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Reminiscence Work in Four Dementia Care Settings in Ireland

The experience of the person with dementia and the facilitator

Catherine Treena Parsons

When Time who steals our years away

Shall steal our pleasures too,

The mem'ry of the past will stay,

And half our joys renew.

Thomas Moore 1779-1852

From The Poetical Works of Thomas Moore, Irish Poet and Trinity Scholar

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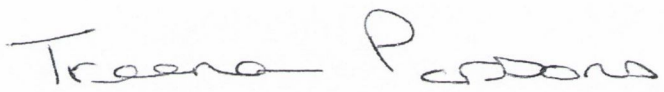

Catherine Treena Parsons

18th April 2015

Summary

This thesis explores the experience of taking part in reminiscence work for people with dementia (PwD) and facilitators in Ireland. It focuses on four dementia care environments which are typical of the settings in which reminiscence is delivered – day care, respite care, acute hospital care and a nursing home. Interviews using semi-structured interview schedules were carried out with PwD taking part in reminiscence sessions and the facilitators carrying out the sessions. Family members who were available were also interviewed to provide additional, contextual material. Data from the resulting 21 interviews together with data from eight observations was analysed using Interpretative Phenomenological Analysis (I.P.A). This thesis explores the benefits and challenges associated with delivering reminiscence work in realworld environments205, which may not always be ideal, and explores some of the environmental and organisational factors which can impinge on the reminiscence experience.

The findings indicate that reminiscence work is an activity enjoyed by those who participate in it, both the person with dementia (PwD) and the facilitator, with benefits on both sides. It has the potential to encourage a person centred environment and to promote Positive Person Work (PPW) as defined by Kitwood (Kitwood 1997).

The findings point to the need to support facilitators in order to carry out this work. The findings also indicate that the families of PwD have relatively little understanding of reminiscence work and minimal input into this intervention and yet could contribute valuable information and assist facilitators to further individualise reminiscence sessions. Further knowledge of reminiscence could also enhance families' knowledge of what goes on within a care environment and also allow them to use this activity within the home environment if they chose and were able to do so. There is also little involvement with the

wider community during reminiscence sessions and this is an area which could be explored further, again with benefits for all concerned.

Lastly this thesis also explores some of the challenges associated with conducting research with PwD, including issues around gaining access to care environments and conducting interviews in a person-centred way.

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Acknowledgments

I would like to thank the many people who helped and supported me during my PhD studies especially my colleagues in the Living with Dementia team and in the SPARC office - Maria, Martha, Marita, Sarah, Colette, Caroline, Vanessa, Emer, Ciara, Janet, Ana and Andrea. I am grateful to them for their help and companionship.

I would like to thank the Atlantic Philanthropies Foundation for funding my PhD studies.

I would like to express my deep gratitude to my supervisor Dr Suzanne Cahill for her advice, guidance and endless patience. I will always be grateful for her support and inspiration.

I would like to thank my family for their help and support at all times during my studies. My husband Nick and daughter Hannah were incredibly helpful with their IT knowledge and they and my daughters Charlotte and Abbie were always there for me and gave me encouragement at all times. I would also like to thank my parents Maureen and Bill Wasson for all their kind words and encouragement.

I would also like to thank my dear friend Maalika Perrera for her unfaltering encouragement. Lastly I would like to thank the participants in this study, who warmly welcomed me into their reminiscence groups and took the time to share their thoughts and experiences with me.

1 Introduction

1.1 Background to this study

Dementia is by and large a progressive irreversible condition with no single cause and at present, no cure (Cahill, O'Shea and Pierce 2012). It is characterised by a progressive decline in cognitive functioning which can affect social and occupational functioning (Stephan and Brayne 2008). It mostly affects older people and can impact on memory, language, communication, mood and personality (Cahill et al 2012). Dementia is an umbrella term used to refer to a collection of symptoms that can be caused by a number of disorders that affect the brain (www.alzheimers.co.uk/dementiaguide). There are more than 100 conditions that cause dementia. The most prevalent dementia sub-types are Alzheimer's disease, vascular dementia, mixed dementia (a mixture of Alzheimer's disease and vascular dementia) and dementia with Lewy bodies or frontotemporal dementia. These sub-types of dementia account for approximately 95% of people with a diagnosis (www.alzheimers.org.uk/dementiaguide). There are other rarer types of dementia such as those associated with Huntington's disease, Parkinson's disease, Creutzfeldt Jakob Disease, Pick's Disease, Down 's syndrome and Korsakoff's syndrome. Additionally, there is a related condition known as mild cognitive impairment (MCI) where people exhibit memory and cognitive problems similar to but not as severe as dementia and where they can continue to live a normal life. People with MCI have an increased risk of developing dementia, but not all progress to dementia and in some cases they may even improve. Not all people experiencing cognitive difficulties receive a formal diagnosis, so the above statistics do not convey the full picture (www.alzheimers.org.uk).

Every individual who is diagnosed with dementia will experience it in a different way. Although there are common symptoms such as memory loss, confusion and communication difficulties, these vary from person to person. Additionally, although dementia is generally progressive and irreversible and symptoms will generally worsen over time, the rate of progression will vary from person to person. The progression of dementia is often viewed as

a series of stages: early stage, middle stage and later stage (Appendix A). Some models have involved as many as seven stages (Reisberg et al 1982). It has been argued that, although these scales/stages are a useful way of viewing the progression of dementia, by concentrating on general characteristics they obscure the uniqueness of the individual and are not conducive to person-centred care (Kitwood 1997).

In addition to the memory loss and cognitive symptoms of dementia noted above, there can be behavioural or non-cognitive symptoms of dementia such as apathy, sleep problems, irritability, depression, agitation, wandering, delusions, paranoia, aggression, and anxiety. These are stressful for the person with dementia (PwD) and the caregiver and can result in decreased quality of life for both (Savva, Zaccai, Matthews, Davidson, McKeith and Brayne 2009; Cahill et al 2012) as well as affecting caregiver health negatively (Kim, Chang, Rose and Kim 2012; Etters, Goodall and Harrison 2008;Connell, Janevic, and Gallant 2001). Such behavioural and psychological symptoms of dementia have been shown to be a key factor determining placement in long term care (Schulz, Belle, Czaja, McGinnis, Stevens and Zhang 2004).

1.2 Prevalence of dementia – worldwide and in Ireland

A recent systematic review of the global literature (1980-2009) and meta-analysis estimated that worldwide 35.6 million people lived with dementia in 2010. The numbers are expected to double every 20 years to 65.7 million people in 2030 and 115.4 million people in 20.50 (Prince, Bryce, Albanese, Wimo, Ribeiro and Ferri 2013).

In common with other countries around the world, population ageing in Ireland and the accompanying changing demographic trends expected will mean that Ireland will witness an increase in the number of people living with dementia. By applying the EuroCode age/gender specific dementia prevalence estimates to the 2006 Irish Census of Population it has been estimated that approximately 41,740 people in Ireland are living with some form of

dementia[1] (Cahill et al 2012). It is estimated that by the year 2026, and in the absence of a cure, the number of people with dementia (PwD)in Ireland is likely to rise and by 2041 there could be as many as 147,000 people living with dementia in Ireland (Cahill et al 2012).

1.3 Drugs used in the treatment of dementia

Whilst there is no known cure for dementia, there are drugs available which can help with some of the symptoms. Four drugs are currently used to treat Alzheimer's disease and are sometimes also prescribed to people with mixed dementia or dementia with Lewy bodies (they are not recommended for people with vascular dementia). Donepezil (an example brand being Aricept), rivastigmine (an example brand being Exelon) and galantamine (an example brand being Reminyl); with memantine (an example brand being Ebixa) used in the later stages. Donepezil, rivastigmine and galantamine work in a similar way by increasing the amount of the chemical acetylcholine. People with Alzheimer's disease have a shortage of this chemical and the drugs prevent the action of acetylcholinesterase in breaking down acetylcholine in the brain. This leads to an improvement in cognitive processes and users have reported benefits such as improvements in memory, thinking, motivation, confidence and reduced anxiety. Side effects have been reported including loss of appetite, nausea, vomiting and diarrhoea (www.alzheimers.org.uk/dementiaguide).

People in the later stages of Alzheimer's disease, including those considered in the middle stages but unable to take the three drugs named above, are sometimes prescribed memantine (Ebixa). People with Alzheimer's disease often have harmfully high levels of glutamate in their brains and memantine works by protecting brain cells from the harmful effects of glutamate. Memantine can temporarily slow down the progression of symptoms in the middle and later stages of Alzheimer's disease and can also help with agitation and aggressive behaviour. Side effects reported have included dizziness, tiredness and increased blood pressure (www.alzheimers.org.uk/dementiaguide).

[1] this figure does not include people with Down's syndrome with dementia

A more controversial aspect of drug prescribing to PwD concerns the use of psychotropic medication, including anti-psychotic medication, to address non-cognitive symptoms. A 2009 review for the Department of Health in the UK prepared by Professor Sube Banerjee estimated that approximately 180,000 PwD were being prescribed anti-psychotic drugs with possibly 140,000 of those being deemed inappropriate (Banerjee 2009a). These medications often have negative side-effects, sometimes referred to as a "chemical cosh" (Ballard and Cream 2005). In the UK, in 2006, the National Institute for Health and Care Excellence (NICE) urged caution and advised that people with Alzheimer's disease, Vascular Dementia and Mixed Dementias with mild to moderate symptoms had an increased risk of cerebrovascular events and death when taking these drugs and those with Dementia with Lewy Bodies were particularly at risk.

1.4 Non-pharmacological treatments and reminiscence work

Due to the side effects and other problems associated with the use of psychotropic medication for non-cognitive symptoms of dementia, it is recommended that non-pharmacological approaches should be the first intervention for non-urgent, non-cognitive symptoms (Royal College of Psychiatrists 2005).

There are many non-pharmacological interventions currently in use with PwD. In a 2004 review of non-pharmacological therapies, Douglas, James and Ballard identified three categories of non-pharmacological intervention, although they noted there could be areas of inter-lap between interventions. The three categories were: alternative therapies (which included interventions such as art therapy, music therapy and aromatherapy), standard therapies (which included behavioural therapy, reality orientation, validation therapy and reminiscence work) and brief psychotherapies (which included cognitive behavioural therapy and interpersonal therapy). It was argued that these non-pharmacological interventions encompassed a move towards a more person-centred care approach in dementia care, with attempts being made to understand the individual's experience of

dementia and to employ strategies to improve their quality of life (Douglas, James and Ballard 2004).

Reminiscence work is considered amongst the most popular of non-pharmacological therapies and is known to be enjoyed by both staff and participants (Woods, Spector, Jones, Orrell and Davies 2005). There is some debate in the literature about whether reminiscence work is actually a therapy (Gibson 2011; Bender, Bauckham and Norris 1999) as it has been argued that it does not meet a number of criteria for it to be legitimately considered as a therapy in its formal sense (Bender 1994). In fact, some experts argue that to define reminiscence as a therapy is incorrect, as seeing it as a therapy fails to consider the many forms it can take and the many people, some unqualified, who carry out the work (Gibson 2004). Woods argued that reminiscence is not strictly speaking a therapy, though it is an important activity with therapeutic potential (Woods 1995). It is for this reason the term reminiscence work is used in this thesis, rather than reminiscence therapy.

Reminiscence has been defined as the deliberate use of prompts, for example photographs, smells, music and questioning, to promote the recall of pleasant memories with a focus on stimulating the person, providing enjoyment and fostering a sense of achievement and self-worth (Dempsey, Murphy, Cooney, Casey, O'Shea, Devane, Jordan and Hunter 2012). Gibson has suggested reminiscence can be divided into two categories. The first is simple or general reminiscence, which is usually aimed at sharing common memories and encouraging social, educational or recreational objectives. It usually uses open-ended prompts or multi-sensory triggers to stimulate reminiscence on topics likely to be of interest to participants and unlikely to trigger painful memories. The second is specific or special reminiscence, which is usually undertaken with individuals or small, closed membership groups. As the name suggests it is more specialised, more individualised and may have an element of life review or self- evaluation involved (Gibson 2011). Within these categories reminiscence can take many forms such as life story work which involves people reflecting on their lives and usually compiling a book or record, group reminiscence which sometimes but not always

results in an end product such as a collage or display and life review which is based on a psychoanalytical approach.

It is also important to remember that as well as being a therapeutic activity, reminiscence is viewed by many as an activity which can simply be enjoyed by the PwD (Gibson 2011) and the value of that should not be underestimated.

1.5 The economic costs of dementia

As well as the emotional and social costs associated with dementia there are also high economic costs, both for the individual and for wider society. The total estimated worldwide costs of dementia were $US 604 billion in 2010 with about 70% of the costs occurring in Western Europe and North America (Wimo, Jonsson, Bond, Prince and Winblad 2013). These costs included informal care, social care and medical care. Research in the UK has shown that the estimated costs associated with dementia (approximately £23 billion) are higher than the costs for cancer and heart disease combined (Subramaniam and Woods 2012). In Ireland a recent research review for Ireland's National Dementia strategy, estimated the economic cost of dementia to be just over €1.69 billion per annum with 48% of that attributable to informal care provided by family and friends, 43% attributable to residential long stay care and 9% attributable to formal health and social care services representing a significant economic burden (Cahill et al 2012).

Although it is acknowledged that dementia is a major health issue which produces significant pressures on the economic and social systems of countries worldwide, it has been noted that resources allocated are not on a par with other health conditions such as stroke, heart disease and cancer (Trepel 2012). In Ireland it has been argued that dementia is neglected, underfunded and under-prioritised (Cahill et al 2012) and there is a substantial under provision of services for dementia in comparison to countries with a similar financial input into the health care system, such as the UK, Australia and Norway(Trepel 2012). In a review

of the economics of dementia care in Ireland Trepel argued that there may be a connection between the under provision of services and the lack of an implemented national dementia strategy which would allow for the planning and implementation of appropriate service provision (Trepel 2012). Although Ireland had a blueprint strategy in 1999 and a research review in 2012 (Cahill et al 2012), the strategy has not yet been implemented.

As well as the economic costs at a societal level, there are economic and social costs at a more individual level. In their research on family caregivers of PwD, detailing statistics over the period 2003-2007, Brodaty and Donkin noted that 60% of U.S. family caregivers of PwD were employed, but of those people more than 30% had missed work because of caring duties, 8% had been forced to turn down promotions and 31% had eventually to give up work (Brodaty and Donkin 2009).

In Ireland there is an absence of public policy on dementia and unlike other European countries the Republic of Ireland still has no National Dementia Plan or Strategy. This is at a time when other countries around the world such as Norway and France and Australia are moving on to implementing their third dementia service plans. Empirical data about dementia in Ireland is very hard to find (Cahill et al, 2012) there is no registry of dementia, no epidemiological studies of incidence and prevalence rates and very limited community care services. Recent years have seen new models of home care services being trialled in Ireland but these services are not embedded in policy documents and are being funded largely through philanthropic initiatives which may not be sustainable in the future. The main bulk of dementia care in Ireland is provided by families and the main cost of dementia care is incurred by informal caregivers (Connolly et al, 2014). In Ireland it is estimated that there are approximately 50,000 people providing informal care for a person showing at least one of six symptoms associated with dementia, with the median daily provision of care provided by these carers estimated at ten hours per day, with some people providing many more hours each day (Cahill et al 2012).

1.6 Dementia care in Ireland

Most PwD in Ireland live in the community and are cared for by family members. Of the 41,470 people estimated to be living with dementia in Ireland, 26,104 of those are thought to be community based, with 644 PwD in acute care, 456 in psychiatric care and 14,266 in long stay residential care (Cahill et al 2012). The actual numbers of PwD in all settings may be higher as dementia is often undiagnosed and a recent study suggested that dementia is often undetected within nursing homes (Cahill and Diaz-Ponce 2010).

The majority of family caregivers are women and as mentioned earlier they are poorly supported by social policy as reflected in the absence or inadequacy of community support services (Cahill et al 2012). Formal home care services are provided through the Home Help Service and the Home Care Support Schemes. These services are either directly provided by the Health Service Executive (HSE), through community and voluntary organisations or through private providers. These services are not underpinned by legislation; there are no quality standards or mechanisms for the regulation of in home services and they not provided on a statutory basis with differences across the country in relation to service provision. Day care provision in Ireland is considered limited and respite care is available (Cahill et al 2012).

For those receiving community care and for those living in residential care or in acute hospitals, an issue of relevance is the increasing use of migrant workers which may have an effect on the experience of care. In common with other western countries, Ireland has increasingly been using migrant workers in the care of older people. A recent report on the migrant workers caring for older people in Ireland (not specifically those with dementia) estimated that, in the settings surveyed, migrant workers accounted for almost one third of all care workers (Walsh and O'Shea 2010). The migrant workers included registered nurses and care assistants and the largest proportion were found in private home care and private long stay care.

The use of migrant workers in dementia care can produce challenges for the organisation, the PwD and the migrant worker (Innes 2009) and these challenges are an important consideration when overviewing dementia care in Ireland. Language and communication, differences in cultural approaches to the care of older people and a lack of understanding of historical and cultural references were noted by older people, their families and employers in the 2010 Walsh and O'Shea study, with employers additionally mentioning the need for extra time spent on education, training and orientation. For the migrant workers the main challenges centred on discrimination which was described as significant, acceptance both from fellow workers and the people they were caring for which tended to improve as time passed, and difficulties with language and communication especially in relation to local accents and colloquialisms which again tended to improve with time (Walsh and O'Shea 2010). However for Irish PwD receiving care from migrant workers, a key challenge will be their reduced ability to understand their accents/language and the mis-match which may arise between cultural values and beliefs. The training of migrant workers to ensure they have a better understanding of Ireland's history and Irish culture is not mandatory nor indeed has it been a priority by health and social care providers.

1.7 My personal experiences of reminiscence work

I have an undergraduate degree in Psychology and a postgraduate (Master's degree) in Social Work. Having worked with PwD for more than twenty years, in a variety of roles, I have experienced reminiscence work in three different contexts. The first was in an informal context, with little in the way of resources or support. The second and third experiences were more formal with more support and resources available. Each experience taught me something about reminiscence but raised questions and highlighted challenges.

The first time I encountered reminiscence work was approximately 20 years ago whilst working with Age Concern as a homecare assistant. My job entailed visiting several elderly clients, who according to my supervisor, had memory problems, no other details were given.

One of the clients I worked with would often leave a selection of photographs, letters and memorabilia lying on her bed. Routinely, I would tidy these to the side and make her bed. I mentioned this to my supervisor, who suggested I spend some time talking to her about the photographs as a form of very informal reminiscence work. There was no extra time or resources allocated for this and only an initial brief discussion at supervision about reminiscence work. The client appeared to thoroughly enjoy talking about the photographs and over the next few weeks I learned much about her life as a younger woman. Her husband had been a doctor and whilst living in India they had set up a hospital in very difficult conditions. She had helped with many aspects of the hospital work and this was obviously a very important part of her life which she enjoyed sharing.

Unconsciously I had, to a certain extent, stereotyped this client, regarding her just as an old lady with memory problems. From our discussions I had become aware of her rich and interesting past and it made me more aware of how important it is to get to know each client and how much that can improve the relationship between carer and cared for.

The second time I encountered reminiscence work was when I worked as a dementia project worker at a day care centre of a local authority nursing home. As part of my role I had to carry out activities with individuals and small groups and then record the outcomes. One of the activities that I carried out was reminiscence work. Using a variety of prompts such as music and photographs I worked with clients, usually on an individual basis. I also observed activity workers carrying out reminiscence work with small groups. The aim of the work was to improve quality of life for the clients and add to the person-centred environment of the day care centre. I was given some initial training and had regular supervision from an occupational therapist. I had plenty of resources, having access to the activity supplies belonging to the home and also a small budget to buy extra resources if needed. I noted that reminiscence was generally enjoyed by the PwD taking part. I also noted that the activity assistants appeared to enjoy the work too and learned more about the clients in their care from the sessions. I noted the many prompts which could be used in reminiscence work.

Music and photographs were very popular, but there were also other prompts which proved very successful.

One example concerned a female client who had worked in one of the Paris Fashion Houses as a young woman. She was French and had, for the most part, lost her use of English and reverted to speaking in French. The staff dealt with this as best as possible, there were several who could speak reasonably good French and one who was fluent in French but often in activities it was difficult to engage this client. One of the activity staff found that by using different materials and sewing patterns, and drawing on her previous skills, a very simple form of reminiscence work could be carried out, without the need for much language.

Through observation of the activity assistants and discussions with them I learned of challenges which can occur during reminiscence work. One such challenge was that occasionally an "unexpected narrative" would emerge during a session, which the activity assistants were not always sure how to handle. One example of this was noted during a session I observed, when one client revealed that shortly after the war, when times were very hard, she had worked for a while as a prostitute. The woman concerned came from a fairly typical middle class family. Her deceased husband had worked in a professional capacity, she had lived in a nice house, in a nearby town and her family were fairly similar. The activity assistants were reasonably sure that her family knew nothing about this and were unsure of how to deal with this disclosure. Another challenge was observed when a client, during a reminiscence session, became very upset and disclosed that her husband had had an affair during the early years of her marriage. She was very distressed by the memory of this and no-one was sure what had triggered the memory. Again, activity assistants were unsure of how best to support her and if her family were aware of this period of her life. The assistants were also themselves distressed by the level of upset she showed and the feeling that they had inadvertently caused the upset.

My third experience of reminiscence work occurred while working as a care manager with a local authority, in a Learning Disability Team. As part of my duties I was reviewing a package

of care for Robert, a young man with learning disabilities who was developing dementia. During his review meeting a clinical psychologist recommended life story work as one possible intervention for him. At the time I was completing my Masters in Social Work and offered to undertake the life story work as a project which I could then write up for my thesis. This was discussed with Robert and, with his permission, over the next sixteen weeks I met him for an hour each week and we worked on his life story. I had sufficient resources in terms of time as I was allowed to take time out of my care management hours. I had material resources as I was given a budget to buy any necessary materials and I had support in that I was given regular supervision by a senior care manager and a clinical psychologist. I also had background support from the staff of the small group home where Robert lived, who provided information and feedback on how he was using his life story book at home, and from his family (a brother and his family), who provided information, photographs and other memorabilia. At the end of the sixteen weeks responsibility for the life story work passed on to his key worker in his home. During this reminiscence work I observed how much Robert enjoyed participating in the life story work and how it appeared to strengthen his sense of identity, reminding him of his achievements and also reinforcing his sense of being a unique individual with his own likes and dislikes. The staff from his home welcomed the life story book, they had concerns that as his dementia developed he might struggle with memory problems and in the future staff, who may not know Robert so well, would not know enough about him to support him appropriately. They hoped the life story book would aid staff to work with him in a person-centred way, allowing them to see Robert as he truly was, with his own unique history, likes and dislikes. His brother, nieces and nephews also thoroughly enjoyed helping him to assemble the book. The family had him to stay one day a week and his brother admitted that at times they struggled to find ways to engage with him. Robert liked his family to work with him on the book and Robert's brother acknowledged that the project had given them all a new, pleasurable activity to share.

These experiences left me with the distinct impression that reminiscence work was an intervention with huge potential in the context of dementia care but I was curious to find out

more about it. How exactly did the individual experience it? What types of triggers/prompts worked better than others? For those responsible for delivering reminiscence in various care settings, what were their views and attitudes to reminiscence? What were their attitudes to the way in which reminiscence might trigger unhappy memories? Did they avoid such topics or did they, like Kitwood, believe that people have a right to experience both happy and sad emotions (Kitwood, 1997). Was reminiscence a more appropriate intervention in certain social care settings compared with others? Based on my own experience I believed that reminiscence could probably yield multiple psycho-social benefits for the PwD, formal care staff and family members but I wanted to find out a lot more about these. In particular, I wanted to find out what PwD themselves thought about reminiscence.

Based on these earlier experiences, I was also aware there could be significant challenges associated with taking part in reminiscence work. I was aware, for example, of the need for resources and support in organisational settings if the activity was to be carried out well. I was aware of the need to build up a rapport with the individual participating in reminiscence in order to be more knowledgeable about that person's interests, likes dislikes, fears and concerns. All of these prior experiences motivated me to set out on the journey of this thesis and to explore some of these questions in a lot more depth. These prior experiences helped to shape the structure and content of this thesis.

1.8 Rationale

Dementia profoundly affects the lives of those people living with it, their friends and their families. The memory and cognitive symptoms of dementia cause much distress and the non-cognitive symptoms are difficult to manage, with medication often deemed inappropriate. At a societal level, dementia care in Ireland is seen as underfunded and undervalued. Health and Social policy in Ireland for PwD is in a state of flux, with a National Dementia Strategy still to be launched and implemented, and calls for specialist training for doctors, nursing staff and care workers unanswered. Dementia care workers, generally underpaid and

working in what is considered an unattractive area of care, are expected to adhere to recommendations promoting quality care (HIQA, 2009) with few resources and without specific guidelines. Additionally, in Ireland, as in many other Western countries, the emerging use of migrant workers brings further challenges. The scarce resources coupled with increasing calls for quality care in dementia settings highlight some of the complexities involved in providing dementia care in a formal setting.

Reminiscence work appears to offer one possible solution to the conundrum of how to provide quality dementia care with limited resources. In the context of best practice in dementia care, it is recommended as an appropriate intervention to address the non-cognitive symptoms of dementia. (HIQA. 2009). It is known to be generally enjoyed by PwD and the facilitators working with them (Woods et al 2005;Gibson 2011) and can be carried out in a reasonably inexpensive way. Reminiscence work is a complex intervention, and the experience of the PwD and the facilitator taking part in reminiscence work in Ireland is under-researched. This thesis aims to elicit the views of the PwD and the facilitators taking part in reminiscence work and explore the value and meaning they place on it.

1.9 The contribution of this thesis to the knowledge of reminiscence work

Through in-depth interviews with 21 people and observations conducted in four settings at two different points in time, this thesis investigates how reminiscence sessions are delivered in four different dementia care settings in Ireland. It explores the different prompts used in different reminiscence sessions, the type of topics covered during reminiscence, participant's satisfaction and dissatisfaction with the sessions, and the facilitators and obstacles (environmental and organisational) which can impinge on the reminiscence experience. By interviewing PwD who participated in these reminiscence sessions, this thesis gives a voice to people who have in the past been silenced and disempowered. As stated the research also

uses observations to provide contextual information and to describe and analyse non-verbal communication associated with the reminiscence experience. Finally, the thesis explores the experience of five different facilitators, investigating their views about the benefits and challenges of delivering and engaging in reminiscence work. The contribution of this thesis to the overall body of knowledge of reminiscence rests in the way in which it explores the subjective experience of taking part in reminiscence work, from the viewpoint of the people who are actually taking part in it (the PwD and the facilitator) in real life settings in Ireland.

1.10 The layout of this thesis

This thesis consists of seven chapters, an introductory chapter, the literature review, the methodology chapter, two findings chapter, the discussion chapter and the conclusion.

2 The Literature Review

The aim of this literature review is to report on and critique the international and national literature on the topic of reminiscence work for PwD in order to gain a better understanding of the use of reminiscence work in dementia care. The review will report on the diverse settings and ways reminiscence can be carried out. It will draw on literature which identifies different reasons behind why reminiscence is used and the quantitative literature on outcome measures associated with reminiscence. The review will examine and critique existing research in this area and acknowledge on-going research in reminiscence.

An overview of some of the salient explanatory models used to conceptualise dementia will be provided in order to identify the models most relevant to understanding the place of reminiscence work as an intervention for PwD. It needs to be acknowledged that different researchers use varying terms when describing reminiscence. As outlined in the introduction of this thesis, the terms reminiscence (to describe the process involved) and reminiscence work (to describe the intervention) are used throughout this thesis.

2.1 Approach to literature search

Using the keywords "Reminiscence Work", "Reminiscence", "Reminiscence Therapy", "Life Review", "Life Story work", "Dementia + Therapy" and "Dementia + non-pharmacological interventions" a literature search was conducted. "Life Review" and "Life Story work" were later included in the search to widen the scope of the search and because some health care professionals use these terms interchangeably.

A diverse range of relevant databases were searched (Appendix B) together with all the major international journals in the field (Appendix C) including nursing, occupational therapy and social science journals, which regularly contain articles on reminiscence work. Journals and databases have been checked on a monthly basis starting in April 2009 and ending in May 2013.

2.2 Reminiscence work as a therapeutic intervention

Although in this thesis reminiscence work is not regarded as a therapy, in much of the literature it is referred to as a therapeutic intervention and is used in many situations and conditions and across the lifespan as exemplified by the huge body and diversity of literature which exists on reminiscence work in general, not specifically with PwD. A large body of literature exists covering the use of reminiscence as a therapeutic tool amongst certain illness categories, such as people suffering from depression (Bohlmeijer, Smith and Cuijpers 2003; Stevens-Ratchford 1993; Youssef 1990) and people facing terminal illness (Wholihan 1992;Weishaar 1999). It can also be used during times of transition for example for children going through the adoption process (Ryan and Walker 1993) and for people with learning disabilities moving through the care system (Kerr 1997).

It is interesting that, in many ways, using reminiscence as interventions for these conditions and life stages parallels its use with PwD where similarities exist. For example, reminiscence work is used with people of all ages suffering from depression and it is known that approximately 20 – 30% of PwD suffer with depression and epidemiological studies have shown a possible pathological association between depression and Alzheimer's disease (Tsuno and Homma 2009). Reminiscence work is used with children going through periods of transition such as the adoption process and PwD can also be regarded as going through a period of transition.

2.3 Origins of reminiscence work in the care of older people

2.3.1 Robert Butler

It is generally acknowledged that Robert Butler, a US Physician, Gerontologist and Psychiatrist, founding director of the National Institute on Aging (NIA)[2] and founder of the US Alzheimer's Disease Association, first recognised the therapeutic benefits of reminiscence work for older people (Butler 1963) and it was Butler who first brought reminiscence to the attention of health service professionals and researchers worldwide (Woodrow 1998). Butler was tremendously influential in the area of aged care research. He was a prolific writer and his legacy to Medical and Social Gerontology has been very considerable (Achenbaum 2013).

Prior to his seminal publication on life review, an interpretation of reminiscence in the aged (Butler 1963), reminiscence was generally viewed amongst health professionals as a sign of pathology and perhaps even of dementia. Butler introduced the idea that reminiscence was a naturally occurring process where people reflect back on their lives and during this process they can review and reintegrate unresolved conflicts (Butler 1995). Butler's views on reminiscence were no doubt influenced by his training in psychiatry and his clinical work. He regularly mentioned the Erickson's life stages in his work on reminiscence. Also, despite his medical background, Butler showed awareness that the medical model is only one of many approaches which can be used to better understand the needs of PwD. He argued that most problems associated with old age are not inevitable or a natural consequence of aging but rather can be related to other issues, such as disease or socio-economic problems (Butler 2002).

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[2] The NIA is a division of the U.S. National Institutes of Health. It is dedicated to understanding the nature of aging and supporting health and well-being in older adults and is designated by the U.S. congress as the primary federal agency on Alzheimer's disease research.

It is also well known that Butler was raised by his grandparents. He spoke about having a close bond with his grandfather and of his love for the stories that his grandfather told him. It is thought that Butler's early years and love for his grandparents together with the routinely poor treatment of older people he observed during his medical training influenced his views on society's treatment of the elderly in general (www.nytimes.com 2010/07/07). It is not known if the stories passed on to him by his grandfather involved an element of reminiscence but it is certainly possible that some of his interest in reminiscence may have started in those early years.

It is unclear why Butler's ruminations on reminiscence generated such heightened interest and prompted so much further research. Coleman suggested that Butler's work appeared to be seized upon as a means of justifying and giving dignity to older people's reminiscence (Coleman 2005). Possibly it was a timely area of research for the 60's and 70's. For as Coleman has pointed out during the 60s and 70s there was a general shift in favour of remembering the past (Coleman 2005) and Butler, with his accessible and persuasive style, was well able to present his authoritative views at just the right time. Certainly, the value of his input cannot be underestimated, since he re-cast reminiscence and shifted the concept from originally being associated with decline to it nowadays being a topic that warrants much research and is encouraged in many health and social care settings.

It is argued that Butler's writing on reminiscence has motivated most reminiscence research since the 60s (Chandler and Ray 2002). Certainly Butler's work has greatly influenced the direction of this thesis by highlighting the importance and value of people's individual reminiscences in a society which in many ways does not value its older people. However one of the major shortcomings of Butler's contribution is that he failed to align reminiscence therapy with dementia and consequently his analysis stopped short of demonstrating the potential Reminiscence had for enriching the lives of PwD.

2.3.2 Peter Coleman

Around about the same time that Butler was drawing attention to the potential of reminiscence for older people in the US, a Psychologist Peter Coleman commenced writing his PhD on the topic in the UK. Coleman's research centred on the adaptive functions of reminiscence and he used taped interviews together with psychological testing to collect data. His work indicated that life reviewing appeared as an adaptive response when accompanied by dissatisfaction with past life; however, he found no significant evidence for the role of simple reminiscence as an adaptive function of reminiscence (Coleman 1974). His work, using case studies, developed over time and he followed up surviving members of his original research group, eventually including more details of the older people's past lives within the context of the social history they lived through.

Coleman moved from an initial, clinical stance in the late 1960s to a broader, social/ psychological stance by the 1980s. It is argued that the development of his work in this way paralleled the way reminiscence research in the UK developed, from an initial clinical perspective towards one which incorporated more of a social psychological perspective (Bornat 2011). His work influenced thinking on reminiscence processes and the way they are historically and socially shaped. For example, his work with war veterans contributed greatly to our understanding of traumatic memories and reminiscence and the reconciliation of memories in later life (Coleman 1999). Like Butler however Coleman in his writing missed some clear opportunities to discuss, analyse and consider the usefulness of Reminiscence as a tool in dementia care.

2.4 Further recognition of the importance of reminiscence in the UK

Another eminent person who greatly influenced earlier thinking and writing on reminiscence in the UK was Malcolm Johnson (Bender, Bauckham and Norris 1999). One of his seminal works was a paper titled "That was your life: A biological approach to later life" wherein he advocated for an understanding of older people's needs in the context of their past

experiences (Johnson 1976). He is also credited for drawing academic attention in the UK to the benefits of reminiscence and for greatly influencing gerontological thinking.

Probably as a result of Johnson's contributions during the late 70's, reminiscence work first became widely used in care settings in the UK when the Department of Health and Social Security (DHSS) initiated a Reminiscence Aids project. This resulted in a "Recall" pack of slides, tapes and other materials for use in wards and residential homes (Woodrow 1998). It is interesting that it was an architect, Mick Kemp, who persuaded the DHSS to fund the Reminiscence Aids project, he had been working on designing accommodation for elderly patients and became interested in the way elderly people liked to talk about the past. Curiously, Kemp was influenced by the work of Butler. He assembled a multi-disciplinary team which included a psychologist, artists, a musician and a photographer. This team designed the audio-visual pack with additional guidance from a panel which included a gerontologist, a psychiatrist, a psychologist, journalists, nursing staff, voluntary workers and elderly people. The success of the pack was attributed to its format of sounds and images which could be presented in any setting, with the aid of staff, who did not need to be experts in reminiscence. It was also thought that the use of the pack helped to legitimise reminiscence in the minds of the public, turning it into a therapeutic activity, and the success and uptake of the Recall packs is thought to be an indication of the eagerness of care staff to have such resources (Bornat 2011).

Some small scale research was later carried out on the use of the Recall packs. One of the original Recall team and another researcher evaluated the use of the pack in a hospital setting with a group of patients with a variety of diagnosis, including dementia (Norris and Abu El Eileh 1982). They observed increased levels of interaction and spontaneity amongst the patients, and staff reported the groups positively influencing their relationship with the patients, leading to a profound effect on the morale and caring philosophy of the ward as a whole (Bender, Bauckham and Norris 1999). One of the interesting aspects of the work on the Recall reminiscence packs was that the team who devised the pack and the panel who

advised represent the many, diverse backgrounds of those who can be involved in reminiscence work. They included people with no particular expertise but an interest in the subject.

Since that time reminiscence work has become increasingly popular in the UK and is used by a wide range of allied health professionals including occupational therapists, activity co-ordinators, nurses and psychologists.

2.5 The National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence (NICE/SCIE) guidelines

In 2006 in the UK the NICE/SCIE guidelines for dementia were published (www.nice.org.uk./guidance/cg42). These guidelines were the first joint health and social care evidence-based practice guidelines produced in the UK and were produced for NICE collaboratively by the National Collaboration Centre for Mental Health and SCIE. They dealt comprehensively with the care and support of PwD including assessment, early intervention, pharmacological interventions and psycho-social interventions. They also addressed the needs of carers (Gould and Kendall 2007). The guidelines made specific recommendations for specific types of dementia, for example Alzheimer's disease and dementia with Lewy bodies and also made more general recommendations which could apply to all types of dementia. Interestingly, in their analysis of the challenges associated with developing these guidelines Gould and Kendall noted that one important challenge was partly epistemological. The fact that dementia could be understood using a medical model or a social model meant there were tensions between the hierarchically based orthodoxy of evidence based medicine and the non-hierarchical knowledge based practice emerging from social work research (Gould and Kendall 2007). The guidelines did manage to incorporate both viewpoints and included diverse research approaches. This may be as a result of the diverse composition of the Guidelines Development Group (GDG) which included clinical and academic experts in old

age psychiatry and geriatric medicine, clinical psychology, nursing, social work, occupational therapy, general practice, one service user and two carers (Gould and Kendall 2007).

In respect to reminiscence as an intervention for PwD, it is noted in the guidelines that although there is insufficient evidence to recommend routinely offering reminiscence to PwD, it has the potential to impact the mood of the PwD positively (www.nice.org.uk). It is also noted in the guidelines for psychological interventions for PwD with depression and/ or anxiety (CG42 1.8.1) that a range of tailored interventions should be considered giving reminiscence as an example (www.nice.org.uk).

In addition to the NICE/SCIE guidelines, in the SCIE Dementia gateway series, which is a website produced by SCIE with a range of resources including information, films, activities and e-learning, in the category of Keeping Active and Occupied, reminiscence is recommended as a way to build the strengths of the PwD. (www.scie.org.uk/dementia).

2.6 The history of Reminiscence Work in Ireland

Reminiscence work appears to be widely used in Ireland, as noted in the methodology chapter and it is mentioned as an activity on the websites of many residential care homes and day centres. However unlike the US or the UK there is no documented history in the Republic of Ireland of when reminiscence was first used or how it has developed as an intervention and how today it is experienced and delivered, nor has there been up until very recently any comprehensive evaluation of Reminiscence in aged care settings, nor attempts made in Ireland to understand more about where and how reminiscence is delivered. Hence the relevance of this PhD thesis which focuses on reminiscence in the context of dementia care in Ireland. There is a growing interest in reminiscence work amongst academics and practitioners in Ireland and their contribution to the knowledge base on this subject is discussed later in this chapter.

2.7 Reminiscence work with PwD

In contrast in overseas countries, and in the context of dementia care, reminiscence work has been the subject of research studies for more than 25 years (Subramaniam and Woods 2012). Studies show that reminiscence can be carried out with PwD for a variety of reasons, either as a therapeutic intervention or more simply as an enjoyable activity or possibly a combination of the two (Gibson 2004). Subramaniam and Woods note that as a psychosocial intervention, reminiscence work is at the interface of cognitive and emotion focused approaches, with a potential to affect both autobiographical memory and well-being (Subramaniam and Woods 2012). Reminiscence work is associated with encouraging sociability and assisting in forming new relationships, promoting identity and self-worth and improving relationships between PwD and care staff (Gibson 2004) but most importantly it is recognised as an activity which PwD enjoy (Gibson 2011).

It is also known that reminiscence work can be useful to reduce the non-cognitive or behavioural symptoms of dementia. Psychotropic medications including anti-psychotics, anti-depressants and tranquillizers are often used to control such symptoms but concerns have been raised that there is inappropriate and unnecessary prescription of these drugs (Margallo-Lana, Swan, O'Brien et al 2001) and that side effects such as sedation and falls may lead to reduced well-being and quality of life (Ballard, O'Brien, James et al 2001). In the UK, in 2009 Professor Sube Banerjee completed a ministerial review of the use of antipsychotic medication with PwD (Banerjee 2009a). He concluded that anti-psychotic drugs appeared to be overused in dementia care and argued that this was a problem not just in the UK but worldwide (Banerjee 2009a). His findings have more recently been supported by those reported from a Northern Irish study where it was shown that a recent increase in the use of psychotropic medication in older people (between 14% - 26%) was witnessed. The same study also showed that some care homes were more likely than others to prescribe, possibly indicative of an institutional culture or of physicians' respective practices. It is interesting that the authors of this Northern Irish study pointed to the paucity of research into non-

pharmacological interventions and a lack of resources as some of the possible reasons for the increased prescription of anti-psychotic medication (Maguire, Hughes, Cardwell, and O'Reilly 2013). However this paucity in using non-pharmacological interventions is probably in some way explained by the lack of empirical evidence about the efficacy of such interventions. However what these writers have failed to highlight is the difficulties involved in obtaining research funding to test out the efficacy of non-pharmacological interventions in dementia care and the difficulties involved in undertaking randomized control trials (RCTs)in this complex area.

A general rule of thumb for years has been that non-pharmacological approaches should be the first intervention for non-urgent, non-cognitive symptoms in a PwD (Royal College of Psychiatrists 2005). Reminiscence work is one of a range of non-pharmacological interventions which can be used with PwD and is known to be enjoyed by both staff and participants (Woods et al 2005).

2.8 Where does reminiscence work take place?

The literature shows that reminiscence work with PwD takes place in a variety of settings. It takes place in day centres (Head, Portnoy and Woods 1990; Tadaka and Kanagawa 2007), in long stay facilities (Pullan 2009; Lai, Chi and Kayser-Jones 2004; Politis, Vozzella and Mayer 2004; Haight, Gibson and Mitchel 2006) and in the community (Schofield and Tolson 2010). The setting in which reminiscence work takes place will undoubtedly impact on the individual's experience. Even within similar settings there will be differences which impact on the reminiscence experience. In their 1990 study of two day centres Head and colleagues found the impact of reminiscence differed between the two day centres and concluded this was because of differences in the environment between the two, which highlighted the need for careful definition of contextual factors in reminiscence work (Head et al 1990).

2.9 How is reminiscence work carried out?

The actual prompts or triggers used to initiate reminiscence have also been researched, and it is acknowledged that more research is needed in this area (Subramaniam and Woods 2012). Prompts can either be general, such as songs from a particular era, or individualised, such as personalised albums or videos (Hepburn, Caron, Luptak, Ostwald, Grant and Keenan 1997; Carol et al 1997). An example of a study into individualised prompts is the 2009 study by Yasuda and colleagues which examined the effectiveness of personalised reminiscence photo videos. It concluded that they were an effective way to trigger reminiscence for a PwD (Yasuda, Kuwabara, Kuwahara, Abe and Tetsutani 2009). Others have concentrated on specific memories and their relation to reminiscence, for example, Chaudhury has carried out much work showing that memories of a person's home can be a very effective way to individualise the reminiscence experience (Chaudhury 2008). Interestingly, in their 2012 systematic review of the impact of individual reminiscence for PwD, Subramaniam and Woods concluded that there is a small body of evidence that life review with a PwD which results in the production of a personalised life story book is associated with improvements in cognition and well-being, whereas less personalized reminiscence work, which does not use personalised triggers is of relatively little benefit (Subramaniam and Woods 2012).

In recent years, much research interest has been invested into using information computer technology (ICT) and multimedia computer systems as prompts to reminiscence work with PwD (Cosley et al 2011; Capstick 2011;Mulvenna, Doyle, Wright, Zheng, Topping, Boyle and Martin 2011;Subramaniam and Woods 2012). A recent guide from SCIE for social care providers on using ICT with PwD included a section on using ICT in reminiscence work. In the guide ICT is acknowledged as an important resource for reminiscence work as it can give virtual access to a wide variety of prompts instantly, can easily be individualised and is flexible (www.scie.org.uk).

Another possible advantage of using ICT in reminiscence work is that bringing together certain multimedia prompts such as videos, sound, music and written materials can be time

consuming, but if presented in a multi-media scrapbook using ICT it could mean more lively content, which is easily accessed (Newell, Carmichael, Gregor and Alm 2002). With most people becoming more and more involved in the use of ICT, including PwD, it is likely that this area of research will grow. In the excellent review referred to earlier in this chapter, Subramaniam and Woods argue that in five years' time it will be normal for PwD to have a digital life story including favourite music, photographs and other items. This, they believe, has the potential to take person-centred care to a higher level (Subramaniam and Woods 2012). Whilst this is quite possible, it is also likely that some people will prefer not to engage with ICT and there will always be a need for other types of prompts, which can touch senses in ways that, at the moment, ICT may not be able to. This thesis examines the use of such prompts as employed in different health and social care settings in Ireland.

2.10 Challenges and Problems associated with Research into Reminiscence Work

Most of the earlier studies undertaken to evaluate reminiscence, in the context of dementia care, were quantitative and many have been criticised on the basis of their having serious methodological flaws including their having faulty conceptualization, with inadequate definitions of the type of reminiscence work being carried out and outcomes expected, lack of adequate controls, limited sample sizes and poor measurement (Coleman 2005; Woods et al 2005). Very few studies have been identified in the literature which use a qualitative approach.

Kiernat's study, one of the earliest reported, provides a good example of work reflecting methodological weaknesses. (Kiernat 1979). In that study, Kiernat looked at the effects of a group life review activity on three groups of nursing home residents all living in the same long term care facility. For an RCT the sample was small, (N=23) and the study continued for only ten weeks, with a variable attendance rate (Kiernat 1979). Although it concluded that

many of the group members enjoyed the activity and showed behavioural improvements during the period of the study, its findings were critiqued by academics who argued that the methodological problems associated with it made it difficult to extrapolate beyond the study (Woods and McKiernan 1995).

The well-known Cochrane review on reminiscence published in 2005 which examined the international literature on reminiscence and dementia was only successful in identifying five studies meeting their selection criteria for RCTs or quasi randomized control trials (QRCTs) (Baines 1987, Goldwasser 1987, Thorgrimsen 2002, Lai 2004 and Morgan 2000). This finding could be viewed as another indication of the methodological problems associated with reminiscence research (Woods, Spector, Jones, Orrell and Davies, 2005). The authors of the Cochrane review noted that these studies had important methodological weaknesses, including small sample sizes and difficulties in carrying out post-treatment assessments. The Cochrane review also noted that, although the findings in general were encouraging, there were limitations to the conclusions since the trials involved different types of reminiscence and different stages of dementia (Woods et al 2005). Although not overtly stated, it could be argued that the Cochrane Review indirectly pointed to the salience of using other research methodologies when conducting studies examining reminiscence work in dementia care. For example in none of the studies involved and reported on in the Cochrane Review have any attempts been made to elicit the views of PwD about their experiences of participating in reminiscence.

To better understand the challenges associated with conducting research into reminiscence work with PwD, it is necessary to look at the very broad range of different factors which may affect cognitively impaired peoples' experience of reminiscence sessions.

The first is the fact that reminiscence work is not a standardised activity and, in the context of dementia, it can involve different methods of delivery, different aims and different outcomes (Gibson 1994). As this thesis will demonstrate, even within reminiscence groups, methods of delivery and prompts used can change from session to session. In addition, reminiscence can

be a "stand alone" activity or it can be used in conjunction with other psycho-social interventions such as music therapy. Secondly, reminiscence work does not occur in a vacuum (Gibson 1994) and in dementia care, it typically takes place in nursing homes, day centres and hospitals. Accordingly, the setting itself in terms of decor and organizational ethos may impact on the way the intervention is delivered and experienced. Thirdly, reminiscence work is carried out by people, all of whom are different - both the facilitators delivering the sessions and those with a cognitive impairment participating. These differences in people, including amongst other attributes, their different personalities, interests, likes, dislikes can impact on the way reminiscence is experienced. In other words, each person will bring his or her own personality and life history to the reminiscence session. Each PwD will be affected by the dementia in different ways and possibly may have other health, social or psychological concerns which may affect the reminiscence experience. Facilitators also have different professional or non-professional backgrounds, different training and different sources of support.

In their 2010 article proposing a conceptual guide for reminiscence research and practice, the authors, whilst acknowledging that research into reminiscence has in the past been problematic due to conceptualization and measurement difficulties, nonetheless proposed that reminiscence research had now entered a more mature stage with isolated studies of increasing sophistication. They gave examples such as the work of Cappeliez and O'Rourke and their work on empirical validation of a model of reminiscence and health in later life (Cappeliez and O'Rourke 2006) which they argued showed greater attention to theory and model building. Interestingly, they also drew on the work of Gibson (Gibson 2004) whose research includes reminiscence work with PwD to provide examples of a more solid grounding of practical application in theory and research (Webster, Bohlmeijer and Westerhof 2010).

In general this research review has revealed that there is a consensus amongst several of the experts in the area that more research is needed in the area of reminiscence work with PwD

(Woods et al 2005) and that rigorous evidence based research has been slow to emerge (Subramanian and Woods 2012). Other experts on reminiscence work and PwD caution that research studies in this area often lack rigorous evaluation (Dempsey et al 2012; Coleman 2005). The next two sections will explore some of the more pertinent quantitative and qualitative research on reminiscence work with PwD.

2.11 Quantitative research into the use of reminiscence work with PwD

Much of the quantitative research dedicated to investigating reminiscence in the context of dementia care focuses on primary outcomes and the extent to which the intervention may affect these outcomes. The 2005 Cochrane review acknowledged that reminiscence therapy could yield various different outcomes. These included (i) enhanced communication, (ii) increased sense of personal identity, (iii) enjoyable activity in company with others, (iv) improved mood and well-being, (v) stimulated memories and (vi) enhanced individualisation of care. Reminiscence has also been associated with the maintenance of identity and the encouragement of feelings of self-worth (Coleman 1986; Gibson 1998) and improvements in coping capability and with the maintenance of positive self-concept (Wong 1995). The ALOIS Register, a study-based register created and maintained by the Cochrane Dementia and Cognitive Improvement Group which contains records of RCTs, Controlled Clinical trials (CCTs) and some Open-label studies, has a record of 47 studies involving reminiscence and PwD and caregivers of the PwD. Of these studies, 43 are noted as completed, three are ongoing and the status of one is unclear. An RCT design is used for the majority of these studies (34), with 11 using a CCT design, one an open label design and one being described as having an unclear design. Quantitative research is deductivist and objectivist and incorporates a natural science model of the research process, often influenced by positivism (Bryman 2004).

2.12 Qualitative research into the use of reminiscence work with PwD

Qualitative research, with its emphasis on words rather than quantification, is regarded as inductivist, constructionist and interpretivist (Bryman 2004) and therefore may be more suited to studies related to the experiences of a phenomenon as is the case of PwD's experience of reminiscence, in this thesis. In their 2012 systematic review and meta-synthesis of qualitative research into the use and effectiveness of psychosocial interventions with PwD, which includes reminiscence work (Lawrence, Fossey, Ballard, Moniz-Cook and Murray 2012), the authors note that recent Medical Research Council (MRC) guidelines in the UK point to the need to not only measure outcomes but also explore the ways in which the intervention is implemented, and qualitative research is particularly suited to exploring the process and identifying the effective components of an intervention (Lawrence et al 2012). Many of the qualitative studies related to reminiscence are small-scale and difficult to compare as they cover different types of reminiscence work, such as life story work or general reminiscence and different settings. Individual qualitative studies provide insight into the use of psychosocial interventions such as reminiscence work (Lawrence et al 2012) and add value to the debate on reminiscence work. They can be regarded as pieces in a puzzle, which can all add to the bigger picture. There are no databases for qualitative research similar to the Cochrane Library or the Alois register, which may suggest that qualitative research is not valued as highly as quantitative research.

In their systematic literature review of life-story work (LSW) in health and social care, McKeown and colleagues identified four papers concerning LSW with PwD which all used a qualitative approach and are all salient research studies (McKeown, Clarke and Repper 2006). One study concerned the construction of family biographies of PwD living in nursing home, collated in albums or videos (Hepburn et al 1997 and Carol et al 1997). One described nursing home staff's account of the introduction of life stories as an assessment tool

(Hansebo and Kihlgren 2000). One described the use of life stories documented in albums as told by relatives to care staff (Batson et al 2002) and the final paper recounted the special reminiscence work carried out in Northern Ireland with PwD whose behaviour challenged staff (Gibson 1991; Gibson 1994). The positive outcomes noted in these studies include enjoyment and stimulation (Batson et al 2002), greater understanding of the PwD and improved care practices as a result (Hansebo and Kihlgren 2000; Gibson 1991; Gibson 1994) and individualisation of discourse away from a pathological discourse (Hepburn et al 1997 and Carol et al 1997). In all studies the intervention was generally enjoyed by the PwD and staff and in one study, family members found the life-story book a useful conversational aid when engaging with the PwD (Batson et al 2002). These positive outcomes all suggest that in these contexts LSW helped staff understand the PwD and see beyond the dementia diagnosis. However the Batson et al study did acknowledge some potentially negative outcomes for the staff participating which will be discussed further in the next section which explores negative outcomes associated with reminiscence work.

2.13 Negative outcomes associated with reminiscence work

The literature reviewed for this thesis reveals few negative outcomes associated with reminiscence work. The study by Batson and colleagues did note some staff members found it emotionally draining listening to stories being repeated over and over by the PwD with memory problems (Batson et al 2002). In the same study staff also noted that taking part in LSW could be emotional for PwD (Batson et al 2002), however experiencing emotion is a normal part of life and as long as the person is not left in a "bad place" then it is not necessarily a negative outcome (Murphy 2002; Gibson 2011).

Interestingly, Coleman has suggested that in some ways the emphasis on the short-term positive outcomes of reminiscence has led to the neglect of reminiscence being recognised as a reconciling and healing activity, which was part of Butler's original article. The neglect of this important element of reminiscence is significant because whilst reminiscence is usually

rewarding, there can be difficulties if it is being used for healing purposes when reflections over past distressing events and painful memories may be traumatic or distressing. Coleman suggests staff may need training in ways of supporting a person to undertake the task of achieving reconciliation in their life story.

The literature shows an element of unease amongst care staff on the subject of reminiscence work and negative emotions. One example can be seen in a study of community nurses undertaking life review with palliative care patients (not specifically PwD), it was shown that nurses had concerns about triggering negative emotions during life review and requested qualified support with this (Trueman and Parker 2006). Caution is advised by many researchers in the field (Gibson 2004). Bender in particular advises of the need to exercise caution when carrying out reminiscence with a generation who have been through world wars and may have been traumatised possibly without ever having admitted to it (Bender 1997). Although this thesis is about reminiscence in the context of dementia, a review of reminiscence and mental health (which included discussion of reminiscence and PwD) recommended that all practitioners should be aware of possible negative side effects such as increased worry or rumination for some people who employ a negative type of reminiscence (Westerhof, Bohlmeijer and Webster 2010).

