

A Psychotherapeutic Exploration of Self and Subjectivity in Dementia

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Table of Contents

Acknowledgments.....	ii
Abstract.....	iii
Introduction.....	1
Aims and Objectives.....	5
Approach and Context.....	7
Chapter 1: Dementia.....	10
Chapter 2: The Subjective Experience of Dementia.....	20
Psychotherapeutic perspectives about the inner world	20
The psychic life and the experience of dementia.....	28
What Psychotherapeutic research is saying about dementia	31
Understanding aspects of dementia as a response to unconscious processes..	38
Ageing as a final developmental task.....	40
Chapter 3: Psychotherapy’s Place in Dementia Care.....	45
Support at each stage of dementia	47
Challenges in this area of research	50
Conclusion.....	54
References.....	58
Appendix 1.....	71
Appendix 2.....	72

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ABSTRACT

This thesis will present a psychotherapeutic exploration into the subjective experience of dementia. Dementia impacts the person in many ways. It is not simply a condition which impairs memory function. It impacts to varying degrees a person's fundamental sense of self. It can distort the individual's experience of themselves and others. Perceptions can come undone, relationships can become rattled, and the connection to who one is becomes less reliable, and therefore more threatening and untrustworthy. So much of the self and how it has developed is attached to unconscious processes. Becoming a person, from infancy through to old age, can be considered to a large extent with unconscious frameworks of evaluation and integration in mind. These processes are a necessary part of the maturation process. These frameworks are not rigid predictors of who one will become - nobody develops in the same way at the same time - however these variations are still understood within the context of psychical developmental frameworks. The self is constructed through navigating these unconscious and instinctual pathways. One's sense of self is therefore not only connected to the brain, but to the mind, the body, and the very many unconscious internal processes and experiences which a person has integrated from the moment of conception. Psychotherapeutic and Psychoanalytic theories have much to say about the construction of self and the unconscious. In this way they are well positioned to present a perspective on the unconscious processes which affect dementia. Dementia can be perceived through the lens of interruption and fragmentation. The self as it was before dementia is now faced with memory loss, breakdown of an internal scaffolding of experience, disturbance of perception, and of biological function. It is not however so simple as to say that dementia takes the person over, and that the experience is one of total annihilation. There is an argument to be made that as long as one is living, one has identity. It is becoming ever more important in a society where people are living longer and many are living with dementia that more room is allowed for the whole experience of dementia to be explored. In so doing, concepts of wholeness of experience and value are retained, and traditional assumptions about the experience of dementia are challenged. Part of that challenge however is to first challenge notions of selfhood and identity, and as subjects and selves, to challenge notions of subjectivity.

INTRODUCTION

Dementia has historically been characterised by cognitive loss. Greater interest has generally been assigned to its impact on memory and the brain, rather than on the experiences of people with dementia, and its meaning for them (Balfour, 2007, p.230). As awareness of dementia has evolved, so have perceptions relating to it. The description ‘senility’ was gradually phased out of the lexicon¹. However in its place, language which described cognitive decline as a ‘disease epidemic’ not unlike polio and other infectious diseases, took its place. After the German Psychiatrists Alois Alzheimer and Emil Kraepelin proposed the term “Alzheimer’s disease” in 1910, a label as society’s new epidemic developed in tandem. By comparing it to polio, the labels of cure and unrelenting disease became synonymous with Alzheimer’s. A “war on Alzheimer’s” has since been launched, spanning four decades (George, 2010, p.256).

Dementia is a condition characterised by the gradual loss of a person’s cognitive capacities. Most dementia cases are diagnosed in those over 65 years of age. However it is not limited to this age group. Statistics for early-onset dementia in those younger than 65 years in Ireland show 10% of those living in Ireland to have dementia (Health Service Executive (HSE), 2017). It is estimated that the number of people with dementia in the coming years will be significant and projections suggest that as many as 132,000 people in Ireland will have dementia by 2041. This is almost three times the number in 2011 (Pierce, Cahill, O’Shea, 2011, p.1). In 2016, an estimated 55,000 people had dementia in Ireland, with over 4,000 people developing

¹ Lexicon: A book containing an alphabetic arrangement of words in a language and their definitions: Dictionary; or The vocabulary of a language (Merriam-Webster, 2017).

the condition each year. This is roughly 11 people per day (Health Service Executive (HSE), 2017).

Cohen (1991) refers to some observations made by Sacks, who describes people with dementia as both warriors and heroes, victims and martyrs, whose prognosis of care usually demands an enormous and progressive emotional, physical, and financial burden. This type of description, although it captures something of the subjective experience of dementia, enforces a type of positive discrimination through its sympathetic language, and reinforces responses of pity and fear leaving little room for anything like empathy, joy, or hope. It is not to say that reactions to dementia, nor the experience of dementia, must be one or the other. However, as dementia evolves and becomes more and more part of a society where people are living longer and living with dementia, so must the perception of dementia (Cohen, 1991).

George suggests that perceptions of dementia as a disease linked to death and defeat, is largely impacted by socially accepted language. Language shapes perceptions of dementia. This language of warfare and death has led people to view dementia as victims, ravaged by disease. Alzheimer's disease is equated with loss of mind, attacks, plaques that strike and kill the brain, and the person with it. This demonises humans' susceptibility to the ageing process, personifying those processes as something external to the person (George, 2010, p.256). This challenge which George presents to one of the widely accepted perceptions of dementia is a vital one. It suggests that perception is endorsed by language and validated by people's assumptions and acceptance of language. In order to challenge arbitrary perceptions of dementia, something must change at the heart of society, literature, research and language.

Growing interest in the non-cognitive factors relating to dementia has been associated with perspectives within Psychotherapy. Psychoanalysis in particular has always been concerned with the developmental process, but it is only recently that this interest has extended to the later life cycle (Balfour, 2007, p.230). Freud's work was concerned with unconscious, psychical, developmental processes which were disrupted or repressed (1963/2001, p.76). His efforts were to explore degrees of repression, and in so doing attempt to fill to some extent the gaps within one's memory (1955/2001, pp.10-11). Freud's analysis suggested that very often it was an event in childhood which set up the persisting trauma in the adult, shaping the unconscious life for the infant and later the adult (1955/2001, p.4). It is essential to acknowledge, as Waddell does, that dementia is not simply a linear progression from youth to old age, nor a return to childhood (2007, p.187); this is far too simplistic and forsakes any individuality or personality. Using models of analysis which draw linkages to childhood is not a means to suggest differently. Similarly, the essence of exploring the subjective experience of dementia through a psychotherapeutic lens is not to map psychical deterioration onto developmental and unconscious processes, but rather to explore the experience of the person with dementia.

Since Freud, many theories have developed which speak to the construction of self and the unconscious life. Bowlby (1969) and Ainsworth's (1978) research on infant attachment, and subsequently research conducted by George, Kaplan, and Main (1984) on adult attachment patterns, suggests that infants form an attachment style equivalent to their early experiences, which will dictate to a large extent how they attach and relate in later life (Bretherton, 1992). Klein (1975) was influenced by Freud's ideas about the unconscious, and continued to explore the inner life (Segal, 1992/2004, p.28). She considered the caregiver as the object of love or hate for the

infant, and this becomes implicit in the infant's experience of loving and hating. The paranoid state is experienced as persecutory, and the schizoid position forms as the child splits off the bad if unable to integrate it (Stevens, 2013, pp.49-50). Winnicott's (1986) theories about the developmental self suggest that the infant struggles with the notion of a shared reality, their growing sense of self compounded by the mother's ability to contain and hold the infant (Rodman, 2003, pp.326-328). More recently, Blinder writes about the self in autobiographical terms, suggesting that this provides a framework inclusive of theme, narrative, and memory, which forms an internalised scaffolding for the constructed self (2007, p.277). These schools of thought are well positioned both to ask the questions, and also to provide the framework to explore subjective experience and constructs of self, because they are interested in the inner life and individual experience. They also possess a shared exploratory discourse, one involved with the language of the unconscious and self, which leads its subject beyond the physical and biological.

Psychoanalysis and Psychotherapy do not attempt to reduce older adults to babies. What they can do is provide an understanding of the adverse reactions to loss and change, which will partly be determined by the individual's developmental experiences (Balfour, 2007, p.232). This drive towards an integrated sense of being is an undeniable component of being human. Humans are natural meaning makers, always seeking out on some level a sense of cohesiveness and meaning. Blinder observes this when he says that narrative identity is important in providing humans with a sense of cohesion (2007, p.277). For natural meaning makers, this is a reliable process. Singer, Blagov, Berry & Oost surmise that it is this capacity for remembering and for making meaning that develops and sustains psychological health and well-being (2012, p.575). Psychotherapy, in light of these interpretations

in a unique position, to explore subjective experience and the interchangeable levels of both loss and joy that can be part of the experience of dementia.

With all of this in mind - the historical links between dementia and perceptions of disease, the rapidly growing statistics which highlight the chronic epidemic of dementia on society, the human desire to make sense of things, and the many layers of the self – the necessity to consider how perceptions about dementia and the experience of dementia can evolve is exposed. This thesis will draw from suggestions which Psychotherapy and Psychoanalysis make about human nature, the inner world, and the unconscious life, and in so doing attempt to deconstruct concepts of identity and subjectivity in the face of dementia. It will consider ageing itself as a developmental task and its impact on the inner world. Finally, it will consider psychotherapy's place in dementia care and dementia research.

AIMS AND OBJECTIVES

Aims:

The aim of this thesis is to explore the subjective experience of dementia and the effect of dementia on the person's sense of self. It has a particular interest in perceptions of dementia and how these impact the experience of dementia. It will explore the loss which is associated with dementia, not only to memory, but also to a sense of self connected with relationship, independence, previously integrated ways of being, and experience of reality (Nussbaum, 2011, p.265; Waller, 2002, p.5). It will also explore other perceptions of dementia outside of loss with a view to considering the whole experience of dementia, and in so doing, the whole person. It will explore the intrinsic links between dementia and the most basic and primal

crevices of ourselves – where will I go, who will I be, what will happen to me, will I be ok? Will they be ok? This thesis aims to examine these questions via the lens of psychotherapeutic theory, theory which is well positioned to make observations about the human condition. It will also investigate why the imagined loss of memory and self is so terrifying, and suggest how Psychotherapy can provide a perspective through which to better understand the experience of dementia.

