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# **A SUITCASE OF MEMORIES: A SENSORY ETHNOGRAPHY OF TOURISM AND DEMENTIA WITH OLDER PEOPLE**

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# ABSTRACT

The growth in the number of older people worldwide is dramatic and associated with this is an increase in the number of people in the UK with a diagnosis of dementia. It is estimated that by 2050, two million people in the UK will have a diagnosis of dementia (Alzheimer's Society, 2017). The implications of this are huge in relation to health, wellbeing, social policy and the individuals affected. Dementia can be devastating and is associated with multiple losses for the affected person and their relationships. In addition to the loss of mental faculties, the loss of an individual's social role and the threat to the sense of self impact on their relationships, overall lifestyle and their ability to contribute to society. People living with dementia are a marginalised group whose voices have often been ignored. However, since the 1990s, there has been a shift towards person-centred research, which involves listening to and involving people living with the condition. There has also been increased awareness of the impact of the dementia on those who not only have to provide care, but also cope with the emotional turmoil of the changing relationship with their partners.

Whilst quality of life research has examined the impact of reminiscence on the person living with dementia, there has been no study exploring the meaning and significance of tourism reminiscence for both the person living with the condition and their partner. This is concerning, as shared quality time has the potential to strengthen the relationship and understanding between partners. Evidence suggests that the better the relationship, the less likely it is that the person who has dementia and their partner are to experience depression. This influences the health and social needs of both, which may ultimately affect whether the person living with dementia is admitted to residential care or remains cared for at home. This research 'listens' to the stories of people living with moderate dementia and their partners to gain insight into the role that tourism and tourism memories can play in enhancing their lives and relationships.

The research was conducted in two phases, and each phase adopted process consent (Dewing, 2007) to ensure that full ethical consideration was given to the participants' changes in mental capacity. During phase one, conversations using holiday photographs as prompts were held with five couples. The themes emerging from the conversations with the people living with dementia reflected on the past and the themes *Memories as Embodied Experiences; Nostalgia and Holidays in Time and Place* all focussed on the positive aspects of recalling holidays. In contrast, the conversations with their partners focussed on the present day and themes of *Loss and Changing Roles and Relationships* as well as the need for *Dementia Friendly Holidays*. The disparity of the results between the participants who had dementia and their partners and the challenges experienced in light of difficulties with communication shaped the second phase: *A Suitcase of Memories*. This is a holiday specific multisensory reminiscence focussing on one couple's experience of recalling their shared holiday memories, culminating in the creation of a digital story. Such use of sensory ethnography has not been used in tourism before and provided rich insights into holidays as life. These are examined as ethnographic narratives that exemplify the experiences of the co-researchers alongside the identification of the themes of *Holidays as Life; Freedom; View seen, viewpoint heard* and *Strengthened self-identity with younger self*.

This study is the first to privilege the voice of those who have dementia and their partners in tourism research. It has provided indepth ethical and methodological explanations and recommendations for undertaking research with those affected by the condition and their partners in light of the challenges of researching with people who have diminished mental capacity, language skills and cognitive function. This research is also the first to use sensory ethnography as a research methodology in tourism scholarship and also recommends its use as a therapeutic tool to stimulate shared memories for couples affected by dementia. Finally, the study has developed a set of recommendations for service providers supporting people living with moderate dementia and their partners and for the wider tourism industry.

# DEDICATION

To Jonathan, Ben, Oliver & Udder!!

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# **CHAPTER 1**

## **INTRODUCTION**

- 1.1. Introduction
- 1.2. Study background
- 1.3. Reflexivity and ethics
- 1.4. Dementia and cognitive function
- 1.5. Study aim and objectives
- 1.6. Thesis structure

# CHAPTER 1: INTRODUCTION

*The past is a foreign country; they do things differently there.*

*L.P. Hartley*

## 1.1. Introduction

The purpose of this introductory chapter is to provide the background to the research and to present the study's aim and objectives. In doing so, I will comment on my own positionality as a researcher in order to foreground my interest in dementia and tourism and briefly discuss the central role of ethics in the project. The chapter will address the rationale for and the scope of the study; outline its key contributions to tourism enquiry; and conclude with an overview of the thesis and a summary of each chapter.

## 1.2. Study background

The dramatic growth in the number of older people worldwide has been well documented (Kalache, Barreto & Keller, 2005; Phillipson, 2006; Peace et al., 2008; Christensen et al., 2009; Spijker & MacInnes, 2013). Since dementia is a disease that predominantly affects older people (although it can also affect younger people), this ageing global population coincides with a rising incidence of the disease (Wimo et al., 2003). The Alzheimer's Society (2017) estimates that by 2050, two million people in the UK will have a diagnosis of dementia. Dementia is defined and diagnosed using the DSM-V classification, although the term *dementia* has recently been amended to *major neurocognitive disorder* since starting this study (DSM-V: American Psychiatric Association, 2013). Whilst this classification has been updated, this study draws more specifically from the previous classification since it describes the intellectual cognitive deficiencies more explicitly. These include impairment of memory, language, and motor skills; difficulty in recognising familiar people and objects; and impairment of executive function, i.e. the ability to plan, organise, reason and think abstractly (DSM-IV: American Psychiatric Association, 2000).

Dementia is a devastating disease associated with multiple losses for the affected individuals and their families, and especially for close relatives such as partners (Robinson, Clare & Vans, 2005; Doka, 2010; Lomax, 2011; Førsund et al., 2015). This disease involves the loss of mental faculties, social roles and sense of self, which ultimately impacts on an individual's overall lifestyle and their ability to contribute to society, as well as having a great impact on relationships. There are different types of dementia, including vascular dementia, Parkinson's disease dementia, frontotemporal dementia and the most commonly occurring, Alzheimer's disease (Ebly et al., 1994). For the purposes of this research, I will use the overarching term 'dementia' to cover all forms of this neurocognitive disorder. There is much research on the scientific basis of dementia and considerable debate over issues of diagnosis (Woods, 2005; Le Couteur et al., 2013). These issues are all beyond the scope of this research, which is concerned with the subjective ontological nature of the disease. Thus, the concept of personhood and relationships within the context of socio-cultural study (Kitwood, 1990, 1997a, 1997b; Kitwood & Bredin, 1992; Downs, 1997; Hughes, 2014) and in this particular case, tourism are the main focus.

By adopting an interpretive person-centred approach, I have examined the critical gerontology and personhood literature and the transformative nature of research that crosses over into other fields such as tourism (Ateljevic, Morgan & Pritchard, 2007). My research is transformative in that it attempts to focus on the participant as a co-researcher instead of a research subject and challenges me as a researcher to transform how one responds to and views people living with dementia. This paradigmatic shift in research mirrors changes in service provision where people are being asked to participate in decision-making around their health and social care needs. I will explore the challenges of being truly transformative when listening to the voices and observing the experiences of people living with dementia, since their words may be difficult to interpret at times and meanings may be lost. In doing so, my aim is to overcome such difficulties with the use of innovative research methods encompassed in the overall methodology of sensory ethnography (Pink, 2015), which will be discussed in Chapter Seven.

This study explicitly seeks to 'listen' to the stories and observe the lives of people living with dementia and their partners to gain insight into the significance of tourism in their lives both before and after their diagnosis. Dementia studies have largely ignored tourism and holidays, predominantly focussing on health and social care issues. However, recently tourism scholarship has recognised the need to explore the issues surrounding dementia and holidays in terms of creating dementia-friendly destinations (Page, Innes & Cutler, 2015; Blanas, Kilindri & Chrysikou, 2016). This research, therefore, contributes to the emerging scholarship that recognises the need to explore dementia within a wider social context and the consequences of a diagnosis of dementia beyond health issues (Harman and Clare, 2006; Van der Ploeg et al., 2013; Genoe & Dupuis, 2014). Thereby, focussing specifically on the potential of reminiscing about holiday memories for people living with dementia and their partners.

Traditionally, people who have dementia were not included in research and their values, beliefs and attitudes were ignored, either through total exclusion or by the use of proxies in decision-making and consent (Read & Maslin-Prothero, 2011). A large part of my study will thus focus on ethics and participant consent in both phases one and two (Dewing, 2002, 2007, 2008). In addition to this, leisure and tourism scholarship has paid very little attention to issues of dementia and is only now exploring humanistic aspects of tourism with older people (Sedgley, 2007; Sedgley, Pritchard & Morgan; 2011, Morgan, Pritchard, & Sedgley; 2015).

In establishing the need for research exploring the meanings of tourism with people living with dementia and their partners, I draw on a range of literature in tourism, dementia studies, social policy, medicine, psychology, gerontology, human geography and anthropology. In doing so, I highlight the parallels between the tourism needs of people who have dementia and other vulnerable groups, such as people who have a learning disability, autistic spectrum disorder and those experiencing mental ill-health. Indeed, critical tourism studies and critical gerontology share much in common (Morgan et al., 2015) particularly the lived experience of dementia embraces person-centred approaches. This is also a key tenet of the unfolding hopeful tourism perspective, which, as described by Pritchard, Morgan and Ateljevic (2011: 942) is strongly committed to the promotion of "human dignity, human rights, and justice in tourism policy and practice". Both critical gerontology and critical or hopeful tourism studies

are thus transformative, emancipatory approaches, which seek to work with under-empowered groups. The fieldwork undertaken for my thesis very much seeks to 'listen' to the voices of a such a marginalised group.

The aim of this research is to listen to the voices and observe the experiences of a marginalised group of people who have until recently been ignored. Much dementia scholarship within the fields of medicine, psychology, sociology and nursing has focussed on functionality and the negative aspects associated with it. My aim is to focus on the sensory, emotionality and embodied aspects in relation to positive life experiences such as tourism and people's shared experiences with partners to create a therapeutic intervention for them to potentially use as couples.

### **1.3. Reflexivity and ethics**

This research project is framed by a constructionist and critical perspective which is an approach strongly entwined with researcher reflexivity. Hence, my reflexive stance as a researcher will become apparent throughout the thesis. In many ways, I regard myself not as a detached scientist but as one of Pritchard, Morgan and Ateljevic's (2011) transformative advocates, engaged in a study, which is values-led. Here, I outline my role as a positioned researcher in the study, firstly as context and secondly in order to illustrate that an individual's background and experiences influence her ways of seeing the social world and her approaches to studying it. This is further explored in an autoethnography in this chapter that recalls my own holiday memories, which I undertook prior to phase two. Bringing my own set of values, beliefs and meanings to the study. The internal gaze (Foucault, 1973) requires an exploration of one's own philosophy and ontological beliefs. My reflexive account also includes my experience working with people who have dementia as a nurse and a researcher, which informs my epistemic and ontological stance. Therefore, with a view to positioning myself within the research, the following account aims to give some insight into my experiences that may have influenced the study. It is therefore written in the first person.

My personal and professional experience of dementia predated my knowledge of academic discourses. Aged 17, I left school to work at the Occupational Therapy department at a mental



health hospital on a Youth Training Scheme (YTS), where I was appalled at the way people with mental health diagnoses were spoken to and treated, particularly the lack of dignity and respect experienced by patients who had dementia. Whilst speaking with my YTS supervisor on the scheme, I reported a number of instances which, in retrospect, constituted undignified care, where people were objectified and their personhood totally denigrated. This was my first experience of how badly people who were marginalised could be treated by the people who were supposed to care for them. I am unsure of what happened next other than my supervisor spoke to the staff in the department about my experience and I was asked to leave. A new placement was arranged for me. This wasn't the last time that I *whistle-blew* in my role as a carer or nurse when observing depersonalised care. At the same time, however, I am fortunate to say that I have also worked with some wonderfully caring people with a sense of empathy and compassion who inspired me in my diverse nursing career.

At a later date, whilst training to be a nurse, I worked in a variety of hospital settings, including coronary care and intensive care. In doing so, I always felt drawn to older people whose needs were complex and multiple but often whose stoicism was apparent and life stories, intriguing. I particularly spent much time in the ward setting with older patients whose speech had been affected, by a debilitating stroke, Parkinson's disease or dementia.

My leaning towards people who have communication and language difficulties may also be due to family experience: as a young child, I would sit with my disabled paternal grandfather, who had fought at Gallipoli in the First World War. He had suffered two strokes and was unable to speak and convey his needs; however, as a former amateur bass baritone, he was still able to sing and express himself to me through music. This deep-seated fascination and empathy for people with expressive dysphasia (i.e. the inability to express themselves) and, the way in which the use of art and music, can assist in understanding their meaning, requests, values and beliefs has remained with me throughout my working life. Observing such suffering in my role as a granddaughter and student nurse and then later as a staff and research nurse led me to develop deep empathy for others, particularly those who had difficulty communicating their needs. My experience showed me how, all too often, people with language difficulties are ignored, since it takes much time and effort to understand their

needs and frustrations and how they often experience depression as a result (Kauhanen et al., 2000).

Such an awareness came to a head during my final year studying for a nursing degree when I worked in the Mental Health Unit at Raja Isteri Pengiran Anak Saleha Hospital (R.I.P.A.S), Brunei Darussalam. Here, the care was custodial and I became profoundly aware of the need to empower older people and people with mental health problems to ensure that their rights were recognised. Hence, what is now recognised as personhood (Kitwood, 1990) and person-centred care has always been deeply embedded in my personal philosophy and practice.

As a nurse who has worked with people who have dementia for over 20 years, from being a care assistant in a nursing home (during my nurse training), to caring for people whilst in hospital following stroke and later as a memory team research nurse and nursing home manager, I have always been drawn to *being with* them and giving them time to try and express themselves through my intuition, and so to connect with them. With regard to undertaking research with people who have moderate dementia, my roles in the memory teams of Bath and Cardiff involved working on the pharmaceutical trials of a number of medications for Alzheimer's disease, vascular dementia and Parkinson's disease dementia. This included helping with the consent process with individuals and their families, undertaking data collection of physical observations such as blood pressure, heart rate and taking blood, administering quantitative scales such as depression scales, carer burden and quality of life scales and undertaking six monthly cognitive assessments. Whilst there is no doubt that such pharmaceutical trials have led to the licensing of some drugs that successfully slow down the deterioration of the condition (i.e. donepezil, galantamine, rivastigmine), my concern at the time was always with the participants' emotional welfare. I spent much time with people who had moderate dementia, listening to them trying to express themselves whilst experiencing dehumanising procedures, and took it upon myself to try and create a more positive experience by being empathic and understanding.

Whilst the participants consented once for the studies, they would return every six months for the same procedures to ascertain changes that might be attributed to drug effects. Whilst the protocol involved a *one-off* consent, as an individual, I always reminded them what they were involved in and why they were going through such procedures, as I felt that they could easily not understand what was being done to them or remember what they had consented to six months previously. Again, my observations during this time contributed to my realisation that people who have moderate dementia could easily be ignored and abused during their involvement in research. Whilst staff were well-meaning in their approach, I always felt the need to connect with the person in more depth and ensure that they understood what they were involved in at that moment in time. I would do everything within my ability to make them feel safe and well throughout.

I identified the flaws in undertaking questionnaires with them, but realised that these were the only appropriate methods at the time for such types of studies. Since then more person- and relationship-centred studies have emerged, where knowledge production is based on the lived experience of individuals and not in attempting to produce generalisable results with large numbers of people.

Resonating with my own experience, Kitwood (1990) identified the concept of *doublethink* amongst health care professionals' in which the taught standard paradigm of dementia care contradicted with their intuitive holistic views gained by experience. It is therefore, not surprising that I experienced considerable conflict between the tenets of the scientific positivistic approach and the dominance of the medical model within my nursing education and my experiential learning. Indeed, my professional engagements led me to question approaches that attempted to reduce people to the sum of their parts. I saw patients in the medical system as complex beings who gave individual meaning to experience and whose voices need to be heard; thus, my study places value on how people interpret, give meaning to and construct reality (Saunders, Lewis and Thornhill, 2007).

In addition, my work as a specialist dementia research nurse in the memory teams of Bath and Cardiff, made me aware of the multiple losses in both the life of the person who had

dementia and their partner, just as is highlighted in the literature (Sabat & Harre, 1992; Bakker, 2003; Clare, 2003; Steeman et al., 2011; Førsund et al., 2015), and in particular, their difficulties in participating in leisure activities and holidays were often communicated to me. The relationship between a person who has dementia and their partner changes over time, as the former requires formal care in many aspects of life. This provision of care is often performed by the partner, whose role is transformed into that of caregiver, having major implications for their relationship (Milne & Hatzidimitriadou, 2002; Basting, 2003; Hellström, 2014).

Indeed, the role of respite breaks has been well documented (Brodaty & Hadzi-Pavlovic, 1990; Pruchno et al., 1990; Donath, Winkler & Grassel, 2009) which often involves separations between the partner and their caregiver who experiences feelings of guilt, as the person who has dementia is often admitted into institutional care for a period of time (Adler, 1992). The opportunity for couples to have a shared holiday with specialist support might be a more appropriate approach to overcome these difficulties associated with separation. The concept of respite is a recent one and aims to offer short breaks and support for carers and people with complex needs by connecting with local organisations such as hotels, clubs and guest houses (Shared Care Scotland, 2017). However, there will always be those whose dementia may make holidaying too difficult despite dementia-friendly approaches, and here the concept of a virtual holiday might be a more appropriate way of holidaying at home.

Against this backdrop, it is unfortunate that there has been very little research exploring the mutual tourism and leisure needs of people who have dementia and their partners. This is concerning, as shared holiday time and activities hold tremendous benefits, as they have the potential to strengthen the relationship and understanding between the person with dementia and their partner. Indeed, research by Ball et al. (2010) suggests that the better the relationship or *mutuality* between couples, the less likely it is that the person affected by dementia will become depressed and the more likely it is that the burdens on the caregiver will be reduced. Shared and separate leisure activities bring different and complementary benefits to both partners and impact on enhancing wellbeing throughout the early stages of the illness (Mapes, 2010, 2016; Dupuis et al., 2012). Hence, my research aims to expand on

this by exploring the meaning and significance of recalling tourism memories for people living with dementia and their partners.

### **1.3.1. Autoethnography**

The reflexive statement above focuses on my nursing background and interest in older people living with dementia and communication difficulties, here, I will introduce myself in a more multi-sensorial way and explore the meaning and significance of recalling my own holidays. My starting point, once again, links to older people's stories: as a child, I would listen to my maternal grandfather's anecdotes about Egypt, where he was based in the RAF during the war. I would sit and imagine all the sights, sounds and smells that he would describe. This made such an impression on me that at one time I was interested in following a career as an archaeologist, and I became fascinated with the story of Howard Carter and the discovery of Tutankhamun's tomb. Whilst I did not follow this path, I continue to have an interest in the culture of the Middle East.

Since then, my independent travels as an adult have taken me to some culturally different places. Indeed, in the writing up of this autoethnography, I found myself reminiscing and being emplaced back in my travels, particularly when using my senses as reference points for the memories. I felt that I was there, in the place, in my mind more. I realise at this stage that one sense alone cannot be explored individually, but an overall melee of sight, sound, touch, smell and taste brings together the feeling of emplacement within those memories. As Merleau-Ponty (1962, cited in Kontos & Martin, 2013) highlighted, we do not experience in one sense alone or at any one time, but experience the overall sensation. My first flight was to Tel Aviv in 1986. I was 18 and travelled with a fellow student nurse to visit my sister, who was working in Eilat. These first memories of Israel involved a melee of the senses such as the smells of different foods – falafels, hummous and olives – mixed with the heat and the sights and sounds of soldiers and tanks in the streets, people shouting and not queuing for the buses. It was exciting, chaotic and frightening. It was so different to anything I had experienced before, but I soon adapted to the place. I travelled to and camped in the Sinai Desert with some friends I had met with my sister. We stayed at Sharm el Sheik at a time when there was no established tourist resort, just a "Snak Bar" in the desert. We met other student nurses from Alexandria, Egypt, swapped stories about our training and belly-danced

around campfires, where the smells and sounds of other languages and music were pervasive. I remember witnessing a sandstorm across the water which lit up the sky and gave the impression of warfare in the distance; the light across the water was red and felt menacing. This was very different from anywhere I had been before and so exciting, my senses were on fire!

Later that year, I flew to Malta with my parents, and once again fell in love with the feeling of being elsewhere. The new sights, smells and sounds once again led me to travel to more destinations in the Mediterranean, especially to places I had heard of from my grandfather. To actually see, hear, touch, smell and taste the places that I had heard him talk about in his stories was enthralling. Later on, in 1994, I travelled to Singapore and Malaysia, and, as mentioned previously, worked in the mental health unit in Brunei Darussalam. The most powerful sensory memory was, as anyone who has travelled to this area will know, the Durian; a pungent fruit that once smelt is never forgotten. It is a delicacy but has the most repellent smell I have ever experienced. The embodied experience of these travels included seeing and feeling the water particles in the air when the humidity was so high, that it led me to feeling hot and constantly perspiring, an opening of the olfactory cells (not always welcome!); the sights and colours of the mud huts contrasted with the imperial buildings left over from the British empire. The sounds of the large insects and bird and animal life as I took part in the local Hash House runs through the rainforests invoked a sense of being alive as I ran through the rainforest soaking up the sensations of the environment.

As a lover of world music, I brought back musical instruments from my holidays, and I have even written some poetry about a mandolin-playing camel called Mustapha, influenced by this time. Today, recalling my holidays through creative writing, music, cooking and the burning of Frankincense has given me the opportunity to share my holiday memories with my children and realise that this can be more powerful than looking solely at photographs. Recalling my holiday memories reminds me of the freedom of exploring: a time not shaped by illness, or by the roles of being a wife, mother or daughter, or conforming to any other role in society. This has been extremely emotive, since I have had very few holidays in the past fifteen years due to illness and financial constraints, so, when recalling my adventures, I can return to that feeling of being alive and free. Indeed, it is only in writing this autoethnography

that I realise how much my research has been shaped and has evolved from these experiences and creative passions in life. However, acknowledging this seems strange, as in the past, being a researcher did not allow for reflexivity for fear of being too subjective. Certainly, when working as a research nurse, the focus was always on attending to the person being cared for and researched, and not bringing in aspects of oneself. However, I now realise that this autoethnographic process is essential in understanding one's view of the world and one's values.

#### **1.4. Dementia and cognitive function**

As stated earlier within this thesis, I will concentrate on the more common characteristics of the condition rather than examine the individual changes occurring in specific types of dementia. From a cognitive perspective, the person who has dementia may experience a deterioration in working memory (short term memory) early on in the illness (Budson & Solomon, 2015). This can cause repetitiveness and the inability to remember information from the past twelve seconds; however, at some time, they may be able to remember much about their own life and records of events in the past. Such autobiographical and episodic memories can be retained for much longer in the course of the disease. However, later in the condition, autobiographical memory deteriorates, and memories of one's own past diminish.

Orientation to place and time can also be affected, making the person fearful of going to unfamiliar places or possibly causing them to get lost, as they may not be able to recognise places. Changes in sleep patterns, alongside other cognitive changes, may affect their perception of time. In addition to this, executive functioning is affected, as the functioning of the frontal lobe of the brain, which is responsible for organising, planning, sequencing, reasoning and making judgements, deteriorates (Hickey & Bourgeois, 2011). When the frontal lobe is affected, the person may display inappropriate behaviours and not recognise social cues, thus creating difficulties in social encounters. Dementia can also affect visuospatial aspects of brain function: the person's visual perception may be affected, which may result in not recognising objects or faces or judging distances (Mohr et al., 1990). For example, handing a cup of tea to someone with visuospatial difficulties may result in them dropping the cup, as they may be unable to judge where the cup is in relation to their hand.

Communication is often affected in dementia. Individuals may experience expressive difficulties such as difficulty in finding words, a reduction in vocabulary, poor coherence and losing track of a conversation, as they can become easily distracted (Bourgeois, 1992). In addition to this, they may develop receptive dysphasia, in which they are unable to understand what is being said to them. As the progression of the dementia continues, communication becomes increasingly impaired, often resulting in the person withdrawing and people around them tending to speak for them: i.e. acting as a proxy (Hickey & Bourgeois, 2011). There is variability in communication abilities amongst individuals and between types of dementia. For example, vascular dementia, which is characterised by mini strokes, can lead to sudden impairment in communication skills, whereas other dementias may exhibit more gradual deterioration (American Psychiatric Association, 2000).

People living with dementia may also experience problems with praxis, being unable to carry out functions such as dressing, washing, and cooking due to problems with movement and coordination (Larner, 2014; Budson & Solomon, 2015). Cognitive impairment can also affect emotion, and motivation, causing apathy, and consequently impacting social behaviour (WHO, 2010). These cognitive changes vary from person to person and fluctuate in severity at differing times. By understanding the cognitive changes, one can attempt to understand how people's lives are affected, and through observing and listening to them, find strategies to help. Unfortunately, when looking at dementia through the lens of cognition and functionalism, the emphasis is on loss, which culminates in negative associations with the diagnosis: an example of this is the description of dementia as a living death (Woods, 1989).

However, there is much more to understand about dementia from a wider philosophical perspective that examines what it means to be human, have a sense of self, agency, identity and personhood in relation to society and relationships. Therefore, there is a greater need to study dementia from a more critical and constructionist perspective to explore the lived experience of individuals who have the disease and to inform society as a whole and the carers and professionals who care for them.



## **1.5. Study aim and objectives**

In order to address the research questions identified in Chapter One, the thesis has the following aim and objectives:

Aim:

To explore the meaning and significance of recalling tourism memories for people living with moderate dementia and their partners.

Objectives:

1. To conduct a literature review synthesising ageing, dementia and tourism with a focus on critical tourism studies and gerontology.
2. To identify the ethical challenges particularly consent processes for tourism research involving older people living with dementia.
3. To identify the significance of recalling tourism memories for older people living with dementia and their partners using reminiscence.
4. To examine the potential of sensory ethnography when exploring tourism memories with older people living with dementia and their partners.
5. To formulate strategies and therapeutic interventions for older people living with dementia and their partners to help sustain their relationships.
6. To formulate strategies and interventions for support agencies/organisations and tourism providers in order to exploit the benefits of engagement in reminiscence tourism activities.

Figure 1.1 maps the objectives of the thesis to the chapters:

**Figure 1.1. Mapping objectives to the chapters**

|  |                         |
|--|-------------------------|
| To conduct a literature review synthesising ageing, dementia and tourism with a focus on critical tourism studies and gerontology.   | Chapters Two and Three  |
| To identify the ethical challenges particularly consent processes for tourism research involving older people living with dementia.  | Chapter Four            |
| To identify the significance of recalling tourism memories for older people living with dementia and their partners using reminiscence in phase 1.   | Chapter Five and Six    |
| To examine the potential of sensory ethnography when exploring tourism memories with older people living with dementia and their partners in light of the challenges faced in going on actual holiday in phase 2 | Chapter Seven and Eight |
| To formulate strategies and therapeutic interventions for older people living with dementia and their partners to help sustain their relationships.  | Chapters Eight and Nine |
| To formulate strategies and interventions for support agencies/organisations and tourism providers in order to exploit the benefits of engagement in reminiscence tourism activities.                            | Chapter Nine            |

## **1.6. Thesis structure**

Chapter One has considered the rationale for the research and explored the significance of the study by discussing the increasing incidence of dementia and the need to examine the experiences of people with the condition from their perspective. The chapter has outlined the aim and objectives of the research as well as briefly highlighting the research approach. To contextualise the researcher's positionality a reflexive statement has described how a combination of my childhood memories, dementia nursing and research experience reinforce the need to explore the significance of recalling holiday memories with people living with dementia and their partners.

Following this introductory chapter, Chapter Two presents and evaluates the major theoretical approaches to dementia. In particular, it discusses the functional basis of the dominant medical model and its impact on ageing and dementia studies and examines how it has recently been challenged by critical gerontology in line with critical theory. It explores the newer approaches to dementia, introducing the concepts of personhood and the embodied self and identity, and briefly examines the recent emergence of dementia-friendly communities. The concluding section outlines the need to explore dementia within the wider context of leisure, the environment, sport and, tourism. Chapter Three identifies the links between tourism, leisure and memorable embodied experiences including dementia.

Given the importance of the ethics of involving people who have dementia in research the thesis devotes a full chapter to ethics. Chapter Four therefore refers to the centrality of ethics and describes the importance of including people who experience cognitive dysfunction into research. The traditional biomedical model is critiqued in light of the need to include vulnerable people with changing mental capacity into studies and recommends adopting ongoing consenting methods in all studies. These are important considerations when designing the research and planning the methodology, and that is why this chapter precedes discussion of the study's theoretical positioning and methodology.

Following chapter four, there are two separate chapters for phase one and phase two, each having its own subsequent analysis and results chapters, in order to give some clarity to the study and reflect its complexity. Thus, the layout of the remaining thesis proceeds as follows. Chapter Five, entitled 'Phase One Epistemology and Methodology', is concerned with the study approach and research paradigm in phase one. It defends the pluralist ontological perspective embraced in this research and reflects on the overarching philosophical premise that human subjects are socially and culturally constituted. It articulates the significance of critical gerontology and the concept of personhood in the study. The chapter describes how the research project is informed by my commitment to promoting the social inclusion and empowerment of people living with dementia.

Chapter Six outlines the analytical approach adopted in phase one and presents the results from the conversations with the people who have dementia and their partners. The chapter concludes by identifying a need to develop a more innovative multisensory approach to researching with people whose cognition is affected in order to represent their experiences effectively and ethically.

Chapters Seven and Eight outline, present and defend the second phase and the study methodology of sensory ethnography. This includes a discussion of the principles that underlie sensory ethnography and how this approach is appropriate within the disciplines of tourism and dementia scholarship. Finally, the key findings are presented as a *suitcase of memories* and include discussions of the fieldwork.

Chapter Nine presents the discussion, including the key contributions of the research and identifies limitations. New avenues for future research in tourism and dementia are identified as are the implications of the study for the tourism sector and for people who have dementia and their partners. The chapter ends with recommendations for those working in the tourism industry and dementia care.

# **CHAPTER 2**

## **THE STUDY OF AGEING AND DEMENTIA**

- 2.1. Introduction
- 2.2. Medicalisation of ageing
- 2.3. The rise of critical gerontology
- 2.4. Medicalisation of dementia
- 2.5. Sociological, philosophical and ontological aspects of dementia
- 2.6. Summary

# **CHAPTER 2: THE STUDY OF AGEING & DEMENTIA**

## **2.1. Introduction**

This chapter explores discourses of dementia from the perspective of the medical model alongside complex multidisciplinary approaches in order to contextualise dementia. Since the incidence of dementia rises with age (Estes, Carroll & Binney, 1989), I will also examine the concept of ageing within the functional biological perspective and its link to health and the concept of medicalisation. I will then go on to examine how the medical model of ageing has contributed to stereotyping and ageism. The subsequent rise of critical gerontology will then be explored as a challenge to the ageist and reductionist viewpoints. The chapter then goes on to explore how dementia has been studied, defined and shaped, and examines how discourses of dementia have historically been influenced by the medical and cognitive models. The paradigmatic shift to personhood and relationship-centred studies is then introduced, which reflects the values of critical gerontology and its influence on the sense of self and identity.

## **2.2. Medicalisation of ageing**

The study of gerontology needs to be placed within the historical and philosophical context of the dominant discourse of medicalisation, which has viewed older people as a homogenous group, defined by their medical needs. This chapter explores the impact that such a view has had on the way society views older people living with dementia.

The discipline of medicine emerged during the Enlightenment period of the eighteenth century where scientific fact surpassed religious faith, witchcraft, caring and healing (Geyer-Kordesch, 2001). Medical doctors based the profession on developing scientific knowledge with an overall aim of curing the patient (Lane, 2001). By developing a health-related profession based on knowledge, education and self-regulation, the position of the doctor within society became an authoritative one. Such dominance led to the birth of the medical model, where all aspects of human existence became defined as medical conditions and came

under the control of doctors and institutions (Zola, 1972; Foucault, 1973; Illich, 1975; Conrad, 2007). This controlling culture subordinated patients and the very nature of healing became the domain solely of the doctor. Tribe (2007:30) observes the fact that such “ideologies are so all-encompassing and saturate our everyday lives and thoughts that it is difficult to think and act outside of their rules”. It is with this premise that the medical model continues to create power relations in society and influences how people view health and illness.

The overarching characteristics of this model are the focus on the pathological aspects of disease and illness, without taking into account factors such as environment, society, psychology and the person’s own ability to heal (Engel, 1977). Indeed, it is such dominance of disease, health and illness that led to the concept of medicalisation.

*Medicalisation describes a process by which non-medical problems become defined by and treated as medical problems, usually in the terms of illnesses and disorders*

(Conrad, 1992:209)

The concept of medicalisation developed in the 1970s through the work of Ivan Illich (1975) and Irving Zola (1972). However, its origins can be traced to the critiques of Jean Martin Charcot (1825–1893) and the emergence of psychiatric and neurological medicine in the mid-nineteenth century. The advent of the medicalisation of ageing predominantly focussed on the body and loss of function. The dominant pathological view was that the ageing body was abnormal, dysfunctional, defective and in decline (Tulle, 2008).

Western societies have historically viewed the scientific paradigm of the medical world as the gold standard in health and illness. Such an influence is mechanistic and has perpetuated the idea of a problem-solving approach to systems of the body and all aspects of health and ageing. Indeed, it was only when Illich (1975: 32) coined the term ‘*medicalisation*’, arguing that it can actually cause harm to individuals with the idea of iatrogenesis (i.e. that medical intervention can in some cases cause more harm than good), that it became a concept of study and critique. Illich (1975) postulated that iatrogenesis occurred at a clinical, social and

structural level. Clinically, he claimed that the side effects of medicines can at times be more damaging than the original illness.

Illich observed that society had become dependent on the medical model, expecting medicine to help solve all problems of the human condition, thus undermining individuals' abilities to naturally cope with processes such as menopause and ageing. As a result, a medical diagnosis could legitimise a whole range of troubles of the human condition and allow people to opt out of their roles in society due to ill health. The so called *sick role* (Parsons, 1951) creates disempowerment and inequality between the person with the illness and the doctor treating them, and contributes to learned helplessness in the vulnerable person (Seligman, 1972). In so doing, medicalisation can oppress some members of society and create social inequality within an exclusive hierarchy (Navarro, 2004). The power of the medical profession has been further perpetuated by the jargon that has mystified and encouraged exclusion, thus allowing doctors practicing medicine to hold dominance over all (Illich, 1975).

As mentioned earlier the dominance of the medical model has influenced the social construction of ageing as a medical problem or pathology, since it diagnoses and attempts to treat conditions associated with the ageing body (Estes, Carroll & Binney, 1989). The scientific positivistic paradigm underpinning medicine has been based on measuring ageing in terms of function and problem identification (Kauffman, Shim & Russ, 2004), regarding the ageing body as a broken machine (Gullette, 2004). Thankfully, such dominance is slowly eroding as the concept of resilience has emerged within gerontological study. Thus, introducing a gradual shift from a negative, functional view of ageing to a more positive, holistic perspective that promotes the concept of self-care (Allen et al., 2011; Wild, Wiles & Allen, 2013; Stephens, Breheny & Mansvelt, 2015).

Despite this, gerontology as a discipline of ageing studies is highly fragmented, drawing from medicine, sociology and psychology. Its emphasis has been rooted within a strong scientific paradigm and influenced by the medical model (Bengsten, Putney & Johnson 2005). There is no doubt that ageing can bring challenges associated with physical losses, but at the same time, life transitions such as bereavements of partners, peer group members and loss of



income can also contribute to poorer quality of life and wellbeing (Hislop & Arber, 2006; Morgan, Pritchard, & Sedgley, 2015). Thus, there is a need to also explore ageing discourses from a number of perspectives, and for those living with dementia. Here, the rise of critical gerontology and the development of personhood and citizenship has gone some way to achieving this (Kitwood, 1997a). Thus, whilst the process of medicalisation strips people of their social context, where they come to be understood in terms biomedical ideology, critical gerontology provides a more rounded consideration.

### **2.3. The rise of critical gerontology**

Critical theory arose from the Frankfurt School, which fundamentally questioned positivism and the scientific laws of obtaining ultimate truths (Habermas, 1984). Critical gerontology, developed in the 1970s and 1980s at a time of welfare and service cuts and the rise of the feminist and disability movements, challenged old-school ideologies of power relations in society (Townsend, 1981, 1986), including the view that older people were a burden on society (Phillipson & Walker, 1987). This critical approach to ageing challenged the negative assumptions and ageist stereotypes of older people that were perpetuated by the medical model (Bytheway et al., 2007). It also challenged the view that circumstances, whether political, economic or cultural, are not fixed but are created historically and can change. Thus, critical gerontology rose out of the need to benefit marginalised groups within society through emancipation and challenging issues around economics, differences in class, gender and ethnicity (Moody, 1993). Critical gerontology has thus gone beyond the traditional biomedical disease model and its associated institutional dominance (Foucault, 1973) and beyond purely interpreting peoples' worlds. Instead, all aspects of life are identified and previous held assumptions, particularly social structures are challenged.

*The critical inquiry perspective is not content to interpret the world but also seeks to change it.*

*(Gray, 2013)*

This approach has given older people a voice in exploring the complexity of their lives (Jamieson & Victor, 1997). By listening to their voices and creating partnerships, new perspectives on ageing have developed that are more optimistic and hopeful (Sedgley, 2007). This critical perspective has also impacted on the way older people, including those who have dementia are treated, for example, health service provision (Keady, Nolan & Gilliard, 1995; Cheston, Bender & Byatt, 2000). To illustrate, I facilitated a focus group at Swansea University in 2012 involving older people who had fallen outdoors; the aim was to explore their issues and needs with regard to informing policy over town planning and the design of outdoor spaces. This shift to the inclusion of the people once researched *on* to being researched *with* heralds a movement within research scholarship that is transformational in nature. Such a change listens to the voice, the meanings and interpretations given and has even extended to the development of nursing theory where some studies of ageing have shifted from a positivistic perspective to one that is more patient/person/relationship-centred (Kitwood, 1997; Nolan, Davies & Grant, 2001; Nolan et al., 2006). By moving to a person- and relationship-centred philosophy, one can open up a rich dimension of ageing research that listens to the voice of older people through qualitative research methodologies (Featherstone & Hepworth, 1993; Moody, 1993; Holstein, 1994; Nazarko, 2015; Jenkins, 2017). Such an approach of regarding theory and research *in* ageing as opposed to theory and research *of* ageing can value the theoretical underpinnings of all disciplines whilst involving the older person in all aspects of research design and methods. This critical approach to gerontology can be applied to dementia research by exploring the lived experience of the person living with the condition through creative research methods that will inform best practice and care. However, the nature of dementia provides difficulties for researchers and it is these challenges that will be identified in more depth throughout the thesis, with a view to examining innovative methodologies to overcome them.

## **2.4. Medicalisation of dementia**

Like ageing, discourses of dementia have historically been shaped by the biological medical model. Whilst the trajectory and significance of the medical model has already been discussed, it is useful to examine how it has influenced our understanding of dementia

research. At the same time, it is important to understand how the emergence of critical theory has challenged society's assumptions about dementia. Much traditional dementia research has developed from the medicalisation of ageing: a disease model that classifies dementia as an organic mental disorder where people diagnosed would be under the care of psychiatrists. This view of dementia as a degenerative disease is reflected in the World Health Organisation's (2017) definition:

*Dementia is a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.*

Within this definition, there is little mention of the impact the disease has on the individual, their relationships and their environment; instead, it focuses on a biological description. Golander and Raz (1996) recognise the impact of the biomedical model as traditionally shaping society's understanding of what dementia is and how it should be treated: for example, treating people who present with behavioural difficulties with medication before trying to understand what effect the disease is having on them (Patel and Hope, 1993). Indeed, the use of neuroleptic medication was widespread in the management of challenging behaviour for many years. The use of these drugs has been discontinued since the Committee on the Safety of Medicines (MHRA, 2012) found a threefold increase in the risk of stroke in people who were prescribed these medications. It is now known that challenging behaviour can be caused by the way the person who has dementia is treated and approached, i.e. not listened to, controlled and disempowered, ultimately leading to frustration and fear. Historically, psychiatry and other health disciplines adopted this medical approach with little or no regard for the human and psycho-sociological aspects of the condition which we consider dementia to be today. In addition to this, the use of language is a key influencer in reducing people to *victims* who are often viewed as "battling the dreaded disease" (Ballenger, 2008: 495) and perpetuating society's negative view of dementia. Also, when considering the

impact of the dementia on partners, many scientific research outcome measures are based on caregiver burden, which fails to take into consideration the potential for positive relationships (George, 2010).

