prior to your withdrawal may be used in analysis.

Benefits and risks

Participation in this study involves minimal risk. Talking about your experiences can make you reflect on some difficult experiences – most often, people do find this helpful however. If you share information that makes the researcher concerned about your welfare or the welfare of someone in your care, they are obliged to act in your best interests (or the person you care for) – they will support you, and may need to discuss this with other people.

Participants may find this a positive opportunity to discuss and reflect on their experiences and to meet other people. In the longer term, it is hoped that people with dementia will be supported to be able to 'go out' more safely.

Will my taking part in the research be kept confidential?

Yes. During the focus group, each participant will pick a 'pretend' name so they cannot be identified. Your participation will not be discussed with anyone else except the researcher's supervision team.

Your focus group discussion will be audio recorded. The recordings will be shared with a university trusted transcription service. The audio-recordings and transcriptions will be stored on university computer server which is encrypted and password protected and only accessible by the researcher. Transcriptions will be anonymised and all participants will be given 'pretend' names so that no individuals may be identified. 'Hard copy' data (e.g. data on digital recorders, printed documents) will be stored in a locker cabinet in the University of Edinburgh which is only accessible by the researcher and is located in a key card-entry office. All data collected will be managed in accordance with the University of Edinburgh Data Management Guidelines. Anonymised data will be held for five years after collection.

What happens to the results?

If you wish, the researcher can contact you when the final results are available and provide them in the form of a short summary. Please let the researcher know if you wish to be informed of this. The findings will be written up as part of Katie's PhD thesis, published in peer-reviewed academic journals and presented at conferences. You will not be identifiable from any of the data presented.

Research findings will be used to facilitate people with dementia and memory problems to be able to 'go out' more safely.

Contact information for further details:

If you wish to contact someone independent of the research team or you wish to make a complaint about this study, please contact Dr Corinne Reid, Director of Research at the School of Health in Social Science (Tel: +44 (0)131 650 4270; Email:

.

If you would like any more information please contact me:

Katie Gambier-Ross

PhD Student

School of Health in Social Science

Email:

If at any time, you would like to discuss your situation, then local support is available by contacting:

Alzheimer Scotland Freephone Helpline: 0808 808 3000

Thank you for taking the time to read this information sheet.

THE UNIVERSITY of EDINBURGH
School of Health in Social Science

Alzheimer Scotland
Action on Dementia

Alzheimer's Society
United Against Dementia

Abertay University

Appendix F - Interview Participant Information Sheet

Research Title: **The experience of ‘going out’ for people with dementia/ memory problems and their family/carers**

Dear Study Volunteer,

You are being invited to take part in a research project about your experiences of ‘going out’. Before you decided whether to take part, it is important to understand what the research is for and what you will be asked to do. Please read the following information and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part.

About the project

Going out is important for everyone to maintain good health. However, one consequence of dementia/ memory problems can be impaired navigational skills and as a result of this, people with dementia are at risk of getting lost and even being reported missing. For many, the worry about getting lost can lead to avoiding ‘going out’ and therefore can have a negative cost to people’s quality of life. This research project is part of a PhD study which aims to understand this experience of ‘going out’, the challenges people face and how they cope with these challenges. By identifying these challenges and coping strategies, we can improve search strategies if people with dementia do go missing and we can support people with dementia to live in a safe and supportive environment.

As a person with dementia/ memory problems or a carer/ partner you are the expert of your own experience and can provide valuable information on how you experience ‘going out’

Who is involved?

The research will be conducted by **Katie Gambier-Ross**, a PhD student at the School of Health in Social Science at the University of Edinburgh. The research will be supervised by Professor Charlotte Clarke, Head of School of Health in Social Science at University of Edinburgh; Professor Heather Wilkinson, ECRED director at University of Edinburgh; and Dr. Penny Woolnough, Senior Lecturer in Forensic Psychology at Abertay University. The project is funded by Alzheimer's Society UK.

The project has been reviewed by the School of Health in Social Science Research Ethics Committee.

Why have I been invited to take part?

As a person with experience of dementia/ memory problems, or as a carer/partner, you are in a valuable position to share your experience to help us to experiences of living with dementia/ memory problems. By participating, you will contributing to wider learning which could help improve the lives of people with dementia.

Do I have to take part?

No. You are under no obligation to participate in the project. Taking part is voluntary and will not make any difference to services you may receive now or in the future.

What will happen if I do decide to take part?

If you decide to take part, you will be provided with information on the project and given the opportunity to ask questions and find out more. Phase one of this study involved focus groups with people with dementia/memory problems and their carers. This phase has been completed and you will be taking part in phase two.

Phase two will involve a series of one-on-one ‘go-along’ interviews between Katie and the participant who has dementia/ memory problems. After Katie completes the series of ‘go-along’ interviews, she will have a once-off sit down interview with their partner/carer.

We will begin by discussing the study and taking signed consent. Then we will begin the interview. There are no right or wrong answers, we want to understand your own thoughts and experiences.

You are free to withdraw from the study at any stage and you do not have to give a reason for doing so. Any data collected prior to your withdrawal may be used in analysis.

