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Dementia: An exploration of the effectiveness and value of support groups

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Abstract

This study considers the problem of dementia from the perspective of the person with dementia. Treatment and attitudes to the disease have changed considerably in recent years but to what extent are interventions meeting the needs of the person with dementia? The person of the person with dementia is increasingly considered in the treatment of the disease as well as growing consideration of how attachment style and attachment behaviours feature in the experience of a person with dementia.

The aim of this study was to follow twenty six participants and their carers over a series of four occurrences of consecutive psychosocial group interventions with the aim of identifying changes in peoples' perception of their quality of life as well as investigating whether a person's attachment style affects their perception of the helpfulness of a psychosocial group intervention.

Participants were visited in their homes on a pre and post basis. Attachment style was calculated, using a revised form of the Adult Attachment Interview questions in a semi-structured interview setting. Observations were made of relational interactions during the home visits as well as engagement and involvement with others in the group setting. A quality of life measure (DEMQoL) was used to measure changes in peoples' experience of their quality of life before and after the group intervention. Results were analysed using mixed methodology within a case-study approach, which was informed by thematic analysis of the complete data set, out of which arose three main themes: the person's relationship with their carer, the group experience and childhood experiences. The AAI questions were scored using Gricean principles to establish attachment style and identify associations between attachment style and perceived helpfulness of a psychosocial group intervention. Findings suggest a significant difference in the pre and post group scores on the quality of life measure. There was no significant difference for the perceived helpfulness of the group. The most significant finding was the importance of the relationship the person with dementia has with their principal carer. Verbatim notes provide examples of relational exchanges and suggest an association between attachment style and quality of relationship.

Chapter 1: Introduction

"Last night the problem facing us really hit me when Margaret forgot how to turn off the television". Anonymous

Dementia is a problem. It is a problem for those who are diagnosed with one of its forms. It is a problem for the families and carers and it is a problem for society (Smith, Atkin, Cutler, 2016). The purpose of this study was to determine to what extent the current provision of a psychosocial group intervention, provided within one NHS Trust, met the needs of people with dementia who participated in this study. The researcher deemed this an important area to investigate so as to inform the appropriateness of interventions offered to people with dementia and their effectiveness in enabling them, and their families, to live well with their diagnosis. Interventions that can address these issues could alleviate considerable suffering and anguish (Waldemar *et al.* 2007) as well as reduce the cost of care, both financial and emotional. (Nice 2013). This chapter provides a brief overview of the background to the problem of dementia; considers recent research and developments in psychosocial approaches; the theoretical approaches that informed this thesis; ethical considerations; methodology; selection process; outcome measures; data collection and analysis.

1. Context

The background for this study is one of the major health concerns for the elderly, namely the Dementias a group of conditions defined as: "The progressive loss of intellectual functions (such as thinking, remembering, and reasoning) of sufficient severity to interfere with a person's daily functioning" (Alzheimer's Disease Care Manual, 2013). Dementia is not a disease itself but rather a group of symptoms that may accompany certain diseases or conditions that have in common a progressive reduction in cognitive functioning that cannot be accounted for by ageing (Brandon and Stern, 2012). The most prevalent form of dementia is Alzheimer's Disease and this is the form that is often referred to by the media and in general. Symptoms may include changes in personality, mood and behaviour. Dementia is irreversible when caused by disease or injury but may be reversible when caused by drugs, depression, hormone or vitamin imbalances (Alzheimer's Association, 2007).

Currently, the estimated figure of people who will be diagnosed with dementia in the UK is 800,000 to 1,000,000 by 2050 (Alzheimer's Society, 2012). This research claims that these figures are set to rise in the future, however, this is disputed by a study led by Cambridge University for the Medical Research Council (2013) that reports a drop in incidence over the past twenty years and highlights issues with research into dementia projections. However, the trend since the introduction of more effective pharmaceutic treatments in the latter part of the twentieth century has seen an increase in people diagnosed with dementia. Coupled with the introduction of memory clinics and the implementation of the dementia strategy in 2009 it could be argued that some of the recent increase in diagnosis can be linked to greater awareness of dementia and the government's strategy in actively promoting early diagnosis (Llife and Wilcock, 2017). Prevalence is related to the age of the population and in an ageing population, it is expected that the prevalence will rise (Fineberg *et al*. 2013). Although there are some encouraging findings in recent research dementia remains a significant health risk to the elderly and it is a particularly distressing condition, both to people with dementia and their families as well as the implications for healthcare resources. For these reasons it has also become a topic of interest to a wider audience, as is defined in the next section.

Dementia has become topical and is referred to regularly in the media either in terms of its prevalence, financial and social costs, as well as exposition of numerous treatment possibilities. For a disease that had been virtually ignored up until the last thirty years or so, this interest is a complete turn-around (Innes and Manthorpe, 2012). Why might this be? The answer could be related to the demographics. Dementia is a disease of the elderly and in the UK the 85-years-plus segment of the population is the fastest growing (Brooks, 2013). However, it is also the case that some elderly people are retaining their health well into older age. Socio-economic differences between groups of elderly people, along with their subsequent life-style differences, provide clues as to why more people in this age group can be healthy for longer, since the healthier segment are more likely to represent a higher socio-economic group (Ageing: the silver lining, 2015). In addressing these issues, the Department of Health has issued the National Service Framework for Older People (2001), which emphasises promoting health for as long as possible.

In this context, the UK Government tasked a range of experts and interested parties to define the way forward in developing a treatment/management plan for dementia, which resulted in a number of publications from the Department of Health (2009; 2012; 2013a). The National Strategy is focused on early identification and diagnosis as there is some evidence to suggest that the earlier dementia is detected and treated, the more likely it is that a person's cognitive and social functioning can be maintained at a level that enables them to cope with the tasks of daily living for longer (Chapman *et al.*, 2006).

As a result of the focus on early diagnosis, treatment and the formulation of a management plan, there has been a proliferation of Memory Clinics in the UK, which are multi-disciplinary, diagnostic settings, whose remit it is to provide a diagnosis, treatment, management and advice (Coyle, 2007). NICE (2013) also recommend early interventions in the form of medication, where appropriate, and memory support groups for people with dementia and their families. These developments herald a long overdue determination in developing effective ways of managing dementia. The overall aim of early diagnosis, treatment and management is that people are enabled to live well with dementia for as long as possible (Ready, 2002, Burns & Buckman, 2013).

In conjunction with early diagnosis, treatment and management, there is a policy for people with dementia to remain in the community and be cared for by family and/or care workers. Concurrently, there has been increased interest in the quality of life of people with early symptoms of dementia. For example, a study by Lodgson *et al*. (2002) claimed that as well as focusing on outcome measures following an intervention, people with dementia, their families and their clinicians seek evaluations that not only measure whether an intervention has improved cognitive functioning, but also whether there has been an improvement in a person's quality of life. As Lodgson *et al*., (2002) state, the fact that a person has a diagnosis of dementia, even during the later stages of the disease, should not be considered a reason for hopelessness; a person's quality of life should be maintained throughout the disease process.

As well as a greater focus on the quality of life of those suffering from dementia there is an increased understanding amongst clinicians of the disease process and recognition of the impact that an early diagnosis can have, particularly for some people, on the progress of the disease. There has been a contemporaneous development of pharmacological interventions that claim to delay the disease process. It is held that early diagnosis and treatment with modern drugs such as acetylcholinesterase (AChE) inhibitors (e.g. Aricept

(Donepezil hydrochloride), Exelon (rivastigmine) and Reminyl (galantamine), may enable people to cope with the tasks of daily living better for longer by maintaining cognitive functioning (NICE, 2011). This appraisal also recommends Memantine for people with moderate dementias for whom AChE inhibitors are not suitable. However, these drugs are not effective for all forms of dementia, for example for those experiencing Vascular Dementia there is no drug treatment. Co-morbidity of depression and dementia is not uncommon and can present difficulties in determining a definitive diagnosis. It has been found that depression in older people has resulted in decreased cognitive performance. Therefore, advances in pharmacological and non-pharmacological interventions for depression have also beneficially influenced the treatment of people presenting with symptoms of cognitive impairment (Katona, Hunter and Bray, 1998, Rabheru, 2004).

Having considered developments in dementia and how it is portrayed, treated and understood in terms of biological and neurological factors, the next section considers developments in psychosocial approaches to the management of dementia.

2. Psychosocial Developments

Whilst recognising that there has been a preponderance of research focusing on people with dementia who are more severely affected and living in care homes, as well as the effects on caregivers, this study aimed to consider the experience of people deemed to be in the early stages of the disease, living at home, being principally cared for by family members. One of the recommendations from NICE (2013), following on from early diagnosis, is that non pharmaceutical interventions, for people with all types of mild to moderate dementia, offer good quality psychosocial support. The form this is most likely to take is that of a structured group involving people with dementia and their family members and/or their carers, with the aim of supporting them through the process of assimilating the implications of a diagnosis of dementia as without adequate support, a diagnosis can be detrimental emotionally and physiologically. (British Psychiatric Society (BPS), 2014). This report also raises concerns that due to time limits and restricted resources, it is not possible to tailor psychosocial support to individuals and their families. The focus of this study is to understand the experiences of people with dementia who participated in a series of psychosocial groups and how helpful they were found to be by the participants. As outlined above, dementia is a serious health and social problem and the challenge is to gain a greater understanding of how psychosocial factors might influence the experience of those living with the disease.

Psychosocial research into dementia has proliferated over the previous five decades and has spanned a raft of perspectives, broadly the principle areas addressed in these studies included: education; information giving; social, environmental, emotional, occupational and cognitive factors.

There has been considerable research activity into the efficacy of a variety of psychosocial forms of treatment in enhancing the cognitive and emotional functioning of people with dementia (Bender and Cheston, 1997; Pusey and Richards, 2001). A further area of interest in considering the treatment of those with dementia is determining the specific care that is most appropriate in relation to an individual's level of cognitive and emotional functioning (Beck, 1998; Sheard, 2004). This is a particularly pertinent area when considering the family and their ability to support a family member with dementia in the community (McNaughton, *et al*., 1995). It is often the case that care within the family and the community breaks down because the relative, who is often the person with dementia’s elderly spouse, finds they are no longer able to cope, either due to lack of support, a limited understanding of dementia and its consequences, or an inadequate or inappropriate care package. It is vital that relatives are supported in their role as families bear the biggest burden for the care of people with dementia and it is estimated that they save the NHS approximately seven billion pounds a year (Alzheimer’s Society, 2007).

Research into the psychosocial aspects of the experience of dementia has provided evidence to suggest that people with dementia who experience regular social interaction are less likely to deteriorate as rapidly as those whose social interactions are minimal (Gurka and Marksteiner, 2002). The author now considers an aspect of social intervention that is purported to have an important bearing on enhancing support, namely attachment style (Miesen.1997). His research claims that considering attachment style enhances the understanding of the experience of the person with dementia within their support structure (Miesen, 1997).

Bowlby's (1953; 1969; 1973; 1980) theory of attachment has been adopted and developed by other researchers who uphold his contention that attachment styles developed in infancy and childhood, influence relationships across the lifespan. This concept has been applied specifically to dementia, principally through the work of Miesen (1993).

Previous research has not yet considered what works for whom in terms of examining how a person’s attachment style might influence their perception of the usefulness of particular interventions. Miesen's work is the most significant in this area, but it has not been incorporated in any depth, into an understanding of how, by taking a person's attachment style into account, the person with dementia’s experience of a group intervention might be affected, or which specific interventions might be helpful. (Olazaran *et al.*, 2010) focus on efficacy, which may be useful in a broad sense but does not add much information about which particular aspects are found to be useful and to whom. Currently, NICE (2006, 2013) stipulate that a psychosocial group intervention be offered to people who have recently been diagnosed with dementia – "a one size fits all" approach. Having introduced the concept of attachment into the discussion of psychosocial groups, the author now considers the theory underpinning the rationale for this study.

3. Theoretical Influences

The theory that informed this study was borne out of a review of the biomedical approach, leading to a consideration of the more holistic, bio-psychosocial model of the understanding and management of dementia. The principle focus of this study is on the development of this model and its application, as well as a consideration of attachment theory and its significance in the understanding of and treatment/management of the experience of dementia. The author begins by identifying the three principal theorists that have influenced the theoretical approach this study has adopted.

The work of Kitwood (1989, 1993, 1994,1997a), Miesen (1992,1993,1999) and Cheston (1996.1997,1999, 2002,2003,2014) will be discussed in detail as their research has effectively dominated the understanding and management of dementia in the UK over the last forty years. The significance of Kitwood's (1989,1993,1994,1997a) work cannot be over emphasised, specifically in relation to challenging the standard paradigm. His work shifted the emphasis from a disease process that offered no hope to people with dementia and limited coping strategies available to families and carers, to a more hopeful picture, focusing on the lived experience of the person with dementia. This move away from the predominant focus of the disease process led to a consideration of proactive strategies for living well with dementia. This thesis follows Kitwood's example and focuses primarily on the experience of the person living with dementia, or as he phrases it "the person who is missing" (Kitwood, 1997, cited in Baldwin and Capstick, 2007, pp 59).

Miesen has described dementia as activating the attachment system and attachment behaviour, describing dementia as a “strange situation” (Miesen, 2004) and has developed a compelling model of dementia based on the subjective experience of the person with dementia, focusing in particular, on loss. The disease potentially carries a threat of substantial traumatic loss leading to grief, depression, anxiety, despair and terror. Despair or terror is associated with the destruction of the self, a sense of emptiness and absence. A lack of empathy and avoidance by others can exacerbate this experience, which, Miesen argues, contributes to diminishing cognitive ability and organic change. Not only does Miesen demonstrate a useful way of understanding dementia, but he also has clear ideas about how, by understanding the meaning of attachment behaviours, the management of people with dementia can be adjusted to avoid a “socially malignant environment” (Miesen, 1997).

Cheston (1997) also takes the view that dementia cannot be understood simply in terms of the medical model. He focuses on the person with dementia, not simply their diseased brain; their emotions and understandings, not simply memory losses; the person in the context of a marriage or a family or both, within a wider society and its values. Cheston and Bender (2003) claim that in attempting to understand the distress of the person with dementia it is necessary to consider the biography of that person, their present relationships and their concerns and worries. Levy and Langer (1994) comment on the effects that a person's emotional state can have on their cognitive ability. Cheston (1996) describes a way of understanding dementia in terms of a model of the mind, using the word “mind” as opposed to “brain” whereby dementia is not defined in terms of memory loss but as difficulty in thinking and responding, which is exacerbated by heightened levels of anxiety. The model is described as “a meaning and safety system”: the four stages of this system are explored and will be reviewed in detail.

The influence of those who have considered the significance of attachment style and attachment behaviours has led to the consideration of the role of attachment style in this study. The contention is that by understanding how a person with dementia's attachment style influences their support structure and, as a consequence, how they experience the disease, suitable interventions can be developed to mitigate the more isolating aspects of the disease. Having considered the theoretical rationale for this study, the next section considers the ethical issues of undertaking research on people with dementia.

4. Ethical considerations

Research undertaken with people with dementia is fraught with ethical and methodological difficulties not least of which is informed consent. It was necessary to ensure that potential participants were able to give informed consent in line with the Mental Capacity Act (2005). In obtaining written consent from all participants the following considerations were addressed. That consent as defined by The Mental Capacity Act (2005) as: an ability to make everyday decisions that affect them in their day-to-day lives, some of which could have long term consequences, which was the benchmark for considering whether a person could or could not give consent to participating in this study. Petri (2010), cited in Ethics in Dementia Research (2011) defined a number of components of informed consent. Whilst recognising that capacity can fluctuate it is also necessary to recognise the significance of a person's competence in that they are either competent or incompetent to make a decision about participating in research. The above highlights some of the complexity in the ethical considerations in obtaining informed consent from people with a diagnosis of dementia and informed the consent process in this study.

Confidentiality was considered and discussed with participants and their families, as was their right to withdraw from the research without jeopardising their treatment. As the population of this study represented a vulnerable group, it was the researcher's responsibility to ensure that no harm would be done to the participants and that the research would not involve any practice known to cause harm. NHS ethical approval was granted through Integrated Research Application System (IRAS).

5. Methodology

The methodology adopted in this research was a case study method of enquiry, consisting of four separate groups of participants each experiencing four sessions of a psychosocial group, which were studied as four separate 'cases'. The term case study has been defined as "an enquiry that investigates a contemporary phenomenon in-depth and within its real-life context; and copes with a strictly distinctive situation in which there will be many more variables of interest than data points" (Yin, 2009, p. 18). As such, in collecting data from a psychosocial intervention, there was more interactive activity than that which was being observed.

6. Selection process

Currently in the UK, most people who are given a diagnosis of dementia are offered the opportunity to join a psychosocial group as part of their standard treatment following a diagnostic assessment at a Memory Clinic. Subjects, in this study, were selected on the basis of being offered a place in a group and being capable of giving informed consent. The researcher contacted potential participants and their families to explain what was being asked of them in participating in the study and to gain consent. The researcher met with the Memory Clinic staff and the facilitators of the intervention groups to explain the objectives of the research and to outline the process of the study.

Those who agreed to take part in the study were visited once in their homes, and then again once more prior to the group interventions, when the pre-group measures were administered. The groups were conducted in a venue provided by the Kent and Medway NHS and Social Care PartnershipTrust. The researcher was not a participant in the groups her role was to observe the intervention groups and score participants' (people with dementia) engagement and involvement in the group process following each of the four sessions.

7. Outcome measures and data collection

The primary outcome measures were the perceived helpfulness of the intervention groups, as measured using the Perceived Helpfulness Questionnaire (devised by author). This rated the measures across the areas of emotions, environment, occupation, education and social. The DEMQoL (2013) questionnaire was administered as a pre and post measure. At each of the group sessions, the researcher rated the level of engagement and involvement of the people with dementia in the intervention groups. People were visited in their homes on three occasions; to explain the process of the research and their involvement as a participant and to obtain informed consent, to administer the pre-group measures and the semi-structured interviews and to run the post-intervention tests. On each of these occasions, the researcher made field notes, guided by a pre-determined set of questions, and observations made during the visits, including the researcher's own reactions and responses. Semi-structured interviews, using a measure of attachment type, based on the Adult Attachment Interview (Main, 1991) took place prior to the group intervention. The process of analysis is outlined below.

8. Analysis

Analysis focused on addressing the research questions:

1. Are group interventions observed in this study perceived as helpful?
2. How does a group experience impact on a person's quality of life?
3. Does attachment style play a role in how participants experience the group?
4. Is there any association between attachment style, experience of the group and quality of life ratings?

The data from the Perceived Helpfulness questionnaire and the responses to the question "D*id you find the group helpful" question?* were analysed in response to question 1. The DEMQoL questionnaire data addressed question 2. Responses from the AAI questions were analysed in response to question 3. For the final question the data from all sources were combined in a thematic analysis. A case-study approach was adopted to address each of the four 'cases' with respect to the questions above. Interrelationships within the data and between ‘cases’ were explored to inform the process of theory building. Before moving on to give more extensive details of the methodology, this next section highlights relevant and current literature studies that have informed the basis of this thesis.

Chapter 2: Literature Review

“A demented man has lost the good he used to enjoy; he is a wealthy man turned poor”.

Pinel (1779)

1. Introduction

An extensive review of the literature that encompasses all of the theoretical approaches and ideas in the field of dementia is beyond the scope of this thesis, however a number of disciplines contributing to research and practice in the dementias will be considered. Specifically, this review will focus on a brief overview of the historical development of the understanding and treatment of dementia, the medical approach and its limitations, in particular the lack of attention given to the subjective experience of the person with dementia. Psychosocial approaches, which put the person’s experience at the centre, will be discussed in more detail, as well as a consideration of the significance of Attachment Theory literature and the impact of the quality of close relationships on the experience of the person with dementia. The experience of dementia can affect a person’s quality of life considerably, which will also be considered in this chapter.

In the majority of medically and clinically related research on Alzheimer’s disease, the afflicted person is viewed as a disease entity to be studied rather than someone who can contribute to an understanding of the illness and its progression. The review highlights that not exploring the individual’s experience of the disease, essentially overlooks a main source for understanding the immense variability in the presentation and progression of the illness (Cotrell and Schulz, 1993, p.205, Prorok, Horgan and Seitz, 2013)). Although there is no uniformity of treatment across the UK, one would expect a person with a diagnosis of dementia to be treated according to NICE (2006, 2013) recommendations. As such, this review considers a number of approaches to treatment that are in accord with NICE guidelines (2006, 2013); these comprise medical approaches, including diagnosis, symptomatology, treatment and/or management, prevalence, Memory Clinics, policy developments and the objectives of treatment. The next section includes an outline of Attachment Theory and its increasing relevance across the lifespan and in dementia. Developments in psychosocial approaches to the treatment and/or management of dementia will be appraised, incorporating Kitwood's theories of personhood, Miesen's approach to treatment including his idea of dementia as a strange situation. Cheston and Bender's model of the mind, based on ideas of meaning and safety. The importance of relationships in the family of a person diagnosed with dementia will also be explored including a consideration of attachment style and its significance in the relationship of the person with dementia and their carers as well as how attachment style may influence a person's experience in a psychosocial group setting. However, before the author can understand the significance of a diagnosis of dementia and its consequences, it is important to have an awareness of the understanding and treatment of dementia in a historical context.

2. Dementia through the ages

People have been affected by Dementia since time immemorial, yet it is a mere century since Alois Alzheimer described the particular form of dementia that now bears his name. Boller and Forbes, (1998) reviewed the understanding of attitudes towards, and treatments of people with dementia and provided a brief overview of the historical development of the theories of dementia. Until approximately fifty years ago there was minimal reference in the literature to Alzheimer's disease. Subsequently, there has been extensive research on diagnostic evaluation and treatment for dementia, globally (Galvin, Pollark and Morris, 2006; Waldemar *et al*., 2007, Neugroschi and Wang, 2011). Over the period this picture has changed radically as research has been carried out covering a wide range of aspects of the disease.

In the relatively short space of fifty years, research into dementia has become the most prevalent of all categories of ageing research. Advances in the understanding of genetics, neuropathology and molecular biology has led to extensive enquiry into diagnostic evaluation (Meulen *et al*., 2003; Huppert *et al*., 2012) and treatment for dementia globally (Galvin, 2006; Waldemar *et al*. 2007, Wortman, 2012). Over this period the picture has changed radically and research is being carried out across a wide range of areas including: early signs and symptoms (Bature 2017), population-based research (Fishman,2017, Sigurdsson *et al*., 2017), perspective of the person with dementia (Herbert and Scales, 2017), sleep patterns (Wams *et al*., 2017) , dementia and related disorders (Thomson *et al*., 2017, Shi et al., 2017), memory intervention (Hawley and Cherry, 2008, Hopper *et al.*, 2013,), outcome measures for psychosocial interventions (Moniz-Cook et al., 2008,) and therapeutic design of the environment for people with dementia (Day, Carreon and Stump, 2000). However, it should be recognised that research in this area has to take account of a wide range of difficulties (Weuve *et al*., 2015). The next section explores how the diagnosis of dementia came about.

3. The Standard Paradigm

Since 1952 Diagnosticians have looked to the Diagnostic and Statistical Manual of Mental Disorder (DSM) for the classification of mental illness (American Psychiatric Association, 1952). It was not until 1968 in DSM ii that Senile and Pre-senile Dementia were mentioned under the heading of organic brain syndromes (OBS). In DSM iii (1987) and

DSM iv (1994) the term OBS was dropped as well as the concept of irreversibility. The term dementia was introduced and defined as “A loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning” (American Psychiatric Association, 1952). As recently as the last thirty years, the dementias have come to be categorised in terms of their clinical presentation, neuropathology and/or aetiology (Grossman, Bergman and Parker, 2006). However, most recently DSM v (2013) has removed the term dementia, meaning “mad” or “insane” in the Greek language, as an attempt to move away from the stigma and negative connotations associated with the term. The revised classification is “major neurocognitive disorder and mild neurocognitive disorder” (DSM v, 2013). This revision possibly reflects the changes in societal attitudes towards dementia.

Concurrent with a more comprehensive understanding of dementia, especially in terms of the effect of the disease, is the emergence of better knowledge of the types of dementia. It is beyond the scope of this thesis to discuss these developments in detail but it is useful to give a brief description of the main categories. Alzheimer’s disease is the most common form and accounts for approximately 62% of all dementias (Alzheimer’s Society, 2013). It is characterised by the way in which it affects the brain, causing cells to die due to the formation of amyloid plaques and neurofibrilliary tangles that alter the chemistry of the brain. Vascular dementia is associated with a disruption of the blood supply to the brain and accounts for approximately 17% of dementias (Alzheimer’s Society, 2013). Dementia with Lewy Bodies accounts for 4% of all dementias, which affects the functioning of the brain as a result of deposits of protein in the nerve cells; its presentation is not unlike that of Parkinson’s disease (Grossman, 2006). Fronto-temporal dementia is less common (2%) and typically affects those under the age of sixty-five-years. A consideration in the diagnostic process is recognition of co-morbid conditions. Although there are numerous conditions that need to be considered and excluded, the most common that needs mentioning here is depression. It has been established that depression is a co-morbid feature of dementia, although incidence rates vary (Gilroy, Laidlaw and Holloway, 2011, Amen *et al*., 2017). The implications are that people who present with dementia and depression are more likely to have higher levels of behavioural and functional problems. However distinguishing between depression and dementia can be difficult in the early stages as they present with common symptoms (Kennedy, George and Lui, 2009).

In the research literature the terms dementia and Alzheimer's disease are often used interchangeably, which is reflected in this thesis. Over the period of the last half-century, the way in which dementia is defined has changed considerably. The next section considers the symptoms of dementia and the way in which it presents itself.

3. a) Symptoms

Although symptoms vary across the major types of dementia, there are broad similarities which are usually classified as early, middle and late. In the early state, which is the focus of this study, people typically present with short-term memory loss, which can affect the ability to even finish a sentence. Confusion is common and may be experienced on waking, being disorientated in time and space, judgement can also be impaired, which is particularly significant for those who still hold a driving license. There can be problems with managing everyday tasks, such as fastening or undoing buttons. Some people with dementia can become distressed or agitated by their inability to manage their lives as they have been accustomed to doing. Symptoms vary from person to person both in range and severity and depending on a number of factors, including the type of dementia involved however, the common denominator amongst them is memory impairment. Symptoms that have been extensively studied include the following: aggression, agitation, anxiety, apathy, delusions, depression, epilepsy, malnutrition, mood instability, psychosis, sleep problems, wandering and delirium (Tsoloki *et al*., 2010; Cipriani *et al*., 2014).

3. b) Treatment/Management

Traditionally, treatment of the dementias has been limited principally to physical care and, in the latter stages of the disease, containment. However, in the past thirty years there has been a proliferation of research by drug companies in search of a chemical compound that could be an effective treatment for the symptoms of dementia. The principle group of drugs that have been identified for mild to moderate dementias are the cholinesterase (AChE) inhibitors, which were introduced in 1992. Initially, the side effects were too severe for them to be clinically effective, however, this group of drugs has been developed to produce safer versions and currently NICE (2011) recommend Donepezil, Rivastigmine, Memantine and Galantamine for people with mild to moderate symptoms. A study by Roundtree, Lopez and Doody (2013) supported this recommendation and found slower cognitive and functional decline based on studies of people in randomised controlled trials and long-term observational controlled studies comparing monotherapy (cholinesterase inhibitors) and combination therapy (cholinesterase inhibitors + memantine). Knapp, Lemmi and Romeo (2013) undertook a trial that found the AChE drugs mentioned above to be cost effective. However, research in this area is not consensual and there are studies that refute the claims made by the proponents of pharmacological treatments (Ghezzi, Scarpini and Galimberti, 2013). Although they cannot be termed a "cure", clinical trials have shown them to be helpful in slowing the process of the disease for some people, if given early enough; (Doody, 2013) hence the drive for early diagnosis. This group of drugs is particularly useful for Alzheimer’s disease and dementia with Lewy bodies but is not effective in some types of dementia, such as vascular dementia. The above suggests that there is no uniform picture of drug treatment to date.

3. c) Prevalence

Dementia is a disease that can affect anyone and there are numerous references to dementia in literature, ranging from Shakespeare’s “The Seven Ages of Man” to “Still Alice” (Genova, 2009). Until the 1980’s/90’s people with dementia were likely to be incarcerated in mental hospitals when they themselves, or their families, became unable to care for them and their fate was largely ignored. Recent changes in the approaches to the management of dementia have resulted in most people with a diagnosis of dementia living at home for longer. In 2007, a report commissioned by the Alzheimer’s Society and undertaken by King’s College London and the London School of Economics found that two thirds of people with dementia were living at home and one in three in nursing homes. At the time there were 700,000 people in the UK living with dementia; this figure is now estimated to be 800,000 (A.S., 2013). The numbers affected has led to a greater interest in the disease, not only by researchers but by policy makers too, as the next section explores.

3. d) Policy

In 1979 the Alzheimer’s Society was founded and has since grown to be a significant voice in areas of research, treatment, education and social change. This growth culminated in the Commission for Social Care Inspection (2008) and the National Dementia Strategy (2009). However, regardless of the increased recognition of dementia as a commonly occurring disease, the stigma from the days of the asylums has not vanished as is illustrated by the recent DSM (2013) revised reclassification. Negative attitudes to dementia were not confined to the media and general public. The Health Secretary Jeremy Hunt (2013), called for General Practitioners to change their attitude towards treating people with dementia, claiming that they do not perform tests for dementia because they believe there is no point in doing so due to the limitations of treatment. His statement was supported by the Alzheimer's Society (2013) whose research revealed that only one in three people receive a formal diagnosis. This also highlights a specific problem that the Dementia Strategy (2009) set out to address, namely the importance of early diagnosis and treatment, since they argue that an early diagnosis is the best weapon available in slowing the process of this disease and, as a consequence, improving the lives of people affected by it. It is a disease that takes its toll not only on the person with the disease but also on their families. As a result of the increased recognition of the ramifications of dementia, there is greater interest both politically and by researchers into the causes and potential treatments of dementia, driven at least in some measure, by the financial implications of this disease of old age in an ageing population. Both financially and socially the cost of dementia is becoming prohibitive (Alzheimer's Society, 2002; 2010). The Health Minister has recently announced financial incentives for GPs to increase/improve diagnosis of dementia as part of the Government's drive for early diagnosis and treatment.

Dementia has progressed from being described euphemistically as a "softening of the brain" to the complex, chemical and neurological understanding that exists today. Out of the research findings has emerged a treatment standard for the UK, the National Dementia Strategy (D.O.H, 2009), underpinned by the NICE guidelines on dementia, which were initially compiled in 2006 and reviewed in 2013. The NICE (2013) guidelines are based on a number of key priorities for implementation which are: non-discrimination for people with dementia, valid consent, rights of carers, coordination and integration of health and social care, memory assessment services, structural imaging for diagnosis, assessment of challenging behaviour, staff training and provision of services in acute hospitals. The guidelines form a directive that treatment and care should focus on meeting individual needs and preferences and, as far as possible, people with dementia should be treated in the community. The impact of dementia on family relationships is also taken into account (NICE, 2006; 2013), since this approach focuses more on the experience of the person than has previously been acknowledged. The next section considers some of the specific recommendations of the NICE Guidelines, the first being the establishment of Memory Clinics across the UK.

3. e) Memory Clinics

Initially a person who they themselves, or their relatives, believe is having problems with their memory, beyond what could be expected for their age, will usually visit their GP with their concerns. It may be useful at this point, to reflect on what might be considered "normal", at a particular point in the lifespan as socio-cultural expectations regarding what is "normal" cognitive ability for older people come into play here and it is not uncommon for memory loss to be confused with normal ageing or other psychological or physical causes (Bytheway, 2011; De Vriendt et al., 2015; Pietrzak *et al.*, 2017). However, the physical functioning of the brain is not all that is to be considered when defining normal ageing as attitudes to ageing are highly significant in determining societal and familial expectations of older age people.

If a GP believes there are grounds for concern, they will carry out routine blood screening and the person will be referred to a Memory Clinic (NICE, 2006, 2013), offering assessment procedures leading to diagnosis and treatment. NICE (2006, 2013) define specific procedures that should be carried out prior to giving someone a diagnosis of dementia, namely the taking of a full history, a physical examination and follow-up investigation of anything arising from the examination, an assessment of the person's medication to exclude any drug that may be adversely affecting cognitive functioning, if the diagnosis is not clear and in early/mild dementia formal neuropsychological testing should be undertaken (NICE, 2013). The most significant assessment advocated is that of cognitive functioning, which is assessed across a range of functions (Sheehan, 2012). The Mini-Mental State Examination (Folstein & Folstein, 1975) and the Mini-Cog (Borson, 2000) are frequently used at primary care level, but more in-depth measures are used in secondary care, such as the CAMCOG (Roth et al. 1986) and the ACE-R (Mioshi *et al.*, 2006). Although assessment and diagnostic tests for dementia abound none are perfect and clinicians report issues with the majority of them, hence there is little uniformity of use in the UK with clinics favouring some assessment tools over others (Watson, 2013).

It can be extremely traumatic for a person and their family to receive a diagnosis of dementia. Therefore, clinicians should be clear as to whether the person or their relatives want to be informed of the diagnosis and careful consideration given to the support that a particular family may need. The aim of Memory Clinics is to provide a diagnostic setting where the person who is being assessed, along with their families, can be given prompt, reliable information and begin the process of managing their day-to-day lives if the diagnostic procedures prove positive (NICE 2006,2016). The next section looks at the ways in which the experience of daily living can be enhanced for people with a diagnosis of dementia.

3. f) Objectives of Treatment

NICE (2013) define a number of objectives for treatment that focus on maintaining a person's ability to cope with the tasks of daily living in a respectful environment where a person with dementia can retain their dignity and live well. However, in reality, for some dementias there is no treatment and for others the best that can be hoped for at present is a slowing of the cognitive decline, as was illustrated in the discussion of pharmacological interventions. In this section, the researcher has discussed the disease process and the impact it has on the lives of people, and this understanding has dramatically changed in recent years. Society has moved from a position of relative ignorance of the causes of the disease to a clearer picture that incorporates biological, psychological and social elements, which is termed a bio-psychosocial model (Engel 1976). Also there has been a shift to a more positive and inclusive view towards dementia

4. Psychological Developments

Concurrent with biomedical advances have been developments in the understanding of the behavioural and psychological aspects of dementia and an increase in the range of psychosocial interventions for its management, these include, Memory Training (Materne, Luszcz, Bond 2014), Simulated Presence Therapy (Cheston *et al.,* 2007), Group Psychotherapy (Cheston and Jones 2009), Reminiscence Therapy (Asiret and Kapucu 2016), Cognitive Behavioural Therapy (Reid, Avens and Waif 2017), Wellness Group (Logsdon *et a*l., 2016.), Validation Therapy (Feil 1993 cited in Jones and Miesen 2004), Cognitive Stimulated Therapy (Dickinson *et al*., 2017). All of these approaches are discussed in a paper by Sanders and Morano (2008) who argue that the focus for treatment has been on improvements in pharmaceutical developments, whilst the growth of the use of psychosocial interventions has been largely ignored. They found that whilst psychosocial interventions, in their varied forms, were used extensively in the community, it was difficult to determine the overall validity of such treatments. They argue for more empirical testing in the area, rather than an over-reliance on research using dissimilar populations or on clinical experience. Increasingly, the significance of attachment as a factor in understanding some of the behaviours exhibited by people with dementia is developing, which will now be considered (Browne and Schlosberg, 2006, Nelis, Clare and Whitaker 2012).

5. Attachment Theory

The development of Attachment Theory is credited to John Bowlby (1969), although much of his work on attachment was in collaboration with others. Four principles were defined as Bowlby's starting point. Firstly, the mother meets the child's physiological needs and in doing so, a bond develops between mother and infant. Secondly, Bowlby argues that there is an in-built predisposition for the infant to be drawn to the breast and subsequently to the mother as a whole. Thirdly, there is an innate need for the infant to be physically close to the warmth of a human body; Bowlby cites Harlow's (1958) work with monkeys to substantiate this view. Bowlby also acknowledges influences from Lorenz (1935 cited in Bowlby 1982) work on imprinting. Thirty years on from Lorenz original work imprinting came to be understood more generally in terms of the processes involved in filial attachment. Lastly, Bowlby refers to the infants' desire to return to the womb. In his early work Bowlby attempted to remain within the confines of Freud's thinking (1940) and that of his supervisor Melanie Klein (1986), and her concepts of object relations.

However, increasingly, as his theory developed, he moved away from drive theory, that had dominated psychoanalytic thinking in the first part of the twentieth century, to describe attachment behaviour as a physiological, behavioural system that develops as a result of the child's interaction with its environment (Bowlby, 1962). Therefore, each child's attachment style is essentially unique and primarily derived from principles two and three, as outlined above. The progression of Bowlby's thinking was to reject principles one and four, which can be seen as a development from Freud's instinct theory (1915).

Primarily, Bowlby (1969) describes attachment as proximity seeking that begins to develop at the age of approximately three months, although this varies from child to child. The early signs of an attachment forming are that the child responds differently to the mother than to others by smiling at her, following her with his/her eyes and vocalising. Evidence of the infant attempting to maintain proximity to the mother can best be seen when she is out of sight, at which point the infant will cry or try to follow her. On her return, the child will smile and hold out his/her arms to be held and may also cling to the mother. This phenomenon is fully developed in most children by the age of nine months and will continue until the child is approximately three years of age. The response to the mother leaving is defined as attachment behaviour elicited as a result of the infant's distress aroused by the mother leaving and is most likely to occur if the infant is in strange surroundings or with strangers. Attachment behaviour is not consistent and can reflect the child's physical or emotional state. Ainsworth (1963) identifies the infant's active role in the relational interactions that occur between mother and infant. Demands are made on the mother, as well as the infant "rewarding" her for responding appropriately by smiling and generally being beguiling. This means of rewarding some behaviour whilst discouraging others is understood as a survival technique (Bowlby, 1982). The sequence of events outlined above is based on the mother being responsive to the needs of the infant, not only its physiological needs but also its emotional needs.

Bowlby suggests that the type of attachment that an infant develops is dependent on the sensitivity of the mother's responses. In exploring patterns of attachment, he begins by affirming that attachment behaviour in itself is not the whole picture, but part of a greater whole and that infants' and mothers' relating patterns vary considerably, although patterns in specific couples are well developed by the end of the first year of life. Strength of attachment had been judged by the strength of the infant's protest when left by the mother in a strange place or with a stranger. However, the work of Ainsworth (1963) and Shaffer and Emerson (1964a) belie this assumption. Their findings suggest that a child who exhibits a strong attachment can, in fact, be less concerned when the mother leaves than an infant who exhibits a less secure attachment.

5. a) The Strange Situation

The seminal work on attachment patterns was carried out by Ainsworth (1978) who, although greatly influenced by Bowlby and with whom she worked in collaboration, suggested that he focused on attachment behaviour to the detriment of attachment as a bond between mother and infant. Bowlby's principle focus in developing his theoretical ideas was on how the infant responded at being left by the mother and its response on her return. Ainsworth, in her work with mothers and infants in Uganda (1967), defined three types of attachment patterns, which was replicated in her work in Baltimore (1971). To test these findings under experimental conditions, Ainsworth devised an experiment known as the 'strange situation', which was set up under experimental conditions and consisted of mothers and their one-year-old infant participating in a number of procedures, based on the premise that the child used the mother as a secure base. The process took twenty minutes in all and was divided into 7 three-minute segments: mother and child alone, researcher joins them, the child is left alone with the researcher, the researcher leaves and the mother returns, the mother leaves the child alone, researcher returns, researcher leaves and mother returns. Previous studies (Ainsworth 1963; 1967; Ainsworth and Bell, 1971) found that children deemed to have a secure attachment to the mother were happy to explore their environment in the presence of the researcher, whilst infants with an insecure attachment were not. However, even the securely attached infants displayed distress when the mother left the room. This phenomenon has been observed and similar results reported by a number of subsequent studies (Lamb *et al*., 1984; Steele, Phibbs and Woods, 2004; Behrens *et al*., 2011; Smith, Woodhouse and Skrowron, 2016). The ‘strange situation’ experiment focused on four principle variants: the infant’s exploratory behaviour, reaction to the mother leaving, reaction to the researcher and the infant’s behaviour on the mother’s return.

Results revealed that the infants fell into three categories; 70% were classified as being securely attached to the mother in that they were able to explore in her presence and although distressed when she left, were happy to see her on her return and could be comforted by her. The second group were described as being ambivalently attached to the mother, being very distressed when she left, fearful and avoiding of the researcher and the infant found it difficult to reunite with the mother to the point of pushing her away and cried more than infants in the other two groups. The third group were described as avoidant – not protesting when the mother left, more accepting of the researcher and thus continued to play, not very interested in the mother’s return and could be comforted by either mother or researcher. The ‘strange situation’ experiment focused on the behaviour of the infant, however, that had to be put in the context of the mother’s responsiveness. A securely attached infant’s experience was of a mother who was consistently sensitive and responsive to the infant’s needs. Whereas, the ambivalently attached infant had an experience of a mother who was inconsistent in meeting his/her needs. The infant who demonstrated an avoidant pattern would have experienced his/her needs being consistently unmet (Ainsworth, 1978).

Although the ‘strange situation’ study was not the first to examine the behaviour of infants and young children in secure and insecure environments, it became the benchmark study for the classification of attachment patterns and provided empirical evidence for Bowlby’s theory of attachment (Ainsworth, 1978). It has been studied under experimental conditions and its results replicated globally (Ainsworth, et al. 2015). However, it is not without its critics (Masters and Wellman, 1974, Takahashi, 1990). Lamb (1977) argued that it identifies only one type of attachment yet children may have different attachment patterns to other family members and indeed, a child may exhibit different attachment patterns in different situations. A study in 1981 by Main and Weston did find differences in attachment patterns of infants to each parent. Ainsworth herself addressed the criticism that the research was unethical due to the distress it caused the infants, which she defended by asserting that the procedure was no more than the infant might have experienced in its day-to-day life (Ainsworth, 1985).

The work of Mary Main is of interest to this thesis since she developed Bowlby’s ideas of attachment behaviours as extending across the lifespan (Bowlby, 1969; 1982) through the development of the Adult Attachment Interview (Main, 1991). Bowlby argued that principle and subordinate attachments could be made at any age, to the point that in old age, if there was no longer a person of the same age available, attachment behaviour would be directed to a younger person. As such, Bowlby asserts that an attachment can be formed to anyone or to a group and attachment and attachment behaviour elicited from "the cradle to the grave" (Bowlby, 1967; 1982, p. 209). This claim is a refutation of psychoanalytic thinking that attachment behaviour in adult life is regressive. Ainsworth also considers this question, in her paper of 1984, which adds support to the idea of attachment across the lifespan and the significance of affectionate bonds and their relationship to attachment. Main was involved in a follow-up study of the children originally described by Ainsworth (1978) in which the original attachment patterns were confirmed, suggesting that attachment patterns developed in infancy were sustained into later childhood (Main, Kaplan and Cassidy, 1985; Main and Cassidy, 1988). The 1985 study also administered the Adult Attachment Interview (Main 1982) to mothers of children who had undertaken the 'strange situation' experiment five years previously, in order to ascertain whether there was a correlation between the mother's attachment style and her infant's response to her. The results demonstrated a strong link between the attachment style of the child and the mother. Main (1988) reported her own and Ainsworth's (1998) findings in regard to the mother's response to the child, being particularly interested in the response of the mother and the dialogue between them after an absence of one hour. She concluded that the child's behaviour in the avoidant pattern was organised to focus away from the mother onto the environment (toys).

5. b) Adult Attachment Interview

In terms of methodology, The Adult Attachment Interview (Main and Goldwin, 1982-1988) is a semi-structured schedule consisting of fifteen questions, with an extra three for adults who have children of their own (Appendix 4.1). The questions address aspects of the person's recall of their childhood experiences and memories to elicit the quality of their narrative in terms of attachment. Analysis is based on studying the verbatim transcript according to three determined "states of mind with respect to attachment" (Main and Goldwyn, 1998). Classifications of attachment styles were described as: secure autonomous, which corresponds to a secure infant; dismissing, associated with avoidant infants; preoccupied, corresponding to resistant and/or ambivalent infants and unresolved, which corresponds to infants described as disorganised and/or disorientated. The latter group of infants displayed extreme distress, alternating with avoidance. In interpreting the above findings Hesse and Main (1999) suggest that if the parent has a disorganised sense of their own attachment experience, then they are likely to relate to the infant in the light of this experience, thereby reproducing a disorganised attachment pattern in the infant. If the infant demonstrates fearfulness of the parent, then Bowlby (1982) claims that the frightening parent evokes a biological response to take flight from that parent, rather than seek proximity.

The above section emphasises the development of the thinking and application of attachment theory that has progressed from Bowlby's early work with infants, to an understanding of attachment styles and evidence to support the notion that relationships in adulthood are influenced by the type of attachment we are able to make. In recent years, there has been further work carried out, that supports the suggestion that attachment behaviours developed in infancy and early childhood outlined above, continue across the lifespan (Hazan and Shaver, 1987; Fonagy, 2000; 2002; Shaver, 2000; George and West, 2001). Significantly, in the field of dementia, there have been a number of studies that have sought to understand some of the behaviours commonly observed in people with dementia, in terms of attachment, which is a critical aspect of this study (Miesen, 1992; 1993; 1997; Cheston and Bender, 1999; 2012, Browne and Shlosberg, 2006). The next section will consider the work of Miesen and his use of Ainsworth's 'strange situation' as a metaphor for the experience of people with dementia. This has particular significance for this study since it suggests there is a link between a person's attachment style and their experience of dementia.

6. The Strange Situation of Dementia

The brief synopsis of the development of attachment theory above is of specific relevance to this study, as will be explored through the work of Miesen and others working with people with dementia. Miesen was an older-age clinical psychologist working in Holland in the 1970s; he pioneered a person-centred focus for the treatment and understanding of dementia. He argued that understanding how people deal with memory problems is the starting point, since this is the classic, early symptom of dementia. Miesen suggested that people with dementia 'know' they have a problem with their memory and attempt to 'hide' this from others around them. Miesen postulated that this is facilitated by conceiving of memory as a particular kind of information-processing model, which will be considered in brief. This model proposes that sensory information is experienced from the six senses, all of which have different ranges. For example, the closer the sensory experience is to its source, the more potent it will be, therefore what is tasted, will be a stronger experience that what is heard. The implication from this therefore, is that in order to relate to someone with dementia, one needs to be in closer proximity if one is relying on the sense of touch or smell. The model proposes that people can only remember what they have experienced. By remembering something previously experienced, something is expressed that has made an impression, which is then imprinted into memory, thus enabling it to be retrieved. This model may be more useful in explaining what happens in dementia than some other models, such as the simplistic storage/retrieval model (Sternberg, 1999) or the multi-store model of memory (Atkins and Shiffrin, 1968). The process, as described by Miesen (1999) works differently for everyone in that people are more attuned to stimuli from some senses as opposed to others, i.e. a person who has difficulty hearing may accommodate that deficit by enhancing their visual information (Miesen, 1999).

Miesen (1999) defined the ways in which people do or do not process information as ‘valid excuses’ (Miesen, 1999 p. 34-35). Although this may be a useful short term strategy the use of such excuses can have a negative effect on information processing, since blocking the process of taking an impression and imprinting that into memory, alters the expression of what was remembered. Everyone’s memory is unique but nevertheless, Miesen (1999) States there are seven assertions about memory:

- All factors can negatively affect the process of making impressions, imprinting them into memory and expressing (recalling) them.
- As time goes on, fewer imprints are made of new impressions.
- As one ages, the total number of imprints ever made are reduced.
- The older someone becomes, the less information they can simultaneously process as impressions and imprint into memory.
- The process of impression formation, imprinting and expression is favourably influenced when multiple senses are used together.