In the McKeown et al literature review of LSW in health and social care, the authors noted that all the studies in their review represented LSW as mostly positive, although not suitable for everyone. They argued that a search for, and presentation of, conflicting knowledge was generally absent and there was a lack of critical debate about the use of LSW in practice (McKeown, Clarke and Repper 2006). It is possible that the situation is the same for research into reminiscence work in general, with an over emphasis on the positive outcomes and an absence of debate on any possible negative outcomes. This thesis addresses this issue by exploring whether the PwD has experienced any negative outcomes associated with reminiscence work, whether facilitators have witnessed any negative outcomes and how facilitators deal with painful memories and negative outcomes.

2.14 The effect of reminiscence work on care staff and nursing staff

In the context of dementia care, reminiscence work outside of the home involves interaction between the PwD and a facilitator, often a formal care worker. As this thesis examines the experience of taking part in reminiscence work from the point of view of the facilitators who, in this thesis, are all formal care staff, as well as the PwD, the literature which includes account of the effects of reminiscence work on formal care staff is of relevance and will be addressed in the section to follow.

Interestingly, the effects of reminiscence work on care staff and nursing staff is often a secondary consideration in research studies with the main focus being on the PwD. It has been argued that this aspect of reminiscence work with PwD is under-researched (Subramaniam and Woods 2012), yet positive effects on staff have been noted as far back as the original trials of the Recall packs in the UK in the 1980s which noted reminiscence had a positive influence on staff and their approach to care (Bender et al 1999). In some studies, the positive effects experienced by staff taking part in reminiscence work appear to have been more significant than those experienced by PwD and are noted as a surprising and unanticipated outcome of reminiscence work. An example is a Danish study which investigated the consequences for nursing home residents and staff of integrating reminiscence into daily nursing care and found that, whilst reminiscence had limited long term effect on the nursing home residents, the staff experienced greater satisfaction within their professional roles. It was shown that staff developed a more positive view of the residents, some of whom were PwD (Gudex, Horsted Jensen, Kjer and Sorensen 2010). Similar outcomes were noted in an American educational intervention aimed at teaching homecare nurses and nurse aides how to implement a reminiscence programme with elderly clients (not all of whom had dementia). The latter study concluded that in addition to positive outcomes for some of the clients, benefits were also experienced by some staff

including personal satisfaction, learning more about their clients and establishing a better rapport with clients (Sellers and Stork 1997).

Similar positive outcomes for staff were noted in a qualitative descriptive study which assessed a family biography workshop (a life story intervention) designed to support family and staff to co-construct the history of PwD in residential care. Staff spoke of being enabled to see the PwD embedded in a family and intergenerational context and therefore feeling empowered to move towards relationship-centred care rather than task orientated care (Kellett, Moyle, McAllister, King and Gallagher 2010).

A much smaller qualitative study which showed unexpectedly strong effects on the formal caregiver is reported in a PhD thesis, which looked at promoting comfort for a PwD by using an individualised reminiscence intervention during bathing (Ruka 2003). Ruka found that, whilst there was some evidence of potential benefits for the PwD, her study showed that reminiscence may have a powerful role in enabling formal caregivers to know the person. Reminiscence was also shown to assist clinicians to interpret the meaning of underlying behaviours (Ruka 2003). This was a small scale, qualitative study but it raised important issues about the effects of reminiscence work on care and nursing staff.

Most of these studies showing positive effects for staff participating in reminiscence work have been qualitative. One exception is a study which used a RCT employing a cross over design (Reality orientation crossed over with RT) and as part of the study the effect on staff was noted (Baines 1987). The results showed positive effects on staff leading to a significant increase in their knowledge of the personal histories of the PwD in their care (Baines 1987).

Another small scale study which directly explored the experience of care staff in delivering reminiscence sessions was a Clinical Psychology Doctoral thesis carried out in the U.K. (Pullan 2009). Data was collected through interviews with eleven care staff, on four wards of a specialist, secure care environment. Using a qualitative approach and I.P.A. to analyse the data, six themes were identified – Barriers to personhood, meeting the person through life

story books, rehumanising the person, rehumanising the professional, a changed relationship and planning for the future.

Pullan argued that care staff had through LSW undergone a journey. At the beginning they argued that the PwD was effectively living in a depersonalising institution and was a lost and hidden person, (echoing Kitwood's malignant social psychology). After the reminiscence the person had moved to a more positive, support environment through the use of the life story books (Pullan 2009). Pullan argued that positive experiences for staff in reminiscence could directly influence the quality of care for PwD.

Whilst reviewing the literature I have been unable to find any studies which have directly assessed the extent to which positive outcomes for staff have been shown to directly influence the quality of life for the PwD in their care, although the Baines study did ask questions of staff regarding their knowledge of clients on the basis that reminiscence work should increase staff knowledge and contribute to culture of person centred care (Baines et al 1987).It could be argued that it is very likely that if care staff feel fulfilled and have more knowledge of a PwD this will have a beneficial effect on the relationship between the carer and the person cared for. Chaudhury argues that just as a family member's quality of interaction with a PwD is influenced by the relationship between the individuals, in a similar way the quality of care provided by a formal caregiver can be influenced by the premise that defines the relationship. More knowledge of the PwD can influence the staff's view of the PwD which can impact on the caregiver's attitude, values and actions (Chaudhury 2008). This improved knowledge and greater understanding of the experience of the PwD can lead to an improvement in the relationship between the PwD and the carer. The latter has been linked with enhanced person-centred care (Douglas, James and Ballard 2004). An example of this in practice is shown in an exploratory study undertaken in the UK into the use of LSW to enhance person-centred care with people dementia. The study was done under the auspice of a NHS Health and Social Care Trust in England (McKeown, Clarke, Ingleton, Ryan and Repper 2010). One of this study's conclusions was that LSW had the potential to enhance

person-centred care by enabling care staff and families to see beyond the diagnosis of dementia and value the PwD more holistically and also by enabling the PwD to feel proud of themselves and their lives (McKeown et al 2010). In this case reminiscence, specifically LSW, could also be viewed as promoting what Kitwood referred to as "positive person work" (Kitwood 1997) by promoting celebration for both the PwD and his or her caregiver by recognising and acknowledging the successes and achievements in a person's life. This thesis aims to add to this body of knowledge by exploring the experience of facilitators taking part in reminiscence work and looking at the benefits and challenges they experience.

It is worth noting that it is not only nursing or care staff who are involved in reminiscence sessions. Volunteers and family members are also known to take part in sessions, sometimes as facilitators and sometimes as participants and the effects on these people are also thought to be under-researched (Subramaniam and Woods 2012). In the evaluation of the Scottish Football Museum Reminiscence project, where volunteers were trained to deliver reminiscence sessions to men with dementia in the community, the evaluation noted benefits for the PwD but it was also noted there were benefits for the volunteers taking part, such as enjoyment, getting to know the PwD better and learning more about the history of football in the local area (Schofield and Tolson 2010). Whilst most of the research points to the potential benefits of reminiscence, a recent evaluation by the REMCARE team [3]which looked at reminiscence group work with PwD and family caregivers arrived at an unexpected conclusion. Although in this study, the reminiscence sessions may have been beneficial for the PwD attending, in the findings it was pointed out this needed to be balanced against the fact that the family caregivers appeared to experience increased levels of stress and anxiety, (Woods et al 2012). Woods et al note that this is a surprising result, especially given that a meta-analysis of psychosocial interventions for caregivers of PwD (Brodaty, Green and Koschera 2003) had indicated that joint approaches are more effective than others but perhaps this illustrates that the PwD and the caregiver, although they are in a relationship

[3] REMCARE – Reminiscence groups for PwD and their family caregivers: A UK based pragmatic 8 centre trial of joint reminiscence and maintenance versus usual treatment, led by Professor Robert Woods

with each other, have differing needs and joint reminiscence will not necessarily meet all those needs, so whilst family caregivers can certainly contribute to reminiscence and can benefit from reminiscence, joint reminiscence sessions may not be the preferred choice.

2.15 The Irish contribution to reminiscence research.

Reminiscence is carried out as a therapeutic intervention with PwD in many different countries and as this review of the reminiscence literature has shown studies have been undertaken in America, (Cook 1991;Moss et al 2002) Canada (Chaudhury 2002, 2008), the U.K.(Thorgrimsen et al 2002;Head et al 1990), Denmark (Gudex, Horsted, Jensen, Kjer and Sorensen 2010), Japan(Tanaka et al 2007;Yamagami et al 2007;Tadaka and Kanagawa 2007;Yasuda et al 2009), Hong Kong,(Lai et al 2004) and Taiwan (Chao et al 2008;Wang, Jing-Jy 2007;Huang et al 2009). Ireland has also made a significant contribution to the global knowledge base on reminiscence. The next section of this chapter reports on the most salient contributions made to date from Ireland.

Faith Gibson, writing from Northern Ireland is one eminent academic and practitioner who apart from theorising about reminiscence in the context of dementia care has interestingly explored the practical applications of reminiscence work. Included in her works is the review of the Northern Ireland life review/life storybook project for PwD. This guide concluded that PwD who participated in this project showed significant improvements in depression, communication, positive mood and cognition (Haight, Gibson and Michel 2006). Her books use a developmental life span perspective as a foundation. These writings cover very comprehensively the many applications of reminiscence with different groups including people with learning disabilities, the bereaved and people with depression as well as PwD. She also explores the different types of reminiscence including intergenerational work and work with minority ethnic groups. Her emphasis on practical applications is particularly useful for those who wish to develop reminiscence programmes. Her most recent book has included an appendix with useful recording charts and forms including a personal history

chart, individual and group session records including one specifically for use with PwD, a facilitator's record and a consent form (Gibson 2011).

A second renowned academic, who has also made a very significant contribution to this body of literature in the Irish context, is Professor Mulvenna from the University of Ulster. Mulvenna's work focuses for the main part on reminiscence and ICT. He has conducted studies with older people in general (not with dementia) but he also discusses reminiscence and dementia within his work. His research includes an evaluation of card-based versus devise-based reminiscence which concluded that there were no differences noted between those using ICT (the device based) and those using the traditional card based prompts thereby implying there were no barriers associated with the use of technology (Mulvenna, Doyle, Wright, Zheng, Topping, Boyle and Martin 2011).

In addition, the preliminary work emerging from the Dementia Education Programme incorporating Reminiscence for staff (DARES) and the development of the structured education reminiscence based programme for staff (SERPS) which emerged from the DARES programme based at the University of Galway is making a significant contribution to reminiscence research in Ireland (Cooney, O'Shea, Casey, Murphy, Dempsey, Smyth, Hunter, Murphy, Devane and Jordan 2012). The DARES study examines the impact of a staff training programme, which includes training in reminiscence therapy, on behaviours and quality of life of PwD living in residential care and on staff attitudes. The study commenced in December 2008, using a mixed method design including randomised controlled trials (www.nuigalway.ie). As part of the larger study the DARES team have already published a concept analysis of reminiscence in dementia which addresses the fact that no definitive definition of reminiscence exists and proposes an operational definition of reminiscence in the context of dementia care which this thesis uses (Dempsey et al 2012). The SERPS project has evaluated the development, delivery and validation of the education programme developed during the DARES project and focuses on what is needed to support staff for successful implementation, and interestingly the opinions of PwD have been included in both

the design and the evaluation of the intervention. The DARES project is ongoing and more research papers are expected to emerge from this work.

This chapter now progresses to examining different ways of understanding dementia in order to place reminiscence work as a therapeutic intervention with PwD in context. As stated in chapter one, there are many different models or paradigms used to help us better understand dementia, ranging from the medical model to the psychological model to the social or disability model. The model we use or the lens we look through this will impact on the way we understand the illness and how practitioners care for people diagnosed. The following section of this literature review will briefly detail the history of dementia and look at some of the critical current explanatory models of dementia.

2.16 Dementia and its conceptualization over time

It is likely that dementia as an illness has always existed (Lishman 1994; Boller and Forbes 1998) but has been conceptualized in different ways over time. Lishman, a British neuropsychiatrist in his history of dementia, notes that the Latin work "demens" meaning out of one's mind was first used in first century Rome. In the 19th century he claims that the term dementia and the concept of "senile dementia" were well known. It was not until 1906 when the German physician, Dr Alois Alzheimer, detailed a study of a female aged 51 who presented with symptoms of memory problems, hallucinations, confusion and cognitive problems that the term Alzheimer's disease was introduced. After her death her brain was examined and neuritic plaques and neurofibrillary tangles were observed. In 1910 the mentor of Dr Alzheimer used the term Alzheimer's disease to describe the brain disorder and it has been in common usage ever since to describe the most common form of dementia (Lishman 1994). At first, and as a result of Alzheimer's identification of the illness in this relatively young woman, Alzheimer's disease was used to refer to people under the age of 65. "Senile dementia" was used to describe people with memory and cognitive problems aged

over 65. Senility or senile dementia was in former times considered a normal part of ageing (Lishman 1994).

Lishman notes that in the early to middle part of the 20th century dementia was a neglected topic falling between neurology, psychiatry and the new discipline of geriatrics. However it did not feature much in the psychiatric or medical textbooks of the time. The situation has changed since the 1960's with amongst other developments advances in neurobiology, the scientific study of nerve and brain function (Lishman 1994). By 1977 dementia had been designated by the Medical Research Council as a research priority in the UK (Lishman 1994).

In their overview of the history of dementia Boller and Forbes note that in the 1960s and particularly in the 1970s there was a surge of interest in dementia research and accordingly a significant number of scientific discoveries were made at this time. (Boller and Forbes 1998). In 1975, and based on Medline, 42 papers were published including "Alzheimer" as a keyword, and subsequent years saw an exponential increase of research in the field (Boller and Forbes 1998). It was also noted that the Diagnostic and Statistical Manual of Mental Disorders (DSM) of the American Psychiatric Association during the 1970's did not use the term dementia, defined as a loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning, and this term was only introduced in the 1980s. Prior to that the terms senile and pre-senile dementia under the heading of "Psychoses associated with organic brain syndromes" and Organic Brain syndrome had been used (Boller and Forbes 1998).

Gubrium noted that the general public became more aware of Alzheimer's disease, partly because of well-known public figures advocating on behalf of carers and those with the disease from the 1980s onwards (Gubrium 1986). As this coincided with a period of strong clinical, genetic and pharmacological scientific research, including a quest to find a cause and a cure it is perhaps not surprising that the predominant model used to understand dementia for both academics and the general public for most of the 20th century has been the biomedical approach. Greater numbers of people were now recognized as having the illness

due to population ageing, and the removal of the original age less than 65 cut off for Alzheimer's disease. This in turn led to the development of Alzheimer's Associations and the interest in the illness.

2.16.1 The biomedical approach to dementia

By subscribing very rigidly to the bio-medical model, dementia can be regarded purely as an organic disease (Ballenger 2008). This type of approach focuses almost exclusively on the brain and on brain structures, brain size (atrophy), brain chemistry, brain lobes, neurotransmitters, plaques, tangles and broadly speaking on brain changes. It is argued that the neuropathological changes associated with the disease result in memory and cognitive symptoms and in behavioural changes.

This approach, which is generally labelled the biomedical model (Sabat 2008) or the neuropsychiatric model (Downs, Clare and Mackenzie 2006), has been the predominant explanatory model of dementia for most of the last century (Innes 2009). It has resulted in an overly medicalised view of dementia, with all memory, cognitive and non-cognitive features being viewed as symptoms of the disease needing management often with the use of drugs (Innes 2009). It could be argued that the biomedical model results in doctors being "in charge of the patient" with the emphasis being placed on the brain and onto the medical management of the illness rather than on the individual experience of the patient and his or her family caregivers. The approach, which places enormous value in finding a cure for dementia, has led to attention being focused on the neurotransmitters, amyloid plaques, neurofibrillary tangles and chromosomes rather than on the person and his or her reaction to the changes going on in the brain (Woods 2001). So whilst this model has contributed enormously to our understanding of the biological and physiological processes occurring in the brain, it could be considered limiting because of its narrow focus. Indeed some researchers have shown that there is no direct correlation between brain diseases and the symptoms of dementia displayed and some experts point to the need to include other factors

(Snowdon 1997, Lawlor 2013). The biomedical model has also been critiqued for being over-simplistic and for neglecting to consider important influential factors such as environmental, social and psychological factors (Downs, Clare and Mackenzie 2006; Sabat 2008; Kitwood 1987).

2.16.2 Alternatives to the biomedical model

During the 1980s and 1990s, researchers worldwide began to question the dominance of the biomedical model as an appropriate way to understand dementia (Gubrium 1986; Harding and Palfrey 1997; Lyman1989). Three main factors appeared to influence the need for an alternative way or for different paradigms to augment the bio-medical model. First, empirical evidence was suggesting that there was not always a direct correlation between the damage caused to the brain by the dementing process and the symptoms experienced by the PwD (Snowdon 1997). Secondly, first-hand accounts of living with dementia began to appear showing that the PwD was not just a passive victim of the disease but also an active agent who sought to cope with his or her illness (Woods 2001). Thirdly, at a political and social level there was increasing support for the need to recognise the discrimination and exclusion that often occurred when people with disabilities including those with dementia, were viewed within a medical model (Gilliard, Means, Beattie and Daker-White 2005; Bartlett & O'Connor, 2010, Marshall and Tibbs 2006). These factors led to the recognition of the key role other non-medical factors such as psychological, cultural, social and emotional played when attempting to gain a better understanding of dementia. The social and psychosocial models and approaches, detailed below, emerged during this period and were influenced by the critical thinking and debate of that time. Given how the psychoanalytical approach clearly underpinned much of Kitwood's thinking a review of this literature will also be undertaken in the section of this chapter to follow.

2.16.3 The Social Model of Disability and Dementia

The Social Model of Disability grew out of earlier work undertaken by a group of disabled people who formed the Union of the Physically Impaired Against Segregation (UPIAS) in 1976. They worked to break down the dominance of the medical view of disability which defined individuals in terms of their limitations (Gilliard et al 2005). This model helped to reshape the way society viewed disability, changing the way that disabled people were presented. So instead of being viewed as victims, the emphasis moved away from any limitations they had and instead focused on the discrimination and social exclusion encountered. There was also criticism of the "disability industry" that had grown out of the earlier view of disabled people, where non-disabled professionals had highly paid jobs in charities associated with particular disabilities but disabled people were not an integral part of these organisations (Campbell & Oliver 1996). The success of this movement led to changes within many of the organisations, for example the former Royal School for the blind in the UK in 1992 changed its' name to SeeAbility to reinforce its' new message of "Seeing beyond disability" (www.seeability.org). The original emphasis in the social model of disability was on physically disabled people, but increasingly the model has included those with learning disabilities and is now being used in relation to people with cognitive impairment including those with dementia (Gilliard et al 2005).

In common with our understanding of physical disabilities prior to the work of the UPIAS, our understanding of dementia as argued earlier, has been dominated by a medical model with a resultant emphasis on treatment, often with drugs, and a search for a cure (Boller and Forbes 1998). Applying the social model of disability to our understanding of dementia makes us aware of the discrimination, marginalisation and exclusion PwD can face (Bartlett & O'Connor 2010). These societal factors can impact on a PwD, compounding the problems they already face because of their cognitive impairments (Chester & Bender, 1999). The social model of disability is a useful model in any research focussing on an illness or a disability, as it reinforces the need to be aware of the issues of discrimination, marginalisation and exclusion and the part they may play in creating a disabling environment.

2.16.4 Psychosocial approaches to dementia

Psychosocial approaches to dementia developed as an addition to the biomedical model, building on the understanding of dementia as an organic illness and taking into account the environmental, social and psychological factors which influence the experience of the illness. Psychosocial models place the individual with dementia at the centre of academic and practice discourses (Innes 2009). Arguably the two most influential writers and researchers here were Tom Kitwood from the U.K. and Steven Sabat from the U.S.A, who, independently, in the late 1980s and 1990s developed alternative models for understanding dementia. These same models have impacted enormously on our understanding of dementia (Innes 2009). Their work has been acknowledged as providing a starting point for examining, challenging and indeed for changing dementia care (Innes 2009).

2.16.5 The work of Kitwood

Kitwood is recognised as being one of the most influential proponents of the psychosocial approach to dementia (Adams 1996). Kitwood was a British psychologist who in 1992 formed the Bradford Dementia Research Group, which later became known as the Bradford Dementia Group. His background, which included a period as a minister, time spent teaching in Higher Education and academic interests in psychology, sociology and education all contributed to his work including the content and style (Baldwin and Capstick 2007).
He developed a psychosocial approach to dementia which drew attention to the need to look at factors other than the purely medical when dealing with a PwD. He recognised that the individual's experience of dementia was dependent not just on the extent of any brain damage incurred but also on other factors such as personality, biography, physical health and social psychology (Kitwood 1993).

He expressed this as an equation

$$D=P+B+H+NI+SP$$

Where D is the dementia presentation, P is the personality, B is the biography, H is the physical health, NI is the neurological impairment and SP is the social psychology (Kitwood 1993).

Kitwood's emphasis on the need to look more holistically at the PwD was further strengthened by research which emerged during the 1990s undertaken by an epidemiologist (Snowdon 1997). In 1986 this Epidemiologist started a longitudinal study centred on a community of nuns in the U.S.A. 678 nuns took part in the study and over many years, extensive medical and cognitive tests, the use of medical and personal history records and post mortem results on brains donated by the nuns revealed that there was no direct link between evidence of the plaques and tangles associated with Alzheimer's disease and the symptoms associated with the disease. Some of the nuns in this study who displayed plaques and tangles in their brains at post mortem would have been expected to display the symptoms of Alzheimer's disease when alive but did not. Conversely, other nuns who had signs and symptoms of Alzheimer's disease when alive had no evidence of the plaques and tangles associated with Alzheimer's disease at post mortem (Snowdon 1997). Snowdon's research clearly showed that the biological processes alone could not explain the emergence of dementia.

Snowdon's findings fitted well with the arguments forwarded by Kitwood who viewed the experience of living with dementia as the result of a dialectical interplay between neurological impairment and psychosocial factors (Downs, Clare and MacKenzie 2006). He identified what he referred to as a "malignant social psychology", where a PwD can find that interactions with others can leave them feeling dehumanised and depersonalised leading to greater disability and dysfunction. Kitwood provided many different examples of the way PwD can be made to feel inferior in society by the way others interact with them. One

example is that of disempowerment whereby PwD may find others doing things for them which they are capable of doing themselves though they may do it more slowly or in a different way. Other examples include people labelling or discriminating against PwD so that they are viewed as different and undesirable and at the extreme as outcasts instead of as normal people suffering from a disease.

In his critique of the bio-medical model and his exploration into an understanding of dementia, Kitwood introduced the concept of personhood and person centred care where attention is focussed on the person and not the disease. It is interesting that the term 'person-centred' has its origins in the psychotherapeutic work of Carl Rogers (Rogers 1951). However, it was Kitwood's seminal work in the 1980s which brought the term into use in the dementia care field. Nowadays, the term person-centred care is widely used in nursing care and dementia care and has become synonymous with good quality care though it is perhaps sometimes over used in a tokenistic way (Brooker 2004; McCance, McCormack and Dewing 2011).

Kitwood was the first to use the term person-centred care in relation to dementia care, and his definition, although much debated and critiqued (Adams 1996; Baldwin and Capstick 2007; Dewing 2008), still holds relevance today. Kitwood defined personhood as "A standing or status that is bestowed on one human being by another, in the context of relationship and social being. It implies recognition, respect and trust" (Kitwood 1997, p.8). He saw personhood as lying at the meeting point of three discourses; transcendence, ethics and social psychology. From transcendence came the idea of being in itself, that all life is sacred. From ethics he drew on the Kantian principle that persons should always be treated as ends in themselves, not as means to other ends. From social psychology he drew on the understanding that people exist within a network of relationships (Baldwin and Capstick 2007).

Kitwood identified a cluster of psychological needs (comfort, attachment, inclusion, occupation and identity with an all-encompassing need for love) that those with dementia

may experience (Kitwood 1997). These needs differ from other models of needs, for example Maslow's hierarchy of needs where higher needs could not be met until lower basic needs had been met (Milliken 1998). He saw these needs as very closely connected, with fulfilment of one to some extent involving fulfilment of the others. Kitwood argued that for most people, who are cognitively intact, these psychological needs are generally well met or deficits could be concealed and dealt with. However, PwD he contended were more vulnerable and less able to meet those needs on their own. Kitwood believed the prime task of dementia care was to maintain personhood in the face of failing cognitive powers through the sensitive meeting of this cluster of needs (Kitwood 1997). It is in the meeting of this cluster of needs, that it could be argued that an intervention such as reminiscence work can be most useful as the outcomes associated with reminiscence work, such as enhanced communication, improved sense of identity, enjoyment, engagement and improved mood and well-being (Woods et al 2005), effectively address these needs, and this is one area this thesis will explore further.

Apart from his major contribution to dementia, in terms of identifying the psychological needs of the PwD and his reference to personhood and person-centred care Kitwood also identified Positive Person Work (PPW) as a way of working with PwD. This approach, he maintained, enhanced personhood, dignity and well-being (Kitwood 1997). He identified 12 characteristics of PPW; Celebration, Collaboration, Creation, Facilitation, Giving, Holding, Negotiation, Play, Recognition, Relaxation, Timalation[4] and Validation (Kitwood 1997).

Kitwood's theories and arguments, although critiqued (Adams 1996; Baldwin and Capstick 2007), have had a great impact on the care of PwD and have helped re-conceptualise and revolutionise dementia care (Innes 2009). His work also helps to provide a better understanding of the use of non-pharmacological interventions such as reminiscence work with PwD which he considered a very useful intervention. He was particularly interested in the way reminiscence could enable PwD to talk about their present situation in a way they

[4] Timalation was defined by him to mean a form of interaction where the prime modality is sensuous or sensual such as massage (Kitwood 1997)

could handle, using memories as metaphorical resources (Kitwood 1997). Kitwood's perspective on dementia will be used to inform the methodology and overall approach used in this thesis.

2.16.6 The work of Sabat

Like Kitwood in the UK, Steven Sabat, an American psychologist, has also played a key role in helping to re-conceptualise our understanding of dementia and Alzheimer's disease by shifting the focus of attention away from the clinical features of dementia (plaques and tangles) and encouraging us to think about the human experience. The main focus of Sabat's research has been on the intact cognitive and social abilities of people with Alzheimer's disease, including aspects of selfhood, the subjective experience of having the disease and the ways in which communication between those diagnosed and their caregivers may be enhanced. He has developed a model which incorporates the biological aspects of dementia with the psychological and social aspects (Sabat 2005). He uses social constructionist theory as a heuristic device to understand the relationship between self and dementia.

His writings reflect the fact that he acknowledges that dementia can result in cognitive losses and losses of behavioural functions but it is also often associated with loss of selfhood or identity. This notion of the loss of selfhood or identity is questioned by him as in his research he has found ample evidence of selfhood persisting even into the later stages of the disease (Sabat 1992; Sabat 2002).

Sabat identified four factors which influence the PwD. These are the brain damage, the person's reaction to the brain damage, the ways in which the person is treated by others and the reactions of the PwD to how they are being treated by others (Sabat 2008). Sabat argued that, at present, little can be done about the brain damage whereas the other three factors can be worked with to alter the impact of dementia on the person. Sabat used social

constructionist theory and the concept of selfhood to explain ways in which the third factor, the ways in which the person is treated by others, can impact on a PwD.

Sabat viewed selfhood as comprising of three parts. Self-one is the self of personal identity, often seen when the person identifies themselves as an individual. Self-two is the self of physical and mental attributes, past and present. Self-three is the multiplicity of social personae that require the co-operation of others to be manifested. Sabat provided many examples of people with varying degrees of dementia who still had evidence of their selfhood intact (Sabat 2002). He demonstrated through his research that loss of selfhood is not directly related to the disease process but is affected by other outside influences. Sabat concluded that Self- three could be supported by others by viewing the PwD as a whole person and not simply in terms of their diagnosis. Using a social constructionist model Sabat showed that a PwD's sense of self-worth may be damaged by their inability to construct a valued social persona due to lack of co-operation from others and the tendency by others to view the person in terms of their deficits. So a PwD previously may have had social personae which included for example caring wife, capable mother, hardworking employee, good golfer, strong swimmer, and good cook, which all helped to increase her feelings of self-worth and self-esteem. After a diagnosis of dementia however, the person may experience a reduced social persona of confused dementia sufferer which is bound to affect the person's feelings of self-worth.

Sabat also uses positioning theory to explain how PwD often feel de-personalised by health care professionals and others (Sabat, 2008). In many ways his thinking mirrors the phenomenon Kitwood referred to as arising due to a "malignant social psychology", where the person is seen in terms of his or her diagnosis and symptoms, which undermines the self-three. Negative positioning Sabat contends can occur when health professionals depersonalise people by treating them in a purely clinical way without any interest or respect in them holistically. Negative positioning can also occur in social situations when outsiders treat PwD as being more disabled than they actually are, leading to isolation and distress.

Sabat argues that this leads to internal conflict within the PwD which diminishes the person's sense of self-worth, and undermines his or her selfhood (Sabat 2008). Negative positioning can happen to anyone, when a person imposes a negative position on to another, but most individuals can reject that position should they so wish, refusing to be positioned in a way disagreeable to them. A PwD may be unable to reject the negative positioning because of failing cognitive skills and verbal abilities.

Sabat's psychosocial approach is drawn from his work as a researcher and the detailed transcripts and analysis of conversations he had with patients with dementia. The strength of the model he proposes is that it acknowledges both the effect that the brain damage caused by the dementia has on the person but in addition emphasises that as social beings, people are affected by those around them and this will impact on their experience of dementia.

It is clear from this review of the works of Kitwood and Sabat that there is a synergy between the writings of these two psychologists working on different sides of the world. Indeed some of Sabat's research papers include instances of him applying Kitwood's concepts to case studies of his own (Innes 2009). However his development of a social constructionist approach and concept of positioning gives a particularly helpful and robust understanding of the impact of others and the care environment on the PwD, and the parallel implications this has for best practice in dementia care.

As mentioned earlier, some of Kitwood's theorising has been underpinned by psychoanalytical approaches and for this reason the next and final section of this literature review will briefly discuss psychoanalytical approaches to understanding dementia.

2.16.7 The Psychoanalytical Approach

In the early part of the 20th century, the psychoanalytical perspective began to emerge as a way of understanding human psychological development (Makari 2008). Psychoanalytical theory is a theory of development through the lifespan which suggests that people as they

develop move through a series of stages in which they encounter tensions and conflicts arising from their biological drives and social expectations. Stated simply, how these conflicts are resolved, or not, influences the person's personality, their ability to learn, get along with others and deal with anxiety (Berk 2004). In relation to dementia and dementia care, the main psychoanalytic influences which have influenced this thesis are Erickson's stage development theory, attachment theory and the work of Menzies Lyth in relation to defence mechanisms used by organisations within nursing and caring settings.

2.16.7.1 Erickson's stage development theory

There are many influential members of the psychoanalytical movement, most notably Freud, (Makari 2008) but in the context of dementia, Erikson is perhaps the most relevant. Freud's theory of development included five psychosexual stages but Freud did not look at later life. Erikson accepted Freud's basic psychosexual framework but expanded on each stage and also added three adult stages.

Erikson maintained that people as they age pass through a series of eight different life stages, with the last occurring at age 60 plus. Each stage is associated with a psycho-social crisis which the individual must either resolve or may not. The last psycho social stage is that of integrity versus despair. If resolved positively Erikson argues that mastering this final tension or conflict can lead to ego integrity (Berk 2004). Accordingly by applying Erikson's theory to ageing people with a progressive dementia it would suggest that as their cognitive abilities are being compromised by the disease, they may have difficulty in resolving this final stage.

2.16.7.2 Attachment theory and dementia

With a basis in psychoanalytical theory (Cortina and Marrone 2003), the issue of attachment is worth noting in relation to dementia as it is now being recognised that although

attachment theory grew out of work with mothers and children, it can be applied across the lifespan and is relevant in work with PwD (Garner 2004). Attachment theory was first used by the Psychologist Bowlby when researching the mother-child bond. It describes the bond that develops between a child and his/her main caregiver (usually the mother) in the first year of life. The quality of the bond differs dependent upon the interactions between the mother and child and four types of attachment have been identified. These have been summarised as secure attachment where the child uses the parent as a secure base to explore and when separated may or may not cry. When the parent returns the child actively seeks contact and any crying is reduced. Avoidant attachment is described as when the child is unresponsive to the parent when she is present, when the parent leaves the child is not usually distressed and the child reacts to a stranger in the same way as he or she does to the parent. During reunion the child avoids or is slow to greet the parent. Resistant attachment is described as when before separation the child seeks closeness to the parents often failing to explore, and after separation when the parent returns the child reacts angrily, possibly continuing to cry and cannot easily be comforted. Disorganised-disorientated attachment shows the greatest insecurity, and at reunion shows a variety of confused, contradictory behaviours (Berk 2004).

Attachment relationships are thought to be important for psychological security, with positive attachment being a source of comfort in times of need and stress, for example during illness (McNelis, Clare,L and Whitaker, C J 2013), which is particularly apposite for those developing dementia. A recent systematic review on the literature of attachment in PwD and their caregivers was carried out by McNelis and colleagues. The review covered empirical studies where the main focus was attachment theory and or dynamics with PwD and caregivers. 18 studies were included, three focused on parent fixation in dementia, three examined attachment behaviour in dementia, five addressed attachment and dementia related behavioural problems and seven focussed on attachment and the caregivers of PwD. The review concluded that attachment behaviours were evident in the various stages of dementia. Studies showed PwD often show attachment to relatives and family, similar to the

way that children do with their parents as described above. However as dementia progresses overt attachment to relatives tends to lessen and parent fixation is more apparent especially in residential care. As memory problems increase, many PwD rely more on symbolic attachment with thoughts and memories providing comfort (McNelis, Clare, and Whitaker 2013). This has particular relevance to reminiscence work, as it could be used to stimulate the memories which provide comfort in the absence of other attachment figures.

Attachment styles developed as children are also thought to contribute to behavioural or non-cognitive symptoms in dementia (Magai & Cohen 1998; Perren, Schmid, Herrman, Wettsetein 2007; McNelis et al 2013)). For example, in one research study, those with an avoidant attachment style displayed more activity disturbances and more paranoid symptoms when they developed a dementia compared with others (Magai and Cohen 1998). Indeed Waddell notes there is increasing evidence that the anxieties and mental disturbances of later life are specifically connected to the struggles of early life (Waddell 2007). We know, for example, that insecure attachment as a child can have a profound effect on adults in later life including their coping abilities and the possibility of their suffering illnesses such as depression (Aneshensel and Phelan 1999).

2.16.7.3 The work of Menzies Lyth

One of the most important studies in relation to dementia care from a psychoanalytical perspective was the 1959 study of nursing students carried out by psychoanalyst Isabel Menzies Lyth. On behalf of the Tavistock institute, she studied the nursing service of a large teaching hospital in London. The focus of the study was to help the nursing service plan the training of student nurses. During the study it became apparent that there was a high level of anxiety, distress and tension within the nursing service. The anxiety caused by the nursing process which involved dealing with vulnerable people often in pain, and carrying out tasks which could be distressing or distasteful, could arouse powerful emotions such as compassion, pity, fear and disgust. Yet these emotions were rarely acknowledged or

supported and the nurses observed were generally self- controlled and composed. There was much absenteeism within the nursing service and many student nurses did not complete their training, and Menzies Lyth argued that there was a link between the tensions arising from the unmet emotional needs experienced by the student nurses and the difficulties within the nursing service. Drawing on the work of psychoanalysts such as Melanie Klein who had explored the relationship between the individual, the group and the wider system and the emotions within that relationship, Menzies Lyth examined the nature and effect of the anxiety levels in the hospital and used the psycho-dynamic hypothesis of defence processes to explain the ways the institution tried to keep the anxiety levels in check. The defence mechanisms used and encouraged by the institution included keeping an emotional distance between the nurse and the patient, depersonalization and denial of the significance of the individual, detachment and denial of feelings and the encouragement of ritual task performance. Ultimately, as the absenteeism and drop-out rate showed, these defence mechanisms were ineffective and also had a negative effect on the job satisfaction of nurses as their role became task focussed, impersonal and detached (Menzies 1972; Menzies- Lyth 1989). At the time of the study the arguments put forward were regarded as controversial but the study is now accepted as a seminal work and has been republished many times. The study drew attention to the emotions and politics at play at an organisational, group and individual level within large healthcare settings (Davidson and Peck 2011).

Kitwood argued that dementia care shared similarities with nursing care in respect to the defence processes which can operate in these settings (Kitwood 1997). Certainly dementia care workers are working with a client group with needs similar to those the nurses were working with. Dementia care workers are working with people who are potentially vulnerable, nearing the end of their life, often with personal care needs which involve potentially distasteful tasks such as toileting needs and emotional needs due to the anxiety and distress caused by dementia. Kitwood argued that the anxieties experienced by dementia care workers centred on two main issues, ageing and fragility and madness and loss of self. These anxieties were exacerbated by the realisation that one day the dementia care

worker may be in the same position – a PwD. Kitwood suggested that unnecessary regimentation of tasks, keeping the PwD emotionally at a distance and the emphasis on the physical side of care could all be viewed as defence mechanisms similar to those encountered by Menzies Lyth in her nursing study. Kitwood noted that these practices could be rationalized by using a medical model of dementia, where it was implied that due to neuropathological changes, the PwD needed little more than physical care. The new culture of care advocated by Kitwood, with its emphasis on person centred care, discouraged these emotional defences and encouraged the dementia care worker to engage meaningfully with the PwD and acknowledge the emotions which arise from care work. Kitwood does warn that the anxieties surrounding dementia are great and if the organisation does not sufficiently support staff in working through their anxieties, the unconscious could create new forms of defence and this would be an issue caring organisations would need to be aware of (Kitwood 1997).

A psychoanalytical approach, such as that developed by Erikson, which places an emphasis on the choices and dilemmas confronted by people at different stages in the life course and how such affect their well-being and adjustment in later life and attachment theory can be useful tools in helping us understand the needs of PwD. Kitwood, a psychologist had practised privately as a psychotherapist and was well acquainted with psychoanalytical theory (Baldwin and Capstick 2007), acknowledged himself that in developing his theory of personhood he drew heavily on counselling and psychotherapy work, which have their roots in the psychoanalytical approach. Kitwood commented that much of what has been learned about the conditions under which personhood emerges, that is childhood, can be applied to the dementing process (Kitwood 1993). Indeed he specifically seemed to draw on attachment theory when he proposed that out of interaction and sensitive responses to infant's gestures, selfhood emerges (Kitwood 1992).

As Kitwood notes, the psychodynamics of caregiving in the context of dementia is a complex matter (Kitwood 1990) and it follows therefore that a psychoanalytical understanding of the

family dynamics of a PwD, could lead to support of the PwD and their family caregivers. Also, as reminiscence work can include tapping into earlier childhood memories an understanding and awareness of Psychoanalytical Theory may help us to better understand issues arising during reminiscence work. Indeed researchers such as Mills have shown that psychoanalytical techniques can be used therapeutically in conjunction with reminiscence work resulting in beneficial outcomes for the persons with dementia (Mills 1997).

The work of Menzies Lyth and Kitwood's interpretation of it in relation to dementia care is very relevant to this thesis. Reminiscence work could be viewed as breaking away from the defence mechanisms noted by Menzies Lyth and Kitwood. Rather than creating emotional distance from the PwD reminiscence work (obviously assuming it is carried out well) encourages relationship building and dealing with both positive and negative emotions. Instead of depersonalization and denial of the significance of the individual it encourages seeing the person as an individual with a past. It involves creativity which is the antithesis of ritual task performance. In moving away from these defence mechanisms or rejecting them, the reminiscence facilitator needs adequate support to deal with the anxieties and tensions which arise from working with PwD and this thesis will attempt to explore this issue and whether the organisations studied managed to achieve this. Psychoanalytical Theory is a useful tool in understanding aspects of dementia and is drawn upon in the writing of this thesis.

The above models and theories on dementia provide frameworks to how dementia can be viewed in our society and how it was conceptualized in this PhD thesis. Reviewing this body of literature also reveals that some overlap exists between the emerging models and approaches discussed. Kitwood's description and analysis of dementia including his argument about PwD being exposed to a malignant social psychology is similar to Sabat's description of positioning theory undermining self-three. This is also similar to the way PwD can be marginalised and discriminated against as described in the Social Model of Disability.

All of the models discussed so far are relevant to this thesis which aims to explore the way in which reminiscence is experienced in different care settings and the extent to which reminiscence can be used as an intervention to promote quality of life.

2.17 Chapter Summary

This chapter has traced the history behind how reminiscence in aged care and in dementia care first developed starting with the seminal work of Robert Butler in the US during the 60's and following through to much more recent work including the Cochrane Review conducted on the topic in 2005 and the more recent systematic review (Subramaniam and Woods 2012). It has shown that reminiscence work is a popular therapeutic intervention for PwD and has argued that much of the existing research on reminiscence has been quantitative and has involved RCTs. These trials have shown the effectiveness of reminiscence in terms of the potential it has to reduce agitation, improve mood and communication. They have failed to hone in on the real live experiences of those most affected by the intervention i.e. those with dementia and those who deliver the intervention. This chapter has shown that there are few published studies which report on the PwD's own perceptions of reminiscence and how the intervention affects them. Accordingly whilst RCTs are powerful they are unable to convey the subjective experience of taking part in reminiscence work. By examining the experience of the PwD who take part in reminiscence and that of their formal and informal caregivers in this thesis, it is hoped this study will add a new dimension to the existing research into reminiscence work and dementia. This thesis will also explore previously under-researched areas of reminiscence work including the possibility of negative outcomes associated with reminiscence work and how facilitators experience taking part in reminiscence work. This chapter has also reviewed the way in which dementia has been conceptualized in the literature over time and has critiqued the bio-medical model. It has attempted to demonstrate the way in which psychoanalytical approaches have helped inform some of the

theories and thinking produced by some of the well-known writers in the field of the social and behavioural sciences over the last 30 years.

Reminiscence work for PwD is an area of research which is expanding and gaining in popularity both within the academic community and amongst the general population. This literature review has covered the therapeutic uses of reminiscence, concentrating on its use with PwD, and placing them within the context of the current understanding of dementia. It has reported on the key studies undertaken on this topic in the years since Butler first drew attention to the potential therapeutic value of reminiscence and will provide a useful framework from which to explore the experience of reminiscence work with PwD and their facilitators in Ireland.

3 Methodology

3.1 Introduction

The last chapter reviewed and critiqued the national and international literature on the topic of dementia and reminiscence. It showed how there is a growing but rather limited body of literature on the subject of reminiscence and dementia most of which is quantitative and there is a consensus in this literature that there is a need for a lot more research in the area. The majority of these studies reviewed in that chapter used RCTs and demonstrated the effectiveness of reminiscence although outcome measures are different across different studies (Woods et al 2005). The last chapter also pointed to the gaps in the literature on reminiscence and dementia and demonstrated how this thesis hopes to narrow some of these gaps. This chapter will now progress to outline the exact research design and research methods which will be used in this study to address the key research questions explored. It will report on the theoretical and ethical issues which have influenced the choice of design.

At the outset it must be acknowledged that respect for the individual with dementia and concern about personhood and dignity guided the pathways taken in conducting this research. Cowdell has observed that research design requires a high level of flexibility in order to be sensitive to the needs of PwD. Her literature review of research studies which actively involved PwD concludes that the most valuable research in this area occurred when researchers demonstrated an inherent belief in the need to work in a way that preserves the personhood of the individuals (Cowdell 2006). This commitment to preserve the essence of the individual was a guiding principle in this research design, and all research decisions were influenced by it.

Innes, in her historical and critical evaluation of dementia studies has argued that it is possible to chart the development of dementia as a subject of social study over time and

identify trends within the subject (Innes 2009). In the 1980s the focus of much research was on family caregivers, with research with formal caregivers remaining generally neglected. The small amount of research carried out on formal caregivers tended to focus on their views and experiences of quality of care received by the PwD.

Innes viewed the works of Kitwood, Sabat and Harre, and Goldsmith as marking a shift in focus to the current situation where there is an upsurge in interest in understanding the experiences of the PwD as reported by the person (Innes 2009). This thesis, with its emphasis on an understanding the experience of the PwD through the respective voices of these people, aims to contribute to this literature. Additionally the inclusion of the experience of the facilitator conducting and taking part in reminiscence work acknowledges the important contribution of the facilitator. It has been argued that taking part in reminiscence work can be an emotionally laden experience for facilitators and the effects of reminiscence work should be considered from a facilitator point of view (Woods 2005; Gibson 2011; Head et al 1990; McKiernan and Yardley 1991). This thesis attempts to do this.

This chapter commences with a review of the philosophical position and theoretical framework relating to this thesis. It first reports on the literature on the subject and then shows how this has been translated into practice in this study. The research design, methods used, approach to sampling, obtaining consent and other ethical considerations will then be discussed.

3.2 Research Questions

As stated in chapter one, the aim of this study is to explore the experience of reminiscence work for PwD along with the experience of conducting reminiscence work from the perspective of facilitators who work with PwD in Ireland. This has entailed designing a study which includes the experiences of PwD, and also the facilitators working with them, in an appropriate and ethical manner. In order to understand the value and meaning placed on

reminiscence by the PwD and facilitators, the key research questions this thesis attempts to address are as follows:

How do PwD and facilitators experience taking part in reminiscence work?

What are the benefits for PwD and facilitators?

What are the challenges of taking part in reminiscence work?

What makes a successful reminiscence session?

What is the impact of the culture of care on the reminiscence experience?

3.3 Epistemological stance

This thesis is underpinned by the epistemological concept of social constructionism and this has influenced the methodological design and choice of data collection tools.

Social constructionism, which has its roots in sociology and psychology, maintains that reality is socially constructed by and between those who experience it, these realities are shaped by the person's life history and experience, together with the cultural and social norms of the society the person lives in (Begley 2009). This thesis has been influenced by the work of social scientists including Gubrium who challenged the bio-medical viewpoint of dementia and argued that dementia had been socially constructed as a disease or illness to meet society's need for order and control (Innes 2009; Gubrium 1986). Gubrium argued that because dementia is socially constructed different interpretations can be placed on events and behaviours (Gubrium 1991). From a social constructionist viewpoint, every person's experience is unique and no two people will experience the same situation in the same way. An example of this is given by Darlaston-Jones in her PhD thesis, exploring retention levels in higher education, where she argues that simply sitting in the same classroom for the same lessons does not make the university experience of students identical (Darlaston-Jones 2007). The same argument can be made for people experiencing dementia. Although they

have the same disease, each person will experience a different reality. This understanding of the social construction of reality fits well with the person-centred approach espoused by Kitwood, where it is argued that an individual's experience of dementia varies according to factors including personality, biography, physical health and social psychology in addition to the extent of any brain damage caused by the disease (Kitwood 1993).

My decision to choose social constructionism as my theoretical position for this thesis has been influenced by my earlier work career and by my exposure to working with and supporting PwD. By adopting social constructionism, I am rejecting positivism with its emphasis on viewing reality as universal, objective and quantifiable and arguing that there are many truths and realities.

A central argument of social constructionism is that the individual's experience of the world is subjective and understood through investigating meaning and interpretation (Begley 2009). In this thesis the findings pertaining to the case studies have been analysed using an IPA, a research method which fits well with social constructionism, as its aim is to deliver the essence of a phenomenon from the point of view of the individual experiencing it.

From a social constructionist viewpoint, the research process is viewed as a co-construction, with the researcher working with the research participant to present an interpretation of the reality of the participant. This, together with the ideals of participatory research, where the emphasis is on the importance of doing research with and for participants (Bartlett and O'Connor 20120) has been a central tenet of this thesis since a major objective of the thesis was to enable PwD to share their experiences of taking part in reminiscence work. This is an area of research which has been somewhat neglected. In order to do that, I had to ensure that I was working with the PwD to ensure his/her voice was heard and their opinions and experiences explored.

3.4 Philosophical Position

A phenomenological approach was chosen as the most appropriate philosophical approach to understand the experience of reminiscence work from the perspective of the PwD and facilitators. Phenomenology is an umbrella term (Bryman 2004). It refers to both a philosophical movement as well as a range of specific research approaches (Finlay 2009) and focuses on the subjective experience of the individual striving to find the essence of the particular phenomena being observed. As an approach to research, Phenomenology can communicate both the structure (the essence of the phenomenon) and the texture (rich description of what phenomenon is like) (Holloway and Todres 2003). This approach should result in eliciting the essential meaning of the issue from the perspective of those directly involved which is the primary intention of this study. At a philosophical level, this thesis is broadly influenced by Phenomenology and IPA which was used as a tool to design the study and also to analyse the data. The following section will explore the origins of Phenomenology and IPA and look at how they informed this thesis.

3.4.1 Origins of Phenomenology

The philosophical roots of Phenomenology are seen in the work of Husserl and Heideggerian who founded the two most popular phenomenological interpretations, Husserlian (descriptive phenomenology) and Heideggerian Phenomenology (interpretive phenomenology) (Smith, Flowers and Larkin 2009) and both approaches will be discussed in the next section of this chapter

3.4.1.1 Husserlian Phenomenology

Husserl defined Phenomenology as the science of the essence of consciousness. His early work focussed on studying experience from a first person point of view. Husserlian phenomenology requires the researcher to step outside their everyday experience in order to

experience the phenomenon at hand (Dowling 2007). So according to Husserlian phenomenology, it is necessary to disengage from activity and attend to the actual experience of it. Husserl developed a phenomenological method which involved bracketing. This is a methodological technique where all preconceptions and everyday assumptions are put on hold or bracketed for the duration of the study (Beech 1999). The technique involves working through a series of reductions, each reduction offering a different way of thinking about the phenomenon being studied. This results in the researcher moving away from the distraction of their own assumptions and back towards the essence of the experience (Smith et al 2009). Husserl called the techniques required to get to the essence of a phenomenon as eidetic reduction.

3.4.1.2 Heideggerian Phenomenology

Heidegger, a student of Husserl, developed an approach to phenomenology which he believed was more phenomenological but less theoretical and abstract than Husserl's (Smith et al 2009). Heidegger discouraged bracketing as a technique as he argued that we should use our contextual relations to things in the world, to help interpret our activities and the meanings we attach to phenomena. He believed people exist in a world of objects, relationships and language and because of this our being in the world is always perspectival as it is dependent on our ideas and the facts known to us and it is temporal and in relation to something which places peoples' meaning-making activities as central to phenomenology (Smith et al 2009).

3.5 Interpretative Phenomenological Analysis (IPA)

Many different research methods and techniques are categorised as phenomenological and variations flourish, each with their own particular emphasis (Finlay 2009). IPA is one example of a variant which is becoming increasing popular in health service research and in the Social Sciences. Originating in Psychology, as a research method, it balances rich

description of phenomenon with interpretation to deliver the essence of a phenomenon from the point of view of the individuals experiencing it. Developed by Jonathan Smith, IPA draws widely from a range of philosophical ideas and interestingly is considered Phenomenological, Hermeneutic and Idiographic (Smith et al 2009).

3.5.1 IPA and Phenomenology

IPA is phenomenological as it aims to explore an individual's own account of an event or experience and aims to make sense of that experience (Larkin 2012). IPA draws on the work of the philosophers Husserl and Heidegger. As noted Husserl's work established the need to focus on experience and its perception, and Heidegger's developed this further taking a more interpretative stance and seeking to consider a person as part of a lived world which includes objects, people and language. Other philosophers who are acknowledged as having a considerable influence on IPA include John Paul Sartre and Merleau-Ponty (Smith et al 2009).

Sartre, who attended Husserl's lectures at the Sorbonne, became an enthusiast of phenomenology and is credited with establishing a "third phase" of phenomenology (Jones 2001). He proposed the idea of psychoanalytic existentialism in his major thesis "Being and Nothingness" (Sartre 1956) which emphasised human existence as characterised by thinking, freedom, choice and human responsibility (Jones 2001). Sartre believed that the self is not a pre-existing entity to be discovered but an on-going project to be unfurled (Smith et al 2009). For Sartre human nature was more about becoming than being. The individual has freedom to choose but within a complex net of issues informed by the person's own life including their personal history and the environment in which they find themselves. In Sartre's view consciousness involves the freedom to choose or negate the given features of the world. Sartre's ideas have been adopted by researchers in nursing and healthcare as a way of enabling them to negotiate the cultural phenomena and the psychological world of the people they are working with (Hunt 1989; Jones 2001).

Merleau-Ponty, another French Philosopher, emphasised the importance of our embodied relationship to the world, arguing that as humans our sense of self is holistic and is not subsumed within the world, but is outside of it, so our bodies are not considered objects in the world but instead are our way to communicate with the world. Merleau-Ponty argued that we perceive others always from our own embodied perspective, so whilst we can observe and experience emotion for another person we can never actually truly share that person's experience, as it is unique to them (Smith et al 2009).

IPA draws on the work of each of these philosophers and aims to elicit an account of an experience from the person who is at the heart of the experience, with a description situated in time and space rather than a generalised account. It is for this very reason that IPA was selected as a research method for this study since the latter attempts to capture and interpret the lived experiences of PwD as they participate in Reminiscence work and the experiences of the facilitators as these pertain to different care settings.

3.5.2 IPA and Hermeneutics

IPA has also been influenced by hermeneutics, the theory of interpretation and the meaning of language and text (Smith et al 2009; Shaw 2010; Frost 2011). With its origins in theology, hermeneutics was originally used in the interpretation of biblical texts but modern hermeneutics also covers interpretation of written, verbal and non-verbal communication. Its use in the Social Sciences is concerned with the theory and method of interpreting human action, with an emphasis on understanding the perspective of the social actor (Bryman 2004). Hermeneutic theory argues that a researcher cannot access another person's world directly. There is always an element of interpretation and the researcher always brings his/her own assumptions and preconceptions to this interpretation[5]. In IPA it could be said that the researcher is involved in a double hermeneutic, as the researcher attempts to make sense of the participant who in turn is trying to make sense of his/her experience (Smith et al 2009).

[5] Although researchers who practice bracketing try to avoid this.

Heidegger drew together phenomenology and hermeneutics and argued that all description involves interpretation. He also argued that our interpretations are founded on our prior experiences, our assumptions and our preconceptions. Whilst acknowledging that these prior experiences exist, he believed priority should be given to the new object we are encountering rather than our pre-existing assumptions, and that the new object may even affect our fore-conceptions.