Objectives:

- To conduct a theoretical desk based exploration of the subjective experience of dementia drawing from academic research and literature, but including also some non-academic sources to convey real experience
- To draw on both psychotherapeutic and psychoanalytic perspectives as models of enquiry which are concerned with unconscious processes, subjective integration, and human experience. In this way they are well positioned to consider dementia and subjectivity
- Ageing will be considered as a developmental task, and a component of the experience
- To explore language and memory as examples of what is valued in society, and therefore influential to perspectives of dementia
- To consider psychotherapy's place in dementia care
- To address the opportunities and the challenges in this area of research, and identify areas for future research.

APPROACH AND CONTEXT

Many studies have been conducted into the subjective experience of dementia. A research project called, 'Quality of Life in Nursing Homes,' used the Tavistock/Bick approach to explore the subjective wellbeing of residents with dementia in nursing homes (Datler, Trunkenpolz & Lazar, 2009). Observational studies, akin to ethnographic or anthropological fieldwork, have also been conducted. Bowlby (1969) is remembered as one of the most significant researchers in this area, in light of his research on attachment. This method of research has since evolved. Mackenzie-Smith conducted their study on elderly patients in a geriatric ward, observing their emotional experiences and responses to the psychotherapeutic interventions of listening and reflecting (2011, p.1). Chiesa (1993) conducted similar research in a psychiatric ward, focusing on the environment of the ward and phenomena like projection between patients and staff (as cited in Winship, 2001, pp.246-249).

This thesis is asking a similar question about the subjective experience of people with dementia, exploring the subjective nature of dementia and the role of unconscious processes. It is also considering the concept of the self which emerges partly from these unconscious processes, and how this might be impacted by dementia. Although the option of conducting an observational study in this area was explored, it was felt that a short-term observational study would not be fully equipped to capture changes over time at such an unconscious level. It is not possible within the remit of this research project to conduct a large-scale study intended to measure subjective changes over time. It was also not considered possible to evaluate subjective experience by focusing the research on carers or relatives of people with dementia, by consequence of this representing the subjective experiences of the carers and not the

person with dementia. For these reasons, it was felt that a desk-based research model would work best, to begin to explore this question, with acknowledgment that there is opportunity for further research into this area using field based research models².

Kitwood makes the important argument that when researching the subjective experience of dementia, sensitivity must be applied when choosing the methodology of enquiry. A rigid empiricist approach will only generate rigid and simplistic categories of explanation. What is required is the use of natural human enquiry in tandem with research methodology. There must be empiricist data collection and the research must be robust of course, but to be confined to the empiricist methods will create rigid research material, which misses the point central to the study of intersubjectivity (Kitwood, 1997, p.13).

This thesis will use some non-academic references as a means to access the real experience of dementia. The nature of conducting theoretical research as a way to explore subjective experience is a contradiction in itself, as it is an objective approach. In order to manage that inherent contradiction, short films, radio clips, newspaper articles, and quotations from people with dementia will be included in the

² Field based research models might include an Observational Study, but one conducted over a long period of time in order to measure change. Stratified Sampling (McLeod, 1994/2015, p.57) selects a group of people with something in common, in this case dementia, exploring through observation their experience. This technique of observation is akin to ethnographic or anthropological fieldwork. The observer in other words takes up a non-invasive role, similar to the position Bowlby maintained in his attachment research (Winship, 2001, p.246). A method of using a cluster randomised control feasibility study, like that which was used by Hung Hsu, Flowerdew, Parker, Fachner, and Odell-Miller to measure the effect of music therapy on neuropsychiatric symptoms of dementia (2015), could also be explored. For example, in a care home setting care staff and patients with dementia might be randomised into a standard care control group, and a group which employs models of Psychotherapy into its care, or alternatively a group where care staff are getting more support themselves, depending on the trial's aim. Although qualitative methods of research are usually the methods employed by Counselling and Psychotherapy researchers, a method which takes subjectivity into account, it is important to appreciate the role that quantitative research plays in outcome based assessment. A trial like this may use qualitative methods to generate the theme and hypothesis, however quantitative methods may be required to test this hypothesis (McLeod, 1994/2015, pp. 93-94).

research. To use only academic material would threaten the very nature of the question this thesis is attempting to investigate.

This research also aims to stimulate the question of whether or not the self can exist in the absence of cognitive function. There is much capacity for further theoretical and field research into this question, and this thesis presents an opportunity for further related research into this topic.

It is important to acknowledge that there is a discomfort inherent in conducting a theoretical research study into the subjective experience of dementia. It is contradictory by its very nature, and relies on the experience of other researchers and theory to convey the experience of those who have dementia. The research is therefore removed from the actual experience. It could be said that this is the case even for those researching via direct qualitative measures. In many ways, the subjective experience can only ever be felt and understood by those who experience it, and those of us researching it can only ever consider what the subjective experience might be like. This is the limitation of this type of research.

This thesis will use the terms Psychotherapy, Psychoanalysis, and Therapy interchangeably.

CHAPTER 1: DEMENTIA

The sky has darkened, and the room with it; the window is struck as though by tiny pellets and water slides down it in bands...And then the rain stops. Gradually, the room is filled with light; the bare criss-crossing branches of the tree are hung with drops and as the sun comes out it catches the drops and they flash with colour – blue, yellow, green, pink. The branches are black against a golden orange sky, black and brilliant...
(Lively, 1987, p.208 as cited in Ferguson, 2014).

Dementia is the term used to describe collective symptoms caused by degeneration and disruption to the brain. It is therefore cognitive function which is primarily affected, but the resulting impact is also on the rest of the body, the individual's relationships, connectivity, and daily activities. O'Brien describes features of dementia as an inability to problem solve, changes in personality, and memory loss. Dementia is only diagnosed if there are at least two or more brain functions affected. These include memory, language, perception, cognitive skills, reasoning, and judgement (O'Brien, 2013, p.214). Its progressive nature means that as symptoms arise deterioration is ongoing, and the extent and pattern of deterioration cannot be predicted (Malloy, 2009). It is not memory loss alone which is progressive, but the simultaneous loss of other functional skills, and subsequently the threat of loss of independence (LoboPrabhu, Molinari & Lomax, 2007).

There are five identified types of dementia. The first is *Alzheimer's Disease*, the most common, beginning with short-term memory loss and becoming progressively more severe (Balfour, 2007, p.223). It is caused by a build-up of protein on the brain creating tangles and plaques which inhibit brain activity. *Vascular Dementia* arises when blood vessels in the brain are blocked, reducing blood flow to the brain and

subsequently damaging brain cells. This is often a result of stroke or other blood vessel damage. *Multi-infarct dementia* is a type of vascular dementia caused by small strokes (The Alzheimer Society of Ireland, 2017). *Lewy Body Dementia* is also caused by protein build-up called Lewy Bodies, causing brain function to fluctuate and is often connected with mobility issues. *Fronto-Temporal Dementia* affects the fronto and temporal parts of the brain in particular, affecting planning, emotional control, and organisation skills (Health Service Executive (HSE), 2017). This includes the type of dementia called *Picks Disease*. In the early stage it can affect the person's personality and behaviour rather than their memory. Later it takes the form of Alzheimer's Disease. Additional types include *Korsakoff's Syndrome* caused by alcohol abuse, and *Creutzfeld-Jacob Dementia* which also arises from a protein abnormality in the brain. Dementia can become a symptom of other conditions such as Down's Syndrome (The Alzheimer Society of Ireland, 2017). *Huntington's Disease* and *HIV-associated dementia (HAD)* are also types of dementia. *Early and Young Onset Dementia* is classified as the fifth type (Health Service Executive (HSE), 2017). Dementia progresses from early, to intermediary, and into late stage (Balfour, 2007, pp.225-226).

Sachdev suggests that an epidemic of dementia is upon us, and insights into ageing are needed urgently (2003, pp.3-9). In the 1970s and 1980s, advocacy organisations in the USA began developing strong messages to collate resources to support the rapidly ageing populations (George, 2010, p.586). In Ireland this message is also strong and getting stronger. In particular, Trinity College Dublin (TCD) has been developing an Ageing Research programme aimed towards understanding and supporting this ageing transformation which is occurring, where more people are

living longer than ever before, and more will live with dementia related disorders (Trinity College Dublin (TCD), 2014). The British Society for Research on Ageing (BSRA) is producing research into multiple areas of ageing, including neurodegeneration and sensory and cognitive ageing (BSRA, 2017). In response to developing dementia, David Sheard developed the Butterfly Care Home for people with dementia in the UK and Ireland in 1995. This was developed in response to a realisation that trolleys and overcoats were not the most suitable form of dementia care, a response which will be explored in greater details in Chapter Two (Sheard, 2015). This is to single out only a fraction of institutions who are answering the call to address the epidemic of ageing and age related conditions, including dementia.

There are various ways from which to approach and understand dementia. It is not limited only to the medical model of understanding. To present only the medical model's presentation of dementia would not be presenting the whole picture. This overview of what dementia 'is,' which in large part presents it in physiological and psychological terms, presents a picture of deterioration and gradual decline. If this was the only perspective presented, one could ask how relevant research into subjectivity in dementia is. In order to really access what the experience of dementia is like, not simply the biology of the condition, it is necessary to consider the impact dementia has on those who have it, and those close to them.

Greg O'Brien, diagnosed with Early Onset Alzheimer's, poignantly describes the condition as like watching someone holding onto a dock on an outgoing tide, who eventually just lets go. He observes that Alzheimer's is a shaft five miles deep, and that he is only comfortable taking people three miles down. The rest is too dark.

This means that his family often feel isolated from him. However as Greg sadly admits, that is the loneliness of Alzheimer's; people just can't get it (The Mind Shaft – Strangers, 2015). Sacks describes Jimmie G, after one particular instance of awakening from a period of amnesia, experiencing blind panic and disorientation; "Christ, what's going on? What's happening to me? Is this a nightmare? Am I crazy? Is this a joke?" (as cited in Sacks, 1985/2011, p.27). Anna Darlington's observation is quieter than the others; "These moments came up on me like the fox, very, very quietly (as cited in Davenhill, 2007, p.287).