- Recognition of imprints is easier than the retrieval of imprints. (Miesen, 1999)

The preceding assertions differ for each sense, which can make things conceptually complex, also differences are expressed by paying more attention to what interests an individual or how tired they are. Equally, something that creates a stronger impression is more likely to be remembered (Miesen, 1999).

Imprints begin to decline from mid-life, however, as dementia progresses, there remain more imprints from childhood as this was the time when the most imprints were made; this explains why people with dementia are more likely to retain memories from childhood, which is understood as a function of the Hippocampus being the first part of the brain to be damaged, specifically in Alzheimer's disease, thereby inhibiting the formation of new impressions (Rabins, 2013). Some imprints are held longer because of the initial social impact they make. Recognition of imprints is easier than recall, which can be enhanced if clues are given that help access the memory, which is why visual aids are often employed for people with dementia (Miesen, 1999).

An important point about this approach to memory is the common myth that people with dementia do not suffer because they are unaware as Miesen (1999) asserts dementia sufferers know that something is happening to them, that things are not right and they respond as they would to a sense of loss. As a result, "People with dementia seek safety" (Miesen, 1999, p. 59) and exhibit attachment behaviour that aims to attract or keep an attachment figure close. He describes how attachment behaviour can be evoked when the person feels threatened, such as experiencing a sudden shock or an attachment figure leaving. If an attachment figure does not respond in a way that is reassuring, then the attachment behaviour escalates with the person exhibiting a range of distressed emotions such as shock, denial, anger, aggression, bargaining, despair, sorrow and eventually grief. This was graphically depicted in "John goes to hospital", a seminal documentary in the field of attachment theory, of a young child's experience of a hospital admission and the subsequent effect on his attachment to his parents (Robinson, 1952, Browne and Shlosberg, 2005). When attachment behaviour is responded to appropriately, the person with dementia becomes calm. Attachment behaviour is precipitated by fear and insecurity; safety is found by being close to others, also known as proximity seeking behaviour.

A frequent occurrence that has been observed in people with dementia is a desire to locate their parents. The person with dementia thinks their parents are still alive and they have a strong urge to go to where they think they are, or to do what they believe their parents want them to do. Miesen terms this phenomenon 'parent fixation', which he studied in relation to cognitive functioning and attachment behaviour with forty participants with dementia who were living in nursing homes. A range of tests was used to measure cognitive functioning and Miesen devised a procedure to replicate the "strange situation" (Miesen 1992; 1993). His findings revealed that people exhibited organised forms of attachment behaviour depending on their level of dementia.

On the basis of these results Miesen (1993) postulated that dementia erodes feelings of safety and security and activates attachment behaviour. In the earlier stages of the disease, attachment behaviour can be employed to seek reassurance from attachment figures but as the disease progresses and the ability to recognise family and carers diminishes, overt attachment behaviour becomes less useful as a means of reassurance (Wright *et al*.,1995). Subsequently, Miesen and Jones, (1997) came to believe that both memory and attachment have a part to play in the phenomenon of 'parent fixation'. As the capacity to make new imprints decreases, disorientation occurs in relation to the present reality and time sequencing. As a result, at this stage of dementia, it is difficult for the person to distinguish what is occurring now and what was in the past. In these circumstances, it is not surprising that parents become important people in the present. Although Miesen's argument is persuasive, this research was carried out on people living in nursing homes and the results may not extrapolate to those being adequately supported in the community. Also, in the original work, the number of participants was relatively low and the authors did not take account of the participants' premorbid attachment styles, which could have influenced parent fixation (Browne and Shlosberg, 2005).

Miesen's (1993) study has been replicated by Browne and Shlosberg (2005), who extended the study to include pre-morbid attachment style. They predicted a significant relationship between pre-morbid attachment style and the presence and/or absence of parent fixation. One-hundred-and-nine participants, who were residents of either nursing or care homes participated. Similar measures were used to test cognitive ability and the Attachment Style Questionnaire was added (Hazen & Shaver, 1987. Family members or friends were involved in the study and were asked to estimate the person with dementia's attachment style. An updated version of Miesen's parent fixation measure (Yahyaoui and Miesen, 2000 as cited in Browne and Shlosberg, 2005) was used. The results found that 54% of participants showed evidence of parent fixation; the relationship between cognitive functioning and parent fixation was consistent with Miesen's findings, as well as more of a fixation to the mother, which was deemed to be consistent with the socialisation of the age group. The prediction that there would be a relationship between pre-morbid attachment style and frequency of attachment behaviours could not be fully explored due to the lack of participants with an anxious, ambivalent attachment style. Participants with an avoidant attachment style were found to be as likely to exhibit parent fixation as those securely attached. Despite its limitations, this was the first study to examine the role of attachment style in the occurrence of attachment behaviour and parent fixation amongst people with dementia (Browne and Shlosberg, 2005). In summary, the findings broadly supported Miesen's results, however, there was no evidence to endorse a link between the level of dementia and overt forms of attachment behaviour. This study also focused solely on participants who were in care homes and were all white British, which could be limiting in terms of making claims of generalisability across the population of people with dementia as a whole.

Osbourne, Stokes and Simpson (2010) extended the work of Miesen (1992,1993, 1999) and Brown and Schlosberg (1995) by considering not only attachment style and cognitive functioning but also examined the influence of demographics, premorbid personality and psychological variables in the understanding of parent fixation in people with dementia. This study also differed from that of Miesen (1992,1993) and Browne and Schlosberg (2005) in that participants were recruited from people living in care homes and in the community. The authors assert that if parent fixation can be described as an attachment behaviour then those living with an attachment figure in their own homes might be expected to demonstrate less attachment behaviour. The authors also state that personality as well as other social variables are present to some extent throughout dementia and will be a factor in understanding parent fixation. This study aims to replicate Browne and Schlosberg's (2005) study by examining the role of demographic, cognitive and psychological factors. The results are considered in terms of Miesen's assertion that parent fixation fluctuates according to how anxious and or safe the person is feeling. The authors of this study identified two types of parent fixation; continuous where parent fixation and attachment behaviour is present, fluctuating where parent fixation may be absent but attachment behaviour is observed. In summary, the results of this study, which were compared to those of Miesen (1992, 1993) and Browne and Schlosberg (2005) replicated some of their findings but also identified differences and can be briefly defined as follows: parent fixation can be understood as a psychosocial phenomenon arising from a relationship between pre-morbid individual characteristics, the environment and cognitive impairment. That those living with an available attachment figure are less likely to exhibit parent fixation but may exhibit attachment behaviour. The clinical implications for the findings of this study are; that it is necessary to include pre-morbid characteristics of attachment style and personality into treatment plans of people with dementia to ensure that their treatment meets their psychological needs. Also advocated is that the subjective experience of the person is given prime consideration. Finally, this study identifies the need to provide opportunities to maintain and develop attachment relationships citing Cheston and Bender (1999).

Parent fixation is not the only way in which a person with dementia expresses fear or uncertainty. For example, it is not uncommon to see people clutching handbags, toilet tissues and numerous other items that are collected and held on to as if they have great significance. Such items could be seen as being in lieu of attachment figures that were never established, or they could be seen as transitional objects (Winnicott, 1953). A study of the use of physical objects was carried out by Stephens, Cheston and Gleeson (2013) who observed residents of a nursing home who had a diagnosis of dementia. The criteria they used to determine whether an object could be deemed to fulfil the role of a transitional object was Winnicott's (1953) criteria: The infant assumes rights over the object and we agree to this assumption; the object is affectionately cuddled, as well as excitedly loved and mutilated; it must never change unless changed by the infant; it must survive instinctual loving, and also hating, and, if it be a feature, pure aggression; it must seem to the child to give warmth or to move, or to have texture or to do something that seems to show it has a vitality or reality of its own; it comes from without from our point of view but not so from the point of view of the infant. Neither does it come from within; it is not a hallucination; its fate is to be gradually allowed to be decathected (attachment feelings are withdrawn), so that over the course of years it becomes no so much forgotten as relegated to limbo. Winnicott (1953) defined the use of transitional objects as representing the attachment figure, and is imbued with the sense of security derived from the attachment figure. In this way, the child could fill the space between external reality and internal reality thus being able to soothe him/herself. The authors of the study in question posit that this process operates in revers in people with dementia in that as it becomes more difficult to understand external reality an object is employed to fill the transitional space as a soothing and reassuring mechanism. A further aspect of this study was to consider the use of precursor objects which differ from transitional objects in that they are more usually given to the person rather than discovered by them, therefore they are not endowed with the same feeling representations as transitional objects, rather their tactile quality is what characterises them as soothing to the person, which may have a relationship to early infant experiences. The observations of people in this study revealed that objects could be used as transitional object, in keeping with Winnicott's criteria, or as precursor objects. The authors suggest that as the capacity to invest in objects is lost relating may be more precursory. Does this suggest that objects may be experiences as soothing but not identified with an attachment object?

Those with a secure attachment style were found to exhibit less attachment behaviour, whereas someone with an insecure attachment to demonstrate more attachment behaviour, which in turn affects the caregiver's well-being. The attachment style of the caregiver is also important, with securely attached individuals reporting a stronger sense of well-being and an ability to cope with the task of caring for a person with dementia (Perren *et al*., 2007). This study advocates an intervention such as a psychosocial support group to enhance the understanding of the caregiver of the person with dementia's 'problem' behaviours. Norton *et al.*, 2009) advocate development of care management strategies such as social and stimulating engagement, which could be fulfilled by a psychosocial group intervention, which will be discussed in greater detail below.

What can be concluded from the studies outlined above? Could it be that in some cases a satisfactory attachment relationship had never been established? With others a previously secure relationship with a spouse/carer can, to some extent, mitigate their experience of dementia? In dementia, if it is the case that no more imprints or impressions can be made, as the disease progresses, will old feelings of abandonment or terror re-emerge? Unresolved old losses can still be experienced as grief and may be reawakened by the current experience of loss in the case of those who have an insecure attachment style? The discussion above suggests that an understanding of the behaviour of a person with dementia can be enhanced by an awareness of attachment behaviours and the significance of the current 'close' relationship, since this contextualises the common occurrence of 'parent fixation' and other attachment behaviours recognising them as an aspect of the 'strange situation of dementia'. With these observations in mind, this next section explores concurrent developments in the field of psychosocial interventions in the treatment and/or management of dementia.

7. Personhood – the Person of the Person with Dementia

Psychosocial interventions for dementia have developed exponentially over the last thirty years, and it was largely the work of Tom Kitwood and the Bradford Group that influenced the way in which people with dementia have come to be treated with the introduction of a person-centred approach (Kitwood, 1994; Bender and Cheston, 1997; Bryden and Friedell, 2001; cited in Baldwin and Capstick, 2007). Some have gone as far as to suggest that “Tom Kitwood is one of the leading figures in the development of our thinking on the nature and process of dementia ….. the overall sweep of Kitwood’s work is vast and it has righty been considered to have altered the way both dementia itself and the provision of care services are conceptualised today” (Baldwin and Capstick, 2007, p. xv).

Kitwood introduced the concept of a bio-psychosocial model of care, a value base, that promoted user-involvement and user-focused services (Baldwin and Capstick, 2007; Wilkinson, 2002). Given the importance of his work for this thesis, Kitwood’s contribution will now be looked at in some depth. The work can be categorised into four principle areas, a critique of the standard paradigm, ill-being and/or well-being and psychological need, personhood and organisational culture and its transformation (Baldwin and Capstick, 2007; Kaufman and Engel, 2014).

In terms of the medical view of dementia, Kitwood criticised the narrowness of the definition of the disease, in that the principle consideration is of the organic disease process itself, rather than a wider consideration of the person with dementia’s experience. Kitwood defined the commonly held medical view of the cause of dementia as evidence of neuropathic change equating to dementia, which constitutes the ‘standard paradigm

(Kitwood, 1989). His argument with this view, is that it is linear with only one outcome - death. It does not take account of the fact that on post-mortem examination, some people who were exhibiting severe dementia had minimal neuropathic changes and conversely, others who had relatively mild signs and symptoms of dementia had significant neuropathic changes, hence 70% of the variance between neuropathology in dementia is not accounted for (Kitwood 1989; 1990; Sabat and Harre, 1992; Bryden and Friedell, 2001). Further, he argues that the relationship between mind, brain and dementia are not explained by the standard paradigm. He cites four phenomena: pseudo-dementia, apparent precipitation, catastrophic decline and moderate or transitory “rementia” that refute the “standard paradigm” (Kitwood, 1993 cited in Baldwin and Capstick, 2007 p. 74). Kitwood’s hypothesis is that in all cases of dementia, there is a combination of structural damage and functional change in brain tissue, and that the pathology found in the brains of people with dementia after death is not primarily causal, but consequential (Kitwood, 1989). His argument, in short, is that dementia is more than a straightforward organic mental illness Kitwood (1989) and he highlights three main factors to support this claim, firstly, that research into neuropathic change does not take account of whether certain kinds of psychological strength help prevent the development of dementia in later life; secondly, that people are often not diagnosed until a significant level of dementia has occurred, often when it has become a problem to someone else, and an opportunity to influence the progress of the disease is lost and thirdly, the emphasis on cognitive functioning, neglects the wider influences on cognition, such as emotional ambience in the context of the emotional and physical environment in which a person with dementia is cared for (Kitwood, 1990). These ideas were supported by a study of social relatedness in people with moderate dementia attending a day centre (Sabat and Lee, 2011). They found that those observed, initiated relationships with others in the group, borne out of a desire to form supportive, social relationships despite some having communication difficulties such as aphasia, apraxia or agnosia. These findings are not consistent with social functioning as defined in DSM IV (1994) but are consistent with Kitwood's ideas of the subjective experience of dementia (Sabat and Lee, 2011).

Kitwood developed his argument by focusing on the dementing process rather than the dementing state (Kitwood, 1990). His data was collected from psycho-biographies of people who had developed dementia and he argued that it "showed clearly that the dementing illness is intrinsically woven into the pattern of life-history and social relationships" (Kitwood, 1990 cited in Baldwin and Capstick, 2007 p. 35)). He spent time with dementia sufferers themselves, collecting real-life vignettes in collating his second round of data. One of his conclusions showed that as a result of the way people with dementia are treated, their sense of self-esteem is diminished, which leads them into a spiral of discouragement and failure, exacerbating the symptoms of dementia without any neuropathic changes but with an effect on neurochemistry. This process of "neurological impairment in an elderly person, attracts to itself a malignant social psychology" (Kitwood, 1990, p. 179), which he describes as bearing down upon an aged person whose psychosocial buffers are already fragile, actually creating psychological impairment. Kitwood's method of collating data in this way was criticised by the medical fraternity (Flicker, 1999). The basis of the criticism was that his methods were unscientific and without rigour, thereby not providing evidence for his claims and failing to take account of recent developments in neuropsychology. These criticisms were echoed by Adams (1996, 1997; Murphy 1995; Dewing, 2008).

A further development in Kitwood's thesis was to put personhood and interpersonal relationships at the centre, whereas the medical model placed dementia in the category of organic disorder with little reference to interpersonal life. This medical view was largely unchallenged until Kitwood developed his alternative view. The medicalisation of dementia served to clarify what had hitherto been unclear (DSM iii, 1987). However, classification alone had its disadvantages, principally in that the disease process was seen to be entirely degenerative and linear resulting in death. The focus tended to be on sentimental accounts of the person's behaviour, specifically cited in negative terms such as 'being difficult', 'not themselves', or exhibiting 'troublesome behaviour'. Attempts to treat these idiosyncrasies were based in behavioural techniques, such as operant conditioning, which reflected the focus of psychosocial interventions of the time (Kitwood, 1993). An important observation revealed in this work was that relatives often reported an incident or series of incidents that precipitated the onset of symptoms known as "apparent precipitation", which included: retirement, redundancy or major role loss, bereavement, rejection, disgrace, stressful conflict, geographical change, accident, assault or burglary and major physical illness or operation (Kitwood, 1994). Numerous cases of rapid decline following life changes, in someone who was deteriorating at a slow pace, would suggest that how someone deals with life events could be of significance in the disease process. However, the evidence suggests that some people cease to deteriorate when their life situation stabilises (Bryden and Friedell, 2001). In fact, they recover some of the lost abilities, which Kitwood describes as 'rementing' Kitwood (1989. Kitwood argues that the dominant discourse is not coherent as no consideration is given to how the brain and mind are connected; hence for every mental event there is a corresponding event carried in a brain that is in a particular structural condition (Kitwood, 1989). Adopting this way of thinking allows the dementing process to be considered in terms of an interplay between the structural condition of the brain, including damage or destroyed nerve tissue, and inter-neuronal connections - the highest level of mental functioning that occurs in relation to the structure of a particular brain. The argument would be that if the structural condition of the brain is all that is considered, then there is a gap between a person's level of functioning and what they are capable of, which can be developed or impeded by non-neurological features, such as psychological and social-psychological factors (Kitwood, 1993).

Essentially, Kitwood's work highlights the fact that 'the person' of the patient is often omitted in accounts of the dementing process when referring to the standard paradigm, since the focus is more often on accounts obtained from carers and relatives. The experience of the person who is suffering is lost or is experienced as an absence (Bryden and Friedell, 2001). When Kitwood initially introduced his concept of personhood it was not clear whether he was defining personhood on moral grounds or purely metaphysical (Kitwood, 1993). It was not until his later work that he defined his meaning more clearly as a meeting point between transcendence, ethics and social psychology, "a standing or a status that is bestowed on one human being, by another in the context of relationship and social being" (Kitwood, 1997a, p. 8). His views on personhood were not universally accepted on philosophical grounds, as there was an overt Christian perspective to some of his claims (Post, 1995; Kittay, 2005). And the debate continues.

A study undertaken by Sabat and Lee (2011) explored the experience of personhood of seven people receiving dementia care. During the interviews they were tasked with working out the system of the care home and adapting their behaviour in order to survive it; this they termed the 'peoplehood' of the system, which referred to using past and anticipated future roles and experiences to manage the present. This included the transient nature of personhood, in this instance, being both an individual and a member of a group and the conflict that occurred as a result of that dual role. Results revealed that the environment of the dementia care setting affected the participants' experiences of personhood in terms of how 'rule bound' it was and that this affected their behaviour. There were also clear effects on participants' sense of personhood as a result of group membership. In efforts to improve their sense of personhood, there was movement between affinities within the group as well as against their individual personhood. This effect was observed even with those who were more cognitively compromised. The authors claim that the results of this study highlight the importance of social relationships for people with dementia and call for further study of the "self" of the person as an individual and as part of a "group" and that care of people with dementia must take account of the person's subjective experience in the context of diminishing cognitive ability. This research supports and extends Kitwood's concept of "personhood" (Nowell, Thornton and Simpson, 2011)

Why then is the person of the patient largely absent? Kitwood's explanation is that the function of the dominant discourse is to maintain the status quo and to avoid some of the difficult and painful issues of dementia, as well as for the individual's experience to be taken seriously (Davis, 1990; Downs, 1997; Brooker, 2003; Evans, 2008). This may seem to be an extreme view but it was the case at the time Kitwood was writing and was borne out by the publication of "My Name is not Dementia" (Alzheimer's Society, 2010) as one attempt to address the issue of a general reluctance to acknowledge dementia and the individual experience of the disease. Loss is a part of life experienced by all, but the person with dementia experiences loss at a number of different levels. For example, a loss of mental capacity, their status, their role in the family as well as a potential inability to assimilate such losses. The experience of the carers can be the dominant 'voice' when the person with dementia or the family seek help. The symptoms of dementia are often presented in terms of 'difficult' behaviours, because the carer cannot understand the meaning of communication attempts by the person with dementia because such attempts to understand are coming from the perspective of the other, rather than the person with dementia who might be making desperate attempts to communicate.

The person with dementia's experience of loss is not given sufficient consideration despite the potential for it to be monumental. If the personhood of the person is ignored they become more and more isolated and their cognitive functioning diminishes. Winnicott (1965) identifies the emergence of subjectivity in the developing child and the significance of the response of the other in facilitating the infant's ability to deal with their experience of their environment. He suggests that the infant requires to be held both physically and psychologically. Kitwood (1993) makes the point that the same requirement is true of a person with dementia and quotes Winnicott's paper "The Maturational Process and the Facilitating Environment" (1965) to support his argument. A gesture needs to meet a facilitating response. The argument is that in dementia, the internal process fragments and the sense of self cannot be sustained, hence the need for others to fill the gaps. In infants the other is facilitating the development of the mind and/or brain whereas in dementia, the carer is working against the deterioration of the brain.

In considering the person and process in dementia (Kitwood, 1993) the person with dementia is viewed as a person with agency, a sentient, relational and historical being. This approach has evolved into a style of research with an ethnogenic view of the person or subject, which is to have a view of the whole person (Harre 1993). This method is characterised by observation of behaviour with some minor interventions, either in peoples' homes or care settings, which has led to a better understanding of the dementing process and resulted in Kitwood (1993) proposing a re-conception of dementia, defined by the following 'equation': SD (clinical manifestation of senile dementia) = P (personality: that which is defined constitutionally in conjunction with social learning) + B (biography in particular vicissitudes of later life) + H (physical health including acuity of senses) + NI (Neurological impairment in terms of location, type and intensity) + SP (social psychology, which constitutes the fabric of everyday life, in particular its effect on the individual's sense of safety, value and personal being.

Kitwood acknowledges that this 'equation' can be regarded as simplistic but he argues that it does take account of most of the phenomena associated with dementia. If Kitwood's argument and method is valid then as a positive effect, people should have remission from their symptoms but as he states, unlike say, deep depression, no-one has come back from dementia to tell us what it was like. His notion of biography particularly stresses the vicissitudes of later life and he states that some people go into the dementing process with their previous support structures relatively intact. Whereas, those who have experienced destabilising or demoralising events may have little or no internal support structures available to them.

The thesis of this study is that an explanation of these differences may be linked to a person's attachment style, so a person with a more secure attachment style is likely to have a greater internal resource. However, if early attachment experience is conceived as being a factor in how a person deals with life events across the lifespan, then it is understood that early attachment behaviour is stimulated by the ‘strange situation’ of dementia (Miesen, 1992;1993.

It is in the area of social psychology where Kitwood sees that changes can be made in defining the malignant social psychology (Kitwood, 1990), to a more conducive social environment. A move away from the common components of a medicalised, institutionalised approach of care, including the “us” and “them” of clinical staff, carers and the person with dementia. “The effect of this malignancy, together with the fact of continual neglect, must surely be included in any explanation of the dementing process that aspires to scientific truth” (Kitwood, 1993, p. 543). Unfortunately, some or all of the above components can be found in services and care-giving establishments to this day.

Kitwood’s work on dementia was, sadly, cut short by his untimely death in 1998. However, in the relatively short time he was engaged in this field he transformed treatment and understanding of dementia. His work can briefly be summarised as adopting a person-centred approach to the treatment of dementia thereby giving validity to everyone’s experience, no matter how severely, cognitively impaired they are, and acknowledging that all human experience is grounded in relationships, which become more significant as the dementing process progresses. He was critical of the medical approach to the understanding and treatment of dementia. The notion of Personhood was a fundamental aspect of his perception of the treatment of people with dementia, believing that in standard treatment the person of the person with dementia is lost, which Kitwood argues contributes to the process of decline as the person loses hope. He puts greater focus on the person’s quality of life throughout their experience of the process of dementia. Indeed, his is a holistic approach that focuses on maintaining function and preventing deterioration and adopts a proactive approach to the treatment of dementia, as opposed to reactively treating symptoms as they arise. He describes ‘meeting’ people where they are, in the sense of engaging with them in the ‘place’ where they are, rather than expecting them to come into your ‘place’ as they may simply not have the cognitive ability to do so. Perhaps his greatest legacy was the Dementia Care Mapping instrument (Bradford Dementia Care Mapping Group, 1997).

Kitwood was not without his critics, some of whom have been outlined above, as the majority of his work was pioneering and could not be substantiated. Also, he was challenging the dominant culture of the day. His methods were criticised as being unscientific and anecdotal, as they were based on gathering the life stories of people with dementia (Murphy, 1995; Adams, 1997; Flicker, 1999). Murphy (1997) also criticised Kitwood for a lack of discussion of his statistical methodology. Principally, criticisms of Kitwood’s methods take issue with his method of collecting data and its subsequent analysis. The counter argument to this however, is that his work was pioneering, given that at this time there was little empirical work with which to substantiate his claims, and where he could draw upon empirical work, such as his own on ‘rementia’(Kitwood, 1989), In defending his methods, Kitwood quotes Popper’s suggestion “that a good scientist should be willing to make risky and falsifiable statements, ahead of actual testing” (Kitwood, 1997a, p. 101).

In contrast to this criticism, the closing statement regarding Kitwood’s work, by Professor Bob Woods (1998), supported his tenacity:

“Tom always had to battle with the “establishment” in order for his ideas to be accepted: my initial resistance was, it appears, shared by others. Tom was determined and persistent, and gradually many of the barriers broke down, especially when the practical application of the theories became self-evident." (Woods, 1998, p. 3).

This acknowledgement of Kitwood's work resulted in his being awarded a Personal Chair entitled "The Alois Alzheimer Chair in Psychogerontology" (Bradford University, 1998). It could be argued that Kitwood's work had advanced to a point by his untimely death, that identified a range of questions for researchers on the understanding and treatment of dementia, the following section explores how some of his ideas were developed.

8. Meaning and Safety Model

Bender and Cheston (1997) developed Kitwood's ideas of a person-centred approach and incorporated Miesen's theory of the influence of attachment behaviour in dementia (Bender and Cheston, 1997; Bender and Cheston, 1997a; Bender and Cheston, 1999; Cheston and Bender, 1999; Cheston, Jones and Gilliard, 2002; Watkins *et al.*, 2002). By developing Miesen's model of memory, they argue that dementia be defined in terms of difficulty in thinking and responding rather than simply memory loss. For example, it can become difficult to think clearly in frightening, angry or anxious situations, especially if there is a reduced ability to process information. For someone with dementia, this becomes an increasing fear in social situations, which can then become a vicious circle. Cognitions are not just slow but under-functioning. The suggestion here is that there are interactions between a person's history, their ageing and their social system. Bender and Cheston (2003) describe their model as a "meaning and safety system", in which the meaning system is "A linguistic/conceptual system that takes the low level configuration of sensory stimuli and interprets them in terms of previously acquired information and values" (Cheston and Bender, 2003, p. 132). This can be of one's own performance by one's own standards or those of others. Therefore, the meaning given to events can affect a person's emotional evaluation and can mediate against depression by making comparisons between past performance and the present. However, if the argument can be made that this form of comparison can be useful, the counter argument to this could propose that if the comparison is unfavourable, then it might precipitate depression; in other words, in part it depends on how interpretations are produced.

The safety system is described as "A non-verbal perceptual system, which utilises the autonomic nervous system and it is claimed to be responsible for initiating the fight/flight response whereby the para-sympathetic nervous system is activated resulting in increased adrenalin in the system" (Cheston and Bender, 2003, p. 132). The safety system takes precedence over the meaning system because of its role in survival, and is experienced as anxiety or fear. However, during interaction with the meaning system, it can also signal pleasure. The safety system can be activated by a range of events and varies from person to person, depending on the specific interaction between the two systems, which can go both ways; the safety system can alert danger, but the meaning system can recognise that the event or situation is not dangerous. The more disorientated the person becomes, the more significant the function of the safety system becomes, so as to inform the meaning system.

Cheston and Bender (2003) describe four stages of dementia in terms of damage to the meaning and safety systems. In the early stages of the disease, there is less efficiency in information processing, awareness and monitoring of the environment, which may manifest as a diminution of attention. The meaning system is not affected and therefore, the person is aware of their diminished performance in relation to what they were capable of before and there is an increased risk of depression at this stage.

The second stage is characterised by language and thought becoming increasingly affected and there is difficulty in accessing the meaning system. The safety system's ability to monitor the degree of threat is compromised and therefore the safety system is activated more often. People with dementia use coping strategies to minimise how they experience their loss of ability, such as denial, blaming or minimising their problems. Whilst these mechanisms may be effective in the short term, long-term, they have the effect of increasing anxiety and insecurity. Bizarre explanations of events are brought into play by the safety system as an attempt to reduce anxiety and to give meaning to events (Cheston and Bender, 2003).

In the third stage, there is obvious damage to the meaning system and the safety system is responsible for determining much of the person's behaviour in order to reduce anxiety. Behaviours such as wandering, asking repeated questions and using aggression become more commonly used. These responses are defined as primitive because past experience is not available to mitigate the safety system. The result may be that the person increasingly relies on earlier experiences, which if threatening, could cause an increased sense of danger (Bender and Cheston, 1997). In the final stage, the authors claim that the safety system cannot recognise what is and what is not dangerous and consequently, the person becomes dependent on others for their safety.

There is similarity between these ideas and those of Miesen's, which the authors acknowledge. There are also differences in that Miesen focuses on attachment theory as a way of explaining and understanding the experience of the person with dementia.

However, it could be argued that this is not at variance with Miesen's view, as this may be the point at which attachment behaviours come to the fore. Cheston and Bender (2003) focus on dementia as a process that erodes a person's sense of security, which they describe as a person-focused approach, that aims to increase a person's emotional security, to create and maintain their self-worth and their sense of identity. The authors advocate therapeutic interventions aimed at achieving these two goals. It would seem that the model they outline is a re-statement of Miesen's previous claims, with an additional focus on the person's sense of security. What is more significant is the work that Cheston and Bender (2003) went on to conduct, which placed the ideas of Kitwood and Miesen into a clinical arena, in the context of their own definition of the set of therapeutic goals, as outlined in Cheston and Bender op. cit. p 193/194. A further difference was that both Miesen (1992; 1993; 1999) and Kitwood (1993; 1994; 1997) were more focused on people with dementia who were living in care homes, whereas Cheston and Bender (2003) concentrated more on people living in the community.

8. a) Experience of Groups

Another clinical application that developed out of Kitwood's (1995) observations was the increasing use of group work with people with dementia "Remembering and forgetting" was a study of group work with people who have dementia (Cheston and Bender, 2003). In this study, the authors argued for the importance of the centrality of the person with dementia and the usefulness of support groups for this population citing Kitwood and Benson (1995) and Yale (1995). In this project, 42 people were recruited based on them having a diagnosis of dementia and an ability to acknowledge, at least some of the time, that they had a memory problem. Their level of dementia was defined as mild to moderate. Most of the participants were living at home with their spouse, although some were living alone or in a care home. People with dementia and their carers were interviewed approximately six weeks before the groups began, at the beginning of the groups, after seven weeks in the group, at the end of the groups and ten weeks after the groups had finished. Of the 42 participants, 27 completed all of the measures. The results revealed that levels of anxiety and depression reduced significantly. The results were discussed in terms of identifying the dynamics of the group on a continuum between two poles, both defined as "personal communication". At one end, were people who were interested to "do" something about their illness, rather than merely talk about it, and at the other end, were people who were overwhelmed by their experience. The authors argued that to be effective, a group needs a balance of both types of person, stating that the central element of group work is to allow people time and space to think about their own experience in the context of others in a similar condition. Hope and threat were themes that were identified as being central to dementia support groups and the role of the facilitator was important in balancing the two. In this sense, the authors argue for the usefulness of support groups for people with dementia.

The significance of this work was that it represented a shift in focus from groups supporting caregivers (Jansson *et al.*, 1987; Zarit, *et al.*, 1998) to those supporting the person with dementia. An early move in focusing on the person with dementia using psychotherapeutic intervention was the work of Feil (1967) with reminiscence groups, whereby group members recalled past activities and events in their lives within a group dynamic. A study by Neal and Briggs (2000) did not find statistically significant results to support Feil's claims of improved cognitive functioning and well-being. However, a study by Coteli, Manenti and Zanetti (2012) found some improvement using reminiscence groups, which highlights the difficulty in finding consistent results in this field of research.

Subsequently, there have been mixed claims for the efficacy of dementia support groups. Studies have made claims and counter-claims and the focus has been on a variety of outcomes. Leung, Orrell and Ortega (2015) studied electronic databases for randomised controlled trials (RCT) of support group interventions for people with dementia to address the lack of evaluation in this area. Their criteria were: that they were RCTs' and they included a non-intervention or control group, an adequate results section and descriptions of the study were provided, provision of data on participants, ongoing studies were identified. From a total of 546 studies only two met their inclusion criteria, which highlights a problem in this research of finding interventions that are sufficiently similar for useful comparisons to be made regarding effectiveness. Does this study highlight a problem in the approach to studying support groups for people with dementia in that by attempting to fit them into established research methods in the form of RCTs are they not excluding consideration of useful interventions? This field of study is often in the domain of small groups of professional who do not have the resources to conduct RCTs. Currently, there is little consensus as to what constitutes a support group, which can range from an informal setting that may be based on self-help and mutual support to a more structured format group facilitated by health care professionals.

Evaluation of effectiveness has been based on a range of outcomes: quality of life ratings, a perceived improvement in mood, social support or self-efficacy (Toms et al., 2015). Little consistency has been found in reports of effectiveness (Logdson, 2007). A review of three databases was conducted by Toms *et al*., (2015) to explore the effectiveness of support groups. Of the qualitative studies a number exhibited shared themes: that participants found groups a 'safe space' to share their experience of dementia with others, people enjoyed meeting people who were in a similar situation to themselves, increased sense of self-efficacy and esteem. Common negative themes focused around caregivers' feelings that their relative may not benefit, that it was difficult to meet people whose level of dementia was more severe than their own, that it is hard to speak in groups smaller in size. This study also considered participant characteristics, which varied substantially to include: gender, age, educational level, co-morbid conditions, dementia diagnosis, level of dementia. It was particularly interesting to discover that 70% of participants across the groups studies were male. Toms *et al.*, (2015) report considerable variation in terms of evidence of effectiveness. The types of interventions also varied considerably. The authors do not arrive at robust conclusions rather they discuss the difficulty of measuring outcomes in group settings for people with dementia as the range of variables are difficult to recognise. This study is a useful attempt to discover the effectiveness of group interventions for people with dementia but it's principle conclusion seems to be to highlight the methodological issues in a study of this nature. The studies outlined above highlight the disparate range of interventions in the field of support groups for people with dementia as well as the methodological issues involved in research in this area.

Subsequently, group work has developed into the area of psychotherapy with people with dementia. Principally this area has been developed by those theorists/clinicians cited above namely Miesen and Jones (1992, 1997), Kitwood (1993), Sabat and Hare (1992) Solomon and Szwabo (1992), Sparrow (1997), Kasl-Godley and Gatz (2000), Evans (2008). However, the most extensive work in this area has been that of Cheston and colleagues (1996, 2002, 2003, 2008, 2009, 2010, 2014a, 2014b, 2014c. Results from this work has claimed that psychodynamic approaches seem to be helpful in understanding intrapsychic concerns for people with dementia. Treatment models have focused on strengthening ego functions and object relations (Kasl-Godley and Gatz, 2009). Results have found reductions in levels of depression (Cheston and Jones, 2008), strengthening social identities (Cheston, 1996), and reduction in anxiety (Cheston, Jones and Gilliard, 2003). There have been exciting development in the area of psychotherapy with people with dementia, however they are beyond the scope of this review as the focus is on support groups for people with dementia.

In this section, a model has been discussed that focuses on the person with dementia's search for meaning, in order to achieve a sense of safety. Ideas arising from this model have been translated into working clinically in groups of people with dementia and their families, resulting in a shift of emphasis from carers of people with dementia to the person with dementia themselves, and their interaction with their carers and/or families. A further area of interest to this study is the place of the person in the family and the quality of life that caregivers and people with dementia experience, since the role of the family has been shown to be a significant factor in how people experience dementia. This will be the focus of the next section.

9. Families and the Person Who is Missing

Although the focus of this study is on the experience of the person with dementia, they cannot be seen in isolation, and the importance of relationships, especially familial relationships, cannot be overstated. Families have to deal with what is frequently perceived as the loss of a family member and it is difficult to say who suffers most, the person with dementia or the family. The loss for the family can become an issue of what Miesen (1999) describes the 'ability to bear'. A person with dementia will eventually have some awareness of that change. They may respond to an awareness of the loss of some of their functioning by changing their activities or carry on as before, perhaps seeking ‘handholds’ for safety. Handholds are defined as the need for a person with dementia to accommodate their memory loss by relying on present, concrete reality or past memories. The impact of this response on the family will depend on the level of help with daily living that the person needs, or the level to which the person, and the family, succumbs to a condition of ‘learned helplessness’ (Bryden and Friedell, 2001). Factors that influence a family’s ability to cope may be health, geographic proximity or financial, to name a few. The consequences of dementia for the family can be severe and perhaps the most significant experience for family members is the experience of grief; of experiencing the loss of their loved one as well as their own loss. This experience varies from family to family and is more difficult for some than others. The way in which families cope with dementia will be a reflection of the quality of their previous relationships.

9. a) Grief/Grieving

Perhaps the most significant relationship is that between the person with dementia and their principle carer. Do they communicate in an open and transparent manner? How have they coped with the changes and/or loss in the past? Every family’s situation is unique and personal to individual members of the family. Grieving is understood as a process of protest, despair and finally detachment (Kubler -Ross, 1969). Bowlby (1982) describes working through the loss as bewilderment, searching, longing for, anguish, despair and recovery. The process of grieving takes time and varies from person to person and culture to culture. The condition of abnormal grieving, whereby no normal grieving appears to be occurring, suggests denial of the loss. Grieving can become evident sometime after the loss and can be disguised as physical symptoms, indeed this can occur when grieving is protracted over a number of years and remains highly emotional to the person (Kubler-

Ross, 1969). Any of these aspects of grieving are pertinent for the person with dementia as well as their families.

Factors that influence the grieving process include the relationship with the person or event, how important they are to them, the personality of the person and how they have dealt with losses in their lives to date, since this will influence their ability to cope in the present. Responses such as denial, blaming, anger, reflection, talking it out, are common in the process. The type of bond between the person with dementia and their family is a factor. If the relationship has been what Miesen (1999) describes as 'exclusive', where the couple appear to exist only for each other to the exclusion of others, that may leave the survivor feeling betrayed and abandoned, particularly if it has been a very long union. Life can lose meaning in such a case.

Coping with the loss of a loved one to dementia, rather than an actual death is different in that the person who is mourned is still alive. Family members cannot actually mourn the loss of their loved one whilst they are still alive and as a result, may wish them dead, evoking feelings of guilt or shame. Miesen (1999) describes three reasons for people to wish the death of the person with dementia, which are to end the person's suffering, to bring an end to the person with dementia's slow decline and end the family's pain at witnessing the process, and the dismay they feel when the person with dementia does not recognise them or when they are distressed and cannot explain why. The family feel powerless and find such feelings very difficult to cope with. The death of the person with dementia would end the uncertainty of their situation. The absence of the person is felt whilst they are still alive. In these circumstances, feelings of hope and blame persist, family members blame themselves, hoping against hope for some miracle, sign of improvement or glimpses of the old self of the person they love. Until the person with dementia dies, the family cannot move on in practical or emotional terms and may feel guilty and distressed for wanting to do so. It is not surprising, therefore, to find that people with dementia and their carers report a change in their perceived quality of life (Bruvik, Ranhoff and Engedal, 2012).

10. Quality of Life

Quality of life has received considerable attention from researchers not least in the area of dementia (Hoe et al., 2004; Smith *et al.*, 2005; Trigg, Jones and Skevington, 2007). In conjunction with early diagnosis, treatment and/or management, a focus for people with dementia is to remain in the community and be cared for by family and/or care workers. Therefore, quality of life is a significant factor in a person's experience of dementia and as such, there is no reason why quality of life should not be maintained throughout the disease process (Alzheimer's Society, 2010). Early research into the quality of life of people with dementia was largely assessed using measures designed for caregivers. This proved to be an unsatisfactory process as it did not necessarily convey the subjective experience of the person with dementia (Bowling *et al.*, 2014). It had been assumed that cognitive impairment would constrain a person's ability to complete a subjective questionnaire. (Trigg, Jones and Skevington, 2007). Their study suggests that people with dementia are able to able to comment reliably on their quality of life. Some Previous research had assumed that people with dementia would report a poor quality of life. However, the authors did not find that to be so but did question whether the person might not consider quality of life to be a high priority for them at that time, or that their level of adapting could be masking their perception. Overall, this study found people with dementia to be a reliable in considering their quality of life but that group scores may be more reliable than those of the individual (Trigg, Jones and Skevington, 2007).

The ability to measure quality of life in people with dementia is a significant factor in enabling a person to live well with dementia. It is also a consideration in evaluating services in terms of cost effectiveness and quality of social support and care, which supports the argument for measures that adequately reflect the subjective experience of the service user – the person with dementia. Recognising these factors has led to a range of questionnaires being developed. Those that are considered to have attained reliability include: QAL-AD, QAL-D, QUALID, CBS, D-QOL and DEMQoL, (Bowling *et al.*, 2014), which has been used in this thesis. Quality of life for people with dementia is an area that is currently receiving considerable attention from researchers yet it is an area that is fraught with difficulty because of the nature of what is being measured, the subjectivity of the respondents and those who devise questionnaires, the reality of cognitive impairment in the target population as well as issues of validity, generalisability and reliability. It is also important to state that self-report questionnaires have not addressed the difficulties of administering to those with more than a mild to moderate level of dementia.

11. Conclusion

The discussion has focused on the work of theorists who take an informed and optimistic approach to dementia care, making strong arguments that dementia need not be a one-way street to hopelessness. Not only have they painted a more optimistic picture, but they have also constructed compelling arguments that have been supported by further research into their concepts and methods of intervention, as well as positive clinical results. They point the way to a view of the diagnosis, treatment/management of dementia that moves away from a focus on cognitive functioning in isolation to a view that incorporates the significance of the relationships that people with dementia are able to form and the environment in which this takes place.

Specifically, this review of the literature has set the current approaches to the treatment/ management of dementia in a historical context that gives an insight into the ways in which ideas, and particularly attitudes, have changed in relation to dementia in a relatively short period of time, resulting in treatment/management approaches becoming more ‘care’ orientated. The effects of government policy changes have also been discussed, including NICE guidelines that have been driven by the increased awareness of the effects of an ageing population, both financial and humanitarian.

The brief overview of attachment theory, focusing on the work of Bowlby, Ainsworth and Main, demonstrated evidence that the patterns of attachment established in infancy and childhood could be identified in individuals across the lifespan. Miesen’s work developed claims that adults use attachment behaviours as a means of seeking a sense of internal safety, akin to having a secure base. His work clearly defined the ways in which attachment behaviour is employed by people with dementia as a means of making sense of a world that has become bewildering and frightening. Not only does his work give us a means of understanding the experience of a person with dementia, but it also provides the tools to communicate that understanding so rather than attempting to bring the person with dementia into our ‘space’, one is enabled to meet them where they are.

The review has sought to demonstrate the impact that Tom Kitwood’s legacy has had in shifting the focus of attention away from considering dementia as simply an organic disorder and focusing on the plight of the carer, to putting the person of the person with dementia at the centre of understanding, treating/managing the dementing process. The work of Cheston, Bender and others was discussed, who developed Miesen and Kitwood's work clinically with their research into and development of group interventions, principally aimed at people with a recent diagnosis of dementia who were living in the community. This more recent research focused more on people with a mild to moderate degree of dementia. Working with small groups of people with dementia recognising the significance of relating to others who share a common experience. This corresponds to a view commonly held in the field of dementia, that early diagnosis and treatment with AChE inhibitors, where appropriate, and support groups for the person with dementia and their carers/families, are current recommendations of NICE (2013) in enabling people to live well with dementia.

The overview of the literature, outlined above, serves as a basis for the research questions of this thesis which are:

1. Are group interventions observed in this study perceived as helpful?
2. How does a group experience impact on a person's quality of life?
3. Does attachment style play a role in how participants experience the group?
4. Is there any association between attachment style, experience of the group and quality of life ratings?

The overall purpose of this study is to determine to what extent the current range of group provision, provided within one NHS Trust, meets the needs of people with dementia. This is an important area to investigate because if it can be determined what participants find helpful, it will enable more specific interventions to be developed, as opposed to a "one size fits all" model that exists currently. Enabling the person with dementia and their families to live well with dementia could alleviate considerable suffering and anguish as well as reducing the cost of care, both financial and emotionally. The next chapter will focus on the methodology used to address the research questions.

Chapter 3: Methodology

"My name is not dementia. I think people wear dementia like a coat, they have a big banner across them saying "I have dementia" . . . I think people should put dementia to one side, focus on something they would like to be" (Alzheimer's Society 2010).

1. Introduction

The literature review provided the background for the suggestion that it is useful to implement psychosocial group interventions in the early stages of dementia as a means of enabling people to "live well with dementia" (NICE, 2013). To this end, the aims of such groups include helping people to think about ways to manage their symptoms of dementia, fostering well-being and confidence, promoting a sense of belonging and purpose and enabling people to feel abler to cope with a diagnosis and meet other people who are in a similar situation (B.P.S., 2014). Group interventions have been found to be useful in achieving some or all of the above aims as well as preserving peoples' quality of life (Kitwood and Benson, 1995). Further, the review indicated that attachment behaviour can be triggered by the experience of dementia (Miesen, 1993). This study explores how a person's attachment style might influence how they make use of a group experience. This chapter briefly outlines the design of the study, which is aimed at addressing the above questions. The recruitment process, the profile of the participants, details of the methods used to collect data, the composition of the group and its process will be outlined. The methodological approach is explored in detail, as well as the methods used to collect the data. Ethical issues for this target group will be considered, alongside researcher reflexivity considerations. Finally, the analytical strategy will be summarised.

The purpose of this study was to examine the research questions by exploring the experiences of people who had been involved in a psychosocial memory support group within one NHS Trust as well as conducting semi-structured interviews and taking notes and observations of the group experience and home visits. A naturalistic design was used involving opportunistic sampling, an explanatory case study approach was adopted as a means of collating data from this target population. A detailed case study protocol (Appendix 4.2) was devised that set out procedures for the collection of the data, so as to ensure that a comprehensive case study database was achieved as a means of addressing issues of reliability. Data was collected using mixed-methods, comprising interviews, observations and assessment instruments from four separate series of psychosocial groups. The next section describes the design and methodology employed in this study.

2. Design and Methodology

The aim, in describing the chosen method, was to explore how and why a case study approach was considered the most appropriate means of exploring complex phenomena (McLeod, 2012) that is the focus of this research. Whilst there is considerable literature on case study methodology, what exists presents a diverse picture. The more recent studies cite older, more well-known research, however, a full and complete overview is beyond the remit of this thesis, which focuses on the rationale for the choice of design. The case study method is widely employed in social science research (Scott and Ives, 1992, Forrester, 2010) and there is a range of variation of the method, from a study of one person, to a study of an organisation. In fact, the term “case study” is used to describe an approach that has a variety of different purposes, which is evident in the literature (Glaser and Strauss, 1967; Miles and Hubermann 1984; 1994; Stake, 1995; Yin, 2009; Mcleod, 2010; Breakwell, Smith & Wright, 2012). Variation also exists in the methodology employed in the case study approach, ranging from observational data from one case, to a complex variety of data collected from a number of cases that can include any number of participants.

Stake (1993) described three types of case study: “intrinsic” being based on one case, which has been widely criticised as lacking representativeness; “instrumental” being focused on building known theory or developing insight and “collective” being instrumental and extending beyond the single case. Yin (2009, page 29) contributed three further definitions: “exploratory”, in which data is collected prior to theory or research questions being identified; “causal”, which explores cause and effect for explanatory explanations and “descriptive”, requiring a theory to guide the collection of data.

As a result of this diversity, there are contradictory views in the literature on the usefulness of case study as a reliable methodology (Meyer, 2001; Hyett et al, 2014). Some criticism has been made of the lack of representativeness and statistical generalisability of findings from case studies too. Flyvberg (2006) claims this is an issue for case study approaches, particularly in relation to real life events.