What are ‘go-along’ interviews?

‘Go-along’ interviews are a style of interviews that involve the researcher and participant doing a contextually-relevant activity together. Katie will accompany you on a walk or another activity outside of your home (e.g. go for coffee or to the shops) and she will ask you a range of questions in relation to your experiences of going out, navigating and perhaps getting lost. You will decide on the route that we take and discussions will be information (like a friendly chat as we do an activity together).

Benefits and risks

Participation in this study involves minimal risk. Talking about your experiences can make you reflect on some difficult experiences – most often, people do find this helpful however. If you share information that makes the researcher concerned about your welfare or the welfare of someone in your care, they are obliged to act in your best interests (or the person you care for) – they will support you, and may need to discuss this with other people.

Participants may find this a positive opportunity to discuss and reflect on their experiences and to meet other people. In the longer term, it is hoped that people with dementia will be supported to be able to ‘go out’ more safely.

Will my taking part in the research be kept confidential?

Yes. During the focus group, each participant will pick a ‘pretend’ name so they cannot be identified. Your participation will not be discussed with anyone else except the researcher’s supervision team.

Your interviews will be audio recorded. The recordings will be shared with a university trusted transcription service. The audio-recordings and transcriptions will be stored on university computer server which is encrypted and password protected and only accessible by the researcher. Transcriptions will be anonymised and all participants will be given ‘pretend’ names so that no individuals may be identified. ‘Hard copy’ data (e.g. data on digital recorders, printed documents) will be stored in a locker cabinet in the University of Edinburgh which is only accessible by the researcher and is located in a key card-entry office. All data collected will be managed in accordance with the University of Edinburgh Data Management Guidelines. Anonymised data will be held for five years after collection.

What happens to the results?

If you wish, the researcher can contact you when the final results are available and provide them in the form of a short summary. Please let the researcher know if you wish to be informed of this. The findings will be written up as part of Katie's PhD thesis, published in peer-reviewed academic journals and presented at conferences. You will not be identifiable from any of the data presented.

Research findings will be used to facilitate people with dementia and memory problems to be able to 'go out' more safely.

Contact information for further details:

If you wish to contact someone independent of the research team or you wish to make a complaint about this study, please contact Dr Corinne Reid, Director of Research at the School of Health in Social Science (Tel: +44 (0)131 650 4270; Email: Corinne.Reid@ed.ac.uk).

If you would like any more information please contact me:

Katie Gambier-Ross

PhD Student

School of Health in Social Science

Email:

If at any time, you would like to discuss your situation, then local support is available by contacting:

Alzheimer Scotland Freephone Helpline: 0808 808 3000

Thank you for taking the time to read this information sheet.

Appendix G - Group Discussion Participant Consent Form

Research Title: **The experience of ‘going out’ for people with dementia/ memory problems and their family/carers**

Please read the following statements in the table below, tick the relevant boxes and sign your name at the end of the agreement.

I have read and understood the Participant Information Sheet for this study	Yes	
	No	
I have been given the opportunity to ask questions about the study and understand that if I need any more information I can contact Katie Gambier-Ross	Yes	
	No	
I understand and consent to take part in a focus group about my experiences of living with dementia/ memory problems	Yes	
	No	
I understand and agree to audio recording and notes being kept during the focus group	Yes	
	No	
I agree to take part in the research and understand that this will not affect my access to any services that I use now or in the future	Yes	
	No	
I understand that I can withdraw from the research at any time and will not be contacted again about this if I choose not to be involved	Yes	
	No	
I understand that I will not be personally named in any report or anything to do with the research and that anything I say will be treated in confidence	Yes	

(unless I say something that indicates that either myself or someone else is at risk of harm and this would be discussed with me prior to telling anyone else)	No	
I understand that any data I produce will be kept in a secure way	Yes	
	No	
I agree to audio recordings of my interviews being shared with a university-trusted transcription service	Yes	
	No	
I understand that anonymised information will be used even if, for whatever reason, I choose to withdraw from the discussion group	Yes	
	No	
I understand that information collected will be managed by the research team only and will be destroyed after a period of five years	Yes	
	No	

Ethical Approval

This study has been reviewed and approved by the Ethics Committee of the School of Health in Social Science.

Please sign below to give your consent to participate in this research

Participant name (printed)

____

Participant signature

____

Participant chosen ‘pretend’ name

____

Name of person obtaining consent (printed) __________________________________

Signature of person obtaining consent

____

Date _______________________

THE UNIVERSITY of EDINBURGH School of Health in Social Science

Alzheimer Scotland Action on Dementia

Alzheimer's Society United Against Dementia

Abertay University

Appendix H - Interview Participant Consent Form

Research Title: **The experience of 'going out' for people with dementia/ memory problems and their family/carers**

Please read the following statements in the table below, tick the relevant boxes and sign your name at the end of the agreement.