Heidegger's ideas have further been explored by theorists like Gadamer, who argued that the phenomenon under study can influence interpretation which can influence the fore-structure (the assumptions the researcher holds) which can then influence the interpretation. In other words there can be almost a circle of influence, which points to the need to engage in interpretation in a spirit of openness.

Other hermeneutic theorists whose works have influenced IPA include Schleiermacher. The latter argued that interpretation is an art which relies on a combination of skills including intuition. Schleiermacher argued that to understand a text, one had to understand the writer almost better than oneself and see both within a holistic analysis, which can result in the researcher understanding the person producing the text. A researcher can therefore bring something extra to a text. In the case of IPA research for example this can be because of the detailed analysis of the text carried out by the researcher (Smith et al 2009).

A concept borrowed from hermeneutic theory which has relevance to IPA is the hermeneutic circle. This concept concerns the dynamic relationship between the part and the whole, where to understand any given part of a text, consideration of the whole is necessary and to understand the whole each of the parts need consideration. Applying this principle to this thesis, if we look at an interview as being a part and the research project as being the whole, then the interview can only be understood within the context of the research project and the outcome of the research project depends on the outcomes of the various individual interviews. This iterative process is important in the IPA process and was adopted in the design of this study.

3.5.3 IPA and Idiography

IPA is also considered idiographic (Smith et al 2009). It is committed to the detailed examination of a particular case (Smith et al 2009). It wants to know in detail what the experience for this person is like, what sense this particular person is making of what is happening to them. Accordingly IPA is concerned with the particular, on two levels, (i) in the sense of detail and depth of the analysis, and (ii) from understanding the perspective of a particular person or persons in a particular context. For these reasons IPA often uses small, purposively selected samples and single case analysis.

3.5.4 How IPA was used in this thesis

This use of IPA in this thesis was strongly influenced by the writings of some of the experts (Smith et al 2009; Finlay 2009; Frost 2011). As defined by Smith and his colleagues, IPA is a qualitative research approach committed to the examination of how people make sense of their major life experiences. IPA is phenomenological in that it is concerned with exploring experiences within its own terms. The Philosopher Edmund Husserl famously urged Phenomenologists to go back to the things themselves and IPA research follows his lead in this regard rather than attempting to fix experiences in predefined or overly abstract categories. In addition I attended an advanced workshop on IPA, read other theses which used the IPA approach and joined a regular internet discussion group on IPA, monitored by Professor Smith.

The influence of IPA on the design of this thesis can be seen throughout various stages of the research process, including methods used, approach to sample recruitment, the development of a data collection instrument, the data collection process and its analysis and write up, including reflections on the process. The use of interviews for data collection is recommended in IPA which is the approach used in this study. Observation is not usually

associated with IPA, however it is recommended that the researcher should be creative in their application of methods as it is acknowledged that successful data collection requires flexibility (Smith 2009) and in this case I felt that the observations added value to the data and would enrich the interview data collected.

Other theoretical approaches were considered for use in this study but following reflection were dismissed. A descriptive phenomenological approach was first considered based on Husserlian phenomenology as this is recommended when little is known about a phenomenon or issue (Penner and McClement 2008) which is the case in this thesis. It would involve bracketing, which as described earlier, is a methodological principle where all preconceptions and everyday assumptions are put on hold or bracketed for the duration of the research project (Beech 1999). However, I felt whilst descriptive phenomenology would be useful in analysing the essence of an experience, it would not capture the particular experience as witnessed and felt by particular people. In contrast it was believed that IPA could achieve this (Smith et al 2009), In addition many researchers argue that bracketing is difficult to fully master and I felt that in this study it could indeed prove problematic as my earlier experiences of reminiscence work helped to influence the research questions (Smith et al 2009; Finlay 2010).

Grounded Theory was also considered for use in this thesis. Grounded theory was one of the first formally identified methods developed for qualitative research and is an approach which aims to generate theory by achieving a close fit between the data and the analysis (Bryman 2004). It was developed as a way of providing a clear, systematic and sequential process to qualitative fieldwork and analysis. It is argued that Grounded Theory is very useful when dealing with a lot of data and when a highly structured protocol is preferred (Smith et al 2009). However, as it has a focus on developing theory (which clearly was not the aim of this thesis) it was felt it was not appropriate for this exploratory study.

Ethnography – the study of peoples' behaviours in naturally occurring on-going settings with a focus on the cultural interpretation of the same (Bryman 2004) was also considered but it

was decided that the data collection methods associated with this approach, the participant observation and intensive fieldwork, would be difficult to achieve given the time restraints inherent in this study.

3.6 Theoretical Framework.

Kitwood and Sabat's respective theories on dementia which have been described in the previous chapter have been drawn on to provide the theoretical framework to help underpin this thesis. Their theories are firmly rooted in Psychology and in part as argued in the previous chapter in Psychoanalytical theory. Kitwood's major thesis is that a PwD is not only disadvantaged cognitively and physically due to the neurological impairment but may also be excessively disabled due to adverse public and professional attitudes and to other psycho-social environmental influences. The environment he maintains often constitutes a malignant social psychology which serves to dehumanise and depersonalise the individual accentuating the level of disability experienced. For Kitwood the term environment refers not only to the architectural setting but also the attitudes and actions of paid and unpaid caregivers.

Both Kitwood and Sabat subscribe to psychosocial models for understanding dementia. This approach compared with the bio-medical model, recognise the need to acknowledge the effects of psychological and social factors on the PwD alongside the biological changes caused by the disease. This model of dementia and its' subsequent implications for care has increased in popularity over the past couple of decades with a move to a more holistic understanding of the disease. The works of Kitwood and Sabat have particularly influenced this thesis, since both proffer a broader understanding of dementia. Kitwood's argument that the PwD has basic human needs, including the need for occupation and engagement has particular relevance to this thesis.

3.7 Methodological Design

The design used in this thesis is qualitative and exploratory drawing on four case studies, chosen to reflect the different settings and modalities in which reminiscence work can be delivered in Ireland. A qualitative approach was considered the only feasible way by which the research could be conducted given the type of research questions that needed to be addressed and given the fact that the people being investigated each had a cognitive impairment some of more intense severity than others. The section to follow will discuss general design issues, the sampling strategy used in this study, how the field work was carried out and ethical considerations associated with this study.

3.8 General Design Issues

As stated earlier, much of the published work on the topic of reminiscence work and dementia has used quantitative studies including RCTs to assess the effectiveness of reminiscence work as an intervention. Although this type of quantitative research is regarded by many as the "gold standard" with its emphasis on numerical data and on causal analysis, it has long been acknowledged that it may not be the ideal approach for the investigation of the subjective experience of a therapeutic intervention such as reminiscence (Woods 1995; Gibson 2011). One of the difficulties in carrying out research with PwD is that dementia is experienced in different ways by different people. Additionally, reminiscence work is not a uniform approach, it involves different activities, different settings and different people (Gibson 1994).

It is argued that qualitative methods are under-used in clinical research including dementia research and yet they provide an important understanding of the experience of dementia in a way that RCTs are unable to (Gibson, Timlin, Curran and Wattis 2004). This thesis' use of qualitative methods enables PwD and their facilitators to share their experience of taking

part in reminiscence work in a way which can contribute usefully to the general understanding of reminiscence work and PwD.

3.9 Ethical considerations and the PwD taking part in this study

Most large Research Institutes or Research Centres have well developed research codes of conduct which acknowledge the responsibility a researcher has towards all participants taking part in a study (Hart 2008). In this study, some of the specific challenges encountered in carrying out research with PwD had to be considered.

Bond and Corner have argued that research with PwD only highlights the challenges that are inherent in the investigation of any complex social phenomenon and there are no unique methodological challenges when researching dementia (Bond and Corner 2001). Whilst possibly not being unique to the PwD, there are issues which are especially relevant to them. One is the issue of enabling a PwD to take part in the research process. Dewing has commented that PwD are made further vulnerable by being excluded from fields or research, and being looked on as subjects rather than participants (Dewing 2002). A PwD may have an insight into the disease that it would be impossible for people without dementia to have. However, the person may need support in order to communicate and also every effort should be made to ensure the person has a full understanding of what voluntary consent to participate entails.

Looking at the area of communication, although subjective expression may be compromised, it is acknowledged that a PwD can communicate their experiences even into the moderate or late stages of the illness (Slaughter, Cole, Jennings and Reimer 2007; Edelman, Fulton, Kuhn and Chang 2005). When conducting research in this area the possibility of memory, cognitive or communication problems affecting the PwD's ability to fully engage in the research should be acknowledged. Phinney notes that most PwD will still have difficulty in taking part in

interviews and this is reflected in the literature which mostly consists of semi-structured interviews and conversations with people in the early stages of the disease (Phinney 2008).

In this thesis, significant measures were taken to make the interview process as easy as possible for the PwD and to support any verbal /communication problems and empower the individual. This included ensuring the PwD could have as much control of the interview process as possible, including choosing the location and format for the interview. It also included taking the advice of experts such as Gibson, Sabat and Chaudhury about effective communication techniques and building on my own knowledge and experience thus ensuring I spoke in a slow, clear manner, ensured good eye contact was maintained and that the interview was relaxed and unhurried (Gibson 2011; Sabat 2006; Chaudhury 2008). The use of additional communication aids such as Talking Mats, which are textured mats on which picture symbols are placed (Murphy, Gray and Cox 2007) was considered but it was decided they would not necessary. Following the advice of experienced researchers (Hubbard, Downs and Tester 2003; Beuscher, and Grando 2009; Moore and Hollett 2003; Murphy 2002) and a PwD who has published advice to researchers based on his own experiences (McKillop and Wilkinson 2004), care was taken in this study to ensure that the interviews with the PwD were conducted in a supportive manner and time was taken to build rapport with each person. This resulted in interviews which although reasonably short, and sometimes veering off topic, did produce relevant results.

3.9.1 Consent

In undertaking research with PwD, the issue of gaining consent to participate in studies has been dealt with in different ways in different studies (Dewing 2002). Some researchers ensure that consent remains understood and agreed at different times during the process of interviewing PwD (Pratt and Wilkinson 2001). Others only obtain verbal or written consent at the beginning of the research process. McKeown, Clarke and Repper (2006) in their systematic literature review of life story work noted that approaches to ethical issues

appeared to be inconsistent in the studies they reviewed with some research papers (Heliker 1997, Hepburn et al 1997) making little or no reference to ethical considerations, others referring to ethics committees but with few further details (Hansebo & Kihlgren 2000), and only one giving comprehensive details of how ethics approval was sought (Clarke et al 2003). It needs to be remembered however that this review did not pertain to life story research with PwD exclusively.

Dewing has pointed out that much of the debate around consent to participate in research being conducted with PwD has focused on the traditional competency based approaches. However, these approaches may not be suitable for a person with cognitive problems. It is known that even in the early stages of dementia the disease can have a significant impact on a person's decision making ability (Kim, Caine, Currier, Leibovici, Ryan 2001) and the traditional competence-based ethical procedures around obtaining PwD (Dewing 2002;Cowdell 2006).

Ensuring that the PwD understands what the research will entail and had sufficient capacity to take part in the consent process as an equal participant and that the process does not leave him/her feeling undermined in any way was central to this thesis and in keeping with the principles referred to in this thesis consent was therefore discussed and obtained from the PwD and relevant family members before the research took place and on-going consent was ensured. An information leaflet (see Appendix E) was distributed through the staff to the participants and verbal consent was obtained by the facilitators of the facility. All participants therefore had an information leaflet before the field work took place.

The issue of obtaining consent by proxy from the relatives was also carefully considered for those who may have lacked capacity or been unable to consent for themselves. Dewing argues that informed consent via proxies is unsatisfactory in the moral context of person-centred values and relationships, as it means that another person is effectively making decisions for the PwD (Dewing 2002). However, as McKillop and Wilkinson argue, even if consent by proxy is not necessary for a study, consultation with caregivers should take place,

as usually they know the person well and will have to deal with any consequences of the study (McKillop and Wilkinson 2004). It was decided therefore to obtain signed written consent forms (Appendix E) from the relatives of those participants with dementia who had relatives involved in their care and to ensure that those relatives had an information leaflet explaining the study. Most importantly and in keeping with ensuring the PwD was treated in a person-centred and appropriate manner, verbal consent was obtained from all participants with dementia on the day of the fieldwork, using appropriate, easily understood language.

On-going consent was also ensured by checking before each session that the participants were happy to have me there and I also ensured at the beginning of each interview that the PwD was still willing to participate. I also remained alert for signs of the person becoming uncomfortable with continuing the interview, and if this happened the interview was terminated. [6]

3.10 General Ethical considerations

All interview and observational data were rendered as anonymous as possible and participants have only been described in very broad terms and in all cases given pseudonyms. All interview and observational data has been kept in a responsible manner, so that the full details of participants are only available to myself and my supervisor.

3.10.1 Ethical Approval for this study

Formal ethical approval was obtained for this research project from Trinity College Dublin on June 15th 2009 (Appendix F) with no changes required.

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[6] This happened in one case at the respite care centre where the PwD became unsettled in the interview when she realised her son had arrived at the respite care centre and made it known that she wished to end the interview. Although I tried to reassure her that her son would be with her very shortly it was obvious the PwD no longer wished to continue with the interview. I respected her wishes and ended the interview.

3.11 The use of case studies

In his definition of case studies, Swanborn proposed that case studies are the study of a social phenomenon in one, or only a few, of its manifestations, in its natural surroundings, during a certain period, focussing on detailed descriptions, interpretations and explanations that several categories of participants in the system attach to the social process, and which exploit several sources of data (such as informants, documents, observatory notes) (Swanborn 2010). He also proposed three levels of case study. The micro-level, frequently used in the health sciences, psychology and psychotherapy, where there is a strong tradition of using studies based on one person, aimed at the healing of this patient or helping this client. The meso-level, frequently used in disciplines such as sociology, anthropology, history, the administrative and organisational sciences and education, where there is research with an emphasis on detailed description and an understanding and explanation of a social process or phenomenon. Finally the macro-level, frequently used in the political sciences, where research projects try to uncover relationships between causes and effects using large scale patterns studying for example nations and states (Swanborn 2010). Using Swanborn's definition the level of case study in this thesis is at the meso-level.

This thesis uses an ideographic case-study approach, which is recommended for the exploration and development of in-depth descriptions from a single case or shared themes of up to ten cases (Smith et al 1999). In this study the case studies reflect a selection of the different setting and modalities in which reminiscence work can be delivered. There are four case studies in total – a Day care centre, a Nursing Home, a Respite Care setting and an Acute Hospital Setting. The case studies are drawn from both rural and urban settings which is important, as it has been noted that whilst rural communities tend to be ageing communities, most dementia research has been centred on urban communities with little known about the experience of living with dementia in rural areas (Innes et al 2004). In Ireland there are regional differences in prevalence rates of dementia, with the Western counties thought to have the highest share of the population with dementia (O'Shea 2007; Cahill et al 2012In

presenting the findings in this thesis as case studies I have drawn on the work of the two acknowledged authorities in this area, Robert Stake (Stake 1995) and Robert Yin (Yin 2003; 2006). Although their approaches to case studies differ as they use different methods, both are based on a constructionist paradigm where the truth is deemed relative and dependent on perspective and is based on a social construction of reality and there is a close collaboration between the researcher and the participant (Baxter and Jack 2008). This corresponds with the epistemological stance of this thesis which espouses a social constructionist viewpoint. Using Yin's definition, the case studies presented would be considered a combination of (i) exploratory, (as the intervention being evaluated has no clear single set of outcomes), and (ii) descriptive (as the study explores an intervention or phenomenon and the real life context in which it occurs) (Yin 2003). Using Stake's definition the case studies would be considered collective, as more than one case is being examined and each case could be viewed as intrinsic (Stake 1995). An intrinsic case study is where the researcher has a genuine interest in the case itself with no intention to build theory (though that could be an option) or to represent other cases (Stake 1995). Intrinsic research is exemplified by Foote Whyte's seminal 1943 study of the behaviour of a section of an Italian-American community, where he concentrated on the meaning of action for the individual and rather than generalising provided a highly valid account of one case (Foote Whyte 1943;Best 2012). In this research, in each case study there is an emphasis on the particular, with no intention to generalise.

Case studies are a useful way of presenting findings and can facilitate the exploration of a phenomenon within its context using multiple sources of evidence (Robson 2002; Baxter and Jack 2008). One of the benefits noted of presenting findings in this way, is that it can lead to discoveries and insights which can be pursued in subsequent studies (Berg 2009) and that is a possibility with this study. The expectation that the interviews with PwD would yield rich descriptive data and that the latter embedded in social constructionism with a focus on collective interactions rather than on individual stories, lended itself strongly to the use of Case Studies in this thesis.

3.12 The Sampling strategy

In IPA research it is recommended that sampling should purposively be conducted to enable insights to be obtained into particular experiences (Smith et al 2009). It is acknowledged that this will usually occur via referral through gatekeepers, through opportunities as a result of contacts or through snowballing (Smith et al 2009) as was the case in this study. In the section to follow, the research settings chosen i.e. case studies and how exactly the sample of ten PwD, five Facilitators and six family caregivers was recruited to the PhD study will be explained.

3.12.1 The settings

The first task in relation to obtaining a sample was to identify sites for recruiting PwD and the facilitators. An important consideration was to achieve a broad spread of dementia care settings in which reminiscence work took place with groups of people. Whilst in Ireland, most PwD live in the community, I was not interested in one to one reminiscence but rather in that delivered in group settings. Nursing homes, day centres and respite care settings were therefore identified as rather typical dementia care settings where reminiscence work probably takes place. Shortly before the field work for this study was due to take place, I was made aware of an innovative reminiscence project which had commenced and was on-going in a Dublin city hospital. Staff at this hospital had heard about this PhD thesis and expressed interest in being included. For this reason a hospital setting was also recruited. However this group was an exception and volunteered spontaneously and could be looked upon as an opportunity contact (Smith et al 2009).

Although no purposively recruited sample can ever be representative of the overall population some efforts were made to obtain diversity in the sample of care settings as noted above with a deliberate attempts to provide a mixture of rural and urban settings. One care

setting was recruited from a village in a rural part of Ireland more than 250 kilometres from Dublin and another from a small town more than 70 kilometres from Dublin. The other two care settings are based in Dublin and its suburbs. In interpreting results from this thesis, the purposive nature of the sample and the qualitative approach taken must always be kept in mind.

3.12.2 Recruiting a Sample of Services Sites where Reminiscence work is being used

Initially I considered attempting to conduct a survey through the Alzheimer's Society of Ireland (ASI) and Nursing Homes Ireland (NHI) in order to gain a better understanding of where in Ireland reminiscence work is conducted. After some thought this approach was dismissed on the basis that it would take much time, response rates would probably be low and it might yield patchy and incomplete information. After some reflection and discussions with other experts on how best to identify and recruit research sites, I resorted to using internet resources to identify nursing homes, day centres and respite care centres that had mentioned the use of reminiscence on their websites. An initial search identified 49 possible sites, 22 Nursing Homes, 24 Day Centres and three Residential Respite Care settings.

A list of eligible dementia care sites was then drawn up, with the urban/rural spread identified and telephone contact was made with the person in charge in each setting.[7] The initial approach was made by telephone contact, followed by a personal visit to each establishment. During this visit, I met with the person initially contacted together with others involved in the reminiscence work. In the respite care setting I met with the C.E.O., the manager and the facilitator. In the day centre I met with the Nurse Manager who was also the facilitator. In the hospital I met with a consultant, and the two facilitators. During these

[7] This differed from setting to setting due to the different management settings within the different facilities. In the nursing homes the Director of nursing was the person approached. In the respite care setting, the C.E.O of the voluntary organisation responsible for the respite care setting was initially approached. In the day centre the Nurse Manager was approached and in the acute hospital setting the consultant in charge of the reminiscence project which had been operating at the hospital was approached.

meetings it was verbally agreed that the establishments would take part in the research. After these visits, I sent emails thanking each of the establishments for their time and interest. The email was then followed up by a telephone call to arrange the field work visits.

Making direct contact as described above with the respite care setting, the acute hospital setting and the day centre resulted in easy access to each of the settings, all three of which were interested and willing to take part in the research. In hindsight this obtaining of access was relatively straight forward for these settings. It had required just two or three phone calls to identify the appropriate person to liaise with, a later longer phone call with the person concerned to explain the aims and objectives of the study and what would be entailed, a personal visit to the facility, an email afterwards and one or two phone calls to set up dates and times for the fieldwork. The third site – the nursing home setting was a lot more difficult to identify.

Drawing up a list of 22 nursing homes identified from a lengthy internet search, the procedure described above was carried out, with three different consecutive nursing homes. In each case, following the procedure described above a visit took place and I met with the director of nursing who took me on a guided tour of the establishment and discussed the reminiscence work taking place in the nursing home and I was introduced to the facilitators. At the end of the three visits, in each case the director of nursing gave verbal agreement to participate in the research. After this a thank you email was sent as described above. However, at this point, despite the initial apparent enthusiasm from each of the Directors of Nursing, for no apparent reason the three nursing homes subsequently refused to take calls and ignored all subsequent emails leaving me to conclude that they no longer wished to take part in the study.

This raises the issue of gatekeeping and the extent to which Nursing Homes restrict access to research being conducted in such facilities and the reasons behind this. It is acknowledged that there can be difficulties in gaining access to PwD because the "gatekeepers" at the care

environment in which they live, are over-protective and refuse access to researchers.[8] Gatekeeping may be done for a variety of reasons, some possibly well-intentioned such as their concern that the research might disrupt residents daily life. Gatekeeping might also occur because of the time pressures and staff shortages which are sometimes found in nursing homes and which are known to make the recruitment of participants in dementia research particularly difficult (Wilcock et al 2006). However, gatekeeping does highlight the issue that in these facilities approached, the decision about whether or not to take part in research was effectively removed from the PwD, that person who, within a truly person centred environment, should be making the decision. It also raises questions about how representative some dementia research is, if gatekeepers are effectively cherry picking research participants.

Finally after the three failed attempts to recruit a nursing home to the study as described, contact was made (through referral by another research student, with personal connections with the management at the nursing home) with a fourth nursing home and following the general procedure described above, agreement to participate in the research was obtained. A detailed description of each setting is given in Appendix H.

3.12.3 Research Participants

3.12.3.1 The PwD

In IPA research, the aim is to select participants who can grant access to a particular perspective on a particular phenomenon (Smith et al 2009). A small sample somewhere between three to six participants is permissible as the idea is to acquire rich narratives about subjective experiences (Smith et al 2009). For this reason, it was decided to interview three PwD and their facilitators in each of the four settings studied. This decision to use small, purposively selected samples is a typical feature of IPA and is in keeping with the IPA

[8] This issue is acknowledged in the ethical guidelines issued by the Social Research Association (SRA2003).

emphasis on a detailed examination of the particular. Indeed IPA can be carried out using data from just one person and for student researchers between three and six participants is normally advised (Smith et al 2009).

In this study, I decided to recruit a total of three PwD in each setting to allow for possible drop outs. This proved fortuitous as in two of the settings, potential interviewees having agreed in advance to participate declined the interview on the day[9]. In keeping with good ethical practice, I accepted their decisions as possibly indicating a withdrawal of consent for the interview.

3.12.3.2 Inclusion criteria

These criteria were that (i) the person must have a diagnosis of mild or moderate dementia, (ii) be an active participant in reminiscence work and (iii) and be assessed by reminiscence staff as being able to communicate verbally.

In summary therefore a total of ten PwD were interviewed, three from the respite care setting, three from the nursing home, two from the acute hospital setting and two from the day centre. The facilitators at each site were also interviewed. This resulted in a total of five facilitators being interviewed as at the hospital two different allied health therapists had joint responsibility for the Reminiscence work and alternated weekly.

3.12.3.3 Sample of Family Caregivers

After these site visits had taken place and interviews conducted, I requested contact details from the Manager/Nurse Manager/Director of Nursing/Facilitators of the facilities of any relative of the PwD who would be willing to be interviewed for the purpose of this research. Family caregiver interviews were not deemed central to the study, as none of the relatives

[9] In one case the PwD felt unwell on the day and in the other case the person attending Day Care preferred to go home rather than stay back and be interviewed.

were themselves taking part in reminiscence and therefore from the point of view of IPA research they could not be counted as experts. The purpose of the interviews with relatives was to add contextual information. I believe that the fact that not every PwD interviewed had a family member able to contribute was not detrimental to the study since the main focus in this study is on the PwD and the facilitator, not on the family caregiver. To have purposively excluded a PwD due to the absence of a family member would suggest that the opinion of the PwD alone was not enough. As stated the opinion of the PwD together with the opinion of the facilitators, and not that of family members, is central to this thesis.

Not all PwD had relatives willing or able to be interviewed. Indeed the facilitators at the acute hospital refused access to Family members as they considered this quite inappropriate. In total and based on this approach six family members (one grand-daughter, two sons, two daughters and one step-daughter) were interviewed. Three from the respite care setting, one from the nursing home and two from the day centre.

This total sample of 21 people therefore provided insights from a position of shared expertise; in this case each person was either a PwD or a facilitator taking part in reminiscence work in a care setting in Ireland, or a family member which again is a typical IPA feature. A short pen picture of each of the PwD and the facilitators is given in Appendix D.

3.12.4 Starting the fieldwork

As described earlier, the fieldwork followed the following format. An initial phone call was made to ascertain who was the person or persons responsible for reminiscence work taking place in the facility. An initial visit took place where I met with the person described above, together with others directly involved in the Reminiscence work (the facilitators and the in the case of the Respite Setting, the Manager). During this visit I introduced myself, explained my background and the aims and objectives of the proposed study and the type of questions

that would be asked of both PwD and of the Facilitators. I also used this visit to familiarise myself with the environment and to seek permission for the research to take place with the person identified as holding responsibility for the Reminiscence work (the C.E.O/Nurse Manager/Consultant/Director of Nursing). The ethics of conducting qualitative research of this nature was also discussed at this time and assistance sought in distributing information leaflets about the research and consent forms (see Appendix E). The person identified as responsible for the reminiscence work in each setting (the Director of Nursing, Manager, Nurse Manager, Consultant) together with the facilitators were asked to approach three PwD who satisfied these inclusion criteria, explaining to them the aims and objectives of the study and seek their consent about study participation. After the initial visit, two further site visits took place.

3.12.5 Interview Schedules

Semi-structured interview schedules for the PwD, facilitators and family members were devised and piloted (see Appendix G) with small adjustments being made to the original schedules after the pilot study.

3.12.6 Data Collection Visits

At the first of the two visits (arranged by phone with the facilitators at a time convenient to them, usually within a month of the initial visit) I observed for the first time the reminiscence group in action. Reminiscence work sessions lasted between 45 and 60 minutes and these notes were later typed. The notes included observation on/of:

- the physical environment, including room layout, decor, light, noise
- interactions during the session between PwD, and between PwD and the facilitator
- non-verbal communication expressed by the PwD such as tapping feet, clapping hands, smiling, frowning, shaking head, staring into the distance

- interruptions to session some verbatim notes of verbal utterances during the session made by PwD and facilitator
- notes on format of the sessions prompts and summaries of conversation threads

This visit allowed me to become familiar with the format of the reminiscence group and meet the participants. At the end of this session, a second visit was arranged, usually within four weeks of the first visit.

At the second visit the reminiscence group was observed in action for a second time, again with observation notes being taken as described above. It was immediately after this second session that the participant's interviews took place. These interviews were recorded and transcribed at a later date. The interviews explored how the PwD felt about taking part in the sessions, whether there was any aspect in particular they liked or disliked, whether they would prefer to be doing something else, and how much choice they felt they had in attending the sessions. The interview schedule was flexible and the questions were adapted for each participant. The interviews tended to last between twenty to thirty minutes, though some time was spent in general conversation before and after the interview.

Immediately following these interviews the facilitator was interviewed. The same approach was used at each of the care settings with the exception of the acute hospital, where two facilitators had joint responsibilities for reminiscence work. In this setting I returned on a third occasion to collect data from the second facilitator.

3.12.7 Data Collection Tools

Hart reminds us that research data collected can be whatever is deemed necessary to address the research questions in a thesis and no particular type of data is naturally better than others though some types of data may fit better with an individual thesis (Hart 2008). Data collection can be influenced by the philosophical orientation of the thesis, the research design

and what is available to the researcher. As the primary aim of this thesis was to explore the experience of taking part in reminiscence from the joint perspectives of PwD and facilitators, the most obvious way to do this was to collect information from the people themselves by asking them directly the appropriate questions. The use of interviews also fits well within the phenomenological tradition as interviews are regarded as the primary data collection tool in phenomenological research, as they enable respondents to describe their experiences in their own words (Holloway 2005). IPA research requires rich data with participants encouraged to tell their story speaking freely and reflectively and in depth interviews are thought to be one of the best ways of accessing this data (Smith et al 2009). In recognition of the memory, cognitive and communication problems which can sometimes affect PwD, it was decided to include observation as another source of data. Observation is an accepted stable of methods textbooks (Clark 2007) and has been described as a fundamental base of all research methods in the social and behavioural sciences (Adler and Adler 1994; Clark 2007). Observation is also thought to be particularly useful in phenomenological research and in situations where interviews are either inappropriate or difficult to conduct (Langdridge 2007).

3.12.8 Interviews

As noted earlier, interviews are regarded as the primary data collection tool in most types of phenomenological research (Holloway 2005). Innes notes that interviews are becoming increasingly popular in dementia research (Innes 2009). Semi-structured interviews are recommended in IPA research with a schedule which can does not restrict the participants (Smith et al 2009) and which can be used to guide the interview. In this study a semi-structured interview approach and a schedule was used as a general guide (see Appendix G). The schedule had been tested in a small pilot project, which was undertaken in the acute hospital setting with a reminiscence group who did not take part in the main study. Some questions were added to the schedule after the pilot project and after further study of similar

projects. For example a question asking if the PwD would recommend taking part in reminiscence work to a new person attending the facility was asked as a different way of finding out what the PwD really thought of the sessions. However, I found that whilst following the general schedules, in each interview many questions needed to be adjusted for individuals and worded in different ways in order to be understood.

Most PwD will have some difficulties taking part in interviews which is reflected in the literature which mostly consists of semi-structured interviews and conversations with people in the early stages of the disease (Phinney 2008). Other considerations in relation to interviewing PwD include, the likelihood of these people tiring easily, losing concentration, getting easily distracted, having word finding difficulties and being unable to comprehend simply constructed questions. All of these issues were taken into consideration in designing the interview schedule and in reflecting on topics for discussion.

3.12.9 Observation

Observational methods are used in quantitative and qualitative research and can range from using standardised observational schedules to using completely unstructured observation. In dementia care research, several observational tools have recently been developed. These include Dementia Care Mapping (DCM)[10], to assess quality of care from the perspective of the PwD and the Lawton scale another observational tool that involves trained observers noting the facial expression, body movements and other cues of PwD (Lawton, Van Haitsma and Klapper 1996).

Observation is not only useful as a tool when researching with PwD but also in general as a useful aspect of observation is that it allows interactions to be seen as they unfold not filtered through other people's perceptions of what is happening (Darlington and Scott 2002). This

[10] Developed by the late Tom Kitwood and Kathleen Bredin this is an observational tool which looks at the care of the PwD from the viewpoint of the PwD, feeding it back to staff in order to create a person centred environment

would be useful for example if a person's observed actions differed noticeably from what they reported during an interview, which could apply to PwD or facilitators.

Observational techniques have been critiqued on the basis of researcher bias. As Clark points out when discussing observation methods for Gerontology, validity in observation is not a given but depends on the interaction between the observer and the observed and the filtering process used to determine what should be included and what should be left out of an observation (Clark 2007). Additionally, researchers also interpret what is observed and Clark notes there is a difficulty in distinguishing between what we believe we see, want to see, expect to see or hope to see (Clark 2007). This is illustrated by Johnson in her re-examination of two observational studies she carried out[11]. 'There are also limits to what the researcher, especially a sole researcher, can physically observe. For example, in a busy environment if a researcher is focussing on a particular interaction he or she may miss out on a different, equally important one in a different part of the room.

It is recommended that researchers employ safeguards to counter these criticisms, such as combining observation with other methods (Clark 2007) and ensuring the context in which the study is taking part is understood, for example through gaining familiarity with the setting, in order to avoid misinterpretation (Darlington and Scott 2002).

Some researchers try to achieve validity by using replicable schedules which make researcher bias less likely. However, it has been argued that observations using systematic measures have limited usefulness in dementia research because they do not fully reflect the experience of the PwD, because of their reliance on using predefined categories (Cook 2002). Indeed, Johnson noted of her observations using structured schedules that the structured

[11] She noted that on one occasion she described how a resident said something and everyone ignored her. She could have used the phrase "nobody heard her" to describe the same event. By observing alone, she did not know for certain, whether the person was being actively ignored by some or all, or whether she had simply not been heard.

nature of the schedules had placed considerable limits on the descriptive data (Johnson 2007).[12]

In this study the decision was not to use structured schedules and forego the validity that they might impart, for the rich, descriptive detail which could emerge from less structured observation. Additional safeguards as discussed earlier were included. The study combined observation with interview, and I had visited each study site prior to carrying out observations. Additionally I had many years' experience of working in dementia care environments and had a good general understanding of these.

As noted earlier, the observations made in this study includes notes on the physical environment, time of day, the participants including those with dementia and the facilitators and physical prompts used. A selection of verbal and non-verbal interactions such as nodding, shaking heads and making eye contact were also been noted. As recommended in the literature brief notes were recorded during the observation with a full write up as soon as possible afterwards (Lofland and Lofland 1995).

3.13 Data analysis

All data emerging from the interviews, together with observation notes has been thematically analysed using IPA and the dominant themes which have emerged are discussed in the findings chapters.

IPA research is characterised by a set of common purposes such as moving from the particular to the shared and moving from the descriptive to the interpretative and a set of common principles. Analysis can be described as an iterative and inductive cycle which uses strategies such as a close line by line analysis of each participant's account, the identification of emergent themes, the emergence of a dialogue between the researcher, the data, and the

[12] However, by choosing the words she did to describe what had happened she encouraged a particular interpretation (Johnson 2007).

researcher's experience to form an interpretative account, and the development of a structure to illustrate the relationship between themes (Smith et al 2009). Data analysis followed the Smith et al guidelines (Smith et al 2009). This involved an initial immersion in the data, including reading and re-reading the transcripts for each account and becoming completely familiar with what each person said and how they reacted. Following this an initial level of analysis took place where anything which seemed to relate to the experience of taking part in reminiscence work was noted, in what was almost a free textual analysis resulting in a comprehensive set of notes and comments on the data. This was followed by development of emergent themes. Usually this would be done on a case by case basis, so each participant's account would be analysed individually, and individual themes identified. However Smith et al recommend when working with larger groups (more than six participants, which is the case in this study), it may be better to assess the key emergent themes for the whole group. In this thesis each case was read through individually, and individual themes identified. These individual themes were then brought together and meta-themes were decided on at a group level so the same meta themes were used across the whole group. Within each case the themes were illustrated with quotes from individual participants. The themes reflected the participants' original words as well as my interpretation (Smith et al 2009). A worked example of this analysis is given in Appendix K.

3.14 My role as a researcher in this study

It is important to acknowledge my role as a researcher and any difference it could have made to the study. One aspect which could have particular relevance is that whilst I spent my early childhood in Ireland, I was born elsewhere and have lived most of my life in England, which is reflected in my accent and there is some research which suggests that this can create an effect where the researcher is treated as an outsider (Randall, Prior and Skarborn 2006) which can affect the outcome of the interview. In this thesis, although the question of where I came from did arise in the interviews, which I answered, it did not appear to adversely affect the

interview process. In fact some participants appeared to try to make a personal connection, one by talking about having been married to an English man, one by talking about having worked in England and two by asking questions about England. The participant's general demeanour was friendly and interestingly the only time I felt I was treated as an outsider, was when a staff member (not the facilitator) brought tea into the interview room in the day centre and I was questioned rather aggressively on where I came from and why I was there. It was interesting that on that occasion, the PwD actually intervened in this conversation, making jokes but establishing my right to be there and in the field notes I noted at the time that the participant had seemed to act almost in a protective manner and had actually shown in her handling of the situation that as Kitwood has pointed out a PwD can often retain and use their social skills well into the course of the disease (Kitwood 1997).

I felt that in general I had enough of a connection with Ireland through family history, cultural knowledge and knowledge of the language to establish enough of a connection to ensure my outsider status was not problematic. I understood the significance of subjects which participants spoke of such as "The Black and Tans", "The Orange Parades" and "Religious confraternities" and recognised Irish hymns, songs and poems. It is also important to remember that I could have been considered an outsider in other ways too, in that I was not a member of the reminiscence group, was not attending or working at the daycentre/respite care centre or in the nursing home or hospital and I did not have dementia.

3.15 Chapter Summary

This thesis explores the experience of taking part in reminiscence work for PwD and the facilitators who deliver the intervention. It focuses on four care environments which are typical of the settings in which reminiscence is delivered in Ireland– day care, respite care, acute hospital care and nursing home care. Interviews, using semi-structured interview schedules, were carried out with PwD taking part in reminiscence sessions and the facilitators carrying out the sessions. Additional contextual information was also gathered from those family members who were able and available to give information. In addition two

observations were carried out in each setting. The data from the resulting interviews together with the data from the observations was analysed using an IPA approach. The findings from this data will be discussed in the next two chapters.

4 The Experiences of PwD and their Caregivers who participate in Reminiscence at Two Respite Settings

4.1 Introduction

In this chapter, findings from the first two case studies conducted in two different respite care settings - (i) a dementia-specific day centre and (ii) a residential respite care centre are presented.[13]. These findings are based on data collected from two observations carried out in each setting together with data collected during in-depth interviews with PwD (two in the day centre, three in the residential respite care), facilitators (one in each setting)and family caregivers (two from the day centre, three from the residential respite care).

The chapter opens with an introduction to the meta-themes. A brief pen picture of the setting and the participants then follows. A fuller description is given in Appendix H (the settings) and Appendix D (the participants) and Appendix J (facilitator training and background). The findings from the day centre are then presented, followed by the findings from the respite care centre. These findings detail the participant's accounts of their experiences of reminiscence in this setting, and as detailed in the methodology chapter, care has been taken to ensure the voice of the PwD is heard, a voice which is sometimes lacking in dementia care research.

4.1.1 Meta theme Connecting

Dementia can significantly isolate people either by virtue of their withdrawing from their own social networks and society or the reverse the public, friends, neighbours and friends withdrawing from them (Nolan, McCarron, McCallion and Murphy-Lawless 2006). Nolan and colleagues found that many PwD in Ireland complained of experiencing social isolation due to withdrawal of friends, exclusion from community life and the existence of barriers to social participation (Nolan 2006). Families can feel as if they are losing the person they know and

[13] These two settings have been grouped together as in each setting the PwD is still living in the community and is only making temporary use of the facility concerned

love to the disease and this is evident in media reports where it is often claimed that a person has been "lost" to dementia. Snyder reminds us that living with dementia often unravels many of the well-worn and familiar patterns of relationships (Snyder 2002) and this is bound to impact on relationships. Cognitive losses and problems with communication can add to relationship problems and cause further isolation.

Additionally the PwD may find he or she is living or having to spend time in an environment, not necessarily of his/her choice with strangers whom they have to interact with on a regular basis. At a time when it might prove useful to be able to forge new relationships, the PwD may experience problems doing this because of cognitive losses and communication problems. The data emerging from this research indicated that reminiscence work had a role in helping the PwD connect with others such as care staff and family members by improving and enhancing communication and by enabling others to view the PwD more holistically. The sub-themes within this meta-theme are communication and engagement with others, connecting with the family and wider community and seeing the whole person.

4.1.2 Meta theme Re-connecting

In their exploratory study into the perceptions of stigma in dementia in Ireland, the researchers noted that life as it was before dementia diagnosis is different from that after diagnosis and continues to change as the disease progresses (Nolan et al 2006). It is not unusual for PwD to experience negative feelings including fear and sadness, loss of confidence , loss of agency and reduced self-esteem (Phinney 2008), often because their sense of personhood has been undermined (Kitwood 1997). Dementia is usually associated with multiple losses including a loss of identity or self-worth (Sabat 1992) and it has been argued that the vulnerability associated with that loss of identity points to the need for a connection with that which is familiar and personal for that person (Chaudhury 2002). Research has demonstrated how reminiscence work can be used to reinforce identity, promote feelings of self-worth and encourage maintenance of self (Coleman 1986; Gibson

1998; Surr 2006). It has been argued that reminiscence in dementia care highlights people's strengths (Thorgrimsen et al 2002) and that by showing a genuine interest in people through reminiscence, a person's sense of identity and self-worth will be reinforced (Gibson 1998). The findings when analysed indicated that reminiscence work had a role in helping the PwD re-connect with their inner self and the person they were before developing dementia and overcome some of the challenges associated with dementia, even if only for a short time. The sub-themes within this meta theme are enjoyment, agency and choice and identity and self-worth.

4.1.3 Meta Theme Supporting the Reminiscence Experience

There are many factors which can affect the reminiscence experience. In order to maximise the reminiscence experience the facilitator may need to consider issues such as the emotional support the PwD may need, the effects of the environment, communication aids and whether prompts are wanted or needed. The findings when analysed indicated that facilitators had an important role to play in supporting the reminiscence experience and the sub-themes within this meta-theme are dealing with sad and traumatic memories, creating a safe place and factors which encouraged or hindered reminiscence.

4.2 The Day Centre - Introduction to the Setting and Participants

Set in a small town more than 70 kilometres from Dublin, this day centre was situated on a quiet road, near the local hospital. It was a purpose built bungalow with an attractive garden outside with garden seats and tables which could be used when weather permitted. Inside the day centre, there were a number of rooms including offices, bathrooms, a kitchen area and one large communal area where activities normally took place. The communal area was furnished with sofas, chairs and tables and care had been taken to give the room a homely and inviting atmosphere. There were knitted throws over sofas, scented candles and art

work on the walls. The room had a screen which could divide it so that more than one activity could take place at the same time. In the smaller screened off area where one of the reminiscence sessions took place there was a fireplace with a mirror above, chairs arranged in a semi-circle and a piano at the back of the room. A standard light was used to light the area and there was also natural light from a glass door which led to outside. The lighting and décor meant the small area resembled a parlour or small sitting room.

There were two participants with dementia interviewed in this setting. Helen was 79 years old. She was widowed, had a large family and liked cooking and baking for them. She had worked in a large warehouse and had been a singer in a band. Geraldine was 81 years old. She too was a widow and had suffered depression after her bereavement. She used to work in a textiles factory. Geraldine liked talking about old times and listening to music. The facilitator at this setting was Mary, a nurse/manager.

Based on Gibson's definition of the different types of reminiscence work in existence, the reminiscence carried out at this Day Care Centre could be classified as simple or general. This type of reminiscence work according to Gibson is usually carried out in a group and uses open-ended questions or readily available multi-sensory triggers to stimulate recall on topics likely to be of interest to participants. It is unlikely to stimulate painful or long buried memories. Its general aim is to achieve sociable, educational or recreational objectives (Gibson 2011).

At the two sessions observed at this dementia specific Day Care Centre, different prompts were used to stimulate reminiscence. At the first, open-ended questions were used (general conversation) and at the second, a computer programme Facebook with downloaded photographs was used. At this Day Care Centre, volunteers were also employed to help out and the same facilitator was employed to conduct the reminiscence at both sessions observed.

4.2.1 The Day Centre Findings

At this day centre, four PwD were observed at the first session and three PwD at the second session. The two PwD interviewed had attended both sessions. The findings are presented using the themes established.

4.2.1.1 Connecting – communication and engagement with others

The observational data yielded many examples of good communication, engagement and interaction. Both of the reminiscence sessions observed at the Day Centre were documented as lively reflected by the frequency and vibrancy of conversation heard. All of the four participants observed at phase one and three of these same respite clients observed at phase two were documented as being animated on several different occasions. It was noted during the observations that conversation seemed to flow easily, and on several occasions, participants conversed with each other while the facilitator was talking to someone else.

Based on the in-depth interviews with two of the participants with dementia, and the observations of both reminiscence sessions, the findings showed how individuals valued interactions with the facilitator Mary and one to one communication between each other seemed to evolve naturally:

"At one stage, Helen talked direct to the facilitator, whilst Iris and Geraldine talked to each other" (observation 1 day centre).

Non-verbal communication was also noted, for example facial and body gestures. In one particular case during the second reminiscence session, one of the participants Iris was noticed thumping a table in frustration:

"At one point, Iris became very animated. She seemed to recognise a shop in one of the photographs and was pointing to the screen and trying to name it, however she couldn't remember the name and showed some frustration by banging the table twice with her fist" (observation 2, day centre).

Likewise other non-verbal communication such as nodding and gesticulating were also noted:

"At this point all are engaged, there is good eye contact between all participants with much non-verbal communication. Iris points to emphasise something, Geraldine nods in agreement" (observation 2, day centre)

The facilitator Mary appeared aware that engagement and communication were not restricted to verbal communication:

"and as I said some people who you would think would not be clued in, you could find them, completely engaged, maybe not verbally taking part but completely engaged in listening and smiling, so you know it's triggering something" (facilitator interview, day centre).

Mary was also aware of the importance of engagement and interaction in building and maintaining relationships between participants:

"so they interact with each other, it is another bonding, it's another way of building relationships with the other people in the group....so they feel a sense of belonging again and a sense of camaraderie, whereby this illness can leave you standing outside completely unsure and desperately afraid, reminiscence most times will bring them in and cause a sense of bonding" (facilitator interview, day centre).

Mary noted that engagement appeared to help overcome some of the fear and uncertainty often experienced by PwD:

"you could see that ah, they were very engaged, there was no fear, there was no uncertainty....you know, ahm, whereby in some instances you can have the uncertainty and the fear particularly around current everyday things that's going on at the minute (facilitator interview, day centre).

Mary's reference to fear in this interview appeared to be general rather than specific. It most likely referred to the fear and uncertainty that many PwD experience trying to deal with memory loss and cognitive deficits daily. In the interview with Mary she reported that reminiscence could help a group that were failing to connect with each other. She provided an example of a reminiscence group she had once facilitated which included one man who apparently had until then failed to integrate with the group and was regarded rather negatively by the others. During reminiscence sessions she stated that he contributed information to the group, sharing recollections about his work for a local family who were quite well known to the group. These recollections were received favourably by others in the group who became more accepting of him. In this example Mary acknowledged that this incident suggested that taking part in reminiscence could help change people's view of a PwD within a group, by showing that they had something interesting to contribute.

4.2.1.2 Connecting – with the family and wider community

There was some evidence, albeit limited that reminiscence helped to connect the PwD to his or her family or wider community in the data collected. As mentioned earlier (for a full description see Appendix H) volunteers worked at this Day Care Centre (one was observed assisting at the second session). In the second session observed the volunteer provided assistance with computers and also provided additional information and anecdotes which added depth and interest to the session. Mary felt there was a role for volunteers in Reminiscence work at the day centre:

"but with reminiscence, (laughs), ahm, I do think reminiscence is best when it comes from within the local area, whereby I also think ahm, ICA, ahm, active retirement clubs, ahm, Macra Na Feirme, there's a role for them to play...in, in, in volunteering and helping out or training in ahm a reminiscence session" (facilitator interview, day centre)

And she implied that the main contribution of volunteers would be common or shared local memory:

"there is a huge, because again common memory...and it really is all about common memory...ahm, you know, ah so that's where,...that's where it generally works" (facilitator interview, day centre).

However, this assumes that all volunteers are from the local area, which may not be the case and also links in with views Mary had expressed, that staff from outside of the local area and unfamiliar with the local area may not be suitable for Reminiscence work (as opposed to other types of care work):

"but in the one area of reminiscence, having ahm, staff who are familiar with the history of the country and the area makes a huge difference..... now I know it's not going to always be possible, it's something we have to be aware of..and not expect someone with this illness to take on another challenge...which is somebody of ahm a different ethnic background maybe, now that can be Eastern European, that can be American, that can be Swedish, I'm not, you know...we have a XXXX (Western European Nationality)...and it's difficult for her" (facilitator interview, day centre)

Mary herself was from outside the area. She said she had learned about the local area over the years, and it is probable others could too, but this highlights the importance Mary placed on local knowledge and raises questions about what exactly Mary considered to be local community and whether she had valid reasons for believing reminiscence could only be carried out by people with a shared history.

Mary also mentioned that Health and Social Care students undertook placements at the Day Care Centre. She reported that sitting in on Reminiscence work sessions was beneficial for them as it helped them see the whole person and appreciate the PwD for who they are:

"...in sitting in with them, ahm, I think for our students that we have coming through here, the most important this is it puts a value on the person that's taking part in the

Reminiscence...but, it is an awareness and appreciation of who these people are and what they've gone through, ahm so it's a learning experience for anybody sitting in and listening" (facilitator interview, day centre).

Another interesting and novel way in which Mary enabled the PwD to connect with the wider community through reminiscence was in her use of outings away from the centre with themed days out as a prompt for Reminiscence. She described one visit to Dublin when she took a small group on an outing which had turned out to be very successful in prompting reminiscence since older parts of Dublin were visited and areas identified for discussion such as Nelson's Pillar and the Clerys' clock:

"...and the bus driver decided that he would take us on a tour of old Dublin. So we went to where Nelson's Pillar was, and one lady had had her wedding reception in The Gresham and she climbed Nelson's Pillar on her honeymoon. And she paid whatever money it was...so we came out and slowly down O'Connell Street and where was Nelson, Nelson's Pillar, the clock at Clerys...where everybody met" (facilitator interview, day centre).

Mary was sometimes able to individualise these visits, which links in with person-centred care and the salience of knowing client's life stories, she talked about an occasion when she arranged a visit to the Guarda Museum for a client whose father had been a Guard, commenting:

"that brought back huge memories to her, you know, and was very important to her and her friends" (facilitator interview, day centre).

Mary valued being able to carry out themed visits with personal significance for individuals, noting that although they were organised primarily for the benefit of an individual, all the clients enjoyed the actual day out. She gave an example of a man who had taken part in a group trip out to the birthplace of a local poet. This visit was not specifically intended to be linked to reminiscence but it turned out that the man had been born about two miles away

from where the poet was born, and for him it become a very personal visit. Mary observed that the man had really benefited from the trip, noting:

"and he was a different man for that 45 minutes whilst we were listening to the story, we were looking at the poems and we were in the museum" (facilitator interview, day centre)

Subsequently, she had decided that another trip out to the poet's birthplace would be organised, this time with a tour of the local area and the services of a guide, primarily for the benefit of the man, although the other clients would enjoy it too.

Mary claimed that outings for the purpose of Reminiscence were not an activity that could be done often. This may have been because of cost as later in the interview she acknowledged that she would like to do more of this type of themed outing if she had an unlimited budget.

Further analysis of data showed that there was limited family involvement in the reminiscence work in this setting despite the fact that Mary spoke of the importance of building up and establishing relationships with the families of clients. For example in-depth interviews with two family caregivers, a son and a daughter revealed that whilst these two family members had high regard for the day centre and were grateful that their family member was able to avail of the service, both had little knowledge about the reminiscence sessions and were not afforded any real opportunity to contribute directly to the sessions.

The daughter caregiver said she was aware that reminiscence sessions took place and had some knowledge about what happened during the sessions. The facilitator had told her that during the sessions the group spoke about olden times and explained that this could make the PwD feel more comfortable. However she failed to get any direct feedback from her mother or from staff about what went on during the sessions. Sometimes her mother would talk about a person or a place on returning from the session and she would guess that this had been mentioned in a session. However, generally her mother said very little about what went on at the centre.

This daughter caregiver appeared to have some idea of the benefits of using reminiscence informally, as she described how at times, when her mother was struggling with holding a conversation, she would "slip into the past" and talk about people known to her and things she was comfortable with, to make her mother feel more comfortable and this seemed to work. However in response to several questions asked, this daughter caregiver could not identify any immediate benefits to her mother taking part in reminiscence sessions at the day centre.

She also stated that the family had not been asked to contribute directly to the reminiscence sessions, either by supplying information or items to prompt reminiscence. She said that when her mother first started attending the centre, she had been asked to supply detailed information about her mother's background, along with other family members. It is normal practice in many facilities to gather information on admission or soon after.

Gibson argues that the records held by many care facilities can be somewhat perfunctory often focusing on what people can or cannot do (Gibson 2011). At the Day Care Centre the facilitator Mary had confirmed that life history was gathered on admission but this was as a place to start from with more information gathered from families and friends as relationships strengthened, which is a more appropriate way to gather information for Reminiscence work. Mary emphasised the importance of relationships between the staff and clients and their families built over time and the importance of the knowledge gained from these relationships:

"...because the more knowledge we have about a person the better it is for us to fill in the gaps. Or to trigger a conversation. Or maybe an area not to go to" (facilitator interview, day centre)

The interview with the son caregiver revealed that he had some knowledge of activities in general at the day centre having once attended an explanatory session at the centre, but interestingly he had never heard of reminiscence and did not know what it involved. He

reported that his mother never talked about what she did at the day centre. He knew she did some activities at the centre that she would not normally do at home, activities which she may have done in the past, and she sometimes brought home craft items that she had made.

Again, like the other family member interviewed, this son caregiver recognized some of the benefits of informal reminiscence, as he said he could certainly understand how talking about the past might be enjoyable for his mother, having witnessed the benefits of talking about the past to her himself. He recalled how sometimes he would be with her and start talking about his work or present day issues and she would seem to switch off. However if he started talking about things to do with her past she would join in and chat. He could therefore see the potential of reminiscence as an activity but had not been informed by staff at the Day Centre about how it was used there and indeed whether it should be used at home. In common with the other daughter caregiver, he had not been asked to provide any photographs or information specifically for reminiscence, and had only supplied general background information on admission.

These findings show that although to a certain extent reminiscence did help the PwD to connect with others in this setting, a lot more could have been done to involve family members in reminiscence either by way of their bringing in memorabilia from home or contributing information.

4.2.1.3 Connecting – Seeing the whole person

Mary believed that reminiscence had a role in enabling people to see the whole person, not just the disease.

"they're not a disease, they're not an abstract, this is an individual and they have so much knowledge" (facilitator interview, day centre).

It could also be argued that reminiscence enabled Mary to get to know and understand her clients with dementia better and therefore communicate with them in a more meaningful

way. She reported that through reminiscence she had acquired more in-depth knowledge about the PwD she was working with.

Chaudhury in his work on reminiscence and past places noted that a PwD can recover their individuality through reminiscence and shine through as a unique and interesting individual for the facilitator (Chaudhury 2002) and this seemed to be the case in Mary's reminiscence work. This was evidenced in her comments as reported in the interview data regarding the day trip to the museum of particular significance to one client because he had been born nearby, when she noted that for the period of the visit the man had become a different, more positive person.