## **2.5. Sociological, philosophical and ontological aspects of dementia**

Critical scholarship challenges traditional academics who consider that people who have dementia do not have opinions, views and values. This shifting paradigm is reflected in social policies in the UK that are increasingly involving older people and people with the condition and highlight the need for citizenship for all. This has been influenced by the central tenet of the disability civil rights movement (Oliver, 1996) and is of relevance to this study, where citizenship and disability (e.g. Darcy & Dickinson, 2009) argue for a whole-person approach, which acknowledges subjectivity, validates situated meanings and values biography, wellbeing and spirituality.

The term “personhood” was first coined in dementia studies by Kitwood (1990, 1993, 1997) in his seminal 1990 paper as well as writings which challenged the standard paradigm of dementia care and brought attention to the issue of personhood within the wider context of society. He also coined the term “malignant social psychology” to describe society’s overall attitude to those living with the condition. His critique included the use of traditional medical research involving people who have dementia that was based on identifying variables. He argued that the interrelatedness and complexities of the variables surrounding them made it difficult to produce reliable and valid data. Thus, he claimed the need to explore the notion of person-centredness through examining the full experiences of living with dementia. This proved a radical paradigmatic shift, which, as previously mentioned, has influenced the development of nursing theory ever since (Nolan, Davies and Grant, 2001).

Much has been written about personhood and the threat of dementia to one’s personhood, agency and sense of self and identity. Such a move away from the dominant medical and cognitive models that imply a slow eradication of the self (Kitwood, 1993, 1997; Sabat, 2002; Wilkinson, 2002; Beard, 2004; Kontos, 2004; Hughes, Louw & Sabat, 2006; Leibing & Cohen, 2006; O’Connor et al., 2007; Hughes, 2014) and existential loss (Brockmeier, 2014) have

helped in our understanding of what it means to be human. Questions have arisen about whether the person continues to have a sense of self when they have lost aspects of their past or when their ability to function cognitively, physically and within society diminishes. Thereby, if we only consider that function and cognition influence the sense of self, there is the potential to no longer view the person as whole (Gubrium, 1986a, 1986b), and subsequently, there is a risk of leaving the person behind (Baldwin & Capstick, 2007). It is vital that deeper ontological questions are raised and considered by exploring the lived experience of the person with the condition.

Brockmeier, (2010, 2014) also challenges the traditional cognitive model, in which memory is an archive that encodes, stores and retrieves information. He proposes that memory is more of a lived, emplaced, embodied experience which allows us ways to reach out to people's memories through more sensory means. In doing so, he advocates the need to explore wider philosophical and ethical debates of what it is to be human, including the role of agency, personhood, sense of self and identity in dementia. Personhood is a complex philosophical concept that spans ethical, theological, spiritual and social psychology scholarship (Tournier, 1978; Heron, 1992; Rogers, 1995; Harre, 1997). Each discipline has its own perspective on the concept, which includes a sense of personal autonomy; experience of an inner sense of self influenced by God or a spiritual being and where the person can achieve a state of development based on life experience. How we interpret personhood and the sense of self will impact on how we approach people who live with dementia. In addition to this, our Western *hypercognitive* society (Post, 2000) perpetuates the fear of losing one's memory, indicating that society continues to view function and cognition as being at the heart of what it means to be a person (Dewing, 2008). Indeed, such a view fails to explore sensory, embodied and spiritual aspects of the self; a further justification for my research. Post (2000) argues that the dementia itself can help to reveal the true sense of selfhood in a person by peeling away layers of cognition.

Hyden, Lindemann and Brockmeier (2014) also advocate a further shift in understanding the lived experience of dementia, by viewing the condition as a transformation, which needs to be explored beyond the realm of disease and loss. They discuss three key themes, the first of

which is dignity, which requires us to look more at what the person is capable of and not to focus on loss. This helps us explore ways of seeing the person find meaning and interaction within their social world (Sabat, 2014). The second theme involves identifying the need to explore the person's experience through understanding their sense of self, agency and embodiment. By understanding this, the importance of supporting the person and understanding how they view themselves and their sense of identity over time is highlighted. Finally, the person should be viewed in the context of their relationships and environment, with partners and families, who often collaborate to make up for the losses experienced, which can contribute greatly towards a sense of wellbeing (Richards et al., 2015). Thus, when considering the sense of self in terms of interrelationships with the environment, historical and cultural contexts and social interaction (Mead, 1934), the role of agency, structure, gender, class, ethnicity, place and time, function and cognition are part of personhood (Bornat, 2015; Higgs & Gilleard, 2016).

The view that it is possible to connect and communicate with a person with moderate dementia at a metaphysical level has also been posited (Hughes, 2014, 2017) and is one where my personal philosophy lies (Mullins, 2017). This may be more clearly interpreted as intuition. In order to understand personhood within dementia, there is a need to consider the embodied selfhood of the person (Kontos, 2003, 2004, 2005, 2006). This viewpoint, in keeping with social constructionism, explores the concept of self and personhood as integral to their background and considers existential, moral, personal and relational constructs. Thus, drawing from Merleau-Ponty's (1962, cited in Kontos & Martin, 2013) theory of perception and *being in the world* and Bourdieu's (1990) concept of habitus. Here, we see personhood encompassing the embodied experience of *being* in the context of place, thereby, providing a rewarding way of connecting with people who have dementia. After all, people living with the condition, are still able to express their emotions, not necessarily in words but in embodied and behavioural ways, despite their difficulties with language. Indeed, our socialisation over time, conditions us to recognise people's personalities and identities through their bodily expressions. By reading people's body language we are able to tell whether they are angry, excited, happy, disinterested and so on. As Walker (1998: 17) observed:

*in reading their bodies – their postures, gestures and expressions – we are simultaneously reading what’s “in” their minds. And it’s our ability to read human bodies in this way that allows us to see human beings as personalities*

By reading bodies, we ascertain certain behaviours that have meanings. The concept of embodied selfhood (Kontos, 2014) goes beyond the psychosocial model to a point where meaning is extracted through behaviour and the body as a form of self-expression. This has huge implications for how the person who has dementia is viewed. Instead of adopting the positivistic medical model where changes in behaviour are seen as one-dimensional and attributed to the pathology of the dementia, when viewing dementia as an embodied experience, a deeper sense of understanding and connecting with the person can be achieved. Thus, it is important when exploring personhood in dementia studies that we move beyond the dualistic medical model of mind and body as separate, and move towards exploring how the person is able to express themselves in non-cognitive ways and thus maintain a sense of self.

Just as the debate continues about the impact of dementia on one’s sense of self, it is important to consider the role of relationships, particularly those with partners/spouses. There is a potential for their own sense of self to alter in terms of their shared identities with their spouse/partner when their role changes to one of carer (Baikie, 2002; O’Shaughnessy, Lee & Lintern, 2010; Hellström, 2014). The concept of couplehood in the context of dementia not only views two people as individuals but also examines how their relationships alter over time and in differing ways. Interestingly, Hellström, Nolan and Lundh (2007a) found that partners continued to value their spouse with a dignity that allows them to maintain their commitment over a period of five years following diagnosis. It is not surprising that a number of studies have found that the better the premorbid relationship, where couples were committed to one another prior to the illness, the more likely they were to be able to maintain their sense of selves in terms of shared identities for longer (Davies, 2011; Molyneaux et al., 2012). However, very little research exploring couplehood has considered the viewpoint of the person who has dementia. Indeed, there is a need for further research that examines relationships from the perspective of the person who has the condition, as Merrick, Camic and Shaunessy (2016) found that participants who had dementia continued to consider their

relationship with their partners as they had before their diagnosis, but also showed an appreciation and concern for them in their new role as their carers.

Thus, research involving people who have dementia within the context of their relationships has challenged the old view of the person as a fragmented self. Indeed, there is evidence to suggest that interactions with people through community groups and their local environments can lead to the person sustaining relationships that contribute towards maintaining their own sense of self and identity (Hampson, 2009; Davies-Quarrell et al., 2010; Hampson & Morris, 2016). Certainly, a review of the literature on ageing and dementia research, which employs methods such as biography, life history and reminiscence suggests that these can portray a much more positive view (Sedgley, 2007; Bornat, 2015; Hyden, et al, 2014; Woods et al., 2014; Gibson, 2011; Bruce & Schweitzer, 2014; Guendouzi, Davis and MacLagan, 2015). In addition to this, the role of reminiscence has been shown to improve cognition, autobiographical memory and wellbeing, which in turn has contributed to maintaining relationships (Cooney et al., 2014; Gonzalez et al., 2015; Huang, 2015; Woods et al., 2016). The literature and my own experience certainly indicates that the use of visual prompts and reminiscence can often initiate stimulation of memory, which in turn can impact on the person's feeling of self-worth (Bourgeois et al., 2001).

There is much to be valued in exploring differing approaches to dementia. Indeed, dementia scholarship has started to emerge outside the realms of positivistic health and social care, studies have explored the importance of the natural environment (Mapes, 2010; Clark et al., 2013), the design of the physical environment (Chaudhury & Cooke, 2014), leisure and activities (Genoe & Dupuis, 2014), sport reminiscence (Tolson & Schofield, 2012; Wingbermuehle et al., 2014), play and design and sensory e-textiles (Treadaway & Kenning, 2016) and the positive effect of music in helping to maintain a sense of personhood, (Vink et al., 2013; McDermott et al., 2013; Särkämö & Tervaniemi, 2015; Beer, 2016). These studies indicate the growing interest in utilising more positive, innovative and creative approaches to dementia research that help towards the person sustaining a sense of self and identity within their social worlds and contributing to our understanding of how to connect with them.



My research, therefore, focuses on the premise that we can assist the person living with dementia in maintaining their sense of self and shared identities with their partners by communicating in meaningful ways, and particularly reminiscence (in this study, in terms of remembering shared holidays). Since we know that emotional memory can remain intact for longer than autobiographical memory (Tappen et al., 1999; Kazui et al., 2000), tapping into positive emotional experiences such as past holidays may help both the person living with dementia and their partner.

## **2.6. Summary**

This chapter has explored and critiqued the historical multidisciplinary perspectives of ageing within gerontology. It has examined the role of medicalisation, which has perpetuated the view of ageing as problematic. The advent of critical gerontology, evolving in line with other areas of scholarship, including feminism and humanistic psychology has been discussed as a way of challenging stereotyping and ageism. The chapter has also explored the impact of critical gerontology on dementia and the way it has opened up a richer understanding of people who have dementia and what it is to like to live with the condition.

The chapter moved on to discuss the deeper philosophical considerations of how dementia impacts on the sense of self, introducing the concept of personhood (Kitwood, 1990, 1997a, 1997b) and relationship-centred study. It goes on to consider the literature that questions self and identity with those whose cognition has deteriorated and challenges the view that the person becomes fragmented. Following a brief discussion about multidisciplinary interpretations of personhood, the sense of self and couplehood in dementia scholarship has been explored through the concept of embodiment and interrelationships with the environment and societal contexts.

Finally, this chapter has briefly discussed the use of creative approaches to dementia scholarship and practice that move beyond aspects of health and social care, before concluding with the consideration of the role played by reminiscence in helping to maintain a sense of connectedness and cognitive function. In so doing, it has examined the role of

embodiment and a sense of place in helping to listen to and represent the person who has dementia, showing that these approaches may help sustain the person's sense of self within the wider aspects of their lives as well as their partners.

The next chapter will extend the personhood debates in terms of the exploring the potential role that tourism and the act of recalling holiday memories may have for individuals living with dementia and their partners.

# **CHAPTER 3**

## **AGEING, DISABILITY AND EMBODIMENT IN TOURISM RESEARCH**

- 3.1. Introduction
- 3.2. Traditional and emerging tourism scholarship
- 3.3. Embodiment and reminiscence
- 3.4. Summary

## **CHAPTER 3: AGEING, DISABILITY AND EMBODIMENT IN TOURISM RESEARCH**

### **3.1. Introduction**

As we saw in Chapter Two, the gerontological and dementia literature traditionally concentrated on negative aspects of ageing and dementia until the advent of personhood studies and critical gerontology. This chapter focuses on the study's broader context by introducing the need for dementia to be considered throughout other disciplines, including tourism scholarship, particularly as dementia affects the whole person, including their leisure, social life, short breaks and holidays. Whilst examining the wider aspects of dementia study, such as engagement in tourism activities, the parallels of critical gerontology and critical tourism scholarship are identified. The chapter also introduces embodiment theory, a more holistic understanding of tourism, involving the whole body, including the senses and emotions.

### **3.2. Traditional and emerging tourism scholarship**

Traditionally, tourism studies were dominated by market-led approaches that based their assumptions on positivistic empirical research which examined tourist typologies that compartmentalised and classified the market, based on consumer behaviours (Calantone & Mazanec, 1991, Selin, 1999). Such studies have tended to perpetuate stereotypes and assume that tourists fit into homogenous groups, thereby failing to consider the diversity of populations in terms of class, gender, race, age and experience. This resulted in the marginalisation of many groups of people within tourism scholarship. However, some tourism scholars have more recently begun to explore peoples' wider experiences. Feminist theory, for example highlighted the limitations of the market led approaches, in which the focus was on white, male and able-bodied groups (Bruner, 1991; Alcoff & Potter, 1993; Aitchison, 2001; Goodson & Philimore, 2004). Hence, much broader understandings of tourism have been gained.

As stated earlier, tourism studies have failed to examine the diversity of experience of those participating in tourism. People with disabilities had been particularly marginalised in terms of tourism opportunities and the barriers they experienced (Smith 1987; Oliver, 1996; Darcy, 2003; Darcy & Dickinson, 2009). Fortunately, recent studies have started to explore the tourism needs for people living with physical disabilities (e.g. Burnett & Baker, 2001; Darcy, 2003; Daniels, Rodgers & Wiggins, 2005; Darcy & Dickson, 2009; Michopoulou et al., 2015; Evcil, 2017), sensory disabilities (Richards et al., 2010; Small, Darcy, & Packer, 2012; Richards, 2013) and the experience of mothers with children living with autism (Sedgley, Pritchard, Morgan & Hanna, 2017) thereby, raising awareness and promoting inclusivity and accessibility within the industry. However, many studies focus on access and mobility, often ignoring the wider experience of disability.

Market led approaches to tourism have also meant that older people have purely been seen as a profitable segment of the market (Anderson & Langmayer, 1982; Javalgi, Thomas & Rao, 1992; Patterson, 2006; Glover & Prideaux, 2009). As a result, older people who find it difficult to participate or are unable, have been ignored. Indeed, the stereotyping of older people in relation to their participation in leisure and tourism has perpetuated a narrative of successful and active ageing.

*Generally, researchers have found that seniors are still physically capable of travelling for pleasure and have a desire to be physically active, as well as participating in, and still enjoying, youthful activities because this helps to keep them feeling young.*

(Patterson, 2006:15)

Such a narrative of positive ageing and youthful older people focuses on the middle classes and excludes those who are disadvantaged on grounds of ill health and socioeconomic hardship. Thus, it oppresses those who do not fit the image of successful ageing (Holstein & Minkler, 2003; Holloway, 2007). There is little consideration for older people or seniors who are not *physically capable* and/or may not be mentally or financially able to participate in such *youthful activities*. Hence, there is, a need to explore the reality of holidays for individuals in terms of the lived experience. Sedgley (2007) started to do this by using biographical research

and merging critical tourism with critical gerontology.

There is evidence to suggest that for those that can take short breaks and holidays, then it can have a positive impact on their wellbeing by encouraging social engagement and engendering a sense of confidence and improved self-esteem (Sedgley et al., 2011; Morgan et al., 2015). It is now recognised that holidays can give older people the time to re-evaluate their lives and learn new ways of coping by being free of the responsibilities and concerns of day-to-day life, such as poor health and economic hardship. Indeed, Morgan et al.'s (2015) study found that a *break away* scheme (managed by the National Benevolent Fund for the Aged: NBFA) provided a valuable opportunity for those who experience loneliness and economic difficulties, in their day-to-day lives to interact socially with others and experience a sense of escaping from their everyday stresses. Thus, the value of tourism in contributing to wellbeing, which in turn contributes to health, cannot be underestimated.

Whilst critical tourism scholarship has started to explore more diverse aspects of ageing, there is little consideration for those who live with dementia. Such an underrepresentation may be due to the challenges associated with undertaking research with people who have questionable mental capacity or may be considered unable to participate on grounds of cognitive dysfunction, alongside the assumption that people who have dementia cannot participate in holidays. However, the advent of the dementia-friendly movement, advocated by the Alzheimer's Society (2016), has emphasised the importance of dementia-friendly holidays. Being *dementia friendly* involves raising awareness in communities and providing training for people to understand the condition in order to empower those living with the condition to remain active citizens in all areas of life. Page, Innes and Cutler (2015) have attempted to consider developing holiday destinations that are dementia friendly. Indeed, a number of dementia-friendly holiday options have been made available in recent years: Dementia Adventure, The Mede, Vitalise, and Mind for You (Tourism for All, 2017), reflecting the fact that people who have the condition are still able to participate, usually during the mild to moderate stages of their condition. However, this is not without difficulty when considering the complexity of dementia for the individual, in relation to liminality, time and space disorientation, altered visual perception and communication difficulties.

Hence, there is the need to recognise that some people who have dementia are still unable to take a holiday due to the degenerative impairments they experience, such as disorientation when travelling and increased stress for the person and their partner. Whilst holidays can be a break from the routine of life, they may exacerbate confusion and disorientation for someone living with dementia. Just as Sedgley, et al, (2017) found in their study of mothers of children with autism, the experience of holidays for some groups may actually be more stressful than spending time at home. With this in mind, the idea of holidaying away from home as the dementia progresses is not always the best option. Familiarity for people who have dementia and their partner creates feelings of security, and as tourism scholars, we need to be sensitive to this. Thus, exploring dementia and tourism is one of the most complex areas of research due to the degenerative nature of the disease and changes in perception, space and time, the senses, judgement, memory and language. These changes impact on the practicality of research and practice. Access to holidays becomes very individualised and needs much attention to explore the idiosyncratic experiences at differing stages of the condition. Thus, as dementia affects people differently, we must not put them into a homogenous group.

### **3.3. Embodiment and reminiscence**

As part of gaining more holistic understandings of holidays, tourism research has also begun to consider the embodied experiences of tourism. Whereas, Urry's (2002) work focussed on the tourist gaze as being dependent on an individual's culture, socio-economic and ethnic background. More recently, embodiment scholarship has emerged to gain a more complex perspective on tourism that also includes identity, place, agency and experience (Crang, 1997; Crouch & Desforges, 2003; Lindstrom, 2005; Small, Harris & McIntosh, 2008; Small & Darcy, 2011). It has been found that understanding embodied experiences is so powerful that it can predict whether people would revisit a place, thereby, having significant implications for the tourism industry (Pine & Gilmore, 1998; Crouch & Desforges, 2003; Wirtz et al., 2003; Sellick, 2004; Pan & Ryan, 2009; Moscardo, 2010; Tung & Ritchie, 2011a; Marschall, 2012a, 2012b, 2015; Kirillova et al., 2014; Kim, 2010; Agapito, Pinto & Mendes, 2017). Indeed, the

multisensory experience is so significant that it influences branding and marketing within tourism and other markets (Lindstrom, 2005; Isaacson, Alakoski & Back, 2009; Agapito, Valle & Mendes, 2012; Agapito, Mendes & Valle, 2013; Pawaskar & Goel, 2014). Returning with souvenirs, photographs and films can help jog a long-lasting account of the holiday experience, which may help to recall the overall embodied experience. Embodiment research has uncovered a much more holistic appreciation of tourism participation. For example, it has highlighted how important holiday anticipation and reminiscence is.

*In fact, after returning home, tourists continue to enjoy the pleasure of their choice in the form of memories that last with a symbolic value in the presentation of the self to friends, colleagues, and family*

(Crouch et al., 2004: 4).

Tourism plays a large part in forming happy memorable experiences for most people, that are reconstructed as stories over time and impact on self and identity (Marschall, 2009, 2012, 2015).

*When tourists are asked about their holidays, they do refer to experiences, and these are memories that are created in a constructive or reconstructive process*

(Larson, 2007: 13)

This in itself highlights the importance of holiday memories and the need to explore the tourism experiences of people who were previously ignored or marginalised. Hence, since the late 1990s, a small number of tourism scholars have started to examine issues of inclusivity in tourism, social justice, equality, anti-oppression and citizenship. As stated earlier, Feminist study, for example has led the critique of patriarchal tourism scholarship (Pritchard et al. 2011). (See Figure 5.1 for the conceptual framework that shapes this research).

While tourism can be viewed as experiencing a landscape that is out of one's ordinary experience, it can be argued that the progressive degenerative nature of dementia already creates this, and just as Urry, (1990, p. 11) describes holidays as a place '*where the individual*



*finds her/himself ...out of time and place'*, this can be a constant experience for the person who has dementia. The person living with dementia could thus, be seen as a tourist in their own reality, and in a constant liminal state.

However, it is possible that by linking to positive past holiday memories, the person may dwell in a moment of pleasure once more. When considering the remembrance of holidays, the possibility of recreating a virtual holiday through the use of 3D technology may be achieved whilst in the comfort of home. This may be an option for people who are unable to travel due to physical or mental illness or disability and may be a consideration for those living with dementia. However, the embodied experience of a holiday cannot possibly be created without stimulating all of the senses at the same time. Bartoletti (2010, p.23) suggests the possibility of recreating the past through *reconstruction and simulation* and recommends that memory tourism needs '*something worth feeling*' (p. 41) and not just seeing. Thus, we return to the need to consider multisensory ways of remembering the holiday experience. Therefore, there is a need to understand the multisensorial embodied tourism experience for those living with dementia in order to inform policy and practice and to challenge the assumptions behind the way tourism is experienced. By following the tenets of critical gerontology and critical tourism, such innovative and creative ways of representing those marginalised in society can improve our understanding with a view to informing practice. It is with this in mind that this study considers exploring aspects of remembering holidays for those living with dementia and their partners.

### **3.4. Summary**

This chapter has illustrated the emphasis on traditionally market-oriented studies in tourism, focussed on homogenous tourist typologies. The advent of the critical turn in tourism scholarship is discussed and the emergence of studies looking at the tourism experience of more marginalised groups in society, such as people living with disabilities and older people is examined. Such approaches have opened up tourism enquiry by exploring complex, unique individual tourism experiences, and thereby challenging the stereotyping of such groups in society.

The paucity of tourism studies involving those with disabilities has been identified, recognising the need for more research. This critique has been extended to the lack of tourism research undertaken with older people, who traditionally have been studied as a homogenous group and those living with dementia. The chapter has also explored the shift from the 'tourist gaze' to holidays as embodied experiences linking together the concepts of embodiment, memories, nostalgia and reminiscence and how the act of remembering holidays can induce a state of wellbeing.

In light of the complexities surrounding the inclusion of people who have dementia into research, the next chapter will provide an in-depth discussion of the challenges, particularly the ethical issues of including people who have mental capacity. It will outline the shortcomings in the traditional bioethical model and approach to studying people living with dementia.

# **CHAPTER 4**

## **ETHICS AND DEMENTIA RESEARCH**

- 4.1. Introduction
- 4.2. The traditional bioethical model of research
- 4.3. Consent and mental capacity
- 4.4. Mental Capacity Act 2005
- 4.5. Inclusion of people living with dementia into research
- 4.6. Meaningful and negotiated consent
- 4.7. Researcher responsibility
- 4.8. Summary

# CHAPTER 4: ETHICS AND DEMENTIA RESEARCH

## 4.1. Introduction

This chapter examines the impact of the traditional bioethical model used in health and social care on research with people living with dementia. The principles governing the ethical code of research participation are examined which includes a discussion of medical discourses and how these marginalise vulnerable groups of people. Mental capacity, consent and decision-making are examined within the historical context of research and the Mental Capacity Act (2005), which aims to include the views of previously marginalised vulnerable people in terms of service provision and research. The chapter then explores the balance between offering the person living with dementia the same rights of inclusion to research as others whilst at the same time being aware of protecting them as vulnerable adults. Alternative negotiable and meaningful methods to consent for potential participants who have questionable mental capacity are discussed. In doing so, the chapter introduces the concept of process consent (Dewing, 2002, 2007, 2008) to ensure that research participants living with dementia are given the same opportunities to participate in research as those with full mental capacity, ensuring that their wellbeing and wishes are respected.

## 4.2. The traditional bioethical model of research

Research ethics in health care research are traditionally governed by the bioethical model, whose fundamental ethical principles of research have been influenced by historical events and have been developed in the field of medical research. The Nuremberg Code of 1947 was the first agreement to formulate ethical principles when undertaking research with human subjects, following the atrocities committed in the Second World War where people were used in experiments in Nazi camps. The Code stipulated that all research participants – or subjects, as they were referred to then – must consent to be included in research. This evolved and was developed into the 1964 Declaration of Helsinki and its subsequent revisions until 2013 (World Medical Association, 2016), which confirmed that research subjects/participants must volunteer and that informed consent can only be truly informed

when the participant has the ability to understand the information being given to him/her and the implications of the research. This includes being made aware of the risks and benefits of participating (Jongsma, Bos & Vathorst, 2015). Whilst the Declaration of Helsinki (2013) is not a legal document, it is based on a globally recognised principle of ethics, defined in the Belmont Report (Ryan, 1978, cited in Childress, et al, 2005): Respect for all persons; Beneficence: balancing risk with benefit; Non-maleficence: first, do no harm; and Justice: everyone should be treated equally (Israel & Hay, 2006; Hellström et al., 2007b).

Against this backdrop, people who have dementia were excluded from research on the grounds of being unable to give fully informed consent due to a lack of mental capacity and decision-making abilities, particularly when a proxy was not present. One justification for this was the fear of the individual being exploited. However, this overprotective approach raised the question of how justifiable it is to exclude people who have dementia from research, recognising that a diagnosis of dementia should not automatically mean an inability to participate in research. Indeed, as previously highlighted, there is an ethical argument against excluding and subsequently marginalising people (McKeown, 2010) after all, who decides that people who have dementia don't have opinions, views, and values? As Robinson, (2002) asks, how is society able to understand the disease and how it affects individuals if they do not listen to the views of the person living with dementia?

Hence, it is not recognised that when excluding the voices of people who have dementia, we risk losing valuable insights into the nature of the condition, as well as opportunities for potential treatment and therapeutic approaches to care and communication (Pratt, 2002). Robinson and Pratt both have dementia and argue that the nature of the experience of the disease cannot be explored without the viewpoints of those affected. In addition to the value of listening to the person's voice, we also have a moral obligation to do so and cannot exclude people living with dementia from research on those grounds alone (Kayser-Jones & Koenig 1994; Wilkinson, 2002; Hellström et al., 2007; Heggstad, Nortvedt & Slettebø, 2012). Indeed, there is evidence to suggest that research participants who have dementia felt valued when other people were interested in their experiences. Having their feelings listened to improved their self-esteem (Keady and Gilliard, 1999). Thus, being involved in research can be

therapeutic for the person who has dementia. Listening to the voice of the person living with the condition is potentially transformative, as it may challenge long-held viewpoints, attitudes and assumptions about the nature of the illness and emancipate those, previously marginalised (Edelman et al., 2005, Cowdell, 2008, Hoe et al, 2009).

Unfortunately, academic research and social gerontological scholarship avoided research into dementia until the late 1980s and 1990s (Zarit, Reever & Bach-Peterson, 1980; Haley, Brown & Levine, 1987; Haley et al., 1987; Anthony-Bergstone, Zarit & Gatz, 1988; Mohide et al., 1990; Teri & Truax, 1994; Dunkin & Anderson-Hanley, 1998). Research that was undertaken concentrated heavily on the negative experiences of dementia and the stress and burden experienced by carers. There was a focus on examining the stages of the disease and the person's cognitive dysfunction, with little consideration for the lived experience or their voice (Hughes et al., 1982; Reisberg et al., 1982). The emphasis on studying cognitive dysfunction was perpetuated by pharmaceutical trials, where drug efficacy was based on an assessment of changes in cognitive decline, such as deterioration in memory, orientation, praxis and executive function. As mentioned earlier, these trials also involved questionnaires with the carers focussing on the person's activities of daily living, and function and the carer's own mood, with little exploration into the phenomenological aspects of living with dementia (Rogers et al., 1998). These studies adopted a quantitative methodology, since measurements were required to ascertain efficacy in the drugs being researched. Whilst there is no doubt that there was, and still is, an urgent need for a scientific approach within pharmaceutical and medical research to gain knowledge about the progression of the disease and the potential for medication to slow or to stop the decline, the emphasis on the negative aspects of dementia have contributed to the deterioration of the person living with the condition (Kitwood, 1993; Moore & Hollett, 2003). The paucity of research exploring the lived experience of living with dementia deprived scholarship and practice of understanding how the disease affected the person holistically and perpetuated a stigma about the condition.

People living with dementia have been excluded from research unless a proxy such as a partner or carer consented for them (Taylor et al., 2012). Today, it is recognised that there is

a moral duty to listen to the voice of such marginalised people in order to advance our knowledge and understanding to improve the lives of people living with the condition, directly or indirectly (Heggestad, Nortvedt & Slettebø, 2012). However, great care needs to be taken to ensure that their human rights are respected when involving them in research. The potential risk of coercion and exploitation needs to be considered (Cubit, 2010) as well as changes in their cognitive function over time and how that affects their decision making.

#### **4.3. Consent and mental capacity**

As mentioned previously gaining informed consent is an ethical requirement for the conduct of any research activity involving human beings. Informed consent is where a person gives their authorisation to be involved in a research activity, with full understanding of what is entailed, its impact and consequences, and has to be given without the influence or control from others (Grady, 2015). This is a complex process with any group of people but where decision-making and mental capacity are questionable, this is not straightforward (Sugarman, McCrory & Hubal; 1998, Nishimura et al., 2013). Exhibiting mental capacity for decision-making involves demonstrating an understanding of the information given and the meaning behind it and appreciating the impact of the research on the person. As well as being able to weigh up the risks and benefits, the ability to demonstrate reasoning and to make the decision as to whether to participate or not, needs to be explored (Grisso & Applebaum, 1998; Karlawish, 2008). Until the advent of the Mental Capacity Act (2005), a person living with dementia was previously either deemed capable of making a decision or not.

Traditional approaches to gaining consent failed to tackle issues around people with questionable mental capacity as it usually involved (and still does in many cases) giving the participant an in-depth information sheet to read, understand and sign in the presence of the researcher. However, the focus on reading the written documentation risked the possibility of not communicating the salient points of the research to the participant (Grady, 2015). Also, such one-off consent does not account for fluctuations in people's moods, feelings or decisions (Downs, 1997). Where people who have dementia may initially be able to express a desire to be involved in research, the insidious progression of the disease gradually reduces their ability to understand and appreciate the consequences of involvement. Scientific studies

have attempted to include an objective measure to ascertain capacity.

These included neuropsychological assessments to assess cognitive function and the degree of cognitive dysfunction. Whilst these measures may give some idea of a person's mental capacity, such tests do not assess a person's ability to express their wishes, emotions and the meanings and experiences behind their decision-making (Murphy et al., 2015). When using these assessments, the person is often left feeling hopeless, humiliated and disempowered, and very aware of their deterioration in mental functioning, and therefore, it could be argued, subsequently harmed (Heggestad et al., 2012); (thus, not fulfilling the ethical principles identified by Belmont, Ryan, 1978, cited in Childress, et, al, 2005). In addition to this, the waxing and waning of dementia means that one-off assessments for consent are unreliable. To overcome these issues consent is often gained, with somebody who had built up relationships with the person over time. However, this in itself raises complex ethical dilemmas that will now be discussed.

#### **4.3.1 Proxy consent**

Consent by proxy for people with questionable mental capacity has often been granted to the closest relative, carer, or in some cases, a legal representative. However, where a proxy is used, the person who has dementia must give their assent. Assent is defined as a research participant's agreement to being involved in research without their full understanding of its nature and the impact it may have on them, whilst their dissent (non-agreement) must be respected (Schrems, 2014). This is based on the premise that by knowing the person well prior to a diagnosis of dementia, the proxy can make a value judgement on the decision-making for the person living with the condition, ensuring that their best interests are considered, based on their previous values and decision-making. Such an approach, where the person who has dementia has difficulties with memory, language, communication and perception can lead to an unequal power dynamic between the proxy and the individual, thereby undermining the very nature of personhood and, once again, potentially leading to harm (Post, 1995, Grady, 2015). Consideration of the present self is ignored, as often proxies revert back to what they think their partner would have decided prior to their dementia diagnosis. Little consideration



is made of the person in the present day and what may inform their current autonomous decision-making (Post, 1995; Tappen et al., 1999; Dewing, 2008).

The inadequacies of proxies' decision-making have been well documented and highlight the differences between the decisions made by proxies and the individuals living with dementia. Evidence shows that proxies (who are usually partners, spouses or family members) have been surprised by decisions the person who has dementia has made in relation to food choices, interactions with activities, experiences and quality of life accounts (Sachs et al., 1994; Keady, 1996; Bamford & Bruce, 2000; Clarke & Keady, 2002; Moore & Hollett, 2003; Sands et al., 2004; Hellström et al., 2007; Bowling, et al, 2015). Interestingly, the use of advance directives for people to communicate their future decisions about whether to participate in research in the event of mental incapacity has also revealed that their proxies failed to predict whether they were willing to participate or not (Bravo et al., 2015).

Also, proxies may experience difficulties in being fully objective in decision-making, since their own perspectives may influence their judgements and decisions (Buchanan & Brock, 1989) or may reflect their own views and not always be in the best interest of the individual for whom they are consenting (Iacono & Murray, 2003). Another aspect to consider when using family members and caregivers as proxies for consent is that it may add to their stress and sense of burden, which may in turn affect their decision-making abilities (Sugarman et al., 2001; Livingston et al., 2010; Chang, Schneider & Sessanna, 2011; Cairns, 2012; Smebye, Kirkevold & Engedal, 2012; Samsi & Manthorpe, 2013). Rational proxy decisions cannot always be made effectively due to the emotional nature of their situation (Wolfs et al., 2012).

The more proxies are listened to, the less we hear from the actual people, their lived experience and the subjective meaning they place on their own experience and the decisions they make (Schulz, 1993; Barnett, 2000; Bartlett & Martin 2002; Wilkinson, 2002; Hopper, et al, 2016). In addition, proxies can underestimate the wellbeing of the person they represent, and thus may limit the opportunities for the person to be involved (Cahill & Wichman, 2000). Also, the quality of relationships needs to be examined, as not all people have their relative's

best interests at heart and those people who live alone or do not have an advocate are likely to be excluded.

Whilst the opinions and backgrounds of significant others are important, the person living with dementia must be asked first when discussing the options for participating in research (Dewing, 2002, 2007, 2008; Grout 2004). McKillop (2002), who has dementia, has worked tirelessly in raising awareness and empowering people who have the condition by speaking about his experience. However, he discusses the importance of the role of family and/or significant others in supporting decision-making, but stresses the need to gain permission from the person living with the dementia themselves first. It was not until 2005 that legislation was passed which started to examine mental capacity in terms of decision making for consent for treatment and research (Dept. of Health, 2005).

#### **4.4. The Mental Capacity Act (MCA) 2005**

When mental capacity is questionable for consenting to care, treatment or research, the Mental Capacity Act (2005) must be implemented. The advent of the Act has helped to overcome some issues of marginalisation in care and research, as previously people with a diagnosis of dementia were regarded as incompetent and their decision-making was automatically taken away. The Act gives guidelines on how to assess a person's capacity and determine his or her decision-making abilities in relation to specific decisions. This has proved beneficial to some degree for informing researchers and involving people in service provision:

*A person lacks capacity in relation to a matter if at the material time he/she is unable to make a decision for him/herself in relation to the matter because of an impairment of or disturbance in the functioning of the mind or the brain*

(legislation.gov.uk, 2016).

Where a person is unable to make a decision, he/she is deemed unable:

- To understand the information relevant to the decision;
- To retain the information;
- To use or weigh that information as part of the process of making the decision; or
- To communicate his/her decision (whether by talking, using sign language or any other means)

(legislation.gov.uk, 2016)

The change in legislation has contributed to a shift in how people with questionable mental capacity are viewed and respected and indicates that mental capacity is a fluid concept, potentially ever-changing and not linear. The previous assumption that all people who have dementia were unable to express their opinions and make decisions has now been challenged. Thus, when exploring issues of decision-making, it is important to consider the relational aspect of the decision to be made, paying attention to the context, the decision and the individual making the decision. Assessing competence is not absolute, as capacity may fluctuate and a person living with dementia may be able to make decisions in one area of life – for example, food preferences – but not in others, where complex issues such as financial matters need to be considered (Hubbard, Downs & Tester, 2002; Vass et al., 2003; Slaughter et al., 2007; Smebye & Kirkevold, 2012). The Mental Capacity Act (2005) states that in the event of limited capacity, the following principles need to be adhered too when participating in research:

- The research must be safe and relate to the condition that the person has
- There must be sufficient proof that the research cannot be conducted sufficiently with people who have capacity
- The benefit to the person must outweigh the risks

(legislation.gov.uk, 2016)

However, the Act does not fully empower those living with dementia, since it values the decisions of families or advocates over those affected by the condition. The issue of choice and involvement for the person who has dementia should be explored first in order to ensure that research participation is truly fair and inclusive.

#### **4.5. Inclusion of people living with dementia in research**

As previously highlighted, traditional research studies about dementia were derived from the biopsychosocial model and involved measuring cognitive function as a marker and a baseline for inclusion criteria. The focus on cognitive decline ignored any reference to the lived experience of the person (Hubbard, Downs and Tester, 2003). Research often concentrated on empirical approaches, even when measuring quality of life for those who have dementia and did not take into consideration the changing nature of the condition. Thankfully we have seen a shift towards listening to the voices of the people living with the condition (Cheston, Bender & Byatt, 2000, Hoe et al., 2009) where such research has provided insights into their lives, and in so doing, has contributed to their empowerment and self-esteem (Cotrell & Schultz, 1993; Downs 1997; Proctor, 2001; Reid, Ryan & Enderby, 2001; Bartlett & Martin 2002; Dröes, 2007). However, the shift to a more critical form of enquiry in dementia research which listens to the voice of the person living with dementia, has raised questions about how research and consent to participate can be achieved ethically. As Hellstrom et al. (2007a) stated, the issue is not about whether to involve the person who has dementia in research but more about finding ways in which we can. Hence, the paradigmatic shift of listening to the voice of the person living with the condition has initiated much debate on how consent may be obtained ethically and morally.

#### **4.6. Meaningful and negotiated consent**

As we can see from above, the changes experienced by people who have dementia pose the argument against one-off consent or assent. This is particularly pertinent where studies are undertaken over a period of time. Until recently, most research focused on people living with dementia in the early stages of the disease, due to the perceived impracticalities caused by

difficulties with communication and cognitive changes. However, the recent shift to researching with people with moderate dementia identifies the need to consider ongoing consent processes that continue to adhere to the four ethical principles.

The Mental Capacity Act Code of Practice (DCa, 2007) advocates that the first part of the consent procedure should focus on making sure that the information is presented to the person in a way that is understood. This may include pictures, leaflets, photographs, verbal explanations and/or alternative ways of providing information from the standard expectation of reading a long information sheet (Monroe et al., 2013). Trust and rapport are vital in ensuring that effective communication is created and that time and timing are considered, especially when the potential participant is unable to retain information over time. Thus, the process of consent should follow a conversational style to allow the person to assimilate the information and give them time to respond. It is important to ensure that a trusted person is in attendance, whether a family member or an advocate, to ensure that the person's wellbeing is observed and that they feel empowered to make the decision. However, it is important that they are present in terms of assessing wellbeing and not with a view to coercion. Assessment tools that ascertain mental capacity during consent have been developed to ensure that they understand what the research is about and its potential impact on them; and to examine their ability to weigh up the benefits and risks to participating in the study. Where their ability is less evident, further assessments can be made, which include documenting their emotional state at the time, whilst acknowledging fluctuations in mood and capacity and taking account of the potential for clearer lucidity at certain times of day (Sherratt, Soteriou & Evans, 2007).