I have read and understood the Participant Information Sheet for this study	Yes	
	No	
I have been given the opportunity to ask questions about the study and understand that if I need any more information I can contact Katie Gambier-Ross	Yes	
	No	
I understand and consent to take part in a series of 'go-along' interviews about my experiences of living with dementia/ memory problems or an interview about my experiences supporting someone with dementia/ memory problems	Yes	
	No	
I understand and agree to audio recordings and notes being kept during these interviews	Yes	
	No	
I agree to take part in the research and understand that this will not affect my access to any services that I use now or in the future	Yes	
	No	
I understand that I can withdraw from the research at any time and will not be contacted again about this if I choose not to be involved	Yes	
	No	

I understand that I will not be personally named in any report or anything to do with the research and that anything I say will be treated in confidence (unless I say something that indicates that either myself or someone else is at risk of harm and this would be discussed with me prior to telling anyone else)	Yes	
	No	

I understand that any data I produce will be kept in a secure way	Yes	
	No	
I agree to audio recordings of my interviews being shared with a university-trusted transcription service	Yes	
	No	
I understand that anonymised information will be used even if, for whatever reason, I choose to withdraw from the discussion group	Yes	
	No	
I understand that information collected will be managed by the research team only and will be destroyed after a period of five years	Yes	
	No	

Ethical Approval

This study has been reviewed and approved by the Ethics Committee of the School of Health in Social Science.

Please sign below to give your consent to participate in this research

Participant name (printed) ____

Participant signature ____

Participant chosen ‘pretend’ name

____

Name of person obtaining consent (printed) _____________________________________

Signature of person obtaining consent

____

Date ________________________

THE UNIVERSITY of EDINBURGH
School of Health in
Social Science

Alzheimer
Scotland
Action on Dementia

Alzheimer's
Society
United
Against
Dementia

Abertay
University

Appendix I - Demographic Questionnaire

Demographic Background Questionnaire

☐ Participant First Name:

Research Title: **The experience of 'going out' for people with dementia and their family/carer**

Name of Lead Researcher: **Katie Gambier-Ross**

1. ☐ **What is your age (in years)?**

2. **What is your gender?** (please tick ✓ appropriate answer)

☐ Female

☐ Male

☐ Other (please specify)

3. **Do you have dementia or memory problems?** (please tick ✓ appropriate answer)

☐ Yes

☐ No

4. ☐ **Do you live at home?** (please tick ✓ appropriate answer)

☐ Yes

No (if no, please state where you live e.g. residential care facility)

Please turn over ➡

5. **Do you live with a carer or family member?** (please tick ✓ appropriate answer)

☐Yes

☐No

6. **Please tick ✓ the statement that applies to you:**

☐I live in a city

☐

I live in a town

☐I live in the countryside

☐Other (please specify)

Appendix J - Topic guides

Walk-along topic guide

1. As we walk around, think about if any of these places have meaning to you?
2. How do you navigate yourself in space?
3. Can you recall a time when you were lost? Tell me about it
4. What interventions do you use when you get lost?
5. Would you ask someone for directions if you are lost?
6. Do you take note of any landmarks?
7. Do you walk on the road or footpath?
8. How do you navigate space using other models of transport e.g. bike, bus, car?
9. What do you think this experience is like for someone with dementia?
10. What did you think about the method? How did it make you feel? Is there anywhere you didn't want to go? Is there anything you had rather not shown or told me? Is there anything you would rather not have included in the recording?

Care partner topic guide

1. Can you recall a time where X got lost?
2. Did you ever report him missing?
3. Could you describe the missing incident from your perspective?
4. What do you think this experience is like for someone with dementia?
5. How do you feel about X going out?

6. Do you go out together often?
7. Does X go out alone often?
8. How do you feel about X going out alone/ without you/ with others?
9. Do you use an interventions?
10. Do you have any coping mechanisms?
11. Have you noticed any changes in X's navigational ability?
12. Do you think that X has independence? Freedom?
13. How do you support his right to independence and freedom?
14. Is there anything I haven't addressed?

Group discussion topic guide

Preamble (10 mins)

Welcome, consent process, housekeeping

Watch clip of Jack and Jill- describe intro then show clip of Jill in the post office 3.13-4.30

Theme 1- Your personal experience of 'going out'

1. How did that video make you feel? Could you relate to it?
2. I thought we could start by going around the group and sharing some personal experiences of 'going out'.
3. Do you go out alone?

4. How do you get around e.g. walk, bus, train, drive?
5. Does anyone use the public transport? What is that experience like?
6. Does anyone drive? What is that experience like?
7. Are there any things you used to do that you can no longer do/ need support with? (capture the change)

Theme 2- Other people's reactions (show clip of Jill bumping into doctor and family reaction 10.14-12.14)

1. Family members, how do you react when your loved one ‘goes out’ / when they get lost?
2. What does everyone think about how the wider public reacts?
3. Do you ever feel encouraged/discourage to go out by your family/ partner?
4. Do you feel there are any things that stop you from being able to go out?
5. Care partners, do you think that you encourage or discourage ‘going out’?