Mary saw the gaining of information about these peoples' personal lives along with the increase in knowledge about the local area as an aid to connecting to the PwD in her care.

4.2.1.4 Re-connecting - Enjoyment

As noted in the literature reminiscence can be fun (Haight and Webster 1995) and it is widely acknowledged that reminiscence as an activity can be very enjoyable (Gibson 2011; Woods et al 2005). Evidence of enjoyment, fun and indicators of well-being, were noted during the two sets of observations and following analysis of the data collected in the in-depth interviews.

In the course of the first observation, and during verbal exchanges between each of the participants it was apparent that all participants were enjoying the joking and camaraderie provoked by one of the participants Helen's disclosure that she had sung in a band when younger:

"the facilitator then asked Helen if it was true that she had sung in a band. Helen very proudly confirmed she had, much to the apparent shock and delight of the other ladies. There was much joking while Helen talked about how much she had earned and what nights she had played" (observation 1, day centre)

Humour as reflected in joking and laughing was noted on several other occasions between the participants during the observations. Participants were also asked directly during the in-depth interviews if they had enjoyed taking part in the reminiscence sessions and the responses were unequivocally positive:

"yeah, I, love looking, looking back on behaviours" (interview with Geraldine, day centre)

Later during her interview the facilitator Mary made the point that reminiscence sessions usually ended happily noting:

" ...it usually ends with a laugh...or a, a smile....ahm, and the day is good" (facilitator interview, day centre)

Overall the participants were positive about the reminiscence sessions, referring to the session which had just been observed as ***"yeah, it was lovely.....it was just lovely" (interview with Geraldine, day centre)*** and specifically identifying the fact that talking with others was particularly enjoyable.

4.2.1.5 Re-connecting – Agency and Choice

The facilitator at this Day Care Centre seemed aware of the need to promote autonomy and enable the PwD to exercise choice, as during the in-depth interview she emphasised the rights PwD had to make a decision about attending day centre in the first place:

"ahm, we, it's usually a contract we make between ourselves and the client, ahm, that if they really don't want to be here and they don't settle, then it's their choice, so it's very much in their hands, in their control from day one. And sometimes that might not suit the family, but at the end of the day this isn't a containment service. Ahm, so if it really is something they don't want to be part of, that is their choice..." (facilitator interview, day centre)

Mary's comments allude to the dilemmas which sometimes arise between the needs and rights or PwD versus those of their family caregivers. Her comments appear to show that in this Day Care Centre, the needs of the PwD were considered paramount.

Interview data show that during the reminiscence sessions, Mary made important decisions about how and when activities and reminiscence would take place. For example she reported that she decided what type of activities to do, depending on the people in attendance and on the mood of the day:

"on that morning, we would decide on the mood of the room, as very important, because ah, you know you can have as many pre-planned things as you want, but if they are not in the humour there is no point in wasting time...so it's see what the mood is like, what the atmosphere is like and what the group dynamics are like" (facilitator interview, day centre).

Mary was aware that reminiscence was not suited to everyone, and that it was important to have good knowledge of the person's biography and life story:

"***you need to know the people you're dealing with" (facilitator interview, day centre)***

She believed that PwD had choice within the sessions and could influence the way a session developed.

"and often times they take control of it and it, so you're basically just facilitating it...you're putting a question out and they and, and , and it, it takes a life of its own" (facilitator interview day centre).

During reminiscence sessions, it was noted that the PwD could exercise some choice and that clients were afforded opportunities to influence the direction of a session. They were for example able to influence the direction of a session, as seen during the second Facebook based session, when a photograph of a car inspired no interest, despite Mary asking leading questions. This resulted in her moving quickly on to the next photograph. In the same session

observation notes show that at one point Iris asked Mary to return to a particular photograph on Facebook, which she had just moved away from, saying:

"Go back I was looking at the other fella" (observation 2, day centre).

The example cited shows that participants had the prerogative to decide what they were or were not going to talk about and when they had finished talking about a particular person or topic.

4.2.1.6 Re-connecting – Identity and Self-worth

In this study, and during the in-depth interview, the facilitator referred to issues about the identity of the PwD and their sense of self. She herself showed insight and awareness of the type of understanding PwD may have:

"they are very aware that they are losing part of themselves and, you know, that things are shifting" (facilitator interview, day centre)

Data analysis showed that positive identity was regularly promoted during both of the two reminiscence sessions observed in this Case Study. Mary used her knowledge of the participants' biographies and life stories to encourage conversation around themes which in turn promoted well-being and valued social roles. For example when she encouraged Helen to tell others that she had been a singer in the band, it was obvious from both Helen's body language and her conversation that she was proud of this former role.

It was also obvious from the positive verbal reactions and the non- verbal reactions including sharp intakes of breath accompanied by smiles together with the general sense of excitement generated that the other participants were impressed by her story.

Well-being was also observed in body language as for example when participants took pride in being able to provide information or answers to questions during the session.

"When Iris supplies the correct answer to a question about a photograph she laughs and rubs her hands with delight" (observation 2, day centre).

The literature suggests that people diagnosed with dementia can sometimes be labelled as "diseased brains" and can be viewed by others solely in terms of their diagnosis, rather than as people with rights, roles, responsibilities, desires and interests. However, the two in-depth interviews with PwD in this setting showed they were keen to talk about their previous occupations, hobbies and roles. Helen talked about her singing career and another participant Geraldine discussed working in a local factory.

During observations all participants were seen to be discussing their working lives during the reminiscence sessions. This may have reflected a desire to look back to past memories of a more valued social persona to increase feelings of self-worth and self-esteem. In a research study investigating the preservation of self amongst a group of PwD living in residential care, the author found the majority of participants discussed social roles related to work which she suggested pointed to this being one of the most important social roles in contributing to maintenance of self for the group (Surr 2006). Bruce and Schweitzer argue that when cognitive losses associated with dementia interfere with the narratives that are important to a person's identity, reminders of life history can be useful (Bruce and Schweitzer 2008) and by talking about each individual's previous work roles Mary was providing a way to link back to those narratives of identity. Accordingly in this thesis, the discussion of work roles amongst the participants may have been linked with efforts to maintain the self.

4.2.1.7 Supporting the Reminiscence Experience -Sad and Traumatic Memories

In order to ascertain whether reminiscence provoked sad or traumatic memories for the PwD and whether this had an impact on their well-being, participants were asked if they had ever felt sad during a reminiscence session, if there was anything in a session which made them feel unhappy or aspects of the reminiscence that they failed to enjoy.

Further analysis of observational data and in-depth interviews revealed no evidence of traumatic memories being triggered off during the reminiscence sessions at this Day Care Centre. In one case the recollections of the death of a young man in a boating accident recounted by Geraldine after looking at a photograph of a boat on Facebook, were listened to and noted in the second observation. This specific recollection did not seem to induce any particularly negative reaction or real distress amongst any of the participants, who talked about it with respect.

The issue of the extent to which reminiscence may trigger both sad and happy memories needs consideration and is an issue explored in this thesis. It is acknowledged that loss is a normal part of life and even though losses may cause considerable pain, loss is something that everyone has to deal with (Gibson 2011). There was one unusual case in this study, where the participant (Helen) spoke of continuing to reminisce in her own mind after a session (not observed) possibly indicating a tendency to ruminate over sad or unhappy matters brought up during sessions.

Researcher – yeah, is there ever anything in a session that would make you feel a bit sad or anything?

Helen – I don't, when they start talking about older people way back then, like grandmothers and that type of thing.... I'm inclined to kind of go back myself and I can forget that there was a class of people you know, like kind of reminiscing in my own mind

Researcher– in your own mind

Helen – yeah, yeah, you know like my grandmother XX (name), things like that and they were talking about X graveyard here one day, you know the graveyard and I said now who have I buried out there, and I've a brother buried out there because he's only three when he died and they wouldn't open up a new plot in St X cemetery for him

Researcher – oh dear

Helen – and we had nobody buried in St X cemetery at that time... so there wasn't any (inaudible few words) and they wouldn't open up a new plot for a child...that's the way it was then

Researcher – that's how things were I suppose, it's a shame isn't it

Helen – so a terrible thing like that

Researcher – so things like that might make you feel sad

Helen – yeah things like that but that's about it, so reminiscing back on things like that, you know would do

Here Helen, who had dementia, was making it clear, that there were certain subjects which for her would trigger sadness, and they could be triggered unknowingly, in this instance by the mention of a certain graveyard. However, by using the phrase "but that's about it", Helen seemed to be indicating that the possibility of experiencing sadness during a session was limited.

Geraldine, another participant with dementia was asked if anything within a reminiscence session saddened her and she may have initially misunderstood the question, as she started talking about when her husband had died and how sad she felt then. However, it could have been that she meant that reminiscence at that time, or concerning that time, would have caused her sadness. However, in general she felt reminiscence did not cause her sadness and in fact she clearly derived much pleasure from these sessions:

"I, no, I just, I, I love to look back" (interview with Geraldine. Day centre).

The facilitator Mary appeared very aware of the potential reminiscence had to trigger sad or traumatic memories. Interestingly she stated that she actively avoided certain topics in general reminiscence sessions because of this. She singled out her tendency in particular to avoid the topic of religion in relation to schooling and commented: ***"funnily enough there is for and against the religious aspect...of reminiscence, right, 99.9% .....the area of***

religion that you can get into trouble with...are school days...and some of our participants had appalling lives at the hands of various religious orders and, that we now know about, ahm, physical abuse...right, and so you need to be very careful and again, you learn quickly not to put the subject of school on the table if you have certain people in the room...but that's the area of faith that we've come a cropper on doing reminiscence so we tend to avoid believe it or not school days" (facilitator interview, day centre).

Based on this statement, it might be deduced that Mary was aware that some older people had been the victims of abusive behaviour during their earlier primary and secondary education and for this reason chose not to discuss such topics. Mary had mentioned that school poems were a very successful prompt but that was the only part of schooling which she used as a prompt, adding: "***but we tend to leave the rest of it alone, we have learned to our cost that really isn't an area to dive into in reminiscence" (facilitator interview, day centre).***

The phrase 'learned to our cost' implies that Mary had experienced actual problems in this area, but she did not elaborate any further on this in her interview. Mary emphasised the importance of knowing the client's life story in order to ensure that traumatic memories were avoided. In particular she pointed to the importance of knowing peoples' family lives and upbringing:

Facilitator "...I am aware of the negative side of reminiscence, which is again, you need to know the participants, you cannot come in without, you know, if ahm, there are certain things that can be, you need to be very aware of, you need to be very aware of was someone raised by a mother, was someone raised not in the home, was somebody raised by a granny, you know, before you start making assumptions about how everybody..."

Researcher – "I remember saying that last week when they were talking about, the eldest quite often going off to a granny or something"

Facilitator – "yes, exactly, we've had quite a few here come through our doors who would have had their mother die at birth...so they would have been raised in somebody else's house, or raised by an aunt or raised by either a father and the siblings in the house... and we would have had one who we've never yet got to the bottom of it, there was a mother but she was raised in XXXX (city in Ireland) and she was in an orphanage. (facilitator interview, day centre)

However, it is unlikely that a facilitator would ever be able to know the entire life story of a PwD, and therefore be able to avoid triggers which may cause sadness or negative reactions. A facilitator therefore needs to be aware that potentially any topic could elicit sadness. Mary showed some awareness of this, noting:

"...so we also have to be conscious of, if we're going to do reminiscence is that, it may bring up tears...and it may bring up sadness, it's not, it may not be always be happy but then what you would do is, I would sometime structure reminiscence just around, if I noticed a certain theme...was coming up with a small, you know, maybe do a quiet session...with, around those things, just for that, if I thought it was pushing buttons, ahm, that may not want to be in a bigger group or that may be very negative" (facilitator interview, day centre)

However, as the interview with Helen demonstrates, there may be a chance that a session has triggered sadness and the facilitator is unaware of this. When talking about the need to be aware that reminiscence can trigger sadness Mary talked about the fact that, in England in particular, there could be problems with reminiscence:

"...now I know in England in particular, because they came through the great war...that in revisiting certain parts of life in reminiscence, you, you can be opening a can of worms that cannot be closed"(facilitator interview, day centre)

Mary seemed to be saying that reminiscence around the subject of war was something to be wary of, and certainly researchers such as Bender caution practitioners to be careful when

carrying out reminiscence with a generation who have been through world wars and may have been traumatised possibly without ever having admitted to it (Bender 1997).

Mary seemed confident about dealing with painful reactions, but appeared to prefer to address these on a one to one basis rather than within a group as she had intimated earlier:

"yeah, what, I would never negate...if someone brings up strong emotion...I would sort of like mark it in my own head, so OK come back to that...at another time with that person...and then you would shift, gently without appearing to shift direction to something else" (facilitator interview, day centre).

She summarized this as:

"move it on, move it on, move it out quickly" (facilitator interview, day centre)

which may actually indicate a certain reluctance to deal fully with sad or traumatic memories at least during the course of a session, which will be explored further in the discussion chapter.

Later on in the in-depth interview Mary acknowledged the importance of her role in directing the group and dealing with possibly painful emotions:

Facilitator - "ahm, so no, what you are is as the, well sort of facilitator and the leader you are always conscious of the emotions either rising up or falling, or the heaviness within the group, and that will be to my knowledge shouldn't, you need to be sort of one step ahead, so you keep it up, keep it going"

Researcher – "so you're able to sort of professionally..."

Facilitator – "yes, very important. Well, the last thing you want to do is lead a reminiscence session that brings somebody down and that you cannot...you cannot cope with, and you cannot, you cannot leave them there"

Mary's belief that people should not be saddened by reminiscence and left distressed concurs with advice offered by experts such as Murphy. In his guide to carrying out life story work with PwD, he advises that a person should never be left in a bad place (Murphy 1994), with similar advice being given by Gibson and Chaudhury (Gibson 2011; Chaudhury 2008).

Mary had already indicated some reluctance to deal with sad or traumatic memories as evidenced when she spoke of the possibility of "opening a can of worms that cannot be closed". A second reason for reluctance was that she thought there may be insufficient time to deal appropriately with difficult memories because of the client's age:

"if you look at Erikson's six stages of life, Ok, Most of our clients are in the lat..latter end, the final stage, and at that time, you don't have the luxury of time..to re to fix or to go back and change OK" (facilitator interview, day centre).

When asked if she herself had ever experienced a negative reaction when taking part in Reminiscence Mary answered that she had not.

4.2.1.8 Supporting the Reminiscence experience -Creating A Safe Place

Mary had undergone dementia training and appeared to have a good understanding of the needs of a PwD and the importance of creating a safe place at the Day Centre and in the environment in which reminiscence was being carried out, supporting the PwD and promoting well-being:

"they have to try and live their lives and cope in a world that has changed so completely they no longer understand it, because of (a) their aging process and (b) they are very aware that they are losing part of themselves and, you know, that things are shifting.

She also continued by making the point that often the families of these people are under enormous strain:

"There is nine times out of ten family strain...even in the most, you know, moderate case of dementia there is family strain, families on an everyday basis cope with ordinary problems, this makes an ordinary problem extraordinary... we provide a place of safety, a place of acceptance and a place of fun" (facilitator interview, day centre).

In her opinion, reminiscence appeared to confer a sense of safety and comfort as referring to one of the reminiscence sessions she commented:

"There was no fear, there was no sense of uncertainty" (facilitator interview, day centre) further elaborating "it (reminiscence) tends to lift the weight off their shoulders for a period of time because there's not a sense of ahm, ah, of having to try....it's there" (facilitator interview, day centre).

Mary likened reminiscence to:

"...it's like walking into a house where the fire is lit, the kettle's on and there's a great warm welcome", (facilitator interview, day centre), which again seems to imply that she thought reminiscence created a "safe place".

As the description of the day centre (Appendix H) shows that there was a concerted effort to provide a "homely" environment which would add to the feeling of a safe place.

4.2.1.9 Supporting the Reminiscence experience - Factors which encouraged or hindered reminiscence within this setting

Based on observational data (verbal and non-verbal) Mary came across as enthusiastic. She had a good understanding of dementia, demonstrated person centred care behaviour in her interactions with participants and seemed able to implement her own at times innovative ideas. The environment was supportive of PwD as reflected in the well thought out design, which was aimed at promoting a warm and comfortable atmosphere. As Snyder reminds us the environment's significance in fostering or inhibiting relational interactions should never

be underestimated (Snyder 2002) and with the use of appropriate furnishings and décor, this day centre had made efforts to ensure communal areas were comfortable and inviting and looked a good place to spend time in the company of others.

At the two sessions observed, there was a good staff to PwD ratio – one facilitator working with four participants at the first session, and one facilitator along with a volunteer working with three participants at the second session. Mary had a good basic understanding of the importance of appropriate prompts and had a strong personal belief that at this particular centre local knowledge was the best prompt for reminiscence. The participants were all from the local area and the reminiscence sessions observed had drawn heavily on local history however it is possible that too much emphasis was placed on local knowledge.

The prompts in use and observed in this setting were conversational only at the first session and both conversational prompts and Facebook at the second session. Mary mentioned the use of poetry, prayers, art, music, and cooking at other sessions (not observed). Mary mentioned that she had purchased commercial reminiscence materials but found they were not always appropriate as they were usually aimed at the English market and covered themes which were not particularly relevant to the participants at the day centre and instead relied on materials such as books of poems, particularly poems learned at school and old magazines such as Ireland's Own.

"...we've got a lot of ah cue cards and stuff that we've bought over the years, ahm, a lot of it very English based..ahm, so some of it is appropriate some of it's not" (facilitator interview, day centre).

Both of these reminiscence sessions were notable for the heavy emphasis on common local history and knowledge of participants' individual interests. Both sessions placed emphasis on places familiar to the participants, similar to the method used successfully by Chaudhury in his place based reminiscence with PwD (Chaudhury 2008). The conversational prompts worked well in this setting and sessions were noted as being lively and animated. Facebook

was a useful tool for prompting Reminiscence in this setting. Photographs were viewed on the site, including photographs of places, important social and community occasions and religious processions. Looking at the screen and recognising photographs did not seem to pose any problems for the participants and they seemed somewhat in awe of the fact that they could see photographs from the past, an example of this was provided by Helen who, when Mary read out a date on one of the photographs ***"1946"***, responded with ***"God bless us all".***

Mary was able to individualise these sessions, for example when a photograph came up she knew would have relevance to a particular participant she directly asked her questions about it. Photographs which prompted conversation included those of cinemas, and "what's on" listings which included details of local bands and shop advertisements. The advertisements led to talk of shops, including who had worked in them, who owned them and who (of those people) was married to whom. Observation notes showed that much of the conversation was participant-led. Along with recognising places and people on the screen, the participants, Mary and the volunteer helper also added anecdotes about the places and people which lead to much discussion and joking. All photographs, except one, prompted responses which were usually enthusiastic.

On just one occasion, as mentioned before, a photograph of an old car came up which despite probing questions from Mary provoked limited response amongst the participants. Due to lack of interest Mary moved on from the photograph.

In this day care setting several factors acted as possible barriers to effective reminiscence. These included absence of in-depth knowledge about family members, thereby missing out on opportunities to further individualise reminiscence. Conversely, several family members may also have benefited from sharing knowledge about reminiscence, as in their interviews the family members showed they could understand the potential benefits of reminiscence but lacked knowledge about the uses of reminiscence with a PwD.

Another potential hindrance was the possible over emphasis placed on staff having extensive local knowledge. This may have affected the variety of people working within reminiscence in the facility and may have adversely affected the richness of the sessions. Although extensive local knowledge is useful in a session, and observation notes showed that conversational prompts using this type of knowledge worked well in sessions, it is possible that staff who did not have extensive local knowledge could have taken part in sessions and may have other strengths to bring to a session.

During the sessions observed as noted above, Mary had invoked sensory images by talking about the smell of hops for example, however she did not use physical sensory prompts which may have enhanced the reminiscence experience, especially for those people whose communication and verbal skills were not so good. Mary said in her interview that she made use of some naturally occurring sensory prompts, such as the smell of bread baking but did not think that the commercially produced sensory prompts were worth the expenditure.

4.2.1.10 Setting Summary

Both the observational data and the interviews carried out and analysed would suggest that reminiscence was an important activity being carried out on a regular basis at this Day Centre. The four participants with dementia observed during the first phase where no prompts were used appeared to thoroughly enjoy the session and good interaction was noted. In the second session observed, which used Facebook as a prompt, the three participants with dementia in the group appeared to enjoy the session and again good interaction was noted. Mary in particular used her own knowledge of client's biographies, linked with knowledge of local history and culture to make these sessions worthwhile and beneficial.

The qualitative data showed how reminiscence helped participants to connect with each other through shared memories. The facilitator Mary also enjoyed the sessions and benefited

by getting to know the participants better and also by learning about the locale and local history.

In both sessions the facilitator Mary directed how the reminiscence session progressed but conversations were very spontaneous and participants with dementia often re-directed the conversation off into other areas. As Chaudhury notes in reminiscence sessions a facilitator should be responsive, spontaneous and open and view the process like a journey with unexpected twists and turns which the facilitator must try to follow (Chaudhury 2002). Observational notes confirm that Mary did react to the reminiscence process in this way.

Although some sad events were discussed during the reminiscence sessions observed, it did not seem to affect participants adversely. However, one participant interviewed indicated that she continued to ruminate over sad memories after the Reminiscence finished.

The facilitator had never personally been adversely affected by taking part in Reminiscence. However, she showed some discomfort with reminiscence topics which may have provoked sad or distressing memories and actively avoided certain topics.

As well as the conversational and Facebook prompts observed during these sessions, music, poetry, cookery and familiar prayers were noted as popular prompts in this setting.

4.3 The Respite Care Centre - Introduction to the Setting and Participants

Set just off the main road in a small rural village more than 200 kilometres from Dublin, this dementia specific residential care setting was situated in a large purpose-built bungalow. It had a large well-kept front garden as well as gardens to the side and rear. Inside the bungalow there was a main corridor with rooms running of it including offices, bedrooms, bathrooms, a dining room and a lounge. There were scenic views from the windows and quiet spaces to sit in various parts of the bungalow. The building was pleasantly decorated

with artwork on the walls and religious memorabilia on walls and bookcases. The reminiscence sessions took place in a multi-purpose room used for activities but also as a communal lounge where residents could sit and watch television or listen to music. Efforts had been made to make the room look homely and comfortable, with chairs with comfortable cushions and knitted throws and footstools available for use. There was a fireplace and good natural light giving the room a light, airy feel.

There were three participants with dementia interviewed at this centre. One of these was Anne who was aged 64 years. She was a widow living with her daughter. She enjoyed singing, dancing, taking part in crafts and walking. Bridie was 86 years old and was a widow who lived with her son and had enjoyed a busy working life when younger, possibly in nursing or care work (she wasn't sure of the details). She liked chatting. The third PwD was Catherine who was 84 years old. She was a widow and lived alone with care from a relative who lived nearby. She had been a keen golfer and still enjoyed talking about it and watching it on television. She had a busy family life and liked socialising with her family. The facilitator was Orla, who came from a non-professional background.

At this dementia specific residential respite care centre, simple or general reminiscence sessions (Gibson 2011) were carried out as part of SONAS, a therapeutic, multi-sensory activity (see Appendix I for full description of the SONAS method).

4.3.1 The Respite Care Centre Findings

The findings in relation to the respite care centre are reported on in the next session using the themes identified earlier.

4.3.1.1 Connecting – communication and engagement with others

Observational data yielded some evidence of a two way flow of communication between respite residents with dementia and the facilitator, yet interestingly there was little evidence

of spontaneous communication between residents. Information recorded during observations showed conversation was usually initiated by the facilitator with little evidence of spontaneous communication between residents. The only spontaneous communication noted in the observational data, occurred during the second observation when a resident (not interviewed) started coughing and another resident (not interviewed) helped her, by patting her and talking to her in a reassuring manner. In this setting, two of the participants showed an awareness of a lack of connection between themselves and the others in the group. Dealing with strangers and with different personalities can pose challenges to a PwD. Observations showed evidence that it was a lot easier for residents to interact with the facilitator rather than with one another. Participants interviewed praised the staff;

"***ah so nice, the staff are just so lovely, you wouldn't believe how nice they are" (interview with Anne, respite centre)***

(referring to staff) "they're nice girls, so they are" (interview with Bridie, respite centre)

The participants however seemed more ambivalent about their fellow residents within the group and there was evidence that they differentiated themselves from the others. Bridie, seeming to refer to the others in the group, noted:

"***some are very good, some are really good, you know, jolly, the others are just sitting there...(imitates someone yawning) they're tired now (laughs) (interview with Bridie, respite centre) .***

When Anne complained about repetition in the SONAS session, which she personally disliked, she said she thought it was good for the others:

"..but, the same things they do, do you know what I mean, the same for this lot" (meaning other members of the group) (interview with Anne, respite centre)

Later in the interview she again spoke of the repetition being very good, and when asked why she thought that, once again she implied it was good for "others"***: "the people that are***

forget, ah the poor devils...see some people in here and, and, and, can't remember anything, you know they.... So I think it's very good for them" (interview with Anne, respite centre).

Anne appeared to be differentiating herself from others attending the respite care centre. Bartlett and O'Connor refer to using language in this way as "othering" and argue that to use language in this way is an attempt to establish boundaries and positions the "other" as not like us (Bartlett and O'Connor 2010).

There was very little connection between the participants in the reminiscence group as evidenced by the lack of spontaneous communication between them and this is something that reminiscence could have helped with. However, taking part in reminiscence seemed to help them to engage. Positive examples of engagement included one observation of a gentleman with dementia in the second reminiscence session observed who initially appeared fairly quiet during the session, but then announced that he wanted to dance. A nearby care assistant, who had been helping another resident back to her seat after a toilet break, joined him in dancing and he led him around the room, quite proficiently. The facilitator built on this act of spontaneity by encouraging others in the group to join in the dancing. In their book The Creative Arts in Dementia Care, Hayes and Povey refer to the importance of creative care and the capacity to play and give an example of a person suddenly getting up and waltzing around the room, in much the same way as the man discussed above did. They argue that this is "play" in its broadest sense, when there are no expectations of rightness and people are open to the moment, experience joy and connect with others, noting that in dementia care it can be the little playful, creative moments such as this that count (Hayes and Povey 2011). Play is also one of the characteristics of PPW which Kitwood noted was supportive of a person-centred environment (Kitwood 1997).

There were however several occasions where in data recorded, observational notes show that residents were not engaged:

"A poem is recited on the tape about a hug. Bridie is looking out the window and doesn't seem to be listening" (observation 2, respite centre).

"Catherine has closed her eyes and is no longer joining in" (observation 1, respite centre).

When a participant showed lack of engagement in this way, it was noted that if Orla had observed the person she would either try to encourage him or her to join in again, by directing a comment or question to the person, or if it appeared that the person was temporarily resting she would just leave the person to rest or sleep. However, the large size of the group meant Orla did not always see when a person had disengaged.

There were some examples of spontaneous communication occurring between residents and the facilitator. For example during the second observation, it was noted that one resident complimented the facilitator after she had played some music on a tin whistle, stating ***"you should be in a band" (observation 2, respite centre).***

Orla encouraged communication with the residents by asking direct questions related to what was happening at the time

"***did you like the songs?" (observation 2, respite centre)***

"do you like that smell....what do you think of it?" (observation 2, respite centre)

The residents responded to the facilitator, sometimes verbally

"mmm not sure about that smell, not for me" (Anne observation 2, respite centre).

The residents also responded non-verbally and this was noted during the observations.

"The facilitator has asked Anne if she knows this poem and she responds with a nod of the head" (observation 1, respite centre)

Orla seemed aware of her role in promoting communication and engagement:

"...you know in responding to interaction like smile or like returning eye contact that's very, very important, you know what I mean to get them tuned in, you know what I mean" (facilitator interview, respite centre)

How much of the communication and engagement was prompted by reminiscence was difficult to gauge accurately, as the session was not solely based on reminiscence. However the songs, music, and poems used were traditional and the residents with dementia would probably have known them in their youth or childhood and singing them probably triggered off memories from the past. The proverbs used may have been known to them from their school days.

Outside of sessions, one family member (Catherine's grand-daughter) mentioned that reminiscence helped communication at home, saying:

"....it's a way for her to keep using her words...because otherwise it can be very, very limited conversation with her, she won't give, she'll listen but she won't, unless she's talking about something that she, she was at, she's not going to give too much out, do you know what I mean"

(Interview with Catherine's grand-daughter, respite centre)

4.3.1.2 Connecting – with the family and wider community

In-depth interviews were conducted with three family members who were identified by Orla as satisfying the criteria for this study (see Methodology chapter). They comprised an adult daughter, son and a grand-daughter in law and each of them lived with and/or had a caring role for the family member. The interviews revealed that the family members knew very little about what went on at the respite centre. Their lack of knowledge was probably partly attributed to a lack of feedback from their relatives possibly due to their memory and cognitive problems but it may also reflect a lack of communication between the facility and the family members. Only one family member, Anne's daughter, mentioned receiving any

feedback about the sessions, and this feedback concerned Anne not liking one aspect of the SONAS session but otherwise there was no feedback from the sessions.

As Catherine's grand-daughter explained in response to a question asked:

Researcher – "does Catherine ever talk about what's gone on, does she ever talk about what they have done in the way of activities or anything"

Catherine's grand-daughter – "no, no, never, like if, usually by the time we've driven out of the drive way she'll say, where am I and I'll say XXXX (village name) and she'll go, oh we're nearly home then, she just wants to go home (laughs)" (interview with Catherine's grand-daughter, respite centre).

Bridie's son said that he knew activities took place at the centre but was unaware of exactly what they were, and did not know that reminiscence was an element of the activities. He said his mother generally did not remember that had she had been to the centre, on returning from respite. He added that he had never heard of reminiscence being used in dementia care.

There also appeared to be some reluctance on the part of family members to involve themselves in the day to day happenings at the respite centre, which did not seem to be related to any policies operated by the respite centre, who welcomed visitors. The reasons for the reluctance of family to become involved could have ranged from the complex issue of whether respite care is more geared towards the family carer rather than the PwD and implications arising from that, to more simple reasons such as suggested by Catherine's grand-daughter who indicated that she felt that it would unsettle Catherine, if she went out to visit the respite centre:

Researcher – "...do you know much about reminiscence?"

Catherine's grand-daughter – " No, I don't, I mean I haven't, I, I wouldn't (inaudible few words), based on I wouldn't go out and see her in XXXX (respite centre)....it's really, like, I

take, I'm the one that takes her out there and picks her up and that's, that's, that's fine, ahm, but if she sees me, she wants home"

(interview with Catherine's grand-daughter, respite centre).

She further iterated:

"...the children (referring to Catherine's children) don't really go out there because I think that the, like I said the short time that she's there it's more disruptive to her, for her, them and for her to understand why they can't take her home, because she'd be saying, I'm going home with you (laughing) you know so" (Interview with Catherine's grand-daughter, respite centre).

It was possible that for these PwD, the arrival of family members at the respite centre was viewed as a signal that the respite stay was over.

As mentioned the interviews revealed there was a gap in family members' knowledge about what actually went on during the respite period and in particular what happened during SONAS sessions by way of reminiscing. Catherine's grand-daughter expressed curiosity and asked me to describe what went on at them, but as she had previously indicated, she did not want to disturb her grand-mother's respite visit in any way:***"...I would love to see a session probably done out there...but I would probably be, it would, I probably should go on a week that she's not there, because she'd be looking at me, I know and like what am I doing (laughing)" (Interview with Catherine's grand-daughter, respite centre)***

In contrast Bridie's son expressed no interest in learning anything further about reminiscence.

Anne's daughter, who herself at one stage worked in a nursing home, believed reminiscence had no beneficial effect on her mother at the moment:

"not at the moment (inaudible few words), it does depend on stages....ahm, I've worked personally now in nursing homes for years with a lot of Alzheimer's ...patients and a lot

of friends of mine would have family, ahm, I think the worse it gets they go off on their own tangent anyway talking and remembering what they want to remember" (interview with Anne's daughter).

Interestingly however during the research interview conducted with her, she acknowledged that her mother Anne now often spoke about things and people from her past.

"but she's talking more about stuff she never spoke about before.....as in her, not never spoke about, but her brothers and sisters, her mother and father...things like that were never relevant, not relevant, she...they don't live near her...and she only went to see them once a year, so they weren't very relevant to her (laughing) you know growing up...now they're very important, they're the most important thing in the world nearly at this stage" (interview with Anne's daughter, respite centre).

Had she known more about these reminiscence sessions she may have been able to better understand why Anne was talking about people from the past and she may have been more supportive of Anne's natural inclination to reminisce. However, this seemed to cause Anne's daughter some consternation as she did not understand the reasons behind this.

The three family members interviewed reported that they had been asked to bring photographs into respite for the purpose of placing residents' identity on medication forms, but not for reminiscence purposes. They could not remember being asked for any specific information regarding their relative which could be used for reminiscence purposes. However, Anne's daughter mentioned that on one occasion her mother had spontaneously brought in a photograph of her now deceased husband, and it had triggered reminiscence:

"well she brought now a photo of one thing, she did bring a photo of my father, she was in respite last week...and she was, had a photo in there (pointing to bedroom) and I said bring him with you if you want....so she brought it and then she was telling them, because XXXX (manager's name) had told me back, she had spoke to them about my father and reminisced in that way" (interview with Anne's daughter, respite centre).

It is very probable that family members could have contributed extremely useful information that would have made reminiscence more person-centred, tailored to individual interests and needs and more fulfilling for each person. Anne's daughter had in an earlier, informal conversation remarked that some of the reminiscence material used at the respite centre was of little interest to her mother, because it was farming related and Anne was not from an agricultural background:

Researcher – "and you were saying ahm, I thought it was interesting what you were saying about how you know, when they, they've got videos at XXXX (respite centre) of things like farming, things like that

Anne's daughter – "oh yeah"

Researcher – "and she's not a farming person so"

Anne's daughter – "so it's a load of nonsense to her (laughing)"(Interview with Anne's daughter, respite centre)

Although the in-depth interviews were designed to explore the topic of reminiscence with family care-givers, it was interesting that each of these three caregivers spoke at length during their interviews about the stresses they encountered looking after their relative with dementia. This was despite the fact that no questions in the interview schedule addressed this topic. Each talked about the strain they experienced due to the physical demands of caring and the emotional stress experienced dealing with issues around diagnosis and support and the progressions of the illness. Orla had also mentioned that some caregivers used the service electively due to their own ill-health - when they themselves needed medical treatment, such as an operation. There is no doubt the family members were grateful to have the respite centre as a resource and relied on it to support their caregiving. The contribution which reminiscence could have made to supporting family caregivers will be explored further in the discussion chapter.

4.3.1.3 Connecting – Seeing the whole person

Orla during in-depth interview made no specific reference to how reminiscence might enable her to view a person more holistically. However, it is notable that she was the only facilitator who did not mention dementia when talking about her clients. Instead she simply spoke about the people concerned and often mentioned their skills and abilities such as musical skills or dancing skills. In this respect she seemed to have an intuitive sense of seeing the whole person in her care. She also seemed to be able to really empathise with her clients as she seemed able to relate to their problems from a perspective of one who has had similar struggles:

"...because I get great satisfaction , yeah, I get great satisfaction from seeing someone who is very quiet, when I was in school I was very quiet, do you know what I mean and you know and just to see these people progress" (facilitator interview, respite centre).

Orla also spoke of gaining satisfaction from seeing the PwD taking part in sessions enjoying themselves and also gaining in confidence:***"...It's great to see someone enjoying themselves and to be happy, do you know what I mean" (facilitator interview, respite centre)***

"...it's good, it's good to see these people that they're very quiet that they're getting more confident within themselves" (facilitator interview, respite centre)

Orla attributed this enthusiasm and wish to see people enjoy themselves and grow in confidence to an innate part of her own personality. The following description shows how she viewed herself and her attitude to her work:

"...I wouldn't be the type of person all day in the office closed in, I, I'm a people person and I hopefully get across with, with them, do you know what I mean" (facilitator interview, respite centre)

Orla seemed to place more emphasis on knowing the client's life story than on knowing the history of the particular locale. On several occasions she mentioned the importance of learning about participant's backgrounds and their retained skills so in this way reminiscence obviously contributed to her knowledge of the individuals and she was able to use that knowledge to individualise the reminiscence for the person concerned, for example when she spoke of knowing that music would calm a particular, troubled individual.

4.3.1.4 Re-connecting – Enjoyment

Observational data collected for this thesis showed several examples where PwD appeared to be enjoying themselves during reminiscence as reflected by non-verbal behaviour such as facial expressions, laughter and smiles.

"Bridie looks animated and is smiling" (observation 2 respite centre)

"a sleepy resident is awake for this part and smiles" (observation 2 respite centre).

At one point in the second observation Orla actually asked participants were they enjoying themselves, thereby receiving direct feedback. It was recorded that ***"all residents agree they are and articulate their appreciation, three pick out specifically the singing as being enjoyable" (observation 2 respite centre).***

Evidence of enjoyment also emerged in response to other specific questions asked of the three PwD interviewed. Questions such as 'do you enjoy taking part in reminiscence' were asked to which all three participants answered affirmatively yet a closer analysis of data showed that responses given were short and somewhat equivocal which may have reflected a certain ambivalence towards Reminiscence or could have been indicative of the person giving a socially acceptable, polite answer :

"Ah, I don't mind it's grand, it's grand isn't it now" (Interview with Anne, respite centre)

Bridie, for example, had indicated in the interview that she enjoyed taking part in the reminiscence sessions, however when asked if there was any part of the session she particularly liked she responded

*"**well, I don't actually know really..." (Interview with Bridie, respite centre).***

So it seems that probing or exploring further with them the aspects of reminiscence they found particularly pleasurable created difficulties for them to answer. Another participant Catherine for example seemed to have some reservations about reminiscence and when asked if she would recommend reminiscence to others she exclaimed:

Catherine - "for ahm, like not to make a day's work out of it if you know what I mean...let it be a kind of pastime"

(interview with Catherine, respite centre)

It is difficult to arrive at an accurate interpretation of what participants really meant by these responses. Their short responses may have been true reflections of their opinions reflecting that they enjoyed reminiscence to a certain extent. Catherine may have been indicating that she liked reminiscence as long as the sessions did not go on for too long and remained fairly superficial. Anne's brief response may have been a socially acceptable response but her answer and Bridie's answer may have reflected difficulties with communication where, in common with many PwD, they were unable to provide more relevant information within the answer. Bridie's son claimed during his interview that although he didn't know if she enjoyed reminiscence, if she said she did during her interview then she probably did as she was not one prone to giving polite answers, which gives further weight to the possibility that she was simply unable to add further to her answer at that time.

4.3.1.5 Re-connecting – Agency and Choice

Reminiscence as delivered at this Respite Care centre drew heavily on the SONAS programme. SONAS as an approach places a strong emphasis on the importance of PwD having choice, and in their publications, they state that SONAS as an approach should never be imposed on a person and the choice to participate rests with each individual person (www.SONASapc.ie).

Orla appeared to understand and uphold this. She reported that the residents were never pressured into joining in and could leave a session if they wanted to. To determine if residents with dementia believed they exercised choice in attending sessions, each was asked if there had been times when they might have preferred not to attend the SONAS/ Reminiscence session. Both participants asked this question reported that they were unable to think of any time when they had not wanted to attend.

Researcher (to Catherine) – "are there any times you don't want to go to it or"

Catherine - "are there any?"

Researcher – "times that you wouldn't want to go. Not in the mood or..."

Catherine – "well, not at the minute, I can't really think" (interview with Catherine, respite centre)

Researcher (to Anne)– "are there ever times you wouldn't want to come? Are there ever times you're not in the mood for it?"

Anne – "for the SONAS?"

Researcher – "yes"

Anne – "ah, no, no, not really, no, no" (interview with Anne, respite centre).

A more pertinent and possibly more revealing question although clearly not the focus of this research was whether participants actually believed they had a choice in being at the Respite

centre. What is useful for carers may be perceived as unattractive to PwD and it is noted that respite care can generate serious conflicts of interest between carers and care recipients (Arksey and Glendinning 2007).

Within the sessions, Orla encouraged choice by asking participants to suggest their song or poem preferences and acting on those choices. The tape which was used to structure the session also encouraged some individual choice:

"On the tape the voice asks would anyone like to share a song or poem" (observation 2, respite centre)

This was responded to appropriately as it was noted that one participant started to sing "It's a long way to Tipperary" and others joined in the singing.

Orla noted that people had their own individual preferences which she would try to accommodate thus enabling agency and choice for the individual. During the in-depth interview Orla said that she routinely engaged in reflective practice after reminiscence sessions and made notes on how sessions could be carried out in future, noting particular likes and dislikes of participants which had arisen during the session including prompts particularly favoured and even seating arrangements:

Facilitator - "....we would see how they react or didn't react and how we felt that we could improve again, do you know what I mean, maybe even seat making arrangements, somebody might want to be set in the middle of, of or near the helper, do you know what like xxxx (man's name)"

Researcher – "they've got their own preferences"

Facilitator – "yeah, do you know what I mean, like he would need more of a helper near him" (facilitator interview, respite centre).

Orla was aware that not everyone might want to join in with all the elements of the session, noting that for example whether a person liked to be touched or not was a very individual thing:

"...touch, now some of them mightn't like to be touched so it's very important that we ask them first".

4.3.1.6 Re-connecting – Identity and Self-worth

Analysis of observational data and that arising from the in-depth interviews with three participants revealed how Reminiscence appeared to offer PwD scope for some small-scale achievements which can reinforce feelings of self- worth in PwD. For example some of the body language observed, such as head nodding or smiling after participants finished proverbs suggested the participants probably experienced well-being through feelings of success and achievement. However, although some of the participants were observed to appear to enjoy this activity, observation notes show not all actively participated which could mean they did not want to or were not able to participate and this may not have been a suitable activity for them. Although it has been argued that the formulaic language used in proverbs remains fairly intact in PwD and therefore completing proverbs should be reasonably easy (Wray 2010), it has been argued that attempting to complete proverbs could prove stressful for some PwD and therefore may not be appropriate(Lindholm and Wray 2011).

During the in-depth interview, Orla made a point of recalling incidents where during reminiscence, the PwD seemed to temporarily forget their current losses and difficulties:

"you can see that those who are very quiet they get their self-confidence and you know and just say they forget obviously who they were for a few minutes, like XXXX (man's name) forgetting he needed the frame, he wanted to get up and dance....and he actually did it" (facilitator interview, respite centre)

The way in which reminiscence can bring out the best in PwD and tap into former interests, former abilities and retained abilities is very evident in this commentary. Orla was aware that this activity could be used to revive and consolidate skills. She told a story of a woman who had memory problems and yet could still play the button accordion: ***"and if you asked her what she did five or ten minutes ago she can't remember but she can remember this, this thing that she had, obviously, been taught when they're young'uns whatever" (facilitator interview, respite centre).***

This tapping into skills allows the person to be seen as a human being and promotes the person's well-being rather than allowing him or her to be defined by the label of dementia.

4.3.1.7 Supporting the Reminiscence Experience – Dealing with sad and traumatic memories

In keeping with the previous setting, participants with dementia in this setting were questioned about whether reminiscence had triggered any sad or traumatic memories to ascertain whether that impacted on their well-being. One participant Anne, was obviously aware of individual choice as in her reply to this question she said:

Researcher – "and are there ever any times that you would feel sad? Anything that would make you sad in a session?"

Anne - "oh not really, not really, no, no, ah no, I don't think I'd be doing it if it was (laughing) (interview with Anne, respite centre)

Another participant, Catherine stated that she might experience fleeting feelings of sadness but appeared to indicated that this were acceptable.

Researcher – "do you ever feel sad (during a session)"

Catherine – "well, I can't say that I do...maybe if some song comes up now...that I know a person who's dead used to sing, you know that kind of thing...then would start you going,

you know what I mean, you will feel kind of upset with that, but that's all. But I love music." (interview with Catherine, respite centre)

The use of the phrase "but that's all" implies that in general Catherine did not experience sadness during reminiscence, and her acceptance of the possibility of some sadness occurring during a session, accords with the guidance of many experts who believe that sadness is as much a natural part of life as happiness and that for many people it is not something to avoid (Bruce and Schweitzer 2008; Gibson 2011).

Bridie, another participant who appeared to have a more severe cognitive impairment than others (as manifested by the difficulties she had in understanding during the interview) may have misunderstood the question and appeared to talk about others (perhaps other residents). Again, it is difficult to discern exactly what she is referring to here; she may have been indicating that she did not enjoy some other residents or staff being present during the actual sessions:

Researcher – "is there anything you don't like about the sessions?" (pause) "is there anything you don't like doing"

Bridie – "no, no, no they're all right, there are one or two...they're off and they're telling you to get out of the way and things like that, you know, but if they do that I just (next few words inaudible)" (interview with Bridie, respite centre).

Orla did not display any wariness or caution about topic selection during the sessions, but she also did not address anything other than very general topics, so the likelihood of any sad or traumatic memories arising was minimal. When questioned about any adverse effects of reminiscence, Orla said she had not experienced any negative emotions herself whilst taking part in reminiscence sessions, neither did she talk about any of the participants experiencing sadness or negative emotions.

4.3.1.8 Supporting the Reminiscence Experience – Creating a safe place

As in the Day Care Centre described earlier in this chapter, in this residential respite care setting Orla recognised the importance of creating a "safe place" for the PwD. When talking about creating the right environment for the session, by ensuring everyone was comfortable she noted that this contributed to a feeling of safety.

"do you know what I mean so, you know, arrangements for seating would be very important for this as well obviously, do you know what I mean, obviously, even, even say the room temperature or anything like that……but it's good though I mean at least it feels safe" (facilitator interview, respite centre)

She also implied that by providing a safe environment negative emotions and challenging behaviour could be reduced. She gave the example of a man who was not at the session that day, who sometimes experienced agitation. Orla had found that as he loved music, she could calm him by using her musical skills:

"and you know, and they're, you know you see poor Tom there now though he wasn't in the session today he's very agitated, but yet he's a very good musician and I'm sure, he used to play the saxophone, yeah, and I know that I tried the tin whistle and he loved it, do you know what I mean, not saying anything, not boasting again but, he felt safe if that makes sense" (facilitator interview, respite centre).

Orla's comments suggested that Tom's agitated behaviour was the reason for his exclusion from the session. Agitated behaviour, which some regard as a pejorative description, can be a way of communicating distress or discomfort as often the problem lies not within the individual but within an environment which fails to meet the person's needs (Cohen-Mansfield 2010). It is therefore important to try to understand what the person is communicating through their behaviour and identify an intervention to match, which is something Orla appeared to be trying to do. In recognising his love of music she was able to provide an activity which calmed him and gave him a sense of safety.

Reminiscence work can benefit individuals with dementia whose behaviour is deemed challenging, however it is more likely that this will be successful on an individual basis. Gibson recommends trying specific, one to one reminiscence with PwD whose behaviour challenges others, as sometimes unravelling the life story of the person can suggest possible explanations for the behaviour and point to possible ways of responding (Gibson 2011). Gibson advises that in reminiscence groups with PwD, care should be taken to ensure that no one is included in the group who is likely to harm another member or to make it difficult for others to participate comfortably. A person experiencing agitation may make others in the group feel uncomfortable and would be more likely to benefit from input on an individual basis. Certainly with the size of the group Orla was dealing with, it would have been unlikely that she could have given Tom the time and attention he needed during a period of agitation.

4.3.1.9 Supporting the Reminiscence Experience – Factors which encouraged or hindered reminiscence

At this residential respite care centre, Orla, the facilitator came across as a warm person and was enthusiastic about her work as reflected in the way she spoke about it during her interview and observations of her general demeanour whilst working. She worked hard to create a good atmosphere within the Reminiscence/SONAS group. She appeared to have a good understanding of the salience of environmental factors for reminiscence, as reflected in her comments about seating, lighting, room temperature and layout made during her interview, factors which can all facilitate the reminiscence process. She claimed that the management were supportive and all concerned were working hard to achieve good person centred care.

The SONAS sessions within which the Reminiscence occurred at this setting are by design very structured although there was some leeway for creativity and flexibility. This structure was a positive influence in this setting as it appeared to give the facilitator confidence. As Gibson points out, reminiscence is not the monopoly of any one profession and people from

different backgrounds both professional and non-professional carry out reminiscence work. She notes that attitudes, values, skills and knowledge are more important than any professional training (Gibson 2011). It was apparent that in her SONAS training Orla had acquired skills that she could use with her group work. For example she mentioned in her interview that she routinely carried out reflective practice, to aid future sessions, a technique she had been taught during her SONAS training. Orla as a facilitator obviously needed structure, but with appropriate training in reminiscence she could have found other ways of delivering reminiscence within a structured environment in addition to SONAS, which obviously worked well for her. Orla appeared to have good intuitive knowledge and understanding of reminiscence, as reflected in her knowledge of the importance of sensory prompts. However, her knowledge and confidence could have been boosted further by formal training in reminiscence work. She was aware of the importance of activities in general:

"oh definitely, oh God yes.... Treena they need some type, type of stimulant even if it's not the SONAS they would need some card making or making cards or moulds which I did before or we had other musicians coming in which was very good, do you know what I mean, something different" (facilitator interview, respite centre)

She was also aware that PwD are vulnerable and may not get enough psycho-social stimulation:

"yeah, so music, music is very important obviously, music and music therapy or anything like that or arts or crafts or anything like that, they do need it, 'cause unfortunately I'd say other places I mean they mightn't get as much stimulation". (facilitator interview, respite centre)

During the in-depth interview Orla appeared aware of the benefits of targeting each of the five senses within reminiscence, specifically commenting on the sense of smell:

"and ahm even the sense of smell, you know what I mean, you know, like bacon or you know, they can remember things from the past do you know what I mean, like their old homes or anything like that, or ahm, flowers in the garden". (facilitator interview, respite centre)

Interestingly, whilst she talked about smell as a sensory trigger, during the actual sessions she did not specifically use this particular sense to stimulate reminiscence, instead concentrating on attitudes (whether the person liked the smell or not) rather than actual experience but she did not take this any further.

Gibson argues that reminiscence groups for PwD should be small with usually no more than two to four members. She further comments that inexperienced leaders too often allow themselves to be persuaded to work with groups which are far too large to be effective (Gibson 2011). Orla had another staff member to help her with the group, but even so the size of the group she was working with was large(N=13) which meant that Orla was unlikely to be able to carry out reminiscence work effectively. Had Orla undertaken specific reminiscence training, it may have enabled her to plan more effective reminiscence work taking into account factors such as group size.

Another factor which may have acted as an obstacle to effective reminiscence from taking place were regular interruptions due to the physical and personal care needs of the participants. These included toilet breaks (which are a necessary and expected occurrence) but also participants being taken out for personal care such as bathing. These interruptions were noted in both observations. They resonate of Menzies Lyth reference to the emphasis placed by care staff on task performances in health care settings (see page 68) and the possible priority given to such tending tasks over and above psycho-social interventions. These interruptions were acknowledged in Orla's interview when she commented:

"There were a few interruptions there now which wasn't a good thing, really Treena" (facilitator interview, respite care centre).

Such interruptions might reflect the institutions' prioritising physical and personal care over recreational activities and may indicate an environment where activities are being carried out in a tokenistic manner, with insufficient resources in the way of time and staffing being allowed for the intervention.

Family members could have contributed significantly more to the success of reminiscence in this setting. The in-depth interviews revealed they held valuable information about these PwD which could have made the reminiscence a lot more person-centred and meaningful to the individual. In addition the family members could have benefited from becoming involved in reminiscence sessions at the respite care centre, as mentioned earlier.

At this respite care setting, some preliminary evidence emerged that participants were communicating well with the facilitator but not so well with each other. This finding is not that unexpected given the nature of residential respite, where strangers are essentially living alongside each other, and where it is unclear how introductions are made when new residents are admitted or indeed whether any effort at all is made to make formal introductions given the fact that these people have a dementia.

A respite environment also has some unique features, including the fact that people remain in respite for different periods of time according to need and vacancies. The respite clientele changes and respite clients will not necessarily see the same people from one respite period to another. The time interval between respite periods can sometimes be several weeks, so even if a PwD becomes friendly with and develops a strong bond with another resident, he/she because of the dementia may not be able to remember that relationship on their next respite stay.

In addition, the geographical area covered by the respite care centre, in common with many respite care centres is quite large. This means that these PwD may not have been sharing accommodation with neighbours familiar to them or people from their own locale. This combination of factors means a PwD staying in respite is less likely to have been able to build

up relationships with others than for example a person regularly attending day care who usually sees the same people from their local area, or a person who has been resident on a hospital ward with others for a period of time. It is therefore not surprising that it might be hard for the PwD in this environment to make connections with others, and this may have been reflected in the lack of connection between the participants within the group. That said, reminiscence could have been used as a way to connect participants with each other. Gibson notes that reminiscence can help people make new friends by discovering common ground or understanding differences and that talking about the past can facilitate talking in the present (Gibson 2011).

4.3.1.10 Setting Summary

At this residential respite setting, those participants with dementia stated that they enjoyed reminiscence but their narratives reflected some ambivalence. There was evidence of playful, creative moments within the sessions. The facilitator also enjoyed the sessions and benefited during reminiscence by learning more about the participants. Reminiscence seemed to facilitate a connection between the facilitator and participants but not between participants and there was evidence of participants differentiating themselves from others in the group and a lack of connection.

Although the SONAS method used was very structured there was leeway for some individual choice within the session which was encouraged by the facilitator.

The large group size seemed to adversely affect certain aspects of reminiscence in this setting and there were regular interruptions due to personal care needs which may have indicative of prioritising physical, personal care over psycho-social needs

There was no evidence of reminiscence prompting traumatic memories for participants and participants believed that some level of sad memories was acceptable within a reminiscence

session. The facilitator had not personally been adversely affected by taking part in reminiscence.

Music, hymns and proverbs were the most frequently used prompts connected to reminiscence in these sessions although Orla mentioned the use of arts, crafts, cooking and flower arranging as reminiscence prompts used at other times and was aware of the usefulness of sensory prompts including naturally occurring sensory prompts such as the smell of bacon cooking. As in the day centre, Orla mentioned that reference to and discussion of places where people lived could prompt reminiscence.

The data showed that families knew about reminiscence and had not been asked to provide information or material for reminiscence purposes. Families were experiencing stress and were grateful for the support of the service and appeared keen not to interfere with their loved one's respite stay.

5 The Experiences of PwD and their Caregivers who participate in Reminiscence in an Acute Hospital setting and a Nursing Home

5.1 Introduction

This chapter presents findings on Reminiscence based on the two Case Studies conducted in (i) an acute hospital setting in Dublin and (ii) in a Dublin based nursing home setting.[14]. The chapter commences with a brief introduction which is then followed by a presentation of findings (observational and those derived from in-depth interviews), from each of the Case Studies.