Frameworks such as *ASK ME: Assessing, Simplifying, Maximising, Enabling*, (Peisah et al., 2013) can help the researcher to feel more confident when assessing the participant's ability to consent. By *Assessing* the person's strengths and weaknesses based on cognitive function and social skills (in the presence of a supportive carer assisting in shared decision-making), the researcher can start to examine their decisional capability. The process of assessing capacity and gaining consent also needs to be *Simplified*, emphasising the importance of knowing the person, through meeting them, exploring their lived histories and building

relationships with them and their relatives. Once this is achieved, the ability to understand what the person who has dementia is consenting to must be *Maximised* in whatever way is possible. When the potential participant is in a non-threatening and familiar environment with people who know their life history, they are more likely to be able to express themselves more clearly and make decisions (Clare, 2010). The final stage involves the person being *Enabled* to consent once all previous stages have been applied.

There is no doubt that for consent to be meaningful, it needs to be active and ongoing (Hubbard et al., 2003; Dewing, 2007, 2008; Murphy et al., 2015) and needs to assess a person's wellbeing throughout all stages of the research. Murphy et al. (2015) adopt a similar process outlining how consent should be obtained, to maximise the potential participant's opportunity for inclusion, as well as the need to end the research on a high, so that the participant is left with a positive feeling about their involvement. Dewing (2007, 2008) incorporates the principles of both approaches into her *process consent* whilst also identifying five stages to follow, (see Figure 4.1). Process consent also stresses the importance of the researcher having expertise working with people with limited mental capacity, such as those who have dementia. Such experience allows for intuitive knowledge about the person's wellbeing to be continually assessed and it is with this in mind that this study followed the stages of process consent.

**Figure 4.1. Stages of Process Consent (Dewing, 2007)**

|  |  |
|--|--|
| First stage – Background and Preparation   | Ensure that the person to be approached has a meaningful person or significant other involved who is aware of the research and its potential impact on the person.   |
| Second stage – Level of well/ill-being that the person experiences and the impact the research may have on this. | Identify potential triggers that may affect mood and recognise any behaviour or form of communication that may indicate a change in wellbeing, such as agitation, restlessness and facial expression, which may indicate a need to withdraw consent. |
| Third stage - explanation of the information sheet   | Use of visual media and props to assist discussion and decision-making.  |
| Fourth stage – Ongoing monitoring  | Monitoring of the person’s wellbeing with their meaningful person, and where signs indicate a reduction in wellbeing, the decision to withdraw and stop the research is to be made.  |
| Fifth stage – Ongoing support and feedback   | Support and feedback from family and/or meaningful people to the person living with dementia will be sought throughout the whole process and at the end of the study.  |

By adopting these processes and the Mental Capacity Act (2005), researchers are now able to feel more confident about including the person living with dementia into research. Unfortunately, despite these frameworks, few studies have used them (Phinney et al., 2016) and many researchers even fail to comment on the ethical processes applied in their studies (Zwijssen et al., 2016; DiLauro et al., 2017; Kapoor & Orr, 2017).

#### **4.7. Researcher responsibility**

The role of the researcher in the field of dementia study is a complex one where many considerations need to be made. The researcher has a moral duty to ensure that if the person who has dementia is being approached for research, then their involvement is in their best interest (Alzheimer-Europe, 2017). The relationship between the participant and the researcher needs to be mutual, with the researcher adopting a reflexive approach that observes and aims to limit power dynamics and establish a respectful connection:

*Relational ethics requires researchers to act from our hearts and minds, to acknowledge our interpersonal bonds to others, and initiate and maintain conversations*

(Ellis, 2007:3)

Such ongoing reflexivity may also highlight the blurring of roles experienced by the researcher, who may be seen as a supporter, carer and/or counsellor. The researcher needs to understand that whilst their role is one of mutuality, there is still a need to define the boundaries of the study and their role as researcher whilst ensuring that the participant's wellbeing is maintained. In addition to protecting the participants, it is also recognised that the researcher has a responsibility to protect themselves. Where the area of study is an emotive one, the emotional wellbeing of the researcher needs to be considered as well as their safety (Shaw, 2003; Bahn, 2012).

#### **4.8. Summary**

This chapter has described the failings of the bioethical model in terms of including and protecting individuals who have dementia in research. It has identified the need to listen to the views and include people who have dementia whilst examining and critiquing the role of proxy consent. Thereby, highlighting the disparity of decision-making between those living with the condition and their proxies. The complexity of assessing decision-making in those who have dementia has been discussed and the Mental Capacity Act (2005) is examined in terms of preventing exclusion based on a diagnosis alone.



The chapter has also examined a range of ways to include those with deteriorating cognition into research whilst identifying the need to shift from the bioethical model of one-off consent. It has been proposed that ethical processes are considered throughout all stages of research in order to give people who have dementia the opportunity to participate. The chapter has therefore examined ways that are negotiated and made meaningful for the person living with dementia. The practical aspects of enabling inclusion into research are identified, alongside the need for the researcher to be aware of their responsibility. The role that reflexivity has to play in terms of reducing power relations and maintaining the wellbeing of the participant is discussed.

My own ethical considerations and practices for this study are discussed in Chapters Five and Seven, for phase one and phase two respectively, where a number of the above points are reflected upon. The next chapter goes on to explore my epistemological and ontological stance, which reflects these ethical principles, and lays the philosophical building-blocks that inform this research.

# **CHAPTER 5**

## **PHASE ONE EPISTEMOLOGY & METHODOLOGY**

- 5.1. Introduction
- 5.2. Theoretical position and conceptual framework
- 5.3. Access and sample
- 5.4. The role of reminiscence
- 5.5. Ethics
- 5.6. Pen portraits
- 5.7. Methods
- 5.8. Analysis
- 5.9. Summary

## **CHAPTER 5: PHASE ONE EPISTEMOLOGY & METHODOLOGY**

### **5.1. Introduction**

Chapter Five presents the study's epistemological and ontological stance. In light of the complexity of researching with people who have dementia, a multiplex conceptual framework is required that incorporates critical theory, symbolic interactionism and phenomenology. The chapter defends the pluralist ontological perspective embraced in this research and reflects on the overarching philosophical premise that human subjects are socially and culturally constituted. It articulates the significance of critical theory and the concept of personhood in the study and builds on the discussion of critical gerontology and tourism scholarship in Chapters Two and Three. The chapter goes on to describe access to the sample group in phase one and how ethical considerations such as process consent (Dewing, 2007, 2008) were applied. It discusses phase one of the study, in which conversations were adopted as the research method, with the help of reminiscence to elicit memory and communication. My aim was to understand the issues around holidays and understanding the needs of both the person living with dementia and their partner, as couples and as individuals, by listening to their voices. Finally, the chapter reflects on the methods, analysis and emerging issues associated with undertaking such research with people living with moderate dementia.

### **5.2. Theoretical position and conceptual framework**

Previous chapters have highlighted the shift within gerontology from positivistic study to more interpretivist research, thereby, examining the lived experience of older people and the issues around self and identity. This study did not set out to seek absolute truth, since its aim is to explore the meaning and significance of recalling tourism memories for those living with dementia and their partners. In doing so, the aim was to explore individuals' personal realities rather than developing a grand theory as quantitative approaches do. In previous chapters we saw how positivistic research has viewed older people who have dementia as a

homogenous group and objectified their experiences, resulting in negative stereotyping of ageing and dementia (Cumming & Henry 1961; Cowgill & Holmes, 1974). Such reductionist quantitative approaches make it very difficult to reflect the person's true response to a question such as when completing questionnaires, as the changes to cognition can impact on the person's ability to understand and respond as required. However, the past 20 years have seen a growth in qualitative studies that have discovered rich insights into the experience of living with dementia by listening to the voices (Downs, 2000; Snyder, 2001; Moore & Hollett, 2003; Droes, 2007; Clare et al., 2008; Nazarko, 2015). Hence, collaborative, participatory research is more likely to generate research findings that are meaningful and inform practice (Gray & Schubert, 2010).

In determining the epistemological and ontological perspective it is essential to do so in a way that explores such meaning and attempts interpretation through differing lenses, considering a number of methodologies that view knowledge as constructed, changing with time, and exploring how people interpret the world around them (Bertaux, 1981). This is particularly pertinent within dementia scholarship where, due to illness, reality fluctuates as the condition deteriorates. Hence, drifting through differing times and places makes it difficult for individuals to make sense of the world around them. Just as Hollinshead, (1992) speaks about the importance of representing a Native American Indian's own perception of their world, so this study aims to convey the person who has dementia's own vision of their world in a snapshot in time, which cannot be directly transferable to other contexts and individuals. This study, therefore adopts aspects of the theoretical foundations of constructionism, where we individually make meaning of the world around us as an epistemic backdrop. By adopting a qualitative methodology, it encourages collaboration with people who have dementia and their partners, to foreground personhood by listening to their voices during conversations, reminiscence and sensory ethnography.

As people who have dementia have traditionally been viewed as fragmented selves (Leibing & Cohen, 2006) and treated as subordinate, this thesis aims to regard the researcher as a collaborator with the participants to help represent their voice through multiple means, and

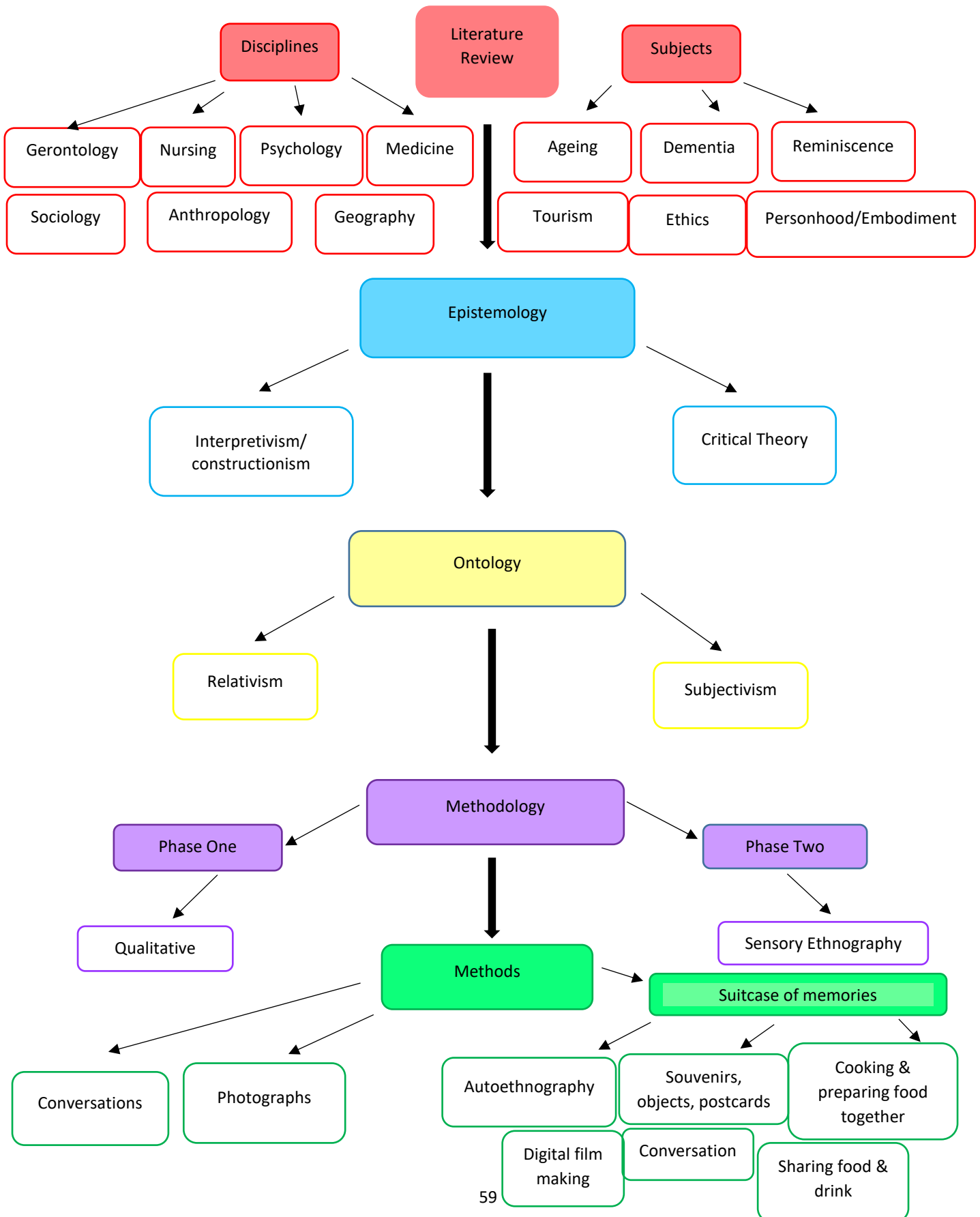
thus help to emancipate them whilst being aware of the transient nature of what is discovered.

### **5.2.1. Critical theory**

Just as an interpretivist perspective aims to explore the meaning of self and identity alongside issues of consent, temporality and changes in cognition (Sabat & Harre, 1992; Caddell & Clare, 2010; Egede-Nissen et al., 2013;), so a critical approach is required that challenges assumptions and makes structural changes as a result from listening to those individuals (Sabat, 2005; Robertson, 2014; McSherry, Suckling & Boughey, 2016). As mentioned previously, we must accept that the research is authentic only in representing multiple realities and experiences of one participant at a moment in time. Thus, its aim is to explore the meaning that the individual places on their experience: i.e. recalling tourism memories in that moment, especially when they can no longer travel. It also aims to explore possible therapeutic benefits such as finding a way to engage and connect with them, emancipate them by giving them a voice and to help maintain their couplehood with their partner. By finding new ways to help communicate with those living with dementia, it is proposed that society may change previously held negative views and assumptions about those living with the condition.

As no research exists exploring the significance of recalling tourism memories with people living with moderate dementia and their partners, the purpose of phase one was to gain an understanding and insight into both the experiences of people who have moderate dementia and their partners' perspectives. This involved interacting with them in a relaxed conversational style (Patton, 2002) using photographs to elicit memories and enhance communication. Thus, the conceptual framework is set out below in figure 5. to demonstrate the complex interdisciplinary literature informing the research and reflect the true epistemological and ontological nature of the study that influenced the methodology adopted.

**Figure 5.1. Study's conceptual framework**



### 5.2.2. Reflexivity

As this chapter explores the theoretical positioning of the study, I need to explain how it has been influenced by my experiences and values. Whilst initially feeling awkward at bringing myself into the study, I now recognise that insight into the researcher's world assists in making sense of the epistemological and ontological orientations that inform any research (Pink, 2015). A reflexive statement (see Chapter One) from the researcher is therefore essential in order to be transparent, to identify potential bias and subjectivity, and to ensure that the data reflects the voice of the person and not the perspectives of the researcher (Ren, Pritchard & Morgan, 2010; Sedgley et al., 2011). As Plummer (2001) points out, researchers will bring their views, values and prejudices to their study through their cognitive lens, hence, it is important to identify them, note how they impact on the research and declare them publicly. By adopting an open approach that explores the reflexivity of the researcher, one can view the process as being a true co-construction of the events (Etherington, 2004: 17), in comparison to the detached role of the researcher in positivistic and empirical studies:

*If human knowledge is co-constructed, then any research project must involve some degree of mutual exploration and discovery. The unmet challenge for the qualitative researcher is to document this process in an open and honest way.*

(Walsh, 1996: 383)

The question arises about how to practice reflexivity so that it gives value to the research and is the researcher's interpretation. As Finlay (2002: 8) states:

*The challenge for researchers using introspection is to use personal revelation, not as an end in itself but as a springboard for interpretations and more general insight.*

Thus, it is clear that the positionality of the researcher impacts on the research and being transparent reduces power relations between participants and researchers (Finlay, 2002).

### 5.3. Access and sample

My initial aim was to interview people with mild dementia whose comprehension and communication difficulties may be less marked. However, since I recruited people through the Alzheimer's Society (AS) and not the NHS memory team, where people were initially diagnosed, the individuals I spoke with were in a more advanced stage of the disease and experienced quite profound expressive dysphasia: difficulty expressing oneself due to problems with speech. Figure 5.2 identifies the participants considered for phase one of the study.

**Figure 5.2. Participants considered for phase one**

| Access              | No. of couples consented | Sample group                           | Methods                        | Ethics   | Reasons for non-inclusion   |
|---------------------|--------------------------|--|--------------------------------|--|---|
| Alzheimer's Society | 7 (14 people in total)   | 5 people living with moderate dementia | Conversations with photographs | Information sheet<br>Consent form<br>Process consent | <ul style="list-style-type: none"> <li>• Sudden bereavement on the morning of the first visit</li> <li>• Spouse fell and fractured hip in between first and second visit</li> <li>• Partner declined due to spouse's inappropriate behaviour</li> </ul> |
|                     |                          | 5 partners (spouses of the above)      | Conversations with photographs | Information sheet<br>Consent form                    |   |

Access for phase one was gained through a senior member of the Cardiff and Vale AS with whom I had links from working as a memory team nurse. Hence, my credentials as a researcher and a nurse working with people who have dementia was already recognised and viewed as appropriate by the AS. The first couple I interviewed had been approached in the AS day centre and given my contact details to see if they were interested in participating. I also attended an AS dementia café in Cardiff, to encourage more participants, where I met



another two couples, and then visited the AS day centre. The first couple I met also attended the dementia café, and through their enthusiasm for the study, two other potential participants agreed for me to visit them to discuss the research. This type of snowball sampling is a form of convenience sampling and is useful when attempting to approach vulnerable, marginalised, stigmatised groups who are usually difficult to access. This has worked well in studies of homeless people where initial access and location can be problematic (Collins & Freeman, 2007). As well as visiting the dementia café, I gave a talk about the research and its possible impact on potential participants at an AS dementia awareness evening. At each venue I gave an information sheet to those couples who expressed an interest in the study to take home and read. This gave them more time to read through, understand the study and think about any questions they might like to ask. I also sat with a number of attendees who had dementia at the dementia café and the AS day centre, chatting with them about the study. All of the partners who consented were their spouses, and interestingly, just as Hellstrom (2014) found when researching aspects of dignity, none of them wanted to be regarded as carers. Once the people who had dementia and their spouses agreed for me to visit them at home, I arranged a suitable time and date with them. In total, seven couples consented. However, two dropped out due to bereavement and injury and one partner declined due to her spouse's inappropriate behaviour.

Whilst the sample size is deemed small in comparison with quantitative research, whose aims are to achieve representativeness and generalisability, here the aim was to have in-depth conversations. Also, the challenges of undertaking research with people who have dementia mean that a small sample is more realistic. Such an approach can provide intensive and dense data that is deeply individual (Cleary, Horsfall & Hayter, 2014). As Fennel (1990: 65) argues, *'...we may learn more from in-depth interviews with only a handful of older people carried out by a sensitive and well-informed researcher'*.

#### **5.4. The role of reminiscence**

In order to initiate conversation and stimulate memories, I planned to use reminiscence during the conversations. Therefore, after the initial visit, I asked the participants to gather

together their holiday photographs in readiness for the research and suggested that they bring out a photograph album, as traditionally leafing through an album is a pleasurable experience and can often initiate conversations about memories. This was planned as an informal way to introduce the research at each visit whilst sitting together in their homes. In effect, the photographs would play a role in eliciting memories of past holidays and discovering whether such reminiscence about holidays proved a therapeutic pastime, just as sporting memorabilia has been proven to do in other research studies with people who have dementia (Tolson & Schofield, 2012; Clark et al., 2015; Carone, Tischler & Denning, 2016).

The study of reminiscence traditionally developed from the psychology of ageing (Butler, 1963; Erikson, 1963). It refers to the art of recalling past experiences and stories with others, as a process to find meaning. The use of reminiscence and life review as a form of psychotherapy changed the negative view that people who reminisced were *living in the past*. Life review became recognised as a powerful psychotherapeutic tool in assisting older people to evolve and adjust to their ageing life (Butler, 1963). It is now recognised that most people; individuals and in groups, informally use reminiscence to recall shared experiences (Schweitzer and Bruce, 2008). Reminiscence transcends cultures, ages and societies and is powerful in building relationships between people. In particular reminiscence has provided ways to reach out and connect with people who have dementia (Brooker & Duce, 2000; Gibson, 2011; Coleman, Treadaway & Loudon, 2016), and, in some cases, reduce depression (Bohlmeijer, Smit & Cuijpers 2003). Reminiscence has also been included in life history work to help professional carers understand the background of the person they care for (Pole & Morrison, 2003; Kindell et al., 2014).

This study set out to use reminiscence as a method to help draw out some preserved memories from past holidays to help initiate communication. Surprisingly, only a small number of studies have adopted this approach with general reminiscence (Newbern, 1992; Norris, 1986; Robinson, 2000). The accuracy of recalling the actual facts of what happened whilst on holiday is not what is being explored here, but rather, the collective remembering and co-constructions and versions of events through emotions and living thoughts as

performances in that moment in time. As Stevenson (2014: 336) observes, remembering place is not achieved through accessing the archive of memory (Atkinson & Shiffrin, 2009): it is a much more embodied experience. Thus, when retelling memories through stories and with the help of reminiscence, one's lives are not drawn out of the filing cabinet of the mind but rather become a more discursive process with twists and turns and ramblings. All the time, reality is being reconstructed, with *lived thoughts* being communicated in a number of ways.

## **5.5. Ethics**

Ethical approval was gained from Cardiff Metropolitan University prior to starting the study. Within the application I discussed the aim of the study, the sample group and process consent.

### **5.5.1. Researcher wellbeing**

Since the research is of an emotive nature, I needed to address my own emotional wellbeing, an important consideration in any health and social care research (Bahn, 2012). In light of this, I arranged debriefing sessions with colleagues and my supervisors following the conversations and throughout the course of my PhD (reading through the transcripts and the periods of analysis can also have an emotional effect on the researcher). Since the research was conducted within the participants' homes, aspects of personal safety were identified. I adopted a lone worker policy (Dickson-Swift et al., 2008), which involved contacting a nominated member of the supervisory team or work colleague after each conversation to inform them where I was going and contacted them on my return. Once I had considered my own wellbeing, I adopted a process consent (Dewing, 2007) approach to ethics for the participants who had dementia for the remainder of the study.

### **5.5.2. Process consent**

The aim of my first two visits in phase 1 was to build a relationship and gain trust with the potential participants and ascertain their degree of mental capacity to consent, and to make an assessment of the person's ability to communicate and understand what I was asking of

them. I needed to review their degree of expressive dysphasia and to ascertain whether they experienced any receptive communication difficulties. My initial visit involved spending approximately two hours with the couples, exploring their interests, activities, family and living history. I left the information sheets with all potential participants to read through together in their own time and consider any questions they might like to ask.

During the second visit, I read through the information sheet (that I created to satisfy the ethics committee) with the couples. The participants who had moderate dementia were unable to read the whole pages and understand the nature of the research and its implications from the sheet. This took much time, since I needed to read slowly and allow for the information to be processed and understood whilst ascertaining their level of understanding, based on their verbal and mainly non-verbal cues without overloading them. I made it clear to them at this stage that the number of visits had not been decided, since it would depend on them. I asked them if they were willing to sign the consent form once I felt comfortable that each individual (person who has moderate dementia and their partner) understood their degree of involvement at that moment in time.

Just as Lloyd, Gatherer & Kalsy (2006) found it effective to allow more time for communicating with people who have profound difficulty expressing themselves, I too avoided directly questioning the participants and attempted to ascertain their responses throughout the conversations. Language skills of people who have dementia can be improved when the researcher takes the time to get to know them and feels a sense of familiarity with them (Haak, 2002). This indicates that the process of consent is not just procedural but is very much a relational one (Heggestad et al., 2012). During all visits I reminded the participants of the research and the practicalities involved verbally.

## **5.6. Pen portraits**

In order to introduce each of the participants, I have provided pen portraits (see figure 5.3), which, as Holloway and Jefferson (2000) identify, as being useful in letting the reader gain a holistic picture of the people involved. In this case they also provide a useful insight into how

the dementia has affected each individual and their partner. All participants were given the choice of pseudonyms in order to protect their identity. Despite all being happy with the use of their real names, I felt it appropriate to use pseudonyms to maintain their confidentiality and anonymity in light of their changing mental capacity over time.

**Figure 5.3. Phase one pen portraits**

**Geoffrey and Margaret**

Geoffrey, aged 74, met Margaret at University in a Student Union bar in 1958. He was studying civil engineering and she studied art. They married and he worked as a civil engineer, while she taught art. One of their greatest joint pleasures was travel, hitchhiking and holidays, particularly involving train travel, as Geoffrey is a keen steam train enthusiast. Their past and current holidays were always planned and organised by Margaret. They own a property in France which they have always enjoyed. However, Geoffrey experienced a stroke and heart attack whilst there and subsequently his memories of France are now also associated with frightening events and health problems. The property is now becoming a burden with regard to its maintenance, since Geoffrey is unable to carry out the work that he once did on the property and garden.

In 2011, Geoffrey was diagnosed with Vascular Dementia, as a result of which he experiences profound expressive dysphasia, which means he often struggles to find the right words. He often knows what he wants to say but cannot get the words out. This is a very typical symptom of dementia and in Geoffrey's case poses the most disabling aspect of his disease at this point in time. At times, Geoffrey would shout and grimace when having difficulty communicating, showing obvious frustration. When he relaxed a little he became tearful, often apologising to Margaret. Such emotional outbursts are out of character for him and may be partly due to the effect the dementia has on his brain as well as the psychological effect of his language difficulties.

Geoffrey and Margaret have no children and their support network is very small. Friends are visiting less frequently since his diagnosis, which they both feel with a sense of loss, and they feel quite isolated. This experience is very common when people are diagnosed with a dementing illness and is reflected in the literature (Ostwald, Duggleby & Hepburn, 2002; Harris & Keady, 2004; Alzheimer's Society, 2013).

The conversations with Geoffrey and Margaret were all conducted in the lounge of their warden-controlled flat, which was light and airy. Margaret had arranged for a carer with the Alzheimer's Society to go for a walk with Geoffrey whilst her conversation took place, as he might have become restless. However, this does raise power issues in light of the fact that she was present during his conversation. On his return, we discussed with him the issues that she had raised during the conversation and offered him the opportunity to comment. Since he had met me before we started the data collection, we had built up a trusting relationship and he was content with the situation.

### **Gareth and June**

Gareth, aged 87, has been married to his second wife June for 25 years. She is younger than him, aged 54. They met through a love of acting and theatre; he was a self-confessed thespian and had even created an open-air theatre. He was very proud of his education and his occupational role as a deputy Director of Education. In addition to their love of theatre, both Gareth and June shared a love of holidays and travel and own a property in France. Gareth was diagnosed with vascular dementia in 2011 following a stroke, and since his physical and mental health have deteriorated, both he and June find it difficult to travel without additional help. They only travel to their home in France now with family (his three children from a previous marriage and six grandchildren).

Gareth is a large man with a deep resonant voice, but quite frail, although when animated during the conversations, he would become gregarious and quite articulate for much of the time. His main difficulties were his short-term memory, orientation to time and place, remembering names and physical weakness and paralysis due to the multiple strokes. The conversations were held in their lounge, with Gareth sitting comfortably in a large armchair surrounded by familiar objects such as trinkets and paintings.

During my conversation with June, we moved to the conservatory, which was an extension of the lounge. June, despite being much younger than Gareth, had a greying complexion and looked tired. Caring for him was proving quite difficult physically and emotionally. Gareth dozed whilst June and I spoke and then he woke up in the middle of our conversation and came over to join us: he was very pleased to see me, having little recollection of who I was or of the research we had just undertaken.

He joined in with the conversation with June, adding rich anecdotes. June agreed for him to stay and we continued in this way, as the conversation was more flowing and natural and elicited some deep and meaningful material between them both. Whilst he enjoyed looking through the photographs, he became far more interactive and raised some interesting points more when in conversation with the two of us. My feeling is that he had always liked an audience.

### Arthur and Belinda

Arthur, aged 84, met his wife Belinda whilst staying at her father's hotel in a seaside resort in 1963. Arthur had been a lecturer and was Head of Department in Mathematics in a technical college, where he had been involved in research. Belinda also lectured in hospitality. He was very proud of "working his way up" throughout the institution. They have one daughter, who is very supportive and lives with her family in Suffolk. They have one granddaughter and two grandsons. Before being diagnosed with dementia, Arthur enjoyed playing bowls and many sports, holidays and travel. He enjoyed music and he and Belinda used to go dancing together. They both enjoyed holidaying abroad and in the UK, experiencing a variety of holidays including walking and sightseeing.

Arthur was diagnosed with Alzheimer's disease in 2010 following difficulties with his memory and orientation. He was able to understand speech, but his conversation was limited: he often used well-rehearsed phrases and showed much word finding difficulty. He lacked insight into his diagnosis of dementia, often denying that he was ill:

*I don't really believe there is anything wrong with me, you see. That's got to be rubbish.*

He was a well-looking gentleman who happily sat on his settee in the lounge overlooking their garden. He confabulated considerably, seeking ways around the discussion with well-rehearsed stories of his life and regularly repeated stock phrases like '*we thoroughly enjoyed*'. He enjoyed looking at their garden and the trees, which attracted much birdlife, and continued to make some decisions over the planting.

Belinda was an assertive lady who was very straight-talking and practical in her approach with Arthur, at times speaking to him like a child. She admitted this and said that he responded quite well to her being in charge, except when there were gardening decisions to be made. She was very smart and upright, having taken pride in her appearance all of her life, and struggled with the lack of freedom to do as she wished, as she could not leave Arthur alone at home. She had some difficulty keeping focussed throughout the conversation, as she was distracted, looking through the window into the garden where Arthur was. She wanted to make sure he was safe and checked that his behaviour was appropriate towards the gardeners, saying that he had become less patient with people as his dementia had progressed.



### **Mike and Phillipa**

Mike has been married to Phillipa (his second wife) for 20 years. He has two children and grandchildren from his first marriage. He is extremely proud of his achievements, from working as an apprentice builder and architect to becoming a master craftsman. He designed the plans for and built the house that they currently live in. His work was also his hobby and Phillipa was in charge of the running of their building and design business. They shared a love of travel and owned a property in Spain for three years.

In 2011 Mike was diagnosed with vascular dementia following a number of small strokes over the previous few years. He struggled to speak, displaying much word-finding difficulty, and repeated himself frequently, indicating that he had short-term memory loss. Mike would become agitated and stressed if he could not see Phillipa, never allowing her to go out of his sight, which created much tension. Phillipa was stressed and looked very tired, welcoming me, with the need for someone to talk to.

The conversations were all held at their home, where Mike proudly gave me a tour of his garden and the large summer house he had built. My conversation with Mike was in their summerhouse, which gave Phillipa some time to be alone, as he was happily distracted with me and the talk of holidays (although he would frequently ask where she was). There were large photographs of their holidays around the walls of their summerhouse, indicating how travel and holidays were important to both of them. These proved excellent prompts as well as the photographs in their albums, since Mike had some vision impairment due to a cataract and possibly a degree of visuospatial difficulties, which would affect how he would see the photographs. He would drift off halfway through the conversations, recalling places that he had been, particularly when travelling through memories of mountains.

During my conversation with Phillipa, we sat in their lounge and she arranged for Mike to play the piano in an extension off the room where he could still see us. This was the one activity where he became immersed in his own company, happy since he also sensed that she was close to him. He played well-practiced tunes with very few mistakes and really enjoyed himself, although Phillipa had heard these tunes repeatedly.

### **Pauline and Bob**

Pauline is 56 and is married to Bob, 58. They met in 1982 in a local nightclub in Cardiff. They have two sons. Both Pauline and Bob enjoyed holidays together in the past which involved caravanning in the UK and they continue to do so at present, although Bob prefers to stay at home now. Pauline worked as an administrator for the Government for seven years and her role involved managing and supervising staff.

Pauline was diagnosed with Alzheimer's disease in 2011, following difficulties noted at work that included deteriorating concentration and problems with her memory and speech. Since Pauline's diagnosis, her visuospatial difficulties have deteriorated rapidly, affecting her ability to continue with her hobbies of needlework, crochet and knitting. She continues with her love of reading through the use of audio books. Our conversations were conducted in their lounge.

My conversations with Pauline proved quite difficult, since the couple didn't have any photographs to use as prompts (despite me asking them previously) and she had great difficulty recalling her holidays. I was unsure whether they had not had the time or interest to gather the photos but did not feel comfortable to ask them, since Bob appeared quite stressed. I felt that as a researcher, I did not want to add to the pressure of his caring role.

Whereas the other participants were fully engaged and interested, I felt that I was less welcome in this case. This impacted on my approach and I felt that I did not want to push the conversations too much. Pauline and Bob's conversations were conducted in their home and blended into one, since they both sat together. There were times when this was awkward, as Bob had a tendency to talk about Pauline as if she wasn't there and talked for her throughout most of the conversation. Pauline agreed for Bob to speak in this way and was obviously used to it. However, I felt it was very difficult to hear Pauline's own voice. This made me uncomfortable as a researcher, since my reflexive stance focuses on the person to communicate with and not to be communicated about. I found myself asking Pauline if she agreed with Bob throughout the conversation and she responded in a passive, resigned way, partly because she had great difficulty expressing herself, but I also sensed that he had always dominated her in conversation, even before she was ill.

The house was very dark and felt quite depressing, and certainly wouldn't have contributed to Pauline's ability to see more clearly. I felt a deep sense of foreboding there and was quite glad when I left to get out into the sunshine.

## 5.7. Methods

Whilst planning the research, I was not aware of how many visits the study would entail, since it would depend on the participants' degree of mental capacity, cognitive skills and health and wellbeing. With this in mind, I decided to go with the flow with each couple. However, I found that three visits were appropriate for all couples. See figure 5.4 for the schedule of visits:

**Figure 5.4 Visit schedule**

| Visit |   |
|-------|---|
| 1     | Initial meeting to introduce myself and start developing a trusting relationship.<br>Discussed the study.<br><br>Introduced the information sheet, verbally read through and explanation given with the potential participants, left the information sheet and consent forms with the participants.<br><br>Requested that they gather holiday photographs together in preparation for visit 2 if they decided to consent. |
| 2     | Continued building the relationship.<br><br>Obtained consent and follow process consent procedure.<br><br>Conducted conversations with both the participants who have moderate dementia and their partners using photographs.   |
| 3     | Continued building the relationship.<br><br>Followed process consent and continued conversations with both the participants who have moderate dementia and their partners using photographs.  |

### 5.7.1. Visit One – Building a rapport

The research was undertaken over a period of six months, since three visits were set up with each couple. McKillop and Wilkinson (2004) highlight the importance of building relationships and conducting research in a familiar and comfortable place. Interestingly, McKillop was diagnosed with vascular dementia in 2001 and has campaigned (and continues to do so) for the rights of people to be heard and for the right to live well with dementia. He has been a

research participant and has written about raising awareness about what it is like to have the condition, whilst recommending a number of considerations when researching with people living with the condition:

*Take an icebreaker – sweets or biscuits. Admire their pets, garden, grandchildren's photographs or whatever you perceive is their passion. A little flattery won't go amiss, but don't go over the top. Smile and pay attention so that if the person gets a bit lost you will know where to pick up – you will be able to repeat their last topic or sentence. If you are unhappy or aching inside put on a brave face or cancel the interview. A stony face will put the person off! Never show pity! But empathise if you can. If dementia has touched your life, slip in your anecdote if you feel it helps you build up a relationship, but don't take over the interview with your auto- biography.*

*(McKillop and Wilkinson, 2004: 121)*

Here is a clear example of where listening to the voice of the person is so enlightening and respected during qualitative research.

I also spoke to the partners about their own feelings, to ensure that their needs would be met, since the research had the potential to raise emotions and reiterate their sense of loss. Since the research involved looking over holiday photographs, most of the people who had dementia were delighted to consent. Since I met with all the couples before the day of consenting for the research, I had already gained an insight into their lives, their emotional states, their ability to understand information and how they communicated, and ascertained what were the best ways for me to communicate with them. Through this, I gained their trust and we started building relationships which were focused on happy discussions about past holidays.

The role of non-verbal communication – our own and that of the person with whom we are communicating – is not to be underestimated in any conversation. Hence, I often mirrored the person's verbal and non-verbal language, reflecting back their movements of the person whilst paying particular attention to the speed, mood and muscle tension of their interaction (Kitwood, 1988; Astell & Ellis, 2006). In doing so, I allowed the person to lead the interaction,

helping to empower them thereby, reducing the power relations between us. As well as being aware of my own verbal and nonverbal communication, I felt that I could give some of the participants a reassuring touch on the shoulder at times. I am sure that my intuition impacted on our communication, which cannot be underestimated when *being* with a person who has dementia. However, one gentleman sat quite a distance from me and I did not feel it appropriate to invade his personal space. Touch, when used in a sensitive and non-threatening way, can have a very effective role in interaction (Jenkins, 2016).

At the end of visit one I asked the partners to gather together their photographs of holidays in readiness for visit two.

### **5.7.2. Visits Two and Three: Developing the relationship further and conducting conversations with people living with dementia, using reminiscence**

When I arrived for the subsequent visits, I was mindful that each of the participants who had dementia might not remember me, or if they recognised my face, they might not remember who I was or why I had come. I held out my hand to shake, gave eye contact and greeted them by name, and introduced myself. Often people who have dementia are ignored, resulting in withdrawal and isolation (Acton et al., 2007). Communicating using slightly exaggerated social etiquette may help towards increasing their sense of self and self-esteem.

*Because of culture's negative attitudes towards ageing, illness and dementia in particular, the experiences the person has had in connection with their condition are likely to have constituted an assault on their self-esteem.*

(Killick & Allan, 2001: 26)

I explained why I was there, and, being respectful of being in their home, waited for them to show me where to sit. During visit 2, they signed the consent forms. Throughout the visits, I chatted with both the individual and their partner about a number of topics and reintroduced holidays into the conversation, reminding them about the research. I have reconceptualised

interviews into conversations, since they move beyond the formal question-and-answer approach and involve a more sensory experience, whilst drinking coffee together and going through photographs. This was also to make the participants feel comfortable, by creating a non-threatening interaction that did not focus on direct questions and answers. Holstein and Gubrium (2004:141) identify conversations as highly acceptable and reliable ways to conduct research, since that is how people communicate more naturally, and thus, they reflect the true nature of social interaction:

*while the conversations may vary from highly structured, standardized, quantitatively orientated survey interviews, to semi-formal guided conversations, to free-flowing informational exchanges, all interviews are interactional.*

The use of conversations as opposed to direct questions can also take away the stress of having to recall information whilst under pressure (Bamford & Bruce, 2000; Ward & Campbell, 2013). The effectiveness of the conversations in generating meaningful data will also depend on the researcher's expertise in communicating with people who have dementia. Thus, the way we interact needs to contribute to building a multi-layered relationship and demands great self-awareness on the part of the researcher.

The conversations were guided in a way to ensure that certain aspects were covered in relation to holiday memories, whilst allowing the participants to bring in their own topics of conversation. I sat with each participant and looked through their photograph albums (with the exception of Pauline), exploring their memories as they unfolded page by page. I would wait for them to respond firstly, and if nothing was said, I would make comments such as *That is a beautiful view, it looks like.....* as a prompt.

Where their partners were in attendance during the reminiscence, their role was primarily an interpretive one. In the cases of Geoffrey, Mike and Pauline, I talked with them in the company of their spouses, since their expressive dysphasia was very marked and despite my communication skills, they needed their partners' knowledge of their *non-cognitive ways of knowing* to help with getting their points across. They all gave verbal consent for their spouses

to be present. When conversing with Geoffrey and Gareth, their language started to flow a little more once they felt comfortable with me and I explained that the facts weren't so important but to let their feelings guide the conversation.

### **5.7.3. Visit Two and Three: Conversations with partners**

The conversations with the spouses also took place in their homes, for practical reasons, as they would otherwise need the assistance of another person to care for their partners. In order to maintain some consistency, I used the photograph albums as a point of reference and again let the conversations flow. As there is no literature exploring the meaning behind recalling holiday memories for the partners of people living with moderate dementia, the purpose was to gain some insight into their reminiscence experience in light of their partner's illness. In some conversations, the partners who had dementia were present and in others they were not. Geoffrey, for example, went out for a walk with a befriender whilst I had the conversation alone with Margaret in their lounge; June and I sat in their conservatory for the conversation whilst Gareth fell asleep and he re-joined us when he awoke halfway through; Belinda and I sat in their lounge where she could see Arthur through the window, who was in the garden monitoring the gardeners; Phillipa and I sat in their sunroom whilst Mike played the piano in the hall, although he kept coming into the room to check that she was nearby. As mentioned previously, Pauline stayed with Bob and their conversation was conducted together.