Theme 3- Getting lost and overcoming challenges (show clip of Jill returning home 12.45-13.45)

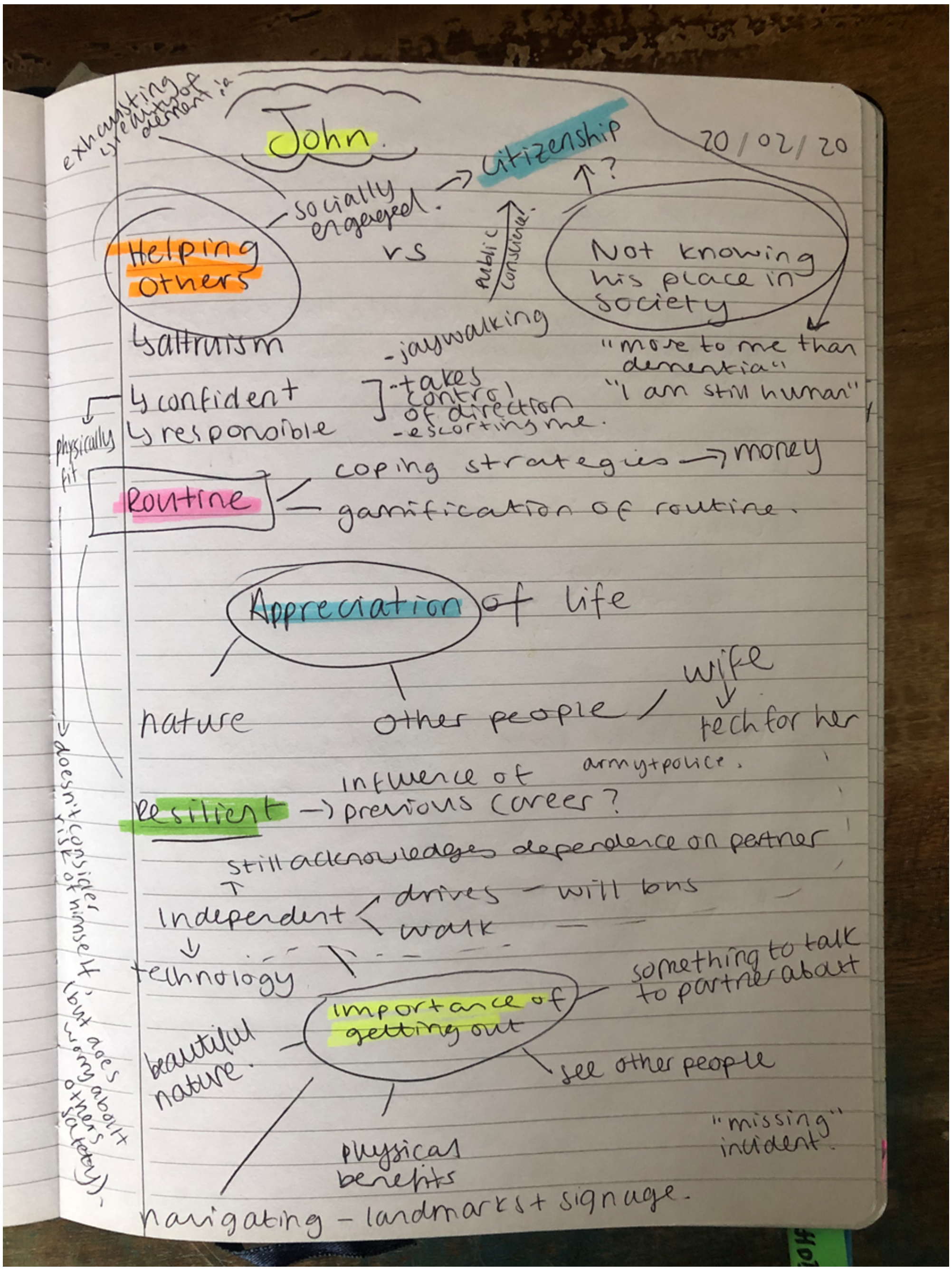
1. Have you ever gotten lost? If so, how do you relocate yourself?
2. Do you have any coping mechanisms to ensure you don’t get lost?
3. What about landmarks? Do you use them?
4. Would you ask someone for directions? (Remember in the video, Jill never asks for help or directions)

5. Have the police ever been involved?
6. How do you think the community/ wider society could support you to be ‘going out’ more safely?
7. Does anybody use technology to help them navigate? Is it helpful? If you do not use it, do you think technology could help you to navigate? Would it promote independence?
8. Does GPS (or other intervention) make you feel safer?

Appendix K – Field Notes Excerpts

John Interview 1 Reflections:

John seems to experience contrasting emotions that he internally grapples with- just going through life as a routine and almost being unhuman but also very happy and budding social life since his diagnosis. He said he can put in effort to put up a front. Is he doing that with me? I must dig in to that next time we meet…. He didn't speak about any negatives of dementia. Is that because there aren't any or does he want to appear positive and upbeat for me? I noticed he was unsecure in his foot movements but we were walking at a slower pace that his usual. He didn't consider himself to have any balance issues or other sensory impairments. Sit down and cuppa in the house was recorded, as was our walk to [famous landmark]. I decided not to record our conversation over lunch in the cafe because I felt like it was intrusive and we had already spoken on theme so much, it was nice to have a wider chat. Story about his diagnosis: his doctor burst into tears and he comforted her. I find that strange and unprofessional. He didn't want to talk about his past career in emergency services planning- he didn't want to be someone who only talked about "when I was in the war" but I think his career has relevance to how he copes with his dementia. He told me he went missing once and we decided to talk about it as we were walking. Bad wind so quality of the audio isn't great (I didn't have a lapel mic with wind muff). Review my audio reflection for a detailed recount of it.