The first section one of the chapter deals with the Acute Hospital setting, first giving a brief pen picture of the setting and the participants. Further details are given in Appendix D (participants) Appendix H (the setting) and Appendix J (facilitator training and background). The chapter then progresses to a discussion and analysis of the findings arising from the data.

5.2 The acute hospital setting - Introduction to the Setting and Participants

The facility where reminiscence took place at the acute hospital was an age-related health care unit within a large urban hospital. The sessions took place in a room within the unit which usually served as a tutorial or meeting room. This was reflected in the décor which included medical posters on the notice board and a large rectangular table with plastic chairs. At one end of the room was a large television screen, with a computer to the side and chairs placed in a semi-circle around the screen.

There were two participants with dementia interviewed in this setting. One was Eamon who was 85 years old. He had undertaken many adventurous jobs in his life and had also been

[14] These two settings have been grouped together as in both, the PwD is either living in residential care or is likely to be discharged into residential care

involved in the family farm. He had a great love of poetry and music. He liked talking about the past and talking to people. The second PwD interviewed was Dora who was 84 years old. She was originally from the west of Ireland but had lived and worked for many years in England, before returning to Ireland with her husband. She was a housewife and mother and used to like dancing. She liked driving and going to church groups. There were two facilitators interviewed in this setting, Ciara and Ruth both from professional healthcare backgrounds.

The same type of reminiscence i.e. simple or general as defined by Gibson and as reported in the previous findings chapter was also in evidence in this acute care setting. At both hospital sessions observed, videos from You Tube, were used to prompt reminiscence.

At this hospital setting the two facilitators alternated in leading the reminiscence sessions on a weekly basis over a six week period. On some few occasions they were both present during the reminiscence sessions. The sessions also involved local volunteers who offered their services at the hospital. Despite requests to interview family members of these two patients no family member was referred to the study, hence in this case study the family caregiver perspective on reminiscence is lacking. In the section to follow data on the experiences of the PwD is presented.

5.2.1 The Acute Hospital Findings

The findings from the data are examined in the next section, using the themes established.

5.2.1.1 Connecting – communication and engagement with others

According to the facilitators, the main aims of the Reminiscence sessions in this acute care setting were to engage and occupy patients and improve their language/communication skills.

"You need to remember the goal of the group, you know that you do want there to be , you know, communicative participation" (Ruth, facilitator 2, acute hospital)

One reason identified for starting the group was that it was difficult to get patients to engage in cognitive linguistic work and reminiscence was found to be a useful way to do this

"it (Reminiscence) just evolved as we were wondering how we could improve our group, what we could do to get people better engaged and better motivated and to kind of target their interest better, you know...and you know obviously then you target better by using interests that are personal to people or that have cultural significance that are shared interests and then you kind of find yourself in the area of reminiscence because you want to use shared experiences to stimulate other kind of memories and interactions and you know to keep things going" (Ruth, facilitator 2, acute hospital)

Both facilitators clearly recognised the importance of encouraging communication and engagement by limiting reminiscence materials to ensure that more in-depth discussions of each could be fostered:

(Talking about the number of YouTube clips used in a session) ***"I suppose we're trying to limit to three or four clips and that people actually have a chat about things" (Ciara, Facilitator 1, acute hospital)***

During the in-depth interview, both Ciara and Ruth mentioned their noticing signs of improved communication and engagement on the part of these patients:

"I think the likes of Dora who doesn't always participate well did come up with a few, ahm, ahm, suggestions and she participated really well and seemed to interact quite well" (Ciara, facilitator 1, acute hospital)

It was also suggested during the interviews that communication and engagement between the patients themselves could sometimes continue after the reminiscence sessions and when patients returned to the wards.

"lots of times a lot of people, and like to go back together, are you coming back now, will I walk back with you, you know that they're really engaging and like there's that sense of camaraderie like and you know maybe hanging around in each other's room afterwards and continuing a conversation about something" (interview with Ruth, facilitator 2)

The data show that facilitating a group engaged in reminiscence was not always easy for staff members. Group facilitation required excellent communication skills and insights into patients' interests and life stories:

"whereas some weeks you have a lot of spontaneous chat where you need only three or four clips.....and other weeks you need a few more to try and I suppose draw out that communication" (Ciara, facilitator 1, acute hospital)

"well, we've had a couple of sessions where the clients just weren't really engaging.....and I suppose we had to use an awful lot of clips and there was no discussion stimulated" (Ciara, facilitator 1, acute hospital)

"saying what do you think and then what do you think and did you hear what John said over there and, you know you're kind of making sure that all, everybody's involved and it sort of seems to benefit people in that they like they, they enjoy, they show enjoyment and engagement with each other, because they do engage, you know" (Ruth, facilitator 2, acute hospital)

In response to a question asked of the two facilitators about why patients might look forward to reminiscence, both reported that the latter offered them the opportunity to communicate and engage.

When patients entered the tutorial/meeting rooms used for reminiscence, it was recorded that on both occasions each facilitator greeted each patient by name. Apart from this interaction, there was little spontaneous communication between participants and facilitators or with each, until such time as YouTube materials were made available on the computer.

Observation notes showed that one of the participants Dora seemed not to be that engaged early in the sessions:

"Dora is not responding to direct questions from the facilitator" (Observation 2, acute hospital)

"Dora closes her eyes for a few moments" (Observation 2, acute hospital)

"Dora falls asleep" (Observation 1, acute hospital)

"Dora is staring out the windows" (Observation 2, acute hospital)

However, later in the same session her communication pattern seemed to improve and she appeared more engaged in response to some of the clips:

"The facilitator was showing some video clips of Nelson Eddy (an American singer and film star popular in the 1930s and 1940s), at one point Dora pointed to the screen and said "I remember seeing that". The facilitator followed this up by asking what cinema she had seen the film at and she named a cinema "(Observation 1, acute hospital)

In the case of another patient Eamon who appeared to be generally talkative during both observations it was noted that he used the YouTube prompts to initiate conversations by telling anecdotes related to the clips. For example, a clip about the boxer Mohammed Ali, led him to recount how he had watched that particular fight in a golf club. This then progressed to an interesting conversation between all three participants at that session about boxing.

In response to music or film clips Eamon often sang either by way of joining in or singing a different song. It was noted that he sang spontaneously on six occasions over the two observations. He would answer questions asked directly by the facilitators and also spontaneously provided information relating to the clips, for example identifying the singer. He also spontaneously engaged in conversation with other participants, when his interest was aroused by a YouTube audio-visual clip.

"Eamon starts talking to Fergal about when Mohammed Ali had refused to participate in the Vietnam War, both Eamon and Fergal join in the conversation and then start to talk about the rhymes which Mohammed Ali was famous for, Eamon starts to say one of the rhymes but stops after a couple of lines , both Eamon and Fergal are laughing about the rhymes" .(observation 2, acute hospital)

The third hospital participant Fergal, was not so talkative. Observation of his behaviour during both sessions showed that he was attentive but frequently he ignored questions asked by the facilitator, only responding in a monosyllabic way. On one occasion during the first observation he was noted to have fallen asleep for five minutes. Most of the time however, he remained attentive to the audio-visual clips and responded to conversations instigated by others about the clips. He also responded appropriately to a request for song titles to be looked up on YouTube, asking for "The fields of Athenry".

Analysis of non-verbal communication such as facial gestures and feet and hand movements showed that all participants showed evidence of some engagement:

"Dora smiled and put her thumb up (in response to facilitator asking if she would like to hear more songs) " (Observation 2)

"Fergal is tapping feet to the rhythm of the song" (Observation 2)

Eamon and Fergal are tapping feet, Eamon is clicking his fingers too (Observation 2)

5.2.1.2 Connecting – with the family and wider community

Both facilitators during the in-depth interviews referred to reminiscence being an aid to improved communication between family members and patients, yet both failed to see the potential role family members themselves could have played in assisting them to use reminiscence more effectively with these patients:

"and also for family members, we've been able to tell them what topics the patients are really engaged in and they've been able to follow up with that on a one to one basis as well " (interview with Ciara, facilitator 1)

Ruth believed that improved communication led to positive change in family dynamics. She commented:

"you could come back and a family member might be waiting there to visit someone and you'll say that oh this is where we were today and they'll talk about it and you might hear back then from family members, look they really enjoy going there I know they can't remember when it's on or anything but...they do enjoy it and you know I had a huge conversation with them about different things.." (interview with Ruth, facilitator 2)

She also made the point about the valuable role reminiscence had in helping patients initiate conversation during visiting time. This she believed took pressure off relatives when visiting:

"and you know family members enjoy it like that but then cause it's not, they're not leading the conversation any more all of a sudden they're hearing a lot of new information that they don't know anything about, you know....so it's kind of, kind of a role shift that the...conversational partner maybe you know, the family member isn't the one initiating everything all the time and keeping things going" (Ruth, facilitator 2, acute hospital)

In their discussion of communication in family contexts and PwD, Allan and Killick refer to the contributions made by researchers such as Sabat and Crisp who have shared co-operative strategies such as turn taking, not interrupting, and awareness of nonverbal communication (Allan and Killick 2008). However, having to employ communication strategies and being 'in charge' of a conversation with a family member in a ways different to how conversations had previously been carried out may be hard work for family members and it is probably a relief to them when this changes as in the situation described by Ruth above.

There could be various reasons why PwD in this situation may be more able to contribute to the conversation. The reminiscence may have improved their communication abilities and their confidence and sense of identity may have been strengthened by the reminiscence sessions. They may have more, novel things to talk about. As noted previously these participants had been discharged from active clinical treatment, and as Ciara noted in her interview they were basically bored and under-stimulated, left sitting idly and could be seen to be deteriorating in terms of their communication and interaction skills. Under these circumstances it is likely that the participants had little to talk about, but the reminiscence sessions may have given them something to share with their family members.

It is curious that I was denied access to family members by the facilitators (who thought it inappropriate to pass on details) yet the same facilitators seemed very aware of the potential role family members play in reminiscence as during both in-depth interviews each referred to this. For example when asked if they had an unlimited budget what if anything they would like to include in a reminiscence session, if they had an unlimited budget, both suggested that one improvement would be the inclusion of families or carers:

"Or even, have an evening session where the families can come in and join in as well" (Ciara, facilitator 1, acute hospital)

"ahm, involve carers in it, that would be great, if we could get you know family members to come in and be kind of trained and helped to facilitate a group....and they mightn't necessarily always have, have to happen within our group as part, as this therapeutic programme for this person from a professional that it could be something that families could take ownership on and it could be something that would just support better communication and interaction amongst them...so if I had the money I would like to train more family members I suppose (laughing) "(Ruth, facilitator 2, acute hospital)

5.2.1.3 Connecting – seeing the whole person

One particular benefit of reminiscence as identified by both facilitators during the in-depth interviews was their being enabled through reminiscence to see the PwD as a "person": Ruth (facilitator 2) made this point well when she said:

"....you know I think hearing the stories of other people I think you know it really, it's just, ahm it's quite, you know it is quite fantastic really because you're getting to hear things and spend time with people and quality time with them and getting to really appreciate who they are as a service user, what they believe in...." (Ruth, facilitator, acute hospital)

"...you're not always just relying on caregiver report all the time...and that you actually can see how those things, those reports might be real for that person" (Ruth, facilitator 2, acute hospital).

Her colleague and co-facilitator reiterated this when she talked about the way in which reminiscence enabled her get to know her patients as "people" rather through their illness. She commented:

"and it helps to, I suppose, remo....you remove the diagnosis away from the person and actually try and get to know them a little bit better....and what their interests are, whereas as I say often in an acute hospital it's just kind of ah you know bed, room 9 bed 1 is dementia, room 9 bed 2 stroke and...you're thinking of people almost as diagnosis's unfortunately and that...so it's quite nice to remember people as people" (Ciara, facilitator 1, acute hospital)

These comments remind us of how vulnerable hospital patients are and how qualified staff can resort to labelling patients seeing them more through their illness rather than as people.

Both facilitators also commented that reminiscence could benefit them through enabling them to engage in new learning about the past and this could add to their better understanding the behaviour of participants within the group:

".....I find that it gives me a chance to, I suppose, on a personal level I learn an awful lot about the past that I wouldn't have a chance to" (Ciara, facilitator 1, acute hospital)

"....I've learned loads, like I've learned loads about a generation that you know isn't my own like" (laughing) (Ruth, facilitator 2, acute hospital)

They also reported how they witnessed improvements in interpersonal relationships between themselves and their patients as a result of reminiscence. In fact one of the Facilitators actually commented that those patients attending this reminiscence session were previously unknown to her as they had not been referred to her in the hospital. Accordingly as a direct result of conducting reminiscence with them she could now relate to them on a one to one basis during encounters on the hospital ward. She said:

"...the three patients who are here today actually aren't on my active case load at all. I've never really met them before doing the reminiscence group...but I will be in and out of, of the rooms on the ward they're in so I suppose I'd stop and have a chat with them on the corridor, and then...you know you've got something to have a chat to them about and again it means that you're not walking in their rooms and seeing everyone else and kind of ignoring these people" (Ciara, facilitator 1, acute hospital).

Comments like this infer that this facilitator (probably in common with many other medical, nursing and allied health staff employed in hospitals) only had time to get to know those particular patients who were part of her case load and taking part in the reminiscence groups gave her the opportunity to get to know others.

5.2.1.4 Re-connecting – enjoyment

There was good evidence of these hospital patients enjoying themselves during the YouTube Reminiscence sessions as reflected both in observations and following analysis of the data collected during the in-depth interviews with the participants and the two facilitators. One participant, Eamon for example in response to a question asked about if he enjoyed being

part of the reminiscence group, commented affirmatively and in fact showed that not only did he enjoy himself now but he would be very keen to continue attending reminiscence even after the 6 week programme had expired. He said:

"But I'd imagine that if, if that, the lady here, what's her name....(researcher gives her name)...XXXX (name), if she could get me, I hope I'm still here next...next Thursday (laughs) (interview with Eamon, acute hospital setting)

During observations, two of the participants, Eamon and Fergal showed signs of enjoyment during the group:

"Both Eamon and Fergal are laughing about the rhymes" (Observation 2, acute hospital)

"Fergal looked towards me at the end of the song and laughed" (Observation 2 acute hospital)

In contrast Dora, seemed to be more ambivalent about the reminiscence and in response to a direct question asked about whether she liked attending the group replied negatively and as follows:

Researcher – "Do you like coming to this group (Pause)

Researcher - "Do you like coming to this group and watching the clips on TV" (Pause)

Researcher - "No, you're shaking your head, No" (interview with Dora, acute hospital)

When questioned further, Dora said she would prefer to be driving. However, the data was somewhat contradictory as when asked about specific activities which took place during Reminiscence, such as singing or chatting, she said that she liked them. The observational data also showed signs of enjoyment:

"Dora is very animated, laughing, repeating words of poem on screen" (Observation 1, acute hospital)

"Eamon and Dora start singing" (Observation 2, acute hospital)

"Dora smiled and put her thumb up when song started" (Observation 2, acute hospital)

"Dora laughed at the end of the verse" (Observation 2, acute hospital)

Other fleeting signs of enjoyment were also noted during observations of Dora's behaviour. For example occasionally she appeared truly engaged, watching the screen attentively; however at other times she appeared to tune out by shutting her eyes, or by staring out the window. In fact on a couple of occasions she fell asleep for a short time.

5.2.1.5 Re-connecting - Agency and Choice

During the in-depth interview with one of the facilitators, Ciara (facilitator 1), she talked about how the patients were recruited to the reminiscence group. She said that only those patients considered likely to benefit from this reminiscence group were selected. This recruitment was done by medical and allied health staff, at a weekly case conference. As mentioned earlier the groups ran for six weeks. Accordingly, at the end of six weeks, if the next group was already fully subscribed and those currently participating wished to continue attending, their names would be placed on a waiting list.

The in-depth interviews with both facilitators revealed some flexibility along with rigidity in inclusion criteria for reminiscence group attendance. For example whilst sensory impairment was supposedly an exclusion criterion, it was noted during observation that a lady and another elderly man had hearing impairments. On the other hand, the criteria of having a MMSE score of 10 and above and allowing only those with good language skills participate in the reminiscence group were rigidly adhered to. Another definite exclusion criterion was challenging behaviours and this ruled out patients who exhibited behaviours such as aggression and sexual disinhibition from participation. According to the facilitators this was because the acute care setting lacked resources to cope with those behaviours within the group. As discussed earlier, this decision to exclude people whose behaviour may upset others in a group is in line with guidance from experts such as Gibson (Gibson 2011), but it is

not known if arrangements were made for these people to engage in other, more appropriate psycho-social activities.

Ultimately, the data collected suggested that the choice afforded to an individual to attend was limited and that the views of the multi-disciplinary team including the medical consultant were dominant. This absence of patients being afforded real choice was possibly understood by these PwD, as during the first observation it was noted that Eamon asked the question could he return to attending the reminiscence session following hospital discharge. At the time of interview, he seemed aware that he was attending the final week of a six week reminiscence cycle, and that he would not automatically be entitled to continue. However, some uncertainty existed as numbers recruited to the next group were low at that time so he may have been able to secure a place. It seemed however that the decision about attending reminiscence was outside his control.

During observations it was recorded that a PwD could leave the group at any point. Indeed on a couple of occasions it was noted during observations that if patients felt unwell or uncomfortable they were taken back to the ward. On one occasion, a woman half way through the reminiscence session and for no apparent reason asked to leave the group. She said she wanted to return to the ward. It was recorded in observational notes that the facilitator then spent some time trying to find out the reason behind her wish to leave. The lady persisted in her desire to return to the ward and her departure was in due course arranged insofar as a porter was called and collected her. One can deduce from all of this that patients were afforded some choice and the facilitators seemed to respect patients' wishes:

"It's not something that everyone can fit in and enjoy, and sh, should be expected to enjoy either" (facilitator 2, acute hospital setting).

In the context of patient choice, autonomy and decision-making about attending reminiscence, Ciara made the point that whether patients stayed in reminiscence or not was entirely up to themselves. Interestingly in her conversation she made a point of

differentiating between patients feeling distressed versus their being distracted and claimed that if ever patients felt distressed by reminiscence or otherwise, the facilitators tended not to actively encourage them to return to reminiscence:

"I suppose our consent is time based so they can leave at any point they want and if they do leave then we will try again for a second week, and it depends on whether it's they've left because of distraction or because they're distressed, if they're distressed we generally don't try and bring them back into it....because it's not the right format, but if it's just because they're distractible and they can only last ten minutes we'll bring them back the following week. But again, be prepared to bring them back half way through the group" (Ciara Facilitator 1, acute hospital setting)

Despite her narrative purporting to offer patients choice, it is curious that this facilitator used the word consent rather than choice when she spoke in depth about the issue. Spaeth, an American physician, in a discussion on medical ethics notes that consent implies a relationship built on power whereas choice is not inextricably linked with another person's proposal and encourages autonomy (Spaeth 2010).Choice infers an active decision, whilst consent infers agreeing to something with a possible element of compliance. Based on Spaeth's thesis, the facilitator's commentary here may reflect an imbalance of power and point to a possible lack of real choice for hospital patients when it concerns therapeutic interventions. This issue will be re-visited in the discussion chapter of this thesis.

During the interview with another hospital patient Eamon, when asked the question if he believed he had a choice in attending he Reminiscence, he stated:

Eamon – "No, no I got a stroke"

Researcher – "you got a stroke, but you've got a choice in coming to this group?"

Eamon – "oh, yes"

Further analysis of his response might suggest that Eamon saw reminiscence as part of his treatment programme because of his illness and for this reason attendance was mandatory and he had no choice. Alternatively it might suggest that his view was because he had a stroke he could exercise no rights over what he could and would do and decisions were made for him.

As the third hospital participant, Dora was not responding well to direct questions, the issue of her exercising choice in relation to her attendance at this reminiscence session was explored indirectly. This was done by asking her whether she enjoyed the group and if she would prefer to be doing other things. Interestingly Dora replied she would prefer to be driving. Preliminary analysis of these data would suggest that Eamon, Fergal and Dora believed that there was no real choice afforded to them in terms of reminiscence group attendance and this is despite the fact that the facilitators believed that patients were afforded choice

Both facilitators had a well-planned programme for each reminiscence session. As mentioned earlier each chose in advance particular audio-visual clips based on the known interests of the participants as reflected in information collected in Social Interest Questionnaires (compiled on admission to the hospital) and on requests made by participants during previous Reminiscence sessions. However, the Reminiscence sessions observed were flexible and both facilitators appeared to have a large repertoire of materials and were able to incorporate participant requests in an ad hoc manner. Both actively encouraged participant involvement in this context:

".... they've got some autonomy over what they can control because they know that they can, their say in the group if we can't facilitate it that week we do take notes and try and bring it in" (Ciara, facilitator 1, acute hospital)

and one of the facilitators commented about the advantage of YouTube over other approaches used in the past:

"but I suppose the beauty of YouTube and the reason we're using it is because we're trying to have it as flexible as possible...so that it can flow with the patients because I think we have had, as I said our previous group (referring to a previous communication group) we would have been, very organised in what we were going to do...and it didn't work, because we didn't always, we might have had a second back up, but it just wasn't stimulating the patients and it wasn't working (Ciara, Facilitator 1, acute hospital).

Her views were strongly supported by my own observations during both site visits, where participants were noted to exercise choice during reminiscence, and where they requested particular audio-visual clips and generally influenced the direction of the conversation:

"Eamon asked for a clip of Hubert Valentine, a singer" (observation 1, acute hospital)

"The group have been looking at sporting footage and Eamon relates an anecdote about visiting Croke Park and how it had cost him 3 shillings (observation 1, acute hospital)

"The facilitator asks if there is anything anyone would particularly like to hear, Fergal asks for The Fields of Athenry" (observation 2, acute hospital)

5.2.1.6 Re-connecting – Identity and Self-worth

Data recorded in observation notes and during the in-depth interviews with two participants were later analysed for evidence of how reminiscence may have affected patient's identity and self-hood. Observational and interview data revealed how participants had strong views about certain topics such as sports or subjects connecting back to their former occupational roles.

Eamon for example spoke at length about his very interesting earlier work experiences and career and Dora appeared to have a strong sense of who she was (identity) and was not afraid of putting forward strong opinions on certain topics. When Fergal and Eamon discussed boxing, and Ruth mentioned that boxing no longer featured much nowadays on TV

Dora stated "that's because it's cruel". Considering Fergal and Eamon had been talking about boxing in positive terms, Dora's commentary could be interpreted as demonstrating assertiveness and a strong sense of identity.

During the in-depth interviews, both facilitators reported instances where patients attending reminiscence had displayed intact selfhood or strong identities. [15]Ruth (Facilitator 2) referred to the way in which the setting and possibly the prompts used tapped into old memories which in turn inspired confidence and brought out the best in these patients. She said:

"but also I think people kind of surprise themselves by the amount that they can recall, in they might feel that they can't you know recall a lot, and they mightn't feel confident about their ability to recollect things...but yet in that type of, in a reminiscence cont..context might really be able to bring a lot of more things that give them confidence that they can recall these and even feel confident by you know recalling memories in front of other people and telling people a story" (Ruth, facilitator 2, acute hospital).

5.2.1.7 Supporting the Reminiscence Experience – Dealing with sad and traumatic memories

Gibson reminds us that facilitators are sometimes cautious of encouraging reminiscence because of the possibility of it causing harm by reviving sad or painful memories. However, as she points out although facilitators should always be aware of the possibility of doing this, they should also be aware of the harm that can be caused by inaction where the PwD is left without appropriate stimulating activities (Gibson 2004). Ciara (facilitator 1) showed awareness of this when she said:

[15] In-tact selfhood is defined by Sabat as comprising of three parts, the self of personal identity, the self of physical and mental attributes past and present and the self of social personae which require the co-operation of others to be manifested (Sabat and Collins 1999)

"we've got 12 people waiting on long term care and they're discharged from every active intervention and they basically they're left sitting in corners in their sitting rooms and you can actually see them deteriorating....in terms of their communication and ahm interaction skills..." (Ciara, Facilitator 1, acute hospital)

She said that in an attempt to address patients' boredom, a social group had been started by the facilitators and this in turn had led to the development of the reminiscence sessions.

In response to some open-ended questions asked during the in-depth interviews about reminiscence triggering distressing emotions, Eamon ironically seemed to link the emotions of sadness with happiness. Interestingly whether because of his stroke or otherwise he seemed to view sadness as an emotion potentially linked to happiness.

Researcher – "and in these sessions, these, these video reminiscence sessions, the YouTube sessions, ahm, is there anything in them that would make you sad?"

Eamon – "well, sad in a good way, or sad in a bad way?"

Researcher – "whichever way" (Interview with Eamon, acute hospital setting)

Eamon talked of a well-known artist whose songs he loved but made him sad, as he (the singer) was now dead and ***"it's so sad that the good go young" (Interview with Eamon, acute hospital setting)***. He later returned to issue of paradoxical emotions (sadness and happiness) intertwined when he was asked if anything in the sessions made him particularly happy;

Eamon "sadness is often the cause of happiness" (laughs)

Researcher – "oh right" (joint laughter)

Researcher "what, one leads to another?"

Eamon "yeah, one leads to another"(interview with Eamon, acute hospital setting)

The notion of sad feelings leading to happiness seems to be paradoxical although it is known that people who have had strokes may experience emotional lability[16]. In the area of music psychology, research has shown that people sometimes report a positive effect after hearing music which they have described as sad music (Schubert 1996). Certainly many people enjoy sad music as well as sad films, and sad novels. So Eamon's linking of these two emotions is quite understandable.

In contrast, Dora when asked about sadness in the context of reminiscence failed to reply. It is not clear why she did not reply and whether her absence of response was because she chose not to share this information or that she was just distracted and had difficulties understanding the actual question. However, during the first observation it was noted that when the facilitator had searched on YouTube for some clips that might bring back happy memories, Dora said ***"and some sad ones" (observation 1).*** When observed none of Dora's body language reflected her being distressed and when saying this it was more as if she was just stating something factual.

During the in-depth interviews, both facilitators were asked if they ever witnessed a PwD becoming distressed during reminiscence. Ciara claimed this had happened only once when a particular gentleman requested one of his favourite songs to be played and then was later found by his daughter upset in his room listening to the song, a song which he was prone to requesting on a regular basis. According to Ciara, his daughter said that he had also asked that this particular song be played at his funeral. In recounting this narrative, the facilitator claimed that she had handled this incident appropriately at the time by calming the man and talking through the issue with his daughter. However her account of the incident warrants further analysis in the light of some leading expert's commentary on reminiscence generating distress.

[16] Emotional lability is when a person exhibits overly excessive emotional reactions and frequent mood changes

Gibson for example advises that when carrying out reminiscence with a PwD the facilitator should be alert for recurring themes. The fact that this man often requested this song was significant, but it was not picked up by the facilitator. He may have requested the song each time because he simply liked the song, or because it conjured up special memories or it could have been, as his daughter indicated, related to the fact that he wanted it played at his funeral. The facilitator, if she had known the significance of the song, could have explored this further with him. If the reason he asked for this song was related to the fact that he wanted it played at his funeral, it is possible that he wanted to explore issues around his eventual death. Webster (Webster 1997) and Cappeliez and colleagues (Cappeliez, Guindon and Robitaille 2008) incorporate death preparation, including the valuing of life lived and becoming less fearful of death, within their classification of reminiscence functions. The man may have been indicating a need for this.

The other facilitator Ruth during the in-depth interview acknowledged the fact some people became sad during reminiscence although in her own experience she had not observed patients having any major adverse reactions. She claimed that sadness during reminiscence could arise for several reasons; the person might be unhappy in the group, or sadness could be related to the reminiscence material itself such as war-time prompts. She also said she had seen people appear distressed during reminiscence sessions which focused on tragic subjects such as the sinking of the Titanic – an event which although they were not personally involved could evoke sad memories.

"...The Titanic, I remember people are (laughing) really sad after that as well and...it's because the, those emotions are real and the time they're in the room these memories are unfolding.." (Ruth, facilitator 2 acute hospital).

Ruth (facilitator 2) claimed that reminiscence around war time could arouse sad feelings, even for those who had not been directly involved:

"and maybe it didn't have as major significance in your life at the time, and people can still, you know, feel quite sad about it, I suppose and maybe it's the whole memories of the aftermath of the war whatever.....you know, that were true of their lives, from their parents or their grandparents, and yeah, those kind of things people can feel sad after..." (Ruth, facilitator 2, acute hospital)

Ciara on the other claimed it was not always possible to anticipate what emotions would be aroused by particular reminiscence material. She gave the example of a reminiscence session which had included a discussion of the bombing of Nelson's Pillar in Dublin. She said she was wary because she had originally thought Reminiscence on this topic could have been problematic but it transpired that talking about this resulted in an interesting discussion with no evidence of undue upset.

"...people who weren't even in Dublin who would have heard of it and I suppose it brought up a lot of issues around that, and there was no I suppose, we were kind of, kind of concerned that there might be negative effects of patients discussing issues like that and there wasn't, so I suppose that was quite a good session" (Ciara, facilitator 1, acute hospital)

In common with other facilitators, data showed some evidence of caution certainly on the part of one of the facilitators about the potential Reminiscence had to trigger distressing memories.

Ciara reported she tended to avoid certain political topics such the Troubles in Northern Ireland and protest marches in case they triggered negative reactions. She felt that there may not have been enough support available within the hospital especially because the person would be returning to an acute medical ward. The way in which patients' emotional reactions can be medicalised in hospital settings was reflected in her words:

Facilitator - "but again we're, we're not equipped to deal with the fall-out from that and ....you know we would have obviously, we can get support from the Psych-Old Age but

again that's quite an extreme reaction...but even just to help calm the person, they're going back on to an acute medical ward...generally, so they don't even have somewhere quiet to go for some time out so...I think we could, we have to be quite careful that we don't.....so unfortunately I think we're going to end up glossing over a lot of subjects..." (Ciara, facilitator 1, acute hospital).

This finding is in accordance with findings from Pullan's study of the experience of care staff delivering reminiscence sessions to PwD (Pullan 2009). The latter reported that when a PwD experienced a traumatic reaction, staff became upset and then felt guilty for creating extra work for their colleagues who were left dealing with the person. This finding from this thesis perhaps points to the need for a support network to be ready and available in case of this rare occurrence.

Interestingly, her colleague Ruth seemed far less reticent about dealing with sad emotions triggered by Reminiscence. She said;

"I think it's important like that you kind of, you know you don't rush off from the topic all of a sudden to cheer everybody up, ahm, because it's important that's part of reminiscence...you're reminiscing on things that maybe aren't you know pos...positive and happy and pleasing"(Ruth facilitator 2, acute hospital).

Obviously this facilitator saw the importance of allowing hospital patients experience both happy and sad memories when participating in reminiscence. She continued by talking about the importance of acknowledging feelings whilst delivering reminiscence sessions and said:

"***you know, talk about it and you know or acknowledge the feelings got, you know that seems to be making you very sad there and ...is it because you knew somebody or is it because it just you know there's a great sense of sadness with all the lives lost" (Ruth, facilitator 2, acute hospital)***

5.2.1.8 Supporting the Reminiscence Experience – Creating a safe place

As mentioned earlier, the reminiscence sessions being studied for this thesis at this hospital took place in a small, tutorial room on a weekly basis. The clinical and educational features of the room were reflected in the décor, which included medical posters on notice boards, and a large rectangular table with plastic chairs. It was obviously a hospital room and furthermore a staff teaching environment as reflected in the educational posters and flyers on the noticeboard advertising staff educational and support events. However, some thought had gone into the layout of the Reminiscence group as evidenced by the fact that the chairs were arranged in a semi-circle around the television screen. The latter promoted easy viewing of the screen containing reminiscence prompts. It also enabled participants to hear and see each other easily. When porters brought patients down from the wards into the room, it was noted that some time was taken to help participants to settle into chairs, or position wheelchairs. Porters and facilitators checked participants were sitting comfortably and items such as blankets were acquired for those who wanted them.

Despite the "unhomely" and clinical/educational features evidenced in this room one of the facilitators firmly believed that compared with the hospital ward the lay out, equipment and features of this tutorial room were conducive to reminiscence. She commented:

"....the fact that we've a good facility, like we've a really good flat screened TV that people can see and you know it's accessible to people ahm and also a good sound system ahm, so you know these kind of things, the facility kind of helps with the group, the room the actual environment in the room, the fact that the lighting can be modified, the sound can be modified, there's ample space for the numbers we want in the group" (Ruth, facilitator 2, acute hospital)

It is interesting that neither the PwD nor the facilitators were in any way critical of the room where reminiscence took place. This may be because the room represented a setting a little less clinical and public compared with their hospital ward.

5.2.1.9 Supporting the Reminiscence Experience – factors which encouraged or hindered reminiscence.

As mentioned, this Case Study was conducted in an acute hospital setting, an environment which the literature notes is far from ideal for PwD (Cahill et al 2012) because of external features such as noise and the complex lay out of hospital wards and other more systemic and structural features such as lack of training in dementia of hospital staff and the emphasis on a fast turn-over. Nolan reminds us that PwD within an acute hospital setting are a very vulnerable group, as they are dealing with their own memory and cognitive problems together with an environment which may be large, unstructured and unfamiliar (Nolan 2007). Observational notes record that both facilitators in this setting, appeared to be very caring and person-centred in their behaviour towards patients, greeting each patient personally and by name, smiling at them and opening up with a welcoming conversation. In the in-depth interviews conducted with both, they acknowledged the importance of creating a safe environment for the reminiscence sessions, and during observations, it was obvious that they took time to ensure participants were sitting comfortably and had blankets, cushions, drinks and whatever else they needed to promote comfort. However, the physical layout of the room may have adversely affected the reminiscence sessions as in my view it was stark, clinical and institutional complete with bright lights, a disinfectant smell, shiny floors, and background noise. The staff also wore uniforms, which could also have contributed to the overall feeling of a medicalised environment. Both staff appeared somewhat unaware of these features.

Another intriguing finding emerging from the in-depth interviews with the two facilitators related to the tensions and pressures these allied health practitioners were subjected to, delivering reminiscence in a hospital setting where the emphasis was more on patient outcomes such as health gains, early discharge and physical functioning and rehabilitation rather than on quality of life. Their comments suggest that management staff did not quite

appreciate the use of reminiscence with hospital patients and that in the acute care setting successful intervention tended to be measured by therapeutic gain. Ruth (facilitator 2) talked about the fact that ironically those most likely to benefit from reminiscence tended to be discharged early or sent for rehabilitation and she questioned the future viability of this type of intervention when she said:

"I think I'm kind of torn here because you know ahm, it I can see how beneficial it is....but yet, it's an acute environment and you know, people once they're medically stable obviously they're ideal to engage in terms of their attentionals and their ability and their capacity to join in and engage, ahm, are better for reminiscence work but you know at that point they should be you know ahm, moving back to the home environment or moving into residential setting or moving into rehab somewhere....you know and this kind of, they, they shouldn't necessarily be waiting here with us so...ahm, I think it's something that should be done definitely but I think that you know ahm, the pressure of how a service operates for where I am and stuff like that .....I think eventually in the next few years will mean that something like this isn't going to be you know viable any more" (Ruth, facilitator 2, acute hospital)

Her words suggest her belief, that within the hospital setting, there was a need to demonstrate some definite therapeutic outcome from her work. She indicated that it was important to be able to justify or report on what functional improvements if any, reminiscence brought about and curiously that a general person-centred aim such as improved well-being would not be accepted by management:

Facilitator – "then, you need to remember the goal of the group, you know that you do want there to be , you know, communicative participation and you also want there to be a degree of cognitive stimulation going on...and so you know in that sense, the people might draw a great sense of well-being out of listening to music but it's not necessarily for the, the purpose that we, we are you know conducting the group for there, that's not the sole purpose, the well-being"

Researcher – "that's not your original aim, sort of"

Facilitator – "yeah, it's one of the aims I suppose...but it's not the main reason we're doing, you know that doesn't sound great you know but (laughing)"

Researcher – "no, no I know what you mean"

Facilitator – "like our time needs to be validated...the therapeutic input" (Ruth, facilitator 2, acute hospital)

The other facilitator Ciara also appeared to be under pressure, by hospital management to be accountable and to justify outcomes for the intervention in this case reminiscence sessions:

(referring to her usual role) "...I suppose it's easier for us to justify to a...to managers why we're doing it in terms of, actually we're trying to improve their functioning that maybe it's going to mean they'll need a less dependent bed in a nursing home...which again will have an impact on cost whereas the reminiscence work isn't necessarily being able to be explained away like that" (Ciara, Facilitator 1, acute hospital)

Videos from the YouTube were used as prompts in this setting, and in the sessions observed were mostly related to music and films. This was a popular prompt and seemed to encourage engagement and communication resulting in some quite lively sessions. Watching the videos prompted participants to join in singing and to recall memories of events in their own lives connected to the videos, for example memories of when they had seen a certain film or when they had watched a particular sporting event.

5.2.1.10 Setting Summary

In contrast to the respite care facilities discussed in the previous chapter, the findings emerging from this case study based in an acute hospital setting reflect the dominance of the bio-medical model. Here doctors and allied health staff selected those patients who would participate in the reminiscence sessions and decisions about this were based on MMSE scores

on the absence of challenging behaviours and on patient potential for rehabilitation. The reminiscence sessions were planned in advance. The environment was stark and clinical; staff wore uniforms and felt under pressure to justify their professional contribution to patient care. If patients became distressed due to sad memories being triggered off by reminiscence, these problems were medicalised and reference was made to referral to Old Age Psychiatry.

Despite this, the participants appeared to enjoy reminiscence and said they did although one participant identified another activity as preferable. Reminiscence encouraged engagement and communication between participants and facilitators benefited by getting to know the participants better and also increased their personal knowledge of the past. Reminiscence was also shown to enable facilitators to see the participants as individuals rather than as patients. Participants were able to influence the direction of the reminiscence session and this was encouraged by facilitators. The use of YouTube particularly clips relevant to these patient's lives appeared to encourage reminiscence.

Reminiscence did not seem to particularly prompt any sad or distressing memories, with the exception of one incident, which was appropriately and easily dealt with. One facilitator commented that topics such as the war or the sinking of the Titanic could cause some distress, even if participants had not been actually involved in the incidents. One facilitator said she avoided certain topics as she felt they were not equipped to deal with any traumatic reactions.

There was no researcher access to families at this site despite several requests for same. Curiously however both facilitators thought that in general family members and relatives could benefit from reminiscence and spoke of liaising with families.

5.3 The nursing home - Introduction to the Setting and Participants

The fourth Case Study for this thesis was based in a moderate sized nursing home situated on the outskirts of Dublin. The nursing home was private and had a bed occupancy of 55 people.

At the time of the site visits the nursing home was undergoing construction to enlarge it, so building work was having a temporary impact on the setting. The nursing home was a large single floor building with access through a locked door via a buzzer entry system. There was a reception desk inside, a door to an office and then corridors leading off the area. The reception area looked welcoming and there was good, clear signage throughout. The rooms used for reminiscence at this setting were temporary fixtures. The first was a medium sized day room, which was due to be closed because of the ongoing reconstruction. The room was pleasantly decorated but fairly empty apart from the chairs (because it was soon to be closed off). The facilitator had however provided a small table with a tray laid out with glasses, a jug of orange squash and a small bowl of chocolate sweets for the reminiscence group. The second room used for reminiscence was usually used as a hairdressing salon. It was open at one end although the facilitator had pulled a curtain across (similar to the ones used in medical facilities to cordon off bays) to give some privacy. Again in this room the facilitator had provided a table with glasses, a jug of orange drink and a plate of biscuits for the group.

Three participants with dementia were interviewed in this setting. Claire was 93 years old and had lived in the nursing home for over three years. She was a widow and came from a large family. Her father had been a prominent man in his local community with strong political ties. Claire had been a housewife and mother of two sons both of whom went on to have very important government jobs. She was very proud of her family. Claire liked music and she used to like dancing. Patrick the second resident with dementia was 81 years old and had lived in the nursing home for five years. He was a widower and had done bar work and shop work when he was young before starting his own business which had been very successful. He liked joking and chatting to people. Liam the third resident with dementia was 79 years old and had lived at the nursing home for just over a year. It was thought he had never married but he had recently started talking about a brief marriage when he was young. He had extended family who visited often and he liked singing, reciting poetry and talking about his family.

The facilitator -Brenda came from a non-professional background.

As with the other case studies simple or general reminiscence sessions took place on a regular basis, decided on by the management and the facilitator. In line with the other three case studies, two observations were undertaken. In-depth interviews were conducted with three residents selected by the facilitator, although at this facility the in-depth interviews were conducted collectively rather than one to one making this session more like a Focus Group (this was a decision made by the PwD). In addition an in-depth interview was carried out with the Facilitator of the reminiscence group. Efforts were also made to interview family members of the three residents selected for this study but only one was available. The data therefore presented in this last section of this chapter has been generated by these mixed methods.

The first reminiscence session used general conversational prompts and a total of four residents participated in this session. The second session used conversational prompts along with a rummage box containing memorabilia including items likely to stimulate the senses such as Vick's vapour rub. The observations took place three weeks apart.

For a full description of the setting (see Appendix H). At this nursing home, unlike the other three settings reported on so far in this thesis, the area where reminiscence took place on the second occasion lacked privacy and the environment was generally noisy as a result of building work going on outside and as a result of a temporary room being used as an activities room, which was situated right beside a high dependency unit from which noise could be heard. It should be emphasised however that this was a temporary situation due to the ongoing building work. A pen picture of the three study participants Patrick, Claire and Liam, the PwD interviewed and Brenda the facilitator is given in (Appendix D) with facilitator training details given in (Appendix J).

5.3.1 The Nursing Home Findings

The findings from the Nursing Home setting are presented below using the themes established.

5.3.1.1 Connecting - communication and engagement with others

Evidence of engagement and communication between the residents and the facilitator and between the residents themselves was noted in observations. Brenda used leading questions to draw participants into conversation but it was also noted that participants conversed spontaneously with each other and this was triggered by the reminiscence topics such as discussions about dancing and schooling. The three participants were noted during both observations to act empathetically towards each other. For example during the first observation at one stage Liam had forgotten the words to a song and two other residents (Patrick and Claire) were observed as supporting him with Patrick commenting encouragingly: ***"you're doing alright, you'll remember the words in a minute" (observation 2 nursing home).***

In the first observation, the facilitator had asked Liam to sing. Liam then asked one of the other residents what song he should sing to which she responded by singing a few lines of a childhood rhyme (the cow kicked Nelly in the Belly). Liam then insulted this participant by commenting ***"that's not a song"*** in quite a sarcastic tone, at which she looked quite hurt. It was noted that Brenda held her hand at this point to comfort her.

Later the following conversation between myself and this participant was recorded in field notes, which seemed to refer back to this incident:

Researcher - ".... Do you enjoy coming and singing and talking?"

R - "I don't think I was doing anything or any talking, was I?"

Liam - "you kicked Nelly in the Belly (said in a sarcastic tone, referring to the rhyme)

Researcher – "you sang a nice Danny Boy"

R – "Oh, I did (seeming to remember) I sang a nice one"

Liam – "and you, and you kicked Nelly in the Belly" (interview, nursing home)

It seems that Liam was not prepared to let go and was determined to remind her of her perceived inadequacies.

It was interesting in this reminiscence group that although the facilitator made a point of saying that she tried to ensure that people with similar levels of cognitive impairment attend, there was a person in this group who appeared to be more severely impaired and she appeared to lack concentration and was not nearly as engaged as others. Observational data also reflected other participants being frustrated by her behaviour. Claire for example on a few occasions commented about this lady's restless behaviour. She also made facial expressions -raising her eyes as if in despair. In the first observation her lack of empathy was especially observed:

" Another participant got up and wandered off to the windows at this point. Claire commented that "this will go on all day" (observation 1, nursing home)

Claire's lack of empathy and apparent rudeness may have been caused by her dementia her inability to conform with social norms and etiquette and her not thinking about the consequences her comments might have on others. Her remarks along with others such as Liam's, raise the question of whether it is appropriate to include people with differing levels of cognitive impairment in a reminiscence group

5.3.1.2 Connecting – with the family and wider community

Brenda said she tried to get to know the families well during visiting time at the nursing home. This helped with trying to develop individualised activities to use with individual residents. Interestingly she said she was not always told the truth by family members:

"they do the care plan and everything, but then an awful lot of people don't tell you the actual truth, I mean...whether they're afraid to tell you that they're not able to do this or they're not able to do that" (facilitator interview, nursing home).

She said the nursing home had completed "one or two" life stories for residents. These she claimed had been useful and the families had loved them, but she also said they did not always have co-operation from family members. She cited an example of a case where despite repeated requests made to a particular family to bring in a resident's photographs for the purpose of making up a life story book, the resident's wife refused. This man's son had actually sorted the photographs out, so they were available, but for some reason the wife refused to bring them in. In this example the man concerned wanted to compile the life story book but his wife, who had control of the photographs he wanted, would not supply them for whatever reason. This lady may not have wanted to share family photos in case they might get lost into the nursing home, or she may not have wanted to address issues around her husband's disease progression. However, sadly her lack of co-operation meant her husband was unable to complete the life story book in the way that he wanted to.

In line with findings from each of the other three Case Studies, the family member interviewed in this setting (Patrick's step-daughter)seemed unaware of reminiscence and had little knowledge of what went on at the nursing home on a day to day basis. She said she had only been told the basics but knew Brenda well and was happy with that.

There was no evidence from the data collected for this thesis of people being connected to the wider community in this setting, although on the days of the site visits, it was noted that the nursing home was busy with many visitors and it did seem to have a welcoming ethos.

5.3.1.3 Connecting – seeing the whole person

Brenda was the only facilitator who referred at one point in her interview to PwD as *"not being Alzheimer's"*, thereby referring to people by their illness rather than their name, which could indicate not seeing the PwD as a whole person. However, in all observations Brenda was noted to act in a person-centred manner, so it could have been that this was just an unfortunate turn of phrase.

Brenda acknowledged that she learned a lot about the PwD in her care as well as learning about local history and past times during reminiscence sessions. In her interview, she described how finding out more about the PwD often led her to understand the person better and understand why they might or might not want to do certain things. She also described how some of the narratives which were shared with her during reminiscence made her think of episodes in her own life(for example family problems) and she was able to fully empathise with the PwD. In this regard, her narrative can be contrasted with that of Mary (Case Study 1 who mentioned she tended never to be affected by reminiscence. This is an indication that Brenda viewed the PwD as a whole person, with whom she could empathise.

5.3.1.4 Re-connecting – Enjoyment

Wilson and colleagues in their case study of the use of conversational laughter by a PwD note that laughter can be used by a PwD to enhance everyday conversational efforts. In this setting Patrick may have been using humour and laughter in this respect (Wilson, McKee, Elford, Chung, Man, Goudie and Hinchliff 2007)as during both sets of observations jokes were spontaneously made by participants with much friendly banter, resulting in smiles and laughter. Patrick for example was observed in both sessions to make jokes and witty remarks, often in response to something others including Liam said or sang:

(After Liam had sang a song) Patrick - "I'd have two pints of stout with that" (observation 1, nursing home)

(After Liam had sang a song, which the facilitator had said he had sang for another resident-Rita)Patrick joked that a romance could be starting (observation 2, nursing home).

During the second observation when the facilitator was talking to Liam and jokingly asked him about all the hearts he had broken it was noted:

Patrick makes a joke about Liam being a heartbreaker" (observation 2, nursing home).

When the three residents with dementia living at this nursing home were asked directly during the interview if they had enjoyed taking part in the reminiscence session, Patrick was the only person who said yes and that he liked the general atmosphere and chatting which took place there. The second study participant (Claire) failed to respond and the third resident (Liam) commented that he liked walking, suggesting maybe that he preferred being outdoors and taking exercise than sitting within doing reminiscence. Later however he said he liked attending the group because:

Liam - "well, you, you can, relate for no reason"

Researcher – "you can relate stories?"

Liam – "and ah, sing a few songs you know" (interview, nursing home)

Liam's commentary suggests he enjoyed the group especially the singing, but quite clearly walking was his preferred activity.

Interestingly, when Patrick was asked whether he enjoyed the sessions his response seemed to infer that he liked reminiscing since it helped him forget things which were not good for him, or perhaps events that caused him some anxiety:

Researcher- so you know when you're here and you're talking and you're singing and everything, does that make you happy...?

Patrick - well it does, it makes you forget them, forget a lot.

Researcher – you forget a lot of things? Yeah (Pause)

Researcher - what sort of things do you forget then?

Patrick – well you think of things that was all good to you

Researcher – yeah, yeah

Patrick – for you forget things that was not good for you

(interview with Patrick, nursing home)

His statement seems to imply that reminiscence for him had a role in helping him concentrate on happier memories rather than sad ones. It could be that reminiscence helped Patrick to reframe his life in a more acceptable form for him.

During the in-depth interview, Brenda the facilitator made a point of saying how she thought that reminiscence was particularly effective for people who were cognitively in-tact

"yeah, now we have a few ladies who aren't ah you know ah, Alzheimer's, they love the reminiscence...they would go on for ever because they can talk and they can remember and the can sort of share their stories" (interview with facilitator, nursing home)

Her comment here seems to suggest that reminiscence may be more beneficial for people who are still cognitively intact compared with those with a dementia. As noted before, in referring to residents as "Alzheimer's" the language she uses is not very person-centred. When asked if she thought residents with dementia looked forward to the reminiscence she claimed they were unable to look forward to the sessions. Brenda said that she enjoyed her job in general as an activity co-ordinator at this nursing home and indicated that she thought the participants enjoyed the sessions:

"I enjoy it, I like, I like my job and I enjoy it and I, I enjoy the, the ladies and we have a bit of fun and we have a bit of a laugh" (interview with facilitator, nursing home).

5.3.1.5 Re-connecting – Agency and Choice

When Brenda was asked the question on what basis residents were selected for reminiscence she said that she generally with support from her Assistant Manager chose those whom she thought should attend. In this way, it was apparent that residents were chosen for reminiscence sessions, and that they did not volunteer themselves. Indeed the interview with Patrick's seemed to suggest that he would like to attend reminiscence on a more regular basis. He said:

Patrick – "they said I was here before and I wasn't"

Researcher – "OK"

Patrick – "I was a day or two"

Researcher – "alright, do you do many things here?"

Patrick – "no, only, only now and again"

During the in-depth interview with Brenda, she reported that she normally tried to limit the reminiscence group to a maximum of six people each of whom had a similar level of cognitive impairment (although this was not the case in the sessions observed as a couple of participants appeared to be more cognitively impaired than others). She claimed that this was important to get the group balance right. Brenda was aware that reminiscence did not suit everybody and possibly aware too that the choice of suitable participants was important for her in terms of the smooth running of a reminiscence session. Like the other facilitators interviewed for this thesis, she also acknowledged that even though she may have planned a session, flexibility was most important. The reminiscence sessions would not always go according to plan and that was down to the individuals taking part in the session:

"and sometimes it doesn't always work, you come in with the best intentions of the world but it doesn't work out that way...so you have to go along, you've got to remember that

this is their home, so you have to go with them rather than with us" (facilitator interview, nursing home)

In the sessions observed Brenda started the conversations and led the general direction, but there was evidence that participants were afforded opportunities to change topics and take the lead in conversation. One example of this was when the group was talking about schooldays and Patrick said ***"I wanted to get away from school".*** Brenda took this as a cue to start talking about Patrick's working life. Accordingly whilst participants seemed to exercise little choice or control over whether or not they could attend a reminiscence session, it was noted that, they were given opportunities during reminiscence to shift the conversation topic away from that started by Brenda, although staying within a similar theme. In this way the reminiscence could be seen to have a "conversational ripple" effect. For example on another occasion, Brenda began talking to the group about dances. She then prompted conversation by asking questions about local dance halls in former times. Then a participant Claire used this as a cue to shift the conversation on to talk about clothing and dresses she wore for dancing:

"I had ten dance frocks..... Claire started making dancing moves in her chair (using her upper body). (Observation 1, nursing home)

In the context of choice and autonomy, during the observations some evidence emerged that if a participant wanted to leave the group, he or she could, although efforts were generally first made to persuade people to remain:

X (another resident not selected for study interview) is walking off, the facilitator says "would you not stay with me a while" X answers "of course I will I just wanted to see what was going on" (observation 2 nursing home)

Brenda also spent time reassuring this elderly lady by holding her hand and gently stroking her arm. She seemed to enjoy this as she sat back in her chair and appeared more relaxed. However, it could be argued that this lady's behaviour was a clear signal that she wanted to

remove herself from the group and from the activity. If that was the case her wishes were eventually responded to and she ultimately had choice in whether she stayed in the group. There was another incident during observation where the facilitator helped a participant return to her room because she had decided she wanted to leave. Accordingly there was some evidence emerging from the observations that residents could exercise choice in whether they remained with the group and returned to their bedrooms.

5.3.1.6 Re-connecting – Identity and Self-worth

Observational data showed that during reminiscence the facilitator Brenda focused on certain subjects such as family life, early education and occupational roles which appeared to reinforce participants' sense of identity in a positive way. For example, Brenda encouraged Patrick to talk about the business he had once owned, which judging on his narrative and mannerisms he was very proud of. She also knew that another resident Claire had sons who held important positions in the Civil Service and she encouraged her to tell other residents about this. Claire's account and body language in her recounting her son's successes suggested that she too was very proud of their achievements.

According to Brenda, each resident had a personal profile and a life history complete with likes and dislikes, and they were encouraged during reminiscence to draw on such memories and use them. Based on discussions with Brenda both informally and during the in-depth interview it was apparent that she gathered a lot of valuable information about residents by talking with both them and their relatives over a long period of time.

A concern with this type of informal information gathering is that it is not always shared with other staff and therefore not used in an optimum way. When information is held by just one person, it is easy for it to remain with that person and not be disseminated. Later if that person retires, resigns or become sick and unable to work valuable information disappears with the person who holds the information. Although not evident in this case, there may also

be power issues involved where a staff member holds on to valuable information, for some reason such as the belief that by holding onto this information they may be more valuable. This raises the issue of who 'owns' the knowledge gathered about a PwD and the best way to use this knowledge.

5.3.1.7 Supporting the Reminiscence Experience – Dealing with sad and traumatic memories

During the in-depth interview with Brenda, her answers to questions posed suggested that she had no reservations about dealing with potentially sad subjects during reminiscence. This finding was further supported by observational data collected. For example in the second observation, she was documented as having asked one of the men Liam, if he had ever been "disappointed" (referring to being disappointed in relationships). Liam went on to discuss how he had two relationships which had not worked out for various reasons and concluded ***"I was disappointed, I was at an age"*** (possibly meaning at an age where he had wanted to settle down).