### **5.7.4. Field notes**

Following each visit, I left their homes and sat in my car writing field notes and a reflexive diary. I loosely followed Gadamer's (1976, cited in Koch, 2006) guide, which includes the consideration of six domains – access; setting; experiences; issues; participant as co-researcher and prejudice – as I felt that I needed some structure. It also reminded me of what I was trying to explore before each subsequent visit. In addition to this, personal reflections were made that included my feelings, attitudes, responses and motivations. Such self-awareness can contribute to the exploration (Rolfe, 2006) and draw from tacit knowledge (Emerson, Fretz & Shaw, 2011). Whilst, tacit knowledge cannot easily be described in the

notes it nonetheless adds to the overall analysis of the research at a deep, rich and meaningful level.

## **5.8. Analysis**

The process of data analysis occurred during all stages of the research: the visits; writing of field notes; listening to the audio recordings and reading the transcripts, and, as often occurs, it proved to be an iterative and inductive exercise (Veal, 2006). I noted my own underlying values and beliefs whilst undertaking the analysis and realised that a degree of reflexivity also occurs when analysing and interpreting other people's voices (Philpin, Jordan & Warring, 2005). Since my role as researcher included attending to my reflexive stance, I understood that it cannot be separated from the study.

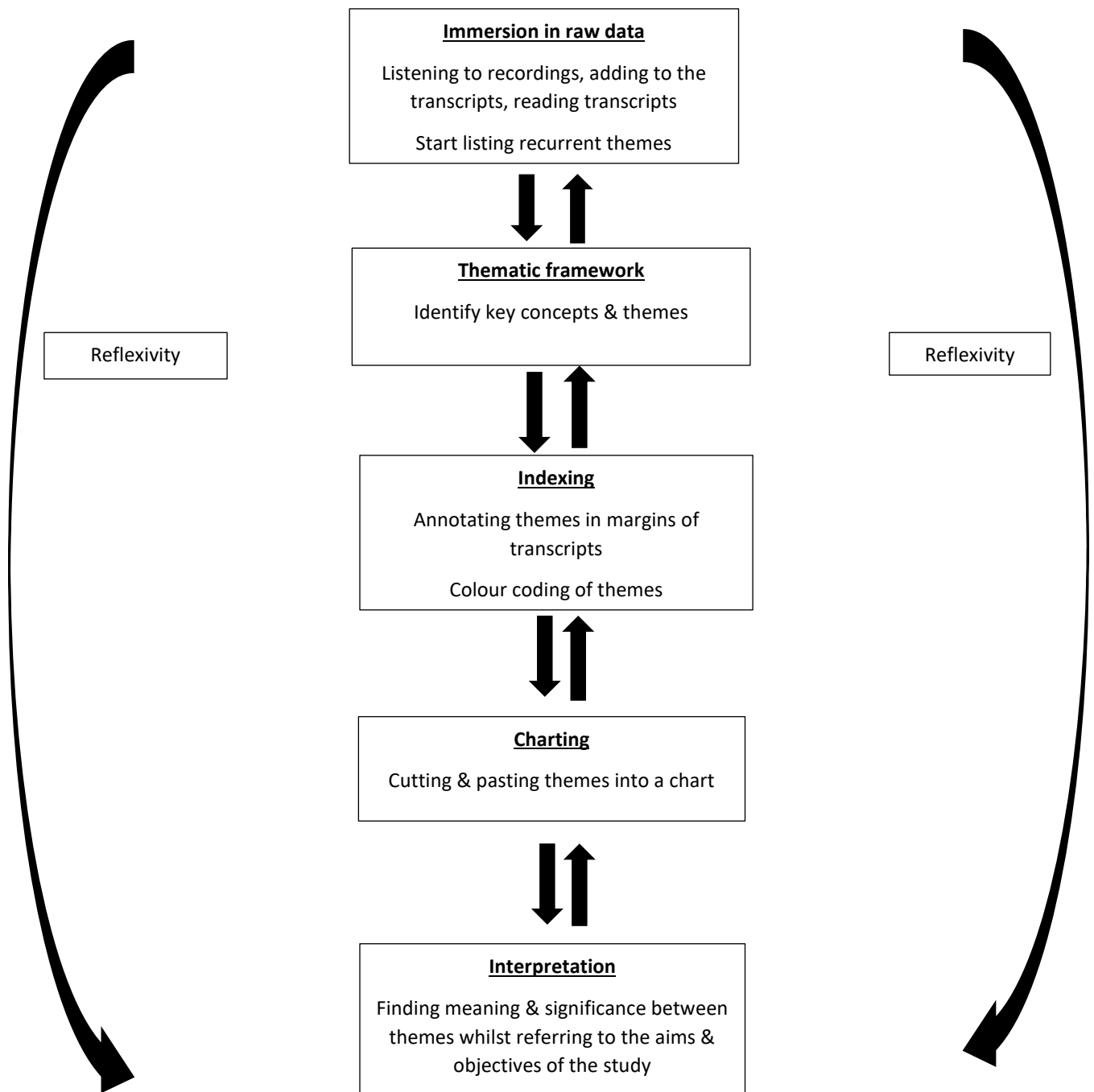
The conversations were transcribed by a third party who had no connection to the study. This decision was made due to the large amount of data generated, which would prove time consuming to transcribe. However, on reflection, the transcriber failed to capture much of what was said on the audio recordings as the voices of the people who had dementia were sometimes difficult to understand, with the ends of their sentences often tailing off, rendering them inaudible. Subsequently, the transcripts did not fully reflect the conversations. Hence, I found myself re-immersing myself in the worlds of the participants by re-listening to the recordings in order to add missing elements that had been lost to the transcriptions. This, in itself, allowed me to become familiar with the transcripts on a deeper level and contributed to the analysis. I had already decided that computer software analysis such as Nvivo would not be appropriate, since I had foreseen a degree of difficulty in identifying the speech on audio recordings prior to the study.

To continue with the process of analysis, I drew from a number of frameworks, since '*themes can be generated in a variety of ways*' (Roulson 2014: 297). Just as Hanna (2014) found the process of analysing data far more complex than textbooks imply, I too noted that my research approach was evolving into a non-discursive form in which one method of analysis may not suffice, and I found myself drawing much from my own intuition. Whilst I aimed to



adopt a structure for analysing the data (Pope & Mays, 2006), I found that the process was not as linear as the framework implied. Bryman (2016) identifies that all stages can be applied interchangeably, and here I regarded the structure more as a guide, moving back and forth between the stages of listening to audio recordings, reading and amending the transcripts, identifying themes and interpreting them in relation to the aim and objectives of the study. I became extremely familiar with the transcripts, reading through them a number of times (after I had already read them to add in some missing text) and then attaching names and ideas to pieces of the texts. From undertaking the conversations, I already had some idea about the concepts and themes that would arise. As these developed, I made further annotations in the margins, in order to stimulate some analytical thought. The text of the themes was colour coded. Here I drew from Lofland et al.'s (2006) approach of applying meaning to them and ascertained their significance and how they related to the literature and to the aims and objectives of this study. Figure 5.5, below, refers to the analysis framework I created that draws from these sources.

**Figure 5.5 Modification of framework approach drawing from the five stages of analysis**  
**(Pope & Mays, 2006; Lofland, Snow & Anderson, 2006; Bryman, 2008)**



## **5.9. Summary**

This chapter has identified the complexity of undertaking research with people living with dementia by firstly presenting the theoretical position of the study, which in turn has informed the methodology and the subsequent research methods adopted. By rejecting the notion of objective truth associated with positivism, the chapter has defended the case for an interpretivist and critical epistemology. By recognising that knowledge is developed through understanding the individual experiences of people living with dementia and their partners, a subjectivist and relativist ontology has been adopted. In this case, when exploring the meaning and significance of recalling holiday memories, the need to explore human experience is identified and calls for a qualitative approach, as the depth of experience cannot be reduced to quantitative data (Hollinshead, 2004). The conceptual framework identified the need to draw from a number of disciplines to reflect the holistic nature of the enquiry, which spans gerontology, critical gerontology, nursing, psychology, sociology, medicine, anthropology, geography and tourism.

Thus, the chapter has outlined the importance of the reflexive positioning of the researcher, bringing my own set of knowledge, values and beliefs to research. By writing a reflexive statement, criticisms around subjectivity have been rejected and the issue of transparency as a researcher have been identified. The chapter has recognised the need to follow an ethical process in order to ensure that such marginalised people are heard, are not exploited and their wellbeing is maintained and reflected at the heart of the study. Hence, the stages of process consent are described.

This chapter also introduced the participants involved in the study through pen portraits of the couples and the meetings and conversations held with them. The role of reminiscence is discussed in terms of a trigger for memories and as a research method in itself. Finally, the complexity of the analysis is examined by following a number of frameworks in order to identify themes from the conversations. The findings are presented in Chapter Six, which includes verbatim quotes from both the participants living with dementia and their partners in order to privilege their voices.

# **CHAPTER 6**

## **PHASE ONE RESULTS OF CONVERSATIONS WITH PEOPLE LIVING WITH DEMENTIA AND THEIR PARTNERS**

- 6.1. Introduction
- 6.2. Conversations with participants living with dementia
- 6.3. Memories as embodied experiences
- 6.4. Nostalgia
- 6.5. Holidays in time and place
- 6.6. Conversations with partners
- 6.7. Loss
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- 6.9. Dementia-friendly holidays
- 6.10. Reflections
- 6.11. Lessons learnt
- 6.12. Summary

# CHAPTER 6: PHASE ONE RESULTS OF CONVERSATIONS WITH PEOPLE LIVING WITH DEMENTIA AND THEIR PARTNERS

## 6.1. Introduction

The chapter will start with an analysis of the ten conversations with the participants living with dementia and their partners. The aim of the chapter is to provide insights into the significance of recalling holiday memories and its potential as a therapeutic aid for both the individual and their partner. The chapter highlights themes that emerged as a result of thematic analysis, namely, *memories as embodied experiences; nostalgia; holidays in time and place* for those who had dementia alongside those of *loss; changing roles and relationships* and the need for training and awareness which may lead to creating *dementia friendly holidays* communicated by their partners. The participants' own words are used where possible (see appendix B) in order to privilege their voices, and the analysis as a result includes verbatim quotes. The chapter will go on to explore some of the challenges faced when undertaking the research. Finally, in light of the disparity of results between the people who have moderate dementia and their partners, the need to adopt a multi-sensorial approach is advocated.

## 6.2. Conversations with participants living with dementia

Undertaking the conversations with the participants who had dementia raised a number of issues, on a positive note, asking them to sign their consent forms clearly gave them all a sense of empowerment and purpose, as many had not been asked for their signatures for a long time. Whilst they all struggled to see the line on the page to sign and needed reminding of what to write, the action of signing one's name is so embedded in memory that they all understood what was expected of them, indicating that they felt a sense of importance and pride in being considered. However, the research has also raised certain practical difficulties: some that were expected and others that had not been considered prior to the study.

These will be examined following the discussion of the emerging themes. The quotations used to exemplify the themes below will show the degree to which the language and structure of the participants' sentencing was not always clear.

### **6.3. Memories as embodied experiences**

The most obvious theme identified from listening to all of the participants who had dementia was the recall of the sensory experiences and my observations of them being communicated more through their bodies than their speech. Despite difficulties with language, all expressed themselves in terms of their senses and movement. This very often involved gesturing a sense, such as smelling and tasting a holiday memory, particularly since the recalling of food and drink cropped up time and time again. In this respect these results reflect Kontos' (2004, 2009) studies that explore the concept of embodied selfhood and contributes to recent discourses of embodiment and dementia in which people living with the condition are viewed as corporeal beings. Thereby, reconnecting to their sense of self through their bodies thus challenging the traditional idea that selfhood depends solely on cognitive abilities. Indeed, the recent literature identifies that a sense of self actually comes from a deeper primordial level (Kontos & Naglie, 2009; Meteyard et al., 2012; Downs, 2013; Zeiler, 2013).

As mentioned above, such displays of embodiment included non-verbal gestures such as hand movements and facial expressions conveying a passion for food, smells, sounds and memories of views. Geoffrey, Gareth, and Mike all displayed these gestures throughout the conversations. In the case of Gareth, whose passion was acting, his embodiment took on the effect of a theatrical performance, with him raising his arms in response to what he was trying to say. His facial expressions of smiling and his laughter brought about a sense of joy at reminiscing at the photographs and indicated a sense of wholeness of experience and pleasure. This joyful corporeality was also seen when conversing with Geoffrey when, at times, he managed to express himself verbally, indicating how the strong positive emotion sometimes gave him his voice back. Interestingly, Threadgold and Grennan (2003) have observed how sensory stimulation can help with relaxation and improve communication. There are also many anecdotal accounts and a few case studies of people who have dementia

transiently retaining certain cognitive skills for a moment in time, when participating in music (Pickles, 2005; Kontos, 2014).

Geoffrey particularly enjoyed the culinary experience of holidays, again indicating that the memory of the tourism experience was a more sensory one and not just cognitive. When looking at the photographs, memories of sights, sounds and smells were the first things that were recalled, as opposed to events and facts. Indeed, it is interesting to note that despite the lack of current literature exploring sensory experiences and emotionality within tourism with people who have dementia, tourism scholarship has started to recognise the concepts of emotionality, corporeality and embodiment as more than a cognitive experience but also a multisensorial and cultural one (Veijola & Jokinen, 1994; Franklin, 2003; Jokinen & Veijola, 2003; Small, 2007; Small, Harris & McIntosh, 2008; Richards et al., 2010; Richards, 2013, Fox, Humberstone & Dubnewick, 2014). When looking at a photograph of himself and Margaret eating at a restaurant, Geoffrey remembered the food and gestured the size of an enormous platter and said: *'for me it's a major part. Pigs that go on fires (pause) a plate with the head of a pig and the plate's like that (pause) it gets really hot in that.'* This memory was shared with Margaret, as she came back into the room *'The chop is bigger than the plate because we reckon they cross their pigs with dinosaurs in Cyprus.'*

When asked what he enjoyed the most about a holiday, Geoffrey tried to communicate his feelings about sitting by the poolside. He appeared to be looking back in time and visualising something in his mind's eye. He sat back in the chair and stared into space for a moment, crossing his hands on his lap, and then immediately sat up and gestured with his hands and tried to speak. Unfortunately, he could not get his words out, and became frustrated until Margaret helped to interpret. Here, Margaret and Geoffrey both shared the memory and she knew what he wanted to relay. He smiled as she reminded him of the names of the exotic drinks they had enjoyed together. This indicated to me the importance of reliving memories together as a couple. Geoffrey had no problems remembering the scene or the emotions attached to the memory but could not bring the words out. It was his gesture of having a drink in his hand – almost a re-enactment of the experience – that helped me to attempt to

interpret what he was trying to say. I felt his sense of joy at remembering a happy time, especially when he started to laugh and smile.

The sensory passion of memories of Italy was also experienced by Gareth. When remembering the taste of food, he conveyed general feelings of joy and happiness:

*You asked me earlier what my favourite place was (pause). It's Italy. It's a combination of people and food (pause). I think the Italian idea of a restaurant (pause), it's absolutely beautiful. And you've got me, you've got me feeling (long pause), so I think in a way I am really home.*

*Gareth*

In this respect, Gareth's inability to fully express himself verbally was not such a problem, since his facial expressions, intonations and hand gestures displayed his feelings. Just as Sutton and Williamson (2014: 318) identify that embodied experiences can supplement aspects of cognition and facilitate communication in people with intact cognition, it appears that this may also be the case for people living with dementia:

*In addition to these ways in which bodily processes influence autobiographical memory, we can also make sense of the stronger idea that the body just is, or perhaps is the vehicle of, such explicit recall.*

Gareth, Geoffrey and Mike communicated to me that they were literally revisiting their past experiences through their body and their senses.

Despite difficulties with his memory and language, Gareth remembered that I had asked him about his holidays earlier on in the conversation and the photographs helped with this. He appeared very animated when remembering them, despite being unable to remember names of places, apart from Italy. He certainly could *feel* the holiday and remembered how he felt at that time, indicating how he relied on his senses to bring about feelings of joy and wellbeing and how his embodied-self displayed this. Pauline referred to liking everything in a holiday: '*I think about all of it really. I like doing all of it, go out and have a look.*' She had little else to say, as her speech was severely compromised, and Bob took over much of the conversation. I did consider at the time the need to communicate with her through touch and her other



senses, which might have elicited more response. However, I did not feel that this would be appropriate with her.

When speaking with Mike, he appeared to be re-sensing a feeling of being on top of a mountain. As he was looking through photographs of a holiday in the U.S. he said, *'Oh gosh, there was an area where we could go'*, and sat back in his chair and crossed his hands and appeared to be embodied in his memory on top of the mountain. I let him stay within his memory for a time, since he appeared very content, before I brought him back to looking at other photographs. This, once again, indicated a connection between embodied memories and wellbeing, but clearly indicated that conversations and visual reminiscence alone are inadequate when exploring the meaning of recalling holiday memories. Mike continued to appear animated in between moments where he would *drift off* as if in a dream, I think he was visualising being in the place and time of the holiday. His facial expression and body language appeared content, despite not being able to express himself verbally. Indeed, it is possible that he recognised the memory more than recalled it thus, recognising something positive can have an impact on quality of life (Trigg, Skevington & Jones, 2007). Once again this may be an example of Mike's embodied selfhood in that particular space and time. He was particularly drawn to the photographs of architecture taken on holiday, which held great meaning to him, and he tried to relay this to me, although he showed his frustration with how the dementia was affecting his speech:

*The very respected buildings which were churches (pause), you see what it's doing to me now? I've got to wait until I can (pause). Not wait but I've got to keep trying (pause), can see it and then it comes, I see a picture, every time I mention anything to you now I'll see a picture of it (pause), the name eventually comes and especially if there's something about it that you might have done, been lucky with if you like or anything like that (pause) I had a lovely time.*

In contrast, Arthur initially showed no emotional response initially to the photographs of holidays abroad and resorted frequently to his well-rehearsed phrase of *'We thoroughly enjoyed'* and *'Over the years we went to many places but always a pleasant holiday'*. It is difficult to know whether he sensed anything when attempting to recall: indeed, it would

have been interesting to see if stimulating his other senses might have helped him remember more in an embodied way: *'God, I don't remember that. Hang on! Do you know, I have no idea where it is'* He tried to speak more factually about the photographs in terms of names of places, especially when he could find the words, but suddenly became excited when remembering a visit to some caves, which then went on to stimulate other memories:

*Where the hell it is, I don't know. Hang on! Something will jog my memory, I know (pause) yes, there we were going down into the caves (pause). We stayed along the coast there, I remember the breeze.*

*We'd go and see places like Sorrento obviously but we saw other parts too. There we are, there's a map here. Don't ask me where the hell it was. This is Sicily, isn't it? What was the other one? We went to Capri.*

He did, also, recall a sensory memory, when seeing a photograph of Niagara Falls in terms of remembering the sounds of his holiday: *'The one thing that impressed me was the noise.'*

As he started remembering, Arthur would refer to memories of his childhood where his mother cleaned the chapel and his father worked in the mines: his eyes appeared to light up and he became more effusive, gesturing with his hands:

*Our holidays were (long pause) and I remember these very early on in my life. We were living in London, Paddington, and we would travel one year to Tylertown and the next year to a little place in Montgomeryshire (pause) it was beautiful. It catered for very pleasant people. Dare I say it was "up market". Absolutely superb and it hasn't changed. It was a beautiful village.*

Interestingly, he appeared to sense and be more embodied in his earlier holidays as a child and in his twenties with Belinda than in later holidays abroad. This could be explained by the *reminiscence bump*, (Rubin, Rahhal & Poon, 1998) where our autobiographical memory allows us to recall more events from earlier years where memorable, positive experiences that have had a powerful impact on one's identity are more accessible (Glück & Bluck, 2007). This once

again, raises the point of autobiographical memory as an embodied phenomenon and not just a cognitive one (Sutton & Williamson, 2014).

#### **6.4. Nostalgia**

A resounding theme that arose when discussing holidays was the sense of nostalgia that was engendered when looking at the photographs. It could be argued that, as the participants were prompted to reminisce about past holidays, feelings of nostalgia would automatically arise. The difference between reminiscence and nostalgia is that reminiscence is the method that evokes the emotion: nostalgia. Whilst nostalgia could be considered under the theme of memorable embodied experiences, I have separated them only in terms of the participants' expressions about the process of remembering their holidays.

When I attempted to bring all participants back to the present day and introduce the idea of holidaying in the present, there were varying responses. Geoffrey and Pauline clearly had some insight into the stress they would experience if they travelled again. There were some times when Geoffrey had insight into time and place, wandering between memories of past holidays and thoughts of holidays in the future at their holiday home in France. He appeared to feel a sense of stress associated with it in terms of the garden work that was needed and his association with the stroke he experienced there:

*We (pause) one of the holidays coming up is a right tearaway. It's going to France (long pause) some of the things that I just can't (long pause) the grass is growing that high.*

Nevertheless, he soon moved on to looking through his photographs and his mood quickly changed to one of joy. They all clearly preferred to revert to enjoying the memories of the past. Gareth was inspired by his nostalgic feelings, which made him excited about future travels, indicating that he had little insight into his condition, Mike and Arthur on the other hand did not respond to any discussion in the present day but returned to the nostalgia of past holidays. Arthur indicated that he enjoyed the *looking back* and made some reference to the amount of time it took him to register the photographs, think about past holidays and

draw meaning from them: *'It's good for me to draw it back, if you've got a week to get it!'* (laughs).

They were all far happier enjoying the conversations and recalling the past holidays: even Pauline, despite her profound expressive dysphasia and visual impairment, appeared to smile and relax when we attempted to converse about past holidays, mostly with Bob's help.

Geoffrey, in particular, enjoyed himself when we discussed and looked at photographs of old transport, linking his occupation as an engineer to his hobby. Many of his and Margaret's holidays incorporated his passion for steam trains as a mode of travel. As he looked through the photographs of the trains, it was apparent that the strong nostalgic memories gave him a sense of pleasure and helped his speech as he relaxed.

*Oh once, this particularly favourite train was to go down and catch the...oh I can't remember it now but the train ride, it was 90 miles and then ho, ho, ho round the island and ho, ho, ho and then come back. And then on the way back you order your food.*

The nostalgia of Italy arose with Mike, just as it had with Geoffrey and Gareth. He remembered the architecture when on holiday: as noted earlier, this may be due to the fact that it also reconnected him with his self-identity as an architect and builder. Indeed, nostalgic emotions have been identified as helping to create meaning through providing positive human experiences (Wilson, 2005) and helping to reconnect to one's identity when recalling holidays (Bartoletti, 2010).

*I remember I loved Italy (pause), we went up to the top obviously where all the very respected (pause), oh dear (pause). The very respected buildings which were churches (pause). Yes, all churches, the area up there was absolutely terrific.*

Mike

Here, we can hear Mike's feelings of nostalgia for the buildings and how the churches were associated with a sense of respect and how it made him feel:

*I can see the place (pause), across the south of Italy, and it was lovely (pause), walls of hotels just before the mountains, and they had things like a place where they would people who played tunes on guitars, and pianos or whatever (pause), aah I remember that (laughs), (long pause, sits back). I built this, you know.*

Indeed, it appears that Mike's sense of nostalgia reminded him of who he was and the meanings he could place in relation to recalling his holidays. As he recalled his holiday, he reminded me that he was the architect and builder of the summer house that we were sitting in and that he was very proud of his work, which was intertwined with his identity. In fact, this resonates with Rosen (1975) who postulated that nostalgia could not only maintain but could actually restore a sense of meaning and purpose to the person whose life had been displaced through multiple losses.

*Oh yes, because in the evening they had this hotel, had a number of men who would do a little bit of dancing and a bit of singing and tried to get everybody to sing as well (pause) oh and (long pause), I like you being here*

*Mike*

Gareth enjoyed the photographs and the remembering of holidays immensely so much so that his sense of nostalgia for travel brought him back to life after he had slept in the chair and thus reinforced how valuable the conversations and photographs were in helping him to recollect positive meaningful memories:

*I just want to travel. There's a number of things I've never seen yet (pause) oh the Nile, it's daft to have an ambition like that isn't it, saying "the Nile". We went from there onto a plane with (long pause), triggered the alarm now (Pause), we went to, oh, God, where was it? It's just flashed into my mind and gone, you see (pause), I was a teacher of Geography, you see. I knew a lot of these things now but I've been stuck in my mind long enough*

Here it appears that Gareth is waking up from the effects of the dementia. All the participants clearly enjoyed being involved in the conversations where they became nostalgic for their past holidays, despite their varying degrees of cognitive impairment. Indeed, the issue of time and place started to emerge out of this nostalgia and became quite significant in terms of the results.

The increase in research using biographical methods over the past decade has highlighted the value that nostalgia can have in exploring the lived experience of the person (Cavannah, 1989; Chamberlayne, Bornat & Apitzsch, 2004; Sedgley, 2007; Merrill & West, 2009). Also, nostalgia is a recognised concept within tourism when identifying people's motivations, behaviours and consumptions (Sellick, 2004; Hsu, Cai & Wong, 2007; Tung & Ritchie, 2011b; Chen, Yeh & Huan, 2014; Leong et al., 2015). Linking a personal connection to a place or a different time is a powerful way of creating memorable experiences and creating a sense of identity in an ever-changing globalised world (Bandyopadhyay, 2008). It is even suggested that new positive life experiences can be experienced when making connections to previous experiences (Marschall, 2015). Therefore, nostalgia cannot be ignored in terms of exploring memorable holiday experiences and its effect on a person's sense of self and identity when going through difficult life transitions such as in dementia.

#### **6.5. Holidays in time and place**

I observed that perception of time and place was a key feature when conversing with the participants. There were many occasions when they were embodied in the past. People living with moderate dementia can have difficulty in distinguishing between past and present and subsequently live in a state of blurring between what is real and what may be imagined. Their perception of present time and place would often merge with the places of the past, indicating that they had difficulty distinguishing reality. Just as Chaudhury, (2008: 102) noted:

*A sense of one's past is more than knowledge of temporally sequenced events and experiences. The structure or order of that sequence is both temporal and spatial. In fact, it is the spatial aspects, the physicality of personally meaningful places, that make place so critical in regenerating the personal narrative of life. In place, we find the dimensionality of time and space merging to form the unitary dimensionality of place. In remembering the past through places, we arrive at the intersections of past and present (and potentially, future), of nearness and distance, and of temporality and spatiality.*

Gareth, for instance talked a little about going on holiday in the present, but he was unaware of the unfeasibility of being able to travel due to his deteriorating health following multiple strokes.

*Put this one to you (pause), what I'm going to say after it, being better. When I go on holidays now, I simply say, "Right, I like there," and that's where we go. What was it like? Completely removed from British things. I like going places I don't know and I like not going to places that I should know and so on (long pause), it's kind of (pause), that's a mixed-up kid (pause), but hey, let's just go. We've had some wonderful times together (pause) San Francisco (pause). I'm beginning to enjoy this experience of talking to you about these things: are we going to do some more? I'm going to start, June and I are going to start holidays again, and June and I had a lot of fun because we like talking to people.*

He would mix up the conversation between present day and past holidays without distinguishing between the two: *'My favourite place (pause), yes, (pause), there are things that drop off Italy which you would like very much: when are we going?'*

I did feel a little concerned that Gareth might have forgotten the reason for the research, since he started talking about holidays in the present. However, he stayed content throughout the conversations and June confirmed that it had been a wholly positive experience for him.

Often holidays would be remembered in the context of other travels and aspects of life. Mike moved between America and Eastbourne within the space of a few words. I think his memories started to flow as one when he started to *feel* the holidays. He described them in terms of his senses: scenic views, hearing music and enjoying the taste of cappuccino coffee. Phillipa filled in the gaps later in relation to the facts. Mike was probably referring to the promenade in Eastbourne at the start of this quote:

*And they had a lovely what they called the miner (pause), minet, (pause) it's a long distance of (long pause) a place where anyone walking down along the seaside could go in there and get a cup of coffee or anything to eat and all the rest of it, but it went right through (long pause) you could walk back about 100 feet and you'd hear the river. Well we always enjoyed having a nice place, a decent hotel with decent food and it was always there in the*

*mornings and that sort of thing. (Long pause) And we went to the very North of America on one occasion. And if you wanted to go into town you went along that road, turned right, well it would depend which way of course you were walking, walking back up towards the mountains, because at the very end, which was about a mile up the road I'd say, you were able to catch a bus almost where we were in the hotel (inaudible, speech wears off). And those buses would take you right through and up over the mountainside. Yeah and we went in George's car doing down from here...and this time we didn't go on the bus, we'd have liked to but we weren't able for some reason, oh we went on with Edwards or Evans now? The people who do, they're on the station area, Edwards it must be, yes, who would take you there for a week or whatever.*

He could see and describe the places quite well despite his language difficulties and his body language displayed his sense of *being there*. He seemed to be seeing the promenade at Eastbourne, then moved to America and then back to a holiday in Britain where the travel and the transport were quite significant. His sense of place was mixed up, as was his sense of time but that did not seem to matter to him, as he was enjoying remembering the overall feelings of his holidays. With Gareth, the importance of a sense of place came through very strongly: *'We have a place now, which is virtually our own little house. We always go that same place: in fact, we must go there today. This is splendid.'*

At times, when looking at the photographs, the participants appeared to be fully immersed in the time and place depicted. At times, when shown a photograph, the participant would remember the place first, not necessarily by name but through recalling being there: *'Someone who understands that if you sit in a chair in China, it's a different sitting down situation than it is for America, I mean it is.'* Gareth.

Indeed, it appears that recalling places has the potential to elicit recalling of time, events and experiences. Chaudhury (2002: 87) found:

*If reminiscence of places has the potential for giving access to memories of life experience in general, we can argue that places have the potential of anchoring, organizing, and facilitating memories. In their key role as the physical context of life events, places can acquire the symbolic power that*



*serves as anchors of memories in general. The physical grounding of a personally meaningful place gives them the organizing potential to give structure to human remembering.*

When viewing some of the photographs of beaches, Gareth recalled his first honeymoon in Portugal with his first wife, but did not remember her. He remembered the fact that he was on honeymoon and where it was, but the significance of who he was with had been forgotten: 'We had two honeymoons, didn't we, love?' Fortunately, June, his current wife found it a little amusing, albeit sad at the same time.

Whilst I attempted to make sense of the connections between time, place and identity, I was also aware of the potential for the dementia to cause delusions:

*Germany, (pause) yes not so keen there, I'll have to try and forget that now and who was responsible for Germany in those days? Adolf, of course. Who's that man by the way? I've not met him in that sense (pause), socially, but I think yes, I met him once and he frightened me a bit. He's one of the few men in this world, if they are still alive, go fight them.*

*Gareth*

The quote above indicates how it is difficult sometimes to elicit meaning and understanding from a person who has moderate dementia. It is tempting to try to tidy up the transcripts to make them neat and to make sense of what is said. However, we could so easily misconstrue the message. Gareth had just seen a photograph of being on holiday in Greece and was confused by the events in time and place and the emotional memories from the war. This was an unexpected outcome, in which reminiscing over pleasurable memories of holidays induced a mildly delusional state. Thankfully, this did not appear to concern Gareth and his experience of recalling holidays remained predominantly positive. The chapter will now go on to examine the themes and experiences of their partners' conversations.

## **6.6. Conversations with partners**

When discussing holidays, the partners, unlike the participants who had dementia, all displayed a sense of sadness and loss associated with their changing relationships and

associated roles since the onset of dementia. It was quite apparent that holidays had been an extremely important part of all of their lives and their relationships. The reminiscence and the photographs seemed, if any, to reinforce what they had lost. In this regard their focus was on the difficulties and practicalities of holidaying together in the present. A large element of the partners' contribution in the study was in relation to prompting their spouses to remember the facts around a photograph, such as what year they went, where the photograph was taken and other associated information, as if trying to test their memory. This is not uncommon: Gillies' (2011: 663) study of carers' journeys found that they wanted to help their family members who had dementia to 'try harder' to answer questions and she argues that it was because they wanted to 'show them in their best light and, in order to satisfy this desire to compensate for inability, repeatedly to test them in the hope that the appropriate memory will resurface.' This did become a significant issue within this study.

#### **6.7. Loss**

The conversations with the partners were more negative with *loss* emerging as a key theme when discussing their holidays. This adds to the literature surrounding loss and dementia where partners have identified that they miss the memories as well as the shared understandings and practical and emotional support from their partners (Baikie, 2002; O'Shaughnessy, Lee & Lintern, 2010). In this research, the partners quickly shifted from recalling past holiday memories to talking about the practical difficulties of holidaying since the onset of dementia:

*I don't think it helps going back. Basically, I think what she is doing now she is finding most tasks difficult, now that is all tasks. So, whereas before it would be like run of the mill, this, that and the other, I think I am a little bit concerned about now if we go on holiday abroad again.*

*Bob*

Interestingly, Bob felt a more profound sense of loss when on holiday than when at home, as it drew his attention to his wife's disabilities and cognitive difficulties. It is as if the time on holiday made the losses more apparent:

*It is sad, I find it sad when we are on holidays now. Because obviously I see more of the things that she is not capable of doing. And I am sad and angry at the same time, not at her (pause), not only for her but myself as well and the family.*

Just as Sedgley et al.'s (2017) study with parents of children with autism found that the noise and atmosphere of airports created stress and anxiety for both the child and the parent, Margaret also found that Geoffrey became frightened at crowded airports. Before his dementia, he had always been excited and in control of the travel plans. She noted how a previously familiar place had become threatening, thus culminating in her sense of loss.

*He would stick by me. But I do know that some people just wander off. The only time that I worry about Geoffrey is if I said to him, "Stay there and wait for me, I will be coming back" and if I was out of his sight I know he wouldn't stay there. He'd start looking for me. But in a crowd or something he would cling onto me because he would be unconfident then.*

Indeed, Margaret and Bob talked about limiting their journeys because of their partners' fears and insecurities during travel brought on by cognitive losses. The conversations continued to discuss the stress associated with going on holiday abroad, emphasising that staying at home or choosing a holiday in the UK was a better option:

*The thing is when we are at home (pause) it does frighten me, because when I am home and she has got me there, there is less problems. So, when we are in each other's pockets on holiday there are more stressful moments. So, we are going away now to a caravan and that will be most probably less stressful than going abroad.*

*Bob*

One of the biggest fears that contributed to the changing decisions associated with holidays was the potential of losing their partners when in an unfamiliar place where they might have a tendency to wander, not recognise places, know the time of day or make an inappropriate judgement:

*Arthur has got lost and though I say to him "Don't move from here," he is inclined to move from there... And I wouldn't have minded if he explored if he kept coming back to the same spot...I would say if it's got to that point where it was happening more and more, and it is, though on one occasion*

*he was only lost for 20 minutes. Seemed like a day to me when I think he could have gone out of that door, and be outside, not just be in here. It's like losing a child: you really don't know where to start because you go and say, "Have you seen an old man with white hair?"*

*Belinda*

This was reinforced by June's words:

*We've had a few times when it's been extremely stressful because Gareth literally has wandered off while I was in the toilet; he disappeared in Llandudno one year. I came back – not there. And that was after I had lost him in town because he hadn't been where I said sit there and have a coffee and when I came back he wasn't there. I had to call the police and it's – well I ended up having...going for tests in the hospital because I thought I was having a heart attack. If there was some sort of training that someone could have sat with him.*

Whilst their partners looked through the holiday photographs with fond memories, this research found that it stirred up a sense of sadness and identified another area of loss in their lives. This sense of loss naturally relates to their changing roles and relationship, not only whilst on holiday but in life generally.

## **6.8. Changing roles and relationships**

Whilst none of the partners wished to acknowledge their role as carers, and remained firmly identified as spouses, they all highlighted how their relationships had changed in terms of roles whilst on holiday. Just as in the literature on couplehood (see Chapter Two) where the changing roles and responsibilities are examined, so too, this study identified changes in relationships (Hellström, Nolan & Lundh, 2005, 2007b; Gillies, 2012; Molyneaux et al., 2012; Førsund et al., 2015; Merrick, Camic & O'Shaughnessy, 2016). In the past, Bob had always left the packing and the planning to Pauline, and he was now feeling quite stressed about having to take on her role in deciding what they needed to take as well as her mobility aids and glasses. Indeed, as Molyneaux et al. (2012), have identified how crossing traditional gender boundaries and roles can lead to anxiety for all members of society.

*The packing is now going to be an issue and taking clothes away. There is more pressure on me because I keep wondering what she needs to take, this that and the other. Yes, she would do the stuff and towels, yes but before she did all this.*

Bob

Belinda also talked of her role encompassing both of theirs. In the past, she was in charge of the packing and Arthur would plan the travel and undertake most of the driving:

*I now have to be planner, driver and map reader as well as doing all the things I did before like the packing and picnics. It's so stressful because I can't ask him if we are going the right way: we used to share this, now it's down to me and I am so tired. Arthur was absolutely excellent. If he went on a road once he would remember that and everything but now Arthur is way down in the bottom of the stream with regard to... and I know now I've got to get it right. But his sense of direction now is not as good at all but from what it was mine's greatly improved.*

On the other hand, they had to take over responsibility for both of them when in an unfamiliar place, indicating a shift in dependency. In fact, some of the participants living with dementia were aware of this change in their relationship. For example, I interpreted Geoffrey's use of the word *maintenance* in the context of him being looked after and no longer able to look after himself on his own:

*I'm alright travelling. Not in any way maintenance (pause), no, I'm not in any way having maintenance about myself. I have to do what Margaret says - increasingly (pause). If Margaret's with me it's alright, it's very very frequent I can't I know the things I want to speak and I know what I want to say, but I can't get (pause), but I let Margaret do the work.*

It came across here that the changing roles created by the dementia had shifted from equal partnership to one of dependence. Margaret felt like her role was changing into a maternal one: *'I know I'm bossy with him and I know I feel like his mother more than his wife now.'*

The stress and responsibility for the partner on holiday was discussed, alongside their own health and issues due to their age. This has resulted in a situation where they have to rely on

others for additional support. As Sedgley et al. (2017) found with mothers of children with autism that it is easier to spend holidays with friends who can offer emotional and practical support, this was also the case here.

*What I would be a little bit fearful of, and I don't think I'm over-emphasising that, I wouldn't want to travel abroad with Arthur alone. So, when we go to the family villa in September I deliberately arranged that one couple comes out with us and stays a couple of weeks and then another couple join us and that second couple would come back with us. I wouldn't be happy doing that on my own: I don't think I could cope with it. Not at my age now, I couldn't cope with it...I'm 79 next month and Arthur is 81 in July, I never know from day to day how I'm going to feel and I just couldn't chance it, whereas if I've got support there it gives me confidence.*

*Belinda*

Phillipa talked more about wanting to go away with her partner, but needing company to help her: *I just wish I had some friends that could come. Mike's family are so busy: it wouldn't be fair to ask them.*

## **6.9. Dementia-friendly holidays**

Most of the conversations with the partners started with the practical difficulties experienced whilst on holiday and moved on to identifying the need for training, awareness and access that might help them to continue to have holidays together:

*I asked for help at any railway station changes we had to make, I really had to hunt where that help was. It wasn't there as I expected it to be there when the train came in. I expected whoever it was to be there waiting for us.*

*Belinda*

A strong need for the industry to understand the needs of people who have dementia and their partners came through. The main areas of stress raised in my conversations with partners were in relation to travel, meals and going to the toilet. It was felt that toilets and mealtimes could be designed with people who have dementia in mind. This might well help reduce the partner's stress, as well as staff having an understanding of the condition.

*I mean, they can't read your thoughts, but if you were able to say to your waiter "Oh my husband, my wife, she has got a memory problem, so if you could just bear with us". And they would understand and say, "I'll come back to you afterwards – it's no problem", you know, and give you the time to deal with that person to see what they want to eat.*

*June*

Dining in particular was identified as an area where staff needed to appreciate that it takes more time for people who have dementia to eat. Also providing menus that are easier to read, that include photographs of the food would also help the person make a decision, since they would not have to try to process the words but identify the pictures more quickly. Also, noise absorbent surfaces would assist in avoiding distractions, thus allowing the person to concentrate more easily.