John was out for a cycle along the canal, got a puncture, didn't have a puncture kit, didn't accept offer of help because he was angry at himself. This is a big regret but it genuinely didn't cross his mind that his wife would be worried. Something about enjoying not to have his mobile phone on him because he was on-call his whole working life. We discussed technology. He said he was open to tracking technology "probably the next time you see me, I'll have one of those tracking things around my neck". He would rather something big and obvious so he wouldn't forget it. Tracking tech- if it gives him more freedom and reassures his wife then he's open to it. Situation with car- "I didn't see that car for a second because it didn't have it's lights on and it blended into the road". As I code interview 1, I wonder if staying active is something I should probe more next time? His background as a trainer meant he liked to give feedback, gave me lots of praise and said he opened up more to me that he usually would. I couldn't tell that had dementia at all! Is that what he wanted? Really positive and enjoyable experience for me. I feel like I spent the day with a friend. John uses humour a lot. I think that is both a coping mechanism and just who he is.

John Familiarisation and Initial Coding Notes:

John sounds like he is stuttering and stammering but I'm not sure if this is just how he talks or if he is working hard to hold a conversation or on the verge of tears (latter is very unlikely)

Newfound social life

Importance of routine

Gamification of routine i.e. making brekkie

Parking the car- importance of having a procedure, learning from mistakes,

Getting lost whilst driving- don't panic, pull over and have a think

Search file for good quote "and if you don't know where you are, how do you know how to get anywhere else?"

Doesn't drive while raining at night, drives automatic car- strategies

Lost train of thought at times

Talks about wife adoringly "bless her little cotton socks"

Too much tech can be dangerous- considering other on the road

I should have probed about blue badge

Self-doubt about locking the car

I feel like I'm an object but life is happening all around me

So he does acknowledge putting up a front…

“More to me than dementia”

Takes on a role of responsibility and likes to help facilitative events and make sure people are doing okay- altruism

Appreciation of others

Praising dementia cafe

Memory loss, difficulty with money, paying the bill-initial signs of dementia

Relief in diagnosis

He does the grocery shopping while Claire works- sense of purpose

Money in bundles, in specific pockets, pay using notes- strategy

Whiteboard for weekly spread- strategy

Doing jobs for daughter- sense of purpose but nervous about it

He golfs but does it more for the social aspect

Controls his own diary- important to him- agency?

Driving

Independence- importance of senior citizens card to get on the bus

Importance to him to get out

Would have gone for a longer walk if I wasn’t there, will probably go again later-

He was waking slowly for me

Loves walking - "It just puts the whole world straight"

Observant of his environment

Strategies- stick with the routes he knows but mixes it up- control

Travelled all over Scotland with his work

Positivity- “suddenly the world's a nicer place”

Appreciation of scenery/what is on your doorstep

"We're going straight across the road"- taking charge, in control

"I like to keep my senses about me"

He doesn’t like distractions such as bikes

Not as agile- sensory impairment?

Considerate of my safety- walks on the side of the water

Engaging with environment- because we're walking on a path along the river, John keeps drawing our attention to the wildlife and scenery

Driving and previous work experience

Happy to ask for help

Everyone is different

Best decision he has ever made- going to a group- social support and engaged with the community

Tries to stay positive but "people only have so much resilience"

Purpose and citizenship brain dump:

Why is this concept of leaving the house so important to people? Is it related to sense of purpose? Being active participants in society

Should I look into disability studies?

There's an interesting conflict emerging between people with dementia wanting to be seen as "still human" and a person but you can't ignore the wider social context this sits in. PCC may work in terms of research in medical practice but when I'm exploring people's experiences, I don't think that fits. What is the wider theoretical context that all of the missing, lost, navigation etc nodes fit in??

I agreed that citizenship is something active that people engage with and my participants definitely do that but I also have to acknowledge that my participants were either self-selected through seeing my flyers or found at Alzheimer Scotland support groups so just by attending these groups they are already 'active citizens'

Quality of life, well-being! Now that's a theme that relates to some of my codes. Are they sub-themes of human rights?