In discussing his disappointment, Liam sounded sad but not distressed as he did not show any signs of emotion such as crying, or looking upset. Liam had also spoken in both sessions about one of his brothers, who had died, but he did not appear upset to talk about this sad subject. Claire, another participant in this study also talked at length about her family and in the first observation Brenda had asked her about one of her brothers, who had died young. Claire spoke of him briefly and then moved on to talk about her father, again she did not seem upset.

However, another incident was noted in the second reminiscence session observed, which concerned a narrative told by a lady in the group. The incident concerned some distressing event at school many years ago, where attempts were made to kidnap a fellow school mate of this lady. The lady said she had become involved and helped to rescue this person. It was

interesting that Brenda acknowledged her story by commenting ***"weren't you very kind".*** However she did not pursue the story and the discussion was moved on to another topic. Further analysis of this incident might suggest that the facilitator Brenda was using a type of defence mechanism (Menzie Lyth, 1960) and only wished to engage superficially with sad or traumatic memories. This could be an example of a repressed memory resurfacing, which can happen with a PwD.

Coleman notes that assimilation of traumatic experiences may be necessary for the creation of a satisfactory life story (Coleman 1999). The story provided by this lady of a possible kidnapping incident years earlier certainly could be counted as traumatic. Whether the story is entirely true or not (as it was quite confused) is unimportant, what is of great importance is the emerging emotions associated with such a narrative (Gibson 2011; Van den Brandt-van Heek 2011; Chaudhury 2008; Murphy 1994).

There is also the possibility that the story told by this lady could have been merely metaphorical. Gibson advises that when carrying out reminiscence with a PwD facilitators sometimes need to decode or translate conversations and experts such as Killick (the poet and writer) who has worked extensively with PwD, argue that their speech can often be rich in metaphorical images which can convey powerful messages (Allan and Killick 2008). In this story, an attempt had been made to snatch or kidnap someone at school and the lady with dementia telling the story claimed she had helped to rescue the person, in frightening circumstances. Viewed metaphorically, did this resident feel someone, was in danger and needed rescuing? Did she perhaps need rescuing from the situation she was in, possibly having dementia or maybe being in a nursing home? Certainly the emotion of fear was in the story and noted in observation notes. These ideas could have been explored in much more depth by a fully trained and experienced practitioner. However, whether the story was metaphorical or an old memory resurfacing, the facilitator's response seemed inadequate.

During the in-depth interview Brenda seemed aware that some people may have traumatic events in their past and for this reason in conducting reminiscence with older people it was in her view very important to know a person's background:

"but you know, in all eh...homes, you have to be very careful about reminiscence, it's very important to find out the background to that person....it's very important" (facilitator interview, nursing home).

She told a story of a resident now deceased who had never wanted to attend reminiscence sessions. Eventually Brenda had found out more about this resident's earlier and rather troubled childhood and this explained her reluctance to attend reminiscence sessions:

Brenda – "but it would seem, it would seem way back before, I thought she was from Dublin but she wasn't and they lived in XXXX (county name), she was evicted, Dev's crowd (Eamon DeValera), she said it, they were evicted so this was why I gather that she never wanted to, because they came to Dublin and they were penniless"

Researcher – "so a lot of bad memories there"

Brenda – "so you have to, you know you have to kind of know, don't you, you know...because you don't, not everyone has a happy memory" (facilitator interview, nursing home).

Coleman talks of World War Two veterans who feel their traumatic war memories cannot be shared as their individual experiences go against the accepted narrative of the time. He gives the example of a survivor of Dunkirk whose experience had left him traumatised but went against the general mythology of 'glorious retreat' that surrounds the story of Dunkirk (Coleman 1999). The reluctance of this person to share her story might have been associated with the fact that it was a particularly difficult narrative for her to share with others. For this reason, Brenda noted that understanding a person's political background and allegiances was important:

"...I always suss out you know which side of the fence, because that's very important" (facilitator interview, nursing home)

Brenda said that she was supported by nursing home management and if she experienced a participant recall a traumatic event, she would always have someone to talk to and support her. In this way her experience was different from the three other facilitators.

Brenda appeared at ease discussing potentially sad subjects and even encouraged people to do so, bringing up the subjects of failed relationships (Liam) and bereavements (Claire). However, it was noted she did not seem to deal appropriately with the disclosure of a participant (not interviewed) with a potentially traumatic memory and just brushed the memory aside with a brief acknowledgment. Brenda placed importance on the need to know a person's background and also their political allegiances in order to deal appropriately with any sad memories. In common with other facilitators in this thesis, she was cautious of touching on the subject of religion in reminiscence, in case it sparked off distressing memories in those who had suffered abuse.

5.3.1.8 Supporting the Reminiscence Experience – Creating a safe place

Brenda reported she spent time before each session trying to ensure the room where the reminiscence took place was made comfortable and welcoming. As mentioned earlier there were temporary obstacles to providing an optimum setting at this nursing home because of the level of noise in evidence and the number of interruptions observed, which were happening because of the temporary disruption caused by the renovations. In both sessions, reminiscence took place in rooms not intended for that purpose. In these less than ideal conditions Brenda tried to create a warm and comfortable environment, a safe place. She set out drinks and biscuits on a table on both occasions, she arranged the seating in a semi-circle to facilitate conversation between participants and in the second session observed she used a

temporary screen to try and provide some privacy for the participants. As Claire remarked in the second observation ***"this is a party".***

Living in a nursing home, as Gibson points out, entails leading private lives in public spaces (Gibson 2011) and individuals can experience this as stressful. A reminiscence session can create a place where a person feels safe and valued and this can offset some of the stresses encountered. However, not all environmental problems were ameliorated by Brenda. The noise from other residents in the high dependency unit noted in the second observation session certainly had an adverse effect on the way the reminiscence sessions progressed. For example during the interview with Claire excessive noise was heard from the unit nearby and Claire seemed distracted by this and questioned this:

"God, who's that bloody moaner that's going on" (interview with Claire, nursing home).

Noise and lack of privacy in general appeared to be a particular problem for Claire, who during her interview, whilst recounting details of her daily routine, and how happy she generally was with the nursing home, especially the staff and the quality of food, started to talk about another resident, who had walked in and taken two of her newspapers, which had caused her some annoyance:

"...you can't leave them down or you have them walk over there....where's the pillow for my back, ah now ah now the fellow and he was well dressed and he walked in and he took up two papers...and I get one every day...and he had yesterday's and he had today's and he had that, and he had it on the floor" (interview with Claire, nursing home)

Later in the interview, she referred back to this again saying:

"now I wouldn't mind him having it if he had nothing, but this fellow was well dressed" (interview with Claire, nursing home)

This could be viewed as Claire feeling she lacked privacy and control within the nursing home, as other residents had access to her possessions.

The lack of privacy and inadequate external environment also impacted negatively on the research interviews themselves. I had suggested to the three residents with dementia that the interviews should take place in a quiet setting but the three participants to be interviewed discussed this between themselves and opted to be interviewed in the room in which the reminiscence had taken place. This meant that whilst each was being interviewed, other residents were reasonably close by and in fact joined in and interrupted on occasion the interviews. The participants seemed to accept this as quite normal and this could have been a sign that lack of privacy was accepted as normal or that they were powerless in an organization where they had significant dependency needs or it could have been that they enjoyed each other's company and welcomed the input of others. An important point to consider is that in this interview situation, I was the outsider and relatively unknown to the participants, so perhaps they felt more comfortable staying together.

5.3.1.9 Supporting the Reminiscence Experience – Factors which encouraged or hindered reminiscence

The enthusiasm of the facilitator Brenda became obvious in this setting. For example she devoted some of her own time and resources into the sessions by assembling a rummage box using items which she owned. Brenda also obviously enjoyed her job and felt well supported in it by management, which gave her confidence which again was reflected in the reminiscence sessions.

The main factor which hindered reminiscence within this setting was the external environmental and the noise and on-going renovations which were of a temporary nature. The nursing home was undergoing construction and because of this the reminiscence sessions were taking place in whatever space was available in less than ideal conditions. However, it is important to recognise that reminiscence sessions often take place in conditions far from ideal, rather than the text book conditions which academics often discuss. The number of interruptions and lack of staff were also detrimental to the sessions.

Reminiscence as observed at this nursing home setting was not always individualised and all participants may not have benefited from it. An example of this was noted in the first session observed. ***The facilitator was trying to talk to S (one of the participants in the group but not interviewed), but he didn't respond instead he fiddled with a piece of paper similar to kitchen roll, which was in his lap. The facilitator said that we would move on from S as he didn't want to talk at the moment.(observation 1, nursing home)***

Brenda appeared to be respecting this resident's right not to join in, but it may have been that the form of reminiscence was unsuitable for S. Another form may have been more appropriate for him. Fiddling with paper can mean the person wants to do something tactile and the facilitator could have provided that, within a reminiscence context.

The prompts used in this setting were conversational only in the first session and conversation together with the use of a rummage box which contained a mixture of items likely to trigger conversation, including some aimed at the senses such as perfume and soft materials. Brenda said that she liked to ensure the rummage box had a good mix of items of appeal to both men and women, for example perfume and aftershave lotion. Brenda mentioned the successful use of poetry as a prompt in other sessions (not observed) and said that music was a particularly successful prompt and was especially good for those who had communication difficulties. Singing took place in the sessions observed and was very popular, being enjoyed both by those who were singing and those who were listening.

5.3.1.10 Setting Summary

In summary reminiscence was carried out in this setting in an environment that was at times noisy and lacking in privacy because of on-going construction work which impinged on the sessions. However, the facilitator tried to compensate by providing a warm, supportive environment including the provision of refreshments.

The facilitator used her knowledge of participants to individualise some of the reminiscence and to promote positive feelings among participants by highlighting achievements. Participants appeared to enjoy the reminiscence sessions although one participant said he would prefer to be doing another activity. The facilitator also enjoyed the sessions, reporting that she benefited from learning more about the participants and also the past in general. One participant indicated that reminiscence helped him to focus on happier memories and forget sad ones.

Participants in the group who appeared to have similar cognitive levels of cognitive impairment (mild) connected well with each other but showed a lack of empathy towards one who was more cognitively impaired. The facilitator claimed that she herself benefited by getting to know the participants better and also increasing her personal knowledge of the past. Reminiscence helped her to see the participants as individuals rather than as patients.

In this setting, unlike others described earlier in this thesis, the facilitator did not avoid potentially sad subjects such as bereavements and claimed she had never personally experienced any negative reaction to a reminiscence session. However, she avoided discussion of religion because of her concerns that some people may have had negative experiences connected to religion.

She believed that knowledge of a person's background was important in order to understand whether certain topics should be avoided. However, a narrative told to the group by one participant which involved a distressing incident was dealt with very superficially by the facilitator, and raised questions about whether she dealt with the sharing of this narrative appropriately.

6 Discussion

6.1 Introduction

The findings chapters (chapters four and five) explored the experience of taking part in reminiscence work from the point of view of the PwD and facilitators in four different dementia care settings in Ireland. Data was collected using in-depth interviews with PwD, the facilitators and where possible with family caregivers. Two sets of observations were also conducted at each of these four dementia care settings. All of the data collected was analysed using I.P.A. The emerging themes showed that reminiscence had the potential to connect the PwD to others and to re-connect the PwD to their essential self and to parts of their self which may have been damaged or lost by the developing dementia. For the facilitator the findings showed that reminiscence tended to be a positive experience, through it facilitators learned new information about their clients and the locale and reminiscence could foster more meaningful relationships between the PwD and the facilitator by enabling the facilitator to see the PwD more holistically. Findings also highlighted some of the challenges, tensions and contradictions involved in carrying out reminiscence work and highlighted the role of the facilitator in supporting the reminiscence experience.

The findings chapters (chapters four and five) highlighted the diverse range of reminiscence work being carried out in these settings. In the four settings studied, six different methods were used to prompt reminiscence and facilitators spoke of using other methods at different times, highlighting further diversity. The four settings chosen, also exemplify the majority of different dementia care environments within which reminiscence work takes place in Ireland. It did not cover all settings, as reminiscence is known to take place in other settings such as in the community (Schweitzer and Bruce 2008).

This discussion chapter will start by discussing the findings against the backdrop of literature as reviewed in chapter two. The chapter will discuss the extent to which the findings from

this thesis support or challenge the existing literature and how the thesis has contributed to this evolving body of literature on reminiscence in dementia care. The chapter will then examine the internal factors and external factors connected to the reminiscence groups which may have affected the reminiscence experience, including: the use of prompts, the group size, the make-up of the group, environmental factors and organisational ethos. It will also address specific ethical issues related to reminiscence work. The chapter will close with a discussion of whether there were any missed opportunities in the reminiscence sessions. A discussion will also be given of the strengths and weaknesses of the methodological approach employed together with my personal views as a researcher on the research process including aspects of the research I would now change.

6.2 Positive outcomes associated with taking part in reminiscence work

For the PwD and the facilitator the findings showed that taking part in reminiscence work was a mostly positive experience. For the PwD the positive themes noted in the findings such as enjoyment, having some choice, displaying and appreciating humour and showing signs of self-confidence are all acknowledged signs of well-being noted in the literature (Woods 2010) and these were all evident to some degree in the findings in the different settings. There were also less obvious signs of well-being and independence as for example when a PWD decided to leave a reminiscence session of his or her own will as was observed in the hospital and nursing home settings. In both cases these people decided that they did not want to be at the session and in so doing displayed a sense of agency which is actually a sign of well-being.

Some positive themes identified in the findings were more apparent in some settings than in others. One such theme is enjoyment. Reminiscence work was considered an enjoyable activity by the PwD in the nursing home, the acute hospital setting and the day centre. In the residential respite care setting, participants were more ambivalent, although observation notes showed non-verbal signs of enjoyment. The general enjoyment derived from

reminiscence work by the PwD in this study appears to be in accordance with the existing literature on the subject which shows that reminiscence is considered an enjoyable activity (Gibson 2011) and is considered the most popular psycho-social activity for PwD (Woods et al 2005). The enjoyment of a session as an outcome is possibly not valued enough within reminiscence research. This may be because it is a very time-limited outcome which only lasts for the duration of the session whereas most research focuses on outcomes which last beyond the session. Yet an outcome which adds to the well-being of a PwD, even if only for a short time, still has merit. This has been recognised in the recent research review for Ireland's National Dementia Strategy which argued that one of the criteria used for judging the success of a psychosocial intervention should be whether it makes people happy during the intervention (Cahill et al 2012).

The less positive attitude towards reminiscence work shown by the participants in the residential respite care centre might be partly attributable to factors which were unique to that setting. Although the respite care centre provided a warm, homely environment and had a facilitator who was enthusiastic and supportive, other factors such as the size of the group, and residents' lack of contact with their family members together with a concern that they may have to remain in long term care indefinitely may have affected their overall well-being and in addition their experience of reminiscence. It is generally recommended that groups for reminiscence work should be much smaller (Gibson 2011; Chaudhury 2008) and the large size of this group may have adversely affected the reminiscence experience for participants. Here the group was much larger than other groups (at its smallest n -11, with facilitator plus one other staff member). Another possible explanation for the ambivalent feelings towards reminiscence in this setting was the frequent interruptions. For example, on several occasions during reminiscence, as noted in the observations, people were being taken out of the session for personal care, and this may have affected the session. The absence of connection between members of the group may also have affected levels of satisfaction. The fact that the participants did not know each other very well, were only there for a short

period of time and perhaps failed to identify with each other may have resulted in an experience which was less than enjoyable.

Kitwood saw wellbeing in dementia as a state where personhood is supported (Kitwood 1997) and during reminiscence sessions, the individual's personhood, in the settings observed in this study, appeared to be supported. There were also signs that their psychological needs: comfort, attachment, inclusion, occupation and identity (which Kitwood maintained had to be met in order to maintain personhood) were addressed during reminiscence sessions. It has been argued that reminiscence work has the potential to be used to enable a person-centred approach to dementia care (Dempsey et al 2012; Nolan, Davies, Brown, Keady and Nolan 2004) and LSW has been shown to have the potential to affect person-centred practice positively (McKeown, Clarke, Ingleton, Ryan and Repper 2010), particularly in helping care staff to understand the PwD. In their report on reminiscence therapy and LSW for PwD, the Scottish based Institute for Research and Innovation in Social Services (IRISS) recognise reminiscence as a way for PwD to articulate their needs and a way for staff to deliver person-centred care (www.iriss.org.uk).

Reminiscence work can link into PPW which Kitwood identified as a way of working with PwD which maintained and enhanced personhood, dignity and well-being. Some aspects of the 12 characteristics of PPW described in the literature review – Celebration, Collaboration, Creation, Facilitation, Giving, Holding, Negotiation, Play, Recognition, Relaxation, Timalation and Validation (Kitwood 1997) were very evident in these reminiscence sessions. For example, Celebration - when a PwD celebrates being alive, with joy and gratitude and the healthcare worker joins in - was noted, one example occurring in the second observation at the respite centre, when one of the group got up and spontaneously started to dance. As the facilitator noted, this client was so caught up in the moment, he seemed to forget he needed the use of a walker. Observing that moment, an element of joy certainly appeared to emerge and it could therefore be classified as a celebration within PPW. Reminiscence with its

encouragement of enjoyment and focus on past achievements would certainly seem to encourage Celebration.

Gift exchange, which may sometimes include accepting gifts of kindness, support or concern from the PwD was also noted during the reminiscence sessions observed, for example it was noted during the sessions at the respite centre and nursing home when participants expressed concern for other PwD, who were having physical and cognitive problems such as coughing fits and having difficulty finding words. An extension of this, and more applicable generally in reminiscence, could be what Gibson referred to as reversing the gift relationship (Gibson 2011). This is where the PwD gives something back either to the facilitator, to family or to the wider community, in the way of local knowledge or oral history. This was experienced by all facilitators, who noted they had learned more about their locale and the past through the participants during sessions.

Play - referring to generally having fun, joking around and playing games - was also evident in the reminiscence sessions and this finding links into the theme of enjoyment already discussed. There were many examples noted between participants of laughter, jokes and playful banter especially in the day centre, nursing home and acute hospital setting. There was some playful banter between participants and the facilitator in the respite care setting but not between participants. Reminiscence as an activity therefore seemed to lend itself easily to promoting play, especially when topics relating to good times in the past were discussed.

Research has already shown that other therapeutic interventions such as dance, music and art can be used to encourage PPW (Kasayka, Hafield and Innes 2001) and this thesis shows that reminiscence work can also encourage PPW which leads to a more positive environment for the PwD.

The findings showed that the facilitators themselves benefited significantly from the reminiscence experience and this critical aspect of reminiscence tends to be overlooked or at

least not sufficiently emphasised in reminiscence work and in the literature. All facilitators spoke of enjoying their work, but they also spoke of learning more about the PwD in their care which as Chaudhury points out, can influence staff perspectives and understanding of the identity of the PwD, which can impact on the caregiver's attitude, values and actions (Chaudhury 2008). Facilitators also spoke of gaining knowledge of the local area, history and culture.

It has been argued that this type of learning may be of particular use to migrant workers in dementia care, whom we know now make up a significant proportion of the workforce and the numbers of whom are likely to increase in future years. Although no migrant worker was involved in this particular study, the issue of training migrant workers, employed in dementia care to be cognizant of Irish cultural issues such as the Gaelic Athletic Association (the GAA), the role of the Church, Mass, rosary and prayer in traditional Irish life, Irish folklore, Irish festival events including the significance of St Patrick's day and of traditional Irish music is so important. A starting point is that all migrant workers would have a basic level of proficiency in the English language and that this would be a prerequisite for employment in dementia care settings. Indeed it is ironic that in the current iteration of the National Quality Standards for Residential Care, such a basic requirement is not mandated (HIQA, 2009). The acquisition of local knowledge may help to develop a sense of shared cultural experience which enables migrant workers to understand and bond with the PwD and also helps them settle into their new country of residence (Walsh and O'Shea 2010). Conversely migrant workers have much to offer in dementia care as they can often share their unique cultural experiences with older people who despite their dementia, may well enjoy an ethnic evening of song and dance.

6.3 The reminiscence experience and connecting to others

Findings showed that reminiscence helped to connect the PwD to facilitators in all four settings, and to each other in three of the four settings. As stated earlier, in the respite care

setting, observation notes showed that there was little connection or spontaneous conversation between participants, only between the participants and the facilitator and in the nursing home there was a lack of connection between the reminiscence group and one of the participants. This section will examine possible reasons for the lack of connection shown in these two settings starting with the respite care setting and then looking at the situation in the nursing home.

In the respite care setting, data showed that at times participants were quite ambivalent towards each other and appeared to differentiate themselves from the others in the group, including using language which positioned themselves as different from the others. Bartlett and O'Connor refer to using language in this way as "othering" and argue that to use language like this is an attempt to establish boundaries and positions the "other" as not like us (Bartlett and O'Connor 2010) and this may be one reason for the disconnect shown between PwD in this setting, this has been noted in other research. For example, research carried out by Pullan, a clinical psychologist, compared group and individual reminiscence sessions in which it was thought that reminiscence had the potential for increasing well-being by enhancing shared social identity (Pullan 2009). One finding was that the PwD in the group sessions showed no changes in perceived sense of identity, which the researcher surmised could be because some PwD categorised others as less able and therefore did not identify with them. The latter impeded a sense of solidarity from developing (Hayward 2008).

One possible reason for treating others in this way and establishing them as different is offered by Freeman, an American psychologist, who used narrative theory to explain the actions of his mother who had dementia and lived in a nursing home. At first, when Freeman's mother was still in the early stages of the disease, she viewed her fellow residents, who she observed as using walkers and often slumped in their chairs as different to her, and she was vehemently not one of them. He noted that in her opinion they had become "non-persons" and this was painful for her to observe. As her dementia progressed, she reached a more content stage and was more able to accept her fellow residents. Freeman argued that

this was because initially, when surrounded by people more impaired than she was and therefore seeing a narrative of decline, she was experiencing narrative foreclosure where the person feels the story of their life is essentially over. This caused her distress. However, as her dementia progressed she entered a different phase where she left narrative behind (Freeman 2011).

Two of the participants in the respite settings used in this thesis (Anne and Bridie) may have been going through a similar process, where seeing others with cognitive impairments was distressing to them and accordingly, in order to retain their own sense of identity, it may have been important for them to reject the narrative of decline they were witnessing, by labelling their fellow residents as "others" and different to them.

Another explanation for the apparent disconnect between the participants in this setting could be related to the unique features of respite care settings. As mentioned in the findings, respite care stays for a PwD can be for different periods of time according to need and vacancies and the PwD may not always be living with and undertaking activities with the same people on every visit. This can make it difficult for the PwD, who may already be experiencing difficulties in communicating and engaging with others, to connect with people who may be virtual strangers. The respite service offered by this facility appeared to be of a very high standard and interviews with family members showed they were very grateful to be able to use the service as they were under considerable strain. There is no doubt that respite care can be an incredibly useful resource for the families of PwD. As field notes for this thesis showed, at this facility it was used not only to give carers a break but also sometimes to enable them to take care of their own health needs, for example undergoing medical procedures. However, it is acknowledged that respite care stays can be a stressful environment for a PwD and they may not be there willingly. The question of whether respite care ultimately benefits the PwD is beyond the scope of this thesis, but it is a setting in which a PwD may find themselves and it can be argued that there is a role for reminiscence in helping the PwD adjust to this environment. It is known that reminiscence can encourage

sociability and assist the formation of new relationships (Gibson 2011) and this could be useful within a respite environment. By discovering common interests, and finding out more about each other reminiscence can enable a PwD to engage with others. Reminiscence can also have a role to play in enabling participants to retain their own personal narrative, by reminding them of the person that they are despite the illness, which can help them deal with witnessing distressing narratives and the possibility of narrative foreclosure as described by Freeman (Freeman 2011) and again this could be useful in a respite environment. However, in order to achieve the benefits mentioned above, it may be necessary to focus on a smaller, more intimate group where PwD would be more inclined to share memories and bond with each other.

The situation was different in the nursing home where there appeared to be a disconnect between some participants and a particular individual in the group (not interviewed) who appeared to be more severely cognitively impaired than the others. It was noted that this participant was treated quite negatively by others in the group, and was spoken to disparagingly both to her and about her, which must have been a very unhappy experience for her. This has been noted before in research, for example in one UK study on the outcomes of community care, some tension between participants was noted with negative comments focused on people with more severe impairments who were seen as different and tended to be marginalised (Bamford and Bruce 2000). Again, this could be a case of "othering" as defined by Bartlett and O'Connor, where the more impaired person is positioned as "not like us" (Bartlett and O'Connor 2010) or it could be related to the participants witnessing a narrative of decline as described by Freeman which they did not want to be a part of (Freeman 2011). This raises the question of whether it is fair to all participants to include PwD in a group who are of a different cognitive level. As in the nursing home in this study, it may leave the more impaired PwD vulnerable to the negative reactions of other PwD and may cause distress.

As the findings show, one of the main benefits raised by facilitators was seeing the PwD as a whole person and this shift from labelling the person because of their illness to seeing the person as a human being with individual likes and dislikes is at the heart of person-centred care and was well articulated by one of the hospital facilitators (see page 167). Viewing the person in this way is also linked to recognition, which is one of the characteristics of PPW, which as discussed earlier Kitwood maintained contributed to a person-centred environment (Kitwood 1997). Recognition refers to recognising the PwD as a unique individual, with an open and unprejudiced attitude. It includes seeing the whole person as well as greeting and using appropriate eye contact and body contact, which was observed in all the settings, where participants were greeted warmly and appropriately by facilitators, from the formal SONAS greeting carried out in the respite care setting to the more informal greetings in the other settings. By reminding the facilitator and others that the PwD is a whole person, with a history, interests and opinions, reminiscence can help to connect the PwD to others and provide "Recognition" for him or her.

Identification with the PwD can be a result of connecting with the PwD and this was evident in the account of Orla in the respite care centre, who spoke of gaining confidence within herself as a result of reminiscence work. Orla had already shown that she identified with the PwD in her care when she spoke about how she understood the quiet ones and enjoyed seeing them progress as she had been quiet at school too. Orla's statement indicated identification and a move away from labelling PwD to viewing the whole person (Pullan 2009). It was also evident in the interview with Brenda when she spoke of empathising with the PwD and how episodes in their lives had made her think of episodes in her own life. It was interesting that the two facilitators who showed more of a connection in this particular respect were the two facilitators who came from non-professional backgrounds. Perhaps professional training encourages a certain distance between the carer and cared for, possibly as a way of protecting the carer so that they do not become too emotionally attached when working with PwD which could render them vulnerable to the emotional stresses related to "burn out". Kitwood argued that staff caring for PwD can sometimes adopt psychological

defences to cope with the emotional demands of their jobs, such as the anxieties (often not expressed or acknowledged) related to fear of aging, frailty and loss of self (Kitwood 1997). Distancing oneself emotionally is one such psychological defence often used in nursing and care settings (Menzies 1972; Menzies Lyth 1989) and although there was no explicit evidence of this in this study, the lack of identification discussed above along with facilitators lack of engagement and discussion with family caregivers about reminiscence sessions could possibly be an indication of this. It is possible that enabling the professional to see the whole person in reminiscence work could have a significant effect on their ability to identify fully with the PwD.

The relationship which develops between the PwD and the facilitator can affect the course of the reminiscence session. As Gibson argued, reminiscence is a process which holds the teller and the told in a relationship with each other (Gibson 1998). Chaudhury has talked of the quality of an interaction between a family member and a PwD as being guided by the nature and characteristics of the relationship between the individuals (Chaudhury 2008) and the same could be said of the relationship between the facilitator and the PwD during reminiscence. Each brings traits such as their own personality, personal history and mood on the day into the reminiscence experience and this affects the outcomes experienced. This has been noted in research on Life Story interviews carried out by Randall et al who reported on the direction a life story interview takes and claimed that they can be more dependent on the relationship which develops between the interviewer and the interviewee than on other factors. They conclude that an interviewer can use three broad ways to draw out an interviewee's story, by steering, supporting or standing by and this is usually done in an unpremeditated natural way, dependent on the interviewer's personality (Randall, Prior and Skarborn 2006). In a similar way, during reminiscence the facilitator helps to direct the general direction of a reminiscence session - choosing initial topics, providing prompts and asking leading questions, usually in a way that reflects their personality.

Viewing the reminiscence experience from a social constructionist viewpoint, it can be seen that each PwD and each facilitator is unique and brings their own life history and experience to the reminiscence experience, which affects how the reminiscence session develops. The reminiscence experience is socially constructed by and between those who take part in it, and each individual will experience it in a different way.

6.4 Agency and Choice and the PwD

Through direct questioning of the PwD, observation and questioning the facilitator in each setting, the issue of whether the PwD was able to exercise choice in relation to the reminiscence sessions was explored. There were two aspects to this issue, the first related to how much the PwD could influence the course of the reminiscence session and the second issue concerned the more general issue of how much autonomy the PwD had in deciding what activities to take part in within the care facility. Kitwood has argued that PwD are often denied opportunities to remain autonomous and exercise choice. He contended that their sense of agency is often taken from them and that this in turn contributes to a sense of ill-being (Kitwood 1997).

The findings showed that during the actual reminiscence session, although the facilitators decided on the initial direction of the session, the PwD was able to exercise choice in all settings and did influence the course of the session. Sometimes this was done by ignoring prompts, for example it was noted in observations at the day centre that participants ignored prompts they had no interest in (specific photographs on Facebook) and asked to return to items they still wanted to talk about. It was observed that choice was encouraged by facilitators during sessions, for example in the respite care centre and in the acute hospital setting when the facilitators asked participants to suggest song, video or poem preferences. Observation notes also showed that facilitators were adept at responding to cues from participants which influenced the direction of sessions. For example in the nursing home during a conversation about school one of the participants Patrick said quite emphatically "I

wanted to get away from school" and the facilitator Brenda responded to this by starting to talk about Patrick's working life, a subject he seemed much more relaxed with.

The issue of how much choice the PwD had in terms of attending the sessions is more complex. Firstly to a certain extent it could be argued that in three of the settings – the acute hospital, the respite care centre and the nursing home – it is likely that the PwD had little say in whether they wanted to be there or not. As Eamon in the acute hospital setting stated in his response to a question asking him if he believed he had choice in attending Reminiscence "No, no I got a stroke". This could be interpreted as meaning that his choices had been impacted by his stroke. If he hadn't had the stroke he wouldn't be in hospital and attending that session. Additionally, it is known that PwD can sometimes be reluctant to use care services but because of outside pressures have to (Brodaty, Thomson, Thompson and Fine 2005). As mentioned earlier for example, for some PwD respite care is not always a positive experience and may be undertaken because of needs related directly to the family caregiver. This means the PwD may not necessarily want to be in the care facility. This dilemma between the needs of the PwD and the needs of the caregiver was alluded to by the facilitator at the day centre Mary, who obviously believed firmly that it should be the choice of the PwD. She commented that whether the PwD attended the centre was their choice and in their control and quite firmly stated that sometimes that might not suit the family but the day centre was not a containment service.

Secondly, how much choice the PwD had in whether they attended activities in general and reminiscence in particular was unclear. It has been noted that the culture of a care facility has a strong influence on the range and quality of activities available (Scobbie 1994).It is known that clients experience verbal coercion and pressure to participate in activities which are of little interest to them and often find it easier to join in rather than challenge (Green and Cooper 2000; Harmer and Orrell 2008). There is a difference between encouraging someone to join in and coercing them, and in the settings observed no-one seemed to be have been coerced. Certainly the facilitators were aware of the importance of the PwD exercising choice

and all stated that if a person decided to leave the session they would be allowed to do so (and this was observed during sessions at the acute hospital and the nursing home, in both cases the facilitators first tried to settle the person and make them more comfortable and then when it was clear they did want to leave, the person was enabled to leave). However, interestingly during interviews participants did note that at times they would rather be doing something else for example Dora in the acute hospital setting had said she would rather be driving.

6.5 Negative outcomes and the reminiscence experience

Reminiscence is not suitable for everyone, and for some PwD, taking part in a general reminiscence session could trigger painful memories. The awakening of traumatic memories during a reminiscence session seemed to be a concern for all but one of the facilitators in this study, and this finding is curious since in practice it is acknowledged that this is rare (Gibson 2011). First of all it is useful to differentiate between sad memories and those that traumatise. Many individuals have experienced trauma, either directly, or indirectly as an onlooker or friend or relative of a person directly involved. Linda Hunt, writing from a social work perspective, has defined the different types of trauma which can affect people and these include trauma connected to war or terrorism, personal attacks, disasters such as a ship sinking and natural disasters such as an earthquake (Hunt 1997). In addition many people experience trauma caused by personal grief for example grief following bereavement especially when the grief has not been fully acknowledged or come to terms with.

Drawing on various European studies looking at those affected by war time conflict (both 2nd World War and more recent conflicts) and studies looking at those affected by violence both within and outside the home, Hunt has concluded that at a conservative estimate it is likely that at least 10 per cent of the population over 60 years of age may be still be suffering from some earlier traumatic experience (Hunt 1997). In common with many other countries, Ireland has had periods of civil unrest and also a civil war and some older people may have

experienced trauma during these times, either directly or indirectly. Additionally, although Ireland was a neutral country during the Second World War, many people living in Ireland were affected by the war. The Republic of Ireland sustained some wartime bombing with fatalities incurred, many were involved in combat or helped in the aftermath of the Belfast bombings as part of the fire service and people arrived in Ireland escaping the trauma of the war, including those who were evacuated because of the Holocaust or had survived the Holocaust (Hegarty 2011). There have also been disasters both natural and otherwise. All of these events, together with the more personal traumas which people experience in their lifetimes, mean it is likely that many older people in Ireland will have experienced trauma or witnessed trauma and been affected by this. It has been suggested that trauma sometimes only surfaces in later life or when dementia develops (Hunt, Marshall and Rowlings 1997; Gibson 2011). Gibson suggests that this may be because the person has been unable to talk about the trauma before, as for some people the only way to survive the present is by forgetting the past. Whilst acknowledging that there is still much to learn about the timing and context of when people decide to recount traumatic events she argues that it is essential that when they do they are supported by skilled and sensitive listeners (Gibson 2011).

Sad memories, as opposed to traumatic memories, are very common. As Gibson has noted, no one grows old without experiencing loss, whether through bereavement of family, friends or pets or through the loss of a home, health, a job or possessions (Gibson 2011). Whilst some of these losses dependent on circumstances might be considered traumatic, many will just be sad memories.

In order to understand the different ways people react to sad memories, it is useful to think of the ways people react to reminiscence. Coleman produced a useful taxonomy grouping people into four types according to their attitude to reminiscence. The first group included those who reminisce readily and whose memories are a source of strength to them, the second group consisted of those who reminisce and brood on their memories, feeling sad and regretful, the third group consisted of those who see no point in reminiscing and the fourth

group consisted of those who avoid reminiscing because of the contrast between their past and the present (Coleman 1986). Using this taxonomy, it can be seen that the first group would benefit from reminiscence work and the third group most likely would not want to take part in reminiscence work and should be supported in that decision. General reminiscence would be unsuitable for those in the second group, who brood on their memories and feel sad and regretful, together with those in the fourth group who avoid reminiscing because of the contrast between the past and present. They may need counselling in order to come to terms with their past so if any reminiscence was to be undertaken with these groups, it would have to be specific or special reminiscence (Gibson 2011). Coleman's typology is very useful and could be used in staff training and in providing guidelines to staff about the appropriate selection of PwD for Reminiscence work.

In the settings observed, the PwD seemed to accept that sadness was a normal part of life, and a certain amount of sadness during reminiscence work was acceptable. Eamon in the acute nursing home setting even seemed to link the emotions of sadness and happiness, saying that one led to the other. Certainly, as discussed earlier, sad songs, films and books can be enjoyed by people and he may have been referring to this. During observations it was noted that PwD did not avoid potentially sad subjects and also did not show undue upset when talking about them. Only one person, Helen claimed during interview that she continued to ruminate on a sad subject (concerning her brother who had died as a young child) and using Coleman's taxonomy (Coleman 1986) this may point to Helen being one of the people inclined to ruminate after reminiscence and therefore possibly not being a suitable candidate for general reminiscence. Otherwise all those with dementia seemed able to deal appropriately with sad subjects during reminiscence, as Anne in the respite centre stated during her interview, if reminiscence made her sad she wouldn't be doing it.

This seems to be at odds with the considerable caution displayed by three of the five facilitators, who actively avoided certain fundamental subjects for reminiscence including religion, schooling and politics during sessions in case they caused upset or trauma. For the

most part there seemed to be no actual concrete reason for avoiding these areas. The only facilitator who had hinted at actually experiencing problems in this area was Mary at the day centre, who had indicated that with the exception of using prayers and poems learned at school, they generally avoided talking about school days as some of the participants had suffered abuse whilst at school and they had "learned at their cost" that this was an area to avoid. In fact the facilitator (Ciara) at the acute hospital had recounted how a spontaneous discussion about the bombing of Nelson's Pillar in Dublin had arisen during one of the reminiscence sessions but there had been no negative reactions amongst the participants and it had been a good session.

Attempting to further analyse, from a psychoanalytic perspective, facilitators' avoidance of such topics and their respective concerns , might suggest that their avoidance was triggered by a conscious or subconscious decision on their part to create emotional distance between themselves and their clients and to remain a little detached (Menzies Lyth 1960). It may also reflect awareness that they feel powerless to control the deep emotions felt by their clients such as fear or panic (Menzies Lyth 1991). Clearly the various incidents cited in this study reflect missed opportunities from the point of view of reminiscence and specific training about reminiscence and on how best to deal with negative emotions would be hugely beneficial in this context.

This avoidance of certain topics in reminiscence work by facilitators is not a new finding and has been noted in other research (Wilson, McKee, Elford, Chung, Goudie and Hinchliff 2007). One example is a study which evaluated the impact on the quality of life of frail, older people participating in reminiscence (it is not known if any had dementia). This study showed that care staff believed that spontaneous interactions about the past could be unpredictable and could evoke distressing memories. The care staff noted they generally avoided potentially distressing dialogue about the past, focussing instead on general talk about children and families (Wilson, McKee, Elford, Chung, Goudie and Hinchliff 2007).

So whilst the decision to avoid certain subjects in case of upset was not restricted to the facilitators in this study, and has been seen in other research, it is unclear whether there is any benefit to the PwD in totally avoiding these subjects. Whilst there is a possibility that certain people could be distressed by the topic, there are others for whom the topic may be of real interest. Wills and Rose, in their research on the use of life story books in a nursing home in Ireland (it is not known if any of the people participating had dementia), showed that the residents who participated were eager to talk about the role of religion in their lives. They noted that religion appeared to influence people's social lives and this was a recurrent theme in the interview narratives and in the life story books, with five of the six participants interviewed mentioning the importance of religious practices and symbols (Wills and Day 2008). It is interesting that the Wills and Day research took place prior to the release of reports into child clerical abuse and abuse in industrial schools controlled by religious institutions in Ireland such as the Murphy Report and the Ryan report in 2009. It could be that facilitators are now more reluctant to address religion and schooling as a topic as they are now more aware of the possibility that the PwD may have encountered abuse. However, for many people this was an important part of their lives and by avoiding these subjects the facilitators were effectively limiting the reminiscence experience for the PwD.

6.6 The experience of taking part in reminiscence work – supporting the facilitators

Given the important role facilitators played in reminiscence work, it is surprising that they appear to receive very limited support in their work and this includes appropriate training. As Kitwood noted, when employees are supported and encouraged in their work they take that sense of well-being into their working day and it is reflected in their work practices (Kitwood 1997).

Although all the facilitators had undertaken some form of dementia specific training, it was most surprising that none had attended specific reminiscence training, and despite the front line and often highly sensitive nature of reminiscence work, none seemed to think that reminiscence training was necessary to carry out reminiscence work. This finding contrasts very sharply with evidence from facilitators, interviewed in the Scottish Football Museum project. The facilitators in this project, who were working as volunteers carrying out sports related reminiscence with PwD, felt that training in reminiscence was important and they would have welcomed more (Schofield and Tolson 2010). Perhaps the very fact that the facilitators in the settings studied did not seem to think reminiscence training was necessary shows a lack of understanding of what this specific type of training could provide and highlights the need for some training. Reminiscence work is acknowledged as an enjoyable activity for PwD but it also has a complex side to it which training could help with (Gibson 2011). When PwD share their stories during reminiscence, along with the anecdotes and superficial conversations some people will be sharing deeply personal narratives and facilitators need to be aware of the need to support people appropriately. This includes ensuring the person is listened to, the narrative treated with respect and issues of confidentiality are considered.

It was interesting that the facilitators had all expressed satisfaction with the support they received in their roles from management and yet the data collected suggested otherwise in three of the settings. Examples here included comments about possible lack of funding for training (in the acute hospital), lack of funding to do reminiscence outings (day centre) a noisy environment (the nursing home), and a larger than recommended group and care interruptions (the respite care centre). In the nursing home and acute hospital settings, it is possible that these facilitators were satisfied that they could undertake person-centered activities that were not necessarily going to promote positive clinical outcomes but rather provide momentary pleasures for both themselves and their clients which might enhance communication and improve even temporarily quality of life. It is also possible that the facilitators did not expect much by way of support and were therefore satisfied with what

was received. Their low expectations could be related to the fact that care work, is often considered low status, and care workers for PwD are often low paid and undervalued (Innes 2009; Bartlett and O'Connor 2010).

Another issue which needs consideration is that reminiscence work can be emotionally draining and facilitators need support with this. From a psychoanalytical perspective it is argued that caring for older people brings particular stress and anxieties to workers about ageing, loss of independence together with memories and fears about their own past and present relationships with older people. This can result in pressure to split positive feelings such as enjoyment and fulfilment experienced in the workplace from negative feelings such as disgust or fear (Zagier Roberts 1994). In order to address this and reduce anxiety it is argued that there is a need for work-related staff support systems to suppress anxieties (Obholzer 1994). Facilitators listening to people recounting personal memories may hear narratives which are distressing, either because of the content or because it triggers something in their own psyche. This has been referred to as an "invisible workload" meaning the rarely acknowledged work that staff undertake in managing their own emotional experiences and dealing with the emotional experiences of others (Ward, Vass, Aggarwal, Garfield and Cybyk 2005). Previous studies have found that bereavements are a major theme during reminiscence for PwD but the discussion of these usually does not cause distress (Harmer and Orrell 2008; Pullan 2009). This was evidenced in the findings of this thesis when it was noted that in the day centre and in the nursing home bereavements were discussed without causing upset. It is thought that the discussion of bereavements in this way may be related to a need to make sense of the past (Coleman 2005). When recollections cause upset to the PwD this can cause distress to the facilitators. In Pullan's study of facilitators delivering reminiscence sessions to PwD two episodes were noted when upsetting or traumatic memories were triggered and each episode affected the facilitators involved. In the first a PwD experienced sadness during a session, leading the facilitator to dread the next session. However the facilitator persevered and found that she developed the skills to cope with the PwD's transient sadness. In the second a PwD had a traumatic reaction to an item in

a life story book. The facilitator was upset for traumatising the person and felt guilty for causing extra work for her colleagues (Pullan 2009). Gibson has argued that if facilitators wish to carry out reminiscence work they must be prepared for and able to cope with whatever recollections and emotions emerge (Gibson 1998) and this points to the need for adequate training and support. Woods reminds us that the effects of reminiscence on the care provider as well as the PwD should be carefully considered and that sufficient time for staff support should be allocated as reminiscence can place emotionally taxing demands on workers (Woods 1995; Woods 2009).

All facilitators were asked if they had ever been personally affected in an adverse way by something they had heard during a reminiscence session. Orla and Mary both denied this but in the acute hospital, Ciara had claimed 'not yet' perhaps hinting at the possibility of it happening in the future and Ruth had said no, adding that she had been lucky so far. The only person who acknowledged a possibly distressing situation for the facilitator was Brenda in the nursing home who recalled an incident during reminiscence, when she had become aware of a situation between two residents which may have been abusive. This same incident had disturbed her and 'knocked her for six' but she said that at the time she had been adequately supported by management in dealing with this incident.

The fact that only one facilitator could identify a difficult scenario like this is very surprising, but perhaps not so surprising when one recalls that the reminiscence sessions investigated in this thesis tended to dwell by and large on superficial topics with little or no possibility for distress arising and no scope whatsoever for traumatic memories to be triggered. It could also be that the reminiscence groups were too large and therefore unlikely to support any distressing revelations or that a distressing revelation might be considered an unacceptable narrative and the PwD would not feel able to share that type of memory. It could be that facilitators did not feel that they could or should be affected by anything that they heard.

In general findings from this thesis show that the work of facilitators in designing and delivering reminiscence sessions is complex and to some extent not highly valued within the

care environment. Star and Strauss, writing from a sociological perspective, talk of 'articulation work', that is the unseen work needed to produce something. They also refer to invisible work, or work ignored or not acknowledged (Star and Strauss 1999) and much work within dementia care, including reminiscence, administered by facilitators could certainly be categorised in this way. The preparation that a facilitator may do to ensure reminiscence session works well, such as the assembling of a rummage box by Brenda in the nursing home, the literature searches carried out by Ciara and Ruth in the acute hospital, the reflective practise carried out by Orla in the respite care centre or the gathering of background information on clients carried out by Mary in the day care centre could all be categorised as invisible work. Star and Strauss note that this type of work is often looked on as a layer of second order work, on top of regular duties, (Star and Strauss 1999) and this would appear to be case for the facilitators in this thesis since it was obvious that much of this type of backup work was done in their own time.

Star and Strauss also talk of enforced deference behaviour (Star & Strauss 1999). They give one example based on a study undertaken (Romero, 1992) where a maid was expected to share her bedroom with an ironing board, a sewing machine and other articles usually found in a spare room. This has similarities to the fourth case study in this thesis where the facilitator in the nursing home was expected to run the reminiscence session in a room normally used as a hair dressing salon. To some extent reminiscence work has to incorporate a certain degree of flexibility but expecting both a facilitator and those with dementia to put up with such sub-optimal environmental conditions makes one question the real rationale for using reminiscence at this time in the setting and points to the low priority it is afforded in institutional care. It may also point to enforcing deference behaviour (Star and Strauss 1999).

Finally and particularly in the context of Ireland now witnessing a large migrant workforce in the residential care sector, the issue of the type of person most suited to act as a facilitator of reminiscence work is important. . One of the facilitators interviewed for this thesis

provided some interesting insights when she stated that in her opinion people from other cultures were not suitable for reminiscence work. She felt that a shared culture was a necessary element of reminiscence work. It is true that a shared culture means people have shared points of reference in reminiscence work, and Gibson has noted that a shared background and familiar accent can be a bonus in reminiscence. I would argue that this is not essential for successful reminiscence work and trying to ensure a shared culture may even unnecessarily restrict the pool of available reminiscence workers and may ultimately be boring for the recipient of the intervention. Practitioners point out that in reminiscence work it is not essential for facilitators to be a font of knowledge about the past, as in reminiscence work the experts are the PwD who are in the group (Gibson 2011; Sim 2003). A few meaningful references can help reminiscence flow but it is not essential to have a deep knowledge of the local culture and many PwD are willing to share their experiences and knowledge. As the findings showed, most facilitators learn a lot about the local area, history and culture within sessions and can acquire a reasonable working knowledge suitable for reminiscence work.

It is also worth noting that people can differ in more ways than one, and coming from the same area is only one aspect of a person's background. Issues such as class, age, culture and gender may be significant, for example a person who was raised in a very affluent household may have had a very different background than a person from the same town who was raised in poverty.

Another point which Sim makes is that a shared background amongst group members (the PwD) is progressively less likely to occur, and in the future it is less likely that a group will consist of people who have all been born and raised in the same locality (Sim 2003). As it is estimated that currently up to a third of the work force caring for older people in Ireland are from abroad, it is likely that some of those people will settle in Ireland, grow older themselves and one day may eventually participate in a reminiscence group. Needless to say, they will have much rich narrative to contribute to reminiscence work.

The challenges faced by people from a different culture working as facilitators of reminiscence are similar to the challenges faced by those from a different generation. Although there are differences there are also common denominators which are shared across the generations and as Sim points out we are all part of the same human family (Sim 2003). Attributes such as a genuine interest, respect for others, warmth and a non-judgemental attitude are more important for facilitators together with knowledge of dementia and reminiscence. The use of non-verbal communication is also so relevant and very powerful when working with PwD.

6.7 What makes a reminiscence session successful? - The use of prompts.

Much of the research conducted on Reminiscence has focused on the role prompts play within Reminiscence work in relation to outcomes (Chaudhury 2008; Cosley et al 2009; Astell et al 2010). Yet the findings of this thesis suggest that prompts appeared not to be a key determinant of the success or otherwise of these sessions observed. For example, the sessions where no physical prompts were used such as in the first session at both the day centre and the nursing home, appeared to be as lively and engaging as sessions in which physical prompts, (rummage boxes computer programmes and the SONAS programme) were used. However, this was a qualitative study and not an RCT and so findings cannot be generalized beyond the settings used in this study.

The findings showed that in the sessions where facilitators failed to use physical prompts (in the first session at the day centre and in the nursing home) facilitators were able to stimulate conversation by using personal and local knowledge and therefore individualising the session. At the day centre, Mary used a technique similar to that discussed by Chaudhury (Chaudhury 2002; Chaudhury2008). She verbally "walked" the participants in her group down a street in the town in which they lived and talked about the shops, cinemas and other

buildings which had existed on the street. This was a very successful prompt and led to many anecdotes and memories being shared amongst the group. This concurs with Chaudhury's argument that places, such as the houses, streets, shops and factories as used in this session have a key role as the physical context of life events and can facilitate reminiscence which in turn can enrich the quality of social exchange in the present (Chaudhury 2002).

In the nursing home, Brenda used her knowledge of the participants' early lives to stimulate conversation, which included discussion of their former occupations and work done, their earlier schooling, relationships and family. Again this was a lively session. These findings in part seem to validate Gibson's advice to facilitators, where she recommends it is much better to start with people, discover their interests first, and then find prompts to match the person (Gibson 2011). Prompts, especially individualised prompts, might enrich a reminiscence experience and this is the subject of much debate in the literature (Gibson 2011).

It could also be argued that certain prompts, whilst not being essential to the reminiscence experience, bring an element of novelty, therefore keeping it interesting for both the PwD and the facilitator. The use of ICT to prompt reminiscence is a reasonably new area in reminiscence work and there is a growing body of research and literature dedicated to it (Cosley et al 2011; Capstick 2011;Mulvenna et al 2011). ICT is becoming more and more a part of everyday life, both for PwD and the facilitators working with them and it could be that using ICT as a prompt could encourage people, both PwD and facilitators, to participate in reminiscence work.

The use of ICT in activities with PwD in general is becoming increasingly popular. Bartlett and O'Connor argue that the use of computer networks and communication, including the use of file-sharing websites such as 'Flickr' and 'YouTube' is fundamentally changing the dementia landscape and these new trends need to be incorporated into the dementia debate (Bartlett and O'Connor 2010). As noted in the literature review (chapter two) in the UK, SCIE have recently issued a guide on using ICT with PwD which includes a section on using ICT in reminiscence work. In the guide ICT is acknowledged as an important resource for

reminiscence work as it can give virtual access to a wide variety of prompts instantly; it can easily be individualised and is flexible (www.scie.org.uk).

In two of the settings studied, the hospital and day care, ICT was actively used during reminiscence sessions. It was noted that participants enjoyed the use of Facebook and YouTube as prompts and had no problems with seeing the screens or hearing the audio output. Analysis of observational data shows that Facebook appeared to be a useful prompt for reminiscence, although interestingly the previous session at the day centre which used conversational prompts only was as lively and animated as the session which used Facebook. Interestingly, in his work, Chaudhury (collecting stories from PwD) has used verbal and visual prompts during guided conversations and has noted that when he used only verbal prompts, such as simply asked questions, for example asking if a person remembered his or her childhood home, he would only get short, disjointed answers. However with visual prompts (such as photographs) in addition to the verbal prompts more extensive answers would be provided and people would share more details (Chaudhury2002). The findings from this set of observations were not in accordance with Chaudhury's works. YouTube and Facebook as prompts were clearly enjoyed by the participants and did encourage engagement and communication in the sessions observed. The mix of audio and visual output may have been particularly useful. Woods and McKiernan note that multi-sensory prompts can be more effective than abstract prompts such as photographs used on their own (Woods and McKiernan 1995).

Another novel prompt which was mentioned by Mary in the day centre was the use of outings to familiar or significant places. Mary had mentioned taking PwD to Dublin, to the birthplace of a local poet and also to the Garda museum and had noted that these outings had been very popular and had prompted reminiscence especially for individuals who had a specific connection to these places. Gibson notes that trips or pilgrimages such as these can be richly rewarding for both the PwD and the carers (Gibson 2011).

Mary stated that these outings were very successful from the point of view of being able to move from the abstract to the concrete. This in her view took reminiscence to a different level. Another way of trying to take reminiscence to a different level, without incurring the costs of actual themed days out would be to use enactment, where a facilitator recreates a familiar past situation in the present such as an outing to the seaside or a wedding as a prompt. Schweitzer and Bruce ague that enactment is an effective reminiscence trigger as it stimulates many of the senses simultaneously and invokes spontaneous responses to a variety of prompts including verbal, kinaesthetic, oral, musical and textural. They further argue that enactment is appropriate for PwD as it does not create a "test" situation, there is no right or wrong response and it does not rely on verbal responses. Enactment was not used in this day centre. This may have been because Mary was unaware of it as a possible prompt or she may have been reluctant to use it. Schweitzer and Bruce note that some facilitators are wary of using enactment because they feel they may not have the charisma or confidence to carry it out but in their experience they have found that those who have taken part in enactment have found it a particularly effective way of engaging with PwD and their own confidence in using this method has increased (Schweitzer and Bruce 2008). Enactment may also be viewed as a form of play, which as previously noted, Hayes and Povey regard as an important part of creative dementia care, as it releases PwD from expectations of rightness and enables them to experience joy and connection with others (Hayes and Povey 2011) and also links in with PPW (Kitwood 1997). However, trips and outings involve significant resources in terms of finance and staff and as Mary noted, this can affect the frequency with which they can be carried out.

Music was observed as a popular prompt in three of the four settings, the exception being the day centre[17] .In the other three settings, the data showed that participants either sang songs, or listened to music as part of reminiscence sessions. This appeared to be enjoyed by the participants and singing and music appeared to encourage the sharing of memories. It was

[17] (although the facilitator in the day centre did mention music was used in that setting as a prompt successfully at other times).

also noted by one of the facilitators that music was helpful for those participants who were encountering difficulties with verbal communication.