*You see, that's the other thing: when you're in a hotel you've got the waiters and waitresses coming around, they don't understand the situation and we saw it this weekend, if they're waiting for you to give your order, the four of you, because the hotel is absolutely full, and Mike's still looking at it trying to decide what to have. And he's quite slow eating, and we saw at least twice while we were away he'd still got food on his plate and his plate was snatched away. I think awareness of things.*

*Phillipa*

*As the dementia takes a hold of you, your table manners go. I mean, he would be probably very irritating to people around him because he scrapes his plate like mad. It drives me mad but I'm not going to say anything because that would just make more problems. He won't stop it. And he sniffs a lot. But if you're going out to a restaurant and he behaves badly. But if you know you're stuck on table 22 you know you go back to table 22 the next night, that's your table, so if you think if there was an option to ask for a more secluded table. He gets uptight straight away because he thinks people are looking at him and they know there's something wrong with him. I often think he should drink wine out of tumblers. He drops his food a lot, because I mean, when he's here I do put a pinny on him because you get fed up with washing, but if people could understand, perhaps we wouldn't be so embarrassed.*

*Margaret*

Margaret felt that a choice of more appropriate drinking glasses may help if the person has difficulty with their fine motor skills and the food on the plates need to contrast with the colour of the crockery to minimise visual difficulties. By avoiding shiny floors and walls and strong patterns, the person may also be less confused by what they see.

Bob voiced concerns about the use of toilets in aeroplanes and the importance of being able to sit next to his wife when travelling.

*I think I am a bit concerned now if we go on holiday abroad again, is simply things like going on an aeroplane. When we go on the aeroplane and you have got the toilets, how do they cope for people? You have got toilets where if you haven't got a major problem you can't go in the invalid toilet where you can go in with somebody and help them out. How does that apply on a plane? They won't understand that I need to be with her. I think that like I said to you last time I saw you about it is a must you have got to sit next to each other on a plane, so without paying the extra to guarantee that seat going there and back, there's an expense you are going to have to pay.*

*Bob*

Once again, Margaret brought up the need for taking more time when boarding aircraft.

*When I got there, I mentioned it when we were booking in. And it's not the walking thing, it's more the steps. If Geoffrey's going up the steps to an aircraft and there are people behind him, and he thinks they're pushing or he's holding people up, again, he doesn't want people to think that he's feeble. He's quite happy to go up, you know, and be assisted onto the airplane, because he did walk up the steps, we didn't go up on the trolley thing, but we were first going and came off last, and that's what made us late, you see.*

*Margaret*

Assisted passage can create more stress, as the person is often made to wait for long periods of time. Consideration needs to be made about how this time could be reduced.

*My worst experience was coming back from Amsterdam where we'd been to see his daughter-in-law and I had to push a wheelchair and a trolley because there was no way... no help...we've actually missed a plane having waited in the airport for four hours. Tour companies, they need to be more*



*aware that there are far more needs, far greater needs than they are supplying...and for staff to be aware, not just those at the top. It's no good the boss knowing all about it: it's the people who are doing the job of meeting the people, if they haven't been trained properly and know what's required.*

*June*

Once again, a recognised system that could identify needs prior to travel might avoid certain stressors. The stress of travelling and organising the logistics of the holiday alone was apparent:

*I said to them "Where shall we wait? And they said, "By the office where you rent the cars" and I said, "But it's raining." He said, "That's where we pick people up". Yes, in the rain and especially Geoffrey. Every time the bus came in sight he'd make off. He'd think "There it is, there it is" and off he'd go. And I kept saying, "No, it's going to come here, if it's our bus it will come here" but they don't always get that a bus is a bus. To cut a long story short, by the time an hour had gone they left us waiting there and I had to get a taxi back to the hotel.*

*Margaret*

Hence, there is a need to ensure staff understand that people who have dementia feel confused when in unfamiliar places and when having to wait for periods of time. Learning communication skills and having an awareness of how to help could avoid potential complications. Bob identified that dementia is largely an unseen illness and that people with visible disabilities are more likely to get assistance:

*I remember last year when we went to an airport she had a stick with her. And as soon as they saw she had a stick, because we were going on a gangway or whatever and then there was the flight stairs, straightaway they said "She has got a stick – if you go to one side, we will go in the lift." As long as people are aware you have got a problem they will help you.*

This was reiterated by Belinda, who identified how access for people with physical disabilities has been considered: *'Now we've done a lot for the physical with these ramps and things but I can't see we've done anything for the mental.'*

Against this backdrop it is not surprising that the need for specialist holiday provision for people who have dementia and their partners was identified. June felt that specialist holidays would be beneficial where partners' needs could be attended to at the same time, such as stress management services and relaxation therapies. This was a resounding theme throughout June's conversation.

*I tell you what would be brilliant: alternative medicine holidays (pause), you know with the Indian head massage and all those treatments you can have. The Reiki and the reflexology – those would be lovely because we both benefit from that... and somebody looking after Gareth and yes. Do you know what I mean? You need that, because you know, Gareth doesn't want to do everything I want to do on holiday.*

June

Unfortunately, the reality is that there are currently only a small number of companies that specialise in holidays for people with disabilities and an even smaller number that specifically cater for the needs of people living with dementia. None of the participants at the time of the research were aware of any. All partners agreed they would consider this type of holiday when their partner's condition deteriorated. However, Margaret was concerned that it would remind her of the dementia and that the role of the holiday was to provide a break from the routine of day centres and hospital appointments. She was amused at the idea of a dementia-friendly holiday when her perception of having a holiday was to escape from the dementia.

*In one way, it would be very nice because you would be with people who understand, you know, the carers would understand just exactly what you were dealing with and how stressful it can be. In another way because you are going to be dealing with other people's dementia (laughter) as well as your own (pause) it sounds a bit stressful. But having said that, Geoffrey loves being with other people with dementia because he says "They're like me."*

These thoughts were echoed by Belinda, who would not want to consider going on a specialist holiday at the present time but indicated that she may find a time in the future where it would be a benefit:

*No, I see enough of it as it is. I don't need to see any more of it, you know? You know going to Whitchurch to Pam and Jan (Alzheimer's Society support) and meeting other people in the same position is lovely but I don't really*

*want it on holiday. Not at the moment. I'm not saying I wouldn't ever want it, but as we are at the minute, no. I'm trying to turn a blind eye to it actually, because I know it could get worse and I want to make the best of what we've got now.*

Belinda implied that a specialist holiday would reinforce the fact that Arthur had dementia and she hadn't come to terms with it at this stage. However, she recognised the need for improved tourism services when people require help with complex needs.

*Well you just pick these little booklets up, don't you, and then you know where to go. But it's support you need. I don't need somebody trailing behind me all the time, I don't need that, but I need to be able that if I'm away, I can think, "Well it's no good ringing Pam and Jan in Whitchurch if I'm 200 miles down there," it'd be nice to know that there's a tourism information centre that I could go there and say, "Well right, now I'm in this predicament, what....?"*

*Belinda*

However, Phillipa saw the idea of a specialist holiday as giving her the opportunity for sociable times with others in a similar position to herself, as she feels isolated and trapped due to Mike's agitation when she is out of his sight.

*Oh yes, I think that a specialist holiday would be wonderful. And I also think if there were some form of organisation, because we haven't got friends, we've always done everything together, I mean yes, we've got people we know and chat to, but we've never gone out in a foursome or a sixsome or an eightsome. And I think if you could meet up with maybe three or four couples that were either husband or wife in the same situation that you could go to somewhere where it would be recognised.*

*Phillipa*

Phillipa also discussed the way a specialist holiday could overcome some of the difficulties she associated with past day trips by sharing her experience with others.

*But I would love to see, I mean if, for instance, and I'm not saying it would be the Alzheimer's Society, but something like that, a bit like they did the coach trips, if they said "Oh, they were going to do three or four days to so and so, and we're going to do you in groups of six, or eight", or something that you weren't on your own, you knew you would be with that group of people that, for instance, if that man's wife couldn't go into the toilet because she'd got a problem I could go with her. Or I could say to that man, "Well, can you make sure that Mike goes into the right toilet?" because Mike will say himself, he's actually gone into the gents' toilet and gone into the ladies to dry his hands and he has done that a few times.*

*Phillipa*

*This thing about people with dementia, once they're out of their day-to-day routine they are always a bit agitated*

*Margaret*

Interestingly, since this research was undertaken, Mind for You has been set up by a lady who has cared for a loved one living with dementia and provides such a service.

## **6.10. Reflections**

The conversations with the participants who had dementia provided rich and meaningful data that showed the value of recalling holidays. But it also identified the practical difficulties of researching with those who have communication and cognitive problems. Despite all participants being given a diagnosis of dementia, I was conscious of the possible sensitivities around using the term. Arthur denied his diagnosis during our initial conversation and I sensed that when I used the word *dementia*, his body stiffened and he started to raise his voice. At this point, I took a cue from Belinda and we moved away from the discussion of diagnosis. I chose to be sensitive to this, as he was very interested in the research and keen to be involved. He clearly showed signs of increased self-esteem when he communicated that it would be lovely to feel *useful* by being able to contribute to the research. He communicated to me that since he had started having difficulties with his speech and memory, he had felt depressed, withdrawn and introverted, because he was

conscious of being slow and was worried about what other people would think and whether they might become impatient with him. The decision to include him in the research, despite his denial of his diagnosis of dementia, proved an ethical challenge at that point in time. I weighed up the risks and benefits. It could be argued that it would have been unethical not to discuss diagnosis, as this was in the title of the research proposal and the information sheet and actually having a diagnosis of dementia was necessary to be included. However, despite increasing dementia awareness in our society, the stigma still exists and many people do not wish to be associated with the condition (Burgener et al., 2015).

However, by choosing to be sensitive, I chose to keep the focus away from his diagnosis and instead discussed with him the memory and cognitive difficulties that he experienced. He was happy to speak about these aspects of his condition and told me that he could not drive anymore due to his inability to judge the speed of the traffic. I listened attentively and actively. We went on to discuss the nature of recalling holiday memories and how we could go about this. As he had been a researcher in his working life, he valued the need for research, and wanted to feel *useful*. When discussing the information sheet with the other participants, they all *brushed off* the word 'dementia' and waxed lyrically about memories and how they loved to recall them, particularly holidays. Gareth had difficulty remembering June's name whilst he recalled the names of places he had visited. Once again, all were aware of their cognitive deterioration but did not want to associate it with the word *dementia*. I therefore took the decision, with the support of the participants' partners, to be morally sensitive, and focussed more on the nature of the research in terms of the cognitive and emotional changes they were experiencing, without focussing on the name of their diagnosis.

When adhering to process consent, the ongoing monitoring involved building the relationships further with working alongside the partners in monitoring their spouse's moods, affect, posture and behaviour for any signs that might indicate that they would not wish to continue. At the start of the visits, each participant remembered me well and welcomed me, recalling some discussion of holidays; however, they had all forgotten that it was in relation to a research study. I reminded them, they verbally agreed and we continued with the conversations.

The need for alternative ways of researching with those affected with the condition is evident. Also, the conversations with the partners identified the complex issues and needs of people who have dementia as well as the challenges associated with developing dementia-friendly holidays and inclusive tourism environments (Bianchi & Stephenson, 2014; Page, Innes & Cutler, 2015; Chrysikou, Tziraki & Buhalis, 2017). It is clear that training and awareness need to extend across the whole tourism sector in order for staff to understand how dementia affects individuals and their partner when on holiday.

### **6.11. Lessons learnt**

As previously identified, I was aware of the importance of developing a relationship with the participants by learning about their life history to give me some background to their lives and interests. Indeed, this proved to be very important in my conversations with the individuals who had dementia. Also communicating with the partners about the best time of day to have the conversations was important thus, appreciating any mood changes, tiredness and other health issues. I was also aware of the need to ensure that each conversation took no longer than two hours, as I did not want to tire the participants.

Attempts were made to overcome some of the communication challenges in the research in terms of the varying degrees of expressive dysphasia. In my experience, people who have dementia often speak in metaphor and use similar concrete words to the words that are lost in an attempt to express themselves. Examples in this study here were *hot water pot* for kettle and *sitting seat* for chair. Confabulation was another challenge, this is the 'unconscious act of filling in the gaps in memory by making up new material, rather than recalling actual information' (Killick & Allan, 2001: 106). Such creative use of language can be difficult to interpret at times but it can also be inspiring to hear somebody speak in this way when they are in a trusting and comfortable interaction. Whilst the use of photographs was aimed to trigger memories and help with communication, some of the participants had visual impairment. Pauline had visuo-perceptual problems and Mike had cataracts, which affected his ability to see the photographs fully. The need to introduce other ways of aiding communication was reinforced.

Other challenges associated with the study included the difficulties in analysing the audio recordings due to the conversations being frequently inaudible. I was aware of the need for non-traditional research methods alongside conversations and to consider more innovative approaches. In my reflected observations I recognised the need for more interactive, sensory approaches where the person was immersed in and had a greater sense of control over the research.

As a researcher and nurse, I made sure that on leaving, I stressed the importance of their contribution to the study. As I found that some of their personal situations were difficult, with no social network or support from social care, I offered to liaise with the memory team, social services and the Alzheimer's Society on their behalf if they required. However, there were times when I became a sounding-board for complaints about treatment within the health service. My challenge was to listen, support and then refer them back to the original conversations about holidays to search for meaning that was relevant to the study. The relationship between myself and the participants involved offering them comfort and support whilst bringing them back to the conversations about holidays. Whilst it is important for the researcher to have much experience working with people who have dementia and their partners, there is also the need to maintain awareness of the aim and objectives of the study throughout.

Due to the nature of dementia affecting the person's speech and their vulnerability, the partners often remained present during the conversations. However, the partners who sat in on the conversations frequently tried to test their spouses' memories whilst we were looking at the photographs. Whilst this did not always seem to concern the participants who had dementia, I was conscious of the power imbalance. On the other hand, this actually helped to foster conversation and engage the person who had dementia.

As well as the limitations, phase one has identified positive aspects of undertaking research with people living with moderate dementia, such as giving the participants a sense of purpose, raising self-esteem and mood. The reminiscence proved a therapeutic aid in eliciting memories and engendering a sense of nostalgia for the participants living with dementia. This

study suggests that once cognition is stripped away, such as reasoning and speech, the sensory self may be more powerful in reminiscing with a view to *being there* in that moment of time. The experience of the people who had dementia was not a negative one, their embodied selves displayed positivity and a sense of joy.

*Oh absolutely. I think this conversation today has been magnificent, (pause) you must come to see us again and we'll talk again on a topic, I think of your choice.*

## **6.12. Summary**

This chapter has presented the emergent themes from both groups of participants, thus identifying the meanings and significance of recalling tourism memories for both the person living with dementia and their partner. The analysis of the results from the conversations with the participants who had dementia did draw out quite complex categories that involved the sense of self in space and time and sensory memory. Interestingly, all participants who had dementia constantly referred back to memories of previous holidays. Whilst four of the five participants communicated that they looked forward to more holidays, it could be argued that they either had little insight into the degree of their dementia affecting the feasibility of going on holiday again or that they still sensed a hope that they would travel again. The results draw attention to the differences between their world compared to their partners in relation to temporal and spatial awareness of the tourism experience. The themes have been discussed in depth in light of the positivity of the people who had dementia compared with the feelings of loss for their partners. The chapter has discussed the value of adopting holiday reminiscences as a therapeutic intervention and a method of stimulating memory for those who have dementia, whilst identifying the limitations in only using visual prompts and the challenges experienced due to communication difficulties. The results from the partners have been discussed in terms of the practical difficulties experienced when on holiday and recommendations have been made for the tourism and hospitality industry. The chapter has also identified that over time, it may become less feasible for couples to go on holiday together due to the degenerative nature of dementia, thereby identifying another loss.



In light of these challenges and the need to contribute further to dementia and tourism scholarship, I instigated a second phase of study. The next chapter will introduce phase two, which aims to bring together the person living with dementia and their partner by exploring the concept of virtual holidays as a therapeutic intervention using reminiscence and multisensory work. Drawing from Susmann and Vanhegan's (2000) study that identifies the role of virtual holidays for those who cannot travel due to severe disability. This second phase will explore the role of recalling the virtual holiday for those living with dementia and their partners.

# **CHAPTER 7**

## **PHASE TWO METHODOLOGY**

- 7.1. Introduction
- 7.2. The development of sensory ethnography
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- 7.9. A suitcase of memories – the methods
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- 7.11. Summary

## CHAPTER 7: PHASE TWO METHODOLOGY

### 7.1. Introduction

The aim of this chapter is to examine the critical methodology of sensory ethnography (SE) and its associated multi-sensory research methods, which make up phase two of this study: the suitcase of memories. Following on from phase one, the theoretical and ontological orientations of the research are the same but with a stronger emphasis on critical theory. The chapter outlines the development of sensory ethnography as a new and emerging methodology and discusses the principles underpinning it. Whilst little applied research has been conducted in tourism and dementia scholarship that attends to the senses, the chapter goes on to explain where this may sit within hopeful tourism. The chapter examines how sensory ethnography's creative, intuitive approach offers an appropriate methodology to overcome many of the barriers associated with researching with people living with dementia and describes how it is practically embedded into this study. It goes on to discuss the methods involved visit by visit, highlighting the senses that stimulated memory and vice versa. Finally, key considerations are discussed in relation to undertaking sensory ethnographic research with people living with dementia.

As the world of the individual with moderate dementia is a truly alien one to me, I needed to relate to them by stimulating their senses, particularly in light of the communication issues I encountered in phase one. Hence, sensory ethnography was identified as a way of achieving this.

### 7.2. The development of sensory ethnography

Pink (2015) coins the term 'sensory ethnography' as an overarching phenomenon to describe a methodological approach to research that does not only privilege vision and voice but also takes into account other senses. It is more of a philosophy than a pure methodology, as it incorporates critical study of the nature of *being* by finding connections between complex experiences whilst exploring ways of understanding and knowing through multisensorial

experiences. Sensory ethnography is critical in the sense that the researcher needs to be reflexive, intuitive and perceptive in order to elicit meaning. This is not always through speech, but can be through deeper intuitive means of communication from the senses (Pink, 2015). It is a new and emerging innovative methodology that acts as a framework for multiple research methods, which does not follow a straightforward, systematic way of gathering data, analysis and dissemination. Emerging from the disciplines of anthropology, cultural studies, geography (Rodaway, 1994; Seremetakis, 1994; Classen, 1998; Howes & Classen, 2014) and embodiment scholarship (Merleau-Ponty, 1962, cited in Kontos & Martin, 2013; Csordas, 1990), sensory ethnography has evolved to allow the researcher to create meaning and understanding through attending to their own sensations and emplacement within the research as well as the participants' (Howes, 2003; Stoller, 2010). As Bull et al., (2006, p.5) state: *'The senses mediate the relationship between self and society, mind and body, idea and object'*

As stated earlier, qualitative researchers, are situated, sensorial, embodied beings that have an impact on research and it is therefore important to be aware of the influence senses have on creating ways of knowing and the meaning we place on experience. The senses encourage *'the conveyance of emotional states through vivid aesthetic sensual immersion'* (Nakamura, 2013: 133). For example, in Edvardsson and Street's (2007: 30) autoethnographic study of nursing accounts or *epiphanies* from their fieldwork in a hospital environment, they found their own senses were important in contributing to meaning-making.

*I became increasingly aware of a number of small epiphanies: sudden intuitive realizations that the use of his senses in these environments was gradually changing the way he asked questions and conducted observations.*

Traditionally, in research where sight is privileged over other senses, the observer is often distanced from what they are observing. This has perpetuated an objectivity in much research. Hence, there is a need to be sensorially immersed in the research to explore the deep layers and richness of data that may be generated.

In light of the results from phase one, this stage provides a more holistic interpretivist and critical approach to observation that highlights the sensory interrelationships with place and time. It allows for exploration into how memory, personal history and *ways of being* associated with the senses contribute to a more richly embodied experience: a personal sensory landscape (Law, 2005). The idea that sensory ethnography helps to *reach beyond* what is usually observed and draws meaning from phenomena that would otherwise be invisible is clear in Sunderland et al.'s (2012: 1056) study of a culturally diverse group of Australian urban residents, many of whom were semi-literate. They explored health in relation to their environment by walking with the locals and experiencing the phenomena with them in a multisensorial way which elicited rich and meaningful responses. They identified that sensory ethnography can assist the researcher by combining with other methods such as photovoice, interviews and observations to explore what it *feels* like to live in certain places and how this impacts on health and wellbeing. In order to understand its value in greater depth, it is important to understand the principles that underpin this methodology.

### **7.3. Principles of sensory ethnography**

The main principles of sensory ethnography will be explored in relation to undertaking research with people living with dementia: emplacement, interconnected senses and knowing in practice (Pink, 2015). Firstly, the concept of emplacement as a key underlying principle runs parallel to the shifting dementia scholarship of connecting with people who have dementia through the concept of *being with* in place and time (Howes & Classen, 2014). Rather than externally and objectively conducting research on people, the researcher becomes emplaced within the world of the co-researchers, moving beyond embodiment where the relationship between mind, body and environment is examined. Bodies are not separate abstract objects but are embedded in the dynamic complex social, cultural, environmental and temporal experiences of life, thus *being in the world* (Merleau-Ponty, 2002).

Another principle is to consider the use of the senses in a multisensorial and interconnected way (Seremetakis, 1994; Ingold, 2000). Whilst we predominantly categorise the senses as

visual (seeing), auditory (hearing), olfactory (smell), gustatory (taste) and tactile (touch), it is important to note that aspects such as kinaesthetics (movement), perception of time and insight can be included in sensory ethnographic research, contributing to the embodiment and emplacement of experience (Classen, 1997; Pink, 2008). This is particularly pertinent when undertaking research with people living with sensory impairments. It is important to view the senses as interdependent and not to privilege one sense over another, as one can run the risk of marginalising participants who may have one or more sensory impairment. This study aimed to explore the richness of human meaning through examining multisensorial, highly complex interrelationships involving body, senses, time and place when identifying the experience of recalling holiday memories. Such multisensorial emplacement can help to establish a sense of *knowing in practice*, through analysis conducted with and by the co-researchers iteratively and inductively. According to Van Manen (1990), the most effective way to explore and enter a person's life is to be a participant in it.

What cannot always be conveyed verbally may be communicated through non-cognitive ways of knowing through intuition. This approach is pertinent to researching with people living with dementia when their cognition is affected, limiting their language, reasoning and understanding, but not always their senses (Bartlett, 2012). The challenge of adopting sensory ethnography is to explore and make meaning from what is sensed and not necessarily what is said.

The principle of sensory ethnography as being critical in its approach emphasises the importance of researcher reflexivity and the reduction of power relations. This allows for constant reflection and reflexivity of the researcher and co-researchers. By working alongside the participants, they can choose the appropriate methods together in that specific moment in time and make decisions about how they want the research to progress. This may be difficult if the co-researcher has problems expressing themselves, but just as process consent (Dewing, 2002) gives a framework for ensuring the person's wellbeing, it can also be adopted when observing non-cognitive ways of knowing to help influence the direction of the research. This approach enables the study to respond to the fluctuating nature of the person living with dementia. Sensory ethnography provides a more creative, fluid process of

exploring people's constructions of places and memories and what happens during that moment in time or experience. In this way, it can contribute to the development of hopeful tourism scholarship in light of the already developed studies on embodiment and sense of place and close links with human geography (Latham, 2003; Pocock, 2014).

#### **7.4. Undertaking sensory ethnography**

There are no guidelines about how to undertake sensory ethnography. Whilst it attempts to re-view traditional methods of ethnography by incorporating the above principles of emplacement, interdependent multisensoriality and new ways of knowing, participant observation traditionally involves seeing and writing. In sensory ethnography, what is seen is not necessarily the dominant means of creating knowledge, but instead the interdependent use of the senses. Before beginning, awareness of my own senses was important in order to explore the potential subjectivity of my experiences (Pink, 2014). It is necessary to understand that, whilst the co-researchers might be from the same culture and social class, differences in age, life experience, generation and the dementia may impact on their own sensory bodies, which may be very different from my own. As such, sensory ethnography recognises the impact of subjectivity, and instead of this being regarded as a limitation, it is explored and taken into consideration, highlighting the very individual nature of recalling experience through the senses. Reflexivity thus is the starting point, allowing the researcher to explore their own sensory ways of knowing through an autoethnographic process, in order to become emplaced with a view to exploring and understanding other people's ways of knowing through the senses. Attending to and documenting one's own sensory ways of knowing helps the researcher to understand themselves and therefore to explore other people's worlds through their sensory ways of knowing. The *being together* in sharing sensory activities such as eating and drinking and feeling emplaced within the co-researcher's environment can create serendipitous, intuitive sensory learning (Pink, 2015). As Barone and Eisner (2012: 1) state, '*Humans have invented forms within a spectrum of sensory modalities in order to "say" in that form what cannot be said in others*'. However, when using a sensory ethnographic framework, verbal communication is not ruled out but can be used to situate the results. Sensory ethnography allows for the use of traditional methods of research alongside adopting innovative sensory approaches. It still values ethnography and can incorporate participant

observation and interviews within its philosophy, but it adds another layer which creates a richer phenomenological approach, thereby creating ways of experiential knowing and giving the researcher more tools when researching with people whose verbal skills may be impaired.

In relation to the analysis, Pink (2015) asserts that there is not a rigid systematic structure where place and time separate fieldwork from analysis. Theories can be generated alongside the fieldwork. Therefore, the first point of analysis can be situated with the production of knowledge, which can be on the first ethnographic encounter with the co-researchers and continue to be conceptualised throughout the research. Analysis can occur intuitively when extrapolating the meanings of the experiences and materials that explore the senses. Analysis is corporeal and intuitive and can occur during the fieldwork and away from the ethnographic encounter. The aim is to explore connections between the experiences, objects and ways of knowing. This is not to say that traditional forms of analysis are not used to identify themes, but *'it may happen during the fieldwork as part of an ongoing ethnographic – theoretical dialogue, as well as through the materials produced by it'* (Pink, 2015: 141). Since this is an emerging field, Pink (2015) urges researchers to document and reflect on the methods utilised and report their findings in order to contribute to the development of sensory ethnography as a methodology.

### **7.5. Sensory ethnography and tourism**

As we can see from Chapter Three, tourism scholarship started to consider the senses with Urry's (1990) seminal work on the tourist gaze. The major critique of sight being privileged over the other senses led to tourism studies viewing the tourist experience as a corporeal embodied phenomenon that involves multisensorial encounters (Franklin & Crang, 2001; Markwell, 2001; Crouch & Desforges, 2003; Dann & Jacobson, 2003; Pan & Ryan, 2009). This is further exemplified in the emerging tourism scholarship that has considered the experiences of people who live with sensory disabilities (Richards et al., 2010; Small et al., 2012; Domínguez, Fraiz & Alén, 2013). Whilst there are no studies to date that adopt sensory ethnography as a methodology in tourism scholarship, sensory geography has lent itself to a similar ethnographic approach. Walmsley (2005), for example, explored the relationship



between taste and other senses and how they can determine a sense of identity, place and belonging through food with the indigenous people of Ecuador. Thus, it is a methodology that can extend itself to critical tourism scholarship by using multisensorial methodologies such as enactment and performance to elicit data (Hunter & Emerald, 2016). This thesis does exactly that, by exploring aspects of tourism through the multiple disciplines that underlie dementia studies.

## **7.6. Sensory ethnography and dementia**

Whilst it is now recognised that research needs to involve people who have dementia in a participatory way, the majority of qualitative research continues to largely rely on observation and interviews (Camic, Tischler & Pearman, 2014; Read, Toye & Wynaden, 2016). Hence, there is a need to represent people's voices through more creative means to help overcome the cognitive difficulties that people experience and to reflect the embodied experience of living with dementia. One such example is Kontos and Naglie's (2006: 314) ethnodrama production of 'Expressions of personhood in Alzheimer's', in which they re-enacted life scenes from their field notes of observations of people living with the condition as well as nurses, occupational therapists and physiotherapists. In doing so, they aimed to represent the patients' experiences in order to engender a sense of empathy. Such a shift in focus from one that privileges text to a more sensory performance helped to disseminate aspects of the embodied self-while living with dementia to others. Their aim – to compliment the paradigmatic shift of personhood through their enactment ethnography – helped the observers to identify people who had dementia as *embodied beings* who deserve the right to be treated with dignity and respect. Whilst dementia scholarship is starting to explore the value of using multiple senses in helping people to express themselves through creative means (Griffiths et al., 2016; Sánchez et al., 2016), researchers mainly continue to use traditional research methods to explore the experiences of those who have dementia. To date, only one study has attempted to adopt sensory ethnography partially as a methodology within dementia scholarship (Bartlett, 2012). However, it only attended to sight, sound and movement and did not truly explore the issue of the participants' and researchers' sense of emplacement or the multisensorial experience.

Sensory ethnography attends to gestures and embodied communication and holds value in helping the researcher to develop more tacit knowledge by attempting to understand the things that the co-researchers do and express in other ways: that is, the dimensions in life that people do not talk about, but have ways of experiencing and communicating that are not necessarily verbal. The value of using sensory ethnography as a research methodology when researching with people who have dementia is that it invites a more experiential and reflexive approach to gaining more knowledge and understanding of experience. Since sensory ethnography is a new and emerging approach, few studies have embraced it as a methodology. This creates quite a challenge for this research, as there is little scholarship to draw from. However, it is with the premise that methods, such as interviewing and focus groups, are limiting and can neglect and omit the very essence of meaning and significance being sought that this study seeks to find an alternative approach.

### **7.7. Access, sample and pen portrait**

In phase two, as in phase one, I needed to explore the ethical issues surrounding the use of sensory ethnography for the suitcase of memories. As part of this process I had to submit Cardiff Metropolitan University's ethics forms, information sheets and consent forms (see appendix A). This included gaining permission for the possible use of audio or videotaping the co-researchers and creating a digital story with them that might also be used for specific academic purposes such as conference presentations and publications. In addition to this, I had to present a list of questions that I was going to include in the conversations. This contradicted with my desire to let the co-researchers lead.

The ethics process also required me to discuss how I was going to recruit the co-researchers, which in reality was a difficult process. In phase one the local Alzheimer's Society (AS) had willingly given permission for me to recruit at their events. However, when I attended a Singing for the Brain activity with the AS for phase two of the study, I was informed by a member of staff that permission for access was no longer granted at a local level, since the charity had become more centralised in its planning and operations. I was given a series of forms to complete about my study and my background and involvement before they could

give permission for access. The level of information requested was intrusive and overbearing since it required in-depth descriptions of my planned research and whilst aiming to protect people living with dementia, such a high level of gatekeeping and control prompted me to search elsewhere for co-researchers.

I, therefore approached two carers whom I know well – one whose father had severe dementia and the other whose husband has Alzheimer’s disease – to find out if the people they cared for would be interested in participating in phase two of my research. Both declined: the daughter did not think her father would have consented to any research if he had full mental capacity, while the partner felt that the research would yield nothing and was quite negative when I spoke of using props to help initiate memory and speech and stimulate the senses. She felt that whatever I did, as the researcher, it would not replicate the *being there* on holiday. These are two examples of how family members are also gatekeepers for recruitment into research. It was apparent that premorbid relationships (prior to illness) play a significant role in how relationships change in light of the dementia and the decision-making that occurs around the disease. In the meantime, an ex-colleague, Carla, contacted me to tell me that her mother had been diagnosed with Alzheimer’s disease five years ago and was living at home with her husband, and that they might both be interested in participating. We therefore arranged a visit at their home between the couple, Carla and myself.

The sample for phase two therefore involved one couple: a husband and wife whose pen portrait is described in figure 6.1. Such research is not examined through large sample numbers but more through the depth of experience of the researcher and smaller numbers of co-researchers. This is supported by Holstein and Gubrium (2004), who postulate that richer and more in-depth insights into social contexts can be gained from small samples. Also, as mentioned previously, the challenges of undertaking research with people who have dementia mean that it is only practical to use a small sample.

**Figure 6.1. Pen portrait phase two**

**David and Georgia**

David, aged 84 and Georgia, aged 80, live together at home and have been married for 58 years. They met as children, as they lived in neighbouring mountain villages in the Swansea valley. David was an industrial chemist who had been made redundant in his 30s and reluctantly became a maths teacher, and Georgia was a civil servant. David was educated to degree level and Georgia, whilst clearly intellectual, had not had the opportunity to go to university due to financial constraints and the expectations for women in the 1950s. I immediately sensed her frustration in relation to this. They had two children, one boy and one girl, who both had successful medical-related jobs. It is interesting to note that their social class and ethnicity were similar to mine. My father had also been an industrial chemist who then moved into teaching chemistry and I was a nurse who had trained in the same era as their children. Thus, there was common ground on which to develop our conversations. They had travelled extensively in their lifetimes, from camping in the UK to holidaying in Europe and later visiting their daughter, who lived in Australia, on three occasions. Their home was comfortable, clean and tidy. Georgia was diagnosed with Alzheimer's disease in 2014. David did most of the housework and cooking, having taken over the role from Georgia. He was tired and Georgia was aware of this and voiced her frustration over not being *trusted* in the kitchen anymore. They were both proud of their gardens, which were tended by both of them, with Azaleas blooming in the back garden. Their favourite joint pastime was to go for a drive to the local seaside village and to enjoy a coffee together after walking along the promenade, since they were both still physically mobile and fit.

## 7.8. Autoethnography

The first stage of any sensory ethnographic practice should involve an autoethnographic enquiry (Pink, 2015), focusing on how the researcher might respond if they were posed with the research question. This can lead to a heightened sense of empathy; in this case, in relation to reminiscing about holiday memories. Through analysing one's autoethnography, we can attempt to understand what our reactions would be when situated in a similar place to the participants rather than just observing and recording their behaviours. Attending to one's own sensory experiences can assist in understanding others, thus extrapolating knowledge from the collaborative research through shared understandings. Indeed, by being aware of how I use my senses from biographical and cultural perspectives, I have become more receptive to how other people use their sensoria. Such a method has allowed me to explore similarities between my own experience and that of the co-researchers, particularly in relation to being emplaced in recalling holiday memories. Being immersed in my own reflexivity increased my empathetic way of knowing and understanding, which informed the development of the suitcase of memories. Through this approach, I could explore the beliefs, values and meanings that the co-researchers placed on the experiences at each visit. As Pink (2015: 98) states:

*The sensory ethnographer would not only observe and document other people's sensory categories and behaviours but seek routes through which to develop experience-based empathetic understandings of what others might be experiencing and knowing.*

Autoethnography has developed recently and lends itself well to tourism scholarship (Botterill, 2003; Sikes, 2006; Noy, 2007; Scarles, 2010). Since the researcher becomes situated within the research and not on the outside, more insight can be provided that is less objective and more relative. Scarles' (2010: 910) visual autoethnographic accounts of tourist experiences create a space for understanding which would previously have been undiscovered:

*Autoethnographic experiences are reconstructed and relived through conversations with respondents through the visuals presented within the space of the interview as both researcher and respondent reflect upon their experiences within the same or similar contexts*

Indeed, within this research, when visiting the co-researchers, when they unpacked their suitcase, so too, metaphorically, did I. Such multisensorial reflexivity has made me appreciate the value of the autoethnographic process of sensory ethnography as a research methodology. When considering rigour whilst adopting this research approach, I explored Lincoln and Guba's (1984) criteria but found it not appropriate, since they do not allow for research that reflects the embodied, emplaced experience in a snapshot of a moment in time. Therefore, their criteria, which include triangulation and transferability, do not apply. There is the issue surrounding what is an accurate representation of events in light of researching with people living with dementia, as their memories may be hazy, and as noted above, this paved the way for adopting a more critical theorist approach. As Denzin and Lincoln (1998: 12) highlight:

*Any gaze is always filtered through the lens of language, gender, social class, race and ethnicity.... individuals are seldom able to give full explanations of their actions or intentions; all they can offer are accounts or stories about what they did and why.*

Thereby I noted that rigour can only truly be applied to studies that are reductionist in nature.

## **7.9. A suitcase of memories – the methods**

This research focussed on creating a metaphorical and actual suitcase of memories as a prop and a metaphor for David and Georgia's identity. The idea was inspired by a friend's theatre company – Taking Flight: Scenes from a Suitcase – which specialises in theatre with actors who are marginalised in society (Taking Flight, 2016). The suitcase represents an individual's identity, and in this instance, the identity of both Georgia and David. Stevenson (2014: 338-9) noted that '*Mind is loaded into performance tools, texts, practices and cultural artefacts we use as we move through landscapes*', and that '*Memories are mediated through artefacts*

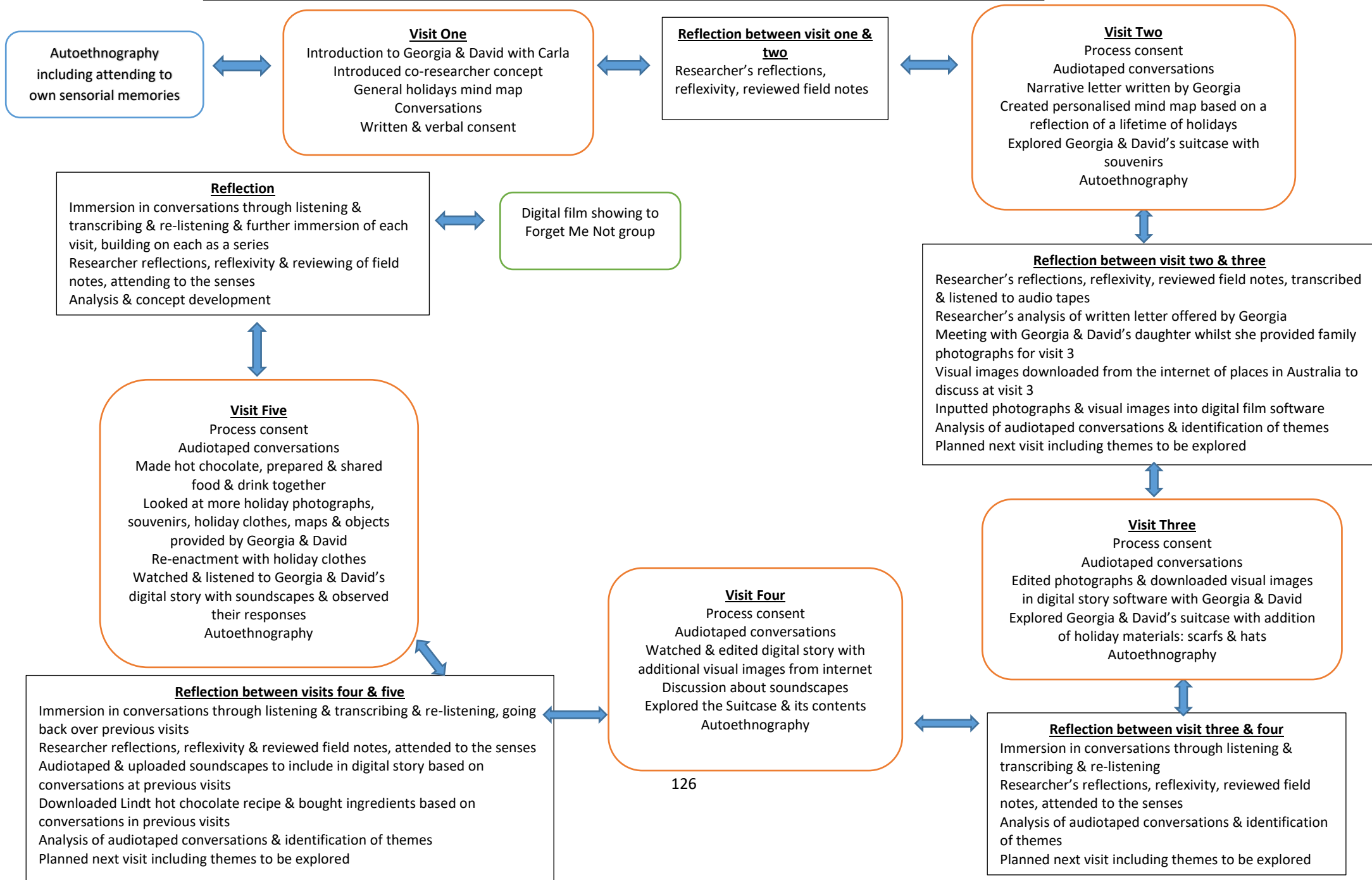
*and technologies*'. Thereby, this use of tangible *things* such as the suitcase and its contents helped as prompts when uncovering their stories. Stories and themes naturally built upon each of my visits and provided new ways of knowing by attending to the senses. When undertaking this research using sensory ethnography, a number of conceptual stages were identified during the practical sessions, making it an iterative approach. For example, as I was immersed in the co-researchers' world during the ethnographic encounters, on returning home I wrote field notes and engaged myself in transcribing the audio recordings of the conversations (11 hours in total), re-listening and re-reading the transcripts a number of times for the analysis. Implicit and explicit meanings were explored when referring to my field notes, listening to the audiotapes and reading the transcripts. The transcripts were coded. At the following visit, I spoke with the co-researchers about the themes that had been identified previously to provide opportunity for them to make further observations and comments. The salient points that arose during the conversations on each visit indicated strong memories and strong associations between the senses and the memories. These were explored by attending to the co-researchers' senses, their expressions and being emplaced in their world.