In order to decide which method was best suited for this study, the researcher considered the type of research questions being asked, since this helped to determine the appropriateness of some methods over others. The explanatory case study method developed by Yin (1984,1993, 2009) is particularly suited to exploring causal links and has been found to be a valid methodological choice when the phenomenon being researched is on-going and the researcher has little control over events. This method also enabled the researcher to make direct observations of the events being studied and to interview the participants directly. Also, Yin (2009) argues that although it is possible to study a unit of a ‘case’, i.e. a participant, and the phenomenon of the group itself; confusion can arise because of the complexity of studying the group whilst simultaneously studying the individual in the group. However, this study does indeed study both phenomena, the individual in the ‘case’ and their experience of a group setting, which did cause tensions that will be explored in chapter six.

The design of this study can be summarised as an explanatory, embedded multiple case study comprised of four ‘cases’ of a group of participants who all experienced four sessions of a psychosocial group and who participated in a semi-structured interview and other measures, detailed below, administered by the researcher in their own homes. The case studies will demonstrate whether a person’s attachment style influences how they are able to make use of a group and how they experience living with dementia. The research design embodies a theory of what is being studied – a hypothetical story of their experience. The study can be described as a multiple case study as four separate ‘cases’ will be examined. They are described as embedded because within each ‘case’ complex data was examined. An explanatory method was used to explore causal relationship between attachment style and the person’s experience of the group to ascertain whether there were any links between the experience of a psychosocial group and a person’s perception of their quality of life and whether a person’s attachment style was a factor in the experience. This approach allows for the group as a whole to be considered as well as the individuals within the participant group. The rational for choosing this particular approach was based on Yin’s (2009, 4th ed.) argument for the case study method as an empirical inquiry that investigates an on-going event within a real-life context (Creswell, 2013b). The second aspect of this approach is recognising that the boundaries between the event and the context are not clearly defined.

The strength of Yin's (ibid.) approach, as outlined above, is the rigour with which the case study is determined by a set of prescribed procedures that ensure the quality of the study. Specifically, in addressing construct validity, internal validity, external validity and reliability by developing a case study protocol (Appendix 4.2) prior to data collection that is adhered to rigorously for each 'case'. The function of the protocol was to provide a template that ensures the focus for the data collection was the same for each 'case'.

Yin (ibid) claims that the case study method demonstrates rigour in a number of ways. In addressing generalisation he cites analytic generalisation, rather than statistical generalisation as in quantitative research, as a valid and rigorous methodological choice, which can be understood in terms of a theory that was developed before data collection that is used as a guide with which to compare the empirical results. Flishman (1999) defines this method as "extensive research", whereby monitoring of phenomena enables the researcher to explain the history and the changes that take place over the period of the research. In carrying out a multiple case design replication can be addressed by replication logic. In this study the logic was that by adopting a naturalistic sampling method similar results may be anticipated from each 'case' and by adhering to the Case Study Protocol for each 'case'. This design also allows for modification of the theory, on which the questions are based, to be developed between groups. If the findings of the first 'case' do not fit with the design, then 'redesign' should occur before the next 'case' begins. If not significant factors may be ignored, this arose was between 'cases' one and three whereby it became clear that to ignore the relationship between the person with dementia and their principal carer would have led to loss of relevant information. The rationale for this redesign will be detailed below. A further strength of this design is that mixed methods of data collection can be applied. Thus allowing for a collection of richer data enabling greater triangulation. Further, this design allows the theory underpinning this study, described above to be explored in terms of theories relating to the individual (quality of life, attachment theory) and group theories (family relationships, group dynamics) enabling the 'case' to be considered from the perspective of the group and of the individual.

This particular approach was chosen as a means of explaining presumed links between participants' experience of a psychosocial group intervention and attributes of the participant that are too complex for survey or statistical analysis. The design is not merely an outline of how the research was conducted but also a means of ensuring that the data collected addressed the research questions and allowed the possibility of greater understanding of a situation, such as this study explored, where what is being evaluated had not a clear set of outcomes. A multiple case study design allows for iteration from one 'case' to another. Also an embedded design for complex data to be examined.

In outlining the design of this study a logical plan has been laid out that addressed collecting data that focused on the research questions and allowed for some inferences to be made about causal relationships among the variables being investigated.

The working definition of the case study methodology used in this research has been defined in two parts (Yin, 2009 p. 18) as follows:

1. This form of case study is an enquiry that:

- investigates a contemporary phenomenon in-depth and within its real-life context, especially when:

- the boundaries between a phenomenon and context are not clearly evident.

2. This case study enquiry:

- copes with the technically distinctive situation in which there may be many variables of interest but not much data on each variable, and
- relies on multiple sources of evidence, where sources of data are brought together in a converging fashion, and
- benefits from the prior development of theoretical propositions to guide data collection and analysis.

This section has argued that a case study approach was deemed to have been the most useful method for this research, since it enabled the researcher to study the whole, whilst studying the individual and vice versa. The next section will outline the profile of participants and how they were selected.

3. Participants

The target population were people with a recent diagnosis of dementia at a mild to moderate level as assessed by clinicians at a local memory clinic. The sample chosen to represent this group, was recruited from those who had been offered a place on a psychosocial support group delivered by a local NHS Trust. At this time, they were asked, by the older age team, if they were interested in being involved in the study, having been provided with basic information, defining the aims of the study and the level of participant involvement (Appendix 2.1). The researcher was then given a list of potential participants and their telephone numbers. This selection process was considered to be the most appropriate procedure possible in the context, although there was no certainty that this would result in a representative sample. The researcher was not involved in any of the selection procedures for the group, nor was any clinical information available to the researcher.

The researcher contacted potential participants by telephone to arrange a meeting in their home to assess their ability to give informed consent, this being the basis for inclusion in the study. Informed consent was addressed by furnishing, in detail and in their own homes, potential participants and their family/carer with information based on the purpose of the research, what participation in the study would involve, the potential benefits of the study, confidentiality and data management was addressed, as was feedback on the outcome of the study, that participation was voluntary and could be rescinded at any time without affecting their treatment, that the research had gained consent by IRAS and had insurance coverage through the University of Kent. As consent is an ongoing process participants were asked if they understood what was being asked of them and if they had any questions at each home visit. The researcher’s contact details were given to enable people to ask questions or withdraw from the study at any time. Exclusion criteria for the study was based on the person’s ability to give informed consent. There were no other excluding factors as the researcher’s aim was to recruit participants that were as broadly representative of the target population as possible. The researcher was given to understand prior to participation selection that those offered a place in the groups had been rated as mild to moderately cognitively impaired. Otherwise, severely impaired cognitive ability would have been included as an exclusion factor.

Of the thirty-six people that expressed an interest in participating, twenty-six people completed the study. All were living in the community either alone or with family. The age of participants varied considerably between those in their late fifties to one person who was ninety eight years of age. However, the majority were in the range of sixty-five to eighty-years of age. There was little ethnic variation amongst the group, with only one couple being of Hong Kong Chinese origin the remainder being white British. No information about participants' socio-economic status was collected. The gender distribution of participants was fourteen females to thirteen males and of the twenty-seven carers, there were fifteen females and twelve males. No further demographic details were obtained by the researcher. As this study initially focused principally on the person with dementia no sample details were taken from family members/carers.

This particular sample population was chosen as they were deemed to be representative of those with a recent diagnosis of dementia at a mild to moderate level, as assessed by the group facilitators prior to commencement of the group, this being the target population for this study. Although the make-up of each group was different, there were no indications to suggest that they were likely to be unrepresentative of the wider population. Early diagnosis and treatment of dementia has been shown to enable people to live better with dementia for longer by maintaining cognitive functioning (DoH, 2009). It was expected that this sample group would provide rich information as they had a recent diagnosis and their cognitive functioning was not too severely impaired. The decision to offer someone a place in the group was based on the person's ability to engage in group activities at a level that could be useful to themselves and to others. The researcher had no input into this decision making. This section has considered the choice of target group for the study. The next section will define the 'case' to be studied.

Table 1: Participants' Demographics

No.	Gender	D.O.B.	Ethnicity	Residential Status
1	Female	1913	White British	Living with daughter
2	Female	1940	White British	Living with husband
4	Male	1942	White British	Living with wife
5	Female	1935	White British	Living with husband
6	Female	1942	Hong Kong Chinese	Living with husband
7	Male	1939	White British	Living with wife
8	Female	1927	White British	Living with husband
9	Female	1927	White British	Living with son
10	Female	1929	White British	Living alone
11	Male	1931	White British	Living with wife
12	Female	1930	White British	Living with husband
13	Male	1928	White British	Living alone
14	Male	1938	White British	Living with wife
15	Male	1924	White British	Living alone
16	Female	1929	White British	Living with husband
17	Male	1942	White British	Living with wife
19	Female	1927	White British	Living with wife
21	Male	1932	White British	Living alone
22	Female	1933	White British	Living with wife
23	Female	1928	White British	Living alone
24	Female	1926	White British	Living with husband
25	Male	1938	White British	Living with husband
26	Female	1940	White British	Living with wife
28	Male	1939	White British	Living with husband
29	Male	1959	White British	Living with wife

4. The ‘Case’

The ‘case’ of which there are four can be defined as the study of a group of people recently diagnosed with dementia: their experience of attending a psychosocial group; their perception of their experience of that group; their experience or their quality of life before and after the group event and whether their attachment style is a factor in any of the above. The study in each ‘case’ began with a visit to the person’s home where a range of methods was used to collect data, as outlined below, that addressed the hypothesis defined in the table 2, which illustrates which methods were used to provide data to match a particular question or, in some cases, to apply to more than one question.

5. Data Collection

The data collection will be considered from the perspective of addressing each question individually.

Table 2: Methods of Collecting Data

Questions	Method	Administered
Are the group interventions observed in this study perceived as helpful?	Group observations Perceived Helpfulness Questionnaire "D*id you find the group helpful"* question	During group sessions Pre-and post-group intervention.
How does a group experience impact on the person's quality of life?	DEMQoL Questionnaire	Pre-and post-group intervention.
Does attachment style play a role in how participants experience the group?	Adult Attachment Questions.	Pre-the-group-intervention.
Is there any association between attachment style, experience of the group and quality of life ratings?	Measures above.	Throughout the data collecting process

1. Are the group interventions observed in this study perceived as helpful?

The assumption made about the first research question was that the group intervention would be perceived as helpful. The researcher developed a measure to address the components of emotion, environment, occupation, education and social issues as these were the focus of the group sessions. The aim of the group being to enable participants to enhance their day-to-day lives.

Based on this content and the information gleaned from an observational study, whereby the researcher had the opportunity to observe and participate in a series of groups, a questionnaire was devised consisting of ten questions, ranked on a five-point Likert scale (Appendix 3.1) that was designed to address the content outlined above. Existing measures had been explored (Cantley and Smith, 2007; Cheston and Jones, 2009; Phung *et.al*., 2013; Short 2013; Leung, Orrell and Orgeta, 2015) but none were found to address the objectives of the specific groups in question. The aim of the Questionnaire was to determine how useful people had found the group experience by observing any differences in their ratings before and after the intervention. Although Snyder *et al*. (1995) describe a very similar group structure in which they were also aiming to determine the perceived satisfaction from a group experience whereby they used evaluative statements to explore participants' experiences of the helpfulness of the group. A study by Watkins *et al*. (2006) found some evidence that a group focusing on changes in awareness had positive results in peoples' experience of dementia. Having explored the above measures the researcher did not find them suitable for this study in terms of addressing the specific content outlined above, hence the development of the Perceived Helpfulness Questionnaire which was further influenced by a longstanding approach in psychotherapy process research Bloch et al. 1979, Elliott et al. 1985, Llewelyn, 1988 that focused on what was perceived to be most important or helpful in psychological therapy sessions.

The experience of administering the questions was that the researcher found that some people seemed to have difficulty in choosing one of the five written response options. It was decided to use a visual response option for the following two 'cases' based on the notion that a visual cue would require less prompting from the researcher and, therefore, lessen the risk of bias.

2. How does a group experience impact on the person's quality of life?

Quality of life is a difficult concept to define in people with dementia, as well as being largely subjective in the general population. However, it has been a subject of interest to those involved in the field of dementia for some time (Ready, 2002; Banerjee *et al.*, 2008) and of particular significance was a study by the Mental Health Foundation for the Alzheimer's Society that aimed to better understand the quality of life indicators for people with dementia (Alzheimer's Society, 2010). Their findings identified a number of recurring themes and found significant differences between people who were living in care homes and those in the community. The study involved people with dementia participating in the research, including those representing minority groups. The authors concluded that although there were a number of measures available (Ready and Ott, 2003; Hoe *et al.*, 2005; Becker, Kaspar and Kruse, 2006) they all had their limitations. In particular, they did not include those who were more severely affected or those representing minority groups. With these reservations in mind, the measure chosen was considered to be the most fitting for the target audience. It also had more endorsements from the study undertaken by the Alzheimer's Society (2010).

The Quality of Life Questionnaire DEMQoL and DEMQoL Proxy (3 c, d) were developed under the auspices of the NHS R&D Health Technology Assessment (HTA) Programme. The task was to develop and validate a rigorous self-measure of health-related quality of life for people with mild, moderate and severe dementia (Smith *et al.*, 2005) to be targeted at a UK population. Chua *et al.,* (2016) surveyed 868 people with dementia and 909 carers who had completed either the DEMQoL or DEMQoL proxy questionnaires to determine that quality of life assessments capture what is really important in terms of determining policy and clinical decisions. Chua *et al.,* (op cit) findings, as well as demonstrating that the measure was rigours, reported findings that were relevant to this study. Namely, that there were associations between depression and quality of life; that cognitive functioning was not correlated with quality of life. Specifically, they found that "worries about social relationships" might be a core factor in a person's experience of their quality of life (Chua *et al.* p 3115), which will be discussed in relation to this study below.

The DEMQoL questionnaire was administered to all participants with a diagnosis of dementia for the first two 'cases'. The experience of observing these 'cases' led the researcher to understand the importance of the relationship between the person with dementia and their family member/carer. Therefore, although the original aim was to focus primarily on the experience of the person with dementia it became clear that the relationship was too important to the person with dementia to be ignored. Therefore, for 'cases' three and four the DEMQoL Proxy questionnaire was administered to the principal carer.

In administering the DEMQoL questionnaire (Smith *et al* 2005)(Appendix 5.1), the researcher showed flash cards to the person with dementia, depicting each possible response as well as re-iterating the responses verbally. As stated in the questionnaire's instructions, gentle probing was used where necessary. To a greater or lesser degree, carers assisted the respondents with their replies. The DEMQoL questionnaire was completed by the principal carer themselves. An improvement in quality of life might be expected following the group intervention, an outcome that has been borne out by previous studies, that have claimed increased quality of life scores followed participation in a memory support group (Trigg, Jones and Skevington, 2007; Logsdon *et al*., 2010).

3. Does attachment style play a role in how participants experience the group?

In addressing the assumption that if people experienced the group as helpful and were comfortable in meeting and mixing with strangers, then they might be more likely to have a secure attachment style, the Adult Attachment questions (AAI) (Main, 1996) (Appendix 4.1) were administered as a semi-structured interview to the person with dementia in the presence of their principle carer, prior to the first group session. A semi-structured interview approach was used when asking the questions (as defined in the AAI protocol), in order to draw out responses where necessary.

Although the interview followed the AAI interview protocol a copy of which can be found in the appendix (Appendix 4.2) as I am not trained as an AAI interviewer they cannot be claimed to be an AAI interviews. Also, the process of administration of the questions was modified according to the needs of each participant in terms of greater prompting, clarification or expanding. The interview was aimed at producing information on a person's attachment experience and state of mind in relation to attachment, sufficient to enable a statement to be made on each person's attachment classification.

At this point, it is useful to consider the contribution Grice (1975, 1989) has made to the literature on AAI scoring. A semi-structured interview can be considered from a narrative content point of view in that the interview process itself tells a story. It is also appropriate to consider that Main (1990) incorporated Grice's maxims into all but the early versions of the AAI scoring and classification systems. Grice proposed that the overall coherence of a narrative can be assessed using four maxims: manner, relative, quality and quantity. Grice's work has deepened the understanding of the way in which language is organised in AAI responses, and thus what is being assessed when coherence versus incoherence is being estimated. This approach has been widely incorporated into research on AAI transcripts (Bakermans-Kranenburg and Ijzendoorn 2009 ; Renn, 2015).

4. Is there any association between attachment style, experience of the group and quality of life ratings?

It was proposed that there would be correlations in the data collected, supporting the idea that no single method of data collection would elicit sufficient information from this sample, principally because there are few methods aimed specifically at people with dementia. For this reason, the researcher had to devise a measure specifically for this study and use measures that were not originally designed for this sample population.

The methods outlined above fell broadly into two principle camps; the first ascertained the person's quality of life and their perceived helpfulness of the group intervention, which could potentially correlate, since if a person perceives themselves to have a good quality of life, then they may also perceive their environment to be beneficial and helpful to them, which, in this case referred to the group intervention; the second, ascertained the person's attachment style. Measures aimed specifically at the target population were not available in every instance and therefore, although standardised measures were used wherever possible, the researcher also devised measures based on material gleaned from the observational study and exploration of the literature.

The methods outlined above were all administered in the context of semi-structured interviews in the participants' own homes. The advantage of using semi-structured interviews was that they allowed the researcher to be flexible and responsive to the information that the participant was giving, enabling what might be considered as significant topics to be explored in more depth, and prompting for more information when responses were minimal. A more structured interview was considered to be too rigid an approach that would not allow for the depth of material that might be gathered, particularly in the context of a study that explored human relations in all their intricacies, with people having problems with their memory. The next section will consider the structure and aims of the groups.

6. Structure and Aims of the Groups

Each group met for four consecutive sessions at a venue identified by the Trust. Of the four groups studied, there were three separate venues. The venues were adequate with respect to the accommodation they offered apart from one where the acoustics were difficult for a number of people who had hearing deficits. Locations were chosen based on proximity to the area in which the majority of group members lived.

The facilitators were members of the local Older Age Service, consisting of clinical psychologists, student psychologists, an Admiral Nurse[1], a Memory Nurse[2] and an occupational therapist. The composition of the groups varied, apart from a clinical psychologist being present in all four groups.

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[1] Admiral Nurses are those who are specifically trained in the field of dementia.

[2] Memory Nurses are those who support people with memory problems in the community.

The group sizes also varied and were comprised of people with dementia and their spouses, and/or their caregivers, and/or their wider family members. Some group members participated in the study, but not all. There were four participants in one of the groups, six in another and eight in the remaining two. However, in terms of context and environmental circumstances, participants and non-participants received the same group experience. In total, the four groups were studied over a period of eight months.

Table 3: Group Structure

Week One	**Week Two**	**Week Three**	**Week Four**
Introductions. What is dementia?	Making the most of your memory.	Well-being, health and relaxation.	Enjoying life, local information and resources to make life easier.
Whole group.	Whole group for presentation then the group split into those with dementia and carers, which were further sub-divided.	Whole group for presentation then the group split into those with dementia and carers, which were further sub-divided.	Whole group.

The structure of the groups was closed, meaning that no further participants were introduced once the series of sessions had begun. Each session lasted for three hours and a set topic was addressed as outlined in Table three. The structure had some flexibility as the facilitators made a point of addressing issues that might be specific to a particular group. The atmosphere was relaxed and informal and all consented to being addressed by their christian names. Everyone wore large name labels at each session to encourage this informal atmosphere and to mitigate the stress of having to remember names. Care was taken when the groups were broken down into sub-groups to ensure that groups of people with dementia were as balanced as possible in terms of the severity of their symptoms, participation levels and commonality. The objective of splitting the groups in this way was to enable people with dementia and caregivers to discuss sensitive topics separately that might be more difficult if discussed together. Light refreshments were served at approximately the mid-point of the session, enabling people to network, which resulted in friendships forming between participants in all of the groups.

The aims of the groups, as defined by the Kent and Medway NHS and Social Care Partnership Trust, (2013) were:

- To be relevant to both those with a diagnosis of memory difficulties and those supporting someone else with a diagnosis.
- To introduce service users to local support services and provide basic information about dementia, strategies and approaches to living well with the condition.
- To introduce service users to others going through similar experiences.
- To provide a facilitated space to discuss the emotional and practical implications of the diagnosis on the family.
- To encourage couples and/or families to talk about the changes they face following a diagnosis of dementia.

The overall aim of the groups was to encourage people to talk, within their families and their wider social context about their experiences of how dementia impacted on their day-to-day lives. It was an opportunity to discuss coping mechanisms and concerns. In short, the aim of the groups was to help people with dementia and their families to better understand the process of dementia, to provide information that would be useful in their day to day living and to facilitate contact with others in their neighbourhood following completion of the group sessions.

The researcher's role during the groups was that of observer, specifically focused on the extent to which people with dementia were able to engage in the process and be involved in discussions and activities. This proved to be a more difficult task than was anticipated due to there being people in the sub-groups that were not participants in the study and the fact that there were a number of sub-groups being observed at a time, which created tensions about what was being studied and what could be studied in this context. The challenges of which will be detailed in chapter six. The researcher observed the group and scored participants' engagement and involvement in the group process following each session. Having detailed the way in which the data was collected, the next section discusses the ethical considerations that were relevant for this study.

7. Ethical Considerations

The most critical ethical consideration was gaining informed consent. Petri (2010, cited in Ethics in Dementia Research, 2011) defined the following components of informed consent: The possession of competence; having volunteered to make a particular decision; having been provided with clear information about the research including risks and benefits; having freely decided to participate in the study in study in the knowledge that they can withdraw at any time. Grisso (1988 cited in Ethics in Dementia Research, 2011) highlights the significance of competence in a person's ability to give informed consent and suggests it be considered in the following way: the person must have sufficient capacity to understand the information given; the person must be able to retain the information and weigh-up the implications of participating; understand how participating in the study will affect him/her; the person must be able to communicate their decision. One of the ways in which capacity is impaired is when there is a disturbance in the mind or the brain, which is the case in dementia. Secondly, is the disturbance sufficient to prevent the person from making an informed decision (NHS-IRAS). When assessing people for research who have a diagnosis of dementia it is reasonable to be aware that their capacity could be impaired and that over time it is likely to deteriorate (Alzheimer Europe, 2011). The above highlights some of the complexity in the ethical considerations in obtaining informed consent from people with a diagnosis of dementia. Research should do no harm to participants and this research did not involve any practice known to cause harm. Participants and their carers were reassured that the information collected, as part of the research, would be held in confidence and in a secure place. It was detailed in the Participant Information Sheet (Appendix 2.1) that participation in the research could be terminated at any time. Each participant was assigned an identification number to ensure anonymity. Ethical approval was sought and gained from NHS Ethics Approval (IRAS) and the research was carried out in accordance with this approval. Overall, care was taken to ensure that participants and their families were treated with dignity and respect throughout. The next section discusses the dual role of being a researcher and a practitioner.

8. Reflexivity

The researcher has a background in nursing as a Health Visitor, working in the community with families across the lifespan and as a psychiatric nurse with in-patients; in both settings, working with people who had a diagnosis of dementia. Subsequent training and twenty-five years' experience as a psychotherapist has led to an interest in attachment, specifically across the lifespan. The significance of the quality of close relationships on the effects of long-term, life-challenging illness has also been a factor in determining the focus of this research. Experience of working relationally with individuals has also led to an awareness of the influence of the person of the researcher in any research activity, but especially, as in this case, where semi-structured interviews were employed. Rather than seeing one's own values, attitudes, perspectives and beliefs as a hindrance in collecting data and observing complex phenomena, it can be accepted as another source. A source that is not accepted at face value but subject to rigorous analysis that can be a valuable adjunct to the data collected from participants. The researcher kept notes of impressions and observations gained at each interview, as well as at the group sessions. Furthermore, as a psychotherapist, the researcher has developed skills that are honed to the significance and nuances of a person's responses, particularly in relation to others. The author was aware of taking a stance in terms of focusing, as far as possible, on the voice of the person with dementia, rather than on professionals or families.

Throughout the process of data collection, the researcher was aware of the effects of interviewing people in their own homes and observing them in a group situation in terms of how the data collection could be biased by the researcher's own values/judgements. The case study protocol was helpful in focusing questioning and observations to be as consistent as possible for all participants.

On numerous occasions, the researcher was moved by the quality of the relationships between the person with dementia and their principle caregiver. In some instances, there was warmth and patient understanding, in others, barely concealed irritation and, in one case, open hostility. There was wide variation between these two poles. The researcher's observations of this closest relationship brought home the significance of that relationship. The researcher observed the differences in the interactions between the researcher and the person with dementia. There were those who seemed relaxed in the company of their partner and those whose relational stance was less positive, who related to the researcher more cautiously and anxiously in the presence of their partner. The researcher was able to observe these differences since they had the opportunity to interact with participants and their families in their homes as well as in the group setting. As a result of these observations it was decided to include the DEMQoL Proxy for 'cases' three and four and to incorporate observations relating to the relationship between the person with dementia and their principal carer. This decision was contrary to the researcher's original aim as so much research in this field appears to be focused on the experience of the carer the aim in this study was to avoid a repetition of this. However, it became clear that the principal carer played a key role in the person with dementia's experience that could not be ignored if a true picture were to be captured. The next section outlines the proposed analysis of the data.

9. Analytical strategy

As the data was collected from a range of sources analysis was specific to each. and took a number of forms as detailed in table 4 below. the 'cases' will be considered holistically bringing together the analysis of the distinct forms of data collected enabling triangulation between the findings.

Table 4: Analytical Strategy

Form of Analysis	Instrument
Analysis based on Gricean principles (1975; 1989a) – focusing on evidence that categorises respondents as either securely or insecurely attached.	AAI questions.
T-test analysis	DEMQoL. Perceived Helpfulness Questionnaire.
Thematic analysis.	Field notes, group observations, AAI, questions responses.
Observational comment.	Group engagement. Field notes.

As specified in the table the AAI questions were analysed using Gricean conversational maxims (1975; 1989a) to enable an attachment style to be ascribed to each person with dementia. For the DEMQL and Perceived Helpfulness questionnaires a t-test statistic was obtained as an indication of the similarities and differences between 'cases'

Having analysed the data using the methods described above the field notes, group observations and AAI question responses; a thematic analysis (Miles and Huberman, 1994) was used to identify themes and patterns within and between the data and the 'cases'. Thematic analysis has been described as an inductive, analytical process, aimed at searching through the data to identify key words that are associated with the research question and re-examining and identifying patterns or themes in the data. A definition that encapsulates this process is "Case studies are analyses of persons, events, decisions, periods, projects, policies, institutions, or other systems that are studied holistically by one or more method" (Thomas, 2011). Other approaches were considered: Interpretative

Phenomenological Analysis (IPA, Smith *et al,* 1990), Grounded Theory (Glaser and Strauss, 1965) and Discourse Analysis (Harris *et al*, 1989). However, as the interviews were not recorded and data was collected from a range of sources, thematic analysis was considered most suitable in dealing with the complex phenomena that this study investigated.

This chapter has addressed the design of the study and discussed the methodological theory that underpinned the chosen method. As well as a profile of the participants and an outline of the procedure for recruiting participants; the structure of the groups; data collection; a consideration of the researcher's interest and experience; ethical issues involved in research with a vulnerable group. and a brief overview of the analytical strategy was given. The next chapter will focus on the analysis of the data.

Chapter 4: The Group Experience

"It is paradoxical that an epoch which has exalted individualism virtually to the supreme value should have had so gross a disregard for individuality" (Kitwood 1994, p. 11).

The focus of this chapter will address three of the research questions:

1. Are the group interventions observed in this study perceived as helpful?
2. How does a group experience impact on a person's quality of life?
3. Does attachment style play a role in how participants experience the group?

The first question was addressed in three ways:

- By analysing data collected from my observations of peoples' involvement in the group and their level of engagement with others and/or what was being presented/discussed.
- Data derived from thePerceived Helpfulness Questionnaire prior to and following the group sessions.
- Finally, at the last home visit I asked the question "D*id you find the group helpful".*

The second research question was addressed by data generated by the DEMQoL questionnaires, administered before and after the group interventions and analysed by performing a related samples t-test.

The third question was addressed using data collected from the AAI questions, which was analysed using Grice's (1975, 1985) work on conversational maxims.

This section has described the focus of the chapter. The next sections will present a description of the group experience focusing in detail on the first 'case' as an example of the format and content that was common to all four 'cases'.

The delivery and content of the four separate occurrences followed the same formula and had the same aims as those detailed in the previous chapter. The groups took place in three separate venues that were all of a 'church hall' type of setting. They were not ideal for one reason or another, either not warm enough, the acoustics were poor or there were limited breakout rooms for splitting into smaller groups. Group members were seated at tables of eight that were arranged around the hall. On each table there were some people taking part in the research and some who were not. There was at least one facilitator at each table whose function was to guide/stimulate discussion. The sessions lasted for three hours with a coffee break in the middle. The sizes of groups varied from the low twenties in number to upwards of thirty people and consisted of people with dementia and family members.

1. Case Study 1

This case study is given in detail as an example that is typical of the other three in terms of format and procedure. Therefore, this level of detail will not be given for the subsequent 'cases'. I collected data by recording my own ratings of peoples' level of engagement (in this context principally attentiveness) and involvement (actively participating) based on a simple recording of my observations from all those participating in the research. Each participant was given a rating from one - four at each group session to represent their level of involvement. The same procedure was used to rate levels of engagement. The data was scrutinised in terms of the levels of involvement in the groups, which may or may not have been verbal, as well as participants' degree of socialisation or isolation expressed in terms of engagement. I will only identify participants who were involved in the research and then by a pseudonym. I spent each group meeting observing those who were taking part in the research across all activities. During the table discussions and activities I allocated my time between the tables based on how many of my participants were at a particular table.

1. a) First Group Meeting

There were eight people with dementia and their spouse/family members in this cohort. I arrived early to greet those who were participating in my research as I was aware that I would probably be the only person that most of them might recognise although there were other members of the Older Age Team present However, Anne was there when I arrived. As her mobility was impaired she was in a wheelchair. When I greeted her she recognised me from somewhere but she didn't know from where. She adopted an air of detachment for almost the whole session, at one point seeming to fall asleep during the presentation. However, when her daughter went to get coffee I noticed that she was actively taking an interest in the conversation next to her. She only contributed to the discussion around the table when asked a direct question; then she was monosyllabic.

Bella was very anxious when she arrived and had to be persuaded by her husband and myself to enter the hall. She sat at the end of a table putting herself on the fringe of the group. She seemed engaged in the proceedings throughout but did not contribute anything spontaneously, eventually she was involved in conversation with Jeanie. Her husband was attentive to her especially initially, she relaxed when the group began and it became more informative rather than interactive. Her husband was very engaged and involved throughout. He noticed his wife's conversation with Jeanie and suggested, to one of the facilitators, that next time he would sit elsewhere and give her an opportunity to engage further with Jeanie.

Eric seemed somewhat wary and his tremor was marked when he arrived. He was friendly when I greeted him. Initially, he contributed little but was engaged throughout. Gradually he became more involved and when directly questioned expanded on what he had been asked. His wife was active on the table.

Jeanie was very anxious when she first arrived and later told me that in the first half hour she had wanted to leave and was determined not to return. She seemed to move in and out of attentiveness initially, this later became sustained. However, she only responded to direct questions. She did become involved in conversation with Bella during the coffee break. Her husband was very vocal and seemed very keen to have an opportunity to air his experience.

Iris and her husband greeted me warmly. She was engaged for the whole period, being very attentive to all the proceedings. She only contributed verbally when addressed by the facilitator in his attempts to involve her in the discussion, at those times she responded fully stating that she wanted to have a voice and to make the most of the groups. Her husband was very active verbally. At the close they both came and said good bye inviting me to go back to their home for a cup of tea any time I was nearby.

Roger and his wife arrived somewhat later than most, which he said he was due to delays on public transport. He seemed cautious but quite able to settle into the proceedings. He and his wife were pleased to be able to attend together and as time went on were involved actively in the discussions. He was engaged throughout and was involved appropriately.

Rosemary seemed quite relaxed when she arrived but I think it is a difficult judgement to make as I was of the impression that as long as her husband was by her side she felt secure. She recognised me but she didn't know from where. It is difficult to gauge her level of engagement, as although she appeared to be engaged I couldn't be sure that she was understanding what was happening and/or whether she was able to be in the present. She responded to direct questions but her responses, as reported by the facilitator, support my statements above. Frequently Rosemary looked to her husband in a way that suggested she needed support or guidance from him.

Eva arrived with her son, she seemed relaxed throughout and was engaged in the proceedings. During the discussion sessions she was an observer rather than a participant. She responded to direct questions from the facilitator and reiterated what she had told me about her sense of isolation, living in an remote village with her son and his family.

Throughout this session all remained in one group to encourage people to feel relaxed. Following the session the facilitators, all members of the Older Age Team, had a discussion to share information and voice concerns they may have had. All of the participating couples were discussed. In all there were13 people with dementia, 4 accompanied by offspring, 10 accompanied by spouses (1 triad). Of these, four couples were involved in the research. Anne and Rosemary were identified as too cognitively impaired to gain much benefit from the groups but it was deemed useful as a support for their carers. The anxiety of Bella and and Jeanie was discussed at length as was Eva's sense of isolation. It was decided that as Bella had seemed to have made a connection with Jeanie that would be encouraged in future sessions as well as allowing her time when her husband was not present to have a voice of her own. Jeanie's husband was considered to be supportive. Eva's isolation was seen to be a problem as they lived in an remote village without any public transport. At this stage the team were considering a referral to Age UK to increase her social contacts.

1. b) Second Group Meeting:

The morning began with an information giving session on memory with the whole group together. following this was a discussion in small groups on living with dementia and how people cope with it. I was occupied in observing the dynamics of the groups around the tables. On table one the research participants were: Jeanie, Bella, Roger and Eric. Principally family couples were engaged with each other. Jeanie was discussing the leaflet, that was on the table for comment, with her husband as was Roger and his wife. Bella had no input but was engaged in listening to her husband who became involved in conversation with Jeanie and her husband. Eric and his wife were discussing the leaflet with the facilitator. Jeanie also became engaged in a discussion with the facilitator and Bella was attentive but did not contribute. Roger and his wife did not engage with the others on the table. There was no general discussion on this table although the facilitator made attempts to engage the couples with each other, it seemed difficult to stimulate a more general response. Rather, family couples seemed comfortable talking to each other only at this stage.

On table two the research participants were Anne and Iris and family members. Anne looked at the leaflet but had no conversation with anyone she was completely isolated as she made no attempt to become involved with anyone. Her daughter attempted to involve her with the rest of the table to little avail. Iris's husband was talking only to the facilitator and not including her. Iris busied herself with the leaflet responding to her husband only. Again there was little discussion across the table. There were only two couples participating in the research but the dynamic was similar to that described above in that couples appeared to prefer talking with each other rather than becoming involved with others.

Table three had two participants who were involved in the research, Eva and Rosemary. Eva appeared to be very interested in the conversation around the table but contributed little initially. However, when spoken to she became animated and listened attentively to others. Rosemary did not contribute at all and spent most of the time exploring the contents of her handbag. Overall, this group listened to each other and took turns in speaking, creating a table-wide discussion. There was more dialogue across this table than those described above.

For the second half of the session two groups were created - people with dementia in one group and carers in another. Carers were further split into spouses/children. The sub-groups were held in separate rooms to facilitate people with dementia and spouses/carers to be able to talk about their experiences more easily. As I could not observe both sub-groups I focused on the people with dementia.

Bella, Jeanie and Ann were on a table together. Bella and Jeanie were in discussion ignoring everyone else on the table. One loud man gradually gained the attention of the whole table. Bella is amused by his jokes but Jeanie did not seem amused and having gained the attention of the others talked about social changes in her lifetime, voicing regret at changes in society in general. Bella spoke of her experiences when she was living in

London, in particular how much she missed the community spirit, which she gave examples of. Ann became involved with a person not part of the study. However, there was little dialogue between them – rather a monologue that appeared to be her standard story that she had also told me and I had heard her relate to others. This conversation continued for most of the allotted time. I was interested to see Ann so animated but I suspect it is because she found a good listener who was very polite, allowing her to continue at length. Bella and Jeanie again became deep in conversation with each other only. Ann continued to talk about her life with a father and a husband in the military and the travels that ensued from their postings, with the rest of the women on the table listening, who did not have the opportunity to contribute. Ann went on to talk about her grandchildren. The student facilitator tried to draw her out on what she did with her grandchildren – a three way conversation developed including Bella. Ann was smiling and animated. Jeanie seemed more able to expand on her day to day experience on this table. She spoke of her distress at not being able to remember recipes that she had cooked for years. There were two clusters on this table one around each facilitator. The student facilitator worked at engaging with the three women but the male facilitator allowed himself to be caught up with the two men resulting in a male/female split.

On the next table were Roger, Eric, Iris and Eva and Rosemary. Iris introduced herself in detail talking about her life in Hong Kong and then living in London and working in the restaurant business. Eric was a little hesitant in his introduction. He appeared to be struggling to find his words. One man (not part of the study) dominated this table telling his life story –everyone else listened – this pattern happens repeatedly in that once he began talking he did not seem to have a sense of turn taking in conversation. Eric spoke of his work life – in less detail and more appropriate in length. Roger spoke of a friend who also has dementia and how useful he has found it to be able to share his experience with him. He then became involved with Eric in a conversation about football but Eric did not seem very interested in this aspect of the conversation. The facilitator asked how having memory problems has affected their day-to -day lives and specifically invited Rosemary to tell the group of her experience. Rosemary seemed not to understand what was wanted of her and wandered into the next room to find her husband. Eric responded to the facilitator's question by detailing how difficult he had found giving up his driving licence, which he felt had curtailed his freedom. Iris responded monosyllabically to the facilitator who was attempting to engage the whole table in the discussion. Eva contributed in a jokey manner that was incongruent as she was talking about her current situation of being isolated and not feeling hopeful about finding a club that she could join, she responded to suggestions but reverted to talking about how she misses her friends in Dorset describing her bungalow there, which she stated she loved and misses. Eric interjected and spoke of missing his work life and described how he tries to be helpful to his wife but feels that she humours him rather than he is a help to her. The facilitator tried to include Iris again but with limited response. Roger is humorous in talking about how he uses his bus pass to travel around the county describing some of his experiences of forgetting where he was going. Eric picked up the jokey theme about giving up driving, which he had previously spoken of in more mournful tones. Iris said she had never driven. When they lived in London they did not need to drive. She spoke about how they are dependant on their daughters to take them shopping, or to medical appointments. However, she has recently taken to going to Canterbury by public transport and really enjoys wandering around. Eva used to drive but she has had to give up her driving licence, which she says adds to her sense of isolation. The facilitator points out that sometimes people can help each other with their memory lapses. Eric talks about how he cannot remember the word dementia – he lies in bed trying to remember it. This was much more of a whole table discussion, which was orchestrated by the facilitator.

1. c) Third Group Meeting

Group members were welcomed and invited to re-cap on the previous week's group. There was no involvement of people with dementia in the feedback that was given. The presentation focused on what influences memory and thinking ability followed by table discussion then a relaxation exercise.

Jeanie looked disinterested throughout the presentation (I learnt later that she had left her hearing aids at home). Ann was alert watching new-comers arriving but not focusing on the presentation. Bella was attentive but did not participate in the discussion. Rosemary and Eva sat next to each other but there was no communication between them. Roger arrived quite late as they had been delayed by an accident in Canterbury. Eric was very attentive throughout the presentation.

Table Discussion

On the first table were Bella, Eric, Roger, and their spouses. When the facilitator addressed a question at Bella her husband spoke for her. The facilitator persists in her attempts to engage Bella who was able to respond without her husband interrupting eventually. Unusually, Eric's wife spoke for him and he seemed content to allow this to happen. Roger and Bella spoke only to their spouses. In this discussion the principal participants were the carers, there was very little input from people with dementia on this table. I wondered if the lack of input from people with dementia was related to the subject matter in that it may have been difficult to consider their own memory impairment and thinking ability

On the next table were Ann and her daughter and Iris and her husband. Ann responded minimally to questions put by the facilitator, her daughter eventually responded on her behalf having attempted to coax her mother to answer for herself. Iris became involved by pointing to information that was provided on the table, she questioned her husband and was engaged in reading the list of words that the facilitator had put out for discussion. She appeared spontaneous - smiling. Anne's daughter again attempted to stimulate her. Ann responded to the discussion about difficulty in hearing that had been introduced by Iris. Ann explained that she has to watch peoples' faces and try to lip read. Iris described her difficulties in hearing and her ways of coping. Ann became quite jokey and animated but not related to the general discussion. I wondered how much her hearing impairment is a factor in her apparent disinterest that I have observed at times.

On the next table were Eva and her son and Rosemary and her husband. There was less spontaneity on this table although the facilitator worked very hard to engage both Eva and Rosemary but there was no verbal involvement from either of them. Eva listened attentively to the general discussion and responded to humorous comments made by people not participating in the research. Rosemary seemed to be either falling asleep or fiddling with her handbag. Rosemary's lack of involvement had been consistent across all three meetings but Eva was usually more engaged. Again I wonder whether the topic was a factor.

Relaxation Exercise

A relaxation exercise was the next part of this session, which involved the whole group. Bella seemed uneasy and looked to her husband as if for guidance. Rosemary engaged minimally. It is not clear whether she understood what was going on. Eva gradually engaged with the exercise. Ann, Bella, Eric, Jeannie, Iris and Roger all participated. Following the relaxation exercise there was a tea break. Almost everyone milled around and chatted. Bella was silent but listened to her husband talk to others. There was a group of Jeanie, Eric, Roger and Iris chatting to each other and their spouses/family. Rosemary and her husband were not talking to anyone. Ann was in a group where one of the facilitators was talking and she seemed very interested in what he was saying. Iris and her husband were talking together.

Following the break the whole group split into two; people with dementia and spouses/carers. In the first group I observed were Ann, Eva, Bella and Jeanie. Eva introduced herself in a jovial manner. Ann responded and was very attentive. Jeanie made minimal input giving her name only. However, she was struggling to hear as she had left her hearing aids at home. Eventually, she seemed to lose concentration - she looked bored and was playing with her scarf. Eva appeared to be being supportive (tactile) towards a person not involved in the research in telling her story, which related to her experience of living with her son, which is also Eva's situation. They concurred that they are both very lucky. Jeanie contributed by talking about living with her husband and how grateful she is for that, stating that she would not like to live with her family (daughters). Eva and Ann interact together outside the main discussion; Eva is tactile. Ann spoke of her experience of living abroad – she became very entertaining and eventually the whole table became amused by her talk of how the English like to be waited on by servants. She repeated herself a lot in this process. The facilitator spoke to Jeanie who does not seem to want to be engaged. There was also very little interaction from Bella. The facilitator initially focused on two people only who were not part of the research but then went on to encourage Jeanie and Bella. Everyone on the table was attentive to each other and there was a lively discussion

On the next table were Eric, Roger and Iris. Eric was able to contribute freely in talking about how the family had responded to his diagnosis, specifically his wife and children. He said he was very grateful for the support he receives from them. Iris said that she does not talk to her the family about her memory problems – initially it was understood that she meant her immediate family, she later clarified that she can talk to her daughters but not her extended family in Hong Kong because they would worry. Roger spoke of how his children noticed his memory problem and prompted him to seek a diagnosis – he said he has been helped by feeling that he is not the only one with problems. He has a friend that also has a diagnosis of dementia and they are a support to each other. Iris reiterated that her daughters do know but she had to convince them that she was having problems with her memory. However, now she has a diagnosis they are more understanding. A Person not participating in the research again dominates the group – they all listen attentively. Roger stated that he feels very supported by his wife and feels no shame as he hasn't done anything wrong. The facilitator at this table was excellent at managing the group and keeping a balance. At some point I noticed that Rosemary had again gone into the carers group to join her husband – no one else had noticed.

1. d) Fourth Group Meeting - Final Session

This final meeting began with a table activity consisting of lots of cards laid out on the table that depicted various activities. Participants were asked to choose those they enjoy. On the first table there was only Ann who was involved in the study. She began by sorting out cards with her daughter. She seemed interested in the cards but did not converse with anyone except her daughter. However, she was lively and responded to the facilitator's questions appropriately.

On the next table were Jeanie, Eric, Iris and Bella. Jeanie picked out her own cards and immediately appeared to be more involved this week (hearing aids in situ). Iris also picked out her own cards and was involved with others on the table laughing and seemingly at ease. Bella was looking at the cards but she was not proactive. she only conversed with her husband who was trying to suggest activities but he elicited little response. She was smiling but appeared peripheral to the proceedings. The facilitator attempted to engage her but her husband answered for her predominantly.

On another table were Eva Rosemary and Roger. Eva immediately became involved in picking out cards. She collected four in all and was very humorous, which others responded to. Roger picked out two cards and discussed them with his wife. Someone had put sweets on the table, which Rosemary helped herself to. She did not attempt to engage in the activity but appeared to be enjoying herself. She responded to the facilitator's joke by laughing appropriately. She was often distracted by fiddling with her handbag. Rosemary interacted mainly with husband and seemed amused at their conversation. It appeared that she interacted when her interest was aroused.

The next part of the session was a presentation given by a person who had had a diagnosis of dementia for some time and who was talking about life after his diagnosis, focusing on how he coped with day to day life and the activities he had become involved in. Everyone listened attentively and responded to the speaker who was very positive and humorous.

The final part of the morning involved filling in evaluation questionnaires by people with dementia and family/carers. Only Rosemary was unable to complete her questionnaire. Whilst everyone was dispersing it was very lively – mostly everyone thanking the staff and wishing other group members farewell.

Observational Comments

This ‘case’ can be characterised by having three people whose level of cognitive impairment was greater than not only those within their own ‘case’ but also across the participant spectrum. I had no access to peoples’ cognitive test results, therefore, this statement is based on my own observations and experience alone. From my observations I extrapolated some ‘ideas’ about the relationship between the person with dementia and their principal carer. For example, Ann seemed more animated and involved when in groups where her daughter was not present. She was, on these occasions, quite gregarious. However, her daughter was encouraging when they were involved in table activities. Bella constantly looked to her husband for direction and/or approval. He would often speak for her rather than encourage her to speak for herself. Conversely, Eric and his wife presented as a couple who were very comfortable with each other and complemented each other during discussions and activities. Jeanie was very anxious at the beginning go the group meetings. her husband was supportive and quietly reassuring, which she appeared to respond to and appreciate. Iris and her husband worked well together and seemed to have a good understanding. Roger and his wife were sometimes separate from the group and seemed to be reliant on each other for confidence. Rosemary and her husband spent much of the time together - quite isolated from the group. During the split groups when people with dementia and carers were in separate rooms Rosemary sought out her husband. Eva and her son have a 'jokey' way of communication. It seemed that they are both comfortable keeping topics at this level. The relevance of these observations will be further discussed below.

The detail of the first 'case' of the group experience was intended to demonstrate what transpired to be a 'typical' picture of the subsequent cases in terms of the engagement and involvement. Obviously, there were some differences between the 'cases' but overall the pattern was consistent. The characteristics of the second 'case' will be identified below.

2. Case Study 2

This 'case' consisted of three women and five men. Ruth arrived with her son, she lives alone and sees her son's family once a week. She stated that her mood is dependant on her dog. Ruth doesn't believe she has a problem with her memory and "*No one can prove it.*" However in discussion she asked if anyone has trouble with dreams as she has woken up having forgotten her own name. She asked if others lose things as she had lost her wedding ring. Her relationship with her son appeared quite distant. He is monosyllabic in most of his responses to her and in group discussions.

John arrived with his wife and daughter. In response to being asked how he is coping he stated that they (his family) make too much of it (his diagnosis), *"They are to quick.*" referring to his wife who jumps up to take over anything he tries to do. He was upset when he had to give up his driving licence but thought it was not him but other drivers that were to blame. His relationship with his wife was reminiscent of mother and child. His daughter also treats him as if he is incapable of doing anything for himself.