The Living With Alzheimer's Film Project (Living With Alzheimer's Project, 2016) hosts a number of short films about Alzheimer's. Through the medium of storytelling, it endeavours to improve the lives of people with Alzheimer's and their families and friends. These films provide a sense not just of the anxiety and decline of Alzheimer's, but also the love and hope felt by the families of the individual, and the individuals themselves. Christopher Wynn's film tells his father's story, in a film called 'Forgetful not Forgotten.' He speaks of his father, saying "...even with Alzheimer's you were still there Dad, I felt you so many times" (Wynn, 2015). In the film "The Memory Box," Brett Chapman observes that "When you've become used to seeing a person in a certain way, even a few moments of apparent clarity feel like a gift" (Chapman, 2016). In 2014, the Social Care Institute for Excellence (SCIE) recorded a short film, interacting with four people with dementia who share their insights and experiences of living with advancing dementia. Some extracts from this film are highlighted below;

I've often got this thing in my mind to say you've done something, you've broken something, you've lost something, you aren't any good to anybody, why are you here? (Barry, 2014, SCIE)

Well you don't feel as if you are in the world. Well, at least I didn't. You don't feel as if you are part of the world (Olive, 2014, SCIE)

I used to do alright one time, but it seems to get a bit harder and harder every year (Bob, 2014, SCIE)

I couldn't go outside and go to the shop or anything. I'd die. Well, I couldn't do it (Judy, 2014, SCIE)

These examples from people who have dementia are an essential part of an exploration of the subjective experience of dementia. The seduction about dementia is that the word itself, and the associations that come with it attached to memory loss, loss of identity, loss of self, and undoing, invite assumptions about the power of memory and memory loss, and how inherently attached self and memory are. Research initiatives like those already mentioned, while promoting awareness about the needs of those with dementia and how to support them, are also largely focused on finding a cause and a cure for the condition, which brings with it a sense of the threat of dementia. Its association with older age also brings with it a sense of nearing the end of one's lifespan, and a sense of an impending end. George remarks upon this dominant language pattern, which is attached to the notion that dementia creates a complete and total loss of self as it annihilates the brain, resulting in a 'living death' or a 'death that leaves the body behind,' creating 'nonpersons' or 'shells' of those left behind by this disease. Person-centred care and the cultural changes it has ignited has done much to shift the worst of these scare mongering assumptions, however this totalising language continues to guide general understandings about dementia as a wiping out of selfhood (George, 2010, p.256). An example of this type of language used in dementia literature, which although well

intentioned, creates this fear and sadness which George (2010) refers to, is seen in Cohen's (1991) paper when he refers back to Sacks' (1983) observation that people with dementia are both warriors and heroes, victims and martyrs.

Kitwood's observation that a model of dementia care based on a person-centred approach was necessary to effectively support those with dementia, was in 1997 a revolution for dementia care (1997, p.20)³. Davenhill's 2007 collection of papers about the experience of dementia through a psychoanalytic lens was equally informative. It hosts writers like Balfour who observe that dementia is not a return to infancy, however in later life there can often be a return to these earlier conflicted states and the way they were experienced before will often be how they are experienced again (Balfour, 2007, p.223). Waddell makes the same point, highlighting that life is not a linear journey from youth to old age (2007, p.187), with Davenhill highlighting that dementia is not a linear progression from awareness to lack of awareness (Phineas, 2002, as cited in Davenhill, 2007, p.227). Sacks, as mentioned, has also been a prominent figure in promoting the idea of subjective experience and mental health. It is a contradiction in ways to at one point praise Sacks for his contribution, and on the other to use his work to highlight the necessity for broader language. It is symbolic perhaps of the contradictions and splits which can be found within dementia research. This in many ways is the challenge of research in general, and research into dementia in particular. One must stay cognisant of the whole picture, and dementia is a picture that is still painting itself, with some champions of dementia literature, like Davenhill (2007) and Balfour

³ Textbooks up until 1997 were not generally mentioning the experience of dementia (Kitwood, 1997)

(2007) for example, beginning to highlight the need for more depth in understanding the experience of it.

In this vein, Signe and Solve's (2005) article observes that both positive and negative experiences are part of the experience of dementia. The carers of people with dementia in particular can experience feelings of burden and satisfaction at the same time. It seems that one of the effects of dementia is this splitting of the good and bad. The person is either there or not there. The message is mainly about fear and sadness, while the hope and satisfaction that is also there is forgotten. Perhaps this compartmentalisation of experience is a means to manage the seemingly unmanageable. Humans naturally seek coherency. This is evident from literature about self and the developmental framework which will be explored in more detail in Chapter Two. This tendency is perhaps no less active in trying to absorb the experience of dementia.

If this need to make sense of things is one of the reasons why there is compartmentalisation in the way dementia is viewed, then society's attachment to memory and the importance of memory as a construct of self is another. Basting (2009) suggests that facing one's fears about dementia and memory loss challenges the stereotype that dementia is a thing to be feared, and the dreadful unknown of memory loss. She acknowledges the impact of dementia at various levels. On an individual level it impacts both the person with dementia and their loved one. On a societal level the cost of caring for someone with a disease that can last up to fifteen years has a huge impact. In addition, the effect of narrative and storytelling, which has long since been a part of how humans perceive the world, suggests that dementia

is a catastrophic event. The question Basting explores is to what extent does this fear and storytelling affect the experience of those with dementia, and the public perception of it? Her assertions that she has seen the fear, pain, and anxiety of dementia, but also the fierce pride, joy, compassion, and humour of it, is uplifting. In fact, Basting's perceptive pierces through the veil of despair and doom which much of the literature about dementia can evoke. The time of dementia is upon us, and living in fear is not serving dementia or those who have it any great purpose. Basting suggests that chasing a cure is not the best use of time. Prevention is better but that too takes time. The best one can do in the moment, during the time of dementia, is to focus on more supportive care practices, and revisit attitudes towards dementia (Basting, 2009, pp.1-4). Kitwood's (1997) work on promoting improved care practices with a person-centred approach has made him a prominent voice in dementia research, however the additional element Basting highlights about revisiting attitudes is enlightening and highlights a further importance. It suggests the need for more than improved care; it suggests improved insight and understanding of the nature of dementia and the subjective experience of dementia.

Following on from the vignettes taken from Social Care Institute for Excellence's (2014) documentary, Judy elaborates about what would be supportive for her as she journeys through advancing dementia; "Let me live." Later she observes that anyone looking to help her should "just be" (Judy, 2014, SCIE). From the same film, Olive describes the difficulty of dementia beyond the memory loss, as the experience of hurting the people you love, and the guilt that comes with this (2014, SCIE). When Judy's daughter asks Judy why she is sad, Judy replies that she is looking back. When asked why it makes her sad to look back, she replies "Oh I don't know, I

probably should have done other things. You just, you can't do anything about it, that's the thing" (Judy, 2014, SCIE). On the question of identity however, the key factor in the conversation about dementia, Judy observes, "It's still me, it's still me. I'm the same." Barry observes "I'm a man, it's me, and I am me. I'm my wife's husband, and my son's dad. ...People say oh she's got dementia, and that's a full stop. End of sentence, end of discussion" (Barry, 2014, SCIE). These observations are the fuel for the flame that is needed to enhance and develop dementia research and approaches to it in a way that thinks about subjectivity, individuality, and the need to consider the whole experience, rather than only its parts.

Summary

This chapter has examined what dementia is, describing it firstly in its medical and physiological terms, those which focus on proteins, disruption, and decline. It has suggested the links between dementia and ageing, and the epidemic on society as people live longer, and live with dementia. It has also delved into the experience of dementia beyond cognitive decline, using the voices of those with dementia and their carers to convey what it is like to have dementia. In examining the work of researchers like Kitwood, it has identified the need for continued research and evolution, not just into models of care but also attitudes towards dementia. Part of this requirement for change in attitude is the requirement to consider the whole picture of dementia, the loss and despair, but also the fact that the person with dementia is still there. This question of identity is embedded within dementia research, and the way in which it is responded to will determine the position society and research takes up in relation to dementia. What is notable from the vignettes from those interviewed for SCIE, is the repetition of the observation about what it is

like, followed by the acknowledgment that ‘that’s what it is like for me anyway’(SCIE, 2014). The suggestion is that experience is totally subjective. There are many commonalities within the experience of dementia, but all anybody can stand over is their own experience. Chapter Two will explore subjective experience through a psychotherapeutic and psychoanalytic lens, considering identity, ageing, and the desire for coherency of self, and how this is relevant to dementia research.

CHAPTER 2: THE SUBJECTIVE EXPERIENCE OF DEMENTIA

Every life is in many days, day after day.

*We walk through ourselves, meeting robbers, ghosts, giants, old men, young men,
wives, widows, brothers-in-love.*

But always meeting ourselves

- (James Joyce, 1922/2002, p.204)

The following chapter will explore the subjective experience of dementia by examining some of the unconscious processes which play a role in the experience of dementia. It will draw on psychotherapeutic and psychoanalytic theory as a means to reflect what can happen at an unconscious level to compound the experience of dementia. In addition, it will explore aspects of experience related to identity, ageing, and the desire for coherency of self which is evident in psychotherapeutic theory.

Psychotherapeutic perspectives about the inner world

Psychotherapy and Psychoanalysis have many theories of thought which explore subjective experience. Referring to them as a means of enquiry into subjective experience is inevitable in many ways, because these theories discuss and evaluate the subject and the self, and make suggestions about what it is to be human. These schools of thought are well placed therefore to consider the subjective experience of dementia. This is because when exploring subjective experience in relation to any condition, one is still simply exploring what it is to be human, with the addition of what it is like to be human with the experience of, in this case, dementia. In addition, Psychotherapy and Psychoanalysis offer insight and make estimations about the

whole concept of self, and the inner unconscious world. Given that the effect of dementia is largely on the inner world, a psychotherapeutic perspective is a valuable tool to explore subjectivity in dementia.

To look firstly at some prominent psychotherapeutic theories which speak to the inner world, Bowlby's attachment theory is perhaps one of the most influential. Bowlby suggested that an infant's hunger for its mother's love and presence was greater than its hunger for food. Loss or lack of this presence has a strong effect on the infant's relational and attachment responses. He focused on the ways in which an infant responds both to loss and to reunion with the mother (Bowlby, 1969, p.xiii). He observed that the influence of the infant's environment at these early stages of life is such that when there is disruption or insufficiencies in it, it will have an impact on the adult life of the person (Bowlby, 1969, p.45). Bowlby also emphasised social influence on development. He connected levels of separation anxiety and independence with defensive processes linked to the infant's environment. Ainsworth (1978) went on to name the attachment styles as ambivalent, avoidant, disorganised, and secure (Bretherton, 1992, pp.765, 769). She developed the Strange Situation, a protocol used to measure patterns of secure and insecure attachment (Sonkin, 2005). These early attachment experiences will often determine the infant's subsequent attachment style. For example, a caregiver who masks emotion will likely trigger an avoidant attachment style in the infant. A child who experiences unpredictability may form an ambivalent attachment style, and will respond to feelings of insecurity by constantly reaching out (Gerhardt, 2004, p.26).