The research process also included my insight and intuition, informed by my experience and knowledge of working with people living with dementia, my autoethnography and the growing relationship I had built up with Georgia and David. Thus, new ways of expression were created through the sharing of experience. These experiences and interactions provided me with the insight to create a digital story with soundscapes, which I played to Georgia and David on my final visit whilst enjoying other sensory delights and examining holiday artefacts and souvenirs and enacting memories when wearing accessories associated with holidays. The process of creating a digital story alongside using other senses when unpacking the suitcase of memories has shown how elements of the research design lend themselves to the process of inquiry and to the outcome of the study. As Parr (2007) noted in her research examining the effects of video filmmaking with people with severe mental ill health, the use of film can engage people in research who are often disengaged from society, whether due to health or social problems.

The rest of the chapter will explain each of the visits in more detail, describing the methods adopted, starting with figure 7.2 as a visual representation of the development of the research as a whole and indicating the iterative nature of the research, analysis and reflections.



**Figure 7.2. A suitcase of memories – multisensorial methods**



### **7.9.1. Visit One**

Carla and I arranged a visit to meet her parents to discuss the research and their potential involvement. As Carla had introduced me to her parents, an element of trust had immediately been established. Carla works within the field of ageing and dementia research and so we were both mindful of not coercing her parents into the study. I assessed that Georgia had the mental capacity to consent to the study by her clear understanding of what I was saying and the questions that she asked: she showed no sign of receptive communication difficulties. However, in light of the study being undertaken over a period of time where her cognition might deteriorate, I followed the process consent approach (Dewing, 2007). Hence, we discussed the involvement of Georgia, David and Carla in monitoring signs where Georgia might feel uncomfortable in the study. Georgia and David were happy to consent to the study, however, Carla needed to remind Georgia what name she needed to sign on the consent form as she faltered and considered signing her maiden name. She did not seem perturbed by this but David looked a little concerned. During this visit, I introduced the couple to a large mind-map that I had created, which covered many aspects of holidaying (see appendix C). This provided both Georgia and David with a visual prompt, as well as the verbal and written information sheets and consent forms. During this first visit, I made it clear that the length of time over which the research would be conducted was uncertain and would depend on the conversations emerging and what they, as co-researchers, wanted to bring to the study. We discussed that they had an equal say in how the research would develop and that I regarded them as co-researchers. Using sensory ethnography makes it more feasible for participants to become co-researchers, since they are able to respond more freely through the senses and communicate how the research should evolve and develop. Such a participatory approach to researching with people who have dementia therefore promotes equality and reduces power relations.

During the visit, they both gave verbal and written consent to participate. Hence, I requested that they gather together any photographs, holiday memorabilia and a suitcase in preparation for my next visit. Whilst I did not audiotape this visit, on leaving their home, I wrote field notes.

### **7.9.2. Visit Two**

Three days after visit one, I returned with flipchart paper, coloured markers, a map of the world, my digital recorder and spare batteries. Surprisingly on arrival, Georgia handed me a handwritten letter which described her views about how the dementia affected her and how she felt about being involved in a study in light of her dementia diagnosis (see appendix D). Georgia and David then led me into the light and spacious dining room, where we sat around the table. I was pleasantly surprised to see that David had brought in their suitcase containing passports, holiday brochures, holiday maps of the Canary Islands with advertised restaurants, a few photographs, a sarong and a tea towel with a picture of an emu. It was placed on a chair at the centre of the room. This reassuringly showed their engagement and commitment to the study. At this stage, whilst they talked, I referred to the mind map (see appendix C) as a prompt, but this was soon discarded as they waxed lyrical about their holidays. On discussion with them, I created a personalized mind map (see appendix E) from their conversation about their holidays.

During the visit we drank fresh coffee together whilst they both reminisced about their travels in the UK, Europe and Australia. They decided that my next visit should concentrate on Australia for their suitcase of memories. Despite having no photographs of these specific holidays, they gave me permission to contact Carla to obtain photographs from her.

Following the visit, I met with Carla, who provided some photographs of the Australian holidays on a memory stick. She discussed with me the positive impact that the study was already having on her parents. In addition, I researched visual images of Australian places that Georgia and David had discussed, in order to help them visually connect with their memories, particularly where photographs were missing. I combined the photographs that Carla had provided with the digital images from the internet and uploaded them onto the software to start creating Georgia and David's digital story. I also contacted Andrea Capstick, who had undertaken digital storytelling with people living with dementia (Capstick, 2011) and she advised me about the practical details of creating a digital story. However, the software that she used was no longer available. I enlisted the advice of a film-maker friend, who explained

the process and advised me to use *Windows Movie Maker*. I wrote fieldnotes, transcribed the audiotape and adopted thematic analysis for the transcripts alongside ethnographic descriptions and interpretations.

### **7.9.3. Visit Three**

Two weeks later, I returned to Georgia and David's home, where I was taken into the dining room. Georgia immediately pointed to the view of their garden through their mirror and spoke about the importance of a view that kept her feeling positive. We chatted for a few minutes and I reminded her of the reason for the research as I was mindful of following process consent (Dewing, 2007). With her permission, I then turned on the audiotape. I firstly asked how she and David felt after the previous visit, reiterated to them what we had done and reminded them that we had decided to focus on Australia in this visit. Georgia then took out the Australian tea towel from the suitcase and told stories of these holidays. I noted that they had added a few maps into the suitcase since my last visit.

We sat together and watched the digital images of Australia on my laptop, which at this stage consisted of photographs interspersed with visual images from the internet that were pertinent to their previous conversations. I asked for their feedback about whether it reflected their memories, whilst we drank fresh coffee. We edited the film together, taking out pictures that held no meaning for them and putting them into the order that they chose. It was clear that the film helped Georgia communicate her experiences more effectively through the use of sound and vision.

Following the visit, I wrote fieldnotes, transcribed the audiotape and analysed the transcripts of the conversations using thematic analysis. Ethnographic descriptions and interpretations were also made and I went on to review that I had edited the visual images correctly, checking back from the audiotape.

#### **7.9.4. Visit Four**

Two weeks later, I arrived at Georgia and David's home and was welcomed in by both of them. Clearly Georgia had remembered why I had come; however, I still felt it important to reiterate to her and to David that we were undertaking research together to explore the meanings and significance of recalling their holiday memories since her diagnosis of dementia. Once again, I gained verbal consent and looked for any signs of ill being in Georgia. Georgia then took me into their dining room and we discussed the view of their garden. We sat and held further conversations about their holidays in Australia whilst we drank the fresh coffee that David had made. We looked at and touched some of the objects in the suitcase, including Georgia's sarong. David had found some commemorative coins that reflected their memory of walking on Sydney Harbour Bridge and some UK road and Ordnance Survey maps. We sat together and watched the edited digital images on my laptop and I asked them to consider different soundscapes and music that we might add to the visual images.

Following the visit, I wrote fieldnotes, transcribed the audiotape and analysed the transcript using thematic analysis. Ethnographic descriptions and interpretations were made, I edited the sounds related to the visual images and included some of Georgia's audiotaped quotes uploading them onto the filmmaking software. I watched the digital film a few times, then downloaded a recipe for Lindt hot chocolate from the internet, as they had both talked about the taste of the drink on many occasions and I wanted to emulate this sensory experience where possible. I also printed a copy of the recipe for Georgia and David and bought the ingredients. As well as the Lindt hot chocolate ingredients I also bought cooked meats, including Parma ham, croissants, chocolate gateaux and a small bottle of Kirsch.

#### **7.9.5. Visit Five**

Two weeks later I arrived at Georgia and David's home with a bag full of ingredients for the hot chocolate and other foods they had spoken about in relation to their holidays. I found David looking tired and dishevelled. Georgia had a cold and was feeling frustrated with this. They both appeared unwell. I reminded Georgia why I was there and gave them the option of

me returning to help them unpack their suitcase on another date when they would feel better. They both agreed that they were keen to continue with the visit despite feeling tired and unwell. I told them that this might be the last visit, depending on whether I needed to make changes to their digital story. Georgia then led me to their dining room, where we looked at the view outside the window, noting that some spring plants had emerged. David had found some more photographs of their European holidays and had scattered them on the dining room table with the maps from the suitcase. At this stage, we prepared food and drink associated with their holidays in Australia together. This involved breaking up the Lindt chocolate to make a drink, stirring it in a metal saucepan with a wooden spoon and smelling the chocolate and spices that made up the ingredients. Whilst we waited for the hot chocolate to infuse, we sat in the dining room and looked through the old photographs, mainly of the Canary Islands, which again generated many memories and stories. We prepared the dining room table together with a buffet which stimulated more conversations. After the sharing of the food and drink, we watched their digital story with the soundscapes. I offered to edit the sounds but they were happy with the overall film. Georgia impersonated some of the sounds reflected on the film, once again sharing her stories. Before I left, Georgia approached the suitcase, which now included her holiday hat. She put it on her head, wrapped the sarong around her shoulders and went to the mirror, re-enacting feeling the heat of Australia.

As I was leaving Georgia mentioned that it would be useful for me to meet their friends at their local *Forget Me Not* group: a support group for people living with dementia and their families where I could show the digital story to the group. David gave me the contact details and we planned to attend the group together.

Following the visit, I wrote fieldnotes, transcribed the audiotape and analysed the transcripts of the conversations using thematic analysis. Ethnographic descriptions and interpretations were made.

#### **7.9.6. *Forget me not* group**

A month later, I attended Georgia and David's local *Forget Me Not* club with them and Carla. This is a support group for people living with dementia and their families, partners and/or carers. There were seven couples. We showed Georgia and David's digital story on a large screen in the local church hall. After the showing, we all enjoyed a cup of tea and cake together. The combination of the visual images and the soundscapes initiated much conversation about everybody's holiday memories. All partners and spouses said that they would like to have help in creating their own suitcase of memories.

#### **7.10. Considerations of undertaking sensory ethnography with people living with dementia and their partners**

As discussed in Chapter Three, people living with dementia experience cognitive decline that affects their memory, language skills and ability to reason and judge. Since their lived experience is coloured by the dementia, it would seem unreasonable to design research methods that focus solely on language and mental functioning. The methodological challenges of researching with people living with dementia have previously been discussed, where observation and interviews are still traditionally recommended (Hubbard et al., 2003). However, these continue to objectify the person and fail to reflect that person's true meanings and ways of knowing. Whilst in the conversations in phase one, I used photographs as prompts, in phase two, I chose a more holistic approach by incorporating a number of sensory prompts in the suitcase of memories to see if creating a multisensorial emplaced experience more effectively elicits memories and helps the participants to reconstruct their holiday memories at the same time. This study has aimed to capture the essence of the person on two levels: firstly, on a cognitive level through conversations, and secondly, on an intuitive level by connecting with the person and being emplaced in their sensory world. Whilst some people are naturally intuitive, not all are able to communicate on this level and some may need training or a toolkit to facilitate a connection in order to undertake such research.

### **7.10.1. Access and Sampling**

Difficulties may arise in accessing individuals for research. Chapter Four discussed proxy consent and its ethical dilemmas and this chapter has highlighted the barriers I encountered with the Alzheimer's Society in gaining access to people who have dementia for phase two. During phase one, I experienced some challenges in sampling where one couple who had agreed to consent were bereaved on the morning of my first visit and another spouse had been hospitalised with a fractured hip between my first and second visits. One lady declined as she and her husband had returned from a very difficult holiday where her husband's behaviour had become sexually inappropriate at times. (People with damage to the frontal lobe can become disinhibited in a number of ways and this was how the dementia presented itself with him: James, 2011). She decided that they would not go on holiday again and therefore did not want to raise the subject or create any further anxiety between the two of them. In this instance, I could understand her decision-making. However, it continues to raise issues about who really consents for research. Whilst speaking with her, she shared her sense of loss with me, indicating the significance that holidays have for people in the sense of it being another loss experienced within the multitude of bereavements associated with dementia (Doka, 2010).

### **7.10.2. Feeling safe**

The development of trust is key to the relationship between researcher and participants/co-researchers in any study. It is even more crucial when researching with people who have dementia, who are vulnerable and often insecure. Therefore, stages of the research need to consider how to develop and sustain a trusting relationship, from access to ending the research. Access to the participants and co-researchers in phases one and two of this study was through a credible referral (i.e. the Alzheimer's Society) and through a colleague. This contributed towards developing trusting relationships from the start and throughout the study. By undertaking the research in their home environments, the participants and co-researchers had control and felt safe within familiar surroundings (Bryan and Maxim, 2006; Hellstrom et al., 2007b; Bartlett et al., 2015). In order to connect with the person who has dementia, they need to feel safe. Mollon's (2014: 1728) concept analysis of *feeling safe*



emphasises that participants must have ‘a sense of control, hope, relaxation and calm’. The person living with dementia may or may not be in control of all aspects of their lives, but if they *feel safe* they may feel more in control. This study, through its critical epistemology, ensured that Georgia and David felt in control by conducting the research in their home and encouraged them to lead and direct the study. Being in their home helped with developing a connection between us all from early on in the study and gave me the opportunity to become fully emplaced within their world in the present day and within the past memories of their holidays.

#### **7.10.3. Relationships – meaningful other**

Whilst the main focus for this research has been on the person living with the dementia, there is a need for a meaningful other person to be involved when adopting process consent, and in this case, when reminiscing about past experiences, as they are shared experiences. As discussed in chapter four, research with people who have dementia often listens to the advice of their partners/carers more and tends to ignore the person (McKillop & Wilkinson, 2004). This research ensured that the attention and the perspective of the person with dementia is central, with their meaningful other involved. It is quite apparent that this research has focused more on Georgia than on David, and this might be because Georgia was more dominant in the conversations and conveyed a philosophical approach to her recollections. Their relationship, however, should not be ignored, as this has a large influence on the research. Knowing each other since their teenage years and being married for nearly sixty years in a stable happy relationship has had a positive influence on their changing roles in light of Georgia’s dementia.

#### **7.10.4. Researcher/co-researcher relationship**

This issue of researcher relationship and researcher responsibility arose where the roles of researcher, therapist, expert and friend became blurred. Just as the theme, *Holidays as life*, showed life as multifaceted, layered and complex, one cannot extract holiday-specific data alone within the intertwining of their life experiences. So too when undertaking research with people who have dementia, other aspects of life emerge. In order to be emplaced within their

worlds, my role as researcher evolved as our relationship developed, with me offering support and guidance to both Georgia and David. Georgia's urgent need to communicate with me whenever David left the room made me reflect on the transient nature of my role as a researcher, dipping into their lives, exploring their worlds and then at some point having to say goodbye. This placed a responsibility on my role and highlighted how demanding the research can be, bringing out the need to design research with an inbuilt duty of care to fully fulfil all ethical principles. Georgia clearly needed someone neutral from the family to talk to. I spoke to her about local support groups that might be able to help but she felt that she would not want to speak to anyone else. This study highlights the need for people to be offered a form of ongoing counselling and I recommend using sensory ethnography as an approach to enable this. The suitcase of memories may provide a way of sustaining support for the person living with dementia. *'You were just a person who came: now you're a friend'* (Georgia).

At all stages of the study, I drew on my experience as a nurse and researcher, keeping sentences short and clear without the use of jargon and repeating myself where necessary (Barnett, 2000). I was also aware of the ABC approach used when working in the memory team in Cardiff (Avoid confrontation, Be practical and Clarify feelings), as advocated by Powell (2000), a speech therapist colleague from the Cardiff memory team. I made it clear that there was plenty of time to explore the photographs and that I or their partners would be aware of any signs that participant was becoming tired or did not want to continue. However, I found to the contrary that most of the participants in phases one and two were so animated and enjoyed the attention and experience so much that it was difficult to end the sessions! People living with dementia are often ignored and marginalised, so this research could be viewed as emancipatory in the fact that it gave them back their voice. This research has reiterated the importance of building trust, taking time and adopting a flexible approach when researching with people who have dementia, as also found by Hubbard et al. (2003), Moore and Hollett (2003) and Nygård (2006).

In traditional qualitative research, the credibility of the results and how they construct meaning and significance is communicated by quotes from the participants (Denzin and

Lincoln, 2000) and whilst I have included significant quotes, the sensory ethnography facilitated a deep connection with the co-researchers that goes beyond the cognitive domain and requires an intuitive approach. It is recommended that sensory ethnography be used with people living with dementia who experience more language, memory and judgement and reasoning difficulties: it might therefore be an appropriate methodology with people at all stages of the condition.

#### **7.10.5. Ending the research**

It is important to consider how the research ends. It is vital that the participants/co-researchers feel that their contribution is valued (Lloyd et al., 2006; Hellstrom et al., 2007). By showing their digital story to their *Forget Me Not* group, Georgia and David had the opportunity to share their experience of undertaking the research and disseminating the findings to other people in their situation. When one gentleman started to respond to the digital story with the soundscapes, I saw how we could continue to connect with people who have become withdrawn and are unable to communicate through speech, and how we need to show families how to do this. Georgia saw how he responded and I would like to think that this showed her the value of her and David's contribution. I have given Georgia and David a copy of the recipe, some more ingredients and a copy of their digital story to enable them to continue their holiday reminiscences. I suggest that the effects of the suitcase of memories be sustained by watching the digital story regularly and that it might help towards keeping the couple's relationship alive when more cognitive and social losses continue to occur.

*That's all we've got left, what can you plan for? The future is not ours (pause)  
the future now is timed. When you're younger you don't think of time.*

*Georgia*

It was hard to say goodbye and end the research, and whilst I am writing this, I feel a sense of guilt that I have not gone back to see them. Whilst they were both aware that this was research (and this will not be the case with all people living with dementia) it was still difficult to say goodbye, particularly in light of Georgia's comment about me becoming a friend. To alleviate my guilt, I left them my phone number to contact me if they needed any

support. I also feel concern for their future and feel a sense of loss, since I was so emplaced within their world for the duration of the research.

#### **7.10.6. Ethics**

In light of the key characteristics above, further consideration needs to be made when exploring the ethical implications of the study. Whilst process consent (Dewing, 2007) provides a framework to follow for the consenting process throughout the study, all researchers conducting studies with people who have dementia need to consider the power relations that can occur between researcher and potential participant and aim to reduce those in order for the person to feel empowered and to maintain a sense of self-esteem. This can be achieved with more critical studies that, where possible, aim to involve the potential participants in the planning, conducting and analysis of the research as co-researchers. This can be achieved where the most appropriate methodology and methods are adopted. By adopting conversations instead of interviews, the person is likely to feel less intimidated and under pressure, as their brain may not be able to respond as previously. Conversations can be freer and benefit from embodied and emplaced ways of knowing that can elicit rich, valuable results. When considering the use of all of the senses, the person is in a better position to contribute to the research, which benefits from intuitive non-cognitive ways of knowing.

For research to be truly ethical, all researchers undertaking studies with people living with dementia need to ensure that the person feels safe, is communicated/connected with in multisensorial ways and has a meaningful person with them. In addition to this, researchers need to be aware of the responsibility of their role and how that will end. All of these aspects were intuitive to me but it is through writing my field notes that I identified these points. I did not set out with any of these ideas prior to the research other than a passion to listen to and represent the voice of the person living with dementia.

### **7.11. Summary**

This chapter has presented the theoretical position of the study, which has informed the chosen methodology of sensory ethnography. It identifies the limitations in adopting traditional research methods with participants who have dementia and briefly critiques the frameworks of rigour, which are not relevant for such a critical approach. The chapter goes on to discuss the development of sensory ethnography as a new and emerging critical methodology and has described how the principles and multiple methods that attend to the senses resonate with hopeful tourism and dementia scholarship. By examining the role that the senses have in reflecting experience, the chapter has explored how they can be incorporated into research and subsequently create a rich dimension that extends beyond language and observation, thus identifying it as an appropriate way to explore the worlds of those living with dementia.

In line with critical theory, a description of the methods has included an initial autoethnography, which is aimed at identifying the need to set the scene from the perspective of the researcher, thus situating myself within the research. The chapter then goes on to introduce the idea of the suitcase of memories, drawing from sensory geography, tourism and dementia studies. By describing each visit, the process of undertaking sensory ethnography is explicit, indicating what methods were used, including process consent throughout to ensure that full ethical consideration was taken. The visits go on to identify how reminiscing using the senses can be applied. I have identified factors such as access and sampling; feeling safe; the need for a meaningful person to be present; the researcher/co-researcher relationship; how to end; and ethics as considerations when undertaking sensory ethnography with people living with dementia. This, in turn, can give guidance to researchers when including people who experience multiple cognitive difficulties into studies.

The next chapter will present the results from the suitcase of memories by describing each visit ethnographically, alongside thematic analysis and researcher reflections and reflexivity. As previously mentioned, Chapters Seven and Eight are separated due to the large amounts of ethnographic data, the complexities of researching with people who have cognitive difficulties and the iterative nature of the overall research.

# **CHAPTER 8**

## **A SUITCASE OF MEMORIES**

- 8.1. Introduction
- 8.2. A suitcase of memories: Visit one
- 8.3. Visit two: Holidays as life
- 8.4. Visit three: Freedom
- 8.5. Visit four: View seen, viewpoint heard
- 8.6. Visit five: Strengthened self-identity with younger self
- 8.7. Forget me not group
- 8.8. Reflections
- 8.9. Summary

## **CHAPTER 8: A SUITCASE OF MEMORIES**

### **8.1. Introduction**

The aim of this chapter is to explore the fieldwork dynamics and processes involved throughout phase two of the research: a suitcase of memories. This starts with a referral to the autoethnography (see Chapter One) of my own experience of the recalling of holidays in order to be fully reflexive and to situate myself amongst the co-researchers. The results are presented as a narrative to assist in exploring the nature of the sensory world of re-living past holidays whilst living with dementia. Analysis and interpretations are made and communicated through the narrative textual descriptions of each visit with the addition of thematically analysed conversations. Finally, the challenges and achievements that occurred throughout the research are identified.

### **8.2. A suitcase of memories: Visit one**

Just as in Chapter Seven, this chapter is structured around each visit, recorded in rich detail. I chose to use thematic analysis where possible, since the conversations involved the participants' storytelling and recalling of memories. In fact, Georgia's communication difficulties were less marked than those of the co-researchers in phase one, so there are more coherent texts to draw from as well as the overall multisensory experience. The reflections on each visit also include sensory ethnographic and autoethnographic descriptions, interspersed with excerpts from the conversations as well as emergent themes, analysis and interpretations.

During visit one, I spoke to David, Georgia and Carla about the study and gave them the information sheet and the mindmap I had prepared (see appendix C). I explained that the plan of the study would be determined by themselves, giving them the voice to make decisions with my support. During this initial visit, David was quiet but expressed an interest in participating, as did Georgia. I felt a sense of sadness from him as he sat quietly listening to Georgia and me. I explained that reminiscing can sometimes be sad, since they may not be

able to go on holiday now. They both said they were not concerned about that, as it was not only due to Georgia's dementia, but more their age that now limited their choices. David became more conversant, saying that they still have a good life, regularly going to the local seaside town of Mumbles for a day trip. David continues to drive, whereas Georgia had stopped since her diagnosis. Their ability to remain mobile has a positive impact on their wellbeing and these day trips clearly help towards maintaining their couplehood and subsequent sense of selves. Their anticipation of the trip and the journey were just as important as the destination itself, reflecting the literature on ageing, mobility and health (Musselwhite & Haddad, 2010; Parkhurst et al., 2014; Musselwhite, Holland & Walker, 2015).

At this visit, whilst initially stating that they had not been on many holidays in their lifetime, Georgia proceeded to wax lyrically on the subject for an hour, clearly enjoying the experience. She appeared animated, happily chatting about past holidays, even though her speech was sometimes stilted and she substituted words for what she meant to say. She tended to stammer towards the end of sentences which often made them incomprehensible: hence she added word fillers such as *whatsisname*. Occasionally she showed signs of word finding difficulty and would lose her train of thought, but soon regained the conversation as we consulted the mindmap: *"Well I suppose the holidays were good and so the memories would be good, the memories are good and strong."*

However, halfway through listening to her talk about her holidays, Georgia remembered a very sad event linked to a holiday where they had to return home early, as their nephew had died. She became tearful, dabbing her eyes with a tissue, recalling the event vividly and describing the emotion she had felt at the time. This was quite unexpected, but just as Marschall (2012b) recognises that recalling memorable touristic experiences may not always be positive, there is the potential for negative memories to be revisited in order to heal. However, it is uncertain whether this is possible for the person who has dementia, and this identifies the need to explore the effectiveness of counselling for those living with the condition. At this stage, after offering comfort, I highlighted the fact that sometimes-recalling memories is not always enjoyable, but indicated to her and to David that it was important to



acknowledge the sad memories and that I would support them through this. She agreed that such memories would be bound to arise and was happy to continue.

We then returned to the mindmap that David had spread onto the coffee table and Georgia again became quite effusive, gesturing with her hands and arms and laughing when they started to recall certain memories. She remembered where David had his wallet stolen and a holiday where an octopus floated past her in the sea. These memories flowed naturally from her and indicated how strong events can be recalled when other aspects of holidays may not be remembered so easily. As well as remembering holidays, Georgia was very keen to talk about her diagnosis and how the dementia was affecting her, her identity, her relationship with David and her role in life. Carla explained that nobody in the family had discussed the dementia and its impact since Georgia's initial diagnosis and their organising of legal and financial issues. This research gave Georgia the opportunity and permission to express her emotions in relation to the diagnosis of dementia and how it affected her. Indeed, discussions of her diagnosis dominated much of the conversation, in between remembering holidays, and I sensed a degree of awkwardness from Carla and David. My feeling is that they wanted to concentrate on the recalling of the holidays for my sake as a researcher. I explained that we were all co-researchers and all that Georgia had to say was relevant. The visit was emotional in many ways, as I felt that it opened the floodgates and gave Georgia the opportunity to express her feelings about her diagnosis. This is evident in the literature exploring how illness dominates and impacts on self and identity (Charmaz, 1983, 1995) resulting in *biographical disruption* (Bury, 1982: 167) and in particular how dementia affects the sense of self (Brown, 2016; Hedman et al., 2016). Georgia interspersed her conversation with recalling holidays, which was helped by focusing on the mindmap as a visual prompt.

At the end of the first visit, after two hours, I had seen tears of sadness and joy and heard much pathos and humour. The importance of holidays in their life and re-living these holidays came through in their verbal and non-verbal expressions. Whilst Georgia's initial response when discussing the research was that they had not been on holiday very much, it soon became clear that they had much to re-live in relation to their holidays and that it was a very enjoyable experience. Gestures, mannerisms and conversations communicated a multitude

of emotions that made it clear that holidays were important throughout all stages of their lifespan and that recalling them was predominantly a positive experience interspersed with sadness. I suggested that David and Georgia might like to gather together some souvenirs, photographs and anything they associated with their holidays and put them in a suitcase for us to explore at the next visit. I went away and wrote reflective field notes.

### **8.2.1. Reflection and planning between visits one and two**

*I wasn't expecting it to go so well and it has already generated lots of memories and stories. I wish I'd brought my tape recorder, as Georgia has said so much already. Where she struggles with her speech, her body language makes up. The mindmap worked well, as we all had something to look at and prompt us. David seemed quite quiet though. I will continue with process consent, even though she has obvious mental capacity for consenting to the study, as this may change over time. What a morning of mixed emotions with the urgent need to speak and let her voice be heard in relation to her diagnosis mixed with positive happy memories. I felt totally welcome and enjoyed sharing holiday memories with them. Georgia was remarkable when she became upset about her nephew: she had a little tear, talked a little about it, and then moved on to remembering about an octopus floating past her in the sea. Whenever there was a pause in the conversation early on, she took the opportunity to talk about her dementia: it is obviously a massive issue and she clearly needed someone to listen and offer some sense to the whole diagnosis.*

### **8.3. Visit Two: Holidays as life**

The approach for the second visit was with a view to *go with the flow* and let the co-researchers take the lead. Since I have much experience in working with and researching with people who have dementia, I know that very often things don't go to plan. When I arrived at their home, Georgia handed me a letter (see appendix D) that she had written in between the visits. It attempted to express her views of how the dementia affected her and clearly showed that she understood the aim of the research.

*I am me, person with dementia, re mutual hol needs – as always time and place, both want and agree with. See no need to have a hospital envioment or regulation as to time to be up and out or in for meals but come and go when we like*

*Georgia*

In writing this, it appeared that Georgia had written her own version of consent and this indicated to me that she had the mental capacity to continue with the study. Whilst this piece of text on the one hand exemplifies the fragmented thoughts and gaps in her thinking, its interpretation is still quite clear. It is a powerful piece of writing since she undertook it voluntarily, attempting to put her thoughts down on paper when she clearly struggled to write them. The writing showed great insight into what I had explained about the study, with four themes coming through: her sense of self, as a person living with dementia; the time and place of the research, being undertaken in their home and at their agreed time, giving her control; she made it clear that she didn't want the research to be undertaken in hospital, where she assumed that most research would usually be conducted. This posed interesting questions in light of phase one of this study, where often the participants' sense of place was sometimes back in the holidays that they were remembering. Their sense of *being* at that time was when on holiday in the past, slipping between past and present. Interestingly, the theme of control over one's time led her to reflect on holidays: the phrase '*come and go when we like*' expressed a major aspect of the freedom associated with holidays.

Linking back to visit one, when I first arrived, Georgia talked about how the dementia affected her and said that she wished there was a *pill* to cure her. She clearly needed to get her voice heard. To date, there is very little psychological care and support for people diagnosed with dementia: they are often left to fend for themselves, and just as the physiological part of the condition can cause depression, the impact of the condition itself often affects mood (Kales, Gitlin & Lyketsos, 2015). Interestingly, this research helped Georgia to get her voice heard and gave her the opportunity to talk about her own feelings in relation to the illness:

*Though memories are good, it was my life: that was me. I was at home I never had anyone and to find all of a sudden it takes away what you feel, I was never a perfect person, I don't think I ever will be now, but it cuts your enjoyment and it cuts the fact that you feel that you are no longer you and not control of what you can do or can say.*

*Georgia*

The dementia clearly had an impact on her sense of self in terms of her beliefs about who she once was, as an independent self, and what has been taken away. However, she continued to use the word *I*, indicating that a form of a sense of self still exists, as in Sabat and Harre's (1992) theories, discussed in Chapter Two. She also talked of a sense of guilt about leaving most of the work to David and feeling that she was a burden on him:

*David is now in charge I am aware that I must.... Whereas before I'd go off and do my own thing. I'd go off to the end of the road but not find my way back (laughter, with a hint of sadness) it is hard to get through to me...I am aware but for some reason I can't stop it, by me saying it to you, my husband is listening so he knows I can't help it.*

*In fact, I'm aware and there's nothing I can do about it, I am wearing him (David) (pause) not only wearing myself out, I am wearing him as well and I am conscious of the fact that I am dragging him and probably holding him back from things that he would like to do and where he'd like to go.*

When David came into the room, Georgia stopped speaking about her dementia and changed the subject, addressing the suitcase on the chair in the dining room. This indicated her sense of self awareness and social skills, and throughout the visit, she referred to her generation as stoics who would '*pull themselves together and just get on with it*'. There was an obvious conflict between how she felt she was supposed to behave and react and how she really wanted to. She clearly needed to talk about her situation and her feelings since the diagnosis. As we approached the suitcase on the chair, both Georgia and David said that they had not taken many photographs on holidays or bought many souvenirs, but that they had gathered together all that they had found. David showed me the suitcase and brought out the maps, touching the well-leafed yellowy brown pages between his thumb and index finger. He appeared much more interested than in the previous visit as he opened them out like concertinas, stretching out his arms whilst sniffing at the paper.

We sat together around Georgia and David's dining table and I listened to them talk freely about their holidays. The suitcase contained passports, holiday brochures and maps, a few

photographs of the Canary Islands and a tea towel. David brought out a map from the suitcase and spread it on the table. I asked them what else they had brought in the suitcase, which prompted Georgia to have a look inside. She held up the tea towel of the emu and said that they kept it as a picture on their wall as a memory of the holidays: she was particularly fond of this. She moved over to touch some of the brochures and photographs and David started talking about their walks whilst showing us the route on the map. As his fingers walked along the areas on the map, so they both recalled the walks and the restaurants they had been to. His tactile finger walking along the map prompted a real-time conversational walk along the promenade, allowing for discussions of the smells of the restaurants. Georgia remembered the smell of fish, which she found abhorrent, and started talking of other memories related to fishy smells. She pulled a face to show how she still dislikes the smell intensely.

It is interesting to note how the memory of a smell may elicit strong feelings and I referred to my experience with Durian fruit in Malaysia. Georgia appeared to be looking back in her *mind's eye*, as she called it, as David was reliving some of the menus they had sampled. The objects took away the potential formality of the conversation and prompted the recalling of memories and free-flowing talk. The meanings of the souvenirs, maps, and photographs contributed towards the reality of the holiday memories, inspiring more conversation. I noted that when touching the objects and talking about them, David attempted to ascertain facts such as where they were bought and when, but Georgia would move on to tell a story and reflect her emotions. She spoke of sights, sounds and smells, linking emotion to her experiences. This indicated more about the significance of those *things* to her. It is difficult to know whether there is a personality or gender difference here in their differing responses or whether Georgia's dementia influenced her emotional reactions. As I noted in phase one, the participants who had dementia seemed to express much more emotion when reliving their holidays, since conveying facts was difficult. The same was true here when Georgia started to relax more and, when recalling her holiday memories, sat back, dropped her shoulders and gave a sigh. I sensed she was feeling relief to find herself again:

*'It is it, it is me, I am still me (long pause), somewhere. I'm glad you came because I'd forgotten about these places.'*

Georgia was clearly enjoying the reminiscence and the interaction particularly as her day-to-day life was full of reminders of the losses she was experiencing, such as her diminished role in the kitchen because she had burnt the toast, misjudged how hot the boiling water from the kettle was and forgotten a few stages in cooking. When remembering *these places*, she started to feel as if she was *there* again on holiday in place and time, which gave her a sense of joy and distracted her from her present-day losses caused by the dementia. It also gave her much to talk about and stimulated her thoughts in a positive way. David seemed to be enjoying the discussion, and whilst they disagreed over some of the facts, I felt that this was a true reflection of their premorbid relationship, where they both held strong opinions and discussed their versions of their memories quite vociferously. The research allowed them to be frank with each other and with me. It seemed as if Georgia had been brought back to life as the visit progressed:

*When you're younger you don't think of time (laughter), or is it because we're getting older and been married for fifty odd years, nearly sixty years you become attuned to your partner so that stands you in good stead and yes, we don't always agree but the background is there. We're still here, he's not a bad old stick.*

It is interesting that Georgia uses the word *attuned*, when speaking about David, implying a sense of the transpersonal connection between each other. Adopting sensory ethnography as a methodology helped to draw out this attunement and allowed me to examine these non-cognitive ways of knowing in order to explore their experiences.

Aspects of the senses emerged naturally within the conversation, particularly in relation to food and drink. Whilst I was aware that I wanted to raise the profile of the senses, I did not need to. The talk of cafes and restaurants prompted David to make coffee, and whilst he went to the kitchen, Georgia once again took the opportunity to talk about her diminished role. From an ethical standpoint, researchers working with people who have dementia need to

have experience in counselling and psychological support and understand the nature of how dementia can affect individuals, as it is clear from this study that a number of other issues and emotions arise. David returned with coffee for the three of us and Georgia quickly changed the subject by picking up the maps: she sat up and her demeanour lightened as she lifted the hot mug to her nose, allowing the steam to mist her glasses, and deeply inhaled the drink. I found myself mirroring her, taking in the strong rich smell of the coffee. We talked about its smell and the steam rising from the mugs and Georgia went on to talk of the Lindt café that they frequented in Sydney, Australia. They spoke of Lindt hot chocolate that they often enjoyed with their grandchildren and at other times, just the two of them. They both went on to describe the richness of the coffee and I wasn't sure if they were referring to the coffee that we were currently drinking or their memories of the coffee at the café they were remembering. I felt fully emplaced within their memories when sharing the taste and smell. David spoke frequently about the Sydney Tower Buffet, a revolving restaurant with panoramic views where they could *eat as much as you want* including bacon, Parma ham, salads and croissants. They talked of the views being outstanding and quite a novel experience.

Georgia took down a photograph on their bookcase of themselves and their family in Sydney, Australia to show me. I felt that this picture had confirmed how significant their holidays in Australia had been for them, especially because they spent them with their family, whilst also being *free to come and go* as they pleased. She mentioned the sound of those *blimmin birds*: David clarified that there were Kookaburras that crowed loudly outside Carla's house and he went on to talk about the bats that hung in the trees in the park. Their memories started to flow.

Since the sensory ethnographic approach is an iterative one, I found myself analysing the conversations as they were happening and noted how their holiday memories twisted and turned, naturally flowing into separate phases. The first, which involved their children when younger; laden with camping equipment and with a sense of tiredness and a slight degree of being burdened. The second phase involved holidays in Europe as a couple when the children had grown up and left home. Here they both spoke of many places they had visited, the conversations to-ing and fro-ing between times and places and gesturing about food drink,

sights and sounds. Whilst we looked at a map, I wrote rapidly, attempting to create a mindmap to reflect their memories (see appendix E). I glanced at the pre-prepared mindmap to give me prompts, but soon realised that it was redundant as they both led the conversations, happily recalling aspects of their 50 years of holidays, with no need for prompting, and Georgia started laughing: *Oh, I've hopped into Italy.*

Georgia recognised that her reminiscing took her to many places and that one minute she was speaking of a view she could remember and then realised it was in Italy and not in the Canary Islands, which is where the conversation started. This shows the nature of how, when remembering holidays, they can merge together. Whilst the sensations of joy and elation were seen when Georgia relived her holidays, she did tearfully return to the present day, reminded by her dementia. I found myself feeling sad, as I could sense her pain and was reminded how in my role as the researcher I could not be objective: I needed to respond to the human side of the experience. She soon *pulled herself together* and became distracted by the emu tea towel. Just as Habermas and Paha (2002) found that objects are powerful in prompting stories, Georgia went on to talk about her memories, including where she bought it and what the weather had been like at the time.

Their third phase of holidays was more recent, in Australia, as they visited Carla who had emigrated there in the mid-1990s. They spent one holiday in Australia travelling around together and three times they holidayed and stayed with her. When re-living the many holidays throughout time, it became apparent that the meaning of what the holidays represented changed at differing stages of their lifespan based on income and family. Taking their children on holiday was seen as a way to share experiences and use holidays in an educational way. Once the children had grown up, Georgia and David tended to go with the flow on holiday and spoke more in sensory and emotive terms. I asked them if they wanted to concentrate on one of these phases or just to carry on reminiscing generally. They both decided that their Australian holidays would be the best to focus on for the study, since they had spent more time there with family and friends. They both felt that they knew Sydney very well and David said *'In fact, I know Sydney better than I know London.'*



This led to David saying that they might consider going to London for a short break now, as travelling further afield would be too stressful. They both continue to want to have adventures and explore. I sensed that I had moved them both out of their world dominated by Georgia's dementia and the negative aspects it brought to their life. David seemed to enjoy the experience and, on reflection, it may have also helped distract him from their present-day situation. Both Georgia and David's conversations and sensory experiences in recalling their holidays were entwined with their individual and shared identities. Initially, they started to recall their holidays chronologically, but once they had both warmed up, they changed to a more fluid recall. The layers of holiday experiences throughout their lifespan were recalled naturally as sensory themes such as tastes and smells of food, sights and sounds, weaved in and out of different times and different places. I felt a tourist in their world, listening and sensing the environment of their home and their holidays whilst enjoying their hospitality. Georgia's own sense of self showed how significant the suitcase of memories was in enabling her to re-identify with herself in relation to her personal identity and her socially constructed self:

*Well I think you will be able to make a story from all of this (long pause) it's not holidays, though is it? (pause) it's our lives (pause) yes different countries but it's as we've lived them (pause) in different places (pause) it's our life (pause), what you have there is our life (pause) it's our life.*

*Georgia*

Holidays and the meanings that can be placed on them when re-living them are very significant in one's life. Despite Georgia's dementia, she was able to reflect and indicate how the holiday memories were intertwined in their lives and had influenced their overall experience, identity and sense of self. It is important to note that whilst the nature of the research is about tourism memories, the wider context of their lives is, not surprisingly, interwoven amongst the conversations: *'You don't feel part of a country but familiar with it and comfortable with it even though we didn't live there, we were part of there.'*

### 8.3.1. Reflection and planning between visits two and three

On leaving, I noted that Georgia made it clear that holidays were a major part of their life and that you could not explore holidays without the context of their shared experiences. This reflects the couplehood literature (Williamson & Shafer, 2001; Baikie, 2002; O'Shaughnessy, Lee & Lintern, 2010; Molyneaux et al., 2012, Hellstrom, 2014; Merrick, Camic & Shaunessy, 2016). Initially her dementia and its impact on her and David overshadowed the visit but as we started to use some sensory prompts, memories of their holidays lifted them to a different time and place. When I first met Georgia, I met a lady struggling to cope with living with dementia. By the end of the first visit, I knew the symptoms of Georgia's dementia diminished as the morning progressed.