Angela arrived with her husband. She is a very alert woman who is frustrated by her degree of aphasia that is characterised by her difficulty in producing speech, which evoked frustration and irritability in her husband. When asked, by the facilitator, how it was having other people doing things for them she replied by saying she felt "*A bit smothered at times and angry that I cannot do the things I used to do but I don't let my husband see."* The level of her husband's shortness and irritation with her was obvious to all.

Frank arrived with his son and daughter. Over the sessions Frank demonstrated how he dealt with his memory problems in his day to day life by being very organised and relying heavily on aide memoirs, which worked well for him. He was mostly animated in groups discussions and quite able to contribute. His son and daughter were very supportive of him and the relationships appeared positive.

Peter arrived with his wife. The over-riding feature throughout the course of the group meetings was his sense of sadness; he was being treated for depression. He spoke little although experienced facilitators did draw him out then he was able to speak of his work life as a bus driver. His wife was supportive and they seemed to have a positive relationship but it is difficult to gauge this relationship because Peter was monosyllabic and lacking in spontaneity.

Paul arrived with his niece. He was a widower of some years and his niece was supportive in practical ways and visited him every day. She spoke very warmly of him and the relationship she had with him and his late wife. Paul lives alone and says he copes by talking to himself, his cat and having a plan. He does not worry about things - he never has. He wasn't very communicative in the discussions but was avidly engaged throughout.

Agnes arrived with her husband. They had been separated for some years but her husband had returned to look after her when she was diagnosed with dementia.   When asked what she would like to get from the groups she replies that she does not know. Her husband was very vocal, she appeared to lose interest in what he was saying and made faces behind his back. Agnes describes her husband as "*In charge - top hat and dustbin*" She declared that she is coping but in a later meeting admitted that she forgets meal times. The relationship between them appears strained and distant.

Jim arrived with his wife. In the first session he spoke expansively about what had led to this point for him; having been treated for cancer and declared in remission only to be diagnosed with Parkinson's disease and losing his driving licence, which was a big blow for him. He says his wife is very busy but gives him jobs to do, which he likes because it helps his mood makes him feel useful. Jim also has problems producing speech and he is emotionally volatile. He experiences his wife as kind and patient with him and they appear to have a positive relationship.

Observational Comments

The level of cognitive impairment in this 'case' was broadly comparable apart from John who appeared less able. The feature that I was most aware of was the quality of relationships in this group. Angela's relationship with her husband was unsupportive to the extent of being unkind. She was involved and engaged in the groups but often had difficulty in finding words to express herself. I had the impression that she enjoyed the social interaction of the groups. The relationship between Agnes and her husband was also difficult in that she was clearly dependent on him in managing her day-to-day life but she was actually contemptuous of him at times. Her involvement in discussions was limited, being seemingly dismissive of the proceedings much of the time. John's relationship with his family was sad in that they seemed to be motivated by positive intentions but in fact he was not allowed to occupy himself other than to watch television or read a paper, which he was incapable of. His contribution in the group activities varied. He was more animated when on a table with other men, particularly when the topic was football. Ruth was very isolated emotionally and had minimal contact with her son. She did not appear to have friends locally. Her closest companion was her dog to whom she was very attached. She was isolated in the group also most often being on the fringe and contributing little.

Methodological Adjustments

The above illustration is an example of the first two 'cases' in that the format and content followed the same formula. The first and second 'case' followed each other closely in time. By this stage my observations had led me to believe that the relationship between the person with dementia and their principal carer was a factor in determining how people were able to live with dementia. Therefore, for the following two cases the principal carer was invited to be included in the research. An information sheet and a consent form was designed for them (Appendix 2.1) Specifically, my observations were more focused on the relationships of the person with dementia and their carers. It was also decided at this stage, in conjunction with my supervisor, that carers would be asked complete a DEMQoL proxy form. Also, the Perceived Helpfulness Questionnaire was presented as a visual analogue scale (Appendix 3.2) rather than a verbal response scale as I had observed that some participants appeared to have difficulty in responding verbally. Subsequently, as a result of a change in supervisor, the DEMQoL proxy data was not analysed and the data from the four ‘cases’ were amalgamated. Having initiated the changes outlined above I observed no obvious differences between ‘cases’ in the subsequent two, which will be outlined briefly below.

3. Case Study 3

The third ‘case’ was made up of four woman and two men. David arrived with his wife. He was involved in table discussions instantly and was often very humorous. He said he recognised that emotion is a block to his memory and went on to say how protective of him his wife is. As the meetings progressed he became quieter - appeared more thoughtful. There was a difficulty for me in relation to this couple as David’s daughter had been a patient of mine for a considerable period and she had chosen to attend the group meetings. I resolved to talk to her alone and she made the decision to tell David and his wife of our previous relationship.

Sheila attended the meetings with her sister. She lived alone in sheltered housing but was very reliant on her sister for day-to-day support. In the presentations and table discussions she was often distracted by looking in her handbag for pills she thought she had mislaid. She did not contribute much to discussions but attempted to engage with those sitting next to her. Her sister, a retired nurse, did interact in discussions. At the first meeting she expressed her anger at the medical care her sister had received prior to being referred to the Memory Clinic. Over the time span of the group meetings she reiterated this grievance. Sheila and her sister had a difficult relationship, which was characterised by Sheila contacting her sister at any time of the day or night because she was anxious that she had lost or forgotten something. Her sister was often quite obviously irritated by Sheila but she makes efforts to be supportive.

Bob Attended with his wife. He was rather hesitant to begin with in the discussion groups but when encouraged he was able to tell his story and respond to others. Overall, he was a quiet but attentive member of the group. He and his wife share common interests including bowls and consequently have an active social life centred on their bowls club. They were also very involved in the lives of their children and grandchildren.

Carol and her son attended the meetings together. She was a quiet, timid woman. At the first group meeting she sought me out to say that she was happy to be involved in the research having forgotten that she had agreed to participate the previous day. She also said that she did not want to talk in the group about what she had told me the previous day, which was a harrowing story about how she and a friend were playing in Carol's father's builders yard when her friend fell and was crushed under falling masonry and subsequently died. Carol had been extremely upset in telling me of this event. She felt it had affected her life thereafter, her son knew nothing of this event. In the groups carol was silent mostly but would respond to direct questions. As she had a quiet voice she was sometimes talked over. However, she was engaged in listening to others and was responsive to humorous remarks and would demonstrate agreement with others. Her relationship with her son appeared distant. He was minimally engaged in the group activities and attended two meetings only.

Dorothy was accompanied to the group meetings by her husband. Throughout the meetings she was very agitated, as she had been when I visited her at her home. She was unable to sit through presentations and discussions often having to pace the room. Her husband was very concerned about her condition as he reported that she was also unable to sleep. Ultimately, she was prescribed medication that lessened her agitation but had the side effect of making her drowsy. Dorothy was obviously struggling and looked exhausted. She made efforts to participate and by the third meeting she was able to contribute a little especially in a smaller group setting.

Katie was accompanied by her husband. She was a lively, alert woman who looked younger than her years. She was initially engaged but quiet in the table discussions but as she became more relaxed she was able to contribute freely and was responsive to others. She described how, when she had first received her diagnosis, she was nervous of using the telephone and spoke of how her husband had encouraged her and she now felt more confident. She and her husband appear to have a positive relationship.

Observational comments

The third 'case' had fewer participants then the previous two but the overall group size was larger, my observations were as follows. David was a retired General Practitioner and his wife a retired nurse. Hence, they were informed regarding the course of the disease. Theirs was a second marriage, which appeared to be a positive, close relationship. In the groups they were both relaxed and participated fully. David often used humour as a means of communication. Sheila had a difficult relationship with her sister who was her only close relative. Her sister, also retired nurse, was angry at the treatment Sheila had receive prior to diagnosis. I understood that in part she was angry because if no one else was caring for Sheila then she had to. Sheila was often distracted in the groups, anxious that she had lost something. She did not contribute much to the discussions. She seemed to prefer one-to-one relationships. Bob was a quiet man but he did engage with the groups and was involved most when he was on a table with other men. His wife was attentive and supportive of him. Carol was isolated as she lived alone and was a widow. Her son did not live locally and she regularly had to rely on neighbours' for help. She was a timid person and although she did not spontaneously offer much in discussions she would when encouraged and she was very interested in the contribution of others. Dorothy was in a very difficult state. she was so anxious that she hardly sat down in any of the groups. Her anxiety was pitiful to observe as she was exhausted and distressed. Fortunately the Admiral Nurse was able to arrange for her to be prescribed appropriate medication. She was able to engage minimally in the groups. Throughout her husband was attentive and concerned for her. Katie showed great interest in all the proceedings and was active when she had something to contribute. She and her husband appeared to have a positive, loving relationship.

4. Case Study 4

The fourth 'case' was made up of five people participating in the research - four men and one woman. The venue for this 'case' was particularly difficult for some people who had hearing difficulties as the acoustics were not good especially as there were many people in the room (in excess of thirty). There was a separate room at this venue that was used when the main group broke downs into smaller elements. When there was a group in this room it was not possible for me to observe my participants as the room was very small and I suspected my presence would be intrusive. Also, one research participant attended the first meeting only and then withdrew as he had terminal cancer.

Henry was accompanied by his wife. Initially he was quiet contributing little but fully engaged. However, as he became more relaxed in this environment be told jokes that were sexually suggestive and inappropriate. During one tea break he told me I was a "*shit stirrer*" His wife responded to his inappropriate behaviour by completely ignoring him. It seems that his 'jokey' presentation may be a coping strategy. In more serious moments he talked about how he had given up most of his former activities. His wife leaves him alone for considerable periods of time as she continues to pursue her own interests. There was no sense of togetherness in this couple.

Penny attended the meetings with her husband. She was a quiet woman who expressed feelings of anxiety. Initially she responding only to questioning offering little spontaneously. As she became more confident she was able to talk about what she can do in terms of day-to-day activities. She declared that she and her husband have quite separate activities and different opinions. She described her husband as doing a lot whilst she did very little.

Kevin was a man in his mid fifties who had been diagnosed with early onset dementia. He attended with his wife. Throughout the first meeting he said nothing at all, whilst his wife was actively involved and engaged. He was monosyllabic when he did contribute but would speak volubly to his wife. My sense was that she was the social face of this couple who presented as having a close relationship, I also had the impression that Kevin was emotionally dependent on his wife.

Mike and his wife attended the meetings together. Throughout the group meetings Mike contributed little but was very engaged in presentations and discussions. At break times they kept their own company or spoke to one of the facilitators but had little involvement with others. There was one small group setting where he seemed more at ease and spoke of how he came to be diagnosed with dementia in a humorous manner.

Observational Comments

This ‘case’ had the least numbers of the four and of the five people that began Bill attended only one session and withdrew due to ill health. The numbers were significant in terms of my observations, in that the overall group was in excess of thirty people and observing so few was difficult as they were more dispersed. However, it was not difficult to observe Henry as he made himself very visible in terms of the manner of his input, which attracted substantial attention as he was loud and, as described above, inappropriate at times. The relationship between him and his wife exhibited obvious differences between them. He being critical of her whilst she maintained a stoical silence. Penny was a quiet presence, she could engage verbally when moved to and she was very engaged in both presentations and discussions. she and her husband seemed to have an understanding, he was supportive of her but maintained his own daily activities that did not necessarily include Penny. The youngest participant was Kevin and I wondered if he was somewhat dismayed at finding himself in a group in which most people were substantially older than himself. He was very quiet in group discussions in the main, which had not been my experience of him in his home. Whereas, his wife was very engaged and positive. They seemed to be a close couple who shared their daily activities. Mike and his wife maintained a distance from the rest of the group throughout. When they engaged it was mainly with facilitators. I did wonder if there were socio-economic issues at play. Mike did, on one occasion, become quite expansive when in a group of men with a male facilitator.

My observations are not solely based on the observations I made of people in the groups as I admit I may have been influenced by my experience of interviewing all the participants on two occasions in their own homes. Therefore, my sense of the relationships was based on more information than the groups alone. This section had focused on presenting an illustration of the each 'case' in terms of the group experience The next section will detail how data from my observations of the groups, data derived from the Perceived Helpfulness questionnaires and responses to the question "D*id you find the group helpful" was* analysed.

5. Perceived Helpfulness

The Perceived Helpfulness Questionnaire was given to all participants engaged in the research before and following the group sessions. The questions were rated on a five-point Likert scale, with one referring to "strongly disagree", two, "disagree", three, "uncertain", four, "agree" and five, "strongly agree'. For questions four and five, the scoring was reversed in an attempt to reduce acquiescent or response bias on the part of participants. For 'cases' three and four a visual analogue scale was used as opposed to a verbal response questionnaire as described above. A data file was compiled on SPSS enabling a related samples t-test to be carried out on the data from all respondents. There was a non-significant difference between the means of the pre and post data for perceived helpfulness of the group (m =-.385, SD= 4.622) t (25)=-.424, p.=67. indicating non significance at the $p < 0.05$ level. The result suggests therefore, that using this measure, there were no indications that the experience of a psychosocial group was perceived as helpful.

Following the group input I asked all participants "*How helpful did you find the group:*" the data collated from this question and the changes in participants' levels of engagement (level of attentiveness), involvement (active participation) across the four group sessions are depicted in tables 1 - 1c below, which illustrate the responses from each 'case'.

Table 1: Levels of engagement/involvement/usefulness for 'case' 1

	Engagement		**Involvement**		**Helpfulness**
Participant	**Session 1**	**Session 4**	**Session 1**	**Session 4**	
Ann	1	2	0	2	She couldn't remember the groups
Bella	2	3	0	3	Pleased about having made friends with Jeanie
Eric	3	4	1	3	Very helpful. Made new friends
Jeanie	3	3	2/3	2/3	Very positive
Iris	3	3	2/3	2/3	Glowing about the help she had gained
Roger	3/4	3/4	4	2/3	Very affirmative
Rosemary	0	1	0	1	Rosemary had no recollection. Husband disappointed that the group had not offered treatment
Eva	4	3	1	2/3	Found groups helpful. Referral to other groups

These results show that for three people their level of engagement developed at the group experience progressed and for Bella and Eric the group was perceived as useful.

Similarly, involvement also increased for four of the participants all of whom found the group useful. Anne's input, however, is unreliable as her memory was impaired to the extent that she couldn't remember the groups one week later. For three people their level of engagement and involvement remained steady throughout. Rosemary who appeared the most cognitively impaired showed minimal change.

Rosemary's husband did not find the groups helpful. He had been expecting treatment to cure his wife of vascular dementia. Bella's response highlights how much she valued the connection she had made with Jeanie.

Table 1: a) Levels of engagement/involvement/usefulness for 'case' 2

	Engagement		**Involvement**		**Helpfulness**
Participant	**Session 1**	**Session 4**	**Session 1**	**Session 4**	
Ruth	2	2	2	2	Not enthusiastic. Referred to a man who dominated some groups
John	2	2	1	2	Could not remember
Angela	3	4	1	3	Very helpful
Frank	3	3	3	3	"Alright"
Peter	2	1/2	1	1/2	Enjoyed the groups. "Got on well with two other men."
Paul	3	3	1	3	They found the groups useful
Agnes	2	2	1	2	"I'm not a sociable person"
Jim	3	3/4	2	3	Pleased with the groups

In this ‘case’ there was very little change with Paul and Angela being the most obvious increasing from 1 to 3 in involvement. It is worth noting that John, Peter and Paul did not attend the last session, which amounts to 25%. There was a mixed response in this ‘case’ to the perception of helpfulness question with an even split between those who spoke positively about the group experience and those who’s responses were ambivalent.

Table 1: b) Levels of engagement/involvement/usefulness for ‘case’ 3

	Engagement		**Involvement**		**Helpfulness**
Participant	**Session 1**	**Session 4**	**Session 1**	**Session 4**	
David	3	2	3	2/3	Very positive
Sheila	2	2/3	1	2	Liked being with other people, interesting information, a lot to take in. Would have liked more
Bob	1	2/3	1/2	3	Useful, would have liked more.
Carol	3	3	1	1	Enjoyed the social contact.
Dorothy	1	3	1	3	helpful - focused on practical issues. Could not be drawn on the interrelational aspects.
Katie	2	3	1/2	3	Both enjoyed and looking forward to the next phase

An interesting feature of this ‘case’ is that Carol’s level of engagement was consistently high while her involvement remained low, which may appear contradictory however what it reveals that whilst Carol listened attentively to the presentations and discussions her level of active involvement was low.

Dorothy was very distracted by her level of anxiety, spending much of the first three session pacing. However, by the four session, by which time she was receiving medication that was aimed specifically at treating her extreme anxiety, and she was more accustomed to the group setting, she was more able to participate at both levels.

Everyone in this ‘case’ spoke enthusiastically of their group experience even Dorothy and her husband for whom it had been a difficult time because she was so severely anxious. However, they found the practical content helpful. This was the only group who were unanimous in finding the group helpful.

Table 1: c) Levels of engagement/involvement/usefulness for ‘case’ 4

	Engagement		**Involvement**		**Helpfulness**
Participant	**Session 1**	**Session 4**	**Session 1**	**Session 4**	
Henry	1	2	2	2	Dismissive of the question
Penny	1	3	1/2	3	Enthusiastic, especially reassured by talking with others living with dementia
Kevin	2	2	0	2	Pleasantly surprised at how positive they were
Mike	1	2	1	1	Lukewarm

In this 'case' there were no common themes. Mike was minimally involved, in that his participation was principally with his wife and the facilitators, throughout whilst Kevin who had not participated much during the first sessions was more involved by the fourth. This 'case' was very small in numbers and again there was an even split between those who were enthusiastic and those who were not. Kevin, who had been pessimistic about attending a support group for people with dementia was pleasantly surprised and was looking forward to attending a cognitive stimulation group as a follow-on.

No attempt was made at this point to consider the relevance of these results, which will be addressed in the chapter 6. This section has addressed the question: How are group interventions for people with dementia perceived as helpful. The next sections will consider the data collected from the DEMQoL questionnaires.

6. The DEMQoL Questionnaire

The question how does a group experience impact on a person's quality of life was analysed using data collected from participants' completion of the DEMQoL Questionnaire. The data in this research was analysed by scoring each item in the following way. There were twenty-nine questions in all. Using the syntax for DEMQoL tool data was entered into SPSS. The scoring for questions one, three, five, six and ten were reversed, in an attempt to reduce response bias. Question 29 specifically addressed the person's perception of their overall quality of life and stated "*We've already talked about lots of things: your feelings, memory and everyday life. Thinking about all of these things in the last week, how would you rate … your quality of life overall?"* which was referred to as the global question and was not included in the total score but analysed separately. No rationale from the authors of the tool was given for this (Smith *et al*. 2005, p. 60).

The data was entered into SPSS and a related samples t-test was conducted to compare the means of the pre-and-post-group scores. The result of the test was: (m = -7.269, SD 14.161) t (25) = -2.618, p = .015 indicating a significance at the $p < 0.05$ level.

6. a) Overall Perception of Quality of Life

The additional overall measure, the global question of overall quality of life, was analysed separately. Again, a paired samples t-test was performed to compare the means of both sets of scores with the result (m = -077, SD .844), t= (25) =-.464, p =.646 indicating non significance at the p = 0.05 level. Therefore, there was no association between this population's overall experience of their quality of life and the intervention of a psychosocial group. Ratings for individual participants can be found in the appendix. (Appendix 5.2) , which support the findings of the t-tests with a few exceptions There was quite a dramatic change for Kevin and for Henry a drop in his perception of his quality of life. The ratings for Ann, Rosemary and John cannot be relied upon as their level of cognition was impaired substantially. All of the above results will be discussed further in the next chapter. This section has focused on the results of the DEMQoL questionnaire and question 29 as two separate results. The next section will address the analysis to the semi-structured interview.

7. AAI Questions - Semi-structured Interview

In addressing the research question: how may a person's attachment style be a factor in their experience of a group intervention*,* semi-structured interviews based on the Adult Attachment Interview (AAI) questions were conducted. Initially, the data was approached as described by Hesse (2008, p. 562). The coding began with the "experience scales", taking as a central theme, "loving verses unloving" behaviour of the individual's parents during the participant's childhood. This was followed by continuous scores on the scales for "overall states of mind with respect to attachment", which included a scale of coherence that, since 1989, has increasingly referred to Grice's work (1975, 1989) on conversational maxims. The coding then moved on to assess scores on scales for the person's state of mind with respect to attachment as described by Hesse (2008) who produced a table identifying a scoring mechanism using conversational maximsThe most appropriate way to analyse this data from a Gricean analytical viewpoint was to rate each of the four maxims, on a five point Likert scale, ranging from one for good, to five meaning poor. Although studies have described up to twelve classifications (Goldwyn 1984b, Ainsworth *et al.,* 19780) the data in this research was not as detailed as in either of these studies therefore, only the three principal classifications were ascribed to participants' scores, which were: secure/autonomous, dismissing/avoidant, and preoccupied/ambivalent. A further class of 'unclassifiable' was to be ascribed if the data did not fit any of the other three categories.

Grice's conversational maxims are defined as follows.

1. Quality: truthfulness of narrative, avoiding of contradictions and providing evidence to support the adjectives used to describe the person's experience of the mother/father.

2. Quantity: succinct whilst answering the question fully. Not overly informative. Conversational turns should be of reasonable length to convey an appropriate response.

3. Relative: answers are relevant to the question and do not veer off into unrelated areas.

4. Manner: clear and orderly response to each question.

Having rated scripts on each of the above, supporting the score for each with evidence from the script, a fifth assessment was made that brought the scores on the four maxims together to award an attachment classification, as detailed below. This was based on Hesse's (2008) guidelines, identified for each category.

An example of each attachment category, using data from the overall participant group. can be found in the appendix (Appendix 4.6) as well as a sum of individual scores on all four of Grice's maxims including a final overall coherence score,

Table two below defines how the total number of participants were categorised into the four attachment classifications described above.

Table 2: Numbers of overall participants in each attachment classification

Secure autonomous	**Dismissing avoidant**	**Preoccupied ambivalent**	**Unclassifiable**
N (%)	N (%)	N (%)	N (%)
15 (57.69%)	7 (26.94%)	1 (3.84%)	3 (11.53%)

In table three the overall number of participants are broken down into the four 'cases'. It can be seen that the numbers in each 'case' are too low for any useful statement to be made regarding distribution of attachment styles in each 'case', albeit a similar pattern emerges as that seen with the overall participant numbers.

Table 3: Numbers of participants' attachment classification in each 'case'

	No. of participants	Secure autonomous	Dismissing avoidant	Preoccupied ambivalent	Unclassified
Group 1	8	4 (50.00%)	2 (25%)	0	2 (25.00%)
Group 2	8	3 (37.5%)	4 (50.00%)	0	1 (12.5%)
Group 3	6	5 (83.33%)	1 (16.67%)	0	0
Group 4	4	3 (75.00%)	1 (25.00%)	0	0

To test the internal validity of this attachment classification tool, a sample of three participants were co-rated by two independent raters and the researcher, so as to assess the level of agreement between them. Inter-coder reliability is widely recognised as a means of testing validity and although it is not an insurance against results being invalid, it is perceived as a measure of research quality (Kolbe and Burnett, 1991). Since it was the researcher conducting the interviews, there was concern that I would rely on latent content and memory of more than the content of the script (Potter and Levine Donnerstein, 1997). With this in mind, it was crucial that inter-coder subjectivity was tested. Participants were identified numerically to protect their identity, to ensure that co-coding was based on a random selection those chosen were the first, the second was omitted as their script was very similar to the first, as the third person withdrew, the fourth person was chosen. Keeping the same numerical sequence the following two participants were omitted, therefore, participant seven completed the sample. Full transcripts of the co-coding exercise can be found in the Appendix (Appendix 4.5). The table below depict the scores allocated by each coder, demonstrating the level of agreement between the coders. There is close agreement between the coders on the scoring of Grice's maxims in relation to peoples' responses to the AAI questions. There is also almost unanimous agreement on the coding of the three participants with only one deviation being that CP considered Ann to demonstrate features of both a preoccupied and an avoidant attachment style. To specifically test the level of intercoder reliability a Kappa calculation was performed as follows:

CP * TN - Kappa = 0.4

TN * MS - Kappa = 1.0

CP * MS - Kappa = 0.4

As would be expected from the ratings illustrated in the tables the combined ratings of MS and TN achieves a score of 1.0 denoting perfect agreement. In the other two pairing the result drops to 0.4 not because there was radical disagreement but because one disagreement in such a small sample skews the result considerably

Table 4: a) Co-coding of Annes's Attachment Style

Coder	Relative	Quality	Quantity	Manner	Total	Classification
TN	3	1	1	1	6	Dismissing avoidant
CP	2	2	2	2	8	Preoccupied avoidant
MS	2	1	2	1	6	dismissing avoidant

Table 4: b) Co-coding of Eric's Attachment Style

Coder	Relative	Quality	Quantity	Manner	Total	Classification
TN	5	4	4	5	18	Secure
CP	4	4	4	4	16	Secure
MS	4	4	4	4	16	Secure

Table 4: c) Co-coding of Roger's Attachment Style

Coder	Relative	Quality	Quantity	Manner	Total	Classification
TN	5	5	4	4	18	Secure
CP	4	3	3	4	14	Secure
MS	4	3	3	4	14	Secure

This section has presented the classification of participants' attachment styles and given detailed examples of the process of ascribing an attachment classification based on the data collected from the AAI questions that was analysed using a method based on Grice's (1975, 1989) conversational maxims to determine participants' overall state of mind with respect to attachment.

8. Summary of Results

This chapter has considered the data from observations of people's engagement/ involvement in a group setting, responses to the Perceived Helpfulness questionnaire, the question "*did you find the group helpful?"* DEMQoL questionnaires, including consideration of question 29 as a separate entity, as well as the AAI questions to address the research questions:

1. Are the group interventions observed in this study perceived as helpful?

2. How does a group experience impact on a person's quality of life?

3. Does attachment style play a role in how participants experience the group?

The results of the Perceived helpfulness questionnaire produced a non-significant result at the $p < 0.05$ level. At the final home visits, following the group intervention, participants were asked if they had found the group helpful. All participants, apart from three who expressed diffidence about the group experience and three others whose level of dementia was such that they were unable to adequately remember the experience, expressed positive statements, from satisfaction through to enthusiasm as depicted in tables 1, 1a, 1b, and 1c above. Therefore, the question cannot be refuted entirely.

The results from the analysis of the data derived from completion of the DEMQoL questionnaire, suggests that that there was a significant difference between the pre-and-post-intervention scores. However, the overall perception of quality of life reported by participants was not significant and this was substantiated by illustrating the results of each 'case'.

It is not possible to extrapolate the effects of attachment style. However, there is consistency in all four 'cases' that a secure attachment style combined with a positive relationship may enable people to better manage living with dementia. This result was common across all 'cases'.

There is little evidence to support other patterns or themes between the 'cases' other other than they are consistently varied. The body of data does highlight the difficulty in identifying commonality between groups in a study of this nature.the next chapter will consider the data from the perspective of a thematic analysis.

Chapter 5: A Thematic Analysis

"*Just because I've got a failing memory it doesn't mean that I'm a failure." (Cheston, Jones and Gilliard 2002)*

In this chapter I aim to bring together the data collected from all sources: my observations of the groups, my notes taken when I interviewed people in their own homes, responses to AAI questions, responses to the DEMQoL and Perceived Helpfulness questionnaires. A thematic analysis was chosen to identify themes within the data and between 'cases'. Therefore, from the results of the thematic analysis examples will be given of how the themes are exhibited within 'cases' and comparisons made between 'cases'. The objective of this analysis is to identify relationships between attachment style and the group experience; specifically to focus on the question

Is there any association between attachment style, experience of the group and quality of life ratings?

In addressing these question a triangulation of the data was used as a means of strengthening the validity of the results, which is relevant in this research as much of the qualitative data was reliant on my observations and experience of the participants.

1. Thematic Analysis

The method of identifying themes in the data began with an exploration of the separate components, as outlined above, which was a useful first step in further familiarising myself with the data. Thereafter, the process described by Miles and Huberman (1994), consisting of data reduction, data display and conclusion, was carried out. The first state of data reduction, was a process whereby field notes, group observations and AAI question responses were reduced by reading through the data set for each component and noting ideas or thoughts that seemed significant in terms of the person's experience of him/ herself, of others, or anything in the data that resonated with me. Ideas that were evoked from the data were noted and irrelevant information discarded, but retained. As stated earlier, at this point I was not constrained by attempting to match the data to the research questions, but rather to allow the data to reveal its own story. The complete data set was then re-read and each relevant statement, be it a word, a sentence or a phrase that fitted the coding, was recorded. Miles and Huberman (1994) refer to this process as 'open coding'. Finally, I explored any relationships with the principal themes to identify inter-relationships. At this stage, items were coded as in Table 1 below.

Table 1: Initial Themes

Field Notes	Group Observations	AAI Responses
a) Relationship with carers	a) Anxiety	a) Level of comprehension
b) Avoidance	b) Avoidance	b) Denial
c) Significance of others	c) Significance of others	c) Childhood memories
d) Self sufficiency	d) Separation	d) Idealising
e) World War 2	e) Physical limitations	e) Anxiety
f) Coping strategies	f) Coping strategies	f) Avoidance
g) Sociability	g) Sociability	g) Self-sufficiency
h) Anxiety	h) Anxiety	h) Separation
i) Dependence	i) Dependence	i) World War 2
j) Researcher relationship with participants	j) Researcher relationship with participants	j) Parental behaviour
k) Memory loss	k) Memory loss	k) Coping strategies
l) Cultural	l) Level of engagement	l) Anxiety
m) Philosophy	m) Isolation	m) Closeness to parents
n) Stigma	n) Humour	n) Researcher relationship with participants
o) Isolation	o) Relationship with carer	o) Memory loss
p) Emotional lability		p) Philosophy
q) Humour		q) Isolation
		r) Loss
		s) Humour
		t) Trauma

These initial items were further reduced as some were subsumed into others, as shown in Table 2.

Table 2: intermediate Themes

Field Notes	Group Observations	AAI Responses
a) Relationship with carer	a) Relationship with carer	a) Relationship with carer
b) Cognition	b) Cognition	b) Cognition
c) Coping strategies	c) Coping strategies	c) Coping strategies
d) Physical/emotional	d) Emotional/physical	d) Childhood relationships
e) Researcher relationship with participants	e) Researcher relationship with participants	e) Separation
f) Culture	f) Group engagement	f) Loss
g) Philosophy	g) Stigma	g) Trauma
h) Stigma		h) World War 2
		i) Emotional
		j) Researcher relationship

From this stage, three main themes emerged, as can be seen in Table 3.

Table 3: Principal Themes

A	B	C
Relationship with carers • Memory loss • Coping strategies • Physical/emotional aspects	Groups • Level of engagement • Sociability/isolation • Relationships	Childhood Experiences • Separation/trauma/loss • World War 2 • Cultural norms/self

The first principal theme to emerge was the relationship with the significant carer, with sub-themes of: memory loss; coping strategies; and physical/emotional aspects. The inclusion of these items as sub-themes can be justified on the basis that by definition, what affects the person with dementia is also likely to have an effect on their relationship with the person they are closest to and depend upon, as well as aspects of day-to-day life that affects people with dementia and their carers.

The second principal theme was the group experience, from which sub-themes of: levels of engagement, sociability/isolation, relationships between people with dementia and their carers in the group setting, as well as their relating style with other group members.

The third theme was that of childhood experiences with sub-themes of: separation/loss/ trauma in childhood, cultural norms/physical affection/self-sufficiency. In this theme, I have also included World War 2 as many of this particular population were children during that time and recounted their feelings about the effects it had had on their childhood experience, both in terms of separation and trauma.

1. a) Relationships with carers

The way in which the person with dementia related to their principle carer was a focus of observation throughout the various interactions I had with families, specifically from 'case' three onwards as discussed above. From my observations, I would argue that the relational dynamics were a factor in the person's experience of their memory problems in their day-to-day lives. Included in this theme were the effects of dementia, both physical and emotional and the coping strategies people used to help them in their day-to-day living. Coding of the responses for the relationship with the principle carer suggested a range of relational dynamics that translated into three principle categories: those that have a distinctly negative aspect, those that were positive-supportive and those that were distant, with little emotional engagement. Coding was carried out by scrutinising the complete data set for all of the relational elements between participants and their principle carers, specifically focusing on the physical and emotional manifestations of their experience of dementia and the coping strategies they developed in their day-to-day lives. Examples of these relational categories can be found in the Appendix. (Appendix 7.1)

Negative Relations

The characteristics of what I have described as negative relations focus on observations of negating, dismissing or minimising the person with dementia, expressed in relational patterns that range from being insensitive but caring to one particular example of hostility and antagonism. Common coping strategies amongst this group were denial, avoidance and advocating self-sufficiency. These relationships were quite difficult to witness in a number of ways: on an emotional level, observing the vulnerability of people with dementia, who were invariably dependent on their carers and, to varying degrees, being unable to acknowledge that in their closest relationships. Pathos was evident, in observing the ways in which both people with dementia and their carers were coping with changes in their relationships, for example to witness how Rosemary's husband protected her whilst she appeared largely oblivious of his concerns; of Jim's gratitude to his wife for giving him jobs he knew she didn't need him to do. Even in those carers who exhibited little compassion, understanding or empathy, their fears and anxieties were being played out in the ways in which they were able to respond to the person with dementia. From a therapeutic perspective I would argue that for people whose are struggling in their relationships a group or couples work with a greater therapeutic focus would be useful in supporting them.

Positive Supportive Relations

The relationships that exhibited supportive and loving dynamics represented the greater bulk of the data. These relational patterns were represented by expressions of caring, empathy, support and mutual affection. There was less evidence of anxiety in these couples who, nevertheless, spoke of their concerns and worries. They also spoke more coherently about the measures they had adopted to cope with memory loss on a day-to-day basis. In this relational category were examples of the ways in which people felt they were supported by their spouses and/or families. However, it is not possible to convey a "sense" of positive relatedness by merely quoting words. The principle difference in my experience of being with people who related openly and warmly to each other was the "feel" of the relationship. They were more able to discuss the reality of their situation and plan for the future. It was a pleasure to spend time with those who were "easy" with each other, as opposed to the experience of those in the negative relationship category described above.

Distant Relations

I labelled the final category of relating as “distant” as there was little evidence of engagement with each other or me. Denial was a significant aspect of this presentation. For one couple it was particularly difficulty to read the nuances of their relational style as Peter was depressed, which may have accounted for the emotional flatness he exhibited and the distance between them.

Physical and emotional aspects of people’s experience were reported or observed by all but one from the “negative” group and one from the ”distant” relational group. Of the positive group, four of a total of sixteen spoke of physical limitations. No one discussed emotional issues arising out of their condition, although two male participants were extremely emotionally labile. Anxiety, agitation and depression were also evident. Loss of skills were identified by some including: no longer being able to drive, complete household tasks, difficulties with communication. There is no suggestion here that there is any significance in the distribution of these aspects of people’s experience, merely that they represent part of the “story” the data reveals.

I have attempted to illustrate patterns of relating that were manifest in the ways in which people behaved towards each other from my observations of them in their homes and in the group setting. In some instances, I was aware that the relationships I made seemed to create something in the participants that I can only describe as hope or strength – someone that made them feel more secure or someone in whom they felt an affinity. This was especially noticeable in Eric, Jeanie, Iris, John, David, Carol and Mike. I did not set out to foster an unrealistic expectation, but I did spend quite lengthy periods of time with all of the participants and their families, with the intent of developing a rapport that would enable them to relax in my presence, to enhance the quality of the responses they gave. Nevertheless, I was concerned that I had taken something into the lives of some of the participants only to withdraw when my data collection was complete. This sense was reinforced by the number of people who invited me to visit if I was in the area and expressions of regret that we would not be meeting again. The next section will consider the observations I made of the intervention groups.

2. The Group Experience

The following themes arose from the group experience whereby I observed peoples' level of engagement with others, as well as their levels of sociability or isolation in relation to others in the groups and their carers. It could be argued that to compare one series of groups with another is unreasonable as each group has a unique experience. Rather, I was looking at the experience amongst individual participants and their carers in a group setting, as opposed to comparisons between people. In coding the data arising from the group experience, the data set was scrutinised in relation to the level of engagement/ involvement of people in the group, including their ability to contribute as well as their degree of socialisation or isolation.

The majority of participants were able to engage and participate to varying degrees. From my observations, almost all were engaged and attentive but contribution levels varied with some people contributing very little (Ann, Bella, Rosemary, John, Agnes, Bob, Carol, Kevin and Mike) and of these, all but Mike, Kevin and Bob were unclassifiable or from an had an insecure rating. Others had difficulty initially but became more engaged and able to contribute more fully as the sessions progressed.(Eric, Jeanie, Roger and Eva), all of whom met the criteria for a secure classification. However, for each one of these participants, I have reported feelings of anxiety or issues with socialisation in my field notes. Hearing was a problem for some as they reported difficulty in hearing in a group setting. this was a problem for some throughout but specifically in one venue where the acoustics were poor.

My experience of observing the groups was more or less identical across the four sets of sessions, other than the final one where there were only four couples involved in the research in this group, which was addressed above. Overall, I observed that the groups were lively encounters in which the majority of people were able to engage and participate with others. There was a relaxed atmosphere and the facilitators were professional and attentive to the needs of those present. The content was considered to be relevant and was appreciated as helpful. However, from my observations and the feedback from families, I would question whether four sessions is sufficient to make a significant difference in the lives of people who have recently received a diagnosis of dementia; this being the time when there is much to deal with, practically and emotionally, with regard to coming to terms with the diagnosis. I observed that for some people it took them two sessions to feel comfortable in the group, by which time there was only one more session before the final meeting. The final session of the second round of groups was also missed by four participants. With only four interventions in all, missing one could have had a significant impact. However, the organisers' response to this observation was that from this group experience, they were better able to triage peoples' needs and refer them on to groups aimed more specifically at meeting those individual needs. They were also constrained by the limited resources at their disposal.

The section above is a description of my observations of the groups and how people were able to use them. I have sought to identify the strengths and weaknesses in this form of intervention. The next section considers the childhood experiences of the participants.

3. Childhood Experiences

Final scrutiny of the data, gleaned from responses to the AAI questions, resulted in identification of the third major theme, which referred to people's childhood experiences. This data was used in the previous chapter to determine participants' attachment classification. However, as previously stated, there was more to be gleaned than a mere "classification" from this data; my relationship with the participants and their families and my observations and notes added a further dimension to the data than the responses alone conveyed. This theme was further subdivided into: World War 2 (WW2), separation / trauma/loss, cultural norms/physical affection/self sufficiency. Examples of peoples' childhood experiences can be found in the appendix (Appendix 7.2)

3. a) World War 2

The first category in this theme was the influence of WW2, which for many was also a cause of separation due to the policy of evacuating children to places that were considered safe or safer than their home towns. The age range of this participant group was extensive, with one person being born the year the First World War began, to the youngest person who was born twelve years after the Second World War ended. Eleven participants commented on their experiences of the war years to a greater or lesser extent.

3. b) Separations

For one person the separation he remembered was not as a result of war, he had been sent to boarding school at the age of eight years. He described memories of crying himself to sleep. For all other participants, they recognised that going to school aged five years would have been their first experience of separation from their mothers. At the time these people were children, the cultural norm was that most mothers would not have worked outside the home. What was identified as traumatic by three people was their relationship with one or both of their parents.

3. c) Cultural norms

What I have identified as "cultural norms" arose out of the information that people gave in response to the question: Did your parents physically hold you? Nine people remembered physical affection, two responded by saying they remembered being comforted physically when they were hurt and the remaining fifteen had no memories of physical affection and explained that with remarks such as: "*We weren't that sort of family"*, *"she was good but not physical"* and "*We weren't a family to show physical affection."* People also commented that although their parents weren't physically affectionate, nevertheless they felt loved. The lack of physical affection might, in present time, be considered unusual but it could be seen as 'normal' at this time. As one person commented: "*It's not like today."* This section has described the themes identified in the thematic analysis that emerged from the data from all participants. The next section will consider the data case by case in terms of identifying and illustrating the narrative of the data in relation to each 'case'. I have argued for the use of thematic analysis as a flexible tool that is capable of providing a rich and complex account of the data. The approach taken was to allow the analysis to be data driven rather then theory driven to allow the narrative of the data to emerge. This section will triangulate the different sources of data to enable statements to be made particularly in relation to the question: I*s there any association between attachment style, experience of the group and quality of life ratings?*

4. Case 1

This was the first group to complete the research. A detailed account of the group experience for this 'case' was given in the previous chapter as a means of illustrating the content and process of the group experience for each 'case'. This 'case' consisted of eight people; six women and two men. Is is clear from table 1 in the previous chapter that there was some change in levels of engagement and involvement but nothing substantial. In response to the question *How helpful did you find the groups?* Neither Ann nor Rosemary could remember, however Rosemary's husband was disappointed as he was hoping for 'treatment'. The remainder of responses were positive, in contrast to the results of the Perceived Helpfulness questionnaire. The DEMQoL results for the overall data were significant. For each 'case' question 29 - a measure of overall quality of life, which produced a non-significant result was analysed for. In this instance four people reported no change from the pre to the post group measure. Again the results from Rosemary, Ann and Bella are not reliable. Eric changed from fair to good, whilst Jeannie moved from good to fair. Attachment classification for this 'case' revealed four people with a secure attachment: Eric, Jeannie Roger and Eva. Ann and Iris as dismissing/avoidant whilst Bella and Rosemary were unclassifiable.

In drawing together results it was useful to explore patterns that emerged from the thematic analysis. To this end the data for this 'case' will be considered as a whole. The negative relationship that were evident were those of Ann and Bella both whom had difficulty in relating in the groups. although Bella did relate well to Jeanie. From the evidence presented it is not possible make any claim for the helpfulness of the group for either of them. Rosemary's experience was also inconclusive as she was unable to participate meaningfully in the groups. Her relationship with her husband was very sad, in that he was desperately trying to maintain their life together to the extent he would lock them into the house to prevent Rosemary wandering. Iris, who was rated as having an insecure attachment style was able to make use of the groups being engaged and involved, she also related well with me on a one to one basis. Her relationship with her husband was positive and my observations were that he was supportive. There was no sense of a negative relationship —rather they seemed comfortable but there was no evidence of any shared activities. However, her overall quality of life moved from very good to good presenting a mixed picture. The four securely attached people (Eric, Jeanie, Roger and Eva) were able to be more active and present in the groups albeit Jeanie was very anxious initially, also Eric and Roger took some time to settle into the group. In this 'case' Eric was the only one person who reported their quality of life as having improved after the group experience. The dominant themes in this group were avoidance, dismissiveness, anxiety and isolation, however I believe these themes were skewed by the three people who were more severely cognitively impaired

In summary, what can be said of this 'case' is that a mixed picture emerges for the reasons outlined above. The only tentative conclusion that can be made is that people with a secure attachment style are more able to make use of a group intervention and to have found it useful.

5. Case 2

This 'case' was comprised of three women and five men. Table one above reveals a more even spread of engagement and involvement in this 'case' with little variation from session 1 to 4. There is more variation in the responses regarding the helpfulness of the group ranging from John who has no memory of the groups, Ruth, Agnes and Frank who were indifferent, whilst the remaining people made positive responses. Quality of life was perceived as not changing for six people with Peter and Paul reporting improvements. The spread of attachment classification was: one man was unclassifiable, the only person to be rated preoccupied/ambivalent was a man in this group, two women and one man were rated as dismissing/avoidant and two men and one woman as secure. Therefore, there was a predominance of insecure attachment styles in this group. John was the person who could not be classified as his responses to the AAI questions did not result in a coherent narrative. I have illustrated in the Appendix (Appendix 7.1) the difficulties John had in his relations with his family, in the groups and in his day-to day living. Whether this can be ascribed to his cognitive ability or his attachment style is a question that this data is unable to address. Examples have also been given that appear to support Ruth's classification (dismissing avoidant) and the difficulty she has in her relationships with her family and with the group setting. There was a pathos in her isolation and her denial of having memory problems. Examples have been given of Agnes's relationship with her husband, which could be characterised as distant and on her part openly hostile. Her level of engagement in the groups was minimal. There was a strong sense of her isolation as she had little contact with family and her husband led a separate life. Peter was the other person with this classification, however as stated above he had been diagnosed with clinical depression, therefore, it was impossible to extrapolate what, of his attitudes and behaviour could be ascribed to his attachment style or depression. Frank was the person with was classed as preoccupied/avoidant, which was not evident in my observations of him in the group setting nor in his close relationships. The theme that characterised Frank was self sufficiency - it seemed very important to him that he was able to continue with the activities of his day-to-day life; to enable this he used a range of coping skills, particularly memory aids. The relationships he had with his children were close and he was very reliant on them in supporting his independence. Of the securely classified people each of them demonstrated positive relationships and engagement with activities of everyday life and they were those who participated actively in the groups. Angela struggled with speech production, especially in the group setting but this did not deter her from contributing. However,, her speech was affected more markedly in response to her husband's irritation and antagonism. Jim also had difficulty with voice production, which made it difficult for him to be heard in the groups. However, he persevered with encouragement from facilitators. Paul was also a quiet member of this group, which fitted with the impression I had of him during the home visits. His relationship with his niece was highly significant for him as were the coping skills he employed to enable him in his everyday tasks.

Overall, this 'case' demonstrated a range of attributes and behaviours that do not fit into specific patterns with the exception that those with a secure attachment and a positive relationship style where this who were more able to make use of the groups and with the exception of Angela exhibited the more positive relationships.

6. Case 3

This 'case' was comprised of four woman and two men. From table 2b in the previous chapter it can be seen that there was a range of changes across the 'case' from which little can be claimed. The group experience was seen as helpful by all. It is interesting to note that two of the participants would have liked more sessions. Quality of life ratings did not change for all but one participant. Carol's rating moved from good to fair. Dorothy's rating was consistently poor, which may be explained by the misery she experienced as a result of extreme anxiety. All were classified as secure apart from Sheila whose was rated as dismissing/avoidant. There are numerous examples (Appendix 7.1) of her behaviour in coping with her interviews with me, her experience of the group and her everyday life. The predominant theme for her was her relationship with her mother as a child. Her only close relative was a sister on whom she was dependant, specifically in terms of reassurance for what she believed she had lost or forgotten. The sense I had of this relationships was that it was strained. To what extent the lack of an emotionally close relationship contributed to her sense of confusion is a question that is posed rather than addressed by this data. The remaining people in this group do not present as a homogenous group, rather they each have expects of their lives that are difficult and their means of coping are individual. Peter, Katie and Bob presented as the most able in coping with living with dementia, this was characterised most strongly by their relationships to their spouses. All reported strong emotional ties, which were evident in my meetings with them in their homes. They were all involved and engaged in the groups, all had a secure attachment rating. Dorothy had a difficult time throughout the period of the research as she was experiencing severe levels of anxiety, which were only beginning to be brought under control by medication towards the end of the group sessions. However, Dorothy's husband was very supportive, attentive and concerned for her. Carol was an exception to the pattern that was being presented by the majority of people who were securely attached. She had experienced a severe trauma in early childhood by witnessing an accident that led to the death of her playmate. She lived alone having a son as her only relative, there was no sense of closeness between them with Carol often being left to the care of neighbours. Carol's input into the groups was limited but she was actively engaged in presentations and discussions. Again this 'case' presents as a disparate group with some people seeming to cope better in their day-to-day lives. Again there is a repeat of the theme observed in 'cases' above, that those who are securely attached and in positive relationships appear to be those who manage living with dementia most effectively.