Attachment theory explores the self in relation to the other, and Object Relations Theory describes the same process in greater detail. The Object Relations framework examines internal and external relational processes developed from infancy. It proposes that within all humans there is an internal representation of Self and of Other, and that these are constantly influencing and responding to each other throughout life. The infant is shaped by these experiences and processes which are fundamentally unconscious and instinctual (Tsigounis, 2011, pp.11-12). Gerhardt also suggests that a responsive and attuned caregiver is necessary to help the infant self-regulate. Self-regulation is something the infant cannot do on its own so it relies on others to sooth it, and simultaneously teach it to self-sooth (Gerhardt, 2004, pp.18-19). Similarly, Coan's social baseline theory suggests that the human brain has constructed itself through the process of evolution to rely on relationships with other brains. Its default is to rely on social regulation and Self-Other co-regulation. If this is not available to it, the brain behaves in suboptimal ways (Shaver and Mikulincer, as cited in O'Brien, 2013, p.77). This desire and need for relationship is such that the human brain has become programmed to function at its best when this is available to it. This stage is preverbal, therefore without language the infant must rely on these instinctual cues. Within all of this, what Gerhardt is observing is the subjective nature of reality. The infant has an internal blueprint that requires interaction with the other to complete itself (2004, pp.9-10). This subjective experience is key when discussing the concept of self. It is not a generic model, but a unique tapestry dependant on experience, perception, environment, and response.

This perspective is also observed if thinking about the self from an autobiographical point of view. The autobiographical self is described as a narrative which is

constructed over time through encounters with others and a wider culture, creating a sense of a lived past and anticipated future. Memories are a key part of the autobiographical self, and they are both explicit and semantic (Blinder, 2007, p.276-277). Explicit memories connect to the conceptual self. As these build a sense of self, they become life-story memories. This sense of self is further enhanced through interaction with family and culture, developing life themes. The theme supports the narrative, which forms the life-story and becomes self-defining. One's internal self-representation and one's external representational world are in this way interwoven (Singer et al, 2012, pp.570-574).

From a psychoanalytic perspective, Freud was influential when it came to matters of the internal, unconscious world. He was concerned with gaps in memory created by what he deemed to be resistance on the part of the patient, and how those gaps could be bridged by accessing parts of the unconscious (Freud, 1963/2001, pp.320-328, 486). His dream analysis, amongst many other aspects, suggest that dreams contain the material of childhood, material that for the most part is blotted out by gaps in one's unconscious memory (Freud, 1953/1991, p.75). His work was similarly concerned with the process of regression and the unconscious life. He observed that much of what is called mood is influenced by the unconscious. When there is mental deterioration, the inhibitions which ordinarily restrain particular actions become weaker and at times cease to contain at all. Conscious memory and reflection which might before have stopped someone from making indecent jokes for example, no longer play their role. The idea of what one does automatically or instinctively is actually that which remains below the threshold of consciousness, restraining indecency and impulse in this way (Freud, 1955/2001, p.223).

Klein developed her work from the Freudian psychoanalytic foundation, which was concerned with the early formative years. She considered the strong connection between the conscious and unconscious life. The infant was engaged with two conflicting impulses; love and hate, or as her later work would elaborate, the life drive and the death drive. Her observations were about anxiety, symbolism and phantasy - the components of everything as she saw it (Mitchell, 1986/1991, pp.11-21, 176). Object relating is a crucial part of how the infant relates at this early stage. Klein believed the mother's breast was either the good gratifying breast or the bad frustrating breast. The way that the infant splits the object and the interaction between the internal and external world is central to its early development (Mitchell, 1986/1991, p.177). The infantile ego under these conditions of extreme love and hate develops defences to attempt to manage its world. Splitting is the mechanism by which the ego separates the intolerable, disowning it. Similarly, projection is the unconscious mechanism by which the infant can put all unwanted feeling outside of itself, into the other, usually the mother or primary caregiver. How the good breast is introjected will influence ego development and structure. Klein also proposed an additional process, where the feelings that are projected into the other are felt by the other on an unconscious level and given back to the infant. This she called projective identification (Mitchell, 1986/1991, pp.19-20). It is the anxiety in the infant that drives these defences and will have a strong influence over development of the ego, the superego, and object relations. She named this early phase the paranoid schizoid position, a persecutory phase for the infant who experiences the uncertainty of both love and hate (Klein, 1946, pp.176-177).

Winnicott also considered subjectivity in his theories about the internal world. Mother and baby are part of an inter-relational process, where the infant lives in a subjective 'only-me' world. The mother adapts around this to facilitate the infant to engage with this subjective experience for long enough that it develops to begin to experience 'me' and 'not-me' (Winnicott, 1986/1990, pp.22-23). He observed that in the beginning the baby is in the environment and the environment is in the baby, and the good enough environment nurtures the maturational process so the individual can move towards independence, the ultimate goal, where ego strength and structure is formed. To get here the child has been enabled to become depressed, to feel the pain of the internal world, but not to have become lost to it (Winnicott, 1986/1990, pp.72-73).

Mitchell and Aron observe that for Bion, the ultimate reality of the self is beyond the reach of knowledge. It is this openness to the unknown that is the fundamental basis for Psychoanalysis (1999, p.27). As Freud once observed, as soon as one deliberately concentrates one's attention, one begins to make selections and will only find what one already knows (1912/2001, pp.111- 112). The ethos of Bion's work is that one cannot know the truth before one starts. This also applies to the position a Therapist has in relation to a client. There is no start or end point, only something constantly evolving. Balfour draws on these perspectives of primary modes of relating, observing similarly that they are states of mind, developing in constant oscillation throughout life (Balfour, 2007, p. 223). Similarly, Lacan emphasises the importance of not over simplifying psychic life. Meaning is complex, and the route to it unpredictable. The Real cannot be bottled and sold as a generic meaning for all (Mitchell & Aron, 1999, p. 27).

A review of these psychotherapeutic and psychoanalytic theories is necessary when considering dementia through the perspective of Psychotherapy, and what Psychotherapy might have to say about dementia. As mentioned in the introduction to this thesis, the intention of an exploration into the subjective experience of dementia through a psychotherapeutic lens is not to map psychological deterioration onto developmental and unconscious processes, nor is it to assume that there is a return in older age to early developmental processes. It is tempting to look at dementia in this way, because there are many aspects of the experience of dementia that reflect the unconscious negotiations of infancy. However, if one starts out with only this perspective, it becomes more and more evident that the effects of a condition cannot fully overwrite uniqueness of self. It also becomes evident that the tendency to want to look at dementia in this way may be linked to the aforementioned human tendency to compartmentalise in an effort to make sense of things. How easy it would be to predict the experience of age if it was a linear return to infancy, and dementia purely an acceleration of that process. However, how devastating an outcome that would be; to go back to the beginning, back to where one has already been. No less devastating than having to make a U-turn on a country walk to retrace ones steps, rather than continuing on the journey, all the time seeing new things and learning about new parts of oneself.

With all of that being said, dementia is a condition which can drastically change a person's life, sense of self, and sense of the world. The fact that the person is still there does not always make the experience any easier, for the person with dementia or those caring for them. Nussbaum describes the loss and unravelling of dementia when he says that he felt his patient Eleanor's question was how she could possibly

turn dementia into hope. She was all the time asking how to find a way to live or die through the loss of words, cognitive function, independence, and self, and what Nussbaum interpreted as the hope for company in the face of unimaginable loss (2011, p.265). Nepo likens Alzheimer's to a loss of context and of the map which one had created for oneself, now distorted and changed. This loss can evoke acute anxiety, and a return to uncharted beginnings (2012, p.46).

Soler suggests from a psychoanalytic point of view that the lack which language introduces, in so far as something is always lost in the exchange of language, allows a patient to consider death and absence. Often it is living which is harder than death, although rarely acknowledged as much as the latter (2016, p.4). Lacan observes that sometimes desire to die is all patients come in with. In these cases, the desire is within the Analyst and not the patient. This desire on the part of the Analyst is accompanied with an awareness that a patient's waning desire is not useless, but rather reflects affect. The Analyst's desire in these moments is needed, until the patient's returns (Fink, 1956/1999, p.4). This body of thought in relation to dementia is very relevant, in the way it speaks to both the good and the bad, the loss and the hope, the lack or absence, and the desire and affect behind it. It speaks to the notion that the experience of dementia encompasses both loss and hope. This presents a challenge to researchers and practitioners, to consider both the internal and external world in tandem, when the inclination can be to look only towards one or the other (Balfour, 2007, p. 231). This will be explored in more detail in Chapter Three, which will explore Psychotherapy's place in relation to dementia.

The psychic life and the experience of dementia

In the abstract to this thesis it was suggested that much of the self and what one thinks of as self and how it has developed, is attached to unconscious processes. Becoming a person from infancy through to old age can be measured, to a large extent, against an unconscious framework of evaluation and integration, which is a necessary part of the maturation process. The self is constructed through navigating these unconscious and instinctual pathways. The influence dementia has on these processes of selfhood is captured by Waddell, who deliberately likens ageing to a process of ripening and rotting. In many ways one's existence is defined by a linear progression of chronological time. She makes the important point however that if, like in Shakespeare's *As You Like It* from which she draws this reference, one ripens only to rot (11, vii, 26-28), it disregards the inseparable links between the process of physiological ageing, and the psychological realm. What she is speaking about here are the links not just between body and mind, but between the brain and the mind, and their reciprocal relationship (Waddell, 2007, p.188). It is not enough to measure ageing and the degenerative process of dementia by simply saying that it is a linear journey from youth to age, or from health to ill health; in Shakespeare's words from ripening to rotting (11, vii, 26-28 as cited in Waddell, 2007, p.187). Doing this disregards the human and unique variations of each individual. In fact the more one considers Waddell's crude and deliberate comparison to ripening and rotting, the more uncomfortable it becomes to consider dementia as a process of development into degenerating. Davenhill and Phineas make a similar observation about the need to be careful about making assumptions that dementia is simply a case of linear progression from awareness to lack of awareness. Rather it is something much more

fluid (Phineas, 2002, as cited in Davenhill, 2007, p.227). With all of this in mind it seems reductive and rigid to refer to dementia as degenerative, as if one generates from conception and then begins a simple backwards process of degenerating. Evans similarly draws attention to this necessary consideration, when she says that although developmental models are useful as a means to consider dementia, dementia patients are adults, not children, and the loss of cognitive function is not linear. Dementia is not infant/child development in reverse (Evans, 2008). The journey of dementia is therefore a more complicated one than it might be assumed if only cognition and biology were considered.