Some of the facilitators also spoke of successfully using prompts linked to creativity in other sessions (not observed) such as cooking, art and poetry. The advantage of using prompts such as these is that they can tap into retained abilities and can be used to explore un-developed or new creative forces within the person. It has been noted that some PwD can actually become more creative, perhaps because the move away from an emphasis on cognition allows them to express other parts of their personality, which can be a positive experience (Schweitzer and Bruce 2008; Bartlett and O'Connor 2010). As with music, the use of creative prompts such as art can also be useful when a person is experiencing communication difficulties, allowing the PwD to express themselves without the use of words (Kahn-Denis 2002).

It was interesting that the use of sensory prompts, involving touch and smell only occurred in two settings at respite, where the data showed that different scents were used as part of the SONAS session and at the nursing home where a rummage box containing Vick's vapour rub was used. In the respite care setting, such prompts appeared not to stimulate Reminiscence and instead the PwD simply commented on whether or not they liked the smell. In the nursing home, the rummage box contained some items which could stimulate the senses, Vick's expectorant rub and a cloth mantilla (a religious head covering) and these were used and stimulated some limited discussion. The literature has shown the use of sensory stimulation can be useful in encouraging reminiscence for some PwD especially those who have difficulties with other senses, such as visual impairments, but in the sessions observed there was little evidence of the use of sensory stimulation.

So whilst the findings showed that the use of prompts may be useful during reminiscence, particularly in engaging PwD who have communication problems and they may produce an element of novelty, they are not an essential element of reminiscence work. Providing the facilitator had knowledge of the individual and or the locale, it was possible to facilitate a

lively, interesting reminiscence session and as has been noted in other research (Tolson and Schofield 2011) facilitation style has a significant effect.

6.8 What makes a Reminiscence session successful? - Group size and composition.

Gibson recommends keeping reminiscence groups for PwD small with probably no more than two to four members (Gibson 2011) and Chaudhury also refers to two to four members being an acceptable size, dependent on the personal dynamics of the individuals and the skills of the facilitator (Chaudhury 2008). It is curious although not entirely surprising given the low value placed on reminiscence, that in this thesis, all but one of the Reminiscence groups (Day Care) were larger than that recommended by experts. It is surmised the group size has an effect on the type of reminiscence which can be undertaken. A large group is really only able to carry out simple or general reminiscence work, as opposed to specific or special reminiscence work, which as previously described is very general, fairly superficial and not particularly individualised.

The fact that only simple or general reminiscence work could be undertaken in these groups meant that to a certain extent only superficial topics could be discussed within the groups. This would concur with the fact that, as discussed earlier in this chapter, facilitators (with one exception) did not report any traumatic or distressing disclosures during reminiscence and it does limit the topics which can be explored during reminiscence.

The size of the group also impacts on how much attention the facilitator can give each individual participant, which may impact on the reminiscence experience. The size of the group is often influenced by organisational needs, which are usually outside of the facilitators control but the impact of the group size on the reminiscence experience should be acknowledged.

The make-up of the group can also have an influence on the reminiscence experience. Chaudhury recommends selecting participants with shared interests and compatible dispositions (Chaudhury 2008) whilst Gibson believes groups can be more diverse providing participants are tolerant with each other (Gibson 2011). However, Gibson recommends not including anyone who is likely to harm other participants or those who may make it difficult for others to participant (Gibson 2011). In the groups studied, the participants were thought to have a similar level of cognitive ability and although they had a range of differing interests and dispositions, they appeared to be tolerant and accepting of each other, with the exception of one group. As discussed earlier, the reminiscence group in the nursing home included a participant (not interviewed) who appeared to have more cognitive difficulties than the others in the group. This seemed to impact on her participation in the group and as reported in the findings, she was subjected to jibes and ridicule from other members of the group. The facilitator attempted to negate the effect of these, but taking part in the reminiscence group cannot have been a positive experience for her. Again the make-up of the group may be influenced by organisational needs and may be outside of the facilitator control, but its impact should be acknowledged.

6.9 What other factors makes a Reminiscence session successful?

The context or environment in which reminiscence work takes place is an issue which has long been highlighted in the literature (Head, Portnoy and Woods 1990). In one study of reminiscence groups in two different settings, the researchers showed that in one setting where previously little interaction had taken place, during an alternative group activity, reminiscence work produced a dramatic positive effect on PwD and the staff. Interestingly, in the second setting where the environment was deemed to be richer in terms of interaction, reminiscence work had little impact. Findings from this study highlighted the importance of the setting in which reminiscence takes place and pointed to the need for careful definition of environmental factors in reminiscence work (Head et al 1990). The setting in which

reminiscence work takes place is just one aspect of environmental issues which should be considered in relation to reminiscence work. There is a growing body of literature on the impact of the built environment in dementia care and the importance of the physical environment including colour, signage, interior design and other factors (Day, Carreon and Stump 2000; Gibson 2011). It was notable that within the settings studied in this thesis, all but one (the acute hospital setting) had made efforts to adapt and personalise the physical environment and to make it more homely. This was evidenced in the furnishings, décor and religious memorabilia which gave the impression of a home-like environment, and the fact that most staff dressed in normal attire and used no uniforms. There is evidence that providing a home-like ambience within a dementia care setting produces benefits for the PwD, including improved emotional well-being, enhanced social interaction and reduced agitation (Day et al 2000). The settings in this thesis which attempted to provide a home-like environment certainly appeared warm and welcoming. Indeed even the nursing home which was being renovated seemed to reflect reasonable efforts in this sphere.

However, the fact that the hospital hosted its reminiscence session in a clinical setting, training room, which was in no way home-like is not necessarily a negative. Gibson has noted that holding a session in an unfamiliar place such as an un-used staff room can promote a feeling of excitement and adventurousness (Gibson 2011). As noted in the findings chapters, neither the PwD nor the facilitators belonging to this setting spoke negatively about the reminiscence environment.

Gibson refers to as 'special places and spaces which encourage reminiscence' (Gibson 2011). This refers to rooms or areas which have been specifically designed to encourage recall of past times. These are becoming increasing popular and there is anecdotal evidence that they promote successful reminiscence (www.bbc.co.uk). None of the settings studied for this thesis demonstrated such places or spaces. Brenda, the nursing home facilitator, mentioned having visited such an environment in a nursing home, and she said in the future she hoped

to create a similar room when renovations had finished in the nursing home. She had talked to management about it, who had been positive about providing such a room.

Another aspect of providing a comfortable environment is the use of refreshments. Gibson notes that the provision of refreshments can be an important element to be considered in reminiscence sessions. Served at the beginning of the session they can relax and welcome people. Served at the end, they can help people bond and they can make a session feel special (Gibson 2011). It was noted that at the respite care setting, the session started just after the residents had enjoyed a cup of tea. In the day centre the residents went off to have a cup of tea after the session and in the acute hospital setting the residents were returning to the ward where they would have refreshments. In the nursing home the facilitator had provided drinks, biscuits and sweets during the session, and this appeared to add to the enjoyment of the session, with one of the PwD mentioning that it felt like being at a party. Refreshments appeared to have some importance in the reminiscence sessions observed, and certainly the practice of providing them seemed to enhance the session.

Another factor which is relevant in the context of promoting an optimum environment when carrying out reminiscence for PwD, is an awareness of the importance of auditory stimuli such as sound levels or visual stimuli such as TV screens, posters etc. It is acknowledged that care facilities can be noisy and it is generally understood that frail, older adults may experience overwhelming amounts of auditory and visual stimulation in traditional care environments. It is known that noise in nursing homes remains problematic despite attempts to create homelike environments. Although little attention has been paid to the impact of sound on PwD in research, Joosse completed a recent study on nursing home sound levels across eight nursing units in four nursing homes. Sound levels recorded were higher than those recommended for other health care organisations (there is no WHO recommendation for nursing homes). 26% of the sound was created by staff talking, with only 3% of this talking directed at or including residents (Joosse 2011). Mealtimes were especially noisy. One of the problems with a noisy environment is that it could be a source of hyper

stimulation which many experts in the area of reminiscence with PwD recommend should be avoided (Gibson 2011; Chaudhury 2008).

Noise did not appear to be a major problem in the acute hospital setting, the day centre or the respite care centre and observation notes showed that noise levels did not seem to pose any problems within these settings. Although at the day centre noise could be heard from the communal lounge it did not seem to interfere with the reminiscence session. The nursing home had major problems with noise levels. In particular, in the second session observed, the noise from the nearby high dependency unit which included the shouting and crying from other residents with advanced dementia or psychiatric problems was most disturbing and reminiscence participants commented negatively on the noise. This excessive noise clearly disrupted the session and made analysing some of the data very difficult. At this nursing home and during reminiscence there was also much staff movement and movement of other residents of the nursing home intruding into the session. Other residents walked around the group which was taking place in an area which others could easily access. Gibson has suggested that sometimes people who have been displaced from their usual sitting area or favourite chair can try to re-assert their right to be there by 'gate-crashing' a session when a reminiscence group takes over an area, and that may have been the case in the nursing home (Gibson 2011). Experts such as Chaudhury and Gibson recommend providing an environment free from distractions and sadly this was not achieved in the nursing home (Gibson 2011; Chaudhury 2008).

However, whilst the impact of environmental issues on reminiscence is acknowledged, research has pointed to the fact that the adverse impact of less than ideal environments can be mitigated by attentive staff who provide a safe and stimulating environment (Monahan 2005).

6.10 Specific ethical issues related to reminiscence work with PwD

In addition to the issues related to consent and choice discussed in the methodology chapter, there are other ethical issues which should be considered in relation to reminiscence work with PwD.

In all types of reminiscence work there is a need to value people and their stories, be sensitive to emotional needs and careful to avoid malignant social psychology (Brooker 2007: Bruce and Schweitzer 2008). This means valuing those stories which may seem boring or repetitive as well as those which are more interesting or intriguing. It also means accepting stories at face value and not correcting them. For example sometimes a PwD will relate a story which cannot be completely factual, with incongruent details yet the story should still be listened to and the emotion involved responded to. Bruce and Schweitzer argue that there is often an emotional truth in such stories even if the details are confused (Bruce and Schweitzer 2008).It has been argued that frail, elderly people have a right to have their stories known and understood (Kenyon 1996) and this includes PwD. In the settings observed in this study, the facilitators did take time to listen to the stories related and did not correct participants.

Gibson has identified the issue of fairness in relation to reminiscence work, where each person has an equal and acceptable opportunity to participate and contribute according to their capacity, motivation and needs (Gibson 2011). In order for reminiscence to be fair, there is an onus on the facilitator to ensure each PwD contributes and participates as much as they want to and need to. In the settings observed it was noted that the facilitators did encourage participants to join in and used their knowledge of participants to encourage conversation. No one voice tended to dominate at any of the sessions observed and investigated.

Sometimes unexpected narratives can arise during reminiscence sessions, when a PwD shares something which they have previously kept private. This did not arise during the sessions observed but it was noted in field notes that one nursing home participant, who was thought to have been unmarried, had recently started talking about a brief marriage whilst

working in America, which none of his family had previously been aware of. If an unexpected narrative such as this does arise, it would be important to support the person by listening and consider issues of confidentiality, including ensuring there is clarity around what the PwD considers private and what the person is willing to share.

There are also other ethical issues which may arise in reminiscence work such as the facilitators being privy to specific information about clients which other staff are unware of. There may be situations where the reminiscence worker may believe that if other staff members had great awareness of these clients life histories they might be better able to understand them. In cases like these, they should always seek permission from the client to share this type of information. Other ethical dilemmas include sharing end products in reminiscence work, such as a life story book where again permission should be sought from the PwD who in effect owns that material. Issues of ownership need to be clarified but in this study there were no end products so this issue did not arise.

6.11 The Influence of the Culture of Care on the Reminiscence experience -Organisational Factors

Whilst ostensibly the reasons for undertaking reminiscence work may be linked to the outcomes usually associated with it, such as improvements in communication, well-being and for enjoyment (Woods et al 2005; Gibson 2011), it is possible that other factors determine the way dementia care decisions are made and it is important to be aware of the organisational processes and ethos which can be embedded and affect dementia care (Bartlett and O'Connor 2010).

Reminiscence could be being carried out merely for organizational and non-therapeutic reasons, such as to enhance the organization's reputation or for inspection purposes to "tick boxes" and demonstrate the activity takes place, rather than for the immediate benefit of the PwD in the facility. Problems can arise if organisational needs like this, take priority over the

needs of the PwD and when reminiscence is tokenistic. In the section to follow the key findings arising from the thesis regarding why reminiscence work was undertaken will be discussed, along with some of the secondary reasons and an analysis will be provided of the impact that these other reasons (hidden agendas) could have on the reminiscence work. Using a social citizenship approach the extent to which the experience of taking part in reminiscence work is affected by the broader societal discourses and structures will be discussed.

In the four settings studied, the primary reason for carrying out reminiscence work according to the five facilitators was to benefit the PwD. The actual type of benefit sought varied between the settings. In the respite care centre, day centre and the nursing home, reminiscence work was being carried out for psycho-social reasons – for enjoyment, to encourage sociability and to provide appropriate stimulation. In the acute hospital setting, according to one of the two facilitators, the initial reason was to attempt to find a way to engage people in cognitive linguistic work, although as shown in the data, psycho-social benefits were also experienced by both patients and facilitators. Ideally a hospital stay for a PwD should balance clinical and medical management with maintenance of cognitive and functional abilities and attention to quality of life (Thompson et al 2008). It would appear in the acute hospital that the initial decision to undertake reminiscence work was more aligned to the management of the medical condition and maintenance of cognitive and functional abilities rather than any attempt to improve quality of life. Fortunately however, as mentioned, the findings showed reminiscence impacted positively on many aspects of quality of life for the people who were patients in this acute hospital. However the decision to undertake this intervention showed a "top down" influence on decisions in dementia care in this setting, where the decision about what type of care or activity is carried out is made by medical staff and management. This is indicative of a hierarchical power structure, where decisions are taken by others and imposed on the PwD.

This difference in rationale for undertaking reminiscence work as reported by hospital staff versus those employed in the respite care , day care and nursing home settings may reflect the different lens through which staff in these respective settings viewed dementia and dementia care. Practices at the respite care centre, day centre and nursing home settings appeared to be underpinned by a psycho-social model of understanding dementia whilst practices at the acute hospital were clearly (as witnessed through the narrative of the facilitators) underpinned by a biomedical approach. This was very evident in the language used, in the tensions experienced by facilitators and in the approach taken. It is important to acknowledge the different paradigms adopted by the organisations as they undoubtedly influence the direction and delivery of care in each setting and of reminiscence.

The reasons noted above for carrying out reminiscence work are primary, acknowledged reasons, but it is possible that there were secondary, unacknowledged reasons. Dementia care providers, in common with health care providers in general, are increasingly under pressure to provide quality services but with efficient use of resources (Roberts et al 2008). The need to provide quality care is also prompted by external forces such as those monitoring processes imposed by governments including in Ireland the regular inspections carried out by Health Information and Quality Authority (HIQA). Dementia care facilities have Supplementary Criteria which they are expected to comply with.

In the case of the respite care centre and the day centre there is a need to satisfy the funding bodies that the facilities are meeting their remit. In the case of the nursing home, which is privately owned, there is a need to attract "customers". One way these facilities can do this is by demonstrating that they provide quality care as well as meeting government regulations. There is no exact definition of "quality care" and as mentioned earlier, Ireland has no dementia specific guidelines similar to the NICE/SCIE guidelines. However by providing psychosocial activities such as reminiscence which are articulated in the HIQA dementia criteria, these facilities are demonstrating an attempt to address the psychosocial needs of

PwD in their care and all three facilities are also meeting the HIQA dementia specific Supplementary standards.

In the acute hospital, a covert reason for carrying out reminiscence work was probably the hospital consultant's interest in research and in writing up the findings of their work for journal publication. If the secondary, more covert reasons for delivering an intervention such as reminiscence result in organisational needs, or professional interests taking priority over the needs of the PwD, problems can occur such as delivering care in a tokenistic way. Bartlett and O'Connor note that some policies and practices in dementia care can be viewed as tokenistic when insufficient resources are provided (Bartlett and O'Connor 2010).

The practice observed at the nursing home, where, the temporary setting in which the reminiscence took place was inadequate and inappropriate for the intervention being attempted could also be viewed as tokenistic. In theory it could be seen that the nursing home was providing this activity but in reality the resources were insufficient and the sessions were inevitably flawed. In a similar vein, in the residential respite care centre the fact that personal care needs (showering and toileting) were fitted in and around leisure time activities, suggested that reminiscence and other activities were not prioritised within the organisation. This routine pairing of dementia with care indicates an implicit prioritising of physical care needs over more psychosocial needs where physical care is seen as the priority and is common in dementia care organisations (Bartlett and O'Connor 2010).

The day centre had a slightly different context, in that the facilitator was also the manager, and as such had the authority to choose activities as she wished. She appeared to be personally interested in reminiscence and to benefit from learning about the people in her care and others who she worked with, so again this may be an example of "top down" directing of activities. She mentioned having limited resources but this did not stop reminiscence work taking place, it just meant that trips out connected to reminiscence were not as frequent as she would have liked. In the day centre, recreational activities were not competing with care activities and therefore more priority was placed on them. In these

settings too, the PwD was obviously at a more mild to moderate stage as they were still living in the community.

An acknowledgement of limited financial resources available for reminiscence arose in two of the interviews with facilitators at the day centre and at the hospital. Mary at the day centre had mentioned that ideally she would like to include more themed visits as part of reminiscence but these were restricted by available finance and in the hospital one of the facilitator's spoke of doubting whether reminiscence training would be available due to funding.

Another consideration when examining why reminiscence was taking place in these settings, was how much input did the PwD within the facility have in deciding what activities they took part in. Although there was evidence that participants could withdraw from sessions if they so wished , it was clear in all four settings that reminiscence was chosen for them by the activities staff and/or the management, rather than the PwD volunteering or seeking out the activities themselves. This may go against current policies of good practice, where the involvement of the people actually using services, in the planning, developing and evaluating of these services tends to be encouraged. Litherland notes that until recently PwD were regarded as passive recipients of services and it has only been in recent years that the emphasis has changed to encourage their active participation in service planning, development and evaluation (Litherland 2008).

Research confirms that PwD can play an important part in service development and evaluation, although appropriate encouragement and enabling strategies may need to be used (Schofield and Tolson 2010;Litherland 2008;Cantely et al 2005; Murphy 2002; Allan 2001). One unintended outcome of staff or management taking over the decision -making and deciding what services, /activities, will be available is that activities chosen are not always the same as those the PwD would choose or wish to take part in. Data show that some of the participants interviewed did not like all the activities which they took part in. In the day centre, for example, Geraldine talked about her painting which she said she was not too

fond of and Dora in the acute hospital said driving was her activity of choice (it was unclear whether she meant being driven as a passenger or actually driving). Their reasons for joining in such activities might well reflect their vulnerability and the power of facilitators in persuading them to join in activities not that appealing to them. They may also want to help the staff by joining in. One way or another it seems that their preferences were not directly taken into account and tailor-made reminiscence activities were not designed for these two PwD. This was something that Bridie a participant in the respite centre had alluded to in her interview. Another participant Helen in the day centre also claimed that she would do anything to help the staff including doing craft work. Similar findings have has been documented before by users of dementia care services. Murphy in his evaluation of dementia community services in Scotland, noted that one woman attending a day centre talked about taking part in the activities to please and help out the workers. He concluded this was a fascinating reflection which turned the relationship of caregiver and cared for within a day centre on its head (Murphy 2002).

6.12 Were there any missed opportunities within the Reminiscence Work -Involvement of the family?

Interestingly, none of the settings actively encouraged the participation of family members in the reminiscence work. For example, relatives were not asked to provide information or items to be used as prompts nor were they given formal feedback and their participation was never actively encouraged. Curiously however families provided background information for general use in the facilities but not specifically for reminiscence work and, there was evidence of informal involvement of families in all settings with facilitators often mentioning how they talked to family members. In the respite care setting one family member recalled how she had suggested her mother (Anne) should take a photograph of her late husband with her on her respite stay, and the manager had reported back that this had led her to talk to the staff about her late husband and reminisce about him. Family caregivers had a limited knowledge

of reminiscence work, although some expressed curiosity and noted that they could imagine it would be useful in dementia care. Only one caregiver (in the respite care setting) expressed unease about her mother talking about the past but this appeared to be because she did not understand why she was talking in this way.

It has been argued that the lack of involvement with families including lack of knowledge acquired from families could be related to ensuring that workers are not distracted from the main task of caring. Writing from a psychoanalytical perspective on the subject of older people in hospital, Darting ton argued that this lack of knowledge, although dysfunctional to the maintenance of the PwD's identity, was functional for the institution as it ensured that the only thing that mattered was the hospital ward and its workings, with everything else considered confusing and disruptive (Dartington 2010). Interestingly, one of the achievements attributed to Menzies Lyth, was in helping staff on a children's ward make the, at that time radical, shift from tolerating mothers visiting to accepting a full maternal presence (Menzies Lyth 1960). It could be argued that a similar shift is needed in fully accepting the input of families within dementia care. Kitwood argued that family members and PwD themselves are the experts in the new culture of care and not the medical practitioners and scientists racing to find a cure and treatments for dementia. Family members have often built up a wealth of knowledge and information about what works best and what fails in caring for a relative with dementia and these information needs to be shared and could be very helpful in informing the design of a reminiscence programme

Research has shown that family involvement can be useful and enrich reminiscence work (Gibson 2011). Chaudhury recommends that families should be treated as allies, and involved as much as possible (Chaudhury 2008). Family members can for example provide information and concrete items such as photographs to personalise reminiscence for individuals, which is acknowledged as one of the ways to enrich reminiscence (Gibson 2011; Chaudhury 2008).

Conversely the findings of this thesis have also shown that participating in reminiscence has the potential to benefit family members. The findings from this study along with other anecdotal reports from caregivers in the media indicate that caregivers often feel they have lost or are losing their loved one to dementia. The cognitive changes and memory loss problems associated with dementia can cause feelings of alienation and confusion amongst caregivers. This was apparent in one of the interviews[18], where a daughter carer struggled to understand why her mother had changed so much since the onset of dementia. Reminiscence can enable family caregivers to connect with the essence of the family member with dementia. It can also enable them to understand their family member with dementia in a way that they may not have been able to before, leading to improved communication. Interestingly, in the caregiver literature, there have even been accounts written up by caregivers about their experiences and in some circumstances narratives reporting how with dementia connections between family members may improve as the true essence of the person emerges (Noonan 2011).

It has also been argued that friends and family members, together with the facilitator, can take joint responsibility for helping the PwD to connect with their essential self, thereby moving away from a narrative of decline and foreclosure towards an acceptance of the whole person as they are. In this context, reminiscence can be a tool to enable this process to take place (Freeman 2011; Randall 2011).

Recent years have also witnessed a trend towards interventions in dementia care including respite care being introduced which focus on both the PwD and his or her family caregiver (Cahill, Pierce & Bobersky, 2014) and including family caregivers in reminiscence sessions would appear to be a natural extension of this. Some research suggests that joint reminiscence work with PwD and families can be enjoyable for families and can be important in reinforcing and strengthening family relationships (Carr, Jarvis and Moniz-Cook 2009; Cahill, Forsyth, Moore, Gibb and O'Caheny 2011). However, the outcomes of the recent

[18] Interview with a daughter carer (Anne) from the respite centre

REMCARE project, discussed in the literature review, which evaluated the impact for PwD and their family caregivers of attending joint reminiscence groups, have signalled the need for caution in relation to joint reminiscence sessions (Woods et al 2012)

6.13 Were there any missed opportunities within the Reminiscence Work - Involvement of the wider community?

Gibson acknowledges the use of volunteers as a positive addition in reminiscence although she recommends training and supervision for them (Gibson 2011). In three of the settings studied in this thesis volunteers provided considerable assistance with the reminiscence sessions. In the acute hospital a volunteer was observed helping during the pilot phase of the fieldwork, in the daycentre a volunteer supported the second reminiscence session and in the respite care centre a volunteer helped in the first session observed. In each of these cases, these volunteers seemed to have brought their own skills, local knowledge and enthusiasm to the session, as well as helping with small tasks. In the day centre it was also noted that the volunteer helped with the use of the computers and also supplied additional local information and anecdotes during the session. In the respite care centre the volunteer sang a song and in the acute hospital the volunteer again offered additional local information when reminiscence discussions were taking place.

Only one of the facilitators mentioned the possible use of voluntary organisations within reminiscence work. This was Mary from the day centre who believed there could be a role for local organisations such as the Irish Countrywomen's Association (the ICA), Macra na Feirme (a farming organisation) or active retirement clubs. There is some evidence from Scotland[19] of the beneficial involvement of voluntary organisations in Reminiscence work with PwD, with benefits for all concerned, (Schofield and Tolson 2010).

[19] The Scottish Football Museum Reminiscence Pilot Project 2010

It has been well documented that PwD can become isolated. A report commissioned by the Alzheimer's Society of Ireland showed that PwD experienced diminished social networks and enforced social isolation together with negative social encounters. The report noted that for some people avoidance was a common reaction to PwD (Nolan et al 2006) probably due to stigma. In light of the negative reactions which PwD have to face as noted above, any intervention which can show PwD in a more holistic light, must be of use, and as discussed above reminiscence has the potential to do that. The benefits of including people from the community (ideally trained, supported and vetted) go beyond the benefits noted for the individuals taking part in the reminiscence experience. For example in the case of the Scottish Football Museum Reminiscence project, it was noted that the media became very interested in this project leading to reports in newspapers and websites (Tolson and Schofield 2006). The findings from this project provided powerful examples of PwD interacting positively with others. This is different from the many negative public images and stereotypes more often encountered in the media. In this way, the inclusion of volunteers can have a cascade effect into the wider community, affecting public opinion in a positive way and feeding into general societal values.

Connecting to family and the wider community has been described as one of the essential domains of quality of life for PwD (Murphy 2006) and a report which interviewed older long stay care residents in Ireland noted that many of the residents wanted to be more connected to the outside world (Murphy 2006). It could be argued that by not facilitating a connection to the wider community, organisations are acting in a way that is not person-centred. It could be said that they are not viewing the PwD as a whole person, with bonds and connections into the community and not respecting their citizenship rights to access their local community.

There are many ways of involving the wider community in reminiscence work with PwD including inter-generational work, and the use of displays or collages which others could view, but these were not in evidence in any of the settings studied.

6.14 The strengths and weakness of the methodology employed

This thesis used mixed methods and a qualitative, phenomenological approach, with data collected using both semi-structured interviews and observations at two points in time. The data was analysed using I.P.A. As mentioned in the methodology chapter, a qualitative approach was chosen as the purpose of the research was to explore the experience of the PwD and the facilitators. A qualitative approach appeared to be by far the most appropriate way to access rich, descriptive accounts indeed in this context quantitative research would have been totally inappropriate. Accordingly whilst quantitative research is often regarded as the "gold standard" of research, Bartlett and O'Connor have argued that rather than there being a hierarchy of evidence with quantitative research at the top, it is more useful to think of a continuum of evidence with quantitative at one end and qualitative at the other end (Bartlett and O'Connor 2010).

Quantitative research tends to be unsuitable for the investigation of the subjective experience of reminiscence work (Woods 1995; Schweitzer and Bruce 2008; Gibson 2011). As the aim of this thesis was to explore the subjective experiences of PwD and facilitators undertaking reminiscence work, qualitative research was deemed most appropriate.

In her thesis looking at the experience of facilitators delivering reminiscence sessions, Pullan noted that she had used a qualitative approach because there were few relevant prior studies and because of this testable hypotheses would have been difficult to generate (Pullan 2009). This comment is also very applicable to this thesis. I.P.A. was used to analyse the data as it is acknowledged that it can communicate the rich description and the essence of a phenomenon (Holloway and Todres 2003), which was the aim of this thesis.

Interviews are recommended in I.P.A research as they allow subjects to tell their own stories and are increasingly popular in dementia research (Innes 2009). As one of the aims of this thesis was to enable the PwD and the facilitator to share their experiences, it was decided interviews would be an ideal tool. However, in some of the interviews carried out, it was difficult to access the opinion of the PwD resulting in some of the interviews yielding smaller

than expected data. Although I followed carefully the advice given by experts in the field regarding interview techniques with PwD, difficulties may have arisen due to cognitive problems or verbal difficulties or because of the way I designed the questions. In retrospect, additional aids could have been used during the interview process to attempt to surmount these difficulties. One aid which could have been considered is a Talking Mat or similar communication device.[20] Talking mats have been successfully trialled with PwD and have been shown to improve the ability of people at all stages of the disease to communicate (Murphy, Gray and Cox 2007).

In their study of the challenges of conducting qualitative research with PwD, Beuscher and Grando note that transcribed interviews can seem thin and they recommend multiple readings and triangulation with field notes and observation to strengthen the data (Beuscher and Grando 2009), these additional data collection tools were used for this thesis.

Observation was used as an additional data collection tool, partly because observation is recommended in situations where interviews are difficult to conduct (Langdridge 2007) which I suspected would be a possibility in this thesis, but also because observation has such a strong history in dementia care research, for example in the work of dementia care mapping, observation is the research tool employed. Litherland has warned that there is a danger in dementia research of over-representing the more articulate PwD (Litherland 2008) and the use of observation in this study, including the observations of non-verbal communication allowed the experiences of all the PwD taking part in this study to be included. Observation was particularly useful in recording transient outcomes, such as the expressions of enjoyment which participants displayed. Had the study relied on interviews only, these transient but important outcomes would have been missed. On reflection, the observational work was effective but it had some limitations including the fact that a sole observer can only simultaneously monitor a limited number of phenomena and may miss out on important interactions. The use of a video camera could have helped with this, but the

[20] A talking mat is a low key technology device consisting of a textured mat on which picture symbols can be placed by a person experiencing communication difficulties.

latter could have been intrusive and may have proven unethical and have adversely affected the sessions.

6.15 Chapter Summary

The findings of this thesis show that reminiscence was an activity which both PwD and facilitators enjoyed, although the extent of this enjoyment varied between settings. Reminiscence appeared to contribute to a person centred ethos by meeting the psychological needs of these people and by promoting PPW (Kitwood, 1997). The environment, group size and group composition appeared to affect the reminiscence experience, with smaller group sizes probably yielding more positive results and problems noted when groups had people with different levels of cognition impairment attend and participate in reminiscence. The unique features of the residential respite care setting, where clients may not know each other and may only be living there for a short time were noted. Different physical prompts were used at each care setting to stimulate reminiscence and the use of ICT seemed particularly successful. However, it was noted that sessions where facilitators used their personal knowledge of the individual or their personal knowledge of locale to prompt conversation were also lively and stimulating.

Each of the five facilitators interviewed for this thesis had not been trained in reminiscence, tended to express no interest in upskilling in the area and appeared to have little support by way of resources afforded or supervision from management staff or others. The need for support and appropriate training was discussed. The issue of whether a shared culture was essential for reminiscence was explored and it was argued that this was not necessary. The data suggest that in some circumstances reminiscence sessions seemed to be carried out in a tokenistic way. Analysis also shows that the range of topics discussed during reminiscence sessions at each of the four settings tended to be limited with certain core topics including schooling, religion, politics and bereavements skirted over or not discussed at all. Facilitators were for the most part reluctant to tackle topics perceived by them to cause distress to the

PwD and because of this I would argue that the reminiscence sessions were somewhat superficial. There were therefore several missed opportunities in the settings observed, and ways identified by which the reminiscence experience could have been enhanced. Most notably there was little input from family members in any of the settings and limited input from the wider community.

7 Conclusion

7.1 Introduction

The origin of reminiscence work dates back to Robert Butler whose pioneering work in the 60's challenged the until then dominant view that reminiscence in older people was a symptom of mental illness (Butler 1963; Chandler and Ray 2002) see pages 31 and 32, chapter two. The belief that carers should know and use life stories to support PwD, is grounded in the belief that the preservation of self is possible (Coleman 1986; Chaudhury 2008; Gibson 2011) and that PwD are not merely diseased or "atrophied brains" but rather they are human beings, capable of enjoying old and new experiences; they can manifest many different social personae (Snowdon 1997; Sabat 2005) and they continue, despite their dementia, to live in and exist in a social, physical and cultural world where they need to be valued, treated with respect provided with psycho-social stimulation and to be engaged in meaningful activities (Kitwood and Bredin 1992; Kitwood. 1997; Sabat, 1998; Woods, 2001).

This change in society's understanding of dementia, from viewing it as an organic fatal nihilistic non-curable disease (bio-medical approach) to the more humanistic perspective has been paralleled by the development of many non-pharmacological interventions of which by far the most popular is reminiscence work (Woods et al 2005). Whilst as noted in chapter two, good quality quantitative research has been limited in this area, even less is known about the subjective experiences of PwD partaking in reminiscence. There is a particular dearth of research, using qualitative methodologies to investigate the topic. One piece of research which did include the subjective experience of the PwD was the recent study linked to the DARES/SERPS programme mentioned in the literature review, chapter two. The viewpoints of the PwD and relatives were included in both the design of the intervention and the evaluation. This is a useful contribution, however it was acknowledged that the input of the PwD was limited (n=3 in the design phase) and it was noted that these PwD found it hard to articulate their opinions (Cooney et al 2012). Leading experts writing in the area have called for more qualitative studies to be carried out (Webster et al 2002; Gibson 2011). This

thesis therefore has been undertaken in Ireland in order to narrow this gap in our understanding to explore this neglected topic in the Irish context from the viewpoints of PwD, the facilitators and family caregivers

Accordingly, this study set out, not to evaluate the effectiveness of reminiscence[21] but rather to explore in-depth and through the subjective experiences of a small group of people, who recently participated in different reminiscence activities (both PwD and facilitators), the value and meaning they placed on it. In this way, the thesis is not seeking to demonstrate the effectiveness of reminiscence (assess the extent to which it may enhance quality of life, improve cognitive function or increase well-being) but rather it attempts to gain a deeper richer understanding of salient issues including (i) the extent to which the PwD may have been afforded a choice to attend reminiscence and/or select the topics covered during the sessions, (ii) the extent to which they enjoyed reminiscence as reflected in their verbal and nonverbal behaviour and (iii) the extent to which reminiscence may have enhanced communication patterns and interactions. The study was also undertaken to gain new insights into why reminiscence was being undertaken in the four settings selected, what prompts and triggers were being used, what type of settings provided the context for the activity and what training and support was available to the facilitators. The research also attempted to explore the role family members played in supporting reminiscence and the extent to which relatives were involved in planning these sessions and working with facilitators. Findings were analysed using I.P.A. which enabled the subjective experiences of the participants to be communicated in a way which uncovered the essence of their experience. This concluding chapter will now attempt to synthesise and integrate the issues which arose out of the findings and which were considered in the discussion chapter. It will cover the experience of reminiscence for the PwD, the experience of reminiscence for facilitators and the factors which affected the reminiscence experience. It will look at

[21] Many different RCTs have attempted to answer this question and as shown in the literature review chapter the results are somewhat equivocal.

practice, policy and research implications and will also acknowledge the limitations of the thesis.

7.2 Reminiscence and the PWD

The findings showed that there were several positive outcomes for PwD who were participants in this research study and were involved in reminiscence work in different settings. These included enjoyment, sharing past experiences, making choices, displaying and appreciating humour and showing signs of self-confidence. Some of the outcomes were quite transient and although traditionally research into reminiscence work has tended to concentrate on outcomes which are experienced beyond the session, short-term outcomes such as momentary enjoyment can be viewed as a successful outcome to a session (Cahill et al 2012; Gregory 2011; Killick 2000). The use of observation to complement the interviews was particularly useful in allowing the researcher to capture transient enjoyment and the almost playful quality noted in all reminiscence sessions observed, where PwD were seen at times to be laughing, singing, dancing and enjoying the moment during sessions. This type of playful enjoyment has been described by Kitwood as an element of Positive Person Work which he viewed as a way of promoting person centred environments (Kitwood 1997).

All participants with dementia interviewed stated that they enjoyed reminiscence work although some were quite equivocal in their narratives, stating in fact they would prefer to undertake other activities. These findings were corroborated by the observational data where some peoples' behaviour was seen to fluctuate. For example they were noted to appear engaged for periods and then become distracted, (for example looking out the window), withdrawing, or at the extreme falling asleep. Interestingly, whilst findings show that most were not afforded choice in terms of attendance, several exercised choice and control over the respective topics selected for discussion and pursued. Although the data

showed evidence of many missed opportunities including the absence, for reminiscence purposes, of staff and family member communication, the avoidance by and large of using reminiscence to stimulate some of the senses (smell and touch) and facilitators' failure to identify and build on clients' obvious talents and interests, nonetheless, with a few exceptions, reminiscence was shown to promote conversation and increase engagement and interaction amongst the participants. In all settings, reminiscence work enhanced connections between the PwD and facilitators and between the PwD and other participants in two facilities.

Previous research on reminiscence has tended to focus on the importance of dyadic relationships such as spousal relationships or triadic relationships such as PwD/spouse/formal carer. However, as discussed earlier in this thesis, reminiscence has the capacity to enable the PwD to connect back into their communities, arguably one of the essential domains of quality of life for the PwD (Murphy 2006) and aligned to a citizenship approach to dementia care (Bartlett and O'Connor 2010). A PwD may have many bonds, social personae and attachments, with social statuses and connections within the community (Bartlett and O'Connor 2010). Findings from this the thesis showed there was very limited use of reminiscence to connect PwD to their wider community and this could be viewed as a missed opportunity in the settings studied.

7.3 Reminiscence and Facilitators

Interestingly, whilst three of the five facilitators interviewed claimed that reminiscence was being done to provide psycho-social stimulation to PwD[22], the data provided preliminary evidence that the facilitators themselves may have derived as much or even more enjoyment from the activity than did their clients as the data seemed to suggest that these staff

[22] The other two stating it was being done to provide cognitive stimulation and improve communication particularly language skills

thoroughly enjoyed the reminiscence sessions. This is a positive finding for the facilitators and also may benefit the PwD whom they care for.

As noted in the introduction of this thesis, dementia care workers are generally underpaid under-valued and working in what some consider unattractive challenging areas of formal care work (Bartlett and O'Connor 2010). In addition, the thesis findings showed that the facilitators invested some of their own private time, energy and possibly in some cases limited income into planning and organizing the sessions. The fact that reminiscence work was an activity enjoyed by these care workers should be considered a welcome bonus. As Menzies Lyth argued, institutional health is characterised not just by performance indicators but by morale indicators and feelings of fulfilment (Menzies Lyth 1991) and staff well-being and mood will no doubt have some bearing on client care relationships in dementia care settings. Accordingly, whilst the way in which staff morale may have impacted on PwD was not investigated in this thesis it is likely that good morale engendered a positive ambience within each of the settings. Another benefit which facilitators mentioned was that apart from learning much about the person in their care, they also learned a great deal about the local area and local history. Again, this is a very positive outcome which has important ramifications for all care staff but particularly migrant care workers, whom as discussed earlier may account for as many as one third of the care work force for older people (Walsh and O'Shea 2010). Learning more through reminiscence about the local geographical area and local history and folklore may improve migrant worker's understanding of the local culture. The latter may then enhance their ability to work with PwD and also help them generally to settle into their new workplaces and homes. Obviously reminiscence alone should not be seen only as a training opportunity for migrant workers but should be used to help non-nationals build on earlier training and education in dementia including the use of pharmacological and non-pharmacological interventions such as reminiscence.

How reminiscence in particular afforded facilitators time to become better acquainted with their clients (PwD) emerged very strongly in some of the data collected. This point was

extremely well articulated by one hospital based facilitator, see page 167 chapter five. Drawing on Kitwood's work on person-centred care and also on Positive Person Work (PPW), findings showed that by enabling the facilitator to see the PwD in a more holistic light, as a person with a past, with interests, with their own valuable narrative, reminiscence work had much potential to enhance person-centred care and to support well-being.

The facilitators each came from different disciplines, nursing, occupational therapy, speech and language therapy, activity therapy and care work. In addition to their vocational and tertiary training, most had also undergone dementia training, but interestingly none had been trained in reminiscence work. What may have been even more surprising is that unlike in other studies (Trueman and Parker 2006; Schofield and Tolsen 2010), none expressed any great desire for specialist training in this area. This is despite the fact that most (three out of five) had developed skills and mechanisms to avoid certain topics which might evoke problematic or traumatic personal life memories. This may well reflect the low status assigned to reminiscence in their respective organizations and the low priority they themselves assigned to this type of non-pharmacological intervention.

One could argue that the deliberate avoidance of certain topics made sessions very limited as those subjects avoided such as religion, politics, childhood and early education had the potential to generate much rich discussion. The issue of whether people should during reminiscence be encouraged to reflect on memories which might evoke sadness, loneliness or distress has not been fully resolved in the literature and findings are somewhat contradictory (Bender 1997; Gibson 2004;Westerhof et al 2010)). Certainly Kitwood, subscribed to the belief that PwD should be encouraged to experience both positive and negative emotion (Kitwood 1997). From a psychoanalytical perspective the avoidance of dealing with potentially painful emotions may have been a defence mechanism deliberately chosen by them in order to remain detached; to eschew their own emotional reactions including fear, sadness and guilt and to distance themselves from their clients (Menzies Lyth). I would argue that if these same facilitators had undergone training in reminiscence and were able to avail

of an appropriate support system, they may have been less afraid of dealing with topics with the potential to arouse painful emotions in PwD. In trying to protect the PwD from painful emotions they limited the range of subjects a PwD can reminisce about and may have actually prevented them from reminiscing on topics they could have potentially enjoyed such as childhood education, births, deaths, funerals, marriages and wakes. For example deciding that religion is an inappropriate topic for older people to reminisce about, particularly older people in rural Irish settings, blocks off opportunities to reflect back on many significant events in these peoples' lives such as, making one's first Holy Communion and Confirmation, one's wedding day in church, baptisms and Christmas and Easter periods. Sim argues that there is much talk about rights and risks in the care of older people and it is important to achieve a balance (Sim 2003). This applies to emotional risks as well as physical risks, and this could include the range of topics covered in reminiscence work. The important issue is that reminiscence should be carried out in a supportive, ethical and sensitive way. Education and training including role playing and experiential learning, play a critical role here and should be a mandatory requirement for all care staff involved in using reminiscence as an intervention with PwD.

7.4 Factors which affected the reminiscence experience

The thesis looked at some of the factors involved in supporting the reminiscence experience, in particular looking at the use of prompts, whether group size and make-up affected the experience and environmental factors.

This thesis has also shown the wide variety of prompts (six in total observed and facilitators referred to using other prompts in other sessions) used in these Irish settings where reminiscence took place and whilst the study did not seek to ascertain which trigger/prompt might have been more effective in fostering good meaningful reminiscence, it is interesting to note that ICT (by way of YouTube and Facebook) was used very successfully in the hospital setting and in the Day Care setting. Interestingly, it was also shown that knowledge of

participant's life stories and of the locale, was also used by two facilitators to successfully generate conversation without the need for any physical prompts. This finding has important implications for practice as it demonstrates that reminiscence work does not necessarily need costly equipment or resources to be successful, and knowledge of individuals is more important.

In the discussion chapter it was noted that in all but one of the settings studied the group size was larger than generally recommended for reminiscence work (Gibson 2011; Sim 2003) and this may have influenced the type of reminiscence work carried out, as with a larger group the topics covered tend to be superficial with an emphasis on providing an entertaining activity which limits the potential of the reminiscence work for the individuals concerned (Gibson 1994). The discussion chapter also acknowledged that the make-up of the group is important, as exemplified in the case of the nursing home, where there was a participant who appeared more cognitively impaired than the others who was treated poorly by the other participants who criticised and mocked her.

This thesis has considered the influence of environmental factors on the reminiscence experience. Interestingly although there is evidence in the literature that a homely environment improves the well-being of the PwD (Day et al 2000), and three of the settings made great efforts to provide a comfortable, homely environment, in the one setting where this was not provided – the acute hospital setting and in the session observed in the office of the day centre, the non-homely environment did not seem to impact the reminiscence experience negatively.

The use of refreshments, at the beginning and end of sessions in three of the settings and during the session in the nursing home, seemed to add to the enjoyment of the session. This was particularly noticeable in the nursing home, where sweets and drinks were provided during the session and a participant noted that it was like being at a party.

The one environmental factor which did seem to impact negatively on one session (in the nursing home) was excessive noise, which was commented on negatively by the participants.

7.5 Other Practice Implications

As stated earlier, findings showed many examples of missed opportunities or circumstances where if more resources (material and non-material) were available these reminiscence sessions could have been hugely enriched. A very obvious case in hand was the absence of any real family involvement in reminiscence by way of relatives being asked for life story information, pictures, mementoes or other memorabilia which might have made the sessions more individualized. In fact some of the data collected during in-depth interview from family members showed that some relatives were not even aware that reminiscence was taking place. One relative believed that reminiscence was a ridiculous activity and she said she was unable to understand why her mother was dwelling on and talking about topics from the past. The data here suggest there is an important educational role for family members regarding reminiscence. In fact one of the facilitators (hospital based) during the in-depth interview was quick to identify the potential family members had to be more actively involved in reminiscence, yet she seemed to think that this was a phenomenon that would require a budget or resources and could not be easily integrated into current practice. The data suggest that family members could have acted as valuable resources but their knowledge base and the information they held about their relatives' biographies and life stories were not sought out or utilized.

Findings from this thesis demonstrate that care staff delivering reminiscence to PwD could benefit from support but tend not to ask for this. Whilst the facilitators interviewed for this thesis all expressed satisfaction with the support received, the fact that none had received specific training in reminiscence work and that there was evidence of avoidance of certain topics during reminiscence sessions implies that they may not be receiving optimum support.

It is argued that because reminiscence has the potential to place emotionally taxing demands on staff (Woods 1995; Woods 2009; Gibson 2011) sufficient time should be allowed for staff support and many experts argue for the need for appropriate training (Gibson 1994) . Although the provision of training and support may place demands on the workplace with some time and financial implications, this has to be weighed against the considerable benefits which taking part in reminiscence can deliver for both PwD and facilitators.

Another practice issue which this thesis has highlighted concerns reminiscence work undertaken by migrant care staff who may be unfamiliar with local cultural, social and socio-political issues and therefore information and knowledge directly relevant to reminiscing. There were concerns raised by one of the facilitators in this study that there might be challenges for migrant workers undertaking reminiscence work. These challenges centred on the fact that a migrant worker may not be sufficiently familiar with the local area and culture to successfully participate in reminiscence sessions. In the discussion chapter I have argued that provided the migrant worker is proficient in English he/she should be able to overcome any shortfalls in knowledge of the local area or culture, through appropriate training and education. As increasing numbers of Irish nursing and care staff are currently exiting the health services, numbers of migrant care staff are and will most likely continue to increase in coming years. The issue of training these migrant staff to better understand dementia, to appreciate the importance of individual life stories and biographies and to grasp the Irish culture in order to develop interventions such as reminiscence cannot be over-estimated. The issue of sharing local knowledge that is relevant to reminiscence thereby ensuring that migrant staff are not disadvantaged should be addressed. Additionally the benefits to the worker which have already been mentioned, particularly learning about the local area and culture, may help the worker engage more in his or her new environment and bond with others.

7.6 Implications for policy

Unlike other countries around the world (Ebersole and Touhy 2006;Martin 2008) up until recently, public nursing homes in Ireland were not subjected to regular inspections, nor were there any standards in place to govern the quality of care delivered in either public or private nursing homes. Since 2009, new residential care standards have been introduced by the Health Information Quality Authority (HIQA) into nursing homes and supplementary criteria have been developed for nursing homes providing dementia-specific care. These supplementary criteria for designated dementia units have been designed to improve the quality of dementia care and to afford PwD more choice, independence, autonomy and stimulation when living in long stay residential care. To improve communication and meaningful engagement, one such criterion recommends, the use of appropriate therapies such as life stories, reminiscence, reality orientation, validation, sensory equipment and music in dementia care. Whilst recommendations such as these are desirable and admirable, there is no provision within these criteria to oversee the quality of the appropriate therapy being delivered nor is there a requirement that staff involved in delivering such interventions undergo adequate training. It is highly unlikely that HIQA inspectors ever actually observe reminiscence sessions in progress. This means that that there is no quality control over reminiscence and therefore nursing homes which purport to offer this type of activity will probably never have it fully evaluated besides through verbal reports (a box ticking exercise).

I would argue based on my years in practice as a care worker and on the research conducted for this thesis that reminiscence is highly skilled work which requires a mature and experienced individual who is well versed in local culture and knows the life stories of PwD. I would also argue that a reminiscence worker needs to be trained and have a mentor available in an on-going capacity with whom he/she can discuss the content of sessions and how such could be improved. I would also argue for the need for HIQA inspectors to be trained in reminiscence work and, where relevant and ethical, to inspect those nursing homes who claim to be delivering reminiscence to their residents with dementia. The type of

questions HIQA staff would attempt to examine include (i) are staff specially trained to deliver this type of intervention? (ii) How do PwD view the activity and (iii) how do migrant workers manage when attempting to use this type of intervention in dementia care?

Apart from reminiscence taking place in residential care settings, this thesis has also shown that it can take place in other care settings such as day care settings not subjected to HIQA inspections and where no standards need be applied. This means that there is no way whatsoever of monitoring what actually happens in terms of the type of Reminiscence that takes place in other care settings not subjected to HIQA inspections. There is a need for care standards to be introduced for home and community care settings and in the context of reminiscence work there is a need for those employed by the HSE and by private providers to be trained and to receive on-going training in the use of reminiscence work.

As mentioned earlier, in Ireland no guidelines exist equivalent to the NICE/SCIE guidelines in the UK which might make a difference to the way Reminiscence is being delivered in Irish care settings. The fact that the NICE and SCIE are evidence based guidelines, encompassing both health and social care issues and are based on evidence and the expert views of both medical and social care perspectives makes them particularly relevant and helpful to practitioners in the field. It has been argued that guidelines are usually intended to improve outcomes and experiences of care, reduce possible harm, reduce variability of services and enhance service user confidence (Gould and Kendall 2007). In addition to the HIQA Supplementary Criteria for dementia settings referred to earlier, I would argue for the development and adoption of guidelines similar to the NICE/SCIE guidelines for Irish health and social care workers, employed in the dementia field. Such guidelines would indubitably enhance practitioner (facilitator) confidence, as they would enable practitioners to draw on evidence based research and the latter combined with their own professional practice would clearly enhance the reminiscence experience. The educational resources available in the SCIE gateway series, linked to the guidelines, would also be of use to practitioners.

Given some of the deficits observed in the reminiscence sessions undertaken in the care settings selected for this thesis, i.e. lack of training of care staff, limited topics for discussion, inappropriate environmental conditions, absence of family member involvement and PwD's own interests and preferences sometimes not being addressed, this thesis findings raise the question as to whether a sub-optimum intervention in dementia care is preferable to no intervention. If inspectors were encouraged to monitor reminiscence, by sitting in on sessions and observing it taking place in settings where residents are exposed to excessive noise, where regular interruptions take place and where residents' privacy rights during reminiscence are not respected, would such facilities pass inspection and would reminiscence work be allowed to continue? Findings from this thesis have shown the real difference between providing reminiscence in a way that may make a difference to the life of a person affected by dementia versus providing it in a tokenistic manner - to fulfil obligations. The data emerging from this thesis seem to suggest that in some cases tokenism was in greater evidence with organizational needs perhaps taking precedence over and above the needs of PwD.

7.7 Research implications

This thesis is small scale and exploratory and merely only opens up the debate about the topic of reminiscence in dementia care settings in the Irish context. Findings suggest that there is a need for a lot more research to be undertaken on the topic in the foreseeable future. In the first instance, there is a need for more information to be collected in Ireland on the broad topic of reminiscence to ascertain which dementia care settings (public, private and voluntary) throughout the country use reminiscence on a regular basis, how often and with whom (people with or without challenging behaviours) is it used as findings from this thesis suggest that the facilitators tended to cherry pick their clients. In addition research which would compare how this intervention compares with other non-pharmacological

interventions such as aromatherapy, pet therapy, and music therapy would be very beneficial.

This was a small scale cross-sectional study taking a snap-shot picture of reminiscence as delivered in a small number of care settings and over a very particular period in time. There is a need for more qualitative research to be done in the area using follow up designs. There is also need to evaluate the extent to which more individualized and tailor-made reminiscence can yield more successful outcomes compared with the more general and simplistic approaches used in this study. There is also a need for more RCTs and for more longitudinal quantitative research to be undertaken evaluating the effects reminiscence may have over time on both the PwD and on the facilitator. For example over what period of time do some of the benefits derived from reminiscence continue?

This study focused on a group of homogenous people. All PwD except one were born in Ireland (Bridie was born in England but had lived most of her life in Ireland), and all belonged to the same culture albeit some were from rural parts and others more urban. All facilitators were female and had no training in reminiscence. Useful future research might recruit a more diverse sample of PwD and care workers and investigate the role of age, gender, training and cultural diversity in relation to outcomes in reminiscence.

This was an exploratory study generating findings which could now benefit from further research. For example, this thesis showed that by and large, topics covered during reminiscence in the settings chosen failed to tap into traumatic or problematic memories which might evoke distress. It would be helpful to conduct some cross-national research in the area to ascertain how other countries deal with this issue. The finding which showed an absence of connection between the PwD in the respite care setting with each other, and which may as discussed have arisen for a number of reasons may be a potential area of future research. It would be useful for more research to be conducted to see if reminiscence could be used more usefully with settings such as the respite care setting to help PwD in that environment to connect with each other. It would be useful to use a different methodological

approach, such as institutional ethnography, with its emphasis on examining how institutional and organisational practices influence personal experience. This type of research is normally associated with long-term care research but could work well in the other settings studied. As well as examining the individual experiences of the participants it would have allowed for the examination of the organisational systems and processes within which those individual experiences were embedded (Bartlett and O'Connor 2010) which would have moved the research beyond the phenomenological and widened the debate.

7.8 Limitations of this thesis

This thesis has several limitations which need consideration. Firstly, as in much interpretative phenomenological research, with an emphasis on the idiographic, the sample size is small. IPA research is committed to the detailed examination of the particular and the aim of the research is to discover the essence of the experience of the people involved. Findings cannot be generalised across a larger population, however an extension beyond the particular group studied can be considered through theoretical generalisability in conjunction with the existing academic knowledge base (Smith et al 2009). Potentially this may point to areas which deserve further research.

Secondly, as discussed in the methodology chapter my personal attributes such as background, character and relationship style and particularly the fact that I did not come from that part of Ireland in which data was collected meant that in a way I was an outsider and this could have influenced the research process. It is important to acknowledge the role of the researcher and any difference it could have made to the study. As Randall et al point out it is certainly possible that different interviewers might elicit different responses, and this could be because of many factors such as gender, age or interviewing style and it is difficult to say for certain what difference these factors make (Randall et al 2006). Each interview is unique and produces its own unique narrative.