*They both were happy to see me and keen to show me their suitcase and its contents. Georgia is very articulate and speaks quite profoundly about their life, holidays and dementia. David was very interested and became more involved compared to when I first met him, enjoying reliving the factual aspects of holidays, especially food and drink. Georgia gestured most of the time. I felt very comfortable re-living their holidays with them and found myself imagining much and relating their stories to my own experience. When they talked of the smell of the coffee with the spices, I returned for a moment to Israel where they added Cardamom. As time went on during the visit, the dementia seemed to shrink, the joy of talking about their sensory holidays mixed in with their lives. David also appeared more animated and happy to tell me their stories.*

Such an emphasis on re-living food and drink has been examined in other studies of remembering holidays with people of differing ages, although none with people living with dementia (Small, 2008; Sims, 2009). Exploring the world of their holidays through reminiscence, helped to open the door to allow other aspects of their life to be discovered and for feelings and emotion to be conveyed in terms of life when living with dementia. This research highlights the need for a person who has dementia to be able to voice their emotions and to be offered counselling and therapy with somebody neutral outside the family. Just as Killick and Lipinska (2010) and Brown (2016) recommend, psychological support can help people to adjust to the changes and losses associated with dementia. The suitcase of memories may be an effective way of doing this, as it may intersperse the sad emotions with

more joyful ones that are meaningful to the individual.

After the second visit, I met with Carla, their daughter to pick up a memory stick with her parents' digital photographs of their holidays, since they could not find many photographs themselves. Whilst I did not wish to privilege sight over the other senses, photographs are an effective, traditional way of recalling holidays. Carla mentioned that my visits had been beneficial for her parents, as they gave them a positive joint activity that drew from their lovely memories. She said that they had spoken to her about the study and said that thinking about the senses made it feel more *alive* to them, and that she took comfort in that. I was not expecting there to be a benefit for the extended family, but on reflection, it gave her a positive focus to discuss with her parents, and as she was part of the holiday memories, she could fill in the gaps. Carla's involvement showed a sense of care and respect for her parents, since she is also coming to terms with her mother's diagnosis. By acting as a link between her parents and me, she was happy to be involved. She clarified that it gave them both a sense of meaning and purpose at a time when their life and roles have changed dramatically. When I returned home, I listened to the audio recordings and transcribed the conversations. I uploaded the photographs from Carla's memory stick onto digital filmmaking software and searched for and uploaded visual images from the internet to add in missing photographs from their conversations about Australia.

#### **8.4. Visit Three: Freedom**

Before we sat down to look at the beginning of the digital film, Georgia went over to the suitcase that was placed on the chair in the dining room and brought out her emu tea towel. She lifted it up and expressed great joy at seeing it: she smiled at the image and rubbed the edges between her thumbs and fingers. It was clearly not being used as a tea towel but kept as a souvenir. I noted that a colourful sarong and Georgia's summer hat were now in the suitcase; it had prompted Georgia to look around the home for other holiday props. She wrapped the sarong over her shoulders for a moment, and then put it back in the suitcase: she was keen to see the digital film that I had spoken about as I arrived. At this stage, I introduced the photographs from Carla and the digital images I had incorporated in the digital

film software to Georgia and David. I sat between them at the dining table, as I needed to help them with editing and creating their digital film on the computer. I showed them the first stage and asked them for their comments to see if the images reflected their memories. If any of the images didn't resonate with them, they *called out* for them to be removed. Once completed, they both felt that the images reflected their holidays and commented on the digital film as a great way to display their photographs:

*I feel quite happy about these pictures: I can remember the nice time I had but not the names of places...it annoys me, mind, that I cannot remember where it was, I can't remember the detail.*

*Georgia*

Seeing these images on the computer generated much discussion, inviting them to comment more freely at times during the conversations. Georgia noted how clear the images were on the computer and how readily available they were whereas: *'Photos go in albums and then they disappear upstairs.'* She articulated feelings and emotions surrounding the photographs when recalling their holiday memories in terms of sights, sounds, tastes, smells and movement.

Just as Tung and Ritchie (2011a) found freedom to be a major theme when listening to older people re-living their holiday memories, much was discussed about the freedom sensed when holidaying without dependents:

*Warmth, friendliness and ability to move where you want, exploring freedom, opera house, I just like paddling along the edge, the water was warm and the sun was shining.*

*Georgia*

Georgia spoke about how she would wander on holiday and how she was once left behind when on a tour. She didn't like to follow everyone else, as she liked to be totally immersed in the moment, without distractions from others. As she spoke, she gestured with her arms in the air, her facial expression lightened and she frequently looked into the distance, as though she was back in the moment of the holiday. She spoke of wearing a red coat when on tours and walks, so that David could find her when she wandered on her own; she laughed and said

that it might be a good idea to find that coat again. Here she was referring to her tendency to get lost nearer home due to her dementia. She laughed but did not go back to discussing her dementia in a negative sense, as she was more embodied in the moments of the holidays:

*'I'm not as tense as I thought I would be. I feel quite relaxed in a way: it's a good way of not bottling things up but letting people know how I feel.'*

Here, Georgia articulated that the research was helping her to express herself. I asked her what the best thing about the holidays in Australia was, to which she replied *'The freedom to come and go as you please.'* When speaking animatedly about the freedom on holidays, Georgia sat with arms on her lap, an occasional distant look on her face, but I sensed that she was very relaxed. The three of us all relaxed during this conversation and I found myself mirroring her body language. However, her mood changed when she started remembering a visit to a prison during another Australian holiday. David filled in the gaps, explaining that they had seen Fremantle prison, an imposing penal colony used for convicts undergoing hard labour when sent from the UK during the development of Australia:

*The prison (pause) looked in (stammer) I looked in through the bars (Pause) it was not in a right place, all this lovely place around here with sailing and there it was somewhere you could definitely be cut off (gesturing with hand) there was no other thing around, of course: they were all sailing and people enjoying life all around that somewhere you could definitely think you were cut off, wherever this was, it's the prison I can see in my mind, the fact that it was isolated, trapped. I remember thinking that I wouldn't want to be stuck there.*

*Georgia*

Her affect changed, looking more serious, frowning and raising her shoulders as if shivering when she started talking: she was clearly reliving the feelings that she had experienced at the time of being there. She talked about how the prisoners were *cut off, isolated and trapped*. My intuition led me to believe that the experience of reliving her holidays through the photographs brought up the issue of freedom. Interestingly, she remembered this despite no photograph of the prison in the digital film, David clarified that the visit to the prison was

during a different holiday in a different part of Australia. Georgia's conversation then shifted immediately to hospitals, saying that there was no need to be in a hospital to do the research, and she went on to talk about the old asylums and her experience at the memory clinic, which was in the same building as the old Victorian asylum. Her flow of thoughts and language became disjointed, but I understood clearly that her feelings of reliving her visit to the prison were similar to her memories of the visit to the memory clinic:

*Holiday needs, no need to have a hospital environment to make you feel normal (pause) well that you're still capable of living a normal life but maybe a hospital is not.*

*Georgia*

She went on to refer to the old asylums and '*not being able to come and go as you please*': a term she had previously used when talking about holidays. This association and sense of place implied a feeling of fear and the stigma associated with hospitals and asylums. Once again, she shivered, raising her shoulders as she said this. Her discussion seemed to have merged her sense of place in the present with a sense of place and freedom and thoughts whilst on holiday and at another time when visiting the memory clinic. The idea of being free to *come and go* arose many times throughout the visit. The meaning placed on the freedom of holidays was possibly in relation to Georgia's lack of freedom now and her fears for the future where her freedom might be further curtailed, as she described a recent experience of forgetting and not recognising where she was when trying to return home from the local shops: a well-trodden journey five minutes away from her home:

*I can't remember how to get back (home), that is infuriating therefore, one stays within a perimeter this is a perimeter, you know, your freedom is getting less as you can't go to wider places (pause) it's gone before you realise you've stepped into the next bit.*

Such insight into her difficulties was quite distressing, as she spoke of her awareness of how she should know where she was in her own street, trying to rationally work out the numbers of her neighbours' houses in relation to her own, but not being able find her way back. Her

mood started to lift when she appeared to accept that she would not leave the house alone and she started talking of her holiday memories again.

*We may be confined nowadays, more confined now, but I don't wander off, but there are times when we used to stroke out (pause) you need the memories when you can't strike out.*

The theme of freedom emerged clearly in this visit: such a fundamental part of being human and feeling alive (Vanier, 1998) but is threatened by having dementia. Georgia started to pick up the props from the suitcase again and her mood continued to lighten. The experience clearly gave her the opportunity to express her embodied feelings and again highlights the need for the researcher to have experience in supporting those affected by dementia. Here, recalling such memories may help the person to feel more alive by bringing the past to the present day and, in Georgia's case, may give life meaning and purpose.

#### **8.4.1. Reflection and planning between visits three and four**

Despite ending the visit on a positive note as we watched the digital film, on leaving I still felt a sense of sadness for both Georgia and David. Her fear of the future came through her discussions and remembering. I wrote field notes reflecting this:

*This research is multi-layered: I have seen so many emotions in the space of a few hours. The happiness of recalling the holidays has brought up emotions for the present day. Hearing Georgia's sentences move swiftly between freedom on holiday to sensing what it must have been like for the convicts in Fremantle prison, to her memory team appointment and her association of the building being in the old Victorian asylum made me realise how intertwined all aspects of life are with happy and sad emotions. It is impossible to explore this in its essence without the rest of life creeping in.*

Clearly, this has implications for researchers and practitioners undertaking reminiscence with people who have dementia, as whilst the subject of the reminiscence may be pleasurable, some emotions may be uncomfortable. When I returned home to edit the images, I

researched Fremantle prison on the internet and found a photograph of a large, imposing building with cell blocks, tunnels and a gatehouse, all associated with the convict era of the 1800s that led to Australia becoming a colony.



I started to understand Georgia's emotions more clearly when I saw the photographs of the prison, highlighting the power associated with the image (Sontag, 1977). I did feel some apprehension about my next visit, as I was concerned that I did not want Georgia to become upset when remembering, but I was also aware that I had given her the opportunity to voice her fears and had supported her. Since I respected David and Georgia as co-researchers, I did not make too many plans for the next visit other than to consider writing down their thoughts about the study and mentioning that in the next visit we might consider discussing sounds for the digital film. At this stage we had edited the film together during the visit.

#### **8.5. Visit Four: View seen, viewpoint heard**

Whilst I made few plans in order to let Georgia and David lead the research, I did want to discuss sounds for the digital film and explore the suitcase in more detail to prompt discussion. As I arrived at their home, Georgia appeared pleased to see me and took me into the dining room. Discussion of the view outside their window into their garden became a regular feature during these visits as we noted the gradual changing of the season from winter to spring. She walked over and drew the curtains back and poised her hand as if to show off her garden with a sense of the theatrical. The sunlight warmed the room and we sensed the



hope of spring as we talked about the daffodils emerging from the ground whilst squinting at the brightness from the previously darkened room. Just as Musselwhite (2014) found when exploring aspects of mobility with older people, the importance of a view and a sense of motion outside can help the person to feel connected to the outside world as well as views of gardens having a significant impact on people's wellbeing (Kaplan, 2001). David came in to join us and spoke about being able to go on day trips more often as the weather was finer, clearly associating me with discussions of trips and holidays. The conversation seemed to elicit a sense of wellbeing and hope in them both. The word *view* then sparked off another direction of conversation as Georgia was reminded about her dementia. She talked about the *view from a mountain* where she and David grew up in villages in South Wales between the mountains. She then said it was *good to get view heard*. She talked about her loss of role in the home again and about not speaking out as much because she would *lose track* and *lose words*. I sensed again that she was glad to have her voice heard and that the research gave her this opportunity.

Often our discussions would meander as I let her conversation flow, reiterating the themes from the previous visits, in particular noting that there was more recalling of her childhood memories and interesting stories from the war, when she was free to walk the mountains and roam around the countryside. At times, her sentences would fade where she could not find the words to express herself, but her facial expressions, demeanour and body language made up for them. They reflected her emotions and sometimes she became tearful. She then pulled her body together by sitting up, putting her shoulders back, shaking her head and wiping her tears away. She smiled and started looking through and touching the objects in the suitcase. The emu tea towel again sparked conversations about their travel to the Northern Territory and seeing Aborigine people. David recalled a story about seeing a cow being knocked down in the dusty roads: clearly a vivid and shocking memory. Georgia made no comment other than: *There's a story with every memory*.

I suspected that Georgia's pulling herself together was how she had always coped in life before. The idea of *getting it off her chest* and then moving on to looking at the holiday

memorabilia made me realise that she felt better for having had her viewpoint heard and was then ready to enjoy the suitcase of memories. The conversations once again ranged from discussing pleasurable experiences of day trips and holidays to sadness and fear of the future. The previous themes of holidays as life and freedom continued to emerge as Georgia described her holiday memories as *pocketed*.

At this stage, I suggested that we watch the revised digital film again and asked them to consider what sounds could be added. I asked them to think about all of their senses, for the study, as my previous visits had concentrated on sight and touch. We sat and watched their digital film and discussed various sounds associated with the images. These included the sound of a didgeridoo that Georgia imitated when seeing the photograph of an aboriginal man and went on to cover her ears with her hands as she recollected the call of the Kookaburra. David spoke of his love of jazz music and talked about his visit to a jazz festival. I clarified what type of jazz he liked. They also spoke of going to the Sydney Opera House for their fiftieth wedding anniversary. This was a significant memory that they shared with Carla and her family. They weren't as animated about the music at the opera house as they were about other holiday sounds, although David remembered it was the Pearl Fishers by Bizet. Interestingly, the significance of the memory was more about visiting the Sydney Opera House with their family than the music itself. Other sounds included the noise of bats in the local park and the cicadas at night.

The love of holidaying by the sea was an important factor for both of them and they shared happy recollections as they talked about the sounds of waves crashing and water lapping at the beach. This included a trip to the Great Barrier Reef, where David snorkelled and Georgia sat by the water. Georgia responded to the photographs of the Australian snakes, which I had downloaded, with the same response as she had in the previous visit: *'Oh yes, I remember (arms folded) I can remember hop, skipping and jumping over the blimmin thing.'*

It is possible that she has always relayed this story in this way. This challenges Crawford's, (1992) view that we continuously change our ways of remembering events over time: perhaps

this stops when the person has dementia and their ways of remembering rely on well-practiced verbal and embodied responses. Georgia's response to the photograph of the snake was a performance in itself, where she would sit up and gesture, throwing her arms in the air and saying, *'I had to hop, skip and a jump over it.'* This was an embodied re-enactment of the event that happened and reflected how the story had been told time and again throughout her life. When we pay attention to the co-researchers' emplaced experiences, we can find new routes of understanding and gain an insight into how the person would tell their stories in the past. This also reminded me of a time when I saw an adder when walking through local woods.

Georgia and David's shared experiences of the holidays were brought to life by the photographs and visual images in the digital film and the objects in the suitcase, which allowed meaningful stories to unfold. David was keen to show me some commemorative coins they had bought during their walk along Sydney Harbour Bridge. The coins were kept in little plastic wallets for safekeeping: he took one out, and as it glimmered as Georgia took interest in them. The use of the objects was planned with a view to help elicit memories. They also offered some symbolic representation of the holidays and their life, as Georgia's sarong reflected the warmth of the holidays and her identity before the dementia, resonating with Twigg and Buse's (2013) research that explores the meaning behind clothes, embodiment and identity with people who have dementia. The meaning of the souvenirs, maps, photographs and holiday clothes contributed towards the realness of the holidays, inspiring more conversation. Interestingly, I noted that when touching the objects and talking about them, the narratives sometimes changed from an emotional one towards attempting to ascertain facts, such as where they were bought and when.

The touching and looking at the souvenirs and maps enriched the study by signifying a sense of realness to Georgia and David's holidays, bringing their stories to life once again in the present day. On seeing the tea towel, they journeyed in their minds from Sydney to another part of Australia with more stories to tell, resonating with Morgan and Pritchard's (2005) autoethnographic encounters that examined the significance of holiday souvenirs and their

associated stories. Just as Stevenson (2014: 339) states that *'materialized pasts reveal our journeys from place to place'*, this reminiscent research reveals the importance of objects in helping recall our stories from place to place and past to present time. Whilst we cannot be certain how accurate the recalling is in relation to the actual experiences, this is not necessarily important. As Marschall (2012b: 2217) notes, *'Such a return to the past can of course not be authentically satisfied but is simulated through invention and reconstruction.'*

Whilst David focussed more on the memories of the food and drink on holiday, Georgia joined in, smacking her lips as she recalled some of the meals they had. They both spoke over each other about their favourite meals and expressed that they both had different tastes, with David preferring savoury tastes whereas Georgia recalled her preference for sweet tastes. They both recalled the taste of the hot chocolate at the Lindt café on a number of occasions. It was clear that their memories involved much discussion about eating out, and food and drink was a significant part of the holidays. I drew from this and made a mental note to introduce some tastes associated with their holidays for a later visit: *'Coffee and Kirsch, milky coffee, gâteau (pause) I have a sweet tooth.'* Georgia naturally moved from talking about their holidays to re-living parts of her childhood again. She spoke a lot about her mother and father during this:

*Of course, the things that we are talking about now are the happy ones; there are other memories that will block up, not block but come up and they are not good, take them out and look at them and hopefully put them back, but I'd say they are a part of you.*

During the previous visit, I had asked whether David and Georgia would like to write an account of their thoughts and feelings about the study, but neither had undertaken this. Georgia mentioned that she didn't write anymore, but I reflected on when she first handed me her written letter after our first meeting. I did not pursue why she no longer wrote but she clearly did not wish to talk about it and I respected her wishes. I felt that a clear message had been given. With regard to David, I felt that he was tired and busy and did not wish to add to his workload. As the visit went on, there was very little talk about Georgia's dementia,

but instead a general reminiscence about their life, particularly when growing up during the war.

#### **8.5.1. Reflection and planning between visits four and five**

I felt more positive leaving Georgia and David at the end of this visit and realised that there had been less discussion about Georgia's dementia and more generalized recalling of childhood experiences together, as well as their holidays. The weather was better and the hope of spring seemed to set the mood for the visit, instilling a sense of hope. I returned home to add sound to the digital film. When doing so, I sensed that I was experiencing a virtual holiday of my own and felt a connection to Australia through Georgia and David's memories. Adding sound to the digital film seemed to heighten the experience when watching it, providing more meaning to the images by eliciting emotions of my own, particularly when the music was added. I also downloaded the Sydney café Lindt chocolate recipe from the internet (see appendix F) and went shopping for the ingredients with a feeling of anticipation of what the next visit might yield. I enjoyed exploring Australia with them and researching pictures and sounds, which made me want to travel there myself and explore a bit of their world that I have not yet seen. I'm sure that when I do go, Georgia and David will be with me in my memory.

#### **8.6. Visit Five: Strengthened self-identity with younger self**

As mentioned in the previous chapter, David and Georgia were unwell with a heavy cold during this visit but they both insisted we continue. I had brought food and drink that were associated with their holidays in Australia. The aim was to bring together a multisensorial experience of recalling their holiday memories with their digital story that included the soundscapes, preparing and sharing food and drink and touching and feeling the souvenirs, objects and photographs in the suitcase. Just as at every visit, Georgia wanted to show me the view through their window into the garden. It could be said that this became a ritual at the start of our conversations. We talked about how the garden had changed since the start of my visits as spring was emerging and the garden was coming into bloom and she was proud of her flowering pink Azalea. Once again, she talked of the importance of a view and being able to look out and see the seasons change to help her remember what time of year it is.

I explained to both Georgia and David my ideas of including their other senses in the reminiscence by making homemade hot chocolate with the recipe from the Sydney Lindt café. Their eyes lit up: I sensed that this gave them a sense of joy and purpose when they were both feeling unwell. I explained that it was experimental, since I had had no time to try out the recipe before my visit, but that the aim was to create a sensory reminiscence session based on their chosen holiday. On reflection, this was a good approach, since it reduced the possible power relations between myself and both Georgia and David as we all followed the recipe together. Before we started, we all smelt the vanilla bean that was long and black and looked like liquorice. I had been unable to source one from Madagascar, as in the recipe, and we all laughed and joked about that. We were not sure where the bean was from but there was a sense of the exotic when examining it. It felt like a dried up old banana skin, tough but bendable and springy. The cinnamon sticks were long, golden brown and smooth. David held one up to his nose as if smelling a cigar and the little round black peppercorns rolled around in the palm of Georgia's hand. She was frustrated because her cold would not let her smell as well as she'd hoped. But when she broke up the dark chocolate, she seemed to enjoy the feel of it in her hands: she threw her head back and inhaled deeply, closing her eyes for a few seconds and saying: *'It's smelling chocolate: you can smell the chocolate even though I have a nose.'*

It is interesting to note how Georgia's sense of smell was stimulated when touching the chocolate. She put the dark chocolate piece by piece into the saucepan, watching it melt rapidly whilst David whisked it up with the spices: vanilla bean, cinnamon and black peppercorns. Quickly the spices were immersed in the swirling dark liquid and the kitchen was filled with the aroma. David continued to stir and whisk the chocolate, whilst smelling the aromas. I think this helped them to feel a bit better by stimulating their senses, he said: *'I can smell the vanilla now.'*

The embodied moment of making the hot chocolate drew out the synaesthetic effects of using the senses of touch and smell together and shutting out sight. The aromas set off their

recall of the Lindt café, linking their senses to a sense of place. As they started to smell them, they both talked of their memories of the Lindt café, particularly in terms of where it was situated. They both closed their eyes and visualised the building and the street: *'One of the pedestrian streets Lindt was on, if I remember: there was a sloping street with steps.'* (David).

They both started discussing their memories of the street outside the café, Georgia closed her eyes in order to see it. She seemed to be imagining that she was there in time and place: *'I can remember it and you come running down it.'* Just as Stevenson (2014:338) notes:

*Memories of place are not confined to inner psychological archives. Rather they amount to multisensory, embodied material phenomena that are inseparable from emplaced practices.*

Smell and taste can be evocative ways to help connect to the past (Seremetakis, 1994). They can also be linked to a sense of healing. David and Georgia had both been very tired and felt unwell when I arrived, but the preparation of the hot chocolate had warmed them up. Lee and Balick's (2001: 120) study of botanical plants in Belize discusses the medicinal properties of cacao, black pepper and vanilla when blended together to create *'the beverage of life, of health.'* It certainly made them feel better throughout the morning. We left the hot chocolate in the pan for the spices to infuse for 25 minutes and returned to the dining room to look through more photographs that David had found. This time gave us the opportunity to explore the aromas of the individual spices that were emanating from the kitchen. Georgia highlighted: *'All good things come to those who wait.'*

David appeared very pleased that he had found more photographs, and new stories materialised with them. As they led the conversation, we moved towards their European holidays, prompted by the photographs. It was interesting to note that whilst they told me many stories about their various holidays on this visit, they concentrated more on the Canary Islands; these were the holidays represented by the recent photographs and maps that David had found. Whilst the photographs and souvenirs made the experience of reliving their holidays more authentic, they could also be a distraction. Indeed, Sheridan and Chamberlain (2011) highlight the potential disruption that objects can have on the research; I, too, found

this. There were many times when Georgia would be waxing lyrical (with some word-finding difficulty, but she could convey her story about the events on holidays), and then David would pick up a photograph, interrupt her and talk about the facts of where the photograph was and when. This stopped Georgia from describing her feelings associated with the places. A few times I tried to help Georgia return to her story, with some success, but at other times she had forgotten the thread of what she was saying and where she had been in her mind's eye which did irritate her somewhat.

After looking over the photographs, David laid the table and I brought out the food that they had mentioned in previous visits. We all sat around the table together and shared the croissants, Parma ham and salad. Georgia broke up the croissants into little pieces and popped them into her mouth, clearly relishing the touch of the pastry and its flavour. As the butter melted in her mouth, she sat back, closed her eyes and said *mmm*. David particularly enjoyed the ham that he tucked into his croissant. We laughed about drinking a little drop of Kirsch for medicinal reasons, and Georgia's cheeks changed from a dull greyness to pink plumpness. Once the hot chocolate was ready, I poured it into mugs for us all: the sound of the thick chocolate and its dark spicy smell gave the room a feeling of warmth and healing and we all had a sense of anticipation. Enjoying the hot chocolate and gateaux, Georgia and David relaxed and their bodies appeared to sink into their chairs, as did mine. All the talk of holidays made me reminisce, and I found myself recalling holidays in Greece where we would drink espresso coffee and eat Danish pastries for breakfast. As we ate, memories from different parts of their lives came flooding back, mixing their rural childhood with holiday experiences. Whereas I was expecting them to reminisce solely about the Lindt café and the Sydney Tower buffet, Georgia started recalling memories of a horse in the garden when growing up, and told the story of her father keeping pigeons during the war. They needed to be inspected regularly for any incoming war-related messages that could indicate espionage! At this point, their stories intertwined between childhood and later holidays, moving back and forwards in time depending on the theme of the memory, elicited by the sensory experience: *'That was the life we lived', (Georgia)*. Interestingly, the stimulation of the senses led them to recalling other memories, possibly where similar emotions were evoked.



David talked of the food on aeroplanes as *'a break in the monotony of flying, it's something to look forward to'*, which reminded him of a flight they were travelling on being rescheduled to Mombasa as the first Gulf War was declared. After we enjoyed the food and drink, we watched their digital story with the addition of the soundscapes. Georgia appeared particularly excited: *'Ready for off!'* and she imitated the sounds of the didgeridoo as they saw the images of the Aborigine men in the streets of Sydney, just as she had on my previous visit, and on hearing the soundscape she confirmed that she recognised the noise they made. Her rehearsed response about the snake was also re-enacted once again upon seeing the picture. Just as Agapito, Pinto and Mendes (2017) found that the sound of the sea was often more significant than a view, so too did Georgia and David, and they spoke often of the sound of waves and enjoying the sense of being near the sea. Such remembering of sensory aspects of holidays is identified in Small's (2008: 778) study exploring childhood memories across the lifespan, where one older participant describes her memories of aspects of her holiday in terms of the *'hot weather'* and the *'cold wonderful water to swim in.'* I felt that when hearing the sounds of the cicadas on the film, there was a sense of warmth associated with it. When Georgia heard her voice on the film, she initially didn't like it and recalled her memories from childhood of her mother having a beautiful voice but saying: *'Yes, my mother would say "yes Georgia always makes a joyful noise unto the Lord" (pause) it's a croak.'* She referred to her singing voice as a child. I offered her the opportunity to edit her voice out of the film but she said: *'I have to accept that my voice is a part of me and that's it, it's my voice. If anyone is thinking of me, the voice is still here.'*

After watching the digital film, Georgia and David both agreed that it was quite meaningful to them in its attempts to create a nostalgic feeling and reconstruction of some of the sensory experience of their holidays. They both expressed their agreement that the film had been a fair portrayal of their holidays and that they had enjoyed watching it. Georgia turned to the suitcase and explored its contents again. She put on her holiday hat, modelling it and looking at herself in the mirror; she relaxed and laughed, reliving memories of Australia. She fanned herself and exhaled loudly as if hot from the sun, then moved purposefully towards the mirror to see herself wearing it. I interpreted this as Georgia wanting to see herself as she was when on holiday. Her re-enactment transcended time and space and helped her to reconnect with

her younger *self* on holiday, who experienced fun and joy. By linking the past to the present through stories of holidays, Georgia's sense of her younger self returned: she embodied a sense of confidence, particularly compared with how she presented herself at previous visits where her identity was clouded by the dementia. She also spoke more confidently, restoring a sense of her own identity as an independent, decision-making woman in contrast to her previous sense of self, seen on earlier visits where she believed she had lost her identity. Thus, she showed signs of reconnecting fully with her previous personal identity before the dementia diagnosis. This identifies with Sabat and Harre's, (1992) theories on the complexities of dementia's impact on the sense of self. Georgia also noted that we were making connections in time and space. *'So, the link is from young to us old and dodderly (laughter): It's linking the time we're still plodding on over all this time.'*

These experiences reinforce that our embodied sensory selves are emplaced in place and time. Georgia's sense of self throughout time and place is layered. She went on to say:

*I can see it in my mind's eye (pause) there were trees, tall trees. I can remember being exhausted and flat out and feeling the heat on top of my face (pause). Those are pictures in my mind that David doesn't see*  
Georgia

This brought joy and a sense of occasion to the research, which reflected the positive emotions associated with the holiday and identifies with Killick's (2010, 2013) observations on the benefits of playfulness, drama and positive emotion when interacting with people who have dementia. Throughout the visit, Georgia gained more confidence in her storytelling and recalling of her memories, thus reconnecting with her younger self both when on holiday and throughout her life, often with humour. I noted that on this visit, Georgia only mentioned her dementia a couple of times, and in a more accepting way:

*I'd like to be thought of as a person and not as somebody as dementia. What I am trying to say is there is that I am still me, it doesn't matter whether no longer can remember exactly who I a (inaudible) what I am doing underneath I am still me (pause) mmm because people look at you, and they think well (pause) you're going to be different at least I don't think I am (inaudible) I am probably a bit more irritable*

*Georgia*

For most of the visit, Georgia was fully emplaced within her past life whilst enjoying the sensory moments in the present. I sensed that she had gained more confidence during the multisensorial experience of the morning and realised that sensory ethnography helps the researcher to develop their intuitive sense with the person who has dementia. Even though we had spent most of the morning experiencing the past, Georgia clearly felt content in the present moment and spoke positively about the future. During previous visits, talk about the present day was overshadowed by her dementia and the losses associated with it. With each visit, this lessened in intensity, and during this last visit she hardly referred to the dementia until the end:

*They bring all the old music, don't they, into these dementia places, I've nothing against them but (pause) we have moved on, we don't always live in the past, there is now and (pause) hopefully the future.*

*Georgia*

We all agreed that this visit would be the last one, since we seemed to have explored all of the senses, but David suggested that we meet together with their Forget Me Not group and show them their digital film. I gave them a copy of the film to keep and the rest of the ingredients for making more hot chocolate, along with the recipe, in the hope that they might continue to relive their holidays through their senses.

### **8.6.1. Reflection**

Georgia's accounts and embodied appearances indicated that the research had helped her to make sense of their life as a couple and as an individual in the present day through the context of remembering past holidays. By re-experiencing their lives on holiday through attending to

all of her senses, she was able to reconnect with herself, which she associated with her younger self: one where the dementia was side-lined. Communication was easier at times on an emotional and sensory level, more than on a cognitive one. David clearly was immersed in the memories of their holidays, linking their memories with their current day trips. They both appeared more positive about their day-to-day lives.

### **8.7. *Forget Me Not* group**

Both Georgia and David were keen to share their experience and film with their local Forget Me Not, Dementia support group. Whilst I had not planned this as a part of the research, it indicated that adopting a critical approach to the study had empowered Georgia and David. This helped bring the study to a positive end, allowed them to share their experiences with other people who have dementia and their partners, thereby, introducing them to the idea of using their senses when reminiscing.

Georgia, David, Carla and I went to the group armed with a few sensory props, including sun-cream, tubs of ice cream, shells and sand, and showed the digital film. The group consisted of eight couples: people living with dementia and their partners who cared for them. Georgia clearly enjoyed sitting within the group and she and David spoke about my visits and the research. She became a performer in her own right, as she talked about the holidays and how they re-lived them through making the digital film, gathering together holiday memorabilia and sharing the food and drink. After showing the digital film, we all shared ice cream and smelt and touched the sun-cream and shells. All the people in the group contributed to the conversation about past holidays on differing levels, apart from one gentleman who, as a result of his dementia, could not speak or respond in any way. His wife told me that she had lost him, and that there was *nothing there*, pointing to his head. However, I noted that when I put on the digital film, his shoulders relaxed, his foot started tapping and a slight smile came across his face especially when the jazz music was played. When I pointed this out to her, she started to cry and I took her to one side to comfort her and to see if they had any jazz music at home that she could play.

*I have seen deeply demented patients weep or shiver as they listen to music they have never heard before, and I think they can experience the entire range of feelings the rest of us can, and that dementia, at least at these times, is no bar to emotional depth. Once one has seen such responses, one knows that there is still a self to be called upon, even if music, and only music, can do the calling.*

*Dr. Oliver Sacks*

This reinforces that we need to be creative in how we connect and re-connect with people who have dementia, using sensory means. Meeting their friends, telling and showing their story to the group helped the research come to a natural end and gave both Georgia and David a sense of purpose, as they could see the value of their involvement as co-researchers by helping others find ways to communicate with their partners.

### **8.8. Reflections**

Although not planned, the visits naturally built on each other, involving more senses. However, Whilst I gave Georgia and David the opportunity to lead the study, there were still times when I introduced some ideas, such as suggesting that we share the food and drink together that they had talked about. When I first met Georgia, she clearly needed to share her feelings about the dementia but over the visits this diminished and that remembering together was significant for both Georgia and David. Georgia mentioned that they were *attuned* to each other, which helped in recalling the memories of shared experiences.

When emplaced in their world, I intuitively related to Georgia as a complex, multi-layered person who has lived for over eighty years and whose stories interweave throughout time and place. Stripping away the pressure of cognition and exploring the sensory aspects of tourism memories led to an exploration of the spiritual, in the sense of finding meaning to life, of what it is to be human, and responding to that meaning. Meaning can be explored through many sources: art, music, God, the environment, and now the re-living of holiday memories, which are usually associated with times away from the routines and responsibilities of day-to-day life. The suitcase of memories drew out the themes of *holidays as life; freedom; a view seen, viewpoint heard; and strengthened self identity with younger self*. It was interesting that Georgia, who is quite a philosopher, spoke about her loss of self

but then continued to reminisce and reconnect with her old self during the remembering. In addition to the themes, the multiple layers of shared and individual experiences of re-living their holiday memories through the senses led both Georgia and David to be fully emplaced in their past experiences whilst being in the present at their home. This research has highlighted the complexities of people's lives and stories in time and place, and that may help people who live with dementia to remain connected to others for longer.

## **8.9. Summary**

This chapter has explored the world of the co-researchers within their home but also within the place and time of their past holidays. It has examined the role that autoethnography can play in developing empathic ways for researchers to connect with people who have dementia. The diverse methods adopted at each visit included mind mapping, using souvenirs and clothes as prompts, re-enactment, the creation of a digital film, including sounds and foods and drinks associated with past holidays to ensure that a fully sensorial experience was achieved.

Meaning and significance when recalling tourism memories using this approach were identified throughout each visit, where themes were identified from the conversations and observations of *Holidays as life; Freedom; View seen, viewpoint heard; and strengthened self-identity with younger self*, alongside ethnographic narratives that examine the experience of the suitcase of memories. In addition to this, the use of field notes and reflections between visits whilst immersed in the study have been examined. Throughout all the visits, achievements and challenges are identified and reflected on, highlighting the complex but successful nature of sensory ethnography as a way to finding meaning with those who have dementia and their partners, and specifically for this study, in light of the challenges they now face in going on holiday. This chapter has shown that people cannot be separated from their lives whilst in the process of being research participants and that the suitcase of memories helped towards sustaining Georgia and David's couplehood by enabling them to communicate their shared embodied memories together. These aspects will be explored in more depth in the final chapter, in which the contributions of the study are discussed.

# **CHAPTER 9**

## **REFLECTIONS & THE WAY FORWARD**

- 9.1. Introduction
- 9.2. Overview of the thesis
- 9.3. Contributions to ethics
- 9.4. Contributions to methodology
- 9.5. Contributions to practice
- 9.6. Future research
- 9.7. Personal reflections

## **CHAPTER 9: REFLECTIONS & THE WAY FORWARD**

### **9.1. Introduction**

This final chapter will provide an overview of the study, revisiting the original aim and objectives and reflecting on its findings and contribution. The chapter presents an argument for more innovative qualitative study with people who have dementia and examines the study's contribution to ethics, its methodology of sensory ethnography in dementia and its creation of a multisensory reminiscence toolkit; an effective method for researching and generally communicating with people who have dementia. It explores the impact of this approach on practice and highlights the value of meaningful multisensory toolkits to help people who have dementia and their partners to reconnect. This chapter proposes that this could also be extended to families, formal carers and professionals within the health and social care sector. In addition, the chapter highlights the results from phase one and sheds light on the importance of training and awareness of tourism staff in helping create dementia-friendly holiday environments. The complexity of this study meant that there were limitations in the research which will be discussed. The chapter concludes with my personal reflections on the PhD journey.

### **9.2. Overview of thesis**

The study's epistemology, grounded in a critical perspective, has influenced my qualitative methodology and the subsequent methods in order to explore the significance of recalling tourism memories from the perspectives of people who have dementia and their partners. The aim of exploring the meaning and significance of recalling tourism memories for people living with moderate dementia and their partners has been achieved through two research phases; the second of which incorporated sensory reminiscence methods. This thesis has highlighted the complexity of dementia and the individuality of a degenerative condition that impacts on mental capacity, memory, speech, orientation and reasoning. However, as noted in Chapter Two, the person living with the condition is still capable of feeling and expressing emotion and responding to their environment. It is suggested that embodied experiences,

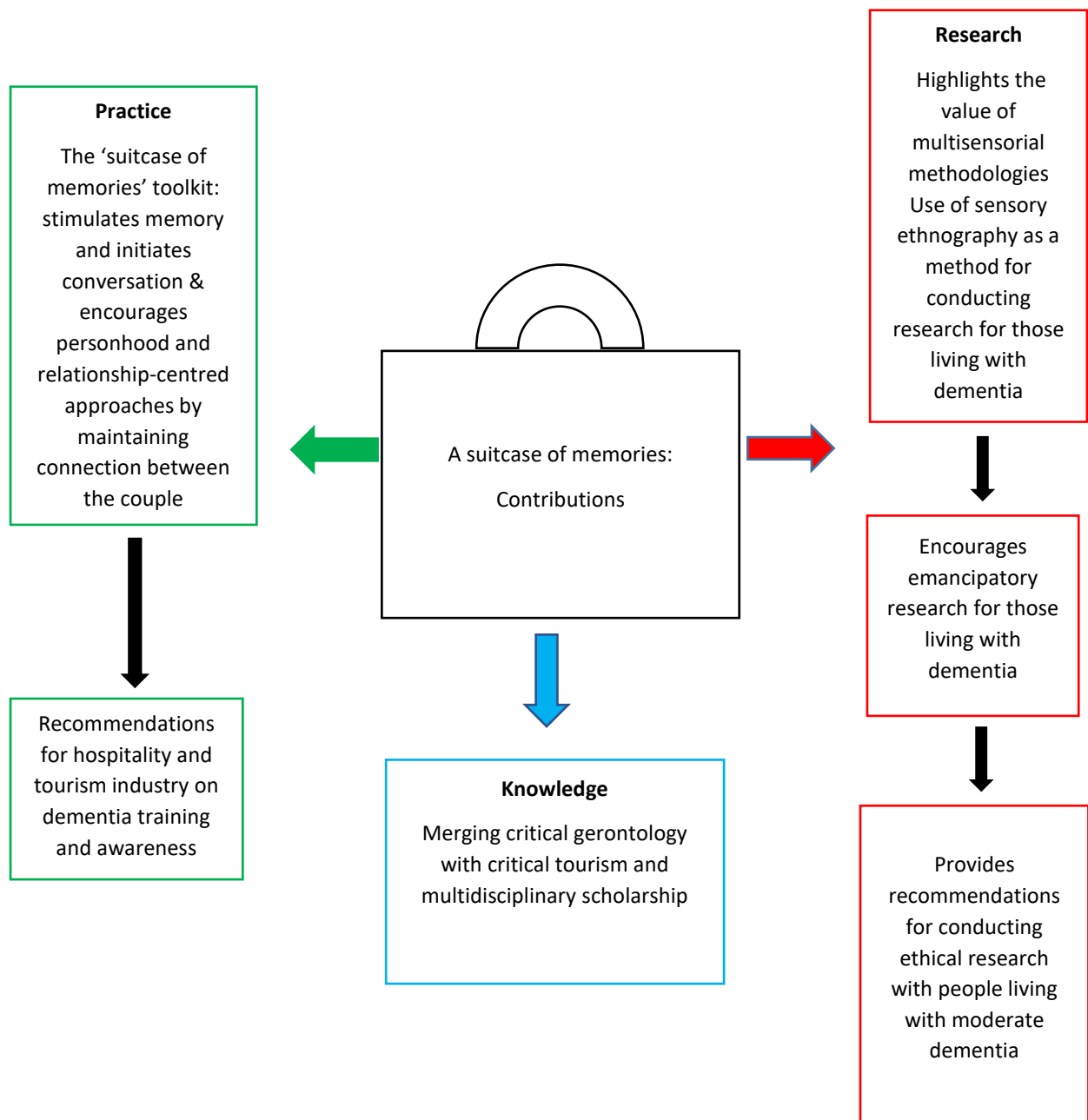


including recalling holiday memories can have an impact on their sense of self and identity in the past and in the present day.