Connecting dementia in relation to tendencies beyond the biological, the tendency which has been a common theme within all of the aforementioned psychotherapeutic research, is the tendency towards coherency. It is this which causes an infant to prune out the aspects of experience which do not support survival and coherency, making all the adaptations it can, even if not healthy or positive, in order to survive (Gerhardt, 2004, p.33). Coherency is also the drive within autobiographical theory which elicits a framework that makes sense (Blinder, 2007, p.276), and is often the reason that even the bad experiences are acceptable at a level, because it is better than nothing at all (Lapworth & Sills, 2001/2010, p.106). In this vein, Balfour observes that the leading anxiety is about the survival of the self, and the goal is to move towards an integrated state. He goes on to observe that from the perspective of later life, there can often be a return to these earlier conflicted states, and the way they were experienced then will often be how they are experienced again. Death, for example, can be viewed through the persecutory lens of the paranoid-schizoid position. If this natural return in later life is accompanied by a diagnosis of

dementia, the return can be far more traumatic, combined with a fear of loss, loneliness and dependency (Balfour, 2007, p.223). Kohut (1977) has similarly observed that many forms of psychopathology can be seen as a person trying to maintain a cohesive self as opposed to a fragmented self (Pervin, 2003, pp.265-272). This certainly seems to be where human instinct lies, for better or for worse.

As much as psychotherapeutic theory says about coherency, it also speaks about fragmentation. This is the paradox within human nature; that the effect of achieving coherency can be to fragment the self in some way, so that it becomes comprehensible, manageable, or containable. Object Relations Theory describes internal and external relational processes developed from infancy, and as part of this the unconscious methods which individuals employ to survive (Cashdan, 1988, pp.3-4). Fairbairn derived his views from the principle that people are not primarily pleasure-seeking, but object-seeking. This differs to Freud's influential instinctual theory which relates to the satisfaction of the expression of instinctual feeling (Freud, 1963/2001, pp. 209-210). Fairbairn on the other hand believed that what humans seek most is emotional contact with others (Symington, 1986, p.238). Both Fairbairn and Guntrip saw the ego as capable of splitting, encompassing the libidinal (child) and antilibidinal (persecuted) ego, representative of the eternal battle between needs desired and needs diminished. This splitting creates the schizoid personality, leaving the outer world cut off from the person, and their inner world compartmentalised. This can create terrible isolation, and a life script with no true sense of self (O'Reilly-Knapp, 2001, pp.1-4). Evans (2008) draws on Psychoanalysis's perspective on fragmentation of the mind and its considerable exploration of early life and childhood, as a model which is well positioned to shed some light on the

experience of dementia. Although dementia is not the same as childhood experience, this likeness is evoked by the experience of fragmentation. Evans makes the very important point however, that deterioration and regression must be differentiated. Prejudice and assumption, if allowed, can commit dementia patients to a 'fate' of this regressive nature, when in fact the person can be supported during each stage of dementia (Evans, 2008). Prior to exploring how a person can be supported at each stage of dementia, there is more to be understood about the linkages between the psychic life and the experience of dementia. The following are examples of where psychotherapeutic theory has informed research into this experience.

What psychotherapeutic research is saying about dementia

Since Kitwood's prominent 1997 paper *Dementia Reconsidered: The Person Comes First* in which he first applied the concept of person-centred care to dementia (as cited in Mitchell & Agnelli, 2015, p.47), research into understanding dementia has expanded. Behavioural and psychological influences on dementia (BPSD) for example, suggest that behavioural and psychological symptoms of dementia impact on its prognosis, and that non-pharmacology therapies like group and music therapy, for example, are most effective in treating these symptoms and supporting the person with dementia (Kazui, Yoshiyama & Kanemoto, 2016).

Considering dementia through a socio-ethnographic lens, Ladson Hilton and Levkoff use a narrative approach to investigate the process of lost identity, confusion, and loneliness for those with Alzheimer's. They suggest that whether dementia symptoms are viewed as a part of the ageing process or as a disease process, they

instigate behavioural and meaning-making changes. Responses by the person with dementia and their families therefore have social and cultural patterns and influences (Ladson Hilton & Levkoff, 1999, pp.453-455). Understanding these types of influences supports a better understanding of the condition and its affects, because it places it within a context that is relevant and means something to the individual.

Kitwood (1997) has contributed significantly to research like this, and into personhood in relation to ageing and dementia. His research has given voice to the subjective experience of dementia, where personality and defence mechanisms are considered to be essential parts of the person's unique experience. His 1997 paper observes that at last the question of subjectivity, and also intersubjectivity, has been added to the conversation about dementia. He also recognises that having this valuable dimension will support the very necessary therapeutic element in dementia care. He observes that for as long as dementia was recognised within clinical categories, the subjective element was not, despite the pioneering of clinicians as far back as 1988. Textbooks up until 1997 were not generally mentioning the experience of dementia. Depression and psychiatric conditions included in their descriptions a component of the experience of the illness, leading Kitwood to ask why not dementia? Was it because people with dementia were not viewed as having an experience? (Kitwood, 1997, p.13). Kitwood draws attention to the unique constellation of needs that a person has, and these needs do not become less unique when a person develops dementia. If one applies the five great human needs - attachment, comfort, identity, occupation, inclusion, and naming love in addition to these as central to all other needs - to the experience of dementia, one can see the points at which the internal world is affected. On attachment, Kitwood draws from

Bowlby's (1979) observation that bonding is instinctual, cross-cultural, and universal by nature. Without the security and comfort which attachment provides, it becomes difficult for a person to function. There is much indication that this need for attachment and security remains when a person develops dementia, and in fact that it might feel as strong as it did during early development, as the person loses memories related to secure attachment in a world filling with anxiety and uncertainty. Drawing from Miesen (1992) he suggests that people with dementia are continuously finding themselves in 'strange' situations, making the attachment need acute. As a person's social life begins to change, inclusion can be threatened. In dementia, the need for occupation persists, however the avenues towards it become less accessible. Identity is connected to narrative, a life story, which dementia interrupts. Identity however is not only about the story one tells oneself, but also the messages received from others. Others therefore become more reliable sources of information than memory when cognitive impairment takes hold (Kitwood, 1997, pp.19-20). Similarly to this, Sacks observes that even if one has no knowledge of one's own memory loss, the expressions on the faces of others will inform them that something is very wrong (2012, p.204). Randall speaks of this also in his research into a narrative perspective on dementia, when he concludes that in dementia, as in childhood, it is others who influence our story, for better or worse (2009, p.323). It is essential that messages become beneficial and comforting sources, rather than additional catalysts of anxiety and loss of control.

Ng (2009) approaches dementia by using infant observation techniques. She observes that although dementia is a condition which affects cognition, the emotional loss is just as, if not more, significant. The loss of communicative function can give the

illusion that there is no coherence of self remaining. There is a responsibility on the part of those connected to the individual to try to make sense of what they see, rather than dismissing it as non-sense. This links back to Sack's (2012) and Kitwood's (1997) points that feedback from those around the person with dementia is a vital contributor to their experience. Fragmentation of the ego in dementia can evoke a sense of despair. Ng, having worked as a Psychoanalyst with patients who have dementia, notes how frequently she observes patients in late stage dementia returning to childlike states. Some of this is due to physical deterioration, an inability to wash or feed without assistance. Verbal fluency is depleted meaning basic expressions are used to communicate, and mental states follow suit. Preoccupation with the past and childhood also exacerbates this process. The inevitability of decline can lead to feelings of anger, guilt, failure, despair, and impotence, for both the person with dementia and their carers. She concludes that using a psychanalytic lens encourages a better understanding of why a patient behaves in challenging ways, as opposed to dismissing the act as one of delinquency. Environment also has a strong impact on the individual. Ng concludes that challenging preconceptions and stigma about the course of dementia is the only route to a better understanding of it (Ng, 2009, pp.83-102).

Steele, Phibbs, & Woods (2004) consider the impact of attachment style on the person with dementia, by considering the life-long impact of reunion behaviour on a person, and the endurance of secure attachment style into late stage dementia. This research explores how attachment style can influence the person with dementia. For example, insecure-avoidant patients are more prone to anxiety, while insecure-ambivalent patients are more likely to suffer from depression and anxiety. In some

cases, the emotional and cognitive decline caused by dementia can cause patients to call out for the help of their deceased parents rather than their caregiving children. This has been termed 'parent fixation' arising from a building overwhelm of separation anxiety (Miesen 1992/1993 as cited in Steele *et al*, 2004). This particular study focuses on how the attachment style of the children caring for parents with dementia might help to balance this attachment confusion arising for their parents.

Pervin draws on an autobiographical framework of which memory is an essential component, to explore the importance of memory to the experience of oneself. He uses the example of Klein, Loftus and Kihlstrom's study, as they ask a similar question. Their study is based on an analysis of individuals with memory loss, arising from brain injury. Participants answered a series of questions about themselves and their lives and histories, leading the study to conclude that one does not need to know how one used to be, to know what one is like (Pervin, 2003, p.296). Essentially, what research like this is supporting is evidence that dementia has particular effects, but that these effects are merged with the individual's own beliefs, culture, language, and ways of being in the world. Ultimately, there is dementia, and then there is the subjective experience of dementia.