Resilience and adaptability is another big one

Stigma is sadly still present

I'm having a real block when it comes to mind mapping Rob and Nic. I don't know why. I think it's because I'm struggling with concerns about Rob- not his capacity to consent but how I capture the richness of our interactions that go beyond the spoken word

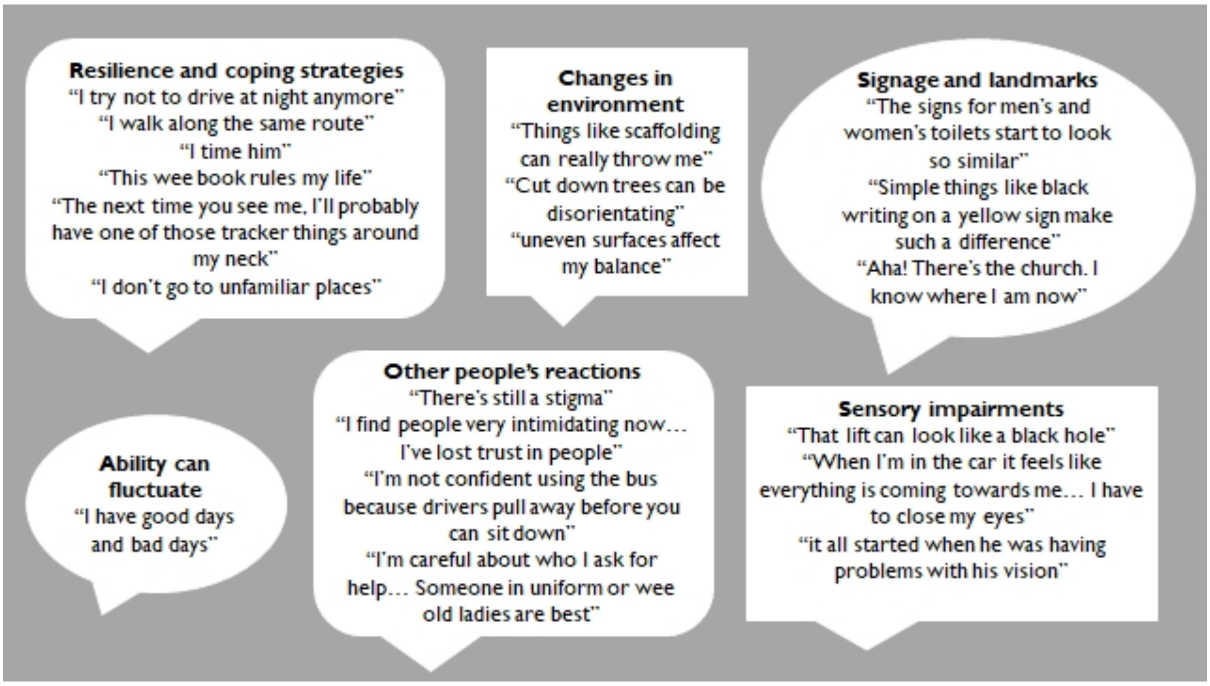
Time for temporality?

I never thought I would write these words but I'm feeling in quite a philosophical/curious mood today. I want to spend some time exploring concepts of time, 'active ageing' and how they interlink. I watched a really good YouTube video that used the example of the film Dunkirk to discuss the phenomenology of time. I haven't explored anthropological perspectives on dementia. Perhaps I should look into this? Does temporality fit in to my research? If so, how? It's definitely an important aspect of the experience of dementia but is it an important part of 'going out'? I don't think I really discussed it with people. But time definitely has a role to play- losing track of time while out, failing to meet someone at a certain time, negotiating transport timetables. Time could play into the initial theme

I'm noticing of 'everyone is different' in terms of rate of 'decline'. Note to self: explore concepts of active ageing and ageing-in-place.

Appendix L - Data Analysis Excerpts

Mid-data generation potential theme ideas:



Resilience and coping strategies
"I try not to drive at night anymore"
"I walk along the same route"
"I time him"
"This wee book rules my life"
"The next time you see me, I'll probably have one of those tracker things around my neck"
"I don't go to unfamiliar places"

Changes in environment
"Things like scaffolding can really throw me"
"Cut down trees can be disorientating"
"uneven surfaces affect my balance"

Signage and landmarks
"The signs for men's and women's toilets start to look so similar"
"Simple things like black writing on a yellow sign make such a difference"
"Aha! There's the church. I know where I am now"

Ability can fluctuate
"I have good days and bad days"

Other people's reactions
"There's still a stigma"
"I find people very intimidating now… I've lost trust in people"
"I'm not confident using the bus because drivers pull away before you can sit down"
"I'm careful about who I ask for help… Someone in uniform or wee old ladies are best"

Sensory impairments
"That lift can look like a black hole"
"When I'm in the car it feels like everything is coming towards me… I have to close my eyes"
"it all started when he was having problems with his vision"

Post data generation theme brainstorming:

I think some of the key themes are:

1. How people with dementia engage with risk- balancing right to freedom vs safety, independence
2. Interacting with others
3. Relationship with carer and asking for help
4. Active citizenship- Importance of social engagement- what people with dementia get out of it but also what they give back to society, something about give and take here which links to citizenship?
5. Resilience- how people cope and come up with strategies
6. Embracing (?) vulnerability- asking for help
7. Missing/lost
8. Emotions
9. How people with dementia maintain "self" through 'going out'
10. Control
11. Out and about

12. Attitude/Outlook of pwd- Confidence is in here but it relates to control, experiencing self-doubt is in here but also related to managing self
13. Physical environment

When I grouped together all of the nodes in NVivo, I came up with this structure:

The themes could be separated under the following headings:

1) Physical environment

2) Self/ individual/ person

3) Others

This separation of themes immediately makes me think of the socio-ecological model. But am I coming from a health promotion angle? I can' deny my motivation to support and encourage the independence of people with dementia

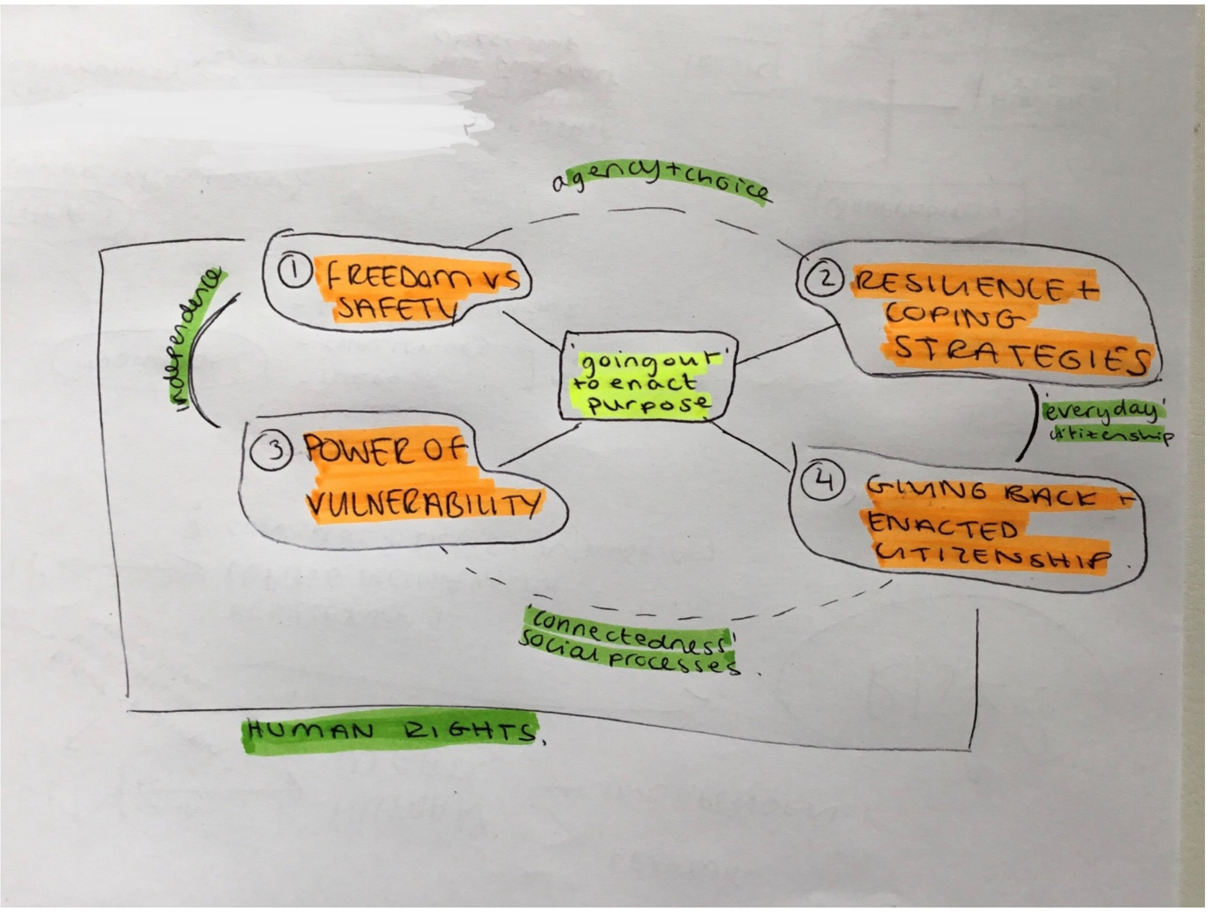
But there were some cross-cutting themes that didn't fit into these categories:

1) Control and decision-making
2) Risk, Independence, freedom and human rights
3) Vulnerability- Have I just put this one down because I like it? Is it really in the data?
4) Citizenship