7. Case 4

This was the smallest of the 'cases' and was made up of three men and one female. Levels of engagement were fairly consistent throughout other than Kevin whose involvement increased from session one to four. There was a split in the perception of the helpfulness of the group with Henry being dismissive and Mike non-committal, both of these responses are consistent with the manner they demonstrated in the groups. The responses of the same participants are of interest for quality of life with Kevin's response moving from fair to very good whilst Henry's from good to fair. It could be posited that Kevin's response arouse out of his experience of the groups being more positive than he had anticipated. Conversely, for Henry was there a growing realisation of his situation? All were rated as having a secure attachment style apart from Henry who was rated as having a dismissing/avoidant attachment style. There are examples (Appendix 7.1) of Henry's relationship with his wife, which exhibited a range of negative characteristics that suggested his isolation in the relationship; with his wife continuing with her interests whilst Henry, having given up most of the things he enjoyed, was left home alone watching television. He also had difficulty in the groups in terms of behaving inappropriately as described above. There was no real sense of emotional closeness between Penny and her husband albeit there were no signs of negativity between them. An interesting remark that Penny made was the as a result of her mother's treatment of her throughout her life she was unable to demonstrate affection. This raised a question, for me, as to how this may have affected Penny's ability to allow herself to feel the vulnerability of a close relationship. Kevin and Mike by comparison described their relationship with their spouse as close and supportive. However, in both instances I observed that a function of these relationships was that the couples were in close relation to each other to the exclusion of others - this was a feature of their relating in the groups. Overall, this 'case' again demonstrated that people rated as securely attached appeared to manage better living with dementia than those who were treated as insecure.

This section has considered the findings from the complete data set. The consistent theme that emerges supports the notion that relationship between people with secure attachment styles and positive relationships are more likely to have stronger close relationships than those who are classed as insecurely attached. This statement has been supported by triangulation of the data whereby this theme can be seen to be evident particularly in the data gleaned from the group and the thematic analysis.This next section considers the overall findings from this chapter.

8. Conclusions

Overall, this data reveals the difficulty in categorising and organising people on the evidence of the measures and observations described above. However, the over-riding theme I was aware of, as a participant researcher, was the importance of the closest relationship to the person with dementia and the environment that is created as a function of that relationship. It was clear, not by measurements but relationally, that those in supportive relationships coped better with their memory loss in their day-to-day lives. The converse was true for those in less supportive relationships. I appreciate that this is not possible to qualify this definitively, rather it highlights the complexity of the role of the researcher as observer/participant in terms of how their observations and experiences, in relation to participants, can be analysed rigorously.

From the above results, the following conclusions were drawn in addressing the research question.

Is there any association between attachment style, experience of the group and quality of life ratings?

The thematic analysis draws out the interrelationships between the results in that those with a secure attachment style with positive relationships are more likely to live better with dementia. Classifying attachment style was initially addressed by determining the person's attachment style based on Grice's (1975, 1989) conversational maxims. Excluding the three people (11.53%)whose level of dementia was such that they were not able to give an adequate response to the question, 69.23% of all participants found the group helpful. The other respondents (11.53%) were indifferent in their response to the group experience; of the three, one was classed as dismissing/avoidant, one as preoccupied and the other as secure.

However, simply accepting this percentage of the population, does not tell the whole story of those who were classed as secure, as the following anomalies were observed. An example was Eric who was classified as secure by myself and two co-coders. At the first home visit he told me he had been more gregarious in his youth but now he was more inclined to stay at home. On a subsequent visit, his wife stated that he had always been a home bird. His response to the attachment questions was to describe himself as being a sociable person, whilst also preferring his own company. In the groups I observed him as being engaged, but his involvement was limited, suggesting a person whose relational style was as an observer, rather than as a participant in groups with people with whom he was not familiar. This pattern did not change over the course of the group interventions. This example serves to highlight the complexity of making statements about a person's attachment style and is a significant factor in determining their social experience.

Conversely, Iris who was classified as dismissing/avoidant was someone who declared that when she was young she did not like to be around a lot of people, whereas now she does. However, her response to the attachment question was that she does not see herself as a sociable person, preferring her own company, but she does feel close to certain other people. Again this pattern illustrates the difficulty of classifying social behaviour.

Although there are interrelationships within the data, no clear patterns have emerged within 'cases' and between 'cases' other than there is some evidence that a securely attached people who are in a positive, supportive relationship person's were more able to make use of the groups, remain more active in their day to day lives and more likely to be able to discuss their memory problems with their spouse/family.

This chapter has presented the themes arising out of the thematic analysis as well as collating results from the previous chapter to consider the patterns that emerged within the ‘cases’ in an attempt to ascertain interrelationships. The next chapter will draw out the conclusions that may be inferred from the results, as well as considering how research can be developed in this area in the future.

Chapter 6

"*An individualised approach* challenges *us to go beyond the narrow idea of dementia as a contraction of life to a new and more complex vision of a unique and creative world . . . in which people with dementia may actually have a more personal, unique and individual experience because of their dementia" (p. 1401). Russell C., 1996*

This chapter will present the overall findings of the study, which will be considered in relation to the literature discussed in chapter two as well as a discussion of the finding of this study in terms of the research questions. A critical evaluation of the research will be given as well as considerations for future study. A reflexive statement will address my role as participant observer.

1. Synopsis of Findings

The overall aim of this study was to ascertain to what extent the current provision of psychosocial groups, provided within one NHS Trust, were found to be helpful. This aim was addressed by the questions below, which will be considered separately.

2. Question 1

Are the group interventions observed in this study perceived as helpful?

In addressing the first question the Perceived Helpfulness questionnaire results revealed that there was no evidence to suggest that a person's attachment style was a significant factor in their perception of the helpfulness of the group. However, in response to the question "*did you find the groups helpful"* eighteen of the twenty six participants found the groups helpful. Of the five participants who did not were Rosemary's husband who was looking to the group for some form of curative treatment for his wife. My sense was that he was deeply disappointed that he did not get the reassurance he was looking for despite being offered more support in caring for his wife as a result of follow up by the Older Age team. from the people with dementia's perspective, Ruth was dismissive of the group, which was consistent with her use of the groups. Frank was active throughout the group sessions but he stated that he felt more aligned to the Age Concern group that he also attended. Henry and Ruth were dismissive, which corresponds to their attachment category.

Consideration of the levels of engagement and involvement of each 'case' revealed little commonality both within and between 'cases'. There were two people in the first 'case' whose level of dementia was such that it was not possible to make useful statements. Bella's result was surprising in that she was more involved than might have been expected despite her husband's insistence on speaking for her and Carol ('case' three) who spoke very little but was very attentive to the proceedings. Kevin ('case' four) who was monosyllabic at the beginning of the sessions but involved and engaged at the end, which I attributed to his sense of relief and hope that he said he had gained. In terms of between 'cases' there were no obvious patterns that were common across the 'cases'. I would argue that there were two principal factors that are worth considering in relation to these results firstly: four sessions of a group are insufficient to allow patterns and themes to emerge, particularly in terms of appraising peoples' psychological concerns, secondly, as my participants represented a proportion of the whole group in which they were involved the group dynamic was diluted. None of the patterns or themes identified within 'cases' were replicated between 'cases', so nothing can be claimed for a between 'case' effect.

One of the aims of the groups I observed was to allow people to think about their experience in the context of others in the same position. Cheston and Bender (2003) identify the themes of hope and threat as being central to support groups, with facilitators balancing the two. My sense was that this aspect was largely missing in these groups. I did observe that the experience of the facilitator was critical to guiding the conversations at each table but there was little opportunity for people to focus on their 'felt' experience of living with dementia. a study by Cheston *et al*. (2018) found that the role of the facilitator was a factor in determining the extent to which people are or are not able to assimilate a diagnosis of dementia. Specifically, a focus too early in the group process on information giving or an imbalance between "telling and asking" (Cheston op. cit. P 68) to the detriment of listening, encouragement and questioning. Toms *et al*., (2015) suggest that a common theme that emerged from support groups for people with dementia are that the group becomes a safe place to share experiences of dementia, that people enjoy meeting people in a smilier situation, they develop an increased sense of self-efficacy and self esteem. The next section will consider the experience of groups from the literature reviewed and beyond.

Watkins *et al*., (2006) considered changes in insight over the course of a group psychotherapy intervention. We can consider this study in greater depth from the vantage point of the findings elicited in this thesis. Specifically, of interest is the experience of Robert (one of the group participants) and the effects the change in awareness evoked for him. The authors draw attention to his coping strategies, which were identified as being one of the sub-themes of this research, in terms of the need to maintain a position of denial at this time i.e Ruth and Henry. Miesen (1999) also calls attentions to coping strategies which he terms 'valid excuses'. Watkins *et al*., (2006) highlight Kitwood's (1996) assertion that it is within a benevolent social psychology that people may be able to consider their diagnosis. However, this highlights the difficulty of addressing this issue when a shift in a person's experience is interdependent on a range of factors and, as a result, each person is dealing with a different aspect of their experience and also at a different level I would argue that the results of this study also revealed that coping strategies are a factor to be considered in research with people with dementia as well as a factor to be respected. I would go so far as to argue that coping strategies fall into the realm of defence mechanisms that are in place for good reason and it is incumbent on researchers to respect them; which leads to a consideration of the social psychology in which a person finds themselves. If, as was the case for John and Angela, who were in a social situation, over which they had very little control, that is negative in one way or another, do we have a right to challenge their coping mechanisms other than to work with the couple to influence the social psychology (their relationship). In my experience people utilise coping mechanisms for good reason and my belief is that it behoves practitioners to respect them or to work with them in a therapeutic style that is supportive in developing insight.

A further study reviewed above was entitled Remembering and Forgetting: group work with people with dementia (Cheston, Jones and Gilliard, 2003). Here the authors identified two poles on a theme of 'personal communication' with people who want to 'do' something about their diagnosis and those who don't want to know. They add that facilitators, in designing group interventions, be mindful in balancing hope and threat. A theme that adds to that above in underlying the need to recognise coping strategies and the level to which they can be challenged within the person's social psychology. In this research there were people who represented each end of the continuum; at the hopeful end were participants Eric, Roger, Paul, David, Kate and Kevin all of whom fall into the secure attachment category. At the other end of the scale, excluding those we have defined at more severely affected, were Bella, Ruth, Agnes and Henry none of whom fall into the secure category. Broadly the studies discussed above have focused on the perceived helpfulness of a group intervention and some links made between helpfulness, attachment style and the results under discussion. We will now move on to consider quality of life in relation to the findings.

3. Question 2

How does a group experience impact on a person's quality of life data?

Data from the second question revealed a *s*ignificant improvement in QoL at the $p < 0.05$ level. This is not to claim that the group intervention was solely, or in part, responsible for this change, nor is it possible to claim a clinical change in the participants' condition was responsible as there was no control group to substantiate such a claim. However, a further suggestion, based on arguments made elsewhere in this thesis, could be that if a person's quality of life is experienced more positively then this may influence the disease process positively (Schneider, 2001; Hoe *et al.*, 2009).

3. a) Overall Perception of Quality of Life

There was no overall perception of an improvement in quality of life following the group experience as defined by a t-test. Visual scrutiny of the data (Table 3 ch. 4) supports this result. The fact that the majority (65%) recorded a response of no change may support the argument that four sessions is not sufficient to influence a person's overall sense of quality of life.

In addressing this question , in relation to recent studies, we will review what has been highlighted in this study in consideration of quality of life. QoL in dementia is important; as the disease is degenerative little impact can be made on that process but there is significant interest in the literature in investigating how QoL might be improved for both the person with dementia and their family/caregiver. QoL permeates every aspect of a person's experience of dementia and links directly to Kitwood's concept of 'personhood' (Ready and Ott, 2011). The move away from proxy ratings for people with dementia continues as more studies focus on ratings by people with dementia (Carrasco *et al*., 2011, Becker, Kaspar and Kruse 2006, Logsdon *et al*., 2002). Alongside this development there has been an increasing awareness that quality of life ratings of the person with dementia differ from those that caregivers attribute to them (Huang *et al.*, 2014). From studies of self-ratings has grown an increased awareness of the complexity of measuring QoL. Specifically, that it is highly subjective and, for example, is not only experienced as mood states but also that factors influencing QoL change across the disease process. For example, in the early stages cognitive changes were associated with QoL ratings; whereas in moderate dementia diminished insight was related to higher ratings of QoL (Hurt *et al*., 2010).

Therefore, as well as having a better understanding of the complexity of measuring QoL a greater knowledge of the usefulness of such measures in evaluating services and interventions has been developed over recent years. A self-report measure was chosen to be in keeping with this study's focus on the experience of the person with dementia. The findings reveal that experience of quality of life was significantly different between the pre and post groups scores across the areas of: "your feelings," "your everyday life," and "your memory", which were covered by twenty-eight questions. However, the global question of "*We've already talked about lots of things: your feelings, memory and everyday life. Thinking about all of these things in the last week, how would you rate your quality of life overall?"* did not result in a change of perception following the group experience. Although there were some people who reported a change for the better in their quality of life no consistent theme emerged that could bee associated with the group experience or attachment style whether the results were considered individually or in the context of the 'cases'. Considering the complexity identified above it is not possible to have a clear understanding of why this might be. However, it might be useful to consider that whilst the experience of the groups influenced people's perceptions of areas of their lives covered by the categories of: "your feelings," "your everyday life," and "your memory" it did not alter the fact that they had a progressive degenerative disease, which had not been emotionally assimilated and, therefore, it was potentially impacting on their perception of their overall QoL. This contention supports the argument of Hurt *et al*., (2010) that in early dementia, when insight is less affected, people are more likely to take a pessimistic view of their quality of life.

There is a dearth of studies available addressing the effects of a group intervention on QoL; a Danish study (Phung et.al, 2013), which was a three-year follow-up on the effectiveness of a psychosocial intervention for people with mild dementia revealed that there were no long-term positive effects of the intervention. However, Mittelman, 2013 considered the significance level of p=0.0005 to be too conservative and when adjusted to p-0.05 the results were significant. Logsdon *et al*., (2010) using the QoL-AD scale managed to show significant results after controlling for age and sex. Clearly, there is a need for further work in this area if we adopt the premise that one of the aims of psychosocial groups is to improve the person with dementia's quality of life; specifically in being clearer in what we are measuring and realistic about what we can expect to change, as in this instance, where participants are only offered four sessions.

4. Question 3

Does attachment style play a role in how participants experience the group?

As can be seen in table 4, chapter four participants fall into four very differently-sized categories. Research has shown that in a sample of 10,000 AAI interviews, the percentages in each classification were as follows: secure, 58%, dismissing 23% and preoccupied, 19% (Bakermans -Kranenburg and Van IJzendoorn, 2009). In comparing the results from this study it can be seen that the secure group at 57.69% is comparable, dismissing 26.94% somewhat higher, preoccupied 3.84% considerably lower, unclassifiable 11.53%. However it is impossible to make any claims on the distribution of attachment style as representative of the wider population from this study as the numbers are too small.

4. a) Attachment Style

Classification of attachment style was primarily assessed using Gricean analytic principles focusing on state of mind. No claims can be made that anything conclusive can be stated regarding a person's attachment style in relation to experience of a psychosocial intervention or of the interrelationship between attachment style, group involvement and QoL ratings unless secure attachment style is linked with a positive relationship. Criticism of the methodology could be made on the grounds of robustness of the method adopted, which relied on a degree of subjectivity in the classification process although subjectivity was addressed by having a sample of the data co-coded by two other coders as well as adhering to the coding principles provided by Hesse (2008).

Although attachment classification did not appear to be significant in relation to this question there was a theme running through the data that suggested differences in results between those who were securely attached and those who were classified as insecure. Specifically, those whose relationship to their principal carer, predominantly spouses, was considered to be positive/supportive were all classified as having a secure attachment style. Of those who found the group experience helpful 69.23% of them were classed as having a secure attachment style. These findings add weight to the argument that attachment style is a factor in determining the quality of a relationship which, has been stressed, as being important to a person with dementia. It is difficult to make any specific claims relating to the effect of the group in terms of these findings, which could have occurred by chance or, that those who did have a secure positive/supportive relationship were those who could make more use of the group. However, it remains that the small numbers involved and that the groups were of four sessions only dictate that no claims can be made as to the role of the group. This result does suggest that further research in this area could be useful in determining the generalisability of this result.

The literature review identified attachment from the early work of Bowlby (1969) through to developments in the theory through the work of Ainsworth (1963, 1967, and 1978); Main and the development of the AAI (1985). Miesen developed the thinking of previous theorists by taking the notion of attachment patterns as significant relational factors across the lifespan into his work with people with dementia. We found that Miesen provided a compelling rationale for the way that attachment behaviours were exhibited by people who found themselves in the 'strange situation' of dementia. Browne & Schlosberg (2006) in reviewing the literature on attachment theory, ageing and dementia confirmed the significance of attachment issues in this population. They commented that most studies focused on people in care facilities, as does Miesen, and call for more research with people living in the community. At this point is would be useful to consider some of the current thinking in regard to attachment and in relation to the findings of this study.

Neils *et al.*, (2012) looked at attachment representations in people with dementia and their carers in relation to the well-being of both. A relationship questionnaire devised by Bartholomew & Horowitz (1991) was used to assess attachment style whereby ninety seven participants were asked to choose between four paragraphs the one that best fit their experience. They utilised four classification categories: secure, preoccupied, dismissive and fearful. The distribution was: 35% secure with 64% in the insecure categories compared with the results in this study 57.69% secure and 42.31% in the insecure categories. There is a substantial difference between these figures, which may be explained by the difference in the total number of participants; 97 against 26. Consideration must also be given to the differences in the methodology used to determine attachment classification. Findings reveal that the dismissive category was represented more frequently than in studies of people in earlier life, which does tally with the findings of this study with dismissive being the most frequent category of insecure attachment. Their reasoning for there being a higher representation of people with dismissive styles was that other studies had also found age related differences in attachment style with a dismissive style being more prevalent in older people. They quote Miesen (2010) in asserting that attachment and the quality of the relationship with the principal carer is related to quality of life. However, they did not find a direct link between quality of life and attachment, which was echoed in this study. For the purpose of this discussion I have not referred to the interrelationship of attachment styles between the person with dementia and their carer. This section has considered the results in relations to question (3). We will move on to consider the findings to the next question.

5. Question 4

Is there any association between attachment style, experience of the group and quality of life ratings?

A thematic analysis identified themes that arose from the complete data set as discussed in the previous chapter. The overriding theme, between and across all 'cases', was the significance of the relationship between the couples I interviewed and contributed to the

finding that was most persuasive across all four 'cases', which was that those who are rated as being securely attached and who were in a positive relationship were more likely to make use of the group, be more active and involved in a social setting and generally manage to live better with dementia.

6. The 'Story' - Relationships

I would now like to turn to what I refer to as the 'story' of the research. My hope before during and after the data collection process was that the data would convey the story - the narrative of the experience of the participants over the course of the research and the group experience, which I have sought to illustrate via the themes that arose from the thematic analysis. The overriding impact was the significance of the relationship between the couples. This was not an aspect I set out to study but it became obvious that it could not be ignored. My focus was to consider the attachment style of the person with dementia principally in relation to their experience of the group intervention. As my understanding deepened over the span of the groups I came to realise that the significance of the relationship permeated the person's entire experience. The importance of the relationship was discussed in the previous chapter; here I would like to consider it in relation to Kitwood's views on the person's social psychology and the consequential effects arising out of the way people are treated. In the previous chapter, I suggested that there was a connection between the relationship of couples and the person with dementia's experience of the disease. I gave examples of those who were or were not in supportive relationships and the influences on their experience.

Kitwood discusses 'previous support structures' and argues that if they are relatively intact when a person begins to experience the effects of dementia they have more to sustain them. For the purpose of this study I have interpreted Kitwood's statement in terms of the relationship between care receiver and care giver. It was obvious in my observations of the people themselves, particularly in regard to the manner in which they had adapted to their diagnosis as well as the relationships they had sustained prior to diagnosis (Eric, Roger,David Katie) i.e. those who had a close relationship prior to diagnosis were those who appeared to cope better after diagnosis. This view is supported in a study by Norton *et al.*, (2009). As my interest in the relationship developed I searched the literature to find that the relationship had been considered from a number of aspects. Predominantly, there was more interest in the carer experience (O'Shaughnessy, 2010, Steadman, Tremont and Davis, 2007), but more recently studies have considered the relational couple from a range of foci. Ablitt, Jones and Muers, (2009) in a review of the influence of relational factors confirms the link between the relationship and the experience and calls for greater involvement of the person with dementia in research studies; and for clinical interventions to focus on the relational aspects of the dementia couple. Edwards *et al.*, (2016) have embarked on a study of the quality of relationships in terms of predictors of outcomes, which should address specific relational factors that sustain the couple, thereby maintaining the person with dementia in their home environment longer.

The Alzheimer's Society (2010) produced a report "Impact on relationships" which explored the effect dementia had on relationships of the person with dementia and their carer. The report is based on semi-structured interviews of ten couples. They found that the impact of dementia on the relationships was extensive and the principal differences in the account given by the person with dementia and their carer was the lack of insight on the part of the person with dementia believing that they were much more capable than they actually were. The conclusion was that a great strain is put on the relationship and highlights the need for support and interventions in the community. Edwards *et al.,* undertook a review of the literature focusing on the quality of family relationships and outcomes of dementia, as a means of evaluating relationship quality and outcome for the person with dementia. Twenty three studies were reviewed that focused on a range of relationship factors. They concluded that there was no evidence that a caring relationship prevents decline in the person with dementia and that from these result it would not be possible to identify people at risk of a poor outcome due to relationship factors. However, they highlighted a number of methodological deficits in the studies that may have been why relationship factors were not identified as having a significant effect. This study also makes a case for the relevance for further study in this area. As stated above a number of participants experience difficulty in their close relationships for which psychological support may have been helpful. Studies of relationships between people with dementia and their carers are of particular interest to this research as the focus was on people with early dementia living at home. This section has considered the significance of the relationship and we will now focus on the strengths and limitations of this study.

7. Critical Evaluation

In considering the limitations of this research, with the value of hindsight, my overall criticism is that it was too ambitious. Principally, in terms of the scope I attempted to cover; specifically, there were too many measures some which proved to be difficult both to administer and to analyse. In particular, the Perceived Helpfulness Questionnaire, which I devised myself, had its weaknesses as the disparity between the results from that measure and the feedback I received verbally from the question "D*id you find the group helpful?"* indicate. My understanding of the problem was that I probably did not ask questions that would have delivered the information I was seeking. For example I could have asked questions that were more focused on the felt experience of having a diagnosis of dementia and whether they had the opportunity to address such issues in the groups Another consideration in regard to the questions was that they were constrained by my attempt to address the content of the groups, which also led to my rejection of validated measures that may not have been as specific as I wanted but, on reflection, that may not necessarily have been a loss. I now realise that if I had asked questions that were closer to peoples' experience I might have elicited responses that were more useful. As well as the example given above I could also have focused on the impact of peoples' memory problems on their day-to-day lives; as well as whether their hopes and expectations of the groups had been realised. Although I used the experience of the series of groups that I observed prior to the study I did not have a sound understanding at that time of the issues that were important to people, for example that there was a range of hopes and expectations that were not necessarily verbalised prior to the groups but became evident in discussion afterwards. For example, Rosemary's husband hope that the group would identify treatment that would 'cure' his wife.

With hindsight I can see that attempting to study the 'case' whilst studying the individual in the 'case' had its limitations, especially when there were many more people in the overall group than there were participating in the research. A further consideration was that the overall group size was in excess of twenty people at best and in the final two 'cases' in excess of thirty.

I also suspect it would have been useful to have recorded and analysed DEMQoL proxy ratings across all the 'cases' as well as the attachment style of principal carers. My focus was to concentrate on the experience of the person with dementia but I now believe it would have been useful to see the person in relation to their significant other.

The data gleaned from the semi-structured interviews could have been much more robust had the interviews been recorded. In this way I lost a good deal of detail and my focus was blinkered in that I attended too rigidly to the AAI Protocol, thereby limiting my recoded notes to responses to the questions. As a result, I lost some of the finer detail of the relationship material, which I came to consider to be highly relevant. I did consider other measures of attachment but I felt that the AAI questions, being a seminal part of the development of attachment theory, was the benchmark. However, the principal disadvantage of using this measure was that the scoring information is not generally available and I had to rely on Hesse's (2008) truncated version. The second area were there were limitations was in the method of analysis. I believe there were too many measures leading to the analysis being somewhat cumbersome.

Overall, I was trying to look at too many aspects of a person's experience of dementia. A Semi-structured interview that was broader in its remit than simply addressing attachment style together with a measure of satisfaction with the group would have been sufficient to address the research questions.

I would identify the strength of the study as the information gleaned regarding the relationship of the couples, which I have illustrated above and in the appendix. It became very obvious to me that, in fact my overriding impression, is of the relational patterns I observed and the effects on the experience of the person with dementia. I see this as a strength of the research, although I recognise that it is not a unique finding to this study, but it is an area that I would be interested in pursuing. I have discussed the strengths and limitations I will now add my thoughts on what I have learnt from this experience.

8. Reflexivity Statement

My journey through this research experience has been momentous; having survived a life threatening illness and four supervisors I find myself in a very different place from where I began. Although sharing peoples' intimate experiences is not new to me I was, nevertheless humbled by the way I was welcomed into peoples' homes and lives. It is in this area of the interpersonal aspect of the study that has been most valuable to me even though, as I discussed above, I was concerned about my use of self in my encounters with people. There were occasions when the observational patterns I witnessed were distressing evoking in me a sense of helplessness that I imagine the person with dementia might feel.

In thinking about these issues I became interested in the work of Sandra Evans (2008) who explores the ways in which psychoanalytic ideas can help us understand the experience of the person with dementia. She argues that poor allocation of resources to dementia services mirror 'forgetting' and 'splitting' (Klein, 1975). A denial of thinking about people with dementia, which is expressed in attitudes of those who think there is no point in developing services for people with dementia. This resonates with Kitwood's (1990) description of a 'malignant social psychology' contributing to further decline in ability. For example, at a personal level we reported Angela whose spouse's attack on her ability to find words increased her anxiety and decreased her social activity. Evans highlights Bion's (1962) concept of 'nameless dread', which resonated with Cheston's fear of losing control (2014) when what is being experienced is a need for containment, which was the role of the mother and is now the role of the spouse/carer. The need for a secure base is also recognised in that the person with dementia is less able to self-sooth and needs that function to be performed by the other. This also relates to Winnicott's (1956) idea of being 'tuned' into the presence of another creating a sense of well-being. In chapter four we touched briefly on the idea that if a person didn't have a 'good enough' experience in childhood there is a likelihood that when they experience the nameless dread of dementia the feelings of those early experiences can be revisited. This can be triggered by loss in dementia either forgotten tragedy or repressed past events (Carol, Dorothy). Evans (2008) concludes by proposing psychoanalytically informed care as a means of developing coping skills to deal with the losses involved in dementia whilst recognising 'not-knowing' as an ego-defence and having the skill to be aware that it may be vital for some to maintain the position of 'not knowing'. This article helped me make sense of my relationship with some of the participants in that I had felt some people had made a strong attachment to me. I came to realise that without being entirely conscious of relating to people at a psychoanalytic level, that was a possible explanation, which they may have experienced as feeling held/contained and understood; consequently, feeling more secure.

This synopsis of Evans psychoanalytically informed article leads us into a discussion of future approaches to the treatment/management of dementia.

9. Further Studies/Interventions

In considering future studies and future interventions the most recent BPS publication featuring Clinical Psychology in in the Early Stage Dementia Care Pathway (2014) directs us to a blueprint for an approach that advocates a person centred approach. The stance this document takes is flagged in the first article; that the person with dementia and their family be at the centre of the process. We have identified above the government policy of early diagnosis, however, the findings of this report identify a psychosocial interventions gap whereby people are being diagnosed in memory clinics and, in many geographical areas, there is very little support following this most feared diagnosis. Bunn et al (2012) take up the theme of shifting research emphasis to developing interventions to provide support for people who have received a recent diagnosis. The study focused on people living in the community reviewing 102 studies; their report features the challenges to the relationship between couples describing a difficult transition to an unequal relationship of carer and care receiver. They conclude by calling for more post-diagnosis support, which they found lacking, echoing the recommendations of the BPS report above. Dugmore, Orrell and Spector (2015) reviewed a range of articles and claim to be the only review to concentrate on community delivery focusing on a mixed design of psychosocial interventions. Their results revealed more positive effects than had random controlled trials but overall their conclusions were mixed and many did not support the findings of the original studies. They found that a task orientated or outcome focus impeded the delivery of interventions as did staff attitudes and or skills deficit. The study highlights the existence of theoretical silos that lack a cohesive theory and makes a range of recommendations for further review of current practice to enable more definitive recommendations for what works to be made, making very similar recommendations at that of Moniz-Cooke *et a*l., (2011). A recent study by Cheston *et al.,(*2017) of an eight week group intervention within the LivDem project is more hopeful in demonstrating that markers of assimilation of problematic experience of dementia demonstrate an ability of people with dementia to progress from a denial of their diagnosis to a position of being able to consider their future of living with dementia without becoming overwhelmed. The authors do question whether the results suggest a therapeutic shift or are they attributable to the focus of the facilitator, or a combination of both. Nevertheless, the transcripts do indicate a lessening of anxiety in the participants. The studies outlined above focus on recommendations for the future whilst recognising there remains little consensus about what works and for whom.

This section will be completed by returning to the theme of person with dementia and their experience of the disease and a brief discussion of clinical practice that focuses on person centred interventions. Nowell, Thornton and Simpson (2011) from a trawl of the literature found that there is much to be said in defining the concept of person centred care but little clinical evidence of work with people in the community. For the last words on future interventions we can turn to some of Cheston's (2014) recent work with post diagnostic support groups, which remain the most common form of support for people and their families who have received a recent diagnosis of dementia. The aim of the group intervention is to enable people to adapt to the emotional challenge of a diagnosis of dementia. The approach used is a process model of therapeutic change. This approach engages with peoples' fear of loss of control of their internal world – their self. Cheston (2014) argues that by gaining greater awareness of the psychological functions involved in the ability to adapt or not adapt will give us greater understanding of what works for whom enabling better supportive interventions, which is the hopeful note on which we will leave this consideration of future interventions.

My own view on how support groups might be more useful to people coping with a diagnosis of dementia is that selection for the group could be more rigorous in terms of level of cognitive ability. That there be a minimum of ten sessions with referral on for further support as needed. For the focus to be principally on the persons' felt experience of living with dementia and the ramifications on the relationship with the principal carer. From my observations I could appreciate the usefulness of some sessions being split between carers and people with dementia. I would also echo Evans (2008) argument for a psychoanalytically informed approach across the treatment/management spectrum.

This chapter has provided a synopsis of the results and discussed them in relation to the research questions. The 'story' of the results was considered specifically emphasising the significance of the relationship between the couples. This theme was of particular relevance as I came to recognise that it is the most significant aspect of peoples' experience. A critical consideration of the strength and limitations of the study were offered followed by a review of my personal learning and a brief discussion of the developments I would like to see in this field as a result of my experience of working with people with dementia.

In conclusion my assertion is that the results of this study have identified the significance of attachment and the person's relationship as reported by Miesen (1999) and others. Kitwood's work (1972, 1993, 1994, 1997a, 1997b), particularly the significance of personhood has also been evident in the results of this study. It suggests that the work of these theorists is extremely relevant in determining future directions for clinical interventions as is demonstrated in the group work of Cheston et al. (2016).

Wallander: *"It's just moments now dad – everything is just moments now. They don't join up."*

Dad: "*What doesn't?"*

Wallander: "*My memories. My life doesn't join up – I can't remember"*

Dad: "*Someone else will remember. Someone will remember for you!"*

Enter Wallander's daughter and granddaughter

Wallander: BBC 1, 2016

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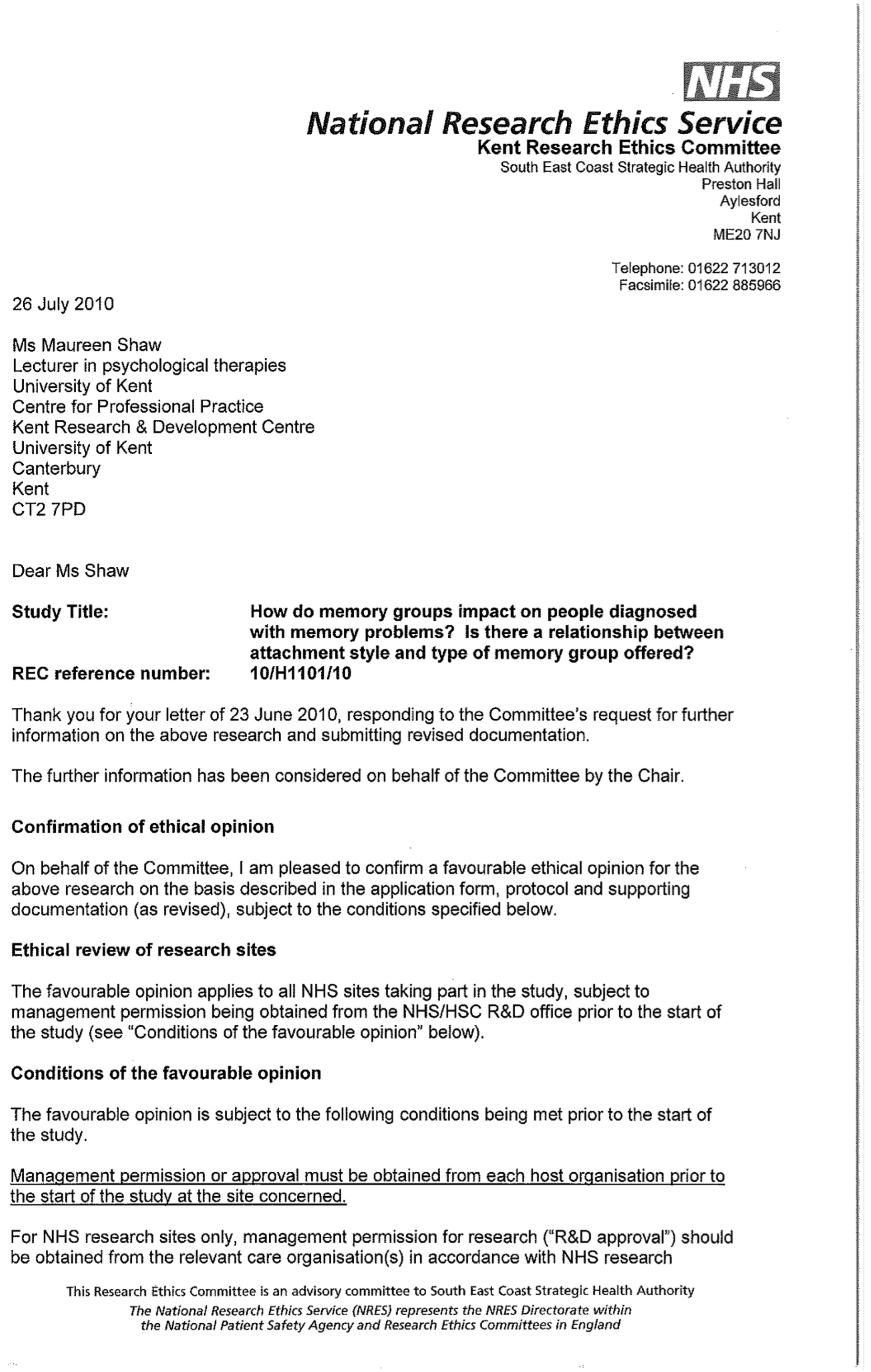
Appendices

1. Ethics Approval



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26 July 2010

Ms Maureen Shaw
Lecturer in psychological therapies
University of Kent
Centre for Professional Practice
Kent Research & Development Centre
University of Kent
Canterbury
Kent
CT2 7PD

Dear Ms Shaw

Study Title:	**How do memory groups impact on people diagnosed with memory problems? Is there a relationship between attachment style and type of memory group offered?**
REC reference number:	**10/H1101/10**

Thank you for your letter of 23 June 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation (as revised), subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research

This Research Ethics Committee is an advisory committee to South East Coast Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Investigator CV	A	30 October 2009
Protocol	A	30 October 2009
CV for Dr Georgia Lepper	A	30 October 2009
REC application		
Covering Letter		19 January 2010
Summary/Synopsis	A	30 October 2009
Letter from Sponsor		30 October 2009
Questionnaire: DEMQOL (Version 4)		
Letter of invitation to participant	A	30 October 2009
GP/Consultant Information Sheets	A	19 January 2010
Participant Information Sheet	B	27 May 2010
Participant Information Sheet: Group Facilitator	A	14 May 2010
Response to Request for Further Information		23 June 2010
Participant Consent Form	B	25 May 2010
Participant Consent Form: Group Facilitator	A	14 May 2010
Questionnaire: Attachment Style Scale		
Questionnaire: Group Aims	A	30 October 2009
Questionnaire: Perceived Helpfulness of psychosocial intervention	A	30 October 2009
Questionnaire: Group participation	A	30 October 2009
Researcher Safety	A	23 June 2010
Evidence of insurance or indemnity		22 July 2009

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H1101/10	**Please quote this number on all correspondence**

Yours sincerely

pp **Dr Ray Godfrey**
Chair

Email: Sharon.Busbridge@nhs.net

Enclosures:	"After ethical review – guidance for researchers"
Copy to:	*Dr Georgia Lepper*

NHS
Health Research Authority

NRES Committee South East Coast - Brighton and Sussex
Health Research Authority
Ground Floor, Skipton House
80 London Road
London
SE1 6LH

Tel: 020 797 22551

02 September 2013

Ms Maureen Shaw
Lecturer in psychological therapies
University of Kent
Centre for Professional Practice
Kent Research & Development Centre
University of Kent
Canterbury
Kent, CT2 7PD

Dear Ms Shaw

Study title:	**How do memory groups impact on people diagnosed with memory problems. Is there a relationship between attachment style and type of memory group offered?**
REC reference:	**10/H1101/10**
Amendment number:	**AM04**
Amendment date:	**01 August 2013**
IRAS project ID:	**35266**

The above amendment was by the Sub-Committee in correspondence.

Ethical opinion

No issues raised. The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

1.1. Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMPs)	AM04	01 August 2013
Participant Consent Form	B	22 August 2013
Questionnaire: Attachment questions	A	29 July 2013
Participant Information Sheet	D	20 August 2013
Attachment style scale (2008)	A	
Questionnaire: Group questionnaire	B	29 July 2013
Protocol	C	30 July 2013
Participant Information Sheet: Carer	A	20 August 2013
Consultant's letter	C	31 July 2013
Attachment circle	A	29 July 2013
Questionnaire: DEMQoL - Carer	4	
Participant Consent Form: Carer	A	22 August 2013

1.2. Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

1.3. R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

1.4. Statement of Compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

:HDUHSOHDVHGWRZHOFRPHUHVHDUFKHUVDQG5 'VWDIIDWRXU15(6FRPP LWWHHPHPEHUV¶ training days ± see details at http://www.hra.nhs.uk/hra-training/

10/H1101/10:	**Please quote this number on all correspondence**

Yours sincerely

pp. T. Laird

Dr John Bull Vice Chair

E-mail: NRESCommittee.SECoast-BrightonandSussex@nhs.net

Enclosures:	*List of names and professions of members who took part in the review*
Copy to:	*Linda Partington, Comprehensive Local Research Network for Kent and Medway* *Dr Georgia Lepper*

NRES Committee South East Coast - Kent

1.5. Attendance at Sub-Committee of the REC meeting on 21 August 2013

Also in attendance:

Name	*Position (or reason for attending)*
Dr John Bull	Consultant Physician (retired)
Mr Maurice Marchant	

2. Participant Information/Consent

2.1. Information Sheet

MAUREEN SHAW
PSYCHOTHERAPY LEAD
Dialling Code for Canterbury:
01227 (UK) or +44 1227
(international)
Tel: 827678 direct line
764000 switch board (ext 3691)
Email: m.shaw@kent.ac.uk

I am Maureen Shaw and I work for the University of Kent. I am doing research that aims to get a better understanding of which types of groups work best for different people. I wondered if you would consider taking part in my research, for my Doctor of Clinical Science (Psychotherapy) degree. The findings of the research will be published in due course.

You do not have to decide whether or not you agree to take part in this research today and before deciding you might like to talk to other people.

In this study we will ask people what they found most helpful about the memory group they attended. In this way we can gain a better understanding of which groups are more suitable for which people.

I am looking for people who have difficulty in remembering to an extent that it interferes with daily life. In brief, the research involves having conversations with me, at your home, about yourself and how you found the group. If you are possibly interested in taking part in this research, I will come and visit you and your family to talk more about what is involved. I would also like your spouse, partner or relative to be involved in the research, which would involve them completing two brief questionnaires. Then if you decide to take part I will ask you both to sign a consent form. I would then visit to talk about how you get on with other people and whether you are a person who likes to mix with others or if you prefer your own company. I would visit you again after the group sessions have finished to talk about how helpful you found them. Each visit would last for about an hour. I will be present at the group sessions as an observer and will ask you to complete a short questionnaire following the second and fourth groups.

I would also like to involve your principal carer in my research by asking them some questions about your quality of life.

Whether or not you decide to take part does not affect your treatment. This research is confidential and you will only be identified by the use of a number. You may withdraw your data from the study at any time up until it is used in the final report. A decision to withdraw at any time, or not to take part, will not affect the standard of care you receive.

If, at any point you wish to make a complaint about the research please contact Simon Kerridge Director of Research Services, Research Services, The Registry, The University of Kent, Canterbury CT2 7NZ.

2.2. Consultants' Letter

Psychosocial interventions in mild /moderate dementia: what works for whom?

Dear Dr

I have invited your patient and their principal carer to participate in this doctoral research project being conducted by Ms Maureen Shaw, an experienced psychotherapist and senior lecturer, supervised by Professor Paul Cambic at the University of Kent.

This study explores the relationship between the sort of psychosocial groups people diagnosed with mild/moderate dementia are offered and their effectiveness in relation to the couple's s attachment style.

The research does not impinge on treatment in any way. People diagnosed with dementia who are offered one of the service's psychosocial groups, would be approached with an invitation to join in the research.

The researcher, to establish their ability to give informed consent, will interview potential participants who express an interest in joining the research. If informed consent is obtained, a further interview will take place to ascertain participants' attachment history. Following the group interventions participants will be interviewed again to determine their perceptions of the helpfulness of the group intervention.

There is no obvious risk to this research and it does not affect treatment whether people choose to participate or not. The research is confidential and participants can withdraw at any time.

If you would like any further information please contact me. I would be pleased to provide a brief summary of the findings and a detailed summaries of the study will be available by the end of the research. To receive a copy, contact me at the above address.

Yours sincerely

Maureen Shaw

2.3. Consent Form

MAUREEN SHAW
PSYCHOTHERAPY LEAD

Dialling Code for Canterbury:
01227 (UK) or +44 1227 (international)
Tel: 827678 direct line
764000 switch board (ext 3691)
Fax: 823224
Email: m.shaw@kent.ac.uk

30th April 2013

Memory groups: Does attachment style affect quality of life rating and the perceived helpfulness of group interventions offered to people with mild dementia or memory problems?

Dear

Thank you for considering taking part in this research. It is important that you feel you have understood what I have told you and what is written in the information sheet, and that you have been given enough information for you to make a decision. Also, that you feel that you have had enough time to talk it over with others. If you have any further questions I am happy to address them now. You will be given a copy of this Consent Form to keep and refer to at any time.

I understand that if I decide at any other time during the research that I no longer wish to participate in this project, I can notify the researcher involved and be withdrawn from it immediately.

I consent to the processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

Participant's Statement

I ____

Agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the information sheet about the project, and understand what the research study involves.

Signed Date

Researcher's Statement

I ____

Confirm that I have carefully explained the nature and demands of the proposed research to the volunteer.

Signed

2.4. Consent Form - Carer

Memory groups: Does attachment style affect quality of life rating and the perceived helpfulness of group interventions offered to people with mild dementia or memory problems?

Thank you for considering taking part in this research. It is important that you feel you have understood what I have told you and what is written in the information sheet, and that you have been given enough information for you to make a decision. Also, that you feel that you have had enough time to talk it over with others. If you have any further questions I am happy to address them now. You will be given a copy of this Consent Form to keep and refer to at any time.

……

I understand that if I decide at any other time during the research that I no longer wish to participate in this project, I can notify the researcher involved and be withdrawn from it immediately.

I consent to the processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

Participant's Statement

I ____

Agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the information sheet about the project, and understand what the research study involves.

Signed Date

Researcher's Statement

I ____

Confirm that I have carefully explained the nature and demands of the proposed research to the volunteer.

3. Instruments

3.1. Perceived Helpfulness Questionnaire (Likert version)

You feel well informed are you about your diagnosis

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

You are aware of the services available to you

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

You feel confident about mixing with other people

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

You feel more isolated since you began having problems with your memory

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

Other people treat you differently since you began having trouble with your memory

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

You been able to adapt to your difficulty in remembering

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

You have changed things at home to help you to remember

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

Your difficulty in remembering has changed how you feel about things

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

You are more aware of your feelings now

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

Your memory problem has affected the way in which you occupy yourself

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

Your memory problems have affected your relationships with family and friends

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

You believe there are people there to help you

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

3.2. Perceived Helpfulness Questionnaire (Visual Analog)

Please read the statements printed in bold and tick the response that most closely fits your own.

You feel well informed are you about your diagnosis

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

You are aware of the services available to you

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

You feel confident about mixing with other people

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

You feel more isolated since you began having problems with your memory

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

Other people treat you differently since you began having trouble with your memory

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

You have been able to adapt to your difficulty in remembering

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

You have changed things at home to help you to remember

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

Your difficulty in remembering has changed how you feel about things

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

You are more aware of your feelings now

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

Your memory problem has affected the way in which you occupy yourself

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

3.3. Study ID DEMQoL (version 4)

Instructions: Read each of the following questions (in bold) verbatim and show the respondent the response card.

I would like to ask you about your life. There are no right or wrong answers. Just give the answer that best describes how you have felt in the last week. Don't worry if some questions appear not to apply to you. We have to ask the same questions of everybody.

Before we start we'll do a practise question; that's one that doesn't count. (Show the response card and ask respondent to say or point to the answer) In the last week, how much have you enjoyed watching television?

☐ a lot ☐ quite a bit ☐ a little ☐ not at all

Follow up with a prompt question: Why is that? or Tell me a bit more about that.

For all of the questions I'm going to ask you, I want you to think about the last week.

First I'm going to ask about your feelings. In the last week, have you felt…….

1. **cheerful**? ** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

2. **worried or anxious?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

3. **that you are enjoying life? **** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

4. **frustrated?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

5. **confident? **** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

6. **full of energy? **** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

7. **sad?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

8. **lonely?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

9. **distressed?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

10. **lively? **** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

11. **irritable?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

12. **fed-up?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

13. **that there are things that you wanted to do but couldn't?**
☐ a lot ☐ quite a bit ☐ a little ☐ not at all

Next, I'm going to ask you about your memory. In the last week, how worried have you been about……….

14. **forgetting things that happened recently?**
☐ a lot ☐ quite a bit ☐ a little ☐ not at all

15. **forgetting who people are?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

16. **forgetting what day it is?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

17. **your thoughts being muddled?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

18. **difficulty making decisions?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

19. **poor concentration?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

Now, I'm going to ask you about your everyday life. In the last week, how worried have you been about……….

20. **not having enough company?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

21. **how you get on with people close to you?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

22. **getting the affection that you want?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

23. **people not listening to you?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

24. **making yourself understood?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

25. **getting help when you need it?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

26. **getting to the toilet in time?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

27. **how you feel in yourself?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

28. **your health overall?** ☐ a lot ☐ quite a bit ☐ a little ☐ not at all

We've already talked about lots of things: your feelings, memory and everyday life. Thinking about all of these things in the last week, how would you rate……….

29. **your quality of life overall? **** ☐ very good ☐ good ☐ fair ☐ poor

** items that need to be reversed before scoring

3.4. DEMQoL - Carer (version 4)

Instructions: Read each of the following questions (in bold) verbatim and show the respondent the response card.