Klein *et al's* (as cited in Pervin, 2003) study somewhat contradicts the evidence of Blinder's autobiographical theory (2007), with regard to the importance of memory to a sense of self. It suggests that memory can be separated from one's experience of oneself, so that they are not mutually exclusive. In contrast, Singer *et al*, from an autobiographical theory perspective, propose that memories build a sense of self, becoming life story memories. This sense of self is enhanced through interaction

with family and culture, developing life themes, however the memories linked to these organising themes are what make these experiences self-defining. Narrative scripts and schematisations are formed when there is repetition of memory and theme (Singer *et al*, 2012, p.570-574). These varying perspectives, although contradictory, create opportunity to examine subjective experience, and to challenge the value placed on aspects of experience, like for example the importance of memory. Given that loss of memory function is one of the most prominent aspects of dementia, Basting explores why memory came to be such a prominent component of how one lives and lives with others. Part of this is its connection to storytelling, which in turn connects with how one experiences and relates to new experiences; tracking oneself and others across time and in-so-doing creating a sense of self. Memory of course takes many forms – long term, short term, episodic which focuses on specific events and people, semantic which relates to more general knowledge, procedural related to how one does something, and implicit and explicit which are unconscious and conscious memory. Memory is not therefore a camera aimed at the past. It is experienced through these many pathways at different times, and a person at any stage of dementia will continue to access these pathways (Basting, 2009, pp.15-18). Basting is not the only researcher challenging the assumptions about memory and dementia. Evans remarks upon the relationship between the thinking and the emotional world, and in particular what role memory plays within these worlds. She observes that within the neural pathways there are both thinking and feeling networks, and that the feeling networks are more primitive. These remain untouched longer than those designed for thinking alone. People without memory function have been known to access memories during times of intense emotion. It has also been shown that music and smell, these sensory emotive aspects, can trigger memory for

those who have none. This occurs when cortical areas are accessed via different pathways. The access is slower, directed through the limbic feeling system, and travels via alternative nerve fibres (Evans, 2008). The ability to make connection and relationship is therefore retained even for those with severe dementia, as is the ability to make new memories (Garner, 2004, Williams & Garner 1998, as cited in Evans, 2008). Basting's research suggest that the cultural norms, particularly Western culture, of being productive and staying active, are so much attached to brain function and memory that when this wains so does the sense of meaning, meaningfulness, and usefulness. Similarly, those particularly with late stage dementia, became enshrouded in the cultural assumptions that carers *give*, while people with dementia *take*. Some of the fears of people with dementia identified in Basting's research include fear of being a burden, fear of the unknown, fear of loss of control, fear of being violated, and fear of a meaningless existence. Basting concludes that the point is not to disregard the fear, but rather it is about also allowing ourselves to feel more than fear, for there is much more to be felt (Basting, 2009, pp.10-11).

George's (2010) observations are important to hold in mind as concepts of self in relation to dementia are explored. It is not good enough to assume the person with dementia loses themselves entirely, and in so doing becomes a shell. The condition is not so ravaging, nor is the person so susceptible to pure annihilation in this way. George acknowledges that one can argue that at the level of policy it may be necessary to use provocative metaphors in order to sustain funding and support for dementia research and care services, and for families shared language co-shared with society can provide coherence and within that comfort, however, the search for

compassion and an understanding of subjective experience lies in language alterations. Dementia is not just a loss of parts of the self and the self as it once was, but a change in self, a stage of life, a part of the person's overall experience. He argues that identity is not lost as long as one is alive (George, 2010, pp.256-257).

Understanding aspects of dementia as a response to unconscious processes

Having examined some ideas about concepts of self, and research which has been conducted into dementia using psychotherapeutic and psychoanalytic models, it becomes possible to suggest in more detail how the unconscious life can impact the subjective experience for the person with dementia. Rayner describes a shrinkage of the self for the person with dementia, which triggers a move towards experiencing the external world more passively. The effect of this passivity or disconnection means that the external world can become persecutory and threatening. It is these changes to the internal world which can manifest in a tendency toward projective mechanisms. Ageing alone can ignite some change in defences. Coupled with dementia, these defences can fall away and projections can emerge more easily. This type of projection means that the individual experiences awful things happening around them, rather than inside of them (Rayner, 1971/1997, pp.256-258).

These primitive connotations which Rayner refers to do bring to mind something akin to childishness, ignited by the sense of newness, and unintegrated ways of being. Breakdown of external awareness is something which creates anxiety certainly, however it is the loss of connection to internalised objects which can be most distressing (Davenhill, 2007, p.209). The projections which Rayner suggests

are defences designed to manage this anxiety, to make the problem about the frightening external world rather than the terrifying internal world. There is in effect an undoing of the development which has created a sense of self. Waddell does liken this to a second childishness, because it can often mean a return to complete dependency. This return ignites a psychic response. Infantile anxieties rise up and infantile defences are triggered to meet these anxieties, as the ability to cope deteriorates. Growing research is supporting the theory that it is not just the cognitive deterioration of dementia that causes these anxieties but the intricate link between the functioning of the brain and the mind (Waddell, 2007, pp.188-189). Waddell describes the case of Mrs Brown as an example of these defences at work for a person with dementia. As Mrs Brown's Alzheimer's progresses, she develops potent feelings of jealousy. These are mainly directed toward her husband. Feelings of persecution and abandonment arise as she loses contact with the internalised model she has developed throughout her life. As an infant, this model would have formed as she learned through early infantile experience that her mother or primary caregiver could have interactions with others, and still love her. She learned that she was not going to lose her mother to others and her survival was not under threat. This model in later life allowed her to understand the same thing in relation to her husband. However, as this model begins to fall away, she experiences a polarised and persecuting version of her husband, and in response takes up a paranoid-schizoid position. In this infantile position she cannot tolerate loss and lack of control. Her response to this is not unlike the infant. She splits off the intolerable, leaving a fragmented world of good and bad in its wake. The tasks of early childhood in this way become the tasks of those with dementia (Waddell, 2007, pp.190-193). Similarly, clinical models have suggested that despite having developed a secure

attachment style, some individuals with dementia can become notably insecure as the condition progresses (Evans, 2006 as cited in Evans, 2008). The conversations which are changed due to diminished communicative ability take on unconscious qualities which can be compared to dreams or psychosis in their fluid, altered sense - the language of the unconscious. External and internal reality become confused. This is not unlike an infant who has not yet made the differentiation between self and the external world (Rayner, 1971/1997, p.260). It is however vital to keep in mind that dementia is not a return to childishness, no more than it is a simplistic progression to lack of awareness.

These types of defences can become most challenging when patients with dementia are in care facilities. In the case of Mrs Brown, her daughter was able to decipher her mother's experience and ease some of the anxiety by meeting it with patience and understating, and by knowing her mother as she had been. Even at that, the case details the times in which patience wains, and its effect. An example of this is when Mrs Brown enquires where the dishcloth should go, while pointing at a piece of rubbish. Her husband points to the bin in irritation. Later he finds the dishcloth folded neatly on top of the bin, realising the message that he missed. As lifelong defences break down like this and anxiety begins to take hold, patients require more than is necessarily available to them in larger care settings (Waddell, 2007, p.198).

Ageing as a final developmental task

Ageing is in itself considered to be a developmental task. O'Brien refers to dying as a final developmental task (2013, p.223). There is considerable enquiry into the age

of cognitive deterioration and the brain activity responsible for it (Christensen & Kumar, 2003, p.91). Sachdev acknowledges the ‘traditional’ signs and assumptions about ageing – greying hair, joint pain, and lapses in memory. These are of course typical assumptions about ageing which do not apply to everyone. However it is, he says, the ageing brain which creates the most concern (2003, pp.3-9). Pollock challenges this concept of ageing by making the point that one is ageing from the moment one is born, and that one of the requirements in this area of research is to challenge the assumptions and preconceptions about ageing (2006, p.54). Pollock’s research includes suggestions about the unconscious processes which can be ignited by the ageing process. If a person has experienced early vulnerabilities which are mirrored later in life, this may make them less able to experience them again. They may subsequently develop pathological responses to loss, or protections designed to deny loss. Although not all reactions later in life are linked with early experience, very often there is a link, and intervention, like for example therapeutic intervention, can be very beneficial in later life to help to process and integrate experience.

The phantasy that old age alone brings with it unknowns which shake ones internal world to the core and elicit reversal of learned behaviour, particularly when the person has dementia, can become seductive. It is important to acknowledge that these unknowns can be felt at any stage of life, particularly where there is an acute sense of loss. Frankl, in his poignant description about life in a German work camp during World War 2, describes the danger of losing a sense of meaning. This created what he called a ‘provisional existence.’ He suggests that this can be experienced by anyone in a situation which elicits an extreme sense of loss or change. Time becomes deformed, creating an ‘inner time’ rather than shared time with the world of others

and future goals. In the absence of a sense of the future, a person may revert to dwelling on the past. For a prisoner this loss of faith often led to giving up, and these prisoners did not survive for much longer once this took hold (Frankl, 1959/2004, pp.79-85). This sense of acute loss and disturbance of the inner world can therefore occur at any stage of life, in response to the situation which evokes it.

This idea about ageing as a developmental task, not simply as a physiological ending, is aligned with dementia research in many ways because dementia is most prevalent in later life. Waddell draws on Bion's observations about emotional and cognitive states and developmental disturbances in infancy which carry into adulthood, and suggests that the same applies to the mental states of old age. She calls this the predicament of the elderly, who must deal not only with developmental states of mind but also with the actual reality of organic impairment (Waddell, 2007, p.189). Rayner suggests that deterioration, depression, and persecutory anxiety can be underlying feelings in ageing, and makes the point that senility, as he calls it, further ignites this process. It is of course presumptuous to say that these are feelings experienced by all those who are ageing, and it is comforting that Rayner acknowledges that these are not universal, however are associated with this stage of life (Rayner, 1971/1997, pp.256-258).

Despite the inevitable linkages between ageing and dementia, it is important that the findings of ageing and dementia research do not become mutually exclusive. Early Onset Dementia for example occurs much earlier in the life cycle, and as Frankl's writing suggests, loss and acute impact to the internal world can also occur at any time. The unconscious processes which can arise however with age are important to

acknowledge when exploring dementia. This is in part because dementia is more common in later life so exploring this stage of life is part of exploring dementia, and in part because when one challenges assumptions about ageing, which writers like Pollock have done, it makes room to challenge assumptions about dementia. Much like George suggests, dementia is not just a loss of self, but a change in self, a stage of life, and a part of the person's overall experience (George, 2010, pp.256-257). No less than ageing is. Holding these two concepts in mind in this way creates another perspective through which to consider the person with dementia.