Whilst phase one identified some limitations to undertaking traditional qualitative research with participants who have dementia due to speech and cognitive difficulties. Phase two adopted a multisensory approach, recognising that senses are likely to often remain intact for longer than the power of speech. Phase two, therefore adopted sensory ethnography using the senses of seeing, hearing, feeling, smelling, tasting, alongside movement and performance. The sensory ethnography enhanced communication between myself as a researcher and the person living with dementia and their partner. Significantly, this is the first research conducted within the field of tourism and dementia studies that considers the perspective of the person living with the condition and merges the critical gerontology and personhood literature with critical tourism scholarship and sensory ethnography. (Figure 9.1 provides a visual overview of the study's multifaceted contributions). Hence, the overall contribution of my study has been to explore multisensory ways to communicating and connecting with people who have dementia and their partners to help sustain their relationships. In doing so, this research has critiqued the ethical issues of undertaking research with people who have dementia, particularly mental capacity and consent and the importance of being sensitive around aspects of diagnosis.

In its study of the lives of people who have dementia and their partners, this research has provided insights into the impact that tourism and recalling holiday memories has on couples. It has thus, given people living with the condition, an opportunity to explore and express themselves and indicates how dementia can affect a person in all aspects of life including tourism and by adopting multisensory forms of communication helped the person and their partner to relax and speak openly about their lives. In this way, the study has also contributed to the couplehood literature by exploring the value of embodiment and use of the senses in maintaining connections where relationships are strained and consequently, help overcome some of the losses of shared memories. Thereby, allowing them to re-connect.

**Figure 9.1. The Study's Contributions**



This study has been the first to privilege the views of those living with dementia within a tourism context. By introducing sensory ethnography, the embodied tourism encounter has been explored for people living with dementia and their partners. In doing so, this research has shown the importance of holiday memories. Just as Urry (2007, cited in Parkhurst, 2014) talked about travelling through the imagination, the suitcase of memories facilitates ways of travelling within the mind and body.

### **9.3. Contributions to ethics**

Where many studies briefly mention ethics, this research foregrounded ethical practices throughout the whole process. The study identified the real life ethical challenges of undertaking research with people who have difficulty with their decision-making abilities and mental capacity and their partners. It has examined the potential applications of meaningful consent for people living with dementia in tourism research and wider scholarship. As discussed in great detail in Chapter Four, much of the biomedical and psychological research in this field previously relied on proxy consents, offering very little discussion about the person living with the condition. This has started to change over the past ten years; however, many research papers still fail to explore the real difficulties in gaining consent and undertaking research with people who have dementia or consider the ethical minefield too complex to undertake.

This study recommends that all ethics committees insist on researchers following a recognised approach for ongoing and negotiated consent when undertaking research with people who have dementia and other vulnerable people whose decision-making is compromised due to ill health and disability. In addition to this, the use of meaningful multisensory materials during information giving must be considered where a written information sheet is impractical. This study also recommends that all researchers working with vulnerable people and those with decisional difficulties have experience in assessing mental capacity and follow the Mental Capacity Act (2005) guidelines, whilst recognising the need to consult the person who has dementia. It is also recommended that researchers have extensive experience of working with people who have dementia and are sensitive to their

emotions, cognitive difficulties and challenges with language and communication. Participant wellbeing needs to be at the heart of any study. Researchers also need to be aware of potential power relations and the need for relationships to be mutual, ensuring that the significant people have the person who has dementia's wellbeing at heart. Therefore, I identify a number of skills and qualities that need to be utilised when researching with those who have dementia (see chapter seven). It is also recommended that the researcher is able to refer or suggest services to the participants, such as counselling, memory clinics and local third-party providers, should the need arise.

Further recommendations extend to researcher wellbeing. Whilst personal safety is routinely examined in current ethics applications, this study endorses the need for researcher supervision. Undertaking this type of study can be emotionally demanding due to the degree of reflexivity involved, and the blurring of the role may lead to a more onerous one that involves offering support to the participants. In light of this, it is recommended that the researcher seeks support from colleagues throughout the study, as reading through transcripts and periods of analysis can also have an emotional impact. Where studies are conducted within the participants' homes, issues around personal safety need to be identified. A lone worker policy should be adopted which involves contacting a nominated member of the supervisory team or work colleague after each visit to inform them that one has safely left the place of study (Dickson-Swift et al., 2008).

#### **9.4. Contribution to methodology**

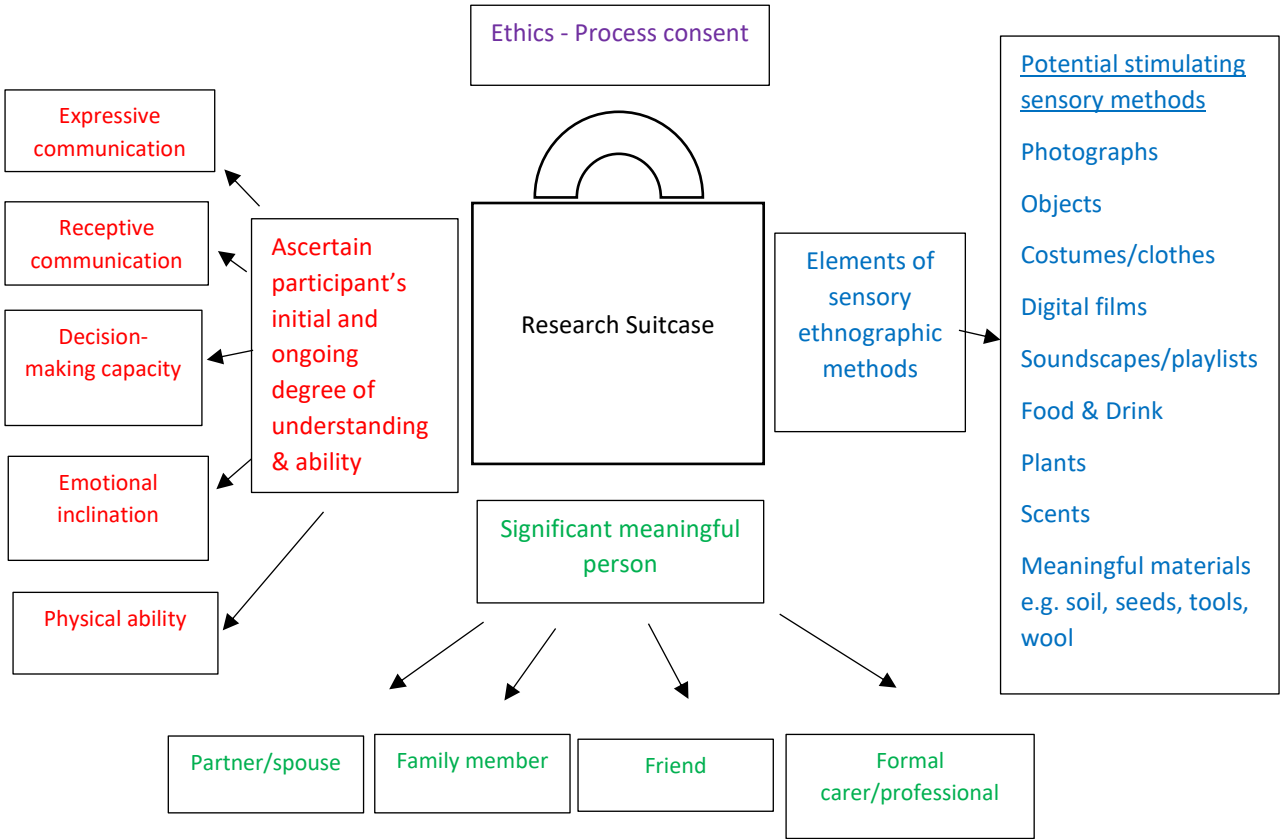
The use of sensory ethnography as a methodology has been espoused in Chapters Seven and Eight. Its value as a research approach with people who have dementia is clear in that it provides these people with an opportunity to participate in a study with their partners, where they might have previously been excluded on the grounds of their cognitive impairment and diminished mental capacity. Such a participatory approach contributes to the emancipatory research literature that privileges the co-researchers' experiences and lets them lead the direction of the research. In addition, this study has contributed to the research literature by recommending the use of sensory reminiscence as a research method. Whilst reminiscence

is a well-recognised intervention for people who have dementia in a caring setting, there is no evidence of its use as a research method to facilitate communication in any of the tourism and dementia literature to date (Woods, 2005; Woods et al., 2015).

The study also found that the value of sensory ethnography had potential benefits for other family members. Thus, Carla experienced the positive feeling of seeing her parents both engaged in a meaningful activity together, which helped with her feelings of loss and helplessness at her mother's diagnosis. The study has also added to the couplehood literature by exploring the experiences of sharing multisensory memories with people living with dementia and their partners. Thereby, challenging the deterministic model of cognition as being reduced to parts of orientation, memory, reasoning and judgement. This research has also crossed multiple disciplines and brought tourism and dementia together. By explicitly discussing the complexities of researching with people living with the condition, the study indicates that traditional research approaches are not always appropriate and suggests the need for more creative and innovative forms of inquiry.

This study has shown the use of sensory ethnography in allowing researchers to overcome the conventional qualitative research challenges when researching with people living with dementia and recommends its use with those at a more severe stage of the condition. Since cognition can be enhanced by introducing meaningful multisensory experiences such as the suitcase of memories, links between the embodied emplaced experience and memory have been found. The value of this also lies in being able to connect with people with differing degrees of dementia whose condition fluctuates. This thesis also provides an insight into how tourism memories might be used with other vulnerable groups whose decisional and mental capacity is affected. Here, the experiences of those who have learning disabilities, mental ill-health and other neurodegenerative conditions such as Huntington's chorea may be explored. Indeed, this study may act as a starting point for others using multisensory methods to elicit embodied and emplaced responses. (Figure 9.2 identifies ways in which such methods can be undertaken). This study is thus, the tip of the iceberg in examining the potential use of sensory ethnography and multisensory reminiscence methods in theory, research and practice with those living with dementia.

**Figure 9.2. Sensory ethnographic methods for researching with those living dementia**



### **9.5. Contribution to Practice**

The findings of this research have identified many implications and recommendations for practice when considering people who have dementia and their partners. The complexity of this research has identified a number of contributions to practice within the field of tourism and in health and social care. Firstly, as discussed in Chapter Six, the results from the conversations with the partners in phase one highlights the relevance for the tourism sector and identified the challenges associated with going on holiday with spouses who have dementia. The difficulties experienced with travelling, dining and going to the toilet came to the fore where the lack of understanding from holiday staff made the challenges more difficult. By determining the difficulties that environments such as aeroplanes, airports, trains and stations can create for those living with dementia, this study proposes guidelines for the tourism sector. The need for tourism providers to raise awareness and train their staff about dementia and how it can affect the individual holiday maker is identified. This includes providing multisensory props to aid communication, such as visual images on menus; improved environmental design and the creation of a system like the blue badge disability scheme or a passport-type document which could inform staff of the holiday maker's needs, e.g. the need for the couple to sit together when travelling, to increase the light when looking at menus and avoid rushing them when being asked to make decisions. This might help towards maintaining the person's dignity, avoid anxiety and reduce confusion. Thus, the study also adds to the literature on dementia friendly environments (Fleming et al., 2017; Waller, Masterson & Evans, 2017) and the tourism and accessibility scholarship (Richards et al., 2010; Richards, 2013; Suntikul, 2014).

The research showed how the suitcase of memories proved to be an effective way of stimulating memory and emotion, which helped initiate communication without creating stress and anxiety for those living with dementia. This in itself is a practical and therapeutic way to help people who have dementia re-connect over a joyful positive experience. The significance of multisensory reminiscence for the person living with dementia through the suitcase of memories cannot be underestimated, since it gave the individual an opportunity to express themselves in both embodied and verbal ways, thus, helping them to stay

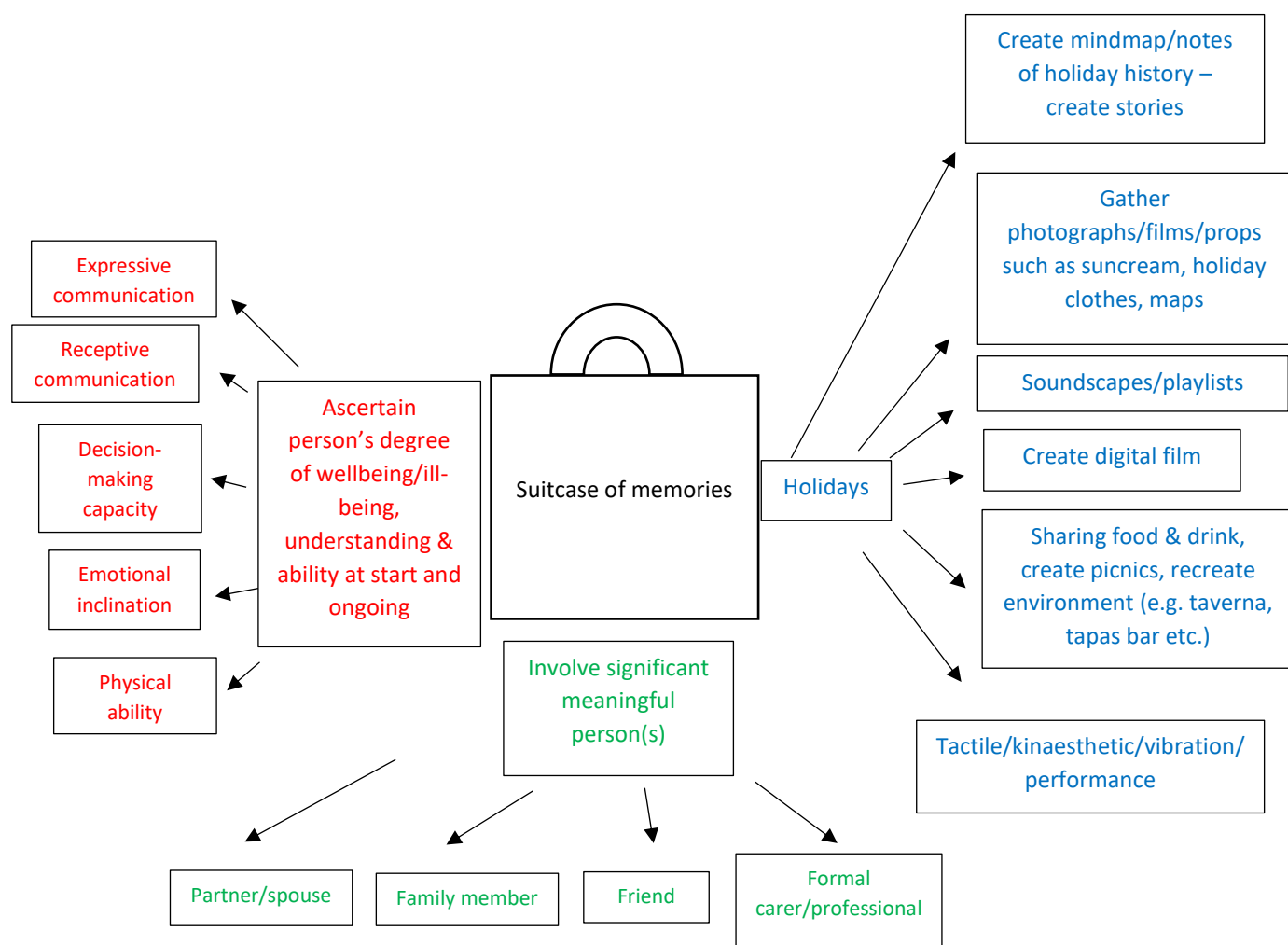
connected with others around them. This is compelling because, as discussed in Chapter Two, people living with dementia are often ignored and withdraw from social interaction.

The suitcase of memories might therefore, be undertaken on a number of levels that are appropriate for people with mild to severe dementia since it provides a non-threatening way for people to express themselves and for the person supporting them to respond. It also provides the opportunity to express oneself through performance (dressing up in holiday clothes) and allows the person to experience a sense of playfulness and humour that might previously have been lost (Killick & Kenning, 2015). This study also recommends examining the effectiveness of the suitcase of memories in therapeutic practice with health and social care professionals.

In this research, the suitcase of memories also drew out a number of themes, notably *freedom; holidays as life; view seen, viewpoint heard* and *strengthened self-identity with younger self*. These all contribute to the feeling of being valued, respected and listened to: all aspects of what makes us human. By encouraging meaningful communication between the person living with dementia and their partner based on their shared histories, the suitcase brought their past and present together. It helped both the person living with the condition and their partner to focus more on positive ways of connecting that shifted the emphasis from their losses towards their couplehood. In this study, the suitcase of memories created a feeling of wellbeing in both the person living with dementia and their partner, which positively impacted on their mental and physical health. I suggest that there is also potential to develop the suitcase of memories with other family members, friends and carers who are often at a loss as to how to continue their relationship with the person who has dementia. Attending to the senses can stimulate emotional memory for all. (Figure 9.3 indicates a toolbox for those considering using sensory ethnography in therapeutic practice).



**Figure 9.3. Contribution to Practice: Things to consider when undertaking a Suitcase of Memories Toolbox as a therapeutic activity**



## **9.6. Future Research**

Attempting to understand the experiences of those who have dementia is vital, as it is predicted that two million people will have this diagnosis by 2050 in the UK (Alzheimer's Society, 2017). This is compared to 850,000 today (Alzheimer's Research UK, 2017). Whilst this study is the first to consider recalling tourism memories for those living with the condition, it is hoped that more researchers will build on this work in a number of ways. Certainly, the role that tourism plays in the lives of those living with mild dementia needs to be explored. The impact of dementia-specific holidays on people living with the condition and their partners is another potential area of enquiry. There is also a need to evaluate the effectiveness of the small number of current dementia friendly holidays and to examine the feasibility of respite care (Shared Care Scotland, 2017) and short breaks for the person living with dementia as well as their partners/carers. Indeed, it is vital that we listen to the voice of people who have mild, moderate and severe dementia and their partners in terms of their needs.

Limitations to this study include the couples being white and predominantly from middle-class professional backgrounds. For example, the co-researchers all had experience of holidaying abroad with three of the couples actually owning their own holiday homes. Future studies need to explore people who have dementia from poorer socioeconomic backgrounds to examine what their memories of holidaying at home and short breaks may elicit. Extending this research to those from different ethnic and socio-economic backgrounds would develop further insights and contribute to the need for ethnic diversity within research. In light of the ageing of migrants who settled in Britain in the 1950s, there is a critical need to examine the lives and experiences of those diagnosed with dementia. This includes their holiday backgrounds where sensory ethnography may also be a viable methodology to use in light of their different language and cultural backgrounds and where people living with dementia often refer back to their mother tongue as the disease progresses.

Whilst this thesis recommends the use of sensory ethnography in all studies with those experiencing cognitive difficulties, further research needs to be undertaken that develops its

role as a research methodology. By using it in longitudinal studies from initial diagnosis throughout the dementia career, valuable insights into how connections may be maintained with couples and families may be examined. I recommend that such studies be filmed to aid analysis and to disseminate its effect within the wider research and practice community. Since diagnosis rates are increasing (Alzheimer's Society, 2017), there is an urgent need to provide effective emotional support, which is proven to contribute to person-centred care. Here, it is important that we examine the role that multisensory toolkits that include films along a range of themes, for example, sport and music can play with those diagnosed with dementia.

It is therefore proposed that future research is undertaken using the *suitcase of memories* to evaluate its further potential as a research methodology and a therapeutic practice for those living with dementia and to examine the significance of using it with other family members and friends who also have to cope with their sense of loss and concern.

### **9.7. Personal Reflections**

Now that I have come to the end of this PhD, I feel the need to reflect on my experiences as a researcher and nurse and to explore the effects it has had on me as a person. When embarking on this PhD, I felt confident and, dare I say, complacent that I had addressed all potential challenges in undertaking research with people who have dementia, since I had worked with and undertaken research with people living with the condition for a number of years. However, this was not the case, once I had started the research and faced the challenges.

Whilst the literature review was undertaken in the traditional sense of reading and analysing papers from multiple disciplines, the thesis has not followed a clear scientific process and as a result has been a challenge to write. The study initially aimed to explore the experience of holidays with people living with mild dementia, however the recruitment process introduced me to people who were living more at a moderate stage, which had implications in how the research was undertaken. Due to the results from phase one, this research evolved towards exploring the meanings and significance of recalling tourism

memories for people living with dementia and their partners. It has not been easy for both myself and the participants where at times, there was much sadness on the part of the participants throughout both phases of the study as well as moments of joy. I overcame a number of challenges along the way, notably I experienced researcher's block after phase one where I was unsure which direction to take in light of the disparate results between the participants in terms of time, place and emotion. But I knew I needed to fulfil my aim, which involved exploring the experiences of both those living with dementia and their partners.

The key to this research is intuition as I have connected with the co-researchers at a level that cannot be seen and is difficult to describe since we cannot rely on full cognitive responses. Thus, my role as co-researcher, has been a humbling one. The use of intuition is the key to unlocking the person who has dementia, with the help of incorporating the senses, but attempting to write about an intangible concept is a difficult venture. It is questionable how many researchers will be prepared to commit to the challenge, and some may choose easier paths and processes.

Writing this thesis has been a challenge, since there is a desire to want to tidy up the visits and give them a more structured outline. However, that is not a true reflection of events. Human interaction is not so straightforward and structured, and when we add dementia into the research, the fluctuation of experiences in time and place are more marked. There was a temptation to communicate the methods and results neatly, together with thematic analysis of the conversations, but that would not reflect the true complexity of the research. I decided not to follow a well-established research process or, as Holloway and Todres (2007: 17) call it, a 'well-trodden path'. Whilst that would have proved a much easier option, the results would not truly reflect the meaning and significance of recalling holiday memories for the person who has dementia and their partner. This research itself has twisted and turned and waxed and waned along with the co-researchers. Therefore, the research was messy and changed from the original aims and objectives, as the research question was refined to one the co-researchers felt was important. I also realise that despite my indepth critique of the bioethical model of research, I found myself conforming to it by

providing written information sheets to the participants in order to gain ethical approval for the study.

This research has had a significant effect on myself where previously my professional roles have been subservient to the doctors I worked with; being the 'jobbing researcher' where my colleagues were seen as experts; often revealing their names on research papers where I had been managing and conducting the studies. This study gave me permission to explore my reflexivity, and whilst being a naturally self-reflective person, my reflexive statement when in the role of a nurse and researcher helped me clarify my beliefs, values and assumptions. This study has given me the confidence to validate my thoughts, experience and understanding of how I have always communicated with people who have dementia and by listening to them, in this research, I have further understood their experiences and needs. Thus, culminating in my recently published book: *Finding the Light in Dementia: A Guide for Families, Friends and Caregivers*. The research has greatly impacted on my practice in terms of seeing the value in connecting with people who have dementia through the senses, and has opened up many more questions than it has attempted to answer.

The overall experience of including those who have dementia in the study, however, was a positive one: the participants also displayed happy emotions at each visit, indicating that they enjoyed the experiences and felt valued. The memories of the participants who had dementia were clearly expressed through embodied responses, and I saw the value of recalling holiday memories as therapeutic, so that glimmers of their old selves emerged and communication and hope were conveyed. Whilst attending the *Forget Me Not* group, I saw the participants disseminate their own research results when showing their digital film to others who were in a similar situation to themselves. Seeing how the research empowered them (as individuals and as a couple) gave me a sense of doing some good.

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# APPENDIX A: ETHICS APPROVAL

9.04.2016  
csm/ethics/approved

Jane Mullins

Cardiff School of Management  
Llandaff Campus  
Cardiff, CF5 2YB

Dear Jane,

Re: Application for Ethical Approval: ***Exploring the meaning and significance of tourism memories for people living with dementia and their partners (Phase Two)***

Ethics Committee Application Reference Number: **2015S0031**

Your ethics application, as shown above, was considered at the meeting of the School Research Ethics Committee on 13.04.2016. Further to requested committee amendments, I am pleased to

inform you that your application for ethical approval was **APPROVED** by the Chair of the Committee subject to the conditions listed below – *please read carefully*

## ***Conditions of Approval***

- Your Ethics Application has been given a reference number as above. This MUST be quoted on all documentation relating to the project (E.g. consent forms), together with the full project title.
- Any changes in connection to the proposal as approved, must be referred to the Panel/ Committee for consideration.
- A full Risk Assessment must be undertaken for this proposal, and be made available to the committee if requested.
- Any untoward incident which occurs in connection with this proposal must be reported back to the panel *without delay*

Yours sincerely,

*On behalf of the Chair of the Ethics Committee*

Louise

**Louise Ballantyne**

**Research Administrator – Gweinyddwr Ymchwil**

**Cardiff Metropolitan University / Prifysgol Fetropolitan Caerdydd**

**Cardiff School of Management/Ysgol Reoli Caerdydd**

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**[CSMResearch@CardiffMet.ac.uk](mailto:CSMResearch@CardiffMet.ac.uk)**

## APPENDIX B: EXCERPTS FROM TRANSCRIPTIONS

- R: I have in the past, in my past I'd had a lot all in all, the (inaudible 00.22.46) in my earlier days. I was footballer, did you know that?
- I: **I do. You played for Everton.**
- R: No, Fulham.
- I: **No, Fulham, sorry.**
- R: That's all right, don't worry.
- I: **Is that the biggest insult?**
- R: No, no, no. It's not really but anyway.
- I: **So, you travelled to the States?**
- R: Yes.
- R2: *I have about another 15 packs of those.*
- I: **Wow, so this is like your ...**
- R2: *Do you remember this one? The people in it are a bit of a giveaway but there we go. (Laughter).*
- R: Oh, that was in the Rockies?
- I: **The Rockies?**
- R2: *No, no.*
- R: No, the shape is there.
- R2: *You look at some of the other photos, darling, in there.*
- I: **Oh, wow. Is that south-east Asia somewhere, is it?**
- R2: *Where did we go, can you remember?*
- R: We went to China.
- R2: *Yes.*
- I: **Have you? Wow, gosh, you have travelled.**
- R: Yes, a little bit.
- I: **Well, not many people have been to China.**
- R: No.
- I: **Oh, that's beautiful.**
- R2: *And we went, do you remember when we went?*
- R: I don't.
- R2: *We went the year that you retired.*
- I: **Oh, was it a special trip, was it?**
- R2: *We decided we were going to go and, you know, it was -*
- R: We decided we would (inaudible 00.24.11)

R2: *It was 20 years ago.*

I: **You know what might be an idea is to make a collage of pictures, you know, that you could put up, so it might just ... because I've done this because you never look at photos in the end or those digital, if you have anything digitally.**

R2: *Well, funny enough, yes, a digital photo frame would be quite good but how do you get these on there, can you?*

I: **You can't get these on there but I mean, what I've done with some of our photos is put them in a big collage so, you know, we did one for my mum for her for Christmas. We all went to Greece together a few years ago so she now sees this lovely positive picture of sunshine and, you know, and the family and things. But it might be an idea and that just might spark your memory a bit, you know, because you've just started talking about your pictures of a life you could have in those pictures.**

R2: *Do you remember where we bought that picture up there, George, the one up there?*

R: Which one, darling, the China?

R2: *The bridge there.*

R: Oh, I do remember that, it was somewhere like -

R2: *In ...*

R: Oh, I'm sorry I can't remember.

I: **Don't worry.**

R2: *In China, George.*

R: Oh, yes it is China. I don't know where the Chinese is, I don't know where.

I: **So it might just spark a few things. Because you've actually been there, you know, and if there are some pictures of you in there as well.**

R: I'm beginning to enjoy this experience of talking to you about these things.

I: **Oh, good.**

R: It's very important.

I: **Yes, it is.**

R: Does that mean the same thing to you too?

I: **Yes, I'm really enjoying it too, it's important for me to hear of your experiences.**

R: Yes, of course.

I: **And to -**

R2: *(Laughter) It was so hot there ... that's all we did for the whole fortnight just terrible (Laughter).*

I: **I can imagine that, perspiring the whole time, you, soaking.**

R: *(Laughter).* I was tough as hell, you know, as a youngster, when I was younger.

I: *(Laughter).* **That looks beautiful with the mountains and things. Did you prefer warmer holidays or did you mind?**

R: I didn't mind.

I: **You liked just going anyway.**

R2: *Oh, he likes –*

R: Are you going to do some more? By the way, you asked me this earlier today, I'm going to start Jackie and I, we're going to start holidays again.

I: **Yes?**

R: Maybe next year.

I: **Okay.**

R: Where are we going? Well, I wouldn't pick to go to China.

I: **Why wouldn't you go to China now?**

R: Well, I don't think I would, not immediately, but I would go to America to the States.

I: **You'd quite like to go to America?**

R2: *There's one down there, is there? One of you, oh there. Let me put that one back in here otherwise we'll get them all mixed up, sorry.*

I: **So, because you have a few problems with your memory now.**

R: Yes.

I: **If you're planning for another holiday what do you think would help you when you're on holiday, say, when you're travelling or eating out or the accommodation or even booking your holiday, what do you think would really help you make it easier?**

R: Someone I can talk to.

I: **Okay.**

R: Who knows the area, who knows the background of what I'm talking about.

I: **Okay. So, like a guide?**

R: Well, I suppose you would call it that.

I: **Yes?**

R: Someone who understands that if you sit in a chair in China, it's a different sitting down situation than it is for America, I mean, it is.

I: **Yes.**

R: You know –

I: **I understand what you mean, I think, the culture's different.**

R: The culture is different.

I: **Yes? And understanding how that culture works you say?**

R: That's right, that's right. Because very often we see none of this, do we, when we travel? We don't give ourselves the time to see these things we should.

I: **Is that because we're so busy sight-seeing, would you say, or so busy travelling?**

R: Some areas in China. No, it wasn't sight-seeing at all in China, unfortunate people. What did you say, love?

R2: *Do you remember that? Do you know where that is?*

I: **That's a lovely picture.**

R: I think vaguely, that's me.

R2: *Yes, that is you. Put your glasses on love you might have a better chance.*

R: Who's the bird on my left hand?

R2: *(Laughter).*

I: **Can I have a quick look while you're ...?**

R2: *I don't know, George, I wonder who it could be.*

R: It's you.

R2: *(Laughter)*

R: Is it?

R2: *20 years ago, yes. So that's a bit of a clue, 20 years ago. Do you know where it is?*

R: I haven't got a clue, darling.

R2: *We were very high up. We went to visit Antony's cousin who worked for Cathay Pacific.*

I: **Oh, wow.**

R2: *And they lived in ... where did we end up when we went to China? Where was the last place we went, can you remember? Actually, it was 19 years ago.*

R: I can't remember, love.

R2: *Hong Kong.*

R: Oh, yes Hong Kong.

R2: *(Laughter) You say that, "Oh, yes, Hong Kong."*

I: **You need that prompt, yes. Was it fab?**

R: Boring place.

I: **Was it?**

R: Yes.

I: **Why was it boring?**

R2: *We were only there 24 hours.*

R: Long enough. The truth is, it was. Boring for me anyway. Not so for Jackie, but.

I: **Do you think you have a favourite place?**

R: Favourite place?

I: **That you've been to.**

R: Put this one to you ... what I'm going to say after it, being better. When I go on holidays now, I simply say, "Right. I like there," and that's where we go. What was it like? Completely removed from British things.

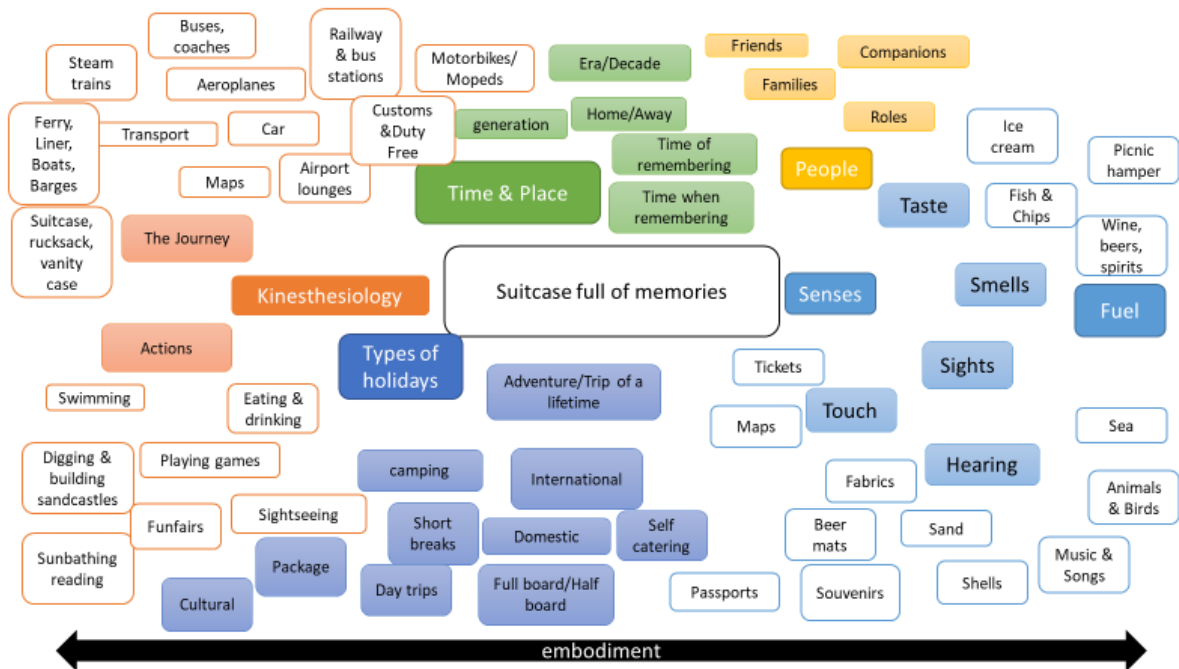
I: **Right. So you like to be in a place away from tourists, other tourists, would you say?**

R: Yes, I couldn't live in Bournemouth for a long time.

I: **No.**

R: We have our own place. I'll tell you this. We have our own place, Jackie and I, we've found it on the edge of the valley.

## APPENDIX C: HOLIDAY MINDMAP (GENERIC)



## APPENDIX D: GEORGIA'S LETTER

camping, etc.  
 Hols over a large period of Time  
 with first young pre & during easy school days  
 leading to travel further when children independent  
 Home land first + Denny & I travelled to get it

CAMPING.  
 BLACK POOL.  
 + since we lived in MANCHESTER for about 20 yrs  
 BACK + for to Wales

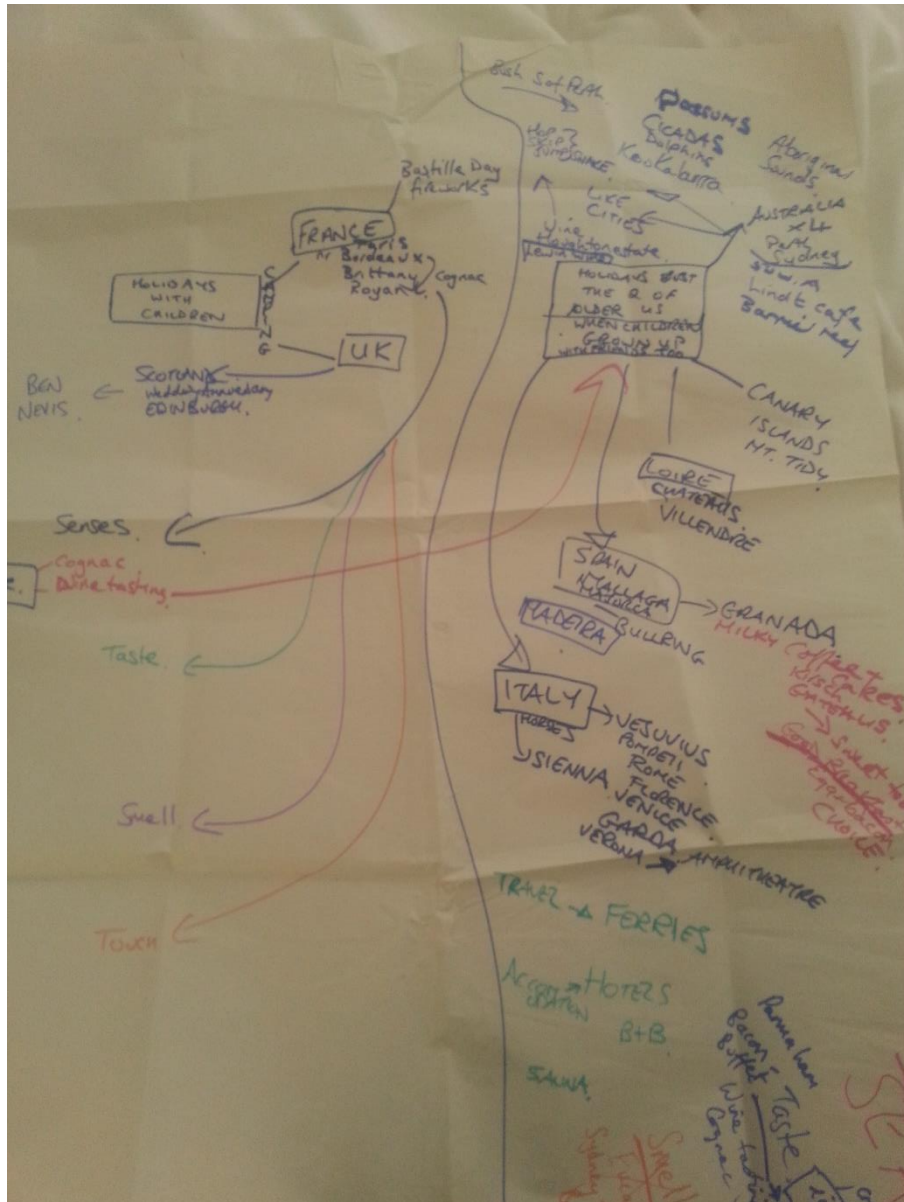
I AM ME ~~some~~ Person with Dementia

Re mutual Hols needs - as always time & place  
 Both want and agree  
 See no need to have a with  
 Hospital involvement or regulation  
 as to time to be up &  
 out or in for meals  
 but come & go as  
 & when we like.

There would be  
 no cooking & cleaning  
 & come & go as & when  
 you please  
 in Present standing go



## APPENDIX E: HOLIDAY MINDMAP (PERSONALISED)



## APPENDIX F: HOT CHOCOLATE RECIPE



### SYDNEY LINDT HOT CHOCOLATE RECIPE

#### Ingredients:

1-quart (1 litre) milk  
1 Madagascar vanilla bean, split  
1 stick of cinnamon  
3/4 teaspoon (3.5 grams) black peppercorns (whole)  
2 bars (3.5 ounces/100 grams each) Lindt Excellence 70% Cocoa, chopped

#### Method:

Heat the milk with the spices in a saucepan over medium heat until it reaches boiling point, but do not let the milk boil.  
Add the chopped chocolate and whisk until smooth.  
Remove from heat and let rest for 25 minutes to release the spices' aroma.  
Strain the liquid and reheat before serving.

#### Yield:

4-6 servings