I would like to ask you about _________ (your relative's) life, as you are the person who knows him/her best. There are no right or wrong answers. Just give the answer that best describes how _________ (your relative) has felt in the last week. If possible try and give the answer that you think _________ (your relative) would give. Don't worry if some questions appear not to apply to _________ (your relative). We have to ask the same questions of everybody.

Before we start we'll do a practise question; that's one that doesn't count. (Show the response card and ask respondent to say or point to the answer). In the last week how much has _________ (your relative) enjoyed watching television?

☐ a lot ☐ quite a bit ☐ a little ☐ not at all

Follow up with a prompt question: Why is that? or Tell me a bit more about that.

For all of the questions I'm going to ask you, I want you to think about the last week.

First I'm going to ask you about _________ (your relative's) feelings. In the last week, would you say that _________ (your relative) has felt…….

1. **cheerful?** **	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
2. **worried or anxious?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
3. **frustrated?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
4. **full of energy?** **	☐ a lot	☐ quite a bit	☐ a little	☐ not at all

5. **sad?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
6. **content? ****	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
7. **distressed?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
8. **lively? ****	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
9. **irritable?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
10. **fed-up**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
11. **that he/she has things to look forward to? ****	☐ a lot	☐ quite a bit	☐ a little	☐ not at all

Next, I'm going to ask you about _________ (your relative's) memory. In the last week, how worried would you say _________ (your relative) has been about……….

12. **his/her memory in general?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
13. **forgetting things that happened a long time ago?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
14. **forgetting things that happened recently**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
15. **forgetting people's names?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
16. **forgetting where he/she is?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
17. **forgetting what day it is?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
18. **his/her thoughts being muddled?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
19. **difficulty making decisions?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
20. **making him/ herself understood?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all

Now, I'm going to ask about _________ (your relative's) everyday life. In the last week, how worried would you say _________ (your relative) has been about……….

21. **keeping him/ herself clean (eg washing and bathing)**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
22. **keeping him/ herself looking nice?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
23. **getting what he/ she wants from the shops**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
24. **using money to pay for things?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
25.**looking after his/ her finances?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
26.**things taking longer than they used to?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
27. **getting in touch with people?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
28.**not having enough company?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
29.**not being able to help other people?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
30.**not playing a useful part in things.**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
30. **his/her physical health?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all

We've already talked about lots of things: _________ (your relative's) feelings, memory and everyday life. Thinking about all of these things in the last week, how would you say _________ (your relative) would rate……..

31. his/her quality of life overall? ** ☐ very good ☐ good ☐ fair ☐ poor

** items that need to be reversed before scoring

4. Semi-Structured Interview

4.1. AAI Questions

Revised Adult Attachment Interview Questions taken from Main, M.

1. Family orientation :Where were you born? Where did you live? Did the family move around much? What did the family do for a living? Did you see much of your grandparents when you were little? If died ask if that was significant? If died did parents speak of them/ did you have brothers or sisters, did anyone else live in the house?

2. I'd like you to describe your relationship with your parents as a young child if you could start from as far back as you can remember

3. I'd like you to choose five adjectives or words that reflect your relationship with your mother starting from as far back as you can remember in early childhood. This may take some time so think for a minute, and then I would like to ask why you chose them. Encourage without leading keep the focus on relationship. If there is prolonged silence suggest that it is ok to take time but the silence seems difficult for the participant move on. Ask for incidents to illustrate the use of a particular adjective that are specific rather than general.

4. Now I would like to ask you to choose five adjectives or words that reflect your relationship with your father starting from as far back as you can remember in early childhood. This may take some time so think for a minute, and then I would like to ask why you chose them.

5. Which parent did you feel the closest to, and why, Why isn’t there this feeling for the other parent?

6. When you were upset as a child what would you do? Observe how they interpret the word upset. Probe the answer When you were upset emotionally when you were little what would you do? Can you think of a time when that happened? Can you remember what would happen when you were hurt physically – Encourage them to remember incidents. If the person says they would go to a parent see what details they give spontaneously. Try to get a sense of how the parent responded – ask clarifying questions if necessary. If the person does not mentions being held by a parent a clarifying question can be asked

7. What is the first time you remember being separated from your parents? How did you respond? Do you remember how your parents responded? Are there any other separations that stand out in your mind?

8. Did you ever feel rejected as a young child? Of course looking back on it now you may realise it wasn’t really rejection but what I’m trying to ask abut here is whether you remember ever having felt rejected in childhood? If yes how old were you when you first felt this way and what did you do? Why do you think your parent did those things ‘ do you think he/she realises he/she was rejecting you. Did you ever feel pushed away or ignored? Were you ever frightened or worried as a child? Clarify/elaborate as necessary

9. Were your parents ever threatening with you in any way – maybe for discipline or even jokingly? Be sensitive to cultural issues. If yes ask usual clarifying questions

10. In general how do you think your overall experiences with your parents have affected your adult personality? Are there any aspects to your early experiences that you feel were a set-back in your development? If yes ask probe further with. Are there any other aspects of your early experiences that you think might have held your development or had a negative effect on the way you turned out?

11. Why do you think your parents behaved as they did during your childhood?

12. Were there any other adults with whom you were close like parents as a child?

13. Did you experience the loss of a parent or other close loved one while you were a young child –for example a sibling or a close family member. If yes ask expanding questions. Did you lose any other important persons during your childhood? Have you lost other close persons in adult years?

14. Were there any other difficult experiences other than those you've already described have you which you felt were potentially traumatic?

15. Now I would like to ask you a few more questions about your relationships with your parents? Were there many changes in your relationship with your parents after childhood – between childhood and adulthood?

16. Current closest relationship**.** How do you feel when you have to be separated?

17. Is there anything you feel you have leaned above all from your own childhood experiences? I'm thinking her of something you feel you might have gained from the kind of childhood you had.

18. Thinking of the present what would you hope your child(ren) may have learned from their experience of being parented by you.

4.2. Revised Adult Attachment Protocol

Taken From Mary Main 1985

This material is not a substitute for training in AAI administration procedure. It is provided because it is important for consumers of AAI research to have easy access to the interview questions. Without them, it is difficult to evaluate published research. Seeing the full interview protocol can also help consumers of AAI based research appreciate the level of interview information and detail underlying AAI scores. It can also help them make important decisions about the adequacy of procedures in various reports they may encounter. The authors of the AAI make the scoring manual available only in conjunction with their training courses. Researchers interested in understanding more about the logic of scoring the AAI can however see the scoring manual for Crowell & Owens' Current Relationship Interview (CRI) which is available in full on this site. The logic and procedures for scoring the CRI closely parallel those for the AAI. The primary difference is that the AAI focuses on relationships to parents and the CRI on relationships to adult attachment figures. At present this is the only detailed source of insights into the criteria for scoring the AAI available to those who do not take the training course. Do not reproduce this material without permission of the author. EW

ADULT ATTACHMENT INTERVIEW PROTOCOL George, C., Kaplan, N., & Main, M. (1985).

The Adult Attachment Interview. Unpublished manuscript, University of California at Berkeley. (Note: This document is for illustration only. Contact the authors for information about training and the most current version of the interview protocol.)

Introduction I’m going to be interviewing you about your childhood experiences, and how those experiences may have affected your adult personality. So, I'd like to ask you about your early relationship with your family, and what you think about the way it might have affected you. We'll focus mainly on your childhood, but later we'll get on to your adolescence and then to what's going on right now. This interview often takes about an hour, but it could be anywhere between 45 minutes and an hour and a half.

1. **Could you start by helping me get oriented to your early family situation, and where you lived and so on? If you could tell me where you were born, whether you moved around much, what your family did at various times for a living?**

This question is used for orientation to the family constellation, and for warm-up purposes. The research participant must not be allowed to begin discussing the quality of relationships here, so the "atmosphere" set by the interviewer is that a brief list of "who, when" is being sought, and no more than two or three minutes at most should be used for this question. The atmosphere is one of briefly collecting demographics.

In the case of participants raised by several persons, and not necessarily raised by the biological or adoptive parents (frequent in high-risk samples), the opening question above may be "Who would you say raised you?': The interviewer will use this to help determine who should be considered the primary attachment figure (s) on whom the interview will focus.

Did you see much of your grandparents when you were little? If participant indicates that grandparents died during his or her own lifetime, ask the participant's age at the time of *each loss. If there were grandparents whom she or he never met, ask whether this (these) grandparents) had died before she was born. If yes, continue as follows: Your mother's father died before you were born? How old was she at the time, do you know? In a casual and spontaneous way, inviting only a very brief reply, the interviewer then asks. Did she tell you much about this grandfather?*

Did you have brothers and sisters living in the house, or anybody besides your parents? Are they living nearby now or do they live elsewhere? –

2. **I'd like you to try to describe your relationship with your parents as a young child if you could start from as far back as you can remember?**

Encourage participants to try to begin by remembering very early. Many say they cannot remember early childhood, but you should shape the questions such that they focus at first around age five or earlier, and gently remind the research participant from time to time that if possible, you would like her to think back to this age period.

Admittedly, this is leaping right into it, and the participant may stumble. If necessary, indicate in some way that experiencing some difficulty in initially attempting to respond to this question is natural, but indicate by some silence that you would nonetheless like the participant to attempt a general description.

3. **Now I'd like to ask you to choose five adjectives or words that reflect your relationship with your mother starting from as far back as you can remember in early childhood--as early as you can go, but say, age 5 to 12 is fine. I know this may take a bit of time, so go ahead and think for a minute...then I'd like to ask you why you chose them. I'll write each one down as you give them to me.**

Not all participants will be able to think of five adjectives right away. Be sure to make the word relationship clear enough to be heard in this sentence. Some participants do use "relationship" adjectives to describe the parent, but some just describe the parent herself -- e.g., "pretty"... "Efficient manager"--as though they had only been asked to "pick adjectives to describe your mother". These individual differences are of interest only if the participant has heard the phrase, "that reflect your childhood relationship" with your mother. The word should be spoken clearly, but with only slight stress or emphasis.

Some participants will not know what you mean by the term adjectives, which is why we phrase the question as "adjectives or words". If the participant has further questions, you can explain, "just words or phrases that would describe or tell me about your relationship with your (mother) during childhood".

He probes provided below are intended to follow the entire set of adjectives, and the interviewer must not begin to probe until the full set of adjectives has been given. Be patient in waiting for the participant to arrive at five adjectives, and be encouraging. This task has proven very helpful both in starting an interview, and in later interview analysis. It helps some participants to continue to focus upon the relationship when otherwise they would not be able to come up with spontaneous comments.

If for some reason a subject does not understand what a memory is, you might suggest they think of it like an image they have in their mind similar to a videotape of something which happened when they were young. Make certain that the subject really does not understand the question first, however. The great majority who may seem not to understand it are simply unable to provide a memory or incident.

The participant's ability (or inability) to provide both an overview of the relationship and specific memories supporting that overview forms one of the most critical bases of interview analysis. For this reason it is important for the interviewer to press enough in the effort to obtain the five "overview" adjectives that if a full set is not provided, she or he is reasonably certain that they truly cannot be given.

The interviewer's manner should indicate that waiting as long as a minute is not unusual, and that trying to come up with these words can be difficult. Often, participants indicate by their non-verbal behaviour that they are actively thinking through or refining their choices. In this case an interested silence is warranted. Don't, however, repeatedly leave the participant in embarrassing silences for very long periods. Some research participants may tell you that this is a hard job, and you can readily acknowledge this. If the participant has extreme difficulty coming up with more than one or two words or adjectives, after a period of two to three minutes of supported attempts ("Mm... I know it can be hard ...this is a pretty tough question... Just take a little more time"), 3 then say something like "Well, that's fine. Thank you, we'll just go with the ones you've already given me." The interviewer's tone here should make it clear that the participant's response is perfectly acceptable and not uncommon.

Okay, now let me go through some more questions about your description of your childhood relationship with your mother. You say your relationships with her was (you used the phrase) Are there any memories or incidents that come to mind with respect to (word).

The same questions will be asked separately for each adjective in series. Having gone through the probes which follow upon this question (below), the interviewer moves on to seek illustration for each of the succeeding adjectives in turn:

You described your childhood relationship with your mother as (or, `your second adjective was", or "the second word you used was"). Can you think of a memory or an incident that would illustrate why you chose to describe the relationship?

The interviewer continues, as naturally as possible, through each phrase or adjective chosen by the participant, until all five adjectives or phrases are covered. A specific supportive memory or expansion and illustration is requested for each of the adjectives, separately. In terms of time to answer, this is usually the longest question. Obviously, some adjectives chosen may be almost identical, e.g., "loving ... caring". Nonetheless, if they have been given to you as separate descriptors, you must treat each separately, and ask for memories for each.

While participants sometimes readily provide a well-elaborated incident for a particular word they have chosen, at other times they may fall silent; or "illustrate" one adjective with another ("loving ...um, because she was generous"); or describe what usually happened--i.e., offer a "scripted" memory--rather than describing specific incidents. There are a set series of responses available for these contingencies, and it is vital to memorise them.

If the participant is silent, the interviewer waits an appropriate length of time. If the participant indicates nonverbally that she or he is actively thinking, remembering or simply attempting to come up with a particularly telling illustration, the interviewer maintains an interested silence. If the silence continues and seems to indicate that the participant is feeling stumped, the interviewer says something like, "well, just take another minute and see if anything comes to mind". If following another waiting period the participant still cannot respond to the question, treat this in a casual, matter of fact manner and say "well, that's fine, let's take the next one, then". Most participants do come up with a response eventually, however, and the nature of the response then determines which of the follow-up probes are utilise

If the participant re-defines an affective with a second adjective as, "Loving ---she was generous", the interviewer probes by repeating the original adjective (loving) rather than permitting the participant to lead them to use the second one (generous). In other words, the interviewer in this case will say, "Well, can you think of a specific memory that would illustrate how your relationship was loving?" The interviewer should be careful, however, not to be too explicit in their intention to lead the participant back to their original word usage. If the speaker continues to discuss "generous" after having been probed about loving once more, this violation of the discourse task is meaningful and must be allowed. As above, the nature of the participant's response determines which follow-up probes are utilised.

If a specific and well-elaborated incident is given, the participant has responded satisfactorily to the task, and the interviewer should indicate that she or he understands that. However, the interviewer should briefly show continuing interest by asking whether the participant can think of a second incident.

- If one specific but poorly elaborated incident is given, the interviewer probes for a second. Again, the interviewer does this in a manner emphasising his or her own interest

- If as a first response the participant gives a "scripted" or "general" memory, as "Loving. She always took us to the park and on picnics. She was really good on holidays" or "Loving. He taught me to ride 4 a bike"--the interviewer says, "Well, that's a good general description, but I'm wondering if there was a particular time that happened, that made you think about it as loving?"

- If the participant does now offer a specific memory, briefly seek a second memory, as above. If another scripted memory is offered instead, or if the participant responds "I just think that was a loving thing to do", the interviewer should be accepting, and go on to the next adjective. Here as elsewhere the interviewer's behaviour indicates that the participant's response is satisfactory.

4. **Now I'd like to ask you to choose five adjectives or words that reflect your childhood relationship with your father, again starting from as far back as you can remember in early childhood--as early as you can go, but again say, age 5 to 12 is fine. I know this may take a bit of time, so go ahead and think again for a minute...then I'd like to ask you why you chose them. I'll write each one down as you give them to me. (Interviewer repeats with probes as above).**

5. **Now I wonder if you could tell me, to which parent did you feel the closest, and why? Why isn't there this feeling with the other parent?**

By the time you are through with the above set of questions, the answer to this one may be obvious, and you may want to remark on that ("You've already discussed this a bit, but I'd like to ask about it briefly anyway..."). Furthermore, while the answer to this question may indeed be obvious for many participants, some--particularly those who describe both parents as loving--may be able to use it to reflect further on the difference in these two relationships.

6. When you were upset as a child, what would you do?

This is a critical question in the interview, and variations in the interpretation of this question are important. Consequently, the participant is first encouraged to think up her own interpretations of "upset", with the interviewer pausing quietly to indicate that the question is completed, and that an answer is requested.

Once the participant has completed her own interpretation of the question, giving a first answer, begin on the following probes. Be sure to get expansions of every answer. If the participant states, for example, "I withdrew", probe to understand what this research participant means by "withdrew". For example, you might say, "And what would you do when you withdrew?"

The interviewer now goes on to ask the specific follow-up questions below. These questions may appear similar, but they vary in critical ways, so the interviewer must make sure that the participant thinks through each question separately. This is done by placing vocal stress on the changing contexts (as we have indicated by underlining).

-----When you were Upset emotionally when you were little, what would you do? (Wait for participant's reply). Can you think of a specific time that happened? -----

Can you remember what would happen when you were hurt? Physically? (Wait for participant's response.

Were you ever M when you were little? (Wait for participant's reply). Do you remember what would happen?

When the participant describes going to a parent, see first what details they can give you spontaneously. Try to get a sense of how the parent or parents responded, and then when and if it seems appropriate you can briefly ask one or two clarifying questions.

Be sure to get expansions of every answer. Again, if the participant says "I withdrew", for example, probe to see what the participant means by this, i.e., what exactly she or he did, or how exactly they felt, and if they can elaborate on the topic.

If the participant has not spontaneously mentioned being held by the parent in response to any of the above questions, the interviewer can ask casually at the conclusion to the series, **"I was just wondering, do you remember being held by either of your parents at any of these times--I mean, when you were upset, or hurt, or ill?"**

In earlier editions of these guidelines, we suggested that if the participant answers primarily in terms of responses by one of the parents, the interviewer should go through the above queries again with respect to the remaining parent. This can take a long time and distract from the recommended pacing of the interview. Consequently, it is no longer required.

What is the first time you remember being separated from your parents?

How did you respond? Do you remember how your parents responded? -

Are there any other separations that stand out in your mind?

Here research participants often describe first going off to nursery school, or to primary school, or going camping.

In this context, participants sometimes spontaneously compare their own responses to those of other children. This provides important information regarding the participant's own overall attitude towards attachment, so be careful not to cut any such descriptions or comparisons short.

7. **Did you ever feel rejected as a young child? Of course, looking back on it now, you may realize it wasn't really rejection, but what I'm trying to ask about here is whether you remember ever having rejected in childhood**

-----*How old were you when you first felt this way, and what did you do?*

----*Why do you think your parent did those things--do you think he/she realised he/she was rejecting you?*

Interviewer may want to add a probe by refraining the question here, especially if no examples are forthcoming. The probe we suggest here is. *Did you ever feel pushed away or ignored?*" Many participants tend to avoid this in terms of a positive answer. *So, were you ever frightened or worried as a child?*

Let the research participant respond "freely" to this question, defining the meaning for themselves. They may ask you what the question means, and if so, simply respond by saying "It's just a more general question". Do not probe heavily here. If the research participant has had traumatic experiences which they elect not to describe, or which they have difficulty remembering or thinking about, you should not insist upon hearing about them. They will have a second, brief opportunity to discuss such topics later.

8. Were your parents ever threatening with you in any way - maybe for discipline, or even jokingly?

-----*Some people have told us for example that their parents would threaten to leave them or send them away from home.*

----- (Note to researchers). In particular communities, some specific kind of punishment not generally considered fully abusive is common, such as "the silent treatment", or "shaming", etc. One question regarding this one selected specific form of punishment can be inserted here, as for example, *'Some people have told us that their parents would use the silent treatment---did this ever happen with your parents*?': The question should then be treated exactly as threatening to send away from home, i.e., the participant is free to answer and expand on the topic if she or he wishes, but there are no specific probes. The researcher should not ask about more than one such specific (community) form of punishment, since queries regarding more than one common type will lead the topic away from its more general intent (below).

Some people have memories of threats or of some kind of behaviour that was abusive. ----

Did anything like this ever happen to you, or in your family?

How old were you at the time? Did it happen frequently?

Do you feel this experience affects you now as an adult?

Does it influence your approach to your own child?

Did you have any such experiences involving people outside your family?

If the participant indicates that something like this did happen outside the family, take the participant through the same probes (*age? frequency? affects you now as an adult? Influences your approach to your own child?).* Be careful with this question, however, as it is clinically sensitive, and by now you may have been asking the participant difficult questions for an extended period of time.

Many participants simply answer "no" to these questions. Some, however, describe abuse and may some suffer distress in the memory. When the participant is willing to discuss experiences of this kind, the interviewer must be ready to maintain a respectful silence, or to offer active sympathy, or to do whatever may be required to recognise and insofar as possible to help alleviate the distress arising with such memories.

If the interviewer suspects that abuse or other traumatic experiences occurred, it is important to attempt to ascertain the specific details of these events insofar as possible. In the coding and classification system which accompanies this interview, *distressing experiences cannot be scored for Unresolved /disorganised responses unless the researcher is able to establish that abuse (as opposed to just heavy spanking, or light hitting with a spoon that was not frightening)* occurred.

Where the nature of a potentially physically abusive (belting, whipping, or hitting) experience is ambiguous, then, the interviewer should try to establish the nature of the experience in a light, matter-of-fact manner, without excessive prodding. If, for example, the participant says "I got the belt" and stops, the interviewer asks, "And what did getting the belt mean?" After encouraging as much spontaneous expansion as possible, the interviewer may still need to ask, again in a matter-of-fact tone, how the participant responded or felt at the time. "Getting the belt" in itself will not qualify as abuse within the adult attachment scoring and classification systems, since in some households and communities this is a common, systematically but not harshly imposed experience. Being belted heavily enough to overwhelmingly frighten the child for her physical welfare at the time, being belted heavily enough to cause lingering pain, and/or being belted heavily enough to leave welts or bruises will qualify.

In the case of sexual abuse as opposed to battering, the interviewer will seldom need to press for details, and should be very careful to follow the participant's lead. Whereas on most occasions in which a participant describes themselves as sexually abused the interviewer and transcript judge will have little need to probe further, occasionally a remark is ambiguous enough to require at least mild elaboration. If, for example, the participant states `and I just thought he could be pretty sexually abusive', the interviewer will ideally follow-up with a 7 query such as, ` well, could you tell me a little about what was happening to make you see him as sexually abusive?'. Should the participant reply that the parent repeatedly told off-colour jokes in her company, or made untoward remarks about her attractiveness, the parent's behaviour, though insensitive, will not qualify as sexually abusive within the accompanying coding system. Before seeking elaboration of any kind, however, the interviewer should endeavour to determine whether the participant seems comfortable in discussing the incident or incidents.

All querying regarding abuse incidents must be conducted in a matter-of-fact, professional manner. The interviewer must use good judgment in deciding whether to bring querying to a close if the participant is becoming uncomfortable. At the same time, the interviewer must not avoid the topic or give the participant the impression that discussion of such experiences is unusual. Interviewers sometimes involuntarily close the topic of abuse experiences and their effects, in part as a well-intentioned and protective response towards participants who in point of fact would have found the discussion welcome

Participants who seem to be either thinking about or revealing abuse experiences for the first time-- "No, nothing ....no... well, 1, I haven't thought, remembered this for, oh, years, but ...maybe they used to... tie me.... "-- must be handled with special care, and should *not* be probed unless they clearly and actively seem to want to discuss the topic. If you sense that the participant has told you things they have not previously discussed or remembered, special care must be taken at the end of the interview to ensure that the participant does not still suffer distress, and feels able to contact the interviewer or project director should feelings of distress arise in the future.

In such cases the participant's welfare must be placed above that of the researcher. While matter-of-fact, professional and tactful handling of abuse-related questions usually makes it possible to obtain sufficient information for scoring, the interviewer must be alert to indications of marked distress, and ready to tactfully abandon this line of questioning where necessary. Where the complete sequence of probes must be abandoned, the interviewer should move gracefully and smoothly to the next question, as though the participant had in fact answered fully.

9. In general, how do you think your overall experiences with your parents have affected your adult personality?

The interviewer should pause to indicate she or he expects the participant to be thoughtful regarding this question, and is aware that answering may require some time.

Are there any aspects to your early experiences that you feel were a set-back in your development?

In some cases, the participant will already have discussed this question. Indicate, as usual, that you would just like some verbal response again anyway, "for the record".

It is quite important to know whether or not a participant sees their experiences as having had a negative effect on them, so the interviewer will follow-up with one of the two probes provided directly below. The interviewer must stay alert to the participant's exact response to the question, since the phrasing of the probe differs according to the participant's original response.

If the participant has named one or two setbacks, the follow-up probe used is

---*Are there any other aspects of your early experiences, that you think might have held your development back, or had a negative effect on the way you turned out?*

If the participant has understood the question, but has not considered anything about early experiences a setback, the follow-up probe used is:

---*Is there any thin about your early experiences that you think might have held your development back, or had a negative effect on the way you turned out?*

Although the word ***anything*** receives some vocal stress, the interviewer must be careful not to seem to be expressing impatience with the participant's previous answer. The stress simply implies that the participant is being given another chance to think of something else she or he might have forgotten a moment ago.

RE: PARTICIPANTS WHO DON'T SEEM TO UNDERSTAND THE TERM, SETBACK. A few participants aren't familiar with the term, *set-back*. If after a considerable wait for the participant to reflect, the participant seems simply puzzled by the question, the interviewer says,

"Well, not everybody uses terms like set-back for what I mean here. I mean, was there anything about your early experiences, or any parts of your early experiences, that you think might have held your development back, or had a negative effect on the way you turned out?"

In this case, this becomes the main question, and the probe becomes

-*Is there anything else about your early experiences that you think might have held your development back, or had a negative effect on the way you turned out?*

10. Why do you think your parents behaved as they did during your childhood?

This question is relevant even if the participant feels childhood experiences were entirely positive. For participants reporting negative experiences, this question is particularly important.

11. Were there any other adults with whom you were close, like parents, as a child?

--- Or any other adults who were especially important to you, even though not parental?

Give the participant time to reflect on this question. This is the point at which some participants will mention housekeepers, au pairs, or nannies, and some will mention other family members, teachers, or neighbours.

Be sure to find out ages at which these persons were close with the participant, whether they had lived with the family, and whether they had had any caregiving responsibilities. In general, attempt to determine the significance and nature of the relationship.

12. Did you experience the loss of a parent or other close loved one while you were a young child--for example, a sibling, or a close family member?

A few participants understand the term "loss" to cover brief or long-term separations from living persons, as, "I lost my mom when she moved south to stay with her mother". If necessary, clarify that you are referring to death only, i.e. specifically to loved ones who had died).

-----*Could you tell me about the circumstances, and how old you were at the time?*

-----*How did you respond at the time?*

-----*Was this death sudden or was it expected?*

-----*Can you recall your feelings at that time?*

-----*Have your feelings regarding this death changed much over time?*

If not volunteered earlier. Did you attend the funeral, and what was this like for you?

If loss of a parent or *sibling. What would you say was the effect on your (other parent) and on your household, and how did this change over the years?*

-----*Would you say this loss has had an effect on your adult personality?*

-----*Were relevant How does it affect your approach to your own child?*

13. a) Did you lose any other important persons during your childhood?

Same queries--again, this refers to people who have died rather than separation experiences).

13. b) Have you lost other close persons, in adult years? (Same queries).

Be sure that the response to these questions covers loss of any siblings, whether older or younger, loss of grandparents, and loss of any person who seemed a "substitute parent" or who lived with the family for a time. Some individuals will have been deeply affected by.

Probe any loss which seems important to the participant, including loss of friends, distant relatives, and neighbours or neighbour's children. Rarely, the research participant will seem distressed by the death of someone who they did not personally know (often, a person in the family, but sometimes someone as removed as the friend of a friend).

If a participant brings up the suicide of a friend of a friend and seems distressed by it, the loss should be fully probed. The interviewer should be aware, then, that speakers may be assigned to the unresolved/adult attachment classification as readily for lapses in monitoring occurring during the discussion of the death of a neighbour's child *experienced during the adult* years as for loss of a parent in childhood.

Interviewing research participants regarding loss obviously requires good clinical judgment. At maximum, only four to five losses are usually fully probed. In the case of older research participants or those with traumatic histories, there may be many losses, and the interviewer will have to decide on the spot which losses to probe. No hard and fast rules can be laid out for determining which losses to skip, and the interviewer must to the best of his or her ability determine which losses--if there are many--are in fact of personal significance to the participant. Roughly, in the case of a participant who has lost both parents, spouse, and many other friends and relatives by the time of the interview, the interviewer might elect to probe the loss of the parents, the spouse, and "any other loss which you feel may have been especially important to you". If, however, these queries seem to be becoming wearying or distressing for the participant, the interviewer should acknowledge the excessive length of the querying, and offer to cut it short.

14. Other than any difficult experiences you've already described, have you had any other experiences which you should regard as potentially traumatic?

Let the participant free-associate to this question, then clarify if necessary with a phrase such as, **I mean, any experience which was overwhelmingly and immediately terrifying**.

This question is a recent addition to the interview. It permits participants to bring up experiences which may otherwise be missed, such as scenes of violence which they have observed, war experiences, violent separation, or rape.

Some researchers may elect not to use this question, since it is new to the 1996 protocol. If you do elect to use it, it must of course be used with all subjects in a given study.

The advantage of adding this question is that it may reveal lapses in reasoning or discourse specific to traumatic experiences other than loss or abuse.

Be very careful, however, not to permit this question to open up the interview to all stressful, sad, lonely or upsetting experiences which may have occurred in the subject's lifetime, or the purpose of the interview and of the question may be diverted. It will help if your tone indicates that these are rare experiences.

Follow up on such experiences with probes only where the participant seems at relative ease in discussing the event, and/or seems clearly to have discussed and thought about it before.

Answers to this question will be varied. Consequently, exact follow-up probes cannot be given in advance, although the probes succeeding the abuse and loss questions may serve as a partial guide. In general, the same cautions should be taken with respect to this question as with respect to queries regarding frightening or worrisome incidents in childhood, and experiences of physical or sexual abuse. Many researchers may elect to treat this question lightly, since the interview is coming to a close and it is not desirable to leave the participant reviewing too many difficult experiences just prior to leave taking.

15. Now I'd like to ask you a few more questions about your relationship with your pants. Were there many changes in your relationship with your parents (or remaining parent) after childhood? We'll get to the present in a moment, but right now 1 mean changes occurring roughly between your childhood and your adulthood?

Here we are in part trying to find out, indirectly (1) whether there has been a period of rebellion from the parents, and (2) also indirectly, whether the participant may have rethought early unfortunate relationships and "forgiven" the parents. Do not ask anything about forgiveness directly, however--this will need to come up spontaneously. This question also gives the participant the chance to describe any changes in the parents' behavior, favorable or unfavourable, which occurred at that time.

16. Now I'd like to ask you, what is your relationship with your parents (or remaining parent) like for you now as an adult? Here I am asking about your current relationship.

----*Do you have much contact with your parents at present?*

----*What would you say the relationship with your parents is like currently? Any special (or any other) sources of special satisfaction?*

This has become a critical question within the Adult Attachment Interview, since a few participants who had taken a positive stance towards their parents earlier suddenly take a negative stance when asked to describe current relationships. As always, the interviewer should express a genuine interest in the participant's response to this question, with sufficient pause to indicate that a reflective response is welcome.

17. **I'd like to move now to a different sort of question--it's not about your relationship with your parents, instead it's about an aspect of your current relationship with (specific child of special interest to the researcher, or all the participant's children considered together). How do you respond now, in terms of feelings, when you separate from your child / children?** (For adolescents or individuals without children, see below).

Ask this question exactly as it is, without elaboration, and be sure to give the participant enough time to respond. Participants may respond in terms of leaving child at school, leaving child for vacations, etc., and this is encouraged. What we want here are the participant's feelings about the separation. This question has been very helpful in interview analysis, for two reasons. In some cases it highlights a kind of role-reversal between parents and child, i.e., the participant may in fact respond as though it were the child who was leaving the parent alone, as though the parent was the child. In other cases, the research participant may speak of a fear of loss of the child, or a fear of death in general. When you are certain you have given enough time (or repeated or clarified the question enough) for the participant's naturally occurring response, then (and only then) add the following probe

-----Do you ever feel worried about (child)?

For individuals without children, you will pose this question as a hypothetical one, and continue through the remaining questions in the same manner. For example, you can say, now *I'd like you to imagine that you have a one-year-old child, and I wonder how you think you might respond, in terms of feelings, if you had to separate from this child." Do you think you would ever feel worried about this child?"*

18. **If you had three wishes for your child twenty years from now, what would they be? I'm thinking partly of the kind of future you would like to see for your child I'll give you a minute or two to think about this one. This question is primarily intended to help the participant begin to look to the future, and to lift any negative mood which previous questions may have imposed.**

For individuals without children, you again pose this question in hypothetical terms. For example, you can say, "Now I'd like you to continue to imagine that you have a one-year-old child for just *another minute. This time, I'd like to ask, if you had three wishes for your child twenty years from now, what would they be? I'm thinking partly of the kind of future you would like to see for your imagined child I'll give you a minute or two to think about this one':*

19. **Is there any particular thing which you feel you learned above all from your own childhood experiences? I'm thinking here of something you feel you might have gained from the kind of childhood you had.**

Give the participant plenty of time to respond to this question. Like the previous and succeeding questions, it is intended to help integrate whatever untoward events or feelings he or she has experienced or remembered within this interview, and to bring the interview down to a light close.

20. We've been focusing a lot on the past in this interview, but I'd like to end up looking quite a ways into the future. We've just talked about what you think you may have learned from your own childhood experiences. 1'd like to end by asking you what would you hope your child (or, your imagined child) might have learned from his/her experiences of being parented by you?

The interviewer now begins helping the participant to turn his or her attention to other topics and tasks. Participants are given a contact number for the interviewer and/or project director, and encouraged to feel free to call if they have any questions.

4.3. Adult Attachment Interview Questions completed

1. Family orientation :Where were you born? Where did you live? Did the family move around much? What did the family do for a living? Did you see much of your grandparents when you were little? If died ask if that was significant? If died did parents speak of them/ did you have brothers or sisters, did anyone else live in the house?

Blackheath Worcs. No siblings. Family didn't move about, Maternal grandfather lived with them - he was very fond of him. Father was an accountant mother didn't work

2. I'd like you to describe your relationship with your parents as a young child if you could start from as far back as you can remember

Close to mother. Father was very strict – frightened him.

3. I'd like you to choose five adjectives or words that reflect your relationship with your mother starting from as far back as you can remember in early childhood. This may take some time so think for a minute, and then I would relationship. If there is prolonged silence suggest that it is ok to take

Ask for incidents to illustrate the use of a particular adjective that are specific rather than general. **Mother was kind, timid**? **Mother frightened of father too. H felt the weight of that.** In what way**, She would worry that I would do something to upset father and I was aware of that**

4. Now I would like to ask you to choose five adjectives or words that reflect your relationship with your father starting from as far back as you can remember in early

childhood. This may take some time so think for a minute, and then I would like to ask why you chose them.

Distant, severe, frightening. stickler for 'doing the right thing' especially as far as the family was concerned. Memories of long walk on Sunday evenings to visit paternal grandfather

5. Which parent did you feel the closest to, and why, Why isn't there this feeling for the other parent? **Mother definitely we had things in common music – I was quite musical as child and she would take me to the theatre, which I loved**

6. When you were upset as a child what would you do? Observe how they interpret the word upset. Probe the answer

7. What is the first time you remember being separated from your parents? How did you respond? Do you remember how your parents responded? Are there any other separations that stand out in your mind? **When I was sent away to school.** How old were you? **Eight** That's very young do you remember how if felt**? I hated it I cried myself to sleep every night for goodness knows how long and I dreaded the end of the holidays. Eventually I got used to it.**

8. Did you ever feel rejected as a young child? **Yes when I was sent away to school. I think it was my father's idea thought if would toughen me up**

Of course looking back on it now you may realise it wasn't really rejection but what I'm trying to ask abut here is whether you remember ever having felt rejected in childhood? If yes how old were you when you first felt this way and what did you do? Why do you think your parent did those things ‘ do you think he/she realises he/she was rejecting you. Did you ever feel pushed

9. Were your parents ever threatening with you in any way – maybe for discipline or even jokingly? Be sensitive to cultural issues. If yes ask usual clarifying questions

Mother would say “wait until your father comes home”. Father was threatening as a presence.

10. In general how do you think your overall experiences with your parents have affected your adult personality? Are there any aspects to your early experiences that you feel were a set-back in your development? **Being an only child**

If yes ask probe further with. Are there any other aspects of your early on **responded no but subsequently said the dynamic between father and mother troubled him.** When I pressed him he responded with **mum and dad used to argue a lot and I didn’t like it. it frightened me**

11. Why do you think your parents behaved as they did during your childhood?

My mother was afraid of my father and he was a bully

12. Were there any other adults with whom you were close like parents as a child?

Father’s brother uncle Ted close to him – spoke warmly of him felt he was accepting of him in the way father was not.

13. Did you experience the loss of a parent or other close loved one while you were a young child –for example a sibling or a close family member. If yes ask expanding questions.

Did you lose any other important persons during your childhood?

Have you lost other close persons in adult years?

Whilst at boarding school H was sent to the coast because he had been suffering with health problems and whilst he was away his maternal grandfather died. He remembers crying in the Principal's office but stopped as soon as he could because he was too old to cry ***telling statement*** **(10) but he cried quietly in the dorm that night when he thought no one could hear him.**

14. Were there any other difficult experiences other than those you've already described have you which you felt were potentially traumatic?

Was there anything else in your early childhood that has affected how you turned out?
Feels his career was determined by parents' influence. ***(pleasing them)*** **Mother had done some nursing and encouraged him into medicine. As a child built his own theatre and seemed to be saying that if he had been allowed that would have been his choice. Father was very able practically and helped H to make things. Mother was musical and encouraged H who played the violin. In his teens he had to make a choice between medicine and a career in music. He chose medicine. For many years he has been involved in with the local theatre taking the leading role of the Dame each Christmas. Took trombone lessons] in adult life and achieved grade**

15. Now I would like to ask you a few more questions about your relationships with your parents? Were there many changes in your relationship with your parents after childhood – between childhood and adulthood? **My mother died when I was in my twenties that was very sad. I felt there were so many missed opportunities that were not possible because of my father. Our relationship was distant all his life. He remarried and we observed the formalities.**

16. Current closest relationship**.** How do you feel when you have to be separated?

We go everywhere together. I don't know if I could manage on my own now. How do you imagine you would feel if you and D had to be separated**?**

Lost

17. Is there anything you feel you have leaned above all from your own childhood experiences? I'm thinking her of something you feel you might have gained from the kind of childhood you had.

I don't thing my childhood was helpful to me as a person. Can you tell me more about that? **I think my experience with my father and being sent away to school made it difficult for me to be close to people and I think that was why my first marriage failed.**

18. Thinking of the present what would you hope your child(ren) may have learned from their experience of being parented by you**. I don't think I was really there for them emotionally when they were growing up.**

4.4. Gricean Analysis Defined

State of mind based on Grice's maxims

Secure autonomous: predictive of secure attachment

Moderate to high scores for coherence.

Discourse characteristics:

Coherent collaborative discourse. Descriptions of attachment related experiences and their effects are reasonably consistent, whether the experiences appear to have been favourable or unfavourable. Discourse does not notably violate any of Grice's maxims.

Features predominating with respect to attitudes towards attachment.

Avows missing, needing and depending on others. Seems open and 'free to explore' interview topic, indicating a ready flexibility of attention. States that attachment-related experiences have affected his/her development and functioning. Seems at ease with imperfections in the self. Explicit or implicit forgiveness of or compassion for parents. Can flexibly change view of person or event, even while interview is in progress, suggestion autonomy and ultimate objectivity. Sense of balance, proportion, or humour. Ruefully cites untoward flawed behaviour of self, as appearing at times despite conscious intentions or efforts.

Dismissing: predictive of avoidant attachment

Low scores on coherence. High scores on idealisation or derogation of one or both parents often accompanied by high scores on insistence on lack of memory for childhood.

Features predominating with respect to dismissing/avoidant attachment

Discourse characteristics

Not coherent. Violates the maxim of quality (consistency/truthfulness), in that positive generalised representations of history are unsupported or actively contradicted by episodes recounted. Violates the maxim of quantity –either via repeated insistence on absence of memory; or via brief contemptuous derogation of, or active contemptuous refusal to discuss, a particular event or figure.

Features predominating with respect to attitudes toward attachment.

Self positively described as being strong. Independent, or normal. Little or no articulation of hurt, distress, or feelings of needing or depending on others. Minimises or downplays description of negative experiences, may interpret such experiences positively, in that they have made the self stronger. May emphasise fun or activities with parents, or presents and other material objects. Attention is inflexibly focused away from discussion of attachment history and/or it implications. Responses are abstract and/or seem remote from present or remembered feelings or memories, and topic of interview seems foreign. May express contempt for other person(s), or, relatedly, for events usually considered sorrowful (e.g. loss or funerals)

Preoccupied: predictive of resistant/ambivalent attachment

Low scores for coherence, high scores for either passive or angry preoccupation with experiences of being parented. (Rarely, preoccupied with frightening experiences).

Discourse characteristics

Violates manner, quantity, and/or relevance, while quality/truthfulness may not be violated. In regard to quantity, sentences or conversational turns taken are often excessively long. In regard to manner, response may be grammatically entangled or filled with vague usages (“dadadas”, “and that”). In regard to relevance, the present may be brought into responses to queries regarding the past (or vice versa), or persons or events not the objects of inquiry may be brought into the discussion.

Features predominating with respect to attitudes toward attachment.

Responses to interview are persistently closely and inflexible tied to experiences with and influences of the parents, even when these are not the objects of inquiry. May attempt to involve the interviewer in agreement regarding parents’ faults, may seem to weakly, confusedly praise parents, but with oscillations suggestive of ambivalence, and/or (rare) may relate frightening experiences involving them. Topic of interview is addressed, but seems inflexible and closed so that interview responses may seem memorised or unconsciously guided, as if the attachment related history is “an old story”. Unbalanced, excessive blaming of either parent or self. Indecisive – for example, evaluative oscillations (“Great mother. Well not really, actually pretty awful. No, I mean actually, really good mother, except when she…”). May be unusually psychologically orientated, offering authoritative “insights” into motives of self or others. The lexicon of “pop” psychology may appear with excessive frequency.

Adapted from Hesse Table 25.3 Page 568.

4.5. Co-rating Results

Participants: 1,4 and 7 - Rater T.N.

Grice's conversational maxims: Relative

Participant 04

Rating: 5

Rater: TNS

Relative = answers are relevant to the question and do not veer off into unrelated areas

Not relative 1 2 3 4 [✓ 5] relative

Evidence from interview data:

The participant's answers were relevant to the question and this is found in the integrity and flow of his narrative.

We see this throughout Q'- 18 but evidence of this can be seen in the following:

Q'3 Did you experience the loss of a parent or other close loved one when you were a young child. 'Not that I remember'.

Q'14 'I think it was good I had my cousin because I think I would have been lonely as an ~~ol~~ only child.'

Q'17 'I think I learned to be independent and make the most of myself'.

Q'18 'that we were supportive and still are'.

Grice's conversational maxims: Manner

Participant No. 04

Rating: 5

Rater: TNJ

Manner = clear and orderly response to each question.

Poor 1 2 3 4 [✓ 5] Good

Evidence from interview data:

Clarity and order are present from the start of the interview to its completion. There are no confusional divergences and the participant remains firmly on task.

Q7 First separation? School I would think but I don't have a memory of that. Other separations? When we bought our own house I missed my cousin and auntie (Line 1-2).

Q8 I was sometimes worried at school. I was small and some of the bigger boys frightened me because they would tease the smaller boys (Line 2-4).

Grice's conversational maxims: quantity

Participant No: 04

Rating: 5

Rater: TN

Quantity = succinct whilst answering the question fully. Not overly informative. Conversational turns should be of reasonable length to convey an appropriate response.

1 2 3 4 [✓ 5]

Evidence from interview data:

There was evidence of good quality in the text as answers felt succint and to the point.

Q10 'Experiences with parents affect personalit

I think parent are influential in shaping their children's personality. I don't think there was anything adverse in my experience with my parents – my dad I think his distance and coldness affected me'.

Q12 Were there any other adults with whom you were close to as a child?

'None that stand out other than the extended family we lived with until we moved'.

Grice's conversational maxims: quality

Participant No: 04

Rating: 5

Rater: TWJ

Quality = truthfulness of narrative, avoiding of contradictions and providing evidence to support the adjectives used to describe the person's experience of the mother/father.

Poor Quality 1 2 3 4 [✓ 5] good quality

Evidence from interview data:

Questions 1–18 had an authenticity and a spontaneity that conveyed a truthfulness. For example:

Q3 (line 1-2) 'five adjectives to describe mother "Strict, kind, fair" he stopped there. Why did you chose those particular words? He hesitated for some time and said "They were what came to mind".

Q6 (line 1-2) Participant demonstrates elaboration and synchronisation ... 'When you were a child what would you do? Oh 'if we hurt ourselves we would go, to Mum or Auntie – They usually told us off' ...

Overall coherence of the narrative based on Grice's maxims:

Participant No. 04

Rater: en

Classification: Secure autonomous

Manner: Score 5

Quantity: Score 5

Relative: Score 5

Quality Score 5

Total 20

Comments:

There was a flow and coherence in this narrative, which was highly compatible with the notion of a Secure autonomous: predictive of Secure attachment.

For further evidence of this classification see rating sheets (Manner, quantity Relative, Quality)

Grice's conversational maxims: quantity

Participant No: 01

Rating: 1

Rater: TN

Quantity = succinct whilst answering the question fully. Not overly informative. Conversational turns should be of reasonable length to convey an appropriate response.

[✓ 1] 2 3 4 5

Evidence from interview data:

Q1 Evidence of confusion (Line 1)

Q2 Short, abrupt answers, conveying no real information

Q3 One or two word answers, some descripti reported

Q4 Short, sharp answers 'he was a naval Man; they had travelled'

Q5 'In her roundabout confused way (Lin

Q6 'Vaguely referred to mother' (Line 1)
No elaboration and some confusion.

Q8 Short, closed replies

Q9 - Q18 Answers, short and to the point.

Q9 - Q18

Participant seems better positioned to answer questions, but little evidence to support statements.

Grice's conversational maxims: quality

Participant No: 01

Rating: 2

Rater: TN

Quality = truthfulness of narrative, avoiding of contradictions and providing evidence to support the adjectives used to describe the person's experience of the mother/father.

Poor 1 [✓ 2] 3 4 5 good
Quality quality

Evidence from interview data:

Q^1 (warm-up) 'Caused her a problem' (Line 3) There was some confusion present 'her daughter reminded her it was her brother's name' (Line 6)

Q^2 (warm-up) Short, abrupt answer, no elaboration.

Q^5 'In her round-about confused way she did come to the mother (Line 1) There is some confusion present.

Q^6 'Vaguely referred to mother' (Line 1) Vague narration

Q^7 Are there any other separations That stand out in your mind? She was born in The first world war.

Grice's conversational maxims: Manner

Participant No. 07

Rating: 1

Rater: TN

Manner = clear and orderly response to each question.

Poor [✓ 1] 2 3 4 5 Good

Evidence from interview data:

Q^{1} (warm-up) There is evidence of confusion and the participant is corrected by her daughter.

Q^{3} The participant does not seem to understand what is required of her as she only give 3 adjectives and does not elaborate upon early experiences with her mother.

Q^{16} The participant demonstrates that she does not fully comprehended the full extent of the questions … 'Oh no I know she is coming back'.

Grice's conversational maxims: Relative

Participant 01

Rating: 3

Rater: TN

Relative = answers are relevant to the question and do not veer off into unrelated areas

Not relative 1 2 [✓ 3] 4 5 relative

Evidence from interview data:

Q^1 & Q^2 initial confusion, but later in the interview there is some evidence of comprehension and of focus.

Q^{10} 'the way people turned out was down ~~to~~ the way they are brought up'

Q^4 - Q^{18} Questions are coherent, but there is a sense that the participant's answer is not in synchrony with the question asked or only partially explored.