Summary

This chapter has explored the idea of subjective experience, a concept which suggests autonomy of experience. An examination of psychotherapeutic and psychoanalytic theories which relate to the self, present a perspective both of the uniqueness of a person, and also of the shared developmental frameworks which suggest a commonality of experience. The purpose of an exploration into the subjective experience of dementia is not to map the experience onto psychological developmental processes, nor is it to suggest that dementia is a linear return to childhood. What it does present however is a framework through which to examine the unconscious life, and suggests how these unconscious processes can impact the experience of dementia. Dementia can therefore be considered through a psychotherapeutic lens. Psychotherapy's interest in the self, the unconscious, and the responses of the psychic life means that it is well positioned to say something about dementia and the experience of the person with dementia. Ageing has also been explored in the same vein, because dementia often affects those in later life. The unconscious processes which can occur in the later life cycle alone can be explored

with a psychotherapeutic perspective in mind, and dementia is an experience which can compound this experience of ageing. That being said, it is important not to assume that ageing and dementia are rigidly linked. For one, dementia can arise at an earlier stage of life, and in addition the unconscious processes attached to ageing itself are not prescriptive. What this chapter has aimed to do is to present a sample of psychotherapeutic and psychoanalytic theory and its research into the dementia experience, and in so doing present the depth of experience for a person with dementia, and a framework through which to consider dementia. Chapter Three will examine the psychotherapeutic theories which have been explored in this chapter, and examine the place Psychotherapy can have in relation to dementia care. It will also consider some of the challenges within this type of research.

CHAPTER 3: PSYCHOTHERAPY'S PLACE IN DEMENTIA CARE

"Can I tell you about the day my brain left me?"
(Anna Darlington, 1994, p.92, as cited in Davenhill, 2007, p.287)

The research findings in Chapter Two suggest a number of connections between psychotherapeutic and psychoanalytic theories, and the experience of dementia. Given that these links exist, it is relevant to examine not just how Psychotherapy can present a perspective on dementia, but also what place Psychotherapy and Psychoanalysis could have in dementia care.

Clinical interest in the provision of Therapy to people with dementia has grown and continues to grow. However, this interest has yet to be matched by evidence of the most successful way to do this (Cheston & Jones, 2009, pp. 421-423). What has become evident however is that Psychotherapy has a place in the care of a person with dementia, at each stage of the condition. Evans (2008), for example, explores what Psychoanalysis might offer a person with dementia at each of these stages. In many ways, this is more inspiring than finding one way to meet dementia psychotherapeutically. This suggestion that there is more than one way for Psychotherapy to play a role in dementia care, is a mirroring of the argument made in Chapter Two that there is more than one way to view dementia itself. In consideration of Psychoanalysis' origins, the 'talking cure' comes to mind. This is a concept which arose from Freud's 'Anna O' case, where Anna O referred to the "talking cure," or "chimney sweeping" as she called it, as a means to access the unconscious and explore its links to psychosomatic symptoms (Freud, 1955/2001, p.30). This association suggests that Therapy or Analysis expects an ability to talk.

If however therapeutic and analytic methodologies have more levels than what is assumed by application of a traditional ‘talking therapy’ model, then this places Psychotherapy in a new position to potentially be part of the care model for a chronic illness like dementia, where language may no longer be accessible. In relation to the public as a whole, current research is beginning to examine the way in which mental health and chronic illness is perceived and valued by society. Kleinman’s (2009) paper on ‘Global mental health: a failure of humanity,’ for example, takes dementia into a global context, examining it in relation to the public sphere. He suggests that ‘ground zero’ is not the 15% which mental health takes up in global health statistics, not is it the less than 2% of expenditure estimated to go towards psychiatric services in Africa, Latin America, or South East Asia, compared with 10% in America. ‘Ground zero’ is the routine treatment of people with mental health conditions, in which he includes dementia, in communities and society. Global health, Kleinman states, is fundamentally moral and this is the aspect missing from current global health measures (2009, p. 603). Incidentally, in Ireland, the Mental Health Reform’s 2017 pre-budget submission requested 37.5m additional spending for mental health supports (Mental Health Reform, 2017). Minister of State McEntee stated that the 2017 budget had provided for additional spending of 35m for enhanced services, including mental health and services for older people (Dail Eireann Debate: Mental Health Services Funding, 2016), however the 2017 budget actually allocated only 15 million additional spending. This amounts to only a 1.8pc increase in funding for mental health, compared to the 2016 Budget (O’Regan, Irish Independent, 2016). These statistical analyses show that mental health is still struggling to be valued in the global conversation, even before a conversation about Psychotherapy’s place in dementia care is included. A detailed exploration of both mental health and

Psychotherapy's place within the public sphere in relation to dementia is not within the remit of this thesis, however it is important to include this question in a chapter which explores the place of Psychotherapy in dementia care and chronic illness. This identifies the potential for further research to be conducted into this area.

For the purpose of this thesis however and this chapter, the place of Psychotherapy will be explored in relation to the ways in which it can be supportive for a person with dementia, based on evidence that there are linkages between the unconscious life of dementia and psychotherapeutic and psychoanalytic theory.

Support at each stage of dementia

As dementia progresses it is understood in early, intermediary, and late stages. In early stage dementia, changes happen gradually (Balfour, 2007, pp. 225-226). Anxiety is common following diagnosis as the reality of the diagnosis is realised. As the condition progresses, the person's relation to their internal ways of being and to external objects is disturbed. The threat of confusion, loss, or abandonment can arise. The ego, which at this early stage is still aware, can feel under attack and threatened by the loss of connection. Balfour observes that the beginning of Alzheimer's is insidious, often not recognised until it has progressed. It is not unusual that some of the subsequent and progressive depletion of awareness can be a form of denial of what is happening and what is to come. A patient of Balfour disassociated from his present state of forgetting, but could recall how it felt to be prodded and poked at as a child when he had a problem with his ear. His earlier state of disturbance was mirroring his current experience, and in many ways was easier to

be with (Balfour, 2007, pp. 230-231). Evans describes a weakening of the ego, and a loss of connection to the self as dementia progresses. Anxiety may lessen while pleasure and instinct may take over. Bodily and communicative functions also begin to deteriorate. In late stage dementia, progressive physical deterioration along with loss of higher cognitive function can mean a return to absolute dependency (Evans, 2008).

Psychotherapy can support someone at the early stages of the condition when cognition is still strong, by drawing attention to coping mechanisms and in this way developing more effective ways to cope. A diagnosis of dementia is likely to trigger some form of defence for the person to cope. There is evidence that suggests the more open a person is to the experience, the less aggressive the development of dementia symptoms may be (Kitwood, 1997, pp.16-17). Evans (2006) suggests that Psychoanalysis may have a place in supporting someone with early stage Alzheimer's to explore unresolved early conflicts (Evans, 2008). The central premise is that the patient's task is to cope successfully with the experience, which includes loss of self and object relationships, by using the treatment relationship as a transitional phenomenon in the provision of, if nothing else, comfort. This ultimately helps the patient to retain a sense of relatedness even in the presence of forgetting and deterioration of relationships (LoboPrabhu et al, 2007, p.150).

Although there is growing evidence to suggest that early psychotherapeutic intervention is very useful for those with dementia (Cheston, 1998, Husband, 2000, as cited in Davenhill, 2007, p.209), there are limitations to how useful this approach can be, as dementia begins to take over and takes with it the patient's ability to

communicate and interject. It is here where it is thought that the Psychoanalytic approach can continue to support the patient (Davenhill, 2007, p.209). Although Freud's 'talking cure' (Freud, 1955/2001) may imply the opposite, what Freud's work suggests is not the story of overcoming a sequence of obstacles, but rather the realisation that there are obstacles to be overcome (Strachey, 2001, p.xvi). This makes the exploration more important than the cure. Evans draws on an example from Solms (1995) work, an Analyst who worked with stroke victims. Psychoanalysis found a way to help these patients to mourn the loss of something which they were not aware they had lost, yet they were aware of a sense of loss. This is reminiscent of Freud's 'Mourning and Melancholia' paper which talks in detail about the loss of one's inner object, often more detrimental than the loss of one's actual love object. It ignites a loss of a sense of wellbeing, perpetuating a sense of loss without knowing its source (Fiorini, Bokanowski & Lewkowicz, 2007/2009, p.38). Evans likens Solms's work to Alzheimer's patients. The amnesia in Alzheimer's is retrograde, so early childhood memories become prominent, as the hold on recent memory lessens. The easing of these conflicts may also ease the patient's state of mind for the later stages of the condition, making the process somewhat less disturbing (Evans, 2008).

Evans's research suggests dementia care is on the whole still impoverished in terms of emotional connection and stimulus (Age concern, 2007, as cited in Evans, 2008). That being said, there are examples where practitioners are recognising this need. As previously mentioned, David Sheard developed the Butterfly Care Home for people with dementia in response to a realisation that dementia care needed to be changed. This culture of 'them' and 'us' has been replaced by a model of care that sees

patients as family, not residents. It uses a detached management style with people working and living together, sharing food and histories, and supporting patients to remember who they were. The focus is on connection. If thinking has been interrupted, then feeling must take president, and the emotional intelligence⁴ model is used to provide emotional care. Sheard's data shows that in these care facilities, the use of neuroleptic drugs was reduced from seventy occasions to one, in a six month period. He concludes that *knowing* you matter is the key to being alive, and *seeing* you matter is at the centre of carrying on (Sheard, 2015, p.44).

Rodriquez's observational study explores the capacity for emotional care within a nursing home. He found that the presence of emotion created awareness of dignity in staff, and engagement in residents (Rodriquez, 2011). Cohen (1991) also observes the need for dignity in dementia care. This is a theme within dementia literature. Rodriquez (2011) concludes that dignity might be the key to managing the effects of dementia. The person is still there, always there, and dignity if held in mind can conquer the projections, the challenges, and the confusion that these changes bring forth.

Challenges in this area of research

One of the major challenges in presenting Therapy and dementia together is that dementia is viewed as a disease. The American Alzheimer's Association (alz.org), describes dementia as a disease, using the medical language of 'diagnosis,'

⁴ Emotional Intelligence as defined by Daniel Goleman is the way in which neurological givens can play out in basic living. It is a way of being able to rein in emotional impulse, not through repression, but rather by learning to read one's innermost feelings. In other words, developing a level of self-awareness and attunement to one's inner world, which in turn facilitates easier engagement in relationships (Goleman, 1996, p. xiii).

‘symptoms,’ treatments,’ and ‘risk and prevention.’ (Alzheimer’s Association (alz.org), 2017). This association with disease places it closer to the medical model than the psychotherapeutic or psychoanalytic models. In studies such as Linden’s which examine side effects of therapy, illness by deterioration is not included in the sample, as it is not deemed suitable for observation (2013, p.287). This is an example of research which excludes rather than supports the idea that Therapy can be part of the life of a person with dementia.