The third limitation of this thesis is that the research used a purposive sample and the facilities which agreed to participate are likely to represent a biased sample since they were willing to have an outsider, move into their work place to observe and investigate at first-hand themselves, their clientele and certain aspects of the working of the organisation. It could be surmised given they were willing to do this, that this indicated a confidence in their ability to deliver high quality reminiscence in a dementia care facility. The research was therefore taking place in facilities which prided themselves on being good quality dementia care settings. It could be that the facilities delivering more sub-optimal interventions would not have allowed the research to take place.

7.9 Chapter Summary

This small-scale, qualitative research study has made an initial yet not insignificant contribution to our knowledge of reminiscence work in the Irish context by investigating in a rigorous way, the experience of PwD and facilitators of taking part in reminiscence work in four dementia care settings in Ireland. Using a phenomenological approach and I.P.A. to analyse the data it has examined the benefits and challenges of taking part in this work from the point of view of both the PwD, the facilitators. It has provided a snapshot of reminiscence work in dementia care in Ireland and as an exploratory study has raised very critical issues, several of which lend themselves well to future research.

This study has argued that reminiscence is an intervention which has substantial benefits for both the PwD and the facilitator. It has the potential to connect the PwD to others, including other PwD, staff, family and the wider community. It has the potential to connect the PwD to their essential self, enabling him or her to experience enjoyment, an improved sense of identity and self-worth and to exercise agency and choice. Reminiscence also has very clear benefits for the facilitators, a finding which has interesting implications. As well as enjoying reminiscence, which is an important benefit in an area of work which can often be underpaid and undervalued, facilitators reported benefiting by being enabled to see the PwD in a more

holistic way. This had the potential to improve their engagement with the PwD which had benefits not just for themselves but for the PwD too. Facilitators also reported learning more about the local area, culture and local history. Again, this is a personal benefit for the facilitators but it also may have particular significance for migrant workers, who make up a sizeable proportion of the work force in the care of older people including PwD. Learning more of the local area, culture and local history has the potential to help migrant workers integrate into their new surroundings.

This thesis has shown that reminiscence work is an activity generally enjoyed by those who participate in it, with benefits to both PwD and facilitators. It has questioned whether reminiscence work is sufficiently understood and valued as an intervention, whether the emphasis is sufficiently placed on the benefits for the PwD rather than the institution involved, whether family and the wider community should be more involved in reminiscence work, whether the lack of involvement with family and community actually impinges on the quality of life of the PwD, whether their rights as a citizen are being upheld and supported and whether facilitators need more training and support to carry out this important work.

It is just over fifty years since Butler first highlighted the therapeutic possibilities of reminiscence. This small scale study adds to the body of knowledge on reminiscence work in particular from an Irish context, and raises issues which are worthy of further consideration and research.

This thesis was conceptualized in 2008, some three years after the Leas Cross exposure of the institutional abuse of older people in one particular Irish metropolitan nursing home.

The media attention that Leas Cross received both within and outside of Ireland and the neglect and institutional abuse of older vulnerable people including those with dementia (exposed through this under-cover reporting), led to much needed policy reform in the Irish long term care sector. Data collection for the thesis took place during a turbulent time when, as a result of Leas Cross, national quality standards for residential care facilities were being

implemented (HIQA 2009) and where a culture of fear and silence was rife. This may in some way explain the challenges the research posed for me particularly in terms of accessing dementia care sites and accessing the sample of PwD and their family caregivers.

Throughout the thesis I have endeavoured to empower PwD- those living in the community using day care services, those resident in nursing homes, those about to be discharged from hospital and those availing of residential respite services who sadly appear to have limited contact with their family members and limited camaraderie with eachother.

Whilst overall these people represent a very small proportion of the 48,000 people now likely to have dementia in Ireland and whilst no major generalizations can be deduced from this small qualitative study, nonetheless some of the key findings generated by the thesis i.e. gaps in staff knowledge and understanding of the potential of reminiscence, their avoidance of core topics and reluctance to to deal with the emotional issues reminiscence may generate and the need for more relevant training and education of the dementia care workforce including migrant workers, need careful consideration.

Finally and in conclusion, the thesis has also shown the real vulnerability of many of these older PwD, whose voices up until recently have remained absent in Irish society and who have been denied some human rights and preferences; Dora who would prefer to be driving rather than being subjected to reminscence, Anne whose relative claimed that many of the topics discussed during reminiscence are not that relevant to her life and Eamon who wished to continue being a participant of the hospital reminiscence group but was left with uncertainty and with no commitment. It has demonstrated the type of inappropriate environments some of these older PwD are obliged to live in such as acute hospitals or nursing homes which lack privacy and are undergoing noisy renovations. It has demonstrated the lack of appropriate training and limited support available to staff.

Overall it has shown the need for more resources to be allocated to dementia care and especially to non pharmacological interventions such as reminiscence work and the need for

better partnerships in care to be developed between formal and informal caregivers. Such wasted opportunities must now be seized and acted upon. My final hope is that with a new Dementia Strategy soon to be implemented in Ireland, appropriate political and budgetary attention will be given to this very important area.

8 Appendices

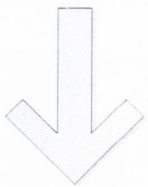
8.1 Appendix A - The Progression of Dementia

Early stage dementia

This phase may only be apparent in retrospect. At the time it may be missed or put down to stress or depression or, in older people, to the normal process of ageing. The start of dementia is very gradual and it is usually impossible to identify the precise moment it starts.

The person may:

- Be apathetic
- Show less interest in hobbies or activities
- Be unwilling to try new things
- Find adapting to change difficult
- Become less good at making decisions or plans
- Be slower to grasp complex ideas
- Blame others for 'stealing' mislaid items
- Become more self-centred and less concerned about others and their feelings
- Forget details of recent events
- Be more likely to repeat themselves or lose their thread
- Become irritable or upset if they fail at something.

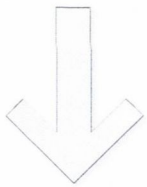


Middle stage dementia

Here the problems are more apparent and impeding.

The person may:

- Be very forgetful of recent events – memory of the distant past is generally better, but some details may be forgotten or confused.
- Be confused regarding time and place
- Becoming very clinging
- Become lost if not in familiar surroundings
- Forget names of friends or family, or confuse one family member with another
- Forget about saucepans or kettles and may leave gas unlit
- Walk around streets, perhaps at night, sometimes becoming lost
- Behave in ways that may seem odd – for example, going out in their nightclothes
- See or hear things that are not there
- Become repetitive
- Neglect hygiene or eating, perhaps saying that they have had a bath or a meal when they have not

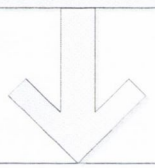


Late stage dementia

Here the person is more severely impeded and needs a great deal of help.

The person may:

- Be unable to find their way around
- Be unable to remember for even a few minutes that they have, for example, just had a meal
- Constantly repeat one or more phrases or sounds
- Be incontinent or simply not understand the need to get to the toilet
- Show no recognition of friends and relatives
- Need help or supervision with dressing, feeding, washing, bathing and using the toilet
- Undress at the wrong time or in public
- Fail to recognise everyday objects
- Have difficulty communicating or understanding what Is said
- Be disturbed at night
- Be restless, perhaps looking for a long dead relative or for a small child now grown-up
- Be aggressive, especially when feeling threatened or closed in
- Make involuntary movements



Factors affecting the progression of dementia

You and the person with dementia will probably want some idea of what to expect in the future. It is not easy to predict the progression of dementia. How the person will change will depend on many different factors.

- We are all individuals with our own unique personalities and life experiences.
- Each type of dementia has a different pattern of progression. For example, people with vascular dementia may find that their symptoms remain steady for a while and then suddenly decline. In people with Alzheimer's disease the decline may be steadier, and for some people there may be a period when their condition seems to stay the same.
- There may be variations even in people with the same type of dementia. This may depend on the areas of the brain affected. For example, in cases of vascular dementia, symptoms may depend on the position of small strokes in the brain.
- The person's physical health may play a large role in how they change over time. A chest infection or a fall may lead to a sudden deterioration, for example.
- The person with dementia may also respond to changes in their physical circumstances. They may be affected if they are moved to somewhere unfamiliar or if their routine is disrupted.
- The attitude and mood of the carer may also have an impact on the person with dementia.
- The person may be upset by noise and disruption, or they may become withdrawn when in a stressful situation with unfamiliar people.

www.alzheimers.org.uk

8.2 Appendix B – Databases

The following databases have been searched:

- PsycArticles
- PsychInfo
- Web of Science
- Index to Irish Theses
- Index to Theses
- BMJ Journals Online
- British Nursing Index Plus
- CINAHL
- Cochrane Library
- Proquest
- Oxford Journals Online
- Pubmed
- ScienceDirect

8.3 Appendix C – Journals

The following journals were searched on a regular basis, other journals were searched on an ad hoc basis and noted in the references:

- The Gerontologist
- Journal of Applied Gerontology
- Ageing and Society
- American Journal of Alzheimer's disease and other dementias
- International Journal of Geriatric Psychiatry
- Dementia and Geriatric Cognitive disorders
- Dementia
- Alzheimer's disease and Dementia: The Journal of the Alzheimer's Association
- Journal of Gerontological Nursing
- Social Science and Medicine
- Journal of Psychosocial Nursing and Mental health Services
- British Journal of Occupational Therapy
- Australian Occupational Therapy Journal
- International Journal of Older People Nursing
- Journal of Mental Health
- Activities, Adaptation and Aging

8.4 Appendix D – Pen picture of each interviewee

8.4.1 The Respite Care Setting

Anne

Aged 64 years: Anne had a diagnosis of dementia and had also suffered from mini-strokes and an aneurysm. Anne is a widow, living with her daughter. Anne had experience of using a computer for work purposes. She enjoyed singing and dancing and had been thought of as a good dancer when younger. She liked to travel. According to her daughter Anne likes to talk about old times. She still likes to go out dancing but doesn't join in now. She takes part in some crafts such as card making but will only do so for short periods of time. She likes to write and uses the local library to research possible story lines. She likes walking and at the daycentre often goes for a walk with one of the caregivers.

Bridie

Aged 86 years: Bride has a diagnosis of dementia and also has osteoporosis. She is a widow living with her son and originally came from England. Bridie had a lot of jobs when she was young and a busy working life. She has forgotten the details of these jobs but she thinks some were in the nursing/carework area. Bridie sometimes likes to chat with others. Bridie enjoys being with her son.

Catherine

Aged 84 years: Catherine has a diagnosis of dementia, and has also had a stroke. She is a widow, living alone, but her grand-daughter in law cares for her. Catherine was a keen golfer and still enjoys talking about golf and sometimes watching it on TV, especially if she knows someone taking part in it. Catherine had a busy family life and liked socialising within the family. She enjoys visits to her home from family including grand-children. According to her grand-daughter in law she likes to be out and about, being driven around and visiting nearby shops, villages and towns

Orla (facilitator)

In her 30s: Orla is married with children. She is from a non-professional background. She has taken part in SONAS training courses, paid for by her employer. She has no specific Reminiscence training.

8.4.2 The Day Centre

Helen

Aged 79 years: Helen is a widow living in her own home. She had been attending the day centre for approximately 7 years, 5 days a week. She has a diagnosis of mixed Alzheimer's disease and vascular dementia. Helen had worked in a large distribution warehouse (no longer in existence). She had a large family and liked cooking and baking for them. Helen had been a singer in a band. Helen likes to talk about old times, she likes knitting, sewing and "putting things together". She likes to teach others and has taught a staff member at the day centre to knit. She likes to contribute by helping out in any way she can at the day centre. She doesn't like doing anything "fiddly". She likes going out to musicals. She enjoys baking and making dinners.

Geraldine

Aged 81 years: Geraldine has a diagnosis of dementia. She was widowed ten years ago. She attends the day centre on a regular basis. She lives in her own home with one of her daughters. She suffered reactive depression after the death of her husband which, it is thought by staff at the day centre, may have masked the first symptoms of dementia. She has some insight into her illness.

Geraldine used to work in textiles in a factory which has now closed. She likes talking about old times. She does painting at the daycentre but is not keen on it. She likes listening to music.

Mary (facilitator)

Mary is a nurse/manager. She is not from the local area but has acquired local knowledge over the years. She has specific dementia care training and experience in grief counselling. She has no specific reminiscence training.

8.4.3 Acute Hospital Setting

Eamon

Aged 85 years: Eamon is originally from a small rural town but has lived in Dublin for over 40 years. Eamon has a diagnosis of dementia following stroke. Eamon is married and had been living with wife until he had the stroke. He is awaiting a long term care placement due to increasing care needs. Eamon had been involved in the family farm when younger. He had undertaken many quite adventurous jobs (not detailed here for reasons of confidentiality as they are quite specific and may make it easy for someone to identify him). Eamon has a great love of music and poetry and likes discussing these subjects. He likes talking about the past and likes communicating with people and believes he is good at this.

Dora

Aged 84 years: Dora was diagnosed with dementia following a stroke. Dora had been living with her husband and was independent prior to the stroke. She is now dependent for all functional tasks and is awaiting long term care.

Dora was originally from a town in the West of Ireland. She had lived and worked in England for many years, marrying whilst she was there, before returning with her husband to Ireland.

Dora was a housewife and mother and noted household tasks and home making as being her prime work. Dora used to like dancing. Dora says she likes driving (it is unclear whether she meant driving herself or being driven by others). Dora likes singing. Dora likes to go to church groups.

Ciara (facilitator)

Ciara is from a professional healthcare background. She is in her early 30s. She has experience in group work and has had some knowledge of reminiscence work from her professional training and also through having undertaken a literature review. She has no specific training in reminiscence work.

Ruth (facilitator)

Ruth is from a professional healthcare background (different discipline to Ciara). She is in her early 30s. Her experience is similar to Ciara's, in that she has some knowledge of reminiscence work from her professional training and from having undertaken a literature review but has no specific reminiscence training.

8.4.4 Nursing Home

Claire

Aged 93 years: Claire has a diagnosis of dementia. She has lived in the nursing home for three years and six months. She is widowed.

Claire came from a large family. Her father was a very influential man in her local area, with strong political ties. Claire was a housewife and mother and two of her son's went on to have very important government jobs. Claire is very proud of her father and her sons. Claire's family were very musical and very sociable. Claire likes music and used to like dancing.

Patrick

Aged 81 years: Patrick has a diagnosis of vascular dementia. He has lived in the nursing home for the past 5 years. He is a widower. Patrick did bar work and shop work when he was young, before starting his own business which became very successful – which he is very

proud of. He likes to make a lot of jokes and banter with people. According to a family member, Patrick used to like reading. He sometimes does bingo and art at the nursing home but has told his family he does not enjoy these activities much.

Liam

Aged 79 years: Liam has a diagnosis of dementia (non-specified). He has been living at the nursing home for just over a year. It was thought he had never married but has recently been talking about having been married when he was a young man living in the USA, his family have no knowledge of this and are unable to confirm this. Liam has extended family who visit regularly. He likes singing and he likes to talk about his family. He enjoys reciting poetry.

Brenda (facilitator)

Brenda is from a non-professional background. She came into care work after looking after a relative and coming into contact with the nursing home because of that and as a result of that being asked to work in the nursing home. She has undertaken activities training and also has undertaken some training which included reminiscence work but it was aimed at people in hospices who were at the end of their life.

8.5 Appendix E – Information leaflets and consent forms

8.5.1 Family Caregiver's Consent Form

As part of my PhD studies at Trinity College Dublin, I am undertaking a study into the use of reminiscence therapy amongst people with memory problems/dementia and their caregivers in Ireland.

The purpose of the study is to explore how reminiscence therapy is delivered in Irish care settings and how the intervention is administered and experienced.

The study will involve observation and interviews with people who are already taking part in reminiscence therapy sessions, either in daycentres, hospitals, in nursing homes or in the community. It will involve both the person with memory problems/dementia and their caregivers, formal and informal. It is expected that there will be one period of observation, then a second observation followed by an interview with the person with memory problems/dementia, and their caregivers. The periods of observation will be as unobtrusive as possible.

As a family caregiver your opinions on your relative's experience of reminiscence therapy would be valued. If you agree, I would like to talk to you, either in person or by telephone at a time convenient to you.

All data collected will be kept confidentially and all material will be rendered anonymous. Parts of interviews may be quoted in the thesis and any subsequent publications but care will be taken to ensure that these are rendered suitably anonymous and cannot be linked with any individual.

Participation in this study is completely voluntary and consent can be withdrawn at any time.

I understand the above and have agreed to take part in this study.

Signed.....

Dated.....

8.5.2 Information and Participant Consent Form

As part of my university work I am carrying out a study into the experience of taking part in reminiscence sessions.

This study will look at how reminiscence therapy is delivered in Ireland and what people think about taking part in reminiscence therapy sessions.

If you agree, I would like to attend and watch some of the reminiscence sessions that you take part in. I will not join in, but will just watch what goes on.

After one of the sessions, if you agree, I would like to talk to you about your experience of taking part in the reminiscence sessions. I will record our conversation on a tape recorder.

I will use the information I get from watching the sessions and from our conversation to write about the experience of taking part in reminiscence sessions.

I will make sure that your name is not used and you cannot be identified from anything written in my study.

Taking part in this study will not affect you in any way.

Each time we meet I will check with you that you are still happy to take part in this study and will answer any questions that you have.

You can change your mind at any time about taking part in this study.

I have discussed the above and have agreed to take part in this study.

Signed.....

Dated.....

8.5.3 Background Information relating to study

This study has received ethical approval from Trinity College Dublin.

At present it is estimated that there are over 38,000 PwD in Ireland and this number is expected to increase. Dementia can affect memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgment. The PwD can also be affected by non-cognitive symptoms such as agitation, aggression and mood disorders. These symptoms can be particularly distressing for PwD and their caregivers. Psychotropic medications are not always appropriate for use in the control of these symptoms and it is therefore generally recommended that in non-urgent cases, non-pharmacological approaches should be the first intervention. Amongst the most popular of the non-pharmacological interventions currently in use is Reminiscence Therapy which research has linked to outcomes including improvements in cognition, communication skills, mood and well-being.

8.5.4 Aim of the Study

The purpose of this study is to explore how reminiscence therapy is delivered in Irish care settings and how interventions are administered and experienced. The study is descriptive and exploratory: it aims to examine for the first time in Ireland, formal and informal caregivers' views about reminiscence as a therapeutic intervention in dementia care. Most importantly, it seeks to hear the voice of the person with a cognitive impairment about his or her experience of reminiscence.

8.5.5 Methodology

This will be a qualitative, exploratory study which will use a multiple case study approach. Data will be collected using observation and semi-structured interviews with the PwD and their caregivers, both formal and informal. It is proposed that an observation will take place

first, and then a second observation will take place with interviews following the second observation. The data will be analysed with emerging themes identified.

8.5.6 Study Sample

The sample will be drawn from:

- Residential/Nursing Homes
- Daycentres
- Community
- Acute Hospital Setting

With an urban/rural mix.

8.5.7 Researcher Background

I have a psychology degree from the Open University and an MSc in Social Work from Royal Holloway, University of London. I have many years of professional experience working with elderly people and PwD. I have undertaken Social Work training in the UK and hold a diploma in Social Work. I am used to working in an ethical manner and following ethical guidelines as prescribed by the Code of ethics of the British Association of Social Workers. Additionally I have considerable training in working with vulnerable people. I have experience of interviewing PwD in many settings, and for different purposes including research, and have a record of doing so in a way that puts the PwD at ease and is respectful and supportive of their personhood. I am used to dealing with matters of confidentiality and will ensure that all materials produced will be rendered anonymous and stored responsibly.

8.6 Appendix F – Ethical Approval

Decision of the School of Social Work and Social Policy Ethical Approval Committee:

REFERENCE NUMBER	*161*
Title of Project	*An exploratory study into the use of reminiscence therapy amongst PwD and their caregivers in Ireland.*
Research Ethics Meeting Date	*15th June 2009*
Approved	*Yes*
To be resubmitted	*No*
Reasons for resubmission	*N/A*
Date	*15th June 2009*

8.7 Appendix G - Interview guides

8.7.1 Interview guide - for the PwD participating in a session.

Short introduction of myself, the research project and check and explain consent issues again.

The interview will follow on from an observation, so the questions will depend on what was observed. The interview will be conversational in approach and the individual being interviewed will have a major impact on the direction of the conversation.

Tell me a little about yourself....

"I've been watching you with...., you were talking about (for example, old times, or when you used to live at...) ....."

or

"you were doing.....(for example, you were looking at your lifestory book together).

"I'm interested in that, can I ask you a few questions about it"?

"Why do you come to this reminiscence group or these sessions "?

"Do you have a choice in joining the group"?

"How did you feel about taking part in the group"?

"Is there anything that you particularly like in these reminiscence sessions"?

If yes

"why do you like this"?

"Is there anything you particularly dislike in these sessions"?

If yes

" why do you dislike this"?

"Is taking part in these reminiscence sessions something that you like to do"?

"Is it something you look forward to"?

"Are there times you don't want to attend a session"?

If yes

"what would happen then"?

"Would you prefer to be doing something else"?

"How do you feel just before going into the reminiscence session"?

"How do you feel just after the reminiscence session"?

"In general, how does participating in Reminiscence make you feel....."?

"Do you ever feel happy during a reminiscence session"?

If yes

"What sort of thing makes you feel happy"?

"Do you ever feel sad during a reminiscence session"?

If Yes

"What sort of thing makes you feel sad"?

"Would you recommend this to other people"?

"Do you think they would enjoy talking about....or doing...."?

"Do you do other activities here"?

"Is there anything else you would like to tell me about the reminiscence sessions"?

"What has talking to me been like for you today"?

Thank you.

8.7.2 Interview guide – formal caregivers

Short introduction of myself, the research project and check and explain consent issues again.

8.7.2.1 Caregivers background

"Tell me a little about yourself and your work here at ...."?.(Ensure age, job description and educational background is covered).

"How long have you been doing reminiscence work with (identify the individuals from the case studies)"?

"How long have you been doing reminiscence work in general"?

"How did you get involved in doing reminiscence work"?

"Have you undergone any training in reminiscence work"?

If yes

"what sort of training did you get"?

"what was your opinion of the training"?

"do you think this sort of work needs specific training"?

"do you think you would need any further training "?

If never trained

"would you welcome training in reminiscence work"?

8.7.2.2 The group

"Why do you do reminiscence here"?

"How are the PwD who do reminiscence selected for the group"?

"Who decides who will attend the group"?

"In your opinion, are there any PwD, better suited than others to this type of session"?

"In your opinion, are there any PwD who would be considered unsuitable for this type of session"?

"How often do these sessions, with the same participants, take place"?

"Who decides what will happen during a session"?

"Is the session planned in advance"?

"Are these sessions planned to run for a particular period of time (for example for x number of weeks, or months)"?

"If so, where in this reminiscence cycle are we now"?

"Is there an end date planned for these sessions or will they go on indefinitely"?

"How did you think today's session went"?

"Did anything go particularly well in your opinion"?

"Were there any problems in your opinion"?

"Is that a fairly typical session"?

"Tell me about any reminiscence sessions you have been in, at any time, that have gone particularly well in your opinion "?

"Have there been any sessions that did not go particularly well"?

If yes

"do you have any ideas why they didn't go well"?

"In your experience what aspects of reminiscence work best with a PwD

And what aspects of reminiscence do not work well with PwD"?

"Do you think taking part in reminiscence has any immediate effects for the persons with dementia"?

"Do you think it has any long term effects"?

"Have you ever seen a client have a negative reaction during a session"?

If yes

"If so what happened "?

"How was it dealt with "?

"What do you think people look forward to most about attending these sessions"?

"What in your view works best as a prompt in reminiscence work"?

"With an unlimited budget what else you would like to include in a reminiscence session"?

8.7.2.3 The caregivers experience of reminiscence

"How do you feel about taking part in reminiscence work"?

"Do you think reminiscence work is beneficial – to the PwD"?

"Is doing reminiscence work beneficial for you"?

"Do you think there are any disadvantages or problems associated with reminiscence work "?

"Do you do other types of activity work with PwD"?

If yes

"Does reminiscence work differ from the other activity work"?

If yes

" In what way does reminiscence work differ from the other activity work"?

"Has taking part in these sessions had an effect on your relationship with....(identify the individuals from the case studies)"?

"Has a session ever had an emotional effect on you"?

"Have you ever felt the need to debrief after a session"?

"Have you ever felt the need to discuss something with someone after a session, for any reason"?

"Is there someone available to you if you felt the need to "?

"Would you recommend reminiscence as an activity for PwD"?

"Would you recommend reminiscence as an activity to other caregivers who are organising activities for PwD"?

"Is there anything further you would like to add to this discussion on reminiscence work"?

Thank you.

8.7.3 Interview Guide for informal caregivers not directly involved in reminiscence sessions

Short introduction of myself, the research project and check and explain consent issues again.

8.7.3.1 About the caregiver

"Tell me a little about yourself"? (ensure age, marital status, occupation and educational background is covered)

"Tell me about your relationship with……(the name of the PwD they are caring for) "?

"Do you provide care for ……."?

"If yes How long have you been providing care for"?

"Do any others (formal or family) also provide care for….."?

"Do you live with ……."?

About the reminiscence sessions

I understand……..(PwD's name) has been attending reminiscence sessions at ….

"How much do you know about these sessions"?

"What do you understand about what goes on at these sessions"?

"In your opinion are these reminiscence sessions beneficial to……."?

"Have there ever been any problems with ….. attending these sessions, as far as you are aware"?

"Have you noticed any short-term effects of these sessions for your relative"?

"Have you noticed any longer-term effects for your relative of these sessions"?

"Does …… ever talk to you about these sessions afterwards"?

"Does.....look forward to these sessions, as far as you know"?

"Has ..... ever tried to avoid going to these reminiscence sessions, as far as you are aware"?

"Have you been contacted to provide information of any sort for these sessions"?

If yes

"What sort of information were you asked to provide"?

"How did you feel about that request for information"?

"Is there anything else you would like to add"?

Thank you.

8.8 Appendix H – Setting descriptions

A description of each setting is given below, giving the context which describes the physical environment and the process which describes how Reminiscence was carried out within the setting. Where only one method of reminiscence is used for both sessions in a setting, only one description of the process is given, to avoid repetition.

8.8.1 The Day Care Centre - The Context

The dementia specific Day Care Centre which forms the first of these Case Studies is a purpose-built facility dedicated to dementia care and operates under the auspice of a Non-Governmental organisation. It is funded jointly by a Charity and by the Department of Health and provides a service to clients from the local area. The Centre provides Day Care, some Home Care and a monthly family support group. The Day Care Centre is situated in a town

more than 70 kilometres from Dublin in a purpose-built bungalow, near a local hospital. According to its publicity material, the centre aims to provide a safe and welcoming environment for the participants, and Reminiscence Work is one of the activities noted to be available at the centre, as detailed on the centre's website.

The communal area in this setting where activities usually took place was set up with scented candles around, knitted throws over sofas and paintings and furnishings which looked as if they had been chosen with care. There was a garden outside with seats and tables which could be used when the weather permitted.

In this setting, Reminiscence sessions were observed taking place in two different areas. The first session observed took place in a small area which had been partitioned off from the larger communal day room using a screen. Two or three activities often take place at the same time in this day centre, and screens are often used to divide the room into smaller areas. Every effort had been made to make the part of the room used for the reminiscence session look homely and relaxing. For example the small area was lit by a standard light, as well as natural light from a glass door which led to the outside. Features within included a fireplace with a mirror above, chairs arranged in a semi-circle and a piano at the back of the room. Despite efforts to make this area separate from the rest of the large room, noise from the communal lounge could still be heard through the partition but observation notes showed that the noise did not seem to interfere with the reminiscence session. However the overall atmosphere was quiet and comfortable. The lighting and décor meant the small area resembled a parlour or small sitting room.

The second session observed took place in the main office used by staff at the Day Care Centre. This was a small room which contained office equipment such as faxes and phones, coat racks and notice boards posting work related items. The furniture had been rearranged so that the participants were able to sit comfortably around a computer screen. There were two computers in the office, sufficiently large so they were unlikely to pose any visual problems for the participants. The office had good natural light and participants seemed

comfortable in the environment. This may have been because it had already been explained that they were using the office so that they could have access to the computers, and they had done this form of reminiscence before.

8.8.1.1 The Reminiscence Group

The research data collection took place during two periods. In the first phase, the clients attending reminiscence who were selected for this research study consisted of four female participants each of whom was diagnosed with dementia and the facilitator. At follow up phase two, three of the same four female participants, the facilitator and a volunteer were included in the research.

8.8.1.2 The Process

The reminiscence sessions observed at this centre took place immediately after lunch in the early afternoon. However, normally the sessions were held in the morning, with the afternoons being used for quieter sessions as the facilitator believed PwD tired easily in the afternoons.

Two different methods of delivery were used in the reminiscence sessions observed in this setting and these are described in the following section.

8.8.1.3 Observations of the first reminiscence session

In the first session observed, the Reminiscence was purely conversational, lively with a distinct absence of the use of aids or physical prompts. The emphasis in this session was on local knowledge, which the facilitator identified as a key reason why Reminiscence was successful.

Mary, started the session by asking direct questions of the participants, but in a friendly manner as opposed to a testing way, and the conversation flowed from there. It became obvious as the session progressed that all the participants had known each other a long time. Mary went round each person and asked them about their former occupations and where they had worked and the conversation flowed easily with all participants joining in. It included discussion about schools and factories which existed in the towns when participants were young. Whilst Mary guided the conversation, participants were enthusiastic and talked about hours of work, monies being handed to their mother on payday and many individual spontaneous anecdotes were shared. When conversation slowed Mary mentioned the names of individual factories, which sparked renewed reminiscence. She also asked questions which included references to the senses to prompt reminiscence.

She then "walked" the participants down a local street, moving slowly from premises to premises, mentioning shops and prompting reminiscence in that way. Each participant answered and joined in with their own reminiscences.

Good eye contact was observed between all participants, with much non-verbal communication in evidence. Mary ended the session by announcing it was time to finish up, and encouraged each person to finish with a memory of a happy event. This led to more animated conversation between the participants with much laughing and joking. It was apparent that all the participants were enjoying themselves and talking among one another so much so that it took another couple of attempts before Mary was able to bring the session to an end, participants seemed in no hurry to end the session. The session finally ended after an hour and a quarter. It was a very lively, animated reminiscence session, notable for the fact that no physical prompts were used. The participants obviously knew each other well, as demonstrated by the way they conversed about mutual acquaintances. They were all from the local area and the facilitator used this knowledge as the basis of the sessions.

8.8.1.4 Observations of the second reminiscence session

The second session observed used Facebook[23] as a prompt for Reminiscence, a prompt which Mary had successfully used before at the centre. It started by Mary bringing up a Facebook page which had old photographs of the town where the Daycentre was situated. The first photograph instantly sparked conversation and Mary encouraged this by asking further relevant questions.. Mary used these photographs to instigate conversation by asking questions and participants provided answers and some discussions developed. All participants were attentive and looked at the photographs on the screen. One participant Iris seemed particularly engaged as demonstrated by her body language when she leaned forward to look more closely. Mary continued to source local photographs on Facebook and prompted the group with general questions. Mostly participants recognised places in the photographs and if they were unable to, either Mary gave further prompts or on a few occasions she moved the conversation on by moving on to a different photograph.

Mary signalled the end of the session by suggesting the participants look at one more photograph of a local scene before having a cup of tea. Mary brought the session to an end, saying that it had been a good walk down memory lane. The three participants left the office looking happy and were observed continuing to chat with each other.

In the second session Mary had a volunteer helping her which Gibson acknowledges can be a very positive addition, although she does recommend training and supervision for the volunteer (Gibson 2011). In this case the volunteer helped with the use of computers and also seemed to have a strong local knowledge as he was able to supply additional information and anecdotes about the photographs shown.

[23]This is a popular computer social networking site where people share photographs and videos

8.8.1.5 The Respite Care Centre – The Context

The dementia specific residential respite care centre which was the site used for this second case study was situated in a large purpose-built bungalow which also catered for day care participants. It was situated in a small rural village more than 200 kilometres from Dublin and could accommodate up to 12 people for residential respite.

The Centre catered specifically for PwD and offered residential respite arranged to suit individual needs. The centre was operated by a registered charity. Most of the clients came from rural backgrounds and had strong ties and family connections to the local area, having lived there all or most of their lives. A small minority of those availing of the service had spent periods abroad, for work purposes usually. A few clients originated from outside but had retired to the area.

The bungalow which housed the respite care centre blended well into the local area as it was similar to many other bungalows in the area. It had a large well-kept front garden, plus some gardens to the side and rear. Inside the bungalow there was a main corridor with rooms running off it including offices, bathrooms, bedrooms, a dining room and a multi-purpose lounge. There were scenic views from the windows and quiet spaces to sit in various parts of the bungalow. The bungalow was pleasantly decorated with artwork on the walls and religious memorabilia on walls and on bookcases. The religious memorabilia was most relevant to Catholics, in line with the client profile at the time, for example statues of the Child of Prague and statues of Our Lady of Lourdes which most people from an Irish Catholic background would be familiar with. Reminiscence took place in a multi-purpose room within the respite centre, which was used for various other activities and was also used as a communal lounge where residents could sit, watch television, read and talk to each other. It was a large, airy, room with good natural day light. Chairs were positioned around the walls and on one wall there was a fire place, with a Television screen and audio equipment to the side of it. Once again like the Day Centre room described in the last section, it seems that strident efforts were made to make this room domestic and homely. The décor was pleasant

and there were art prints on the wall. Most of the chairs had comfortable cushions and some had knitted throws arranged on them. Foot stools were available for use.

When questioned about any adverse effects of Reminiscence, Orla said she did not experience any negative emotions herself whilst taking part in reminiscence sessions, neither did she talk about any of the participants experiencing sadness or negative emotions.

8.8.1.6 The process

SONAS was used as the medium through which Reminiscence took place during the two sessions observed and was the approach regularly used at this respite centre. The SONAS session was led by an Activities Organiser, who, as mentioned earlier, had undergone specific SONAS training.

Both sessions observed took place in the late morning and lasted approximately half an hour. Both sessions followed the exact same format, and observational notes from both are presented in the findings in this chapter, although to avoid repetition, only one session is described in this section. Lunch was served after the session, in a separate room.

At the first session observed initially 10 participants attended the Reminiscence session with one more joining later on in the session bringing the total number of participants up to 11. At the second session observed 11 participants took part in the session, with two more joining the session later bringing the total number participating to 13. The three participants who agreed to be part of this study and who were interviewed attended both sessions. The facilitator Orla had a non-trained staff member to assist her.

Prior to the Reminiscence session commencing, it was observed that all of the residents had enjoyed a cup of tea. Cups were cleared away and the session was introduced by Orla using the SONAS audio tape. First hand-clapping to music took place, followed by the SONAS signature welcome song which involved the group leader going around each individual and welcoming that person by name, sometimes holding hands with the person. This was

followed by movement with music and then sensory stimulation involving smelling and tasting items. Singing then began followed by a period of individual massage for those who wanted it. A period of using musical instruments, along with singing followed. The session then progressed to reciting proverbs. Orla would start the proverb and then some participants responded with the ending of the proverb. A poem was then recited on the tape which was followed by a formal goodbye, similar in structure to the formal welcome at the beginning.

The reminiscence element within these sessions, which was less than in the other settings, seemed to be most strongly linked with the singing of songs, the reciting of poems and the proverbs. Participants were encouraged to suggest songs to sing which they did, including in one case a hymn. Orla developed this by then leading a discussion about when they would have sung these songs in old times, at school or at church. Although Reminiscence in this residential care setting was structured, there was some scope for improvisation and spontaneity.

8.8.1.7 The Nursing Home – the context

The nursing home at the time of the site visits was undergoing construction to enlarge it. It was a large single floor building with access through the rear of the building, situated in a small suburb of Dublin.

Access to the nursing home was through a locked door via a buzzer entry system. There was a reception desk inside, a door to the office and then corridors leading off this area. The first Reminiscence session took place in a medium sized day room, soon be closed due to the on-going construction work. There were five residents already in the room, seating in a circle at the end of the room nearest the door. Two of the residents were in wheelchairs, three were seated in chairs. There was good light in the room, provided by 2 large windows and a patio door at the rear. There were vertical blinds on the windows, through which you could see

construction workers at work. There was relatively little noise though, so insulation must have been good. The room was decorated with nice wallpaper but was otherwise fairly empty, with no paintings, probably because the room was soon to be closed as previously mentioned.

Inside the circle of people was a small table, with a tray laid out with glasses, a jug of orange squash and a small bowl of chocolate sweets.

The second observation session took place in a room usually used as a hairdressing salon. The room was open at one end, and people frequently walked up and down the corridor at the end (both staff and clients). A door led on to a unit dedicated to people with more challenging behaviours – there was a lot of noise coming from the unit including shouting and crying. A curtain (similar to the type used to cordon off bays in medical units) was pulled across at the end of the room by the facilitator, presumably to give some privacy. There was a table with orange drink in a jug, glasses and a plate of biscuits by the wall. There was also a large box there. There was little decoration around the room and some hairdressing equipment was evident.

8.8.1.8 The Process

The reminiscence group started as soon as I entered and sat down. The facilitator introduced me and asked if it was alright if I joined them, there was general agreement. I went round the group and was introduced to each person by the facilitator and said hello. One resident A came over and hugged and kissed me (the facilitator mentioned as she was heading towards me that she likes to do this). As well as names, the facilitator mentioned where each person came from, three were from Dublin two from the same county in the West. "So three Dubs and two XXXX (the county)" said the facilitator which was greeted with laughs and smiles.

Having introduced everyone, the facilitator started the session by asking about A's name, why she was called that, where the name came from. A was quite restless and the facilitator

calmed her by stroking her arm and holding her hand. She then asked E about his name, and about his family. He said that he had lost a brother quite young, he talked about this for a few minutes, but did not seem upset. The facilitator acknowledged this and then moved the conversation on. She then talked to S about his name, and they started talking about a song with that name in it. A was quite restless, she started coughing and said she wanted to leave. The facilitator calmed her, persuading her to sit for a little while and offered her a drink which she took. The facilitator tried talking to M but he didn't respond, he had a piece of paper similar to kitchen roll, on his lap and was fiddling with that. The facilitator said that we would move on from M at the moment, as he didn't want to talk at the moment. The facilitator moved on to T and asked about her name, she was talkative and quite jokey, saying that she was called T because her mother "was running out of saints" and she would have preferred a film star name. The facilitator started talking about how people in Ireland are often called Mary but that isn't common now, E and S added comments to that agreeing with it. A got up and wandered off to the windows at this point. T commented that "this will go on all day" referring to A. The facilitator started talking about school days. A was trying the handle of the patio door which was locked. She spent a few minutes looking outside, there were workmen walking about. A came and sat back down again. The facilitator got up and poured drinks for everyone and passed them round. Chocolate sweets were then offered round the group. The facilitator started talking about schools again, and walking to school. E and S responded with anecdotes and mentioned individual schools they had gone to, the facilitator knew these schools and knew whether they were run by nuns etc. and was able to add comments and questions to keep the conversation going. S said "I wanted to get away from school". The facilitator obviously knew S's background and used this as a cue to start talking about S's jobs. He had started in bar work and shop work but had built up to owing his own successful business. The facilitator encouraged him to tell me about his business "Tell Treena what you ended up doing". S told me and sounded quite proud, I responded enthusiastically.

By this time M had nodded off. There was some interaction between T and S, talking about families, their brothers and sisters, and T's sons. A got up again and the facilitator offered her

a sweet, she stood beside T. E made a joke about the sweets. The facilitator talked to T about her father. S joined in. T talked at length about her father, of whom she seemed to be very proud. The facilitator mentioned her brother who had died young. T acknowledged this and said it was very sad but moved on talking again about her father. She did not seem upset. A had sat down again, and the facilitator tried to talk to A but she started coughing, the facilitator gave her another drink. The facilitator talked to E about his nieces who visit. The facilitator then asked S about his family who visit. E asked S a direct question about his family who visit.

The facilitator moved the question on to "first dances" and asked E about this. S joined in with appropriate comments. E made a joke. A stood up and went and stood beside T. E recognised one of the places that S was talking about (places where dances took place, ballrooms etc.) and commented on that. A said the name of the place they were talking about. The facilitator asked "Did you go there A" A didn't respond. The facilitator then asked T if she had gone dancing. T said "every night of the week". The facilitator asked if that was with her sisters, T said no, she was talking jazz, not Irish dancing. E asked T "you do jazz". T talked about her dance frocks "I had 10 dance frocks". A asked "where did you put your dance frocks". A sat down again. T started making dancing moves in her chair (using upper body). E asked if T had any children. T said yes, but her youngest had just died. He had been (a very responsible government job), the facilitator mentioned as an aside, not in this current government, a previous one. T then told a story about another son, who had red hair and they joked that he was a tinker's child. About how he had gone to a school where the Sister in charge had a brother who had been killed by the Black and Tans. T's son knew about this and would sing rebel songs, to get in her good books. T laughed about this, as did E and S. A got up again, and said "I'm 93 next month and still looking for a boyfriend". A goes over to S age and talks to him about her age while the facilitator talks to T. E says "aren't you marvellous" to her, referring to her age. The facilitator asks E "would you give us a song". She then asks A, who had sat down again "what kind of a song would you like". A sings a childhood rhyme. E says "that's not a song". The facilitator hold A's hand. E starts singing, and sings word

perfect. T and S watch E intently, A is staring into the distance. At the end all clap. The facilitator says to A "he sang that for you", "did he" A responds. S jokes that a romance could be starting. The facilitator suggests that E sings another song. A stands up. A moves towards me and asks for a kiss, I give her a hug, she then says no she wants a kiss, I suggest she sits down to listen to E, who has just started singing which she does. E forgets some of the words of the song and seems a bit flustered. S and T give encouraging responses "you're doing alright, you'll remember the words in a minute". E recovers composure and starts singing again. At the end again, all clap. E asks "did you like that" T and S respond positively, S makes a few little jokes "I'd have 2 pints of stout with that". A is restless again, the facilitator suggests taking her back to the bigger lounge, A gets up to leave but then says, "I'd like to hear him sing" pointing to E. A and the facilitator who are walking to the door, pause and the facilitator asks E to sing. He sings another song. The facilitator thanks E and then A and the facilitator leave the room.

At this point M wakes up. I keep the conversation going, talking about how good a singer E is, and isn't it nice to listen to music and songs. When the facilitator returns I informed her that M had seemed uncomfortable on waking and was rubbing his side as if in pain. She went and got a nurse. When she returned, I said goodbye to the group as a whole, thanked them for letting me watch and said I hoped to come back again if that was alright. There was general agreement and they all said goodbye.

In general, the session had been lively and flowed well, with no prompts just conversation. The facilitator obviously knew the backgrounds of the individuals. A had been very restless, but did join in spontaneously and appropriately on occasion. M had slept through most of the session. T, S and E had joined in well, there had been good eye contact between all three, appropriate comments and questions and support when for example E had forgotten his words. Although some sad subjects had been mentioned, there was no evidence of distress. The conversation had covered past topics but also included the present, for example, family

visiting. The session had been undisturbed and the presence of the workmen outside did not seem to impinge on the session.

In the second session observed, the facilitator again used a mostly conversational structure, but she also used a rummage box to prompt conversation. The box contained items which she had collected herself to use as prompts, such as a mantilla (a head covering), a snuff box, an old style razor and some items of jewellery. There were items which were likely to prompt reminiscence for both men and women, for example the women's mantilla and the men's razor. She had also included items which could be smelt such as a jar of "Vicks" which is an expectorant rub. She used the items to prompt conversation by passing the item around the group and then asking questions about it. For example, she passed the mantilla around and asked if anyone knew what it was. The participants asked questions about it, for example asking if it was hand-made. The facilitator explained what it was used for; it was worn by women attending church. The session followed a similar format to the first session and included drinks and biscuits, which led to one participant commenting that it was like a party.

8.8.2 The Acute Hospital

The acute hospital setting was in a purpose built age-related health care unit, within a large urban hospital. The unit had 30 acute and rehabilitation beds and a 20 place day hospital, with regular therapeutic input from physiotherapists, occupational therapists, and speech therapists. The participants in this setting were in-patients in the unit who had a diagnosis of dementia and were either awaiting discharge home once suitable arrangements had been made or were awaiting long term care. They had been discharged from active interventions. The average length of stay on the awaiting long term care list in 2009 was 95.8 days.

As one of the facilitators summarised

"The main duty, the main aim of our care, our main work is involved in getting people functionally independent in order to facilitate discharge home. But we do have a whole

lot of people who for various reasons aren't going to go back to their former living circumstances so we would be looking at I suppose maintaining their functional status." (Interview with Facilitator 1)

The YouTube reminiscence was run in a six week cycle, facilitated by the speech and language therapy department and the occupational therapy department, with occasional assistance from a volunteer helper. The sessions were aimed to last approximately 45 to 60 minutes.

The sessions took place, mid-morning, once a week, in a room within the unit which was usually used as a tutorial or meeting room. This was reflected in the décor, which included medical posters on the notice board, and a large rectangular table with plastic chairs. At one end of the room was a large Television screen, with a computer to the side of it, which was used to access the YouTube site. Chairs were arranged in a semi-circle around the Television screen. Porters brought patients into the room, and helped them to settle into chairs, or for those in wheelchairs settled them into the semi-circle. The numbers taking part in the sessions varied depending on factors such as clinical needs and varied on the days observed between three and seven patients with one caregiver leading the group. A Social Interest Questionnaire had been completed on all patients, and this together with previous interests shown in earlier sessions, influenced the initial YouTube clips accessed.

8.8.2.1 The acute hospital setting – the process

The reminiscence within this setting was delivered using an innovative approach, involving the use of YouTube, a video sharing website, where users can upload and share videos on any subject. As the format was the same in both sessions, only one session is described to avoid repetition.

The group was started by the caregiver welcoming the patients and then introducing one of the YouTube clips. The clips chosen vary and were often musical, to do with sporting events

or to do with political events or significant historical episodes. Although the caregiver started the session with a clip, the majority of the remaining clips were chosen by the patients during the session, and there was a spontaneous flow to the session. The atmosphere was relaxed and although the caregiver did give prompts and guided the session, the general direction was prompted by the patients. Watching the clips sparked reminiscence along with general conversation. For example after watching a clip showing a boxing match one of the clients spontaneously told the group how he remembered watching that particular fight in a golf club in a seaside town which then led to a discussion between the patients about boxing and whether it could be considered a "cruel" sport. The caregiver strove to ensure all patients interests were covered for example when games were being discussed and the men were appearing to dominate the conversation she introduced talk about games which were more often played by girls. The group kept to time and was brought to an end by the caregiver, who thanked the patients and arranged for porters to take them back to their wards.

8.9 Appendix I – Description of SONAS

The SONAS™ Programme is an effective, evidence-based therapeutic activity for people who have significant communication impairment, primarily as a result of dementia.

The SONAS approach was developed in 1990 by Sister Mary Threadgold RSC and SONAS aPc is a not-for-profit training organisation and registered charity, which has trained more than 5,500 healthcare employees in the use of the approach.

The SONAS programme involves cognitive, sensory and social stimulation. The aim is to activate each participant's potential for communication, thereby enhancing quality of life.

SONAS sessions involve stimulation of all five senses, along with exercises, sing-alongs and a time for personal contributions. Sessions are recorded on CD, with a set format and some

variation of content. Repetition is encouraged in order to foster familiarity, confidence and security for participants.

The SONAS philosophy is very person-centred, valuing the individual with a strong emphasis on communication and the building of relationships. There is a strong ethical framework, with the rights of each person to respect, choice and privacy promoted.
There are group and individual sessions. The SONAS Individual Multi-sensory Session (SIMS) is an adaptation of the SONAS Group Session for use on a one-to-one basis.
(www.SONASapc.ie)

8.10 Appendix J – Facilitator Training and Experience

8.10.1 The Respite Care Centre

The facilitator Orla had no professional training but had undergone SONAS training (see Methodology chapter). She appeared to have great confidence in using SONAS as a method for Reminiscence and referred to it as a kind of "backbone". This, I interpreted to mean that it gave structure to the session. She appeared to embrace the diversity of activities, the structure and multi-sensory stimulation SONAS afforded:

"...and that's it there's an opening and there's a closure, whatever, and they know what's to come and someone said isn't that great we had a bit of everything, we had music, we had dance, we had singing, we had proverbs and we had touch and we had smell, like the whole lot is all combined together" (facilitator interview, residential respite centre).

Orla reported that she had enjoyed the SONAS training and felt adequately trained and well supported. She had not undergone any specific reminiscence training.

8.10.2 The Acute Hospital

The facilitators were asked if they had specific training in reminiscence. Both these facilitators came from professional backgrounds, speech therapy and occupational therapy and had training in group work and therapeutic work. However, they had not received any specific training in reminiscence work.

When asked directly if they had received any specific reminiscence training Ruth commented:

"no but ahm, I suppose I haven't been on any specific reminiscence training courses but certainly in my undergraduate training like we would have looked at ahm, I suppose we would have done modules on dementia and ahm cognitive impairment and we would have looked at them from communication...from you know models or frameworks of intervention in terms of impairment, disability and I suppose handicap as well, that was our model, then like but you know, ahm so now we're kind of looking at I suppose impairment functionality and kind of the person's social inclusion....reminiscence falls into that area, but we wouldn't have had formal training in it would just have been introduced to the concept of it" (Ruth facilitator 2)

Whilst Ciara noted :

"no, we've just done literature reviews and we would have done some training at an undergraduate level around reminiscence work and group work and suppose just putting all those things together" (Ciara facilitator 1)

Both facilitators had conducted a literature search independently and this together with their knowledge of group work and therapeutic work gained from their undergraduate education was in their opinion sufficient for their needs. The facilitators mentioned using resources such as journals, libraries and organisations such as Reminiscence Network Northern Ireland and CARDI. Ruth noted that being able to research a topic such as this was part of her on-going professional development.

"...you know more specifically looking into reminiscence that's kind of come out of my own continued professional development and saying OK, this here is an interest I have right now, here is a client group that we're going to work on with this, what do I need to know, ahm how does this need to be improved or developed further, where do I need to go to get more information and that kind of comes from your undergraduate training as well" (Ruth facilitator 2).

8.10.3 The Nursing Home

The facilitator Brenda had come from a carer background, having been a carer to family members and had then joined the nursing home. She had undertaken a six month part time course in meaningful activities for people with Alzheimer's disease at a university in Dublin whilst working at the nursing home. The course had included discussion of SONAS and also discussion of Reminiscence. She had also undertaken a course at a local hospice which had included some Reminiscence, but this was aimed more at people who were at the end of their life, and not necessarily for PwD. She said there was on-going training in the nursing home on different subjects, for example recognising elder abuse, and this included training in activities. She felt generally well supported.

8.10.4 The Day Centre

The facilitator Mary was a qualified nurse and stated that she had experience in working with older people and in her interview stated that she had experience in grief counselling though it is unclear if she had formal training in this. She had undergone training in dementia care, as had all the team at the Day Centre. Interestingly Mary had no specific Reminiscence training. She reported that she had considered doing Reminiscence training but had not as yet undertaken this training. She said staff at the Day Centre based their Reminiscence work on what they had seen working over ten years that the centre had operated, together with knowledge of the individual participants. During informal conversation with Mary prior to

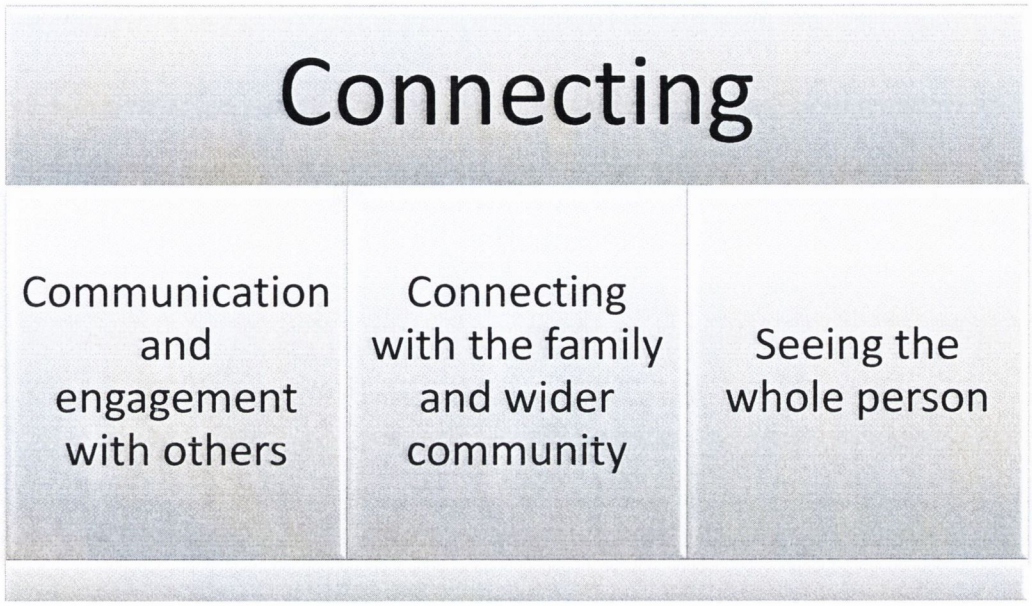
the study commencing it was apparent that she had a good awareness of the different types of Reminiscence work and the different prompts which could be used.

8.11 Appendix K – Worked example of analysis

8.11.1 Example Text (interview with Orla, Respite care centre)

Comments	Text	Theme
Viewing PwD in a positive light Referring to her own confidence issues – identifying with the PwD Picking up visual cues Seeing signs of upholding the identity of PwD Referring to her own natural Enjoyment from seeing others	R – and do you enjoy doing this? O – I do, I do, because I get great satisfaction, yeah, I get great satisfaction from seeing someone who is very quiet, when I was in school I was very quiet, do you know what I mean and you know just to see these people progress...you know and even the smile on their face and the eye contact you know that they're with you and you know, tapping and holding their hands and gesture and the smell, it's all, it's good, it's good to see these people that they're very quiet that they're getting more confident within themselves, do you know what I mean, yeah, and I kind of like that because I'm a people person anyway and it's great to see someone enjoying themselves and to be happy, do you know what I mean"	Seeing the whole person Seeing the whole person Communication and Engagement Identity and self-worth Seeing the whole person

8.12 Example Theme showing sub themes



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http://www.cochrane.org/reviews/en/topics/56_reviews.html [Accessed 28/09/09.

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