Overall coherence of the narrative based on Grice's maxims:

Participant No. 07

Rater: YN

Classification: Secure autonomous : predictive of secure attachment.

Manner: Score 4

Quantity: Score 4

Relative: Score 5

Quality Score 5

Total 18

Comments:

The participant responds with a clear and ordered narrative augmented with concrete examples. There is an authenticity to the narrative with a fine balance between positive memories and poignant losses.

See Rating sheets for evidence of classification.

Grice's conversational maxims: quantity

Participant No: 07

Rating: 4

Rater: YN

Quantity = succinct whilst answering the question fully. Not overly informative. Conversational turns should be of reasonable length to convey an appropriate response.

1 2 3 [✓ 4] 5

Evidence from interview data:

The whole narrative seems to be appropriately paced and has a fullness of story-line.

Q When the researcher asks the participant about describing his father through the use of adjectives the participant says 'Fun... he would play football with me. He had a temper though if he thought you weren't trying or messing around'. The participant uses examples and reflects upon these in an engaging way.

Q There is synchrony and attunement with questions and answers: for example: When I went to school — 'I didn't like it at first I didn't like Mum to leave'.

Grice's conversational maxims: Manner

Participant No. 07

Rating: 4

Rater: TN

Manner = clear and orderly response to each question.

Poor 1 2 3 [✓ 4] 5 Good

Evidence from interview data:

The participant offers clear and orderly responses to the questions. There are some moments of vagueness and impairment of recall (Q13 line 6: Q4 line 2).

The participant comprehends the question and is able to provide some details in his responses:

Q4 'Fun he would play football with me. He had a temper though if he thought you weren't trying and were messing around'...

Q2 I'd like you to describe your relationship with your parents as a young child, if you could start from as far back as you can remember. Very good, secure, happy I'd say I had a good childhood.

Grice's conversational maxims: quality

Participant No: ~~04~~ 07

Rating: 5

Rater: TN

Quality = truthfulness of narrative, avoiding of contradictions and providing evidence to support the adjectives used to describe the person's experience of the mother/father.

Poor Quality 1 2 3 4 [✓ 5] good quality

Evidence from interview data:

Throughout the text (Q^{1}- Q^{18}) there is a sense of truthfulness of narrative. This is evidenced in Q^{17} when the participant says 'Being honest he felt has been an asset. He was always to be honest with people' (Q^{17}: Lines 3-4).

Q^{3} The participant not only offers adjectives but grounds these in concrete examples 'She was very generous - when she baked a cake she would always bake one for my Nan' (Line 4-7)

Grice's conversational maxims: Relative

Participant [illegible] 07

Rating: 5

Rater: YN

Relative = answers are relevant to the question and do not veer off into unrelated areas

Not relative 1 2 3 4 [✓ 5] relative

Evidence from interview data:

There is a sense that the participant answers the specific question and does not veer off I think this is present throughout the narrative (Q^1 - Q^{18}).

There is a flow and coherency to the narrative as evidenced in Q^4 (Line 3-7) When I went to school – I didn't like it at first... etc.

There is evidence that the participant has understood what is being asked of him and replies appropriately (Q^1-Q^{18}).

Participants: 1, 4 and 7 - Co-rater: C.P.

Grice's conversational maxims: Quality

Participant No. 7

Rating: 4

Co-Rater: Dr Claire Parkin

Quality = truthfulness of narrative, avoiding of contradictions and providing evidence to support the adjectives used to describe the person's experience of the mother/father.

Poor Quality	1	2	3	4	5	Good Quality

Evidence from interview data: It all makes sense. No contradictions.

Grice's conversational maxims: Relative

Participant No. 7

Rating: 4

Rater: CP

Relative = answers are relevant to the question and do not veer off into unrelated areas

Not relative	1	2	3	4	5	Relative

Evidence from interview data: All answers seem relative

Grice's conversational maxims: Manner

Participant No. 7

Rating: 4

Co-Rater" Dr Claire Parkin

Manner = clear and orderly response to each question.

Poor	1	2	3	4	5	Good

Evidence from interview data: No comments recorded

Grice's conversational maxims: Quantity

Participant No: 7

Rating: 4

Co-Rater: Dr Claire Parkin

Quantity = succinct whilst answering the question fully. Not overly informative.

Conversational turns should be of reasonable length to convey an appropriate response.

1	2	3	4	5

Evidence from interview data: Short answers. Succinct. Not greatly informative in places.

Overall Coherence of the Narrative Based on Grice's Maxims:

Participants No: 7

Co-Rater: Dr Claire Parkin

Manner: Score 4

Quantity: Score 4

Relative: Score 4

Quality Score 4

Total 16

Comments:

This one is also Secure Autonomous.

Grice’s conversational maxims: quantity

Participant No: 1

Rating: 2

Rater: Dr Claire Parkin

Quantity = succinct whilst answering the question fully. Not overly informative.

Conversational turns should be of reasonable length to convey an appropriate response.

1	2	3	4	5

Evidence from interview data

Not much quantity in places – very short, under developed answers

Repetitive use of theme “just got on with it”

Grice’s conversational maxims: Relative

Participant No. 1

Rating: 2

Rater: Dr Claire Parkin

Relative = answers are relevant to the question and do not veer off into unrelated areas

Not relative	1	2	3	4	5	Relative

Evidence from interview data: The first question is confused but the others are relative. Some correct and relative answers when prompted by daughter.

Q4 also confused: but was she saying she was stuck in relation to her husband or dad?

Grice's conversational maxims: Manner

Participant No. 1

Rating: 2

Co-Rater: Dr Claire Parkin

Manner = clear and orderly response to each question.

Poor	1	2	3	4	5	Good

Evidence from interview data: Clear on some questions – confused or annoyed by others, not always coherent not exactly derogatory about? As opposed to stating a? That they were strict back then.

Grice's conversational maxims: quality

Participant No. 1

Rating: 2

Rater: Dr Claire Parkin

Quality = truthfulness of narrative, avoiding of contradictions and providing evidence to support the adjectives used to describe the person's experience of the mother/father.

Poor	1	2	3	4	5	Good

Evidence from interview data: Quite a few contradictions. Could not describe adjectives very well'

- Dismissive in places (Q8)

- Matter of fact about dad's being strict.

- Clear indication of independence and strength: positive self-description

- No, repeatedly, explicit links to parents obvious

- No dependence on others (Q16)

Overall coherence of the narrative based on Grice's maxims:

Participants No: 1

Co-Rater: Dr Claire Parkin

Manner: Score 2

Quantity: Score 2

Relative: Score 2

Quality Score 2

Total 8

Comments:

This last one is harder to classify because there are features of pre-occupied and dismissing!

Grice's conversational maxims: Quality

Participant No. 4

Rating: 4

Co-Rater: Dr Claire Parkin

Quality = truthfulness of narrative, avoiding of contradictions and providing evidence to support the adjectives used to describe the person's experience of the mother/father.

Poor	1	2	3	4	5	Good

Evidence from interview data: Some answers are quite brief, however there is a truthfulness and narrative apparent in answers 1 and 6.8.9.10 etc. Where answers are more descriptive in terms of info. Recall.

Some features are independent of 'parents' so not 'tied' in that respect e.g.: Q 7, 14, 16, 17, 18.

Grice's conversational maxims: Relative

Participant No. 4

Rating: 4

Co-Rater: Dr Claire Parkin

Relative = answers are relevant to the question and do not veer off into unrelated areas

Not Relative	1	2	3	4	5	Relative

Evidence from interview data: All answers are relevant and do not veer off course.

Grice's conversational maxims: Manner

Participant No. 4

Rating: 4

Co-Rater: Dr Claire Parkin

Manner = clear and orderly response to each question.

Poor	1	2	3	4	5	Good

Evidence from interview data:

All are clear.

Grice's conversational maxims: Quantity

Participant No: 4

Rating: 4

Co-Rater: Dr Claire Parkin

Quantity = succinct whilst answering the question fully. Not overly informative.

Conversational turns should be of reasonable length to convey an appropriate response.

1	2	3	4	5

Evidence from interview data:

Q1Pretty succinct and reasonable quantity. Less quantity on the other question answers, but all succinct answers without being waffly or overly informative. All are appropriate.

l maxims: quantity

Overall coherence of the narrative based on Grice's maxims:

Participants No: 4

Co-Rater: Dr Claire Parkin

Manner: Score 4

Quantity: Score 4

Relative: Score 4

Quality Score 4

Total 16

Comments:

This one is Secure Autonomous.

Participants: 1, 4 and 7 - Co-rater: M.S.

Grice's conversational maxims: Quality

Participant No. 1

Rating: 2

Rater: M.S.

Quality = truthfulness of narrative, avoiding of contradictions and providing evidence to support the adjectives used to describe the person's experience of the mother/father.

Poor	1	2	3	4	5	Good

Evidence from interview data: Her confusion was a factor in her ability to answer the questions appropriately. Also she seemed to be quite reluctant to engage initially, she did however seem more cooperative as the interview progressed. My sense was that she responded to someone taking an interest in her.

She was almost entirely unable to support the adjectives she chose with examples. There was no evidence of a lack of truthfulness or of contradiction but the overall quality of the narrative was poor as there was minimum response to most questions e.g.

Q3: <u>Now I'd like to ask you to choose five adjectives or words that reflect your Childhood relationship with your</u> mother. She was very kind – yes, busy *then distracted herself by talking about the cat that had just walked into the room. Drew her back to the* *question – again she remarked on the questions being stupid. I explained it would be helpful if she could take a minute to think of any other words to describe her relationship with her mother. She thought and came up with Practical. I couldn't get anything further that was relevant.*

Q4: Now I'd like to ask you to choose five adjectives or words that reflect your childhood relationship with your father. She talked about him being a naval man and where they had travelled to but she was confusing her father with her husband. I asked her what she remembered about her relationship with him. He was very strict was about the gist of what I could get from her.

Q7: What is the first time you remember being separated from your parents? How did you respond? Do you remember how your parents responded? Are there any other separations that stand out in your mind? She was born at the beginning of the First World War. She cannot remember early separations. Later there were many separations as father was a naval man and although the family did share some of his postings there were lots of time when they were in Whitstable and he was elsewhere. Do you remember how you felt about that? It was normal life –went on wherever we were.

Further evidence can be found in the data.

Grice's conversational maxims: Manner

Participant No. 1

Rating: 1

Rater: MS

Manner = clear and orderly response to each question.

Poor	1	2	3	4	5	Good

Evidence from interview data: Showed repeated irritation with some of the questions e.g.

Q2: *I had to repeat the question and she responded the second time by asking me why I was asking her stupid questions.*

Q3: She was very kind – yes, busy *then distracted herself by talking about the cat that had just walked into the room. Drew her back to the question – again she remarked on the questions being stupid.*

Q8: Did you ever feel rejected as a young child? If yes at what age and why did parents behave so? Her response to this question was No. I couldn't draw her and she resorted to asking me again why I was asking her stupid questions.

Q9: Were your parents over frightening or threatening. Again commented on how stupid these questions are, the participant was also resistant to answering some of the questions, which are outlined under the maxim quantity.

Grice's conversational maxims: Quantity

Patient No. 1

Rating: 1

Rater: MS

Quantity = succinct whilst answering the question fully. Not overly informative. Conversational turns should be of reasonable length to convey an appropriate response.

1	2	3	4	5

Evidence from interview data:

Most questions were answered inadequately with little or no elaboration – she was difficult to draw out on almost all of the questions e.g.

Q2: *She said alright we all got on together.*

Q3: She was very kind – yes, busy *then distracted herself by talking about the cat that had just walked into the room. Drew her back to the question – again she remarked on the* *questions being stupid. I explained it would be helpful if she could take a minute to think of any other words to describe her relationship with her mother. She thought and came up with* Practical. *I couldn't get anything further that was relevant.*

Q4: He was very strict was about the gist of what I could get from her.

Q6. <u>When you were upset as a child what would you do</u>? Vaguely referred to mother but seemed more comfortable with: just got on with it and reiterated that she had three brothers and a cousin**.** Observe how the person interprets the term 'upset' she asked me to define 'upset'. She couldn't see to relate to it "upset**"** no. <u>Can you remember what would happen when you hurt yourself? Can you think of a specific example?</u> No response to this question when I probed her she said – fell over just got on with it**.** Her style of response was quite staccato throughout. <u>Did your parents physically hold you?</u> Can't remember.

There is further evidence in questions 6, 7, 8, 9, 11, 12, 15, 16, 17, 18.

There was also evidence that this participant has difficulty in responding in any depth to the emotionally laden questions.

Q3: See above

Q6: See above

Q8: <u>Did you ever feel rejected as a young child? If yes at what age and why did parents behave so? Her response to this question was</u> No**.** I couldn't draw her and she resorted to asking me again why I was asking her stupid questions?

Q 9: were your parents over frightening or threatening. *Again commented on how stupid these questions are. She spoke again of her father being very strict. I asked her if she was a little bit frightened of him. She defended him saying* that's the way it was fathers were strict.

16 Current closest relationship. How do you feel when you have to be separated? *Again she seemed to want to avoid the emotional aspect and focused on the practicalities – other people coming in to help her to bed and to get up in the morning.* Does it trouble you when L (daughter with whom she lives and is very dependent on for her day to day needs) goes away? "Oh no I know she is coming back."

See also questions: 5, 7, 11,12 and 15

Grice’s conversational maxims: Relative

Participant No. 1

Rating: 2

Rater: M.S.

Relative = answers are relevant to the question and do not veer off into unrelated areas

Not Relative	1	2	3	4	5	Relative

Evidence from interview data: I continually had to probe and re-focus her.

Q2: *I had to repeat the question and she responded the second time by asking me why I was asking her stupid questions. I then had to ask her the question again.*

Q3: yes, busy *then distracted herself by talking about the cat that had just walked into the room. Drew her back to the question – again she remarked on the questions being stupid. I explained it would be helpful if she could take a minute to think of any other words to describe her relationship with her mother. She thought and came up with* Practical. *I couldn’t get anything further that was relevant.*

Q4: She talked about him being a naval man and where they had travelled to but she was confusing her father with her husband. I asked her what she remembered about her relationship with him. He was very strict was about the gist of what I could get from her.

Q5: In a roundabout confused way she did come to mother but she also said we had an Ayah (when they lived in India) and went on to talk about her siblings and her cousin – how they were so close.

Q8: Her response to this question was No. I couldn't draw her and she resorted to asking me again why I was asking her stupid questions?

Q13: Not as a child but during the second world war lost a brother and a cousin. I imagine that was difficult –she seemed to not want to engage with the emotional aspect and responded with so many people lost family.

Overall coherence of the narrative based on Grice's maxims:

Participant No. 1

Rater: MS

Classification: Avoidant

Manner: Score 1

Quantity: Score 1

Relative: Score 2

Quality: Score 2

Total 6

Comments: The low coherence score would suggest an avoidant classification

The low score on quality is mainly due to a lack of supportive evidence or absence of memory. There are repeated referrals to the need to 'be strong'. There is no acknowledgement of feeling hurt, distressed or dependence on others. Attention was often focused away from discussion her early attachment experience and its implications.

These comments are borne out by the evidence identified under the individual maxims.

Grice's conversational maxims: quality

Participant No. 4

Rating: 4

Rater: Maureen Shaw

Quality = truthfulness of narrative, avoiding of contradictions and providing evidence to support the adjectives used to describe the person's experience of the mother/father.

Poor	1	2	3	4	5	Good

Evidence from interview data: the narrative was without contradictions and there was no reason to question its truthfulness. This participant did not give a lot of detail but the responses he did gave were adequate to support an understanding of the nature of his relationships with his parents. There was a sense of liveliness about his memories – especially when he spoke of his cousin.

Q2: Can you describe your relationship with your parents between the ages of five and twelve? "Kind but strict you had to watch your Ps and qs." I asked him if he could remember a specific incident. He said that he and his cousin had fun but there were rules.

Q4: five adjectives dad. A long hesitation then he said – cold, austere shook his head and seemed a little emotional. I asked him if he was ok and he nodded and we continued. I asked if there were any other words he would use – again long hesitation distant – dad was distant. When I asked if he could give me an example he was thoughtful and then said I can’t really think of anything specific – I don’t remember doing much with him. It was as if he was in the background all the time.

Q6: When you were upset as a child what would you do**?** Oh if we hurt ourselves we would go to mum or auntie – they usually told us off because we had been doing something we shouldn’t (he and his cousin). It sounds as if you put you and your cousin in the same place. We were very close – he chuckled and said he was a bit like my twin**.** Observe how the person interprets the term ‘upset’. Upset is interpreted by being hurt physically. Can you think of a specific example? Just if we had been climbing or playing out in the street – nothing serious. “Mum or auntie would see if we were alright – bleeding or anything**”.** If they say they went to a parent for comfort ask how the parent would respond. “They were kind if we were hurt and say it would be alright but they would be cross if we had been doing something we shouldn’t have”**.** What about if you were emotionally upset – he pondered this we didn’t discuss how we felt**.** Did your parents physically hold you? I don’t remember being held but I felt my parents loved me.

Grice's conversational maxims: Manner

Participant No. 4

Rating: 4

Rater: MS

Manner = clear and orderly response to each question.

Poor	1	2	3	4	5	Good

Evidence from interview data:

The questions were responded to clearly and I had no difficult understanding him or that he had any problem understanding what was being asked of him. His manner was cooperative and engaged.

His responses were thoughtful as Q8 illustrates: Did you ever feel rejected as a young child? **No.** Were you ever frightened or worried as a child? I was sometimes worried as school I was small and some of the bigger boys frightened me because they would tease the smaller boys. Did you tell your parents about that? I don't remember that - no idea whether I told mum or just got on with it – it wasn't just me.

Q10 illustrates his responsiveness to the question: Experiences with parents affected personality. I think parent are influential in shaping their children's personality. I don't think there was anything adverse in my experiences with my parents – my dad I think his distance and coldness might have affected me. There's seems to be a regret about this. Was there anything in your childhood that you feel were a setback to you? Nothing in particular that I can remember other than what I have said.

Grice's conversational maxims: Quantity

Participant No. 4

Rating: 4

Rater: MS

Quantity = succinct whilst answering the question fully. Not overly informative. Conversational turns should be of reasonable length to convey an appropriate response.

1	2	3	4	5

Evidence from interview data: This participant was in deed succinct as he did not volunteer lengthy responses but answered the questions in enough depth to convey a sense of his early attachment experiences with his parents.

Q3: five adjectives to describe mother. Strict, kind, fair he stopped there. Why did you choose those particular words? He hesitated for some time and said "they were what came to mind". I asked if he could give an example from he was very young. He was thoughtful and said he didn't have a clear memory but could vaguely remember trips to the park but he felt he had to do what mum said.

Q4: five adjectives dad. A long hesitation then he said – cold, austere shook his head and seemed a little emotional. I asked him if he was ok and he nodded and we continued. I asked if there were any other words he would use – again long hesitation distant – dad was distant. When I asked if he could give me an example he was thoughtful and then said I can’t really think of anything specific – I don’t remember doing much with him. It was as if he was in the background all the time.

Q6: When you were upset as a child what would you do? Oh if we hurt ourselves we would go to mum or auntie – they usually told us off because we had been doing something we shouldn’t (he and his cousin). It sounds as if you put you and your cousin in the same place. We were very close – he chuckled and said he was a bit like my twin. Observe how the person interprets the term ‘upset’. Upset is interpreted by being hurt physically. Can you think of a specific example? Just if we had been climbing or playing out in the street – nothing serious. “Mum or auntie would see if we were alright – bleeding or anything”. If they say they went to a parent for comfort ask how the parent would respond. “They were kind if we were hurt and say it would be alright but they would be cross if we had been doing something we shouldn’t have”. What about if you were emotionally upset – he pondered this we didn’t discuss how we felt. Did your parents physically hold you? I don’t remember being held but I felt my parents loved me

Grice's conversational maxims: Relative

Participant No. 4

Rating: 4

Rater: MS

Relative = answers are relevant to the question and do not veer off into unrelated areas

Not Relative	1	2	3	4	5	Relative

Evidence from interview data: There were no instances of irrelevant responses or occasions when the person did not respond appropriately.

Q8: Did you ever feel rejected as a young child? No. Were you ever frightened or worried as a child? I was sometimes worried as school I was small and some of the bigger boys frightened me because they would tease the smaller boys. Did you tell your parents about that? I don't remember that no idea whether I told mum or just got on with it – it wasn't just me.

Q9: were your parents over frightening or threatening? Oh no just the "Wait till you father gets home" What would happen then? It would depend on what we had done (he and his cousin) if it was minor she might forget to tell him and it would depend if she was in a good mood. This was delivered in a quite matter of fact way as if it didn't trouble him

Q10: Experiences with parents affected personality. I think parent are influential in shaping their children's personality. I don't think there was anything adverse in my experiences with my parents – my dad I think his distance and coldness might have affected me. There's seems to be a regret about this.   Was there anything in your childhood that you feel were a setback to you? Nothing in particular that I can remember other than what I have said.

Q14: Were there any other difficult experiences other than those you've already described have you which you felt were potentially traumatic? I think it was good I had my cousin because I think I would have been lonely as an only child.

Overall coherence of the narrative based on Grice's maxims:

Participant No. 4

Rater: MS

Classification: secure/autonomous

Manner: Score 4

Quantity: Score 4

Relative: Score 4

Quality Score 4

Total 16

Comments: This was a coherent discourse. The descriptions of attachment were consistent with no contradictions. There were no violations of Grice's maxims. He was able to acknowledge his emotional needs by recognising that he would have been a lonely child had he not been living with his cousin with whom he was close. He was also able to admit that he would be somewhat anxious if he were to be separated from his wife as he is now more dependent on her. He is able to recognise that attachment issues have affected him as an adult. There was a sense of balance about this discourse.

The evidence for these comments is highlighted under the individual maxims.

Grice's conversational maxims: quality

Participant No. 7

Rating: 3

Rater: MS

Quality = truthfulness of narrative, avoiding of contradictions and providing evidence to support the adjectives used to describe the person's experience of the mother/father.

Poor	1	2	3	4	5	Good

Evidence from interview data: In this discourse the person makes statements about having loving parents and provides examples of support and kindness yet he runs away when he is upset, which is quite contradictory. Otherwise he is able to provide evidence to support the adjectives he uses to describe his parents and provide some examples.

Q3: She was strong – I remember her digging the garden and she walked everywhere hardly ever took a bus. Any other words you can think of to describe her? (This took some time) she was very generous – when she baked a cake she would always bake one for my Nan. Can you think of anything that was to do with you? She would come and meet me from school sometimes and I liked that.

Q4: Fun – he would play football with me. He had a temper though if he thought you weren't trying and were messing around. Can you remember anything in particular with you? A time when we went fishing and I was bored and messing around he lost his temper with me. He was helpful as well – he helped me understand things and do woodwork

Q6: When you were upset as a child what would you do? Run away. When I asked him to clarify he said that he would want to be on his own when he was upset. He clarified upset by saying that he would get upset when someone was ‘telling me what to do’

Can you remember what would happen when you hurt yourself? Go to mother or father for comfort. If he hurt himself somehow. He said his mother would say “come on I’ll kiss it better” and his dad would comfort him but he would also say something like “come on be a big boy”. Did your parents physically hold you? No we weren’t a family that showed affection.

Q10: Are there any other aspects of your early experiences that you think might have held your development or had a negative effect on the way you turned out? He replied by saying no but then went on to mention leaving school at the time he did. I tried to draw him but he didn’t really elucidate any further. Was there anything else in your early childhood that has affected how you turned out? I don’t think so.

Grice's conversational maxims: Manner

Participant No. 7

Rating: 4

Rater: MS

Manner = clear and orderly response to each question.

Poor	1	2	3	4	5	Good

Evidence from interview data:

This participant's manner was cooperative and he responded appropriately to each question. However, the discourse did not flow at times as he seemed to have little to say, which could be construed as not being sure of what was expected of him. I also had the impression that he was quite a shy man who kept himself to himself outside the family – going to the local football matches alone, gong to local live music gigs alone and using his bus pass to visit places alone.

Q5: which parent did you feel the closest to, and why. Why isn't there this feeling for the other parent? Hard to say I always felt both of them were there for me. I felt mum and dad were always around.

Q7; what is the first time you remember being separated from your parents? How did you respond? Do you remember how your parents responded? Are there any other separations that stand out in your mind? When I went to school – I didn't like it at first I didn't like mum to leave. Mum would try and get me to go into the classroom I wouldn't let her go and the teacher would come out and take me in. Do you have a clear memory of that? Not really just a vague memory but mum told me when I was older she said it upset her to leave me like that.

Q8: Did you ever feel rejected as a young child? No I can't remember feeling like that. Were you ever frightened or worried as a child? End of school holidays. Never liked school from infants until he left as fifteen. He went on to say that he found it difficult to make friends at school and was bullied in secondary school.

Grice's conversational maxims: quantity

Participant No: 7

Rating: 3

Rater: MS

Quantity = succinct whilst answering the question fully. Not overly informative.

Conversational turns should be of reasonable length to convey an appropriate response.

Low	1	2	3	4	5	High

Evidence from interview data.

This discourse was succinct although in most instances sufficient information was given. At other times there was some avoidance.

Q3: Ask for incidents to illustrate the use of a particular adjective that are specific rather than general**.** She was strong – I remember her digging the garden and she walked everywhere hardly ever took a bus. Any other words you can think of to describe her? (This took some time) she was very generous – when she baked a cake she would always bake one for my Nan. Can you think of anything that was to do with you? She would come and meet me from school sometimes and I liked that.

Q4: Fun – he would play football with me. He had a temper though if he thought you weren't trying and were messing around. Can you remember? anything in particular with you? A time when we went fishing and I was bored and messing around he lost his temper with me. He was helpful as well – he helped me understand things and do woodwork.

Q10: Are there any other aspects of your early experiences that you think might have held your development or had a negative effect on the way you turned out? He replied by saying no but then went on to mention leaving school at the time he did. I tried to draw him but he didn't really elucidate any further. Was there anything else in your early childhood that has affected how you turned out? I don't think so.

Grice's conversational maxims: Relative

Participant 7

Rating: 4

Rater: MS

Relative = answers are relevant to the question and do not veer off into unrelated areas

Not Relative	1	2	3	4	5	Relative

Evidence from interview data:

Answers were consistently relevant to the question.

Q4: which parent did you feel the closest to and why? Why isn't there this feeling for the other parent? Hard to say I always felt both of the were there for me. I felt mum and dad were always around.

Q10: he replied by saying "No" but then went on to mention leaving school at the time he did. I tried to draw him but he didn't really elucidate any further. Was there anything else in your early childhood that has affected how you turned out? "I don't think so."

Q16: did you ever feel rejected as a young child? "No I can't remember feeling like that." Were you ever frightened or worried as a child? "End of school holidays." Never liked school from infants until he left at fifteen. He went on to say that he found it difficult to make friends at school and was bullied in secondary school.

Overall coherence of the narrative based on Grice's maxims:

Participants No: 7

Rater: MS

Classification: secure/autonomous

Manner: Score 4

Quantity: Score 3

Relative: Score 4

Quality Score 3

Total 14

Comments: Overall, this discourse is coherent and would merit a classification of secure autonomous. However, there is a flavour of ambivalence that is evidenced in the individual maxims.

4.6. Examples of Responses to AAI Questions and Ratings

Secure attachment

Participant 4:

Quality: rating 4

Evidence from interview data: the narrative was without contradictions and there was no reason to question its truthfulness. This participant did not give a lot of detail but the responses he did give were adequate to support an understanding of the nature of his relationships with his parents. There was a sense of liveliness about his memories – especially when he spoke of his cousin.

Q2: Can you describe your relationship with your parents between the ages of five and twelve? "*Kind but strict - you had to watch your Ps and Qs*." I asked if he could remember a specific incident. He said that *"he and his cousin had fun but there were rules."*

Q4: Five adjectives to describe dad. A long hesitation then he said – "*cold, austere" he shook his head and seemed a little emotional.* The researcher asked if he was ok, *he nodded and the interview continued.* The researcher asked if there were any other words he would use – *again long hesitation "distant – dad was distant".* When asked if they could give an example, he was thoughtful and then said "*I can't really think of anything specific – I don't remember doing much with him. It was as if he was in the background all the time."*

The participant answered the questions in enough depth to convey a sense of his early attachment experiences with his parent.

Manner: rating 4

The questions were responded to clearly and the researcher had no difficulty understanding him or any sense that he had a problem understanding what was being asked of him. His manner was cooperative and engaged.

Q8 illustrates thoughtfulness of his response: Did you ever feel rejected as a young child? "*No*." Were you ever frightened or worried as a child? "*I was sometimes worried at school. I was small and some of the bigger boys frightened me because they would tease the smaller boys".* Did you tell your parents about that? "*I don't remember that - no idea whether I told mum or just got on with it – it wasn't just me.*"

Q10 illustrates his responsiveness to the question: How do experiences with parents affect personality? "*I think parents are influential in shaping their childrens' personality. I don't think there was anything adverse in my experiences with my parents – my dad I think his distance and coldness might have affected me".* There seems to be a regret about this. Was there anything in your childhood that you feel was a setback to you? "*Nothing in particular that I can remember other than what I have said."*

Quantity: rating 4

This participant was indeed succinct as he did not volunteer lengthy responses but gave enough information to convey a flavour of his early relationships.

Q6: When you were upset as a child what would you do? "*Oh if we hurt ourselves we would go to mum or auntie – they usually told us off because we had been doing something we shouldn't."* It sounds as if you put you and your cousin in the same place?

"*We were very close" – he chuckled and said "He was bit like my twin."* Observe how the person interprets the term "upset". Can you think of a specific example? "*If we had been climbing or playing out in the street – nothing serious, Mum or auntie would see if we were alright – bleeding or anything".* If they say they went to a parent for comfort, ask how the parent would respond. "*They were kind if we were hurt and say it would be alright but they would be cross if we had been doing something we shouldn't have".* What about if you were emotionally upset? – *He pondered this and said "We didn't discuss how we felt".* Did your parents physically hold you? "*I don't remember being held but I felt my parents loved me".*

Relative: 4. There were no instances of irrelevant responses or occasions when the person did not respond appropriately.

Q9: Were your parents ever frightening or threatening? *"Oh no just the wait till you father gets home"* What would happen then? *"It would depend on what we had done, if it was minor she might forget to tell him and it would depend if she was in a good mood".* This was delivered in quite a matter of fact way as if it didn't trouble him.

Q14: Were there any other difficult experiences, other than those you've already described, which you felt were potentially traumatic? *"I think it was good I had my cousin because I think I would have been lonely as an only child".*

Overall coherence: rating 16/20

This was a coherent discourse. The descriptions of attachment were consistent without any contradictions. There were no violations of Grice's maxims. The participant was able to acknowledge his emotional needs by recognising that he would have been a lonely child had they not been living with his cousin with whom he was close. He was also able to admit that, in the present, he would be somewhat anxious to be separated from his wife as he is now more dependent on her. He was able to recognise that attachment issues have affected him as an adult. There was a sense of balance about this discourse.

Dismissing-avoidant – blocking discourse either consciously or unconsciously and being reluctant to develop or explore experiences, especially those that were potentially distressing.

Participant 10:

Quality: rating 2

This participant was able to give a narrative that was lacking in contradictions but her answers were very terse. Although the questions were answered, the information given was minimal and she was unable to communicate a sense of the relationship with her parents – although the distance and the coldness of the mother was conveyed.

Q 3- "*She was vague, moody, distant, preoccupied. She looked after us but we were not close to her"*. Why have you chosen those particular adjectives*? "That's how I experienced her I never had a sense of her being totally there. There was no warmth"*. She was quite coherent in answering this.

Q 6 - When you were upset as a child what would you do? Observe how they interpret the word upset. *"Go to my own room and lock the door"*. What sort of things would upset you? *"Altercation with my brother"*.

Q8 - Did you ever feel rejected as a young child? "*When she started school she felt rejected by the other kids but not by her parents.*"

Manner: rating 2

Overall there was an orderly response to the questions on prompting; original responses were terse and needed some clarification to elicit meaning.

Q 4 – "*Father interested in interplanetary society*." What else do you remember about him? *"He was friendly and clever – interested"*. On probing she came up with *he was interested in me – paid me attention.*

Q 12 Were there any other adults with whom you were close like parents as a child? Quite a confused response, the researcher deciphered: "*sent to (Place name where she was evacuated) aunt and uncle, which she changed to grandparents but she had already said that she didn't know any of grandparents.* And you felt close to them? "*Yes, they were kind.*"

Quantity: rating 3

Evidence from interview data: questions were not answered fully. The evidence the participant gave to support the description of her parents was not very elaborate. She gave the impression that she understood the questions and was cooperative but she demonstrated little interest in the focus of the questions.

Q 11- Why do you think your parents behaved as they did during your childhood? *"I suppose they did their best - I don't know we wouldn't talk about such things."*

Relative: rating 4

Principally her responses were relative but they were also slightly off the mark.

Q 14 - Were there any other difficult experiences other than those you've already described, which you felt were potentially traumatic? *She were a keen cyclist and when she was evacuated she cycled home but was made to go back*

Q 16 - Current closest relationship. How do you feel when you have to be separated? *Here she referred to her son who was with her and went on to explain how she saw the family regularly, (her son corrected her on a number of points)* I tried to bring her back to the original question by asking about how she felt about being on her own most of the time. *She said she didn't think about it and referred to a pile of books in front of her and said that she read a lot* (her son wasn't sure how much of what she read was taken in).

Overall Coherence: rating 11

The scores for quantity and quality are the most significant in this narrative as they convey the clear lack of supporting evidence. There is a sense of responses being remote and the topic of the interview foreign (of little interest to her). Her parents were not exactly derogated but there is little consideration of them. Self- reliance is identified and appears to be valued.

Preoccupied – ambivalent - the person predominantly presents a confused narrative focusing on early attachment memories and feelings provoked by the AAI questions.

Participant 19:

Quality: rating 3

There was not a sense of untruthfulness but more a sense of nostalgia and/or ambivalence e.g. in relation to her mother "*You could have a bit of the craic with her*", which had also a contradictory air as most of the narrative was punctuated with references of mother 'beating' the children and of her bad temper. She was able to expand on her choice of adjectives but it tended to be around the theme of mother's temper.

Q 9 - Were your parents ever threatening with you in any way – maybe for discipline or even jokingly? Be sensitive to cultural issues. If yes, ask usual clarifying questions. "*Mother was, she would threaten to 'belt' us if we didn't behave*". How did that feel? *"I hated it".*

Q 11 - Why do you think your parents behaved as they did during your childhood? *"Like I said mammy couldn't control herself and daddy tried to protect us from her".*

Manner: rating 2

Her manner was disjointed and rambling with frequent long diversions; she was repeatedly distracted and preoccupied with her tablets.

Q 13 - Did you experience the loss of a parent or other close loved one while you were a young child –for example a sibling or a close family member? If yes, ask expanding questions. "*Paternal grandfather – I missed him" (fiddling in her handbag).* Did you lose any other important persons during your childhood? *"No".* Have you lost other close persons in adult years? "*My husband – seven years ago".* I had difficulty drawing her on how they felt about the death of her husband and her grandfather. She was distracted by her pills and seemed unable to focus on the question. I came back to this question at the third visit and she acknowledged that she and her husband weren't very close – *"husband was a bully".*

Q 16 - Current closest relationship. How do you feel when you have to be separated?

"I am on my own now and have only [Name of sister] to drive mad". Interesting comment on her relationship with their sister on whom she is dependant.

Quantity: rating 2

The participant was unable to answer succinctly and needed to be brought back to the subject continually. Her conversational turns were often long and rambling. Memories of her early life were dominated by memories of her mother's treatment of her.

Q 3 - I'd like you to choose five adjectives or words that reflect your relationship with your mother starting from as far back as you can remember in early childhood. The use of a particular adjective that is specific rather than general. "*Mother was very strict and would beat us if we didn't do as we were told or if we did something wrong*". Can you give me an example? *She responded with a rambling story about losing a book and continually invited her sister to substantiate her story.* Why did you choose those words to describe her? *"She was so strict".* Can you think of any other words to describe her? *"If she was in a good mood she could be alright".* Can you tell me a bit more about that in relation to yourself? She turned to her sister and said *"[Name] what was mammy like when she was in a good mood?"* Her sister referred her back to what had I had asked, vis-a-vis her own experience. “*You could have a bit of the craic with her*” (fun, chilling out together). Did you like those times? “*Yes, but it didn’t happen often, most of the time she was in a bad mood”*. Again this account was interspersed with non sequiturs.

Q 10 - Are there any aspects to your early experiences that you feel were a set-back in your development? *“Mammy’s thumping”.* (Fiddling in her handbag and asked her sister a question about her pills). When your mum was angry and hit you that was difficult for you? *“It used to upset everyone” looking at her sister*. Why do you think she behaved like that? *“She couldn’t control her temper – that’s what daddy used to tell her”.* If yes, probe further with are there any other aspects of your early experiences that you think might have held your development or had a negative effect on the way you turned out? “*Being evacuated – I liked it but it split the family up”.* This information was not delivered in a coherent, orderly fashion.

Relative: rating 3

Her answers could only be considered as relative with excessive prompting. There was a constant theme of her mother’s bad temper, which she would return to at every opportunity.

Q 6 - When you were upset as a child what would you do? *When mother hit her – would hit her on the head. “Go by myself”.* She interpreted “upset” as mother being angry and hitting her. So much seems to come back to mother.

Q 7 - What is the first time you remember being separated from your parents? How did you respond? Do you remember how your parents responded? Are there any other separations that stand out in your mind? *“When I went to school”.* How was that? *“It was* *alright – [Name] was there". looking to her sister.* So [Name] being there made it alright for you? *She agreed*. She does not mention being evacuated here, which was surprising in the context of how she had begun this interview.

Overall coherence: rating 10

Comments: Overall, this narrative fits the classification of resistant ambivalent, principally as there was a level of incoherence in her account. Specifically, her account is dominated by memories of her mother's treatment of her whilst father is held to be the 'idealised' parent. Her account was rambling and she was often distracted by looking in her handbag for pills. She also wanted to focus on fun (the craic), *"good fun and messing about with us*" whilst simultaneously reverting back to mother's bad temper and mother hitting her, demonstrating some ambivalence.

Unclassifiable: three participants attracted this classification principally because of their inability to respond to the questions appropriately. In each case, this was due to their level of cognitive impairment. The following examples illustrate this point:

Participant 2:

Quality: rating 2

Evidence from interview data: The researcher does not believe there was anything untruthful about her narrative and there were no contradictions, but the quality was poor, which could be ascribed to her inability to "stay" with the subject, rather than withholding information. She was not able to support her statement about her mother. There was little quality to any of their responses and the researcher's attempts to draw her further, did not add much to the narrative.

Q 3: Can you give five adjectives that describe your relationship with your mother? She struggled with the question and *diverted herself by telling me she was taking anti-depressant medication.* I brought her back to the question and she finally got to "*she helped me*." I asked her to clarify and she said *"When I was at school. I was very young, I was frightened. She was kind."*

Why did you choose those particular words? She didn't seem to understand the question. I didn't think it was fair to pursue her any further as I could see she was uncomfortable. It didn't seem possible for her to think sequentially.

Participant 11:

Manner: rating 1

Q 3: Can you choose five adjectives or words that reflect your relationship with your mother? It was extremely difficult to keep him focused, the main thrust of his reply was: "*mum was kind but wouldn't take any nonsense she would give us a clip around the ear if she thought we deserved it."* He kept wandering off to memories about his brother and looking to his wife a lot. At one point she said "*I don't know*" as his wife thought he was expecting her to know what he was talking about. I wondered if he confused his wife with his mother in terms of how he felt about them emotionally.

Participant 8:

Quantity: rating 2

When you were upset as a child what would you do? Observe how they interpret the word “upset”. Probe the answer. “*If she didn’t know where we were.”* Observe how the person interprets the term “upset” My understanding was that she interpreted “upset” to mean that she thought that she was being asked about her mother getting upset and what would happen when she didn’t know where the children were. Can you remember what would happen when you hurt yourself? Can you think of a specific example? “*Mum would comfort.*” It was difficult to get an example as she kept wandering off in directions that were hard to follow. Did your mother physically hold you? *“Yes, when we were hurt”.*

Participant 8:

Relative: rating 2

Q9: Were your parents ever threatening with you in any way – maybe for discipline or even jokingly? Be sensitive to cultural issues. If yes, ask usual clarifying questions. The researcher couldn’t draw her on this; she seemed to think she was being asked about threats from outside the family, in the street; it wasn’t coherent.

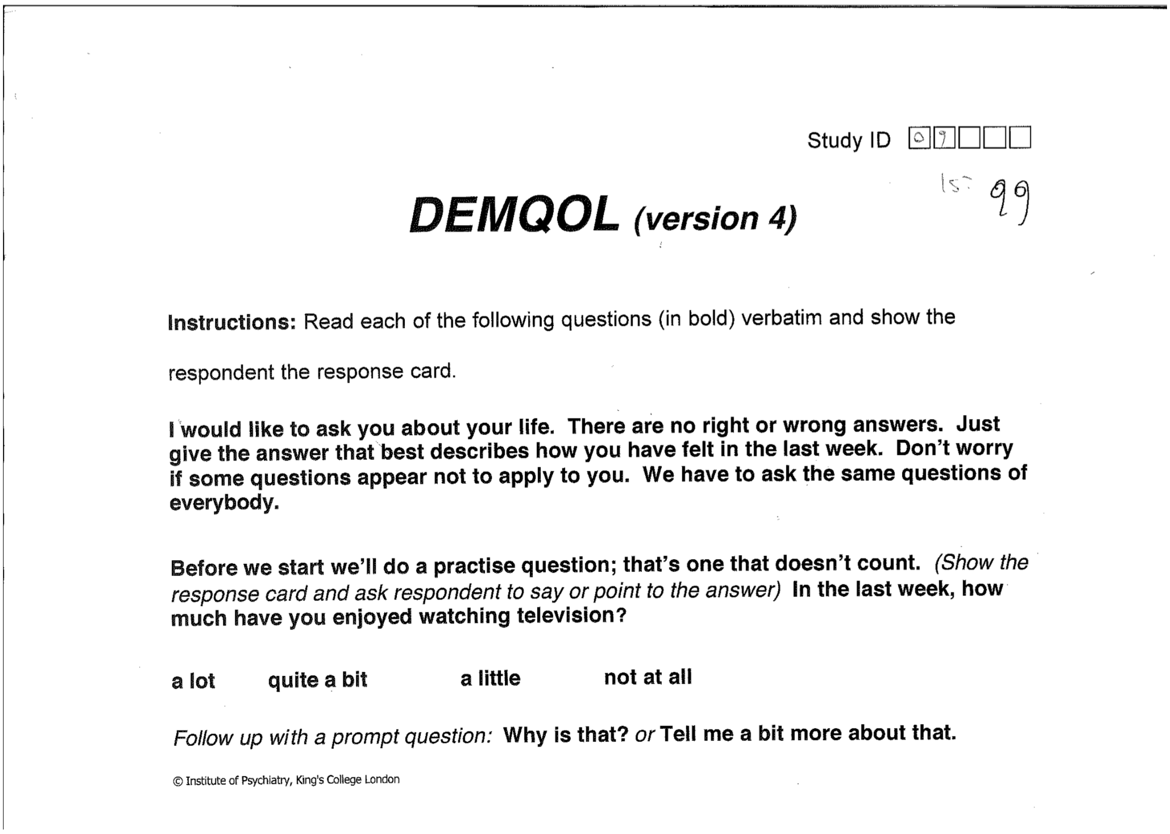
Participant 11:

Overall coherence: rating 5

Comments: this narrative achieved a low score on all four maxims. The outstanding feature of his recollections was the impact WW2 had on him. Because he was basically unable to respond to the questions adequately, there was insufficient information to classify him.

5. Completed Measures

5.1. DEMQoL



Study ID 0 9

1st 99

DEMQOL (version 4)

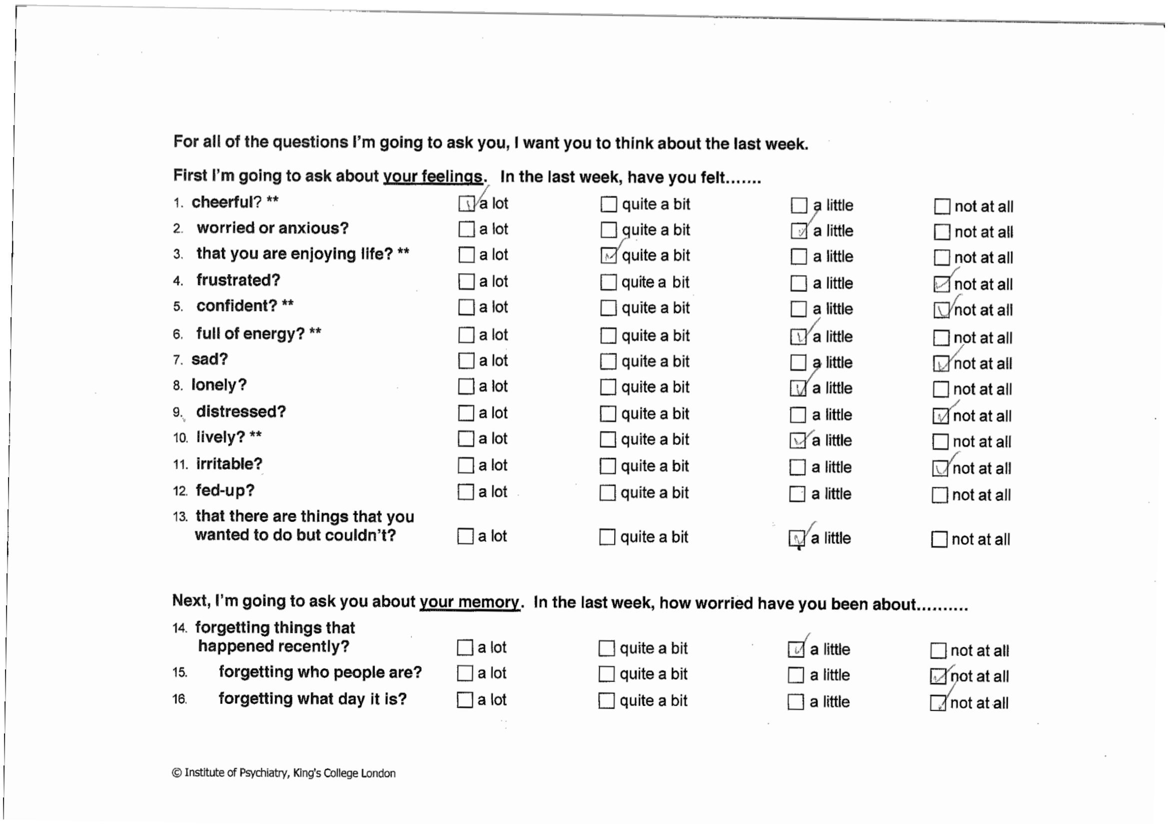
Instructions: Read each of the following questions (in bold) verbatim and show the respondent the response card.

I would like to ask you about your life. There are no right or wrong answers. Just give the answer that best describes how you have felt in the last week. Don't worry if some questions appear not to apply to you. We have to ask the same questions of everybody.