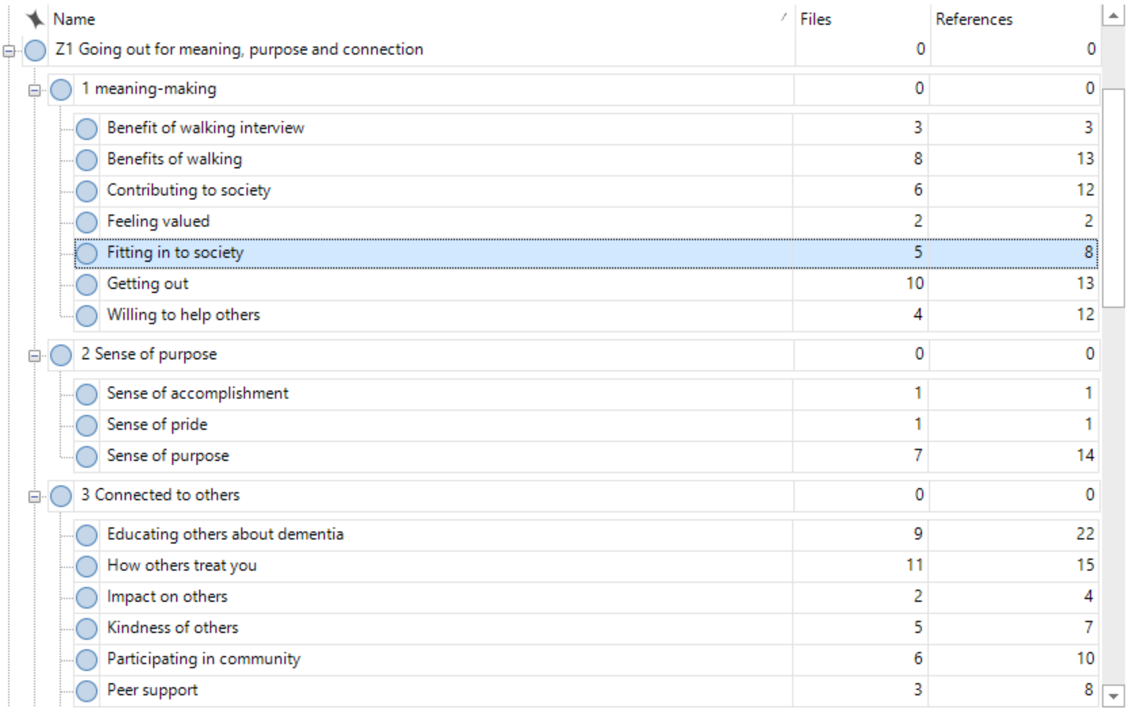
Arguably, resilience and coping mechanisms is also a cross-cutting theme... Does this tie into agency? Or is control and decision-making more about agency?

I’m making progress but this doesn’t feel like the end product…

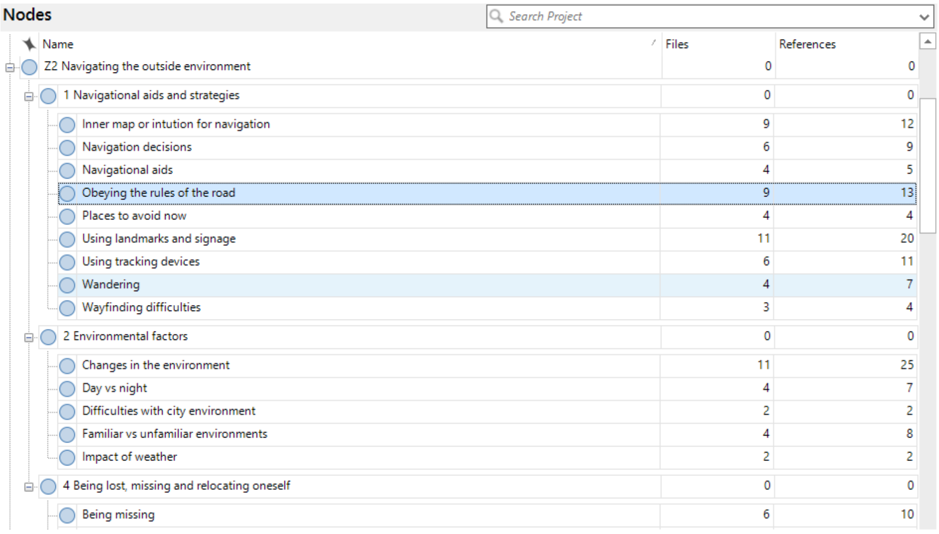
Getting closer to the final themes (but not capturing embodied and emplaced experiences):



NVivo Screenshots- final restructuring of themes before writing up:



Name	Files	References
Z1 Going out for meaning, purpose and connection	0	0
1 meaning-making	0	0
Benefit of walking interview	3	3
Benefits of walking	8	13
Contributing to society	6	12
Feeling valued	2	2
Fitting in to society	5	8
Getting out	10	13
Willing to help others	4	12
2 Sense of purpose	0	0
Sense of accomplishment	1	1
Sense of pride	1	1
Sense of purpose	7	14
3 Connected to others	0	0
Educating others about dementia	9	22
How others treat you	11	15
Impact on others	2	4
Kindness of others	5	7
Participating in community	6	10
Peer support	3	8



Name	Files	References
Z2 Navigating the outside environment	0	0
1 Navigational aids and strategies	0	0
Inner map or intution for navigation	9	12
Navigation decisions	6	9
Navigational aids	4	5
Obeying the rules of the road	9	13
Places to avoid now	4	4
Using landmarks and signage	11	20
Using tracking devices	6	11
Wandering	4	7
Wayfinding difficulties	3	4
2 Environmental factors	0	0
Changes in the environment	11	25
Day vs night	4	7
Difficulties with city environment	2	2
Familiar vs unfamiliar environments	4	8
Impact of weather	2	2
4 Being lost, missing and relocating oneself	0	0
Being missing	6	10