Another challenge in this area is that despite the relevance of this type of research and the evidence that psychotherapeutic techniques can support someone with dementia, the number of high quality studies into it are small (Douglas, James & Ballard, 2004, p. 177). Hess also suggests that the number of clinical studies and examples in this work is small compared to other studies (2008, p.282). This places this body of research at a disadvantage, particularly if attempting to place Psychotherapy into the public sphere as a strong candidate for dementia care.

The other question which arises from an exploration into psychotherapeutic dementia care is one which Jones asks; What constitutes benefit, and is limiting anxiety and enhancing the quality of life somehow enough? He suggests that perhaps it is not enough, and examining the effects of patient fit environments, for example, is more important (Jones, 1995, p.606). Similarly, research which focuses on the ageing population as a strain on services stands out in jarring contrast to studies promoting therapeutic intervention. Ducharme’s study into this area, entitled “Preparing for the Geriatric Tsunami,” certainly doesn’t evoke a sense of compassion or acceptance of old age, but rather objectifies the older population. His focus however on the demand

that increased life span will place on emergency services and multi-disciplinary geriatric capabilities to manage complex non-medical problems, is a realistic one (Ducharme, 2017, p.273). In this medical model, therapeutic support will be ever more important for the person with dementia, and other illnesses, and will potentially become part of the societal recreation Ducharme suggests is needed to support an ageing population (2017, p.276).

In contrast, studies like that conducted by Apóstolo, Cardoso, Rosa & Paúl (2014) into the benefits of cognitive stimulation on the elderly in nursing homes support the argument about the importance of individualised treatment in later life, and may serve to stimulate the examination into the treatment of dementia. Shatsky's (2013) study on the other hand, suggests something else entirely, as he highlights the importance of thinking outside the therapeutic frame rather than abandoning attempts if the case is outside the usual frame (Ganzer, 2013). This proposition is one which invites consideration of collaborative care for dementia, where it is not therapy alone but therapy in conjunction with other supports which may be required. Integrated models of care and integrated care pathways feature in the Health Service Executive's (HSE) plans for the prevention and management of chronic illness (Heath Service Executive (HSE), 2017), so this is perhaps the most beneficial way in which to approach care, in the hope that Psychotherapy will be part of the model. However, Jones's (1995) question about what actually constitutes benefit is one which is yet unanswered, and is evidence of the fact that the biggest challenge, and also opportunity, is continued research into how and why Psychotherapy and Psychoanalysis can take this position. Evans (2008) makes the point that embarking on a psychoanalytically informed dementia service could have many educational and

resource implications, in particular for health and social services. If the language of a psychoanalytically-informed practice could become part of the services which are in place to treat dementia, it stands a chance of filtering through all layers of service, encouraging a more thoughtful and compassionate practice (Evans, 2008).

Summary

This chapter has explored Psychotherapy's place in relation to dementia care, an exploration which is necessary to include in a thesis which has explored the ways in which the unconscious language of Psychotherapy and Psychoanalysis speaks to the unconscious life of dementia. Psychotherapy is in a position not only to offer a perspective on dementia, but also to become part of the model of care for people with dementia. Although it is not within the remit of this thesis to fully explore Psychotherapy's place in the public sphere, this enquiry emerges from this type of research, and has been noted as an area for further research. Some global statistics on mental health have been provided to support this. Other opportunities for research have been identified, in particular those relating to integrated models of care. It has also presented a sample of research papers comparing and contrasting Psychotherapy's value in dementia care, concluding that there is value in beginning to include the language of Psychotherapy into dementia care settings.

CONCLUSION

This thesis has explored the subjective experience of dementia, and in so doing has argued that firstly there is an experience, and secondly that it is subjective, meaning it is unique to each person. Ultimately, there is dementia and its effects, and then there is the subjective experience of dementia for that person. It has suggested that this subjective experience is linked to unconscious processes which play a very real part in a person's response to dementia. These processes can be likened to those which have always played a part in the person's subjective experience, linked to the developmental and unconscious life which Psychotherapy and Psychoanalysis have much to say about. Theories relating to attachment, formation of self, defence mechanisms, and integrated ways of being are those which can be applied to the experience of dementia as a means to better understand the experience. Research into dementia in this way is not intended to compare the experience of dementia with the experience of infancy, nor is it to suggest that dementia is a return to childishness. Rather, it presents a model which can explore the unconscious life. Given that there has been much research to show that this unconscious life plays a part in the experience of dementia, it is an important part of dementia research.

This raises the subsequent question of whether or not Psychotherapy and Psychoanalysis can become a valued part of dementia care. The medical model which is attached to the care of 'disease,' coupled with challenges within the public sphere in relation to care services, presents a challenge to this proposal. This is certainly an area for further research, to begin to consider Psychotherapy and Psychoanalysis as components in the care of dementia and other chronic illnesses.

However, although a natural consideration born from this research topic, it was not the main aim of this thesis.

The aim of this thesis was to present the argument and evidence to support the suggestion that there is a subjective experience for people with dementia, and that Psychotherapy and Psychoanalysis are well positioned to suggest what this experience might be, and furthermore to suggest that this experience must be considered. In so doing, the experience of the person with dementia can be better understood, and therefore better supported. Challenging current perceptions of dementia and the discourse attached to these perceptions is critical to this exploration, as is challenging accepted values in society, such as the importance of memory.

If dementia can be considered as another stage of life, and something which encompasses as much hope as it does despair and anxiety, then it becomes something other than a diagnosis of fear and dread. Ultimately however, the experience of dementia is complex, and this exploration has not attempted to simplify it or disregard the acute loss and anxiety of dementia. What it has attempted to do is challenge assumptions about the experience of dementia, and in so doing introduce room perhaps for both the positive and negative aspects of experience to exist. Through the discourse of Psychotherapy and Psychoanalysis, this possibility can be accessed.

There is more to be considered about how dementia is perceived in society. The application of language, and assumptions about the importance of memory, and

about identity, are just some of the values which have been challenged in this thesis. Kitwood's work is well renowned for placing a focus on person-centred care, but the evolution must continue, towards a better understanding of who we are caring for and how we understand dementia and its effects. Yes, the white coats and sterile environments do not work; Yes, person-centred care does work; But what else? Psychotherapy is well placed to impact this evolution. It has a role to play in saying something about dementia.

In addition to considering Psychotherapy and Psychoanalysis as components of dementia care, and their place in the public sphere, other options for further research which have been identified include conducting a field based research project, like an observational study or clinical trial, which can measure changes over time, and observe and evaluate the unconscious processes which impact dementia. The question inherent in an exploration of subjectivity in dementia is the question; what is the self, and does the self exist without cognitive function? There is opportunity also for further research into this question.

Despite the body of research presented in this thesis about self and subjectivity, this question is yet unanswered. However, the more challenging question arising from this exploration of self is perhaps whether it actually matters where the self is, and pinpointing what happens to it when a person has dementia. Evidence that there is an inherent human need for cohesion, suggests that this desire to locate aspects of self affected by dementia, might be a symptom of this need to make sense of things, and of the anxiety and fear which current perceptions of dementia evoke. This thesis suggests that perhaps what matters more is simply that a person's experience is

considered during all stages of life. Kessel, Cole, and Johnson propose that this analogy "where is the self?" be taken seriously. However, they also suggest that self is still only crudely defined. In the face of growing brain research which seeks to localise functionality and purpose, they ask whether or not it will be acceptable to one day propose, "That cell there, right in the middle of hippocampus (or wherever) - that's the self!" (as cited in Dennett, 1992). This reflects in many ways the expanse that a search for 'self' would entail, when the more pressing need is instilling an appreciation of the subjective experience in dementia.

As the vignettes from Judy (2014), Barry (2014), and Olive (2014) demonstrate, subjectivity by its nature is unique to each person's experience. Clinical understandings about dementia offer some framework through which to consider it, but ultimately one *is* and continues to *be* until one dies, and is oneself. Dementia is not an invasion that eliminates the person, but rather is a condition which changes one's experience. It is very possible therefore to suggest that human-ness, humanity, is stronger than disease, and that no matter what the change to the inner world, one's subjective experience should never be overlooked. With many aspects of this exploration still unanswered, and some aspects unanswerable, what this research has aimed to do, albeit through the foggy pane of objectivity, is to convey the message that there is a subjective experience for the person with dementia, and it belongs to the enduring self, who is and always should remain the most valuable component of all.

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Appendix 1

The sky has darkened, and the room with it; the window is struck as though by tiny pellets and water slides down it in bands...And then the rain stops. Gradually, the room is filled with light; the bare criss-crossing branches of the tree are hung with drops and as the sun comes out it catches the drops and they flash with colour – blue, yellow, green, pink. The branches are black against a golden orange sky, black and brilliant. Claudia gazes at this, it is as though the spectacle has been laid on for her pleasure and she is filled with elation, a surge of joy, of well-being, of wonder.

The sun sinks and the glittering tree is extinguished. The room darkens again. Presently it is quite dim; the window violet now, showing the black tracery of branches and a line of houses packed with square light. And within the room change has taken place. It is empty. Void. It has the stillness of a place in which there are only inanimate objects: metal, wood, glass, plastic. No life. Something creaks; the involuntary sound of expansion or contraction. Beyond the window a car starts up, an aeroplane passes overhead. The world moves on. And beside the bed the radio gives the time signal and a voice starts to read the six o'clock news”

(Lively, 1987, p.208 as cited in Ferguson, 2014).⁵

⁵ Complete poem by Lively, 1987, as cited on p.10

Appendix 2

The Road Not Taken – by Robert Frost

Two roads diverged in a yellow wood,
And sorry I could not travel both
And be one traveller, long I stood
And looked down one as far as I could
To where it bent in the undergrowth;

Then took the other, as just as fair,
And having perhaps the better claim,
Because it was grassy and wanted wear;
Though as for that the passing there
Had worn them really about the same,

And both that morning equally lay
In leaves no step had trodden black.
Oh, I kept the first for another day!
Yet knowing how way leads on to way,
I doubted if I should ever come back.

I shall be telling this with a sigh
Somewhere ages and ages hence:
Two roads diverged in a wood, and I—
I took the one less travelled by,
And that has made all the difference.⁶

(As cited in MacMonagle, 2003, p.94)

⁶ This poem by Robert Frost, although a metaphor for making an important life decision, is intended here to represent the idea of who one was, and who one is now – losing and finding oneself amidst the chaos and memory loss of dementia, either through relationship, memory boxes, music, or someone's presence. It holds something of the sense of the split of dementia, and the possibilities of both despair and hope, which have been discussed in this thesis.