Before we start we'll do a practise question; that's one that doesn't count. *(Show the response card and ask respondent to say or point to the answer)* **In the last week, how much have you enjoyed watching television?**

a lot **quite a bit** **a little** **not at all**

Follow up with a prompt question: **Why is that?** *or* **Tell me a bit more about that.**



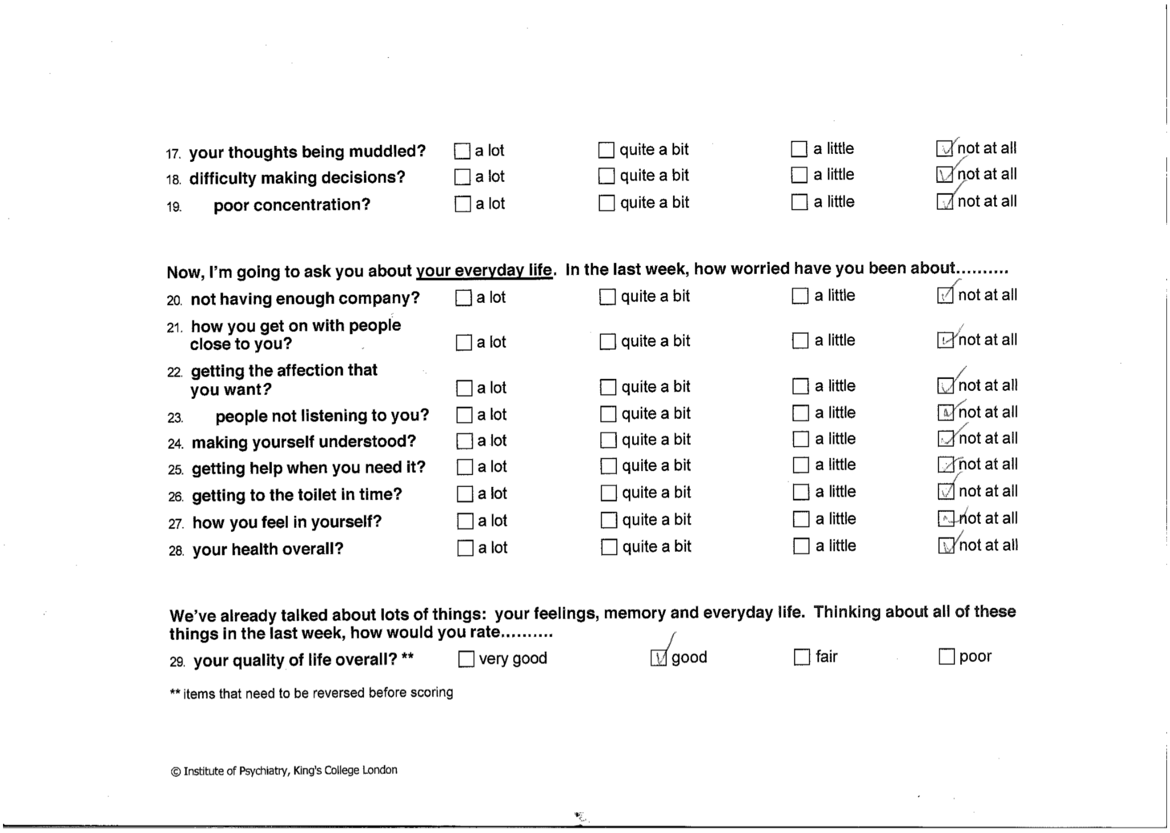
For all of the questions I'm going to ask you, I want you to think about the last week.

First I'm going to ask about <u>your feelings</u>. In the last week, have you felt.......

1. **cheerful? ****	☑ a lot	☐ quite a bit	☐ a little	☐ not at all
2. **worried or anxious?**	☐ a lot	☐ quite a bit	☑ a little	☐ not at all
3. **that you are enjoying life? ****	☐ a lot	☑ quite a bit	☐ a little	☐ not at all
4. **frustrated?**	☐ a lot	☐ quite a bit	☐ a little	☑ not at all
5. **confident? ****	☐ a lot	☐ quite a bit	☐ a little	☑ not at all
6. **full of energy? ****	☐ a lot	☐ quite a bit	☑ a little	☐ not at all
7. **sad?**	☐ a lot	☐ quite a bit	☐ a little	☑ not at all
8. **lonely?**	☐ a lot	☐ quite a bit	☑ a little	☐ not at all
9. **distressed?**	☐ a lot	☐ quite a bit	☐ a little	☑ not at all
10. **lively? ****	☐ a lot	☐ quite a bit	☑ a little	☐ not at all
11. **irritable?**	☐ a lot	☐ quite a bit	☐ a little	☑ not at all
12. **fed-up?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
13. **that there are things that you wanted to do but couldn't?**	☐ a lot	☐ quite a bit	☑ a little	☐ not at all

Next, I'm going to ask you about <u>your memory</u>. In the last week, how worried have you been about..........

14. **forgetting things that happened recently?**	☐ a lot	☐ quite a bit	☑ a little	☐ not at all
15. **forgetting who people are?**	☐ a lot	☐ quite a bit	☐ a little	☑ not at all
16. **forgetting what day it is?**	☐ a lot	☐ quite a bit	☐ a little	☑ not at all



17. **your thoughts being muddled?**	☐ a lot	☐ quite a bit	☐ a little	☑ not at all
18. **difficulty making decisions?**	☐ a lot	☐ quite a bit	☐ a little	☑ not at all
19. **poor concentration?**	☐ a lot	☐ quite a bit	☐ a little	☑ not at all

Now, I'm going to ask you about <u>your everyday life</u>. In the last week, how worried have you been about..........

20. **not having enough company?**	☐ a lot	☐ quite a bit	☐ a little	☑ not at all
21. **how you get on with people close to you?**	☐ a lot	☐ quite a bit	☐ a little	☑ not at all
22. **getting the affection that you want?**	☐ a lot	☐ quite a bit	☐ a little	☑ not at all
23. **people not listening to you?**	☐ a lot	☐ quite a bit	☐ a little	☑ not at all
24. **making yourself understood?**	☐ a lot	☐ quite a bit	☐ a little	☑ not at all
25. **getting help when you need it?**	☐ a lot	☐ quite a bit	☐ a little	☑ not at all
26. **getting to the toilet in time?**	☐ a lot	☐ quite a bit	☐ a little	☑ not at all
27. **how you feel in yourself?**	☐ a lot	☐ quite a bit	☐ a little	☑ not at all
28. **your health overall?**	☐ a lot	☐ quite a bit	☐ a little	☑ not at all

We've already talked about lots of things: your feelings, memory and everyday life. Thinking about all of these things in the last week, how would you rate..........

29. **your quality of life overall? ****	☐ very good	☑ good	☐ fair	☐ poor

** items that need to be reversed before scoring

5.2. Overall Quality of Life - Individual Scores

Participant	Pre-group score	Post-group score
Ann	good	good
Bella	very good	fair
Eric	fair	good
Jeannie	good	fair
Iris	very good	good
Roger	good	good
Rosemary	good	good
Eva	good	good
Ruth	good	good
John	good	good
Angela	fair	fair
Frank	fair	good
Peter	good	very good
Paul	fair	good
Agnes	fair	fair
Jim	good	good
David	very good	very good
Sheila	good	good
Bob	very good	very good
Carol	good	fair
Dorothy	poor	poor
Katie	good	good
Henry	good	fair
Penny	good	good
Kevin	fair	very good
Mike	good	good

5.3. Perceived Helpfulness Questionnaire

Please read the statements printed in bold and tick the response that most closely fits your own.

You feel well informed are you about your diagnosis

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

You are aware of the services available to you

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

You feel confident about mixing with other people

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

You feel more isolated since you began having problems with your memory

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

Other people treat you differently since you began having trouble with your memory

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

You have been able to adapt to your difficulty in remembering

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

You have changed things at home to help you to remember

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

Your difficulty in remembering has changed how you feel about things

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

You are more aware of your feelings now

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

Your memory problem has affected the way in which you occupy yourself

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
🙂		😐		🙁

6. Statistical Analysis

DEMQoL Paired Samples t-Test

		Paired Differences					t	df	Sig. (2-tailed)
		Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference				
					Lower	Upper			
Pair 1	DEMQoL total of pre group scores - total of post group scores	-7.269	14.161	2.777	-12.989	-1.550	-2.618	25	.015

DEMQoL Question 29 - Paired Samples t-Test

		Paired Differences					t	df	Sig. (2-tailed)
		Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference				
					Lower	Upper			
Pair 1	question 29 pre - question 29 post	-.07692	.84489	.16570	-.41818	.26434	-.464	25	.646

Results: Perceived Helpfulness Questionnaire - Paired Samples t-Test

		Paired Differences					t	df	Sig. (2-tailed)
		Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference				
					Lower	Upper			
Pair 1	pre group score - post group score	-.385	4.622	.907	-2.252	1.482	-.424	25	.675

6.1. Kappa score for co-coding for attachment classification

TN * MS

Case Processing Summary						
	Cases					
	Valid	Missing	Total			
	N	Percent	N	%	N	%
TN * MS	3	100.0%	0	0.0%	3	100.0%

TN * MS Crosstabulation					
	MS	Total			
	Secure	Dismissive			
TN	Secure	Count	2	0	2
		Expected Count	1.3	0.7	2.0
	Dismissive	Count	0	1	1
		Expected Count	0.7	0.3	1.0
Total	Count	2	1	3	
	Expected Count	2.0	1.0	3.0	

Symmetric Measures					
	Value	Asymptotic Standard Error[a]	Approximate T[b]	Approximate Significance	
Measure of Agreement	Kappa	1.000	0.000	1.732	0.083
N of Valid Cases	3				

CP * MS

Case Processing Summary						
	Cases					
	Valid	Missing	Total			
	N	Percent	N	Percent	N	Percent
CP * MS	3	100.0%	0	0.0%	3	100.0%

CP * MS Crosstabulation					
	MS	Total			
	Secure	Dismissive			
CP	Secure	Count	2	0	2
		Expected Count	1.3	0.7	2.0
	Preoccupied	Count	0	1	1
		Expected Count	0.7	0.3	1.0
Total	Count	2	1	3	
	Expected Count	2.0	1.0	3.0	

Symmetric Measures					
	Value	Asymptotic Standard Error^a	Approximate T^b	Approximate Significance	
Measure of Agreement	Kappa	0.400	0.098	1.732	0.083
N of Valid Cases	3				

CP * TN

Case Processing Summary						
	Cases					
	Valid	Missing	Total			
	N	Percent	N	Percent	N	Percent
CP * TN	3	100.0%	0	0.0%	3	100.0%

CP * TN Crosstabulation					
	TN	Total			
	Secure	Dismissive			
CP	Secure	Count	2	0	2
		Expected Count	1.3	0.7	2.0
	Preoccupied	Count	0	1	1
		Expected Count	0.7	0.3	1.0
Total	Count	2	1	3	
	Expected Count	2.0	1.0	3.0	

Symmetric Measures					
	Value	Asymptotic Standard Error[a]	Approximate T[b]	Approximate Significance	
Measure of Agreement	Kappa	0.400	0.098	1.732	0.083
N of Valid Cases	3				

7. Thematic Analysis

7.1. Examples of Relational Themes

Negative Relations

The characteristics of what I have described as negative relations focus on observations of negating, dismissing or minimising the person with dementia, expressed in relational patterns that range from being insensitive but caring to one particular example of hostility and antagonism. Common coping strategies amongst this group were denial, avoidance and advocating self-sufficiency. Examples of these relational patterns are in evidence in the following examples:

She began to tell me she had been living in hot parts of the world with her father and her husband. Her daughter corrected her on whom she had been with and where; she looked very puzzled [by daughter's comment]. Here it seems the daughter is insensitive to the mother's confusion and her manner is abrupt. Her way of coping with her mother's memory loss is to correct her in an abrupt manner. The mother is very elderly (99) and immobile, rendering her very dependant. (01/1)

She greeted me and replied to me asking how she was by telling me she is a fighter "You have to get on with things – be strong." This is an example of how she demonstrates being self-sufficient. (01/5)

She expressed interest in having another cup of coffee, I took her cup to her daughter who said that she had just had one and did not make her another. There is no discussion here, the daughter was simply dismissive. (01/2)

I asked if it worried her if she didn’t know what day it was. She was trying to say that she would have a calendar but there wasn’t one here. At which her daughter came rushing into the room and held up a clock that stated the time, day and date. However, when her daughter had left she whispered to me that the day and date were not visible to her as they were hidden by books on a shelf, which was perfectly true. This seems to convey a flavour of this relationship, whereby the daughter needs to be “right” and is unable to respond to her mother empathically (01/3.)

The following excerpt may be a clue to the negative dynamics of this relationship.

The daughter told me her mother had a difficult time with her father because he didn’t like her; he had wanted all boys. She said that her mother had always been quite distant and cited a situation whereby if she was told something about someone else her response would be to talk about something to do with herself. She said that her mother had given her husband a hard time – she was very demanding, expecting him to fetch and carry for her, that he had made a rod for his own back. She described her mother as being very self-centred. (01/4)

This next example is of a couple where the husband is quite dominant and dismissive of his wife, albeit not in an unkind way –rather unthinking or insensitive. However, he admitted that he forgot at times that his wife’s memory was impaired and, as a result he was sometimes impatient with her. He also recognised that he had told her not to dwell on the past but he now understood that it is often possible to reach the present through the past.

He went on to say that his wife was someone who, at a party would sit in a corner and be quite happy. I asked her if she was happy to take a back seat and she said she was. Mr B said that she had always been like that – "*no get up and go.*" He also said that she didn't have any hobbies, didn't like gardening or anything. But he got involved in everything – doesn't like not doing anything. It was difficult to break into his monologue and talk to Mrs B. My impression was that the relational pattern I observed of the husband being dominating and somewhat unaware of his wife's needs, whilst having a disparaging attitude towards her way of dealing with the world, was a long established pattern in their relationship. I could get no sense of whether she was more dependent on him than she was previously. (02/1)

The following depicts how behaviours may be kindly meant but, nevertheless, have a negative impact. The family have no expectations of Mr J being able to do much for himself or around the house, to the extent that his wife dresses him and sits him in a chair from which she doesn't like him to move. Mr J was extremely anxious, which, I would argue, was not alleviated by sitting without any distraction for most of his waking hours.

He mentioned such things as always being told to sit in the chair, how his daughter will not be able to manage (if he becomes infirm) because she has her own family to look after, that he can't do the things around the house that he used to. (11/1)

His wife sat with us and repeatedly cut across him, often telling him his experience was incorrect or wrong. These exchanges tended to focus around his anxieties, which she dismissed and he kept coming back to. (11/2)

"*Can't stop them - too quick.*" He was referring to his wife who jumps to do anything that he tries to do. She says it is because his tremor is so severe. (11/3)

Mr J. attempts to cope by denying the impact of his memory loss, asserting that he has completed tasks that he hasn't and by saying *"his wife makes too much of it*." (11/4)

The following couple exhibited the most negative dynamic I observed as the husband seemed to be quite antagonistic towards his wife, resulting in her having greater difficulty in communicating verbally. Mrs D's illness primarily presents as aphasia and it appears, by her own admission, that it is confounded by anxiety, which her husband seems to provoke. Mr D. himself, seemed to have some anxiety about his wife's diagnosis and wanted me to comment on the hospital report as to the validity of the diagnosis whilst withholding from my sight what the report stated; I felt I was being tested – that his antagonism was a projection of his anxiety onto me. I wondered if his antagonism towards his wife was also a projection of anxiety as a means of coping with his fear of what the future might hold.

Mrs D. had difficulty in maintaining a conversation as she constantly struggled to access the words she wanted to use and although I was comfortable with her taking all the time she needed, her husband would be impatient and try and guess the words she wanted to say. When she would say something that was incorrect he would raise his eyes to heaven in mock exasperation. He also intimated to me that his wife was stubborn and strong willed. (12/1)

The husband disputed her response and went on to say that she didn't call her friends anymore and was reluctant to speak to them when they called her. She acknowledged this too. The sense I had, which was not clearly articulated, was that she was embarrassed. I subsequently learned that she found talking on the telephone very difficult. Her husband didn't seem to realise this. (12/2)

How do you feel when you have to be separated? Husband and wife exchanged looks and I think he was really interested in what she would say. After hesitating she said. "It would be difficult because I don't drive anymore." I asked her if she would miss him and she replied. "Yes of course." My sense was that she did not feel able to say what she felt in front of him. (12/3)

She then went on to say that "It is getting worse." I asked her how she felt about that. She replied that the difficulty she experienced was in getting her words out. I asked if there were any situations in particular that she found more difficult. She surreptitiously pointed to her husband. She then went on to say that she could talk to me without too much of a problem. I asked what was different about talking to me. She replied "I spoke the same language." I asked if she meant that she felt that I would understand and she confirmed this. The impression I had was that she did not look to her husband for support and understanding. (12/4)

Each time they were both in the living room. He ostensibly allowed Mrs D and I to talk together whilst he read the paper but whenever I caught his eye he was watching us and would chip in when Mrs D couldn't find the word she was looking for, or to correct her. My impression was that the relationship was antagonistic. (12/5)

The following example is of a couple who seem to have lost how to be with each other as a result of the disease process. Mr B copes with his dementia by hiding behind an avoidant defence of joking in a disparaging manner and Mrs B has retreated from a husband who no longer “does what he is supposed to do” whilst maintaining her own activities. There seemed to be little empathy between them.

We chatted and his wife said that he has given up his hobbies and doesn’t do much these days, in fact she seemed irritated that he sits in front of the television most of the day and will watch “*any old thing.”* (25/1)

How do you feel when you have to be separated? Here he was trying to avoid the question by joking. Eventually he said that he would miss P if they had to be separated and he didn’t know how he would manage to look after himself. (25/2)

We chatted and Mrs B told me of her passion, which is flower arranging; she talked at length of the shows she takes part in. Husband made disparaging remarks [about wife’s activities] throughout. (25/3)

Positive supportive relationships

The relationships that exhibited supportive and loving dynamics represented the greater bulk of the data. These relational patterns were represented by expressions of caring, empathy, support and mutual affection. There was less evidence of anxiety in these couples who, nevertheless, spoke of their concerns and worries. They also spoke more coherently about the measures they had adopted to cope with memory loss on a day-to-day basis.

He said that he was using his bus pass to travel about, mentioning that he had been to Dungeness, he had been to see a cousin that he hadn’t seen for years. He seemed to be enjoying his freedom. This appeared to be a means of coping, by finding an alternative occupation to those he could no longer do. (07/1)

As a couple, they have found that attending a group for people with dementia and their partners, has helped them to cope. Socialising with others who could relate to their own experience was important to this couple. (04/2)

He feels supported by his wife, which helped him to cope. (04/1)

They seemed to be a close couple, affectionate to each other. However, the wife took the lead in answering and asking questions initially, but then did defer to him and he seemed quite comfortable in complementing her and speaking for himself. Their communication style was open and complimentary of each other. (04/2)

How do you feel when you have to be separated? *"I don't like it – he is my rock I like to have him around."* This person was anxious especially in social situations and the support and presence of her husband was important to her in enabling her to cope with the changes in her life. She was openly able to admit her dependence on her husband. (05/1)

He feels supported by his wife and feels no shame because he hasn't done anything wrong. Interestingly, this person was the only participant to mention shame. (07/1)

She and her son joked quite a lot and made light of the questions that could have been difficult to answer. They seemed close and used humour throughout as a means of communication. Humour could be seen as an avoidant strategy, which to some extent, was my impression of the purpose that it served but, also, I understood that their 'jokey' style of communication was a means of normalising their relationship. (09/1)

"My wife died three years ago, I miss her a lot – we didn't have any children so we were very close to each other but my niece and her husband are very good they keep an eye on me and I see them every day. (Niece's husband) takes me down to the RNLI every Sunday morning."

This person was able to speak openly of his feelings about the loss of his wife, but went on to say that he had been able to make an adjustment from losing the relationship with his wife, by focusing on his relationship with his niece and her husband, which was significant in enabling him enjoy his day to day life. (15/1)

His wife is very busy but gives him jobs to do – this helps his mood as he feels useful. This man was eager to explain to me how important it was for him to feel useful, which his wife understood and was sensitive to. (17/1)

"*We go everywhere together. I don't know if I could manage on my own now."* How do you imagine you would feel if you and D had to be separated? *"Los*t." They seemed very close – have a lot in common. This man had managed to maintain a level of independence but valued the companionship of his wife. (18/1)

Looking at this wife he said *"We are very close – we're close as a family* (they have two daughters*) and we do a lot together. I don't like being apart from - she's my soul mate."* I had a strong impression of this couple's relational style with each other as warm and complimentary and they openly discussed their support for each other. (28/1)

"We haven't been separated for a long time now. I would miss her very much. I am quite dependent on her especially now." Would you say practically or emotionally? "Both." (29/1)

Distant relationships

I labelled the final category of relating as “distant” as there was little evidence of engagement with each other or me. Denial was a significant aspect of this presentation, as can be seen in the following examples:

There seemed to be an emotional distance between the participant and her son who hardly spoke throughout the time I was there – he seemed ill at ease. The son made me a coffee and then retired to another part of the house. (10/1)

They seemed in step with one another but it was difficult to gauge as Mr G was so flat in affect and his responses were so minimal. (14.1)

This lady is something of an enigma in that I learned less of her in the three meetings than all the other participants that I met. Her husband seems to be the presenting “face” of this couple and she nestles behind him. He spoke continuously about himself and his role on the local medical practice board where he was a patient representative. It seemed very important to him – the status it gave him. He had very little to say about his wife or in conversation with her. (16.1)

On my second and third visits, Mrs C’s was son present. There did not seem to be a closeness between them. He seemed to know little of his mother’s “story”. (22/1)

The second example given above, of distance in the relationship, demonstrates the difficulty in reading the nuances of peoples’ relational styles as Mr G appeared to be extremely depressed, which may have accounted for the emotional flatness he exhibited and the distance between them.

7.2. Childhood Experiences

World War Two

I asked Ann if there anything that was potentially traumatic? "*The war*" - her husband was in the navy and she lived with the worry that she could get a telegram at any time to say he had been torpedoed. It was a difficult time to bring children up on her own – but you just had to get on with it. These statements were gleaned from Ann's disjointed account. Although I had asked her about a childhood trauma Ann had interpreted as a trauma to her and hence responded in this way, However, it is an example of the experience of WW2 and an example of her self-reliance.

MS: Were you ever worried as a child?

Ruth: "*I was worried about the war coming. I was 14 so I understood a lot of what was going on. I didn't want to be evacuated on my own*."

MS: Was there was anything else that might have affected how you turned out? *Mike: Outbreak of war. During the air raids even though but mum and dad were there - well dad was not there all the time because he was an air raid warden. They would be comforting but I was still frightened. I think that is why they decided that mum and I would come to Whitstable."*

MS: How do you think that affected you personally?

Mike: *"I think I became quite a nervous child*."

These extracts give a flavour of the ways in which people remembered their experiences of living through World War Two. This was also a time of separation for some, as illustrated below:

MS: Were any other separations that stand out in your mind?

Eva: "*Not as a young child no but when I was evacuated I didn't really understand why I had to be in Wales when my mum and dad and my brother were in London. I thought they didn't want me anymore. I know it sounds silly. It was awful, I missed home so much it made me ill and mum had to join me for the rest of the war.*

MS: Are there any other separations that stand out in your mind?

David: When I was sent away to school."

MS: How old were you?

David:*"Eight*."

MS: That's very young, do you remember how it felt?

David: *"I hated it, I cried myself to sleep every night for goodness knows how long and I dreaded the end of the holidays. Eventually I got used to it."*

MS: What is the first time you remember being separated from your parents?

Ruth: "*When I started school, which was difficult. I didn't like school but I don't remember my parents being sympathetic."*

MS: What is the first time you remember being separated from your parents? Roger: "*When I went to school – I didn't like it at first, I didn't like mum to leave. Mum would try and get me to go into the classroom, I wouldn't let her go and the teacher would come out and take me in."*

MS: Do you have a clear memory of that?

Roger:"*Not really just a vague m*emory

MS: Were you ever worried as a child?

Bella:*"Not at home but I worried at school.*"

When I prompted her on this she said that she was frightened of some of the teachers because they used to shout and hit the children who MS: In general, how do you think your overall experiences with your parents have affected your adult personality?

Sheila*: "Mammy's thumping."*

MS: When your mum was angry and hit you - that was difficult for you?

Sheila: "*It used to upset everyone"* looking at sister.

MS: Why do you think she behaved like that?

Sheila*"She couldn't control her temper – that's what daddy used to tell her."*

MS: Now I would like to ask you to choose five adjectives or words that reflect your relationship with your father, starting from as far back as you can remember in early childhood.

Kevin: *He wouldn't let me go out to play with other kids – had chores to do* first. It made me feel different from the other kids. He liked a drink too and *woe betide you if you got on the wrong side of him when he'd had a drink.*

MS:It sounds as if your relationship with your father was quite difficult?

Kevin:"*Yes, it was when I was little, it got better as I got older and we would go with him to football matches. Mum was kind when he was not around and they were quite close but as I got older I began hate his mother because she didn't stand up to him and protect me.*

MS: Can you think of a particular instance?

Kevin:"*One of my first memories is of learning to ride a bicycle – losing my balance and falling off and hurting myself, father was angry and told me I wasn't trying and mother said nothing even though my leg was bleeding."*

How old do you think you would have been? "*About five or so. I was terrified of my father throughout my childhood and was not close at all. He was a bully especially when he had been drinking, which was often. He was very unreasonable – you couldn't talk to him."*

MS: Do you have any memories of good times with your father?

Kevin:*"No, none at all."*

MS: Are there any other aspects of your early experiences that you think might have held your development or had a negative effect on the way you turned out?

Kevin: :*Yes, the way he treated me. I has been depressed on and off all my adult life and I blame my childhood for this.*

MS: In general, how do you think your overall experiences with your parents have affected your adult personality?

Kevin: "*I think it knocked my confidence. I think I could have done better at school but he kept telling me I was thick. I don't take risks – always play safe.*"

Penny described a number of incidents depicting mother's spitefulness against her. Would be sent to bed before her much younger brother as a random punishment. In mum's eyes she couldn't do anything right. Her husband broke in to confirm. Describes herself as always being afraid of getting it wrong. Dad was ok but didn't stand up to mum. Kept out of the way. Dad didn't take her part. She describes feeling let down by him and thinks that coloured her relationship with him as she grew up. Was angry in her teens. Mother once hit her on the head so hard that she burst her ear drum. The statement were made to me in general conversation rather than in response to questioning.

MS. In general, how do you think your overall experiences with your parents have affected your adult personality?

Penny: "*Having no affection.*"

Although there were some graphic descriptions of how some people believed their childhood experiences had affected them adversely, there was no direct evidence to support the notion that this influenced their attachment style or their ability to cope in their present situation. Of the four examples above, three were classed as having a secure attachment and the fourth was classed as dismissing/avoidant.

Of the group that experienced physical affection all but two were classified as being secure, whilst eight of the remaining fifteen who had no memory of physical affection, were also in the secure category

7.3. Case Study Protocol

Purpose of Protocol

This study will investigate the relationship between attachment styles and client engagement, perceived helpfulness and outcomes of a group psychosocial intervention as well as a quality of life rating. The study will be based on four consecutive cycles of a group intervention involving three separate groups of participants.

Questions

The questions this case study will address are: How does a memory group impact on people diagnosed with memory problems? Is there a relationship between attachment style and type of memory group offered? How has the group experience influenced the person's perception of their quality of life?

Does a psychosocial group intervention influence how a person who has recently been diagnosed with dementia, views their quality of life?

Does a person's attachment style affect their perception of the usefulness of a psychosocial intervention?

Introduction

The following theoretical framework will structure this case study. Over the last fifteen to twenty years there has been considerable research activity into the efficacy of a variety of psychosocial forms of treatment in enhancing the cognitive and emotional functioning of people with dementia (Pusey, Richards, 2001; Bender, Cheston, 1997). A further area of interest in considering the treatment of dementia is in determining the specific care that is most appropriate in relation to the individual's level of cognitive and emotional functioning (Beck, 1998; Sheard, 2004. There is some evidence to suggest that people with dementia who experience regular social interaction are less likely to deteriorate as rapidly as those whose social interactions are minimal (Gurka; Marksteiner, 2002). If social interaction is shown to be a factor influencing (cognitive) functioning there are significant implications for the treatment offered to people with dementia and their families.

Therefore, research focus has moved away from the traditional medical model of dementia to a dialectical bio psychosocial model of the experience and progression of the condition. This change in thinking has influenced the way in which people with dementia are treated and cared for resulting in an increasing emphasis on their emotional needs. The work of (Kitwood, 1997), (Yale, 1995 cited in Cheston, 2002) and others, has been influential with clinicians adopting their ideas and establishing support groups for people with dementia. More recently there has been greater emphasis on the importance of relationships for people with dementia, and a focus on supporting them in forming and sustaining meaningful relationships (Adams, 1999), (Sheard, 2004). A further area that has received significant attention from researchers in recent years is the field of Attachment Theory. Bowlby (1969) sets out the ways in which he understood the significance of the attachment bonds an infant makes to the mother. He describes two principal styles of attachment: secure or insecure with sub-divisions within these. Bowlby argues that the type of attachment that is formed influences the relationships we make for the rest of our lives. This theory has become influential in considering the emotional experience of people across the life span including the difficulties people encounter if their attachment style is more or less insecure. (Miesen 1992) describes the ways in which an understanding of attachment needs of people with dementia can be used to alleviate distress and help the relatives to have a better understanding of what is happening in their relationship with their spouse/relative.

Data collection procedures

Data will be collected from various sites of the Kent and Medway Partnership Trust East and Coastal Older People's Service. The contact person will be Alison Culverwell, Head of the Service. Data will also be collected at participants' homes.

Data collection plan

The first visit will be to give participants detailed information of the study and to obtain informed consent. The participant information sheet will be covered in detail. The second visit will follow approximately one week after informed consent has been obtained. The final visit will follow the group intervention.

At the time of the first visit participants will have received a participants information letter and will have verbally agreed to my visit. The purpose of this visit is to explain my research project and the reasons for doing it, and to obtain informed consent. Basically, I will say: "As part of your treatment you have been offered a place in a group. My research is to look at how useful you find the group. I am also interested in whether you see yourself as a sociable person or someone who prefers their own company and how you rate your quality of life" I will invite questions from the prospective participant and their relative. I will also inform them that I will be a part of the group as an observer.

I will return in approximately one week to collect the pre intervention measures which include: Attachment histories taken through semi-structured interviews using a measure of attachment type, based on Hazan and Shaver's (1987, 1990) measure of adult attachment, attachment questions, The Hierarchy of Relationship Involvement Exercise (Bateman & Fonagy (2006). The DEMQOL measure will also be administered at this time as well as the perceived helpfulness questionnaire. Following the group the Hazan & Shaver questions, the DEMQUOL measure and the perceived helpfulness questionnaire will be repeated.

Preparation prior to site visits

Identify the admin person in the Older Age Service who I will liaise with to obtain participants' details. Be absolutely conversant with case study protocol to ensure that I am being consistent with each participant.

The questions I have identified for myself in terms of what is to be expected at the home visits

What was the set up when I entered the house? Who was present? What was their proximity to each other? How was I received?

Who asked questions and who answered mine?

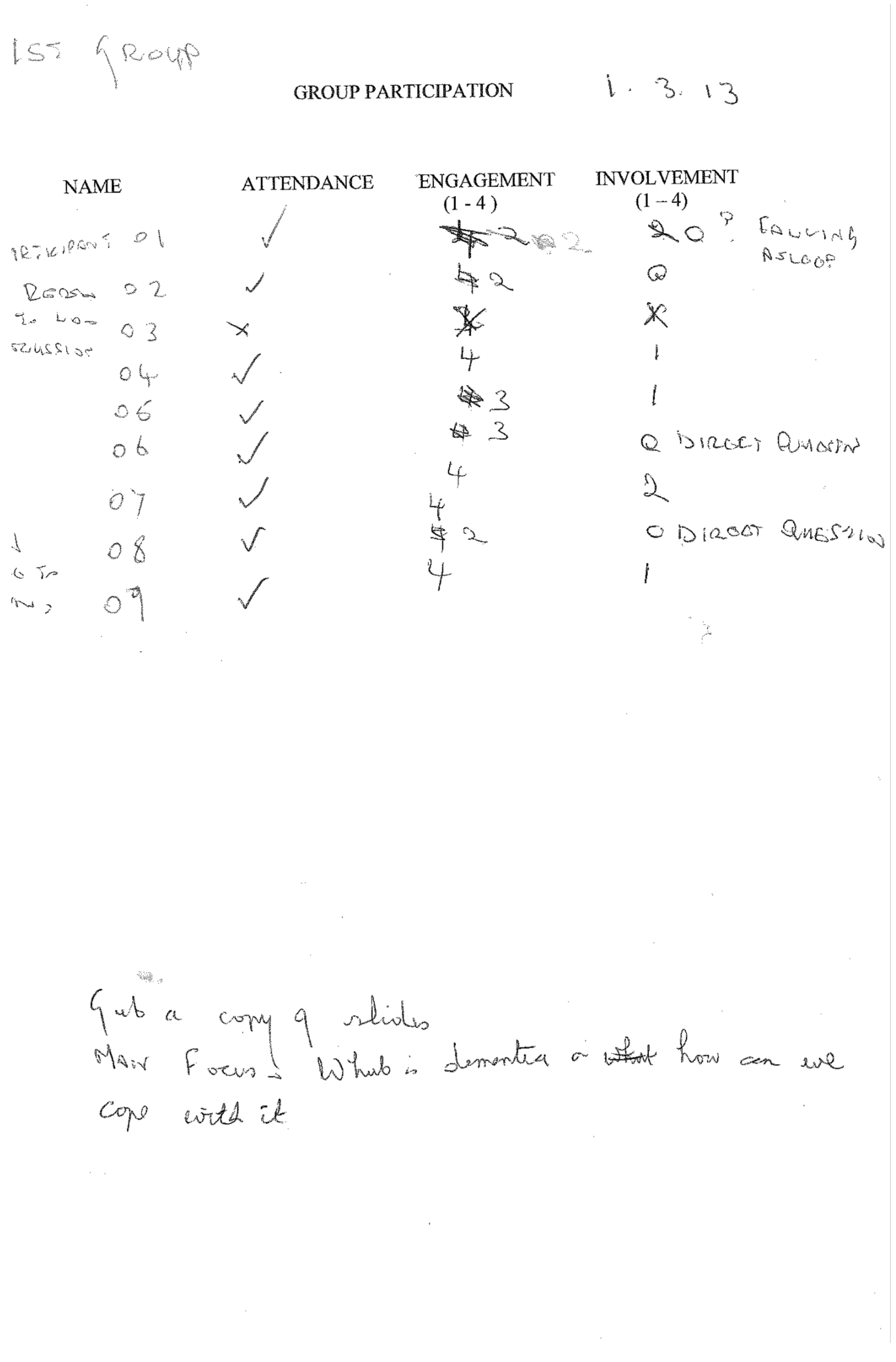
Did the participant speak for themselves or did the spouse/carer take the lead?

How did they relate to one another?

If I am offered a cup of tea and I am left alone with the participant I will observe how he/ she relates to me? Are there any obvious signs of anxiety/distress/discomfort? If so what changes occur when the spouse/carer return? I will make these observations on each of my visits particularly noting any changes to the previous visit. Specifically, How I was received? warmer/recognised/less cautious or not. On the second visit I will ask the spouse/carer if I can complete the questionnaire alone with the participant and observe whether they are comfortable/uncomfortable, anxious/not anxious. Any signs of distress or confusion. The same procedure will be enacted on the third visit.

8. Observations/Notes

8.1. Completed Group Observation Forms



1ST GROUP

GROUP PARTICIPATION 1. 3. 13

NAME	ATTENDANCE	ENGAGEMENT (1 - 4)	INVOLVEMENT (1 – 4)
PARTICIPANT 01	✓	~~4~~ 2 2	~~2~~ 0 ? FALLING ASLEEP
REASON 02	✓	~~4~~ 2	0
TO LOW 03 SESSION	✗	~~X~~	X
04	✓	4	1
06	✓	~~4~~ 3	1
06	✓	~~4~~ 3	0 DIRECT QUESTION
07	✓	4 4	2
↓ 08 GO TO	✓	~~4~~ 2	0 DIRECT QUESTION
N? 09	✓	4	1

Got a copy of slides
Main Focus → What is dementia & ~~what~~ how can we cope with it

2nd Session

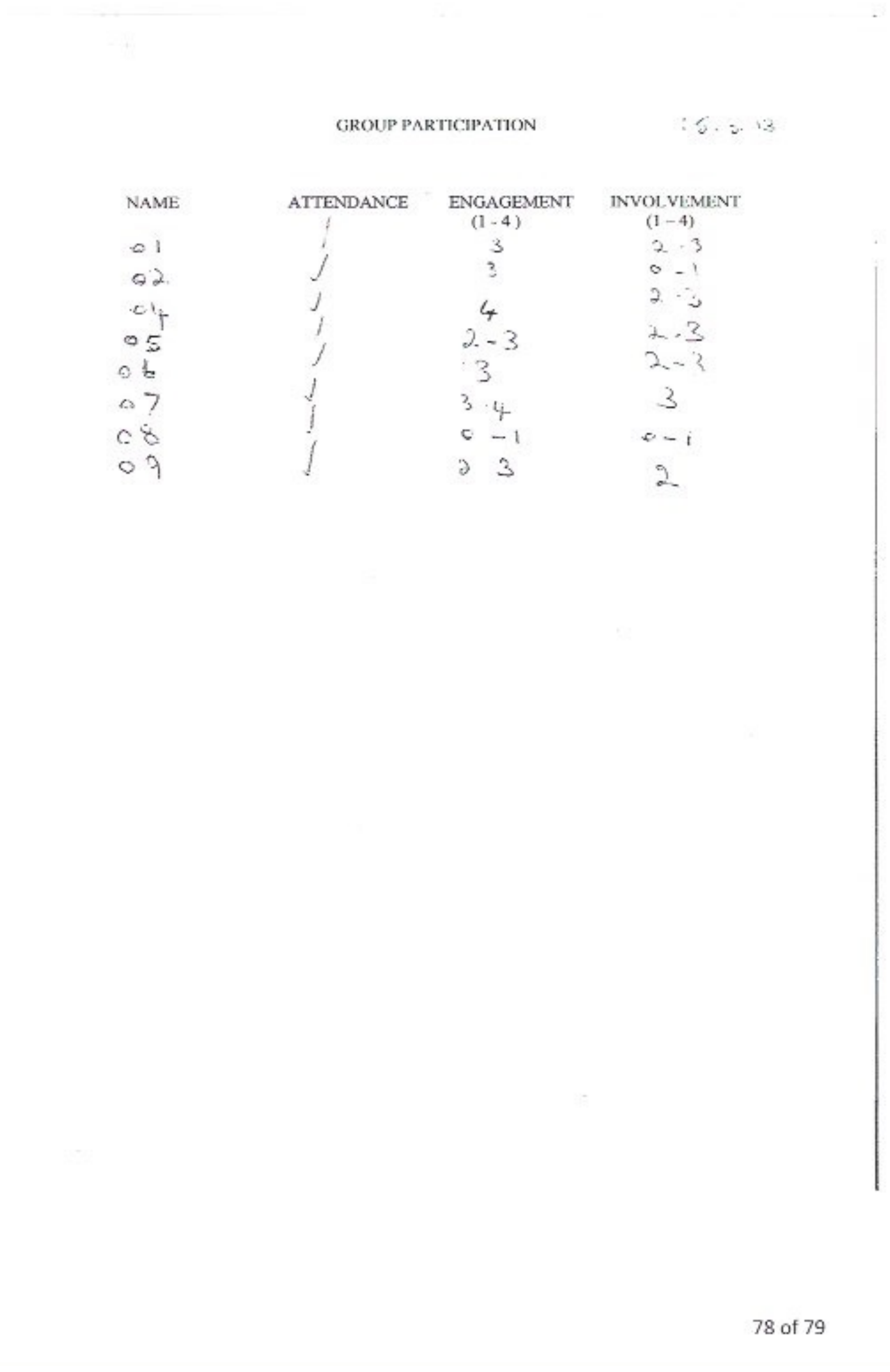
GROUP PARTICIPATION

8 – 3 – 13

NAME	ATTENDANCE	ENGAGEMENT (1 - 4)	INVOLVEMENT (1 – 4)
01	✓		1 – 2 Sleepy
02	✓	2	0
~~03~~	✗		—
04	✓	3/4	3/4 Active & attentive
05	✓	2/3	
06	✓	2	2 mostly listening to others
07	✓	3/4	3
08	✗	—	—
09	✓	3	3
~~10~~	✗	—	—

04 Good interjection spontaneous

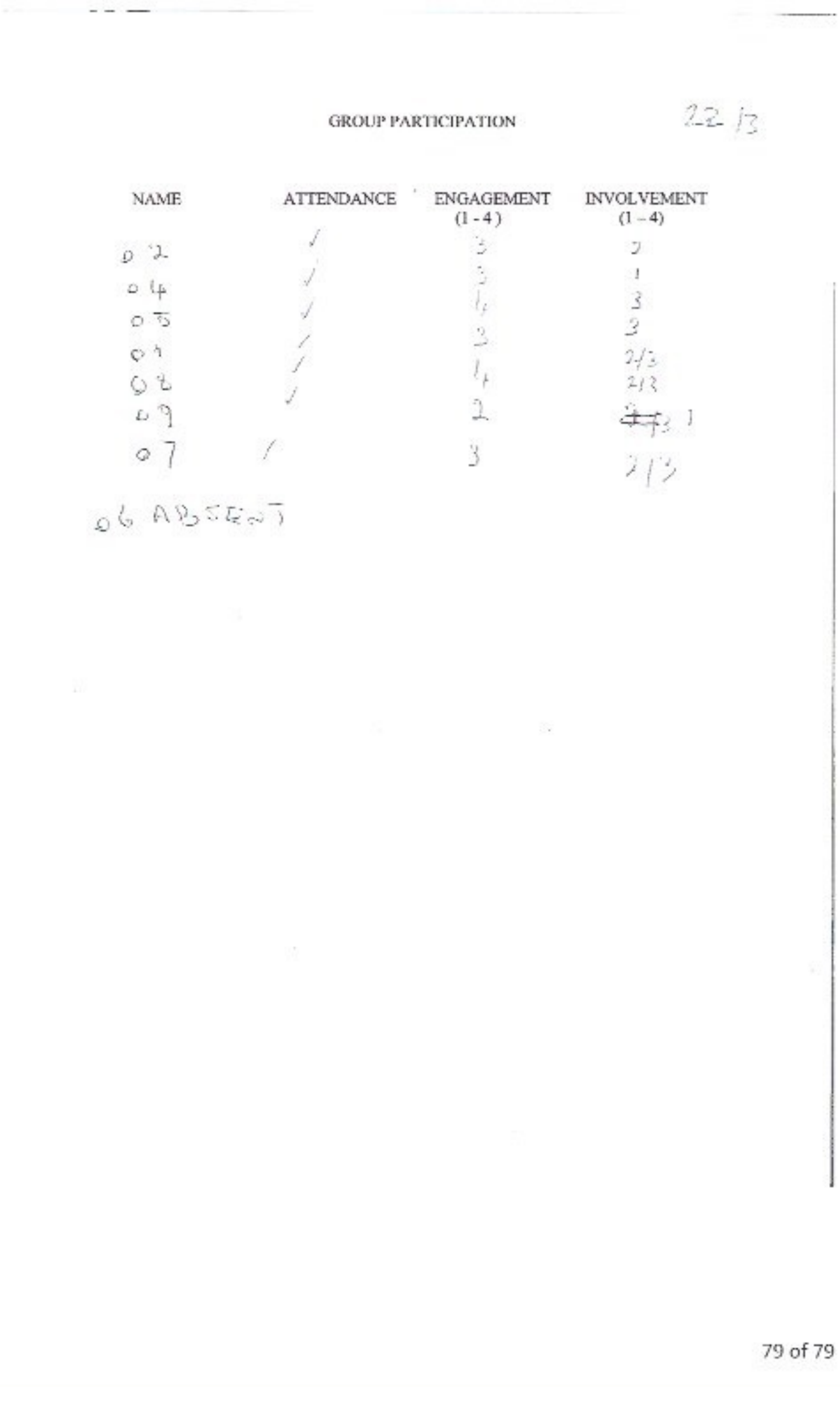
01 – 05 sat together quietly and other wordy



GROUP PARTICIPATION 16.5.13

NAME	ATTENDANCE	ENGAGEMENT (1 - 4)	INVOLVEMENT (1 – 4)
01	✓	3	2-3
02	✓	3	0-1
04	✓	4	2-3
05	✓	2-3	2-3
06	✓	3	2-3
07	✓	3-4	3
08	✓	0-1	0-1
09	✓	2 3	2

78 of 79



GROUP PARTICIPATION

22/3

NAME	ATTENDANCE	ENGAGEMENT (1 - 4)	INVOLVEMENT (1 – 4)
02	✓	3	2
04	✓	3	1
05	✓	4	3
01	✓	3	3
08	✓	4	2/3
09	✓	2	~~2/3~~ 1
07	✓	3	2/3

06 ABSENT

79 of 79

8.2. Group Observation Notes

Session 1 - information giving – memory
Table 1
05,02.07.04.
06 conversed with husband
2 conversations developed forming 2 separate groups.
Family couples talking to each other
05 engaged in discussing leaflet with partner
07 talking between each other
02 no input but listening to husband in conversation with 05
04 engaged with wife and convenor
05 engaging with Julia and 02 who doesn't speak
07 not mixing with rest of table
NO GENERAL DISCUSSION ON THIS TABLE

Session 2 - Split Groups
People with dementia/carers. Carers further split into spouses/children
asked to begin by introducing themselves
Table 1
02, 05. 01
02 and 05 talk together 02 amused at male's jokes 05 did not seem amused and talked about differences in her lifetime. 02 spoke about her experiences when she was living in London
01 very engaged with a person not part of the study. However there was little dialogue – rather a monologue and I felt it was the standard story she has also given me. This conversation continued for most of the allotted time. Nice to see 01 so animated but I suspect it is because Rose is a good listener and very polite.
There were two clusters on this table one around each convenor. I thought the student did well to try and engage with the three women but the male convenor allowed himself to be caught up with the two men.
02 responding to 05 lots of smiles
01 continues to talk about her life with a father and a husband in the military and the travels that ensued from that with the rest of the women on the table listening R doesn't get a word in
01 talked about grandchild Emily tried to draw her out on what she did well re grandchildren – a 3 way conversation developed 01 smiling animated
Emily tried to draw out 02 – rather limited response
05 much more able to expand on her day to day experience

Session 3 - 15.3.13
Pre group presentation
05 looking disinterested

Plan for today: What influences memory?
Table 1
04, 05, 02
02 husband speaks for her – she responds to Elizabeth's questions with husband interrupting
04 wife speaks for him
main participants are carers.
05 participates very little but is listening to others

General Discussion:
All attentive but no interaction 08, seemed to be falling asleep and fiddling with her handbag
05 had forgotten her hearing aid

Relaxation exercise:
05,01,07,04,06 trying to go with it. 02 looks to her husband 08 minimally 09 gradually

Tea break;
group of 05, 04. 07 6 chatting together

Split groups Dementia group 1
09, introduces herself in quite a lively manner
01 responds – very attentive
05 minimally – name only - struggling to hear (left her hearing aid at home!) losses concentration looks bored and is playing with scarf.
All attentive to each other
05 talks about living with her husband - would not like to live with her family (daughters)
Denis talks to 05 but she does not seem to want to be engaged
convenor focuses on two people only initially but goes on to focus on 05 & 02 gradually
Limited spontaneity in this group.

Fourth Group 22nd March 2013

Activity on the tables - lots of cards laid out depicting various activities

Table 1

Table 2

05,04,06, 02

05 picking out her own cards – immediately more involved this week

06 also picking out her own cards – involved laughing

02 looking but not active - involved with husband – smiling but peripheral

10.30 speaker everyone listened attentively to the speaker who was someone with a diagnosis of dementia talking about life after a diagnosis of dementia.

all filling in evaluation questionnaire – only 08 unable to complete

When everyone dispersed it was very lively – mostly everyone thanking the staff and wishing other group members farewell.