Volume One

Attachment, Caregiving and Coping in Daughters Caring for
their Mothers with Dementia

Lisa Whitehouse
D. Clin. Psy. 2000

University College London

ProQuest Number: U642947

All rights reserved

INFORMATION TO ALL USERS
The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript
and there are missing pages, these will be noted. Also, if material had to be removed,
a note will indicate the deletion.
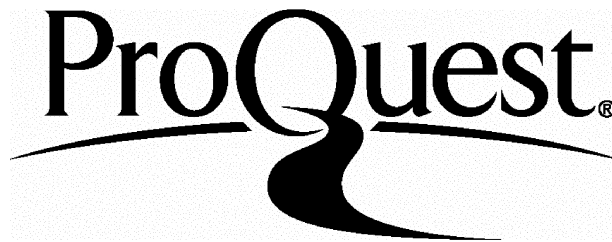
ProQuest U642947

Published by ProQuest LLC(2016). Copyright of the Dissertation is held by the Author.

ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

"So the past goes on re-arranging itself in surprising new ways. It is not over, never finished with. It keeps returning. And always to surprise us".

Linda Grant, (1998)

from *"Remind me who I am, again"* - autobiography of a daughter caregiver

Table of Contents

Chapter Three: Results of the quantitative data analyses   67

Chapter Four: Results of the qualitative data analysis   83

Chapter Five: Discussion   98

Acknowledgements

I would like to thank the following people for their help and support in completing this thesis:

The caregivers who generously gave up their valuable time to talk to me. Their willingness and openness in answering so many questions was outstanding.

Dr Howard Steele for the time and commitment he put into reading draft copies of my chapters and for the coding of the Adult Attachment Interviews.

Ms Emily Phibbs for showing me the research ropes and her invaluable support from start to finish.

Mark, my husband, for being there during the course of my clinical training. I couldn't have done it without his support and his ability to see the brighter side of life.

Finally, to my parents; for their advice and support in helping me get where I am today.

Abstract

Caring for a relative with dementia is thought to be one of the most stressful and disruptive life events in the family life cycle (Zarit and Edwards, 1996). The effects of caring for a relative with dementia are well documented, with some caregivers coping well and others developing psychological difficulties (Zarit and Edwards, 1996). However, little is known about the risk and protective factors involved for individual caregivers.

Caring for a mother with dementia is a task primarily undertaken by daughters (Stone and Kemper, 1989). Past research has shown that the kin relationship between caregiver and care recipient affects the experience of family caregiving (Li, Seltzer and Greenberg, 1999). This study set out to investigate whether the quality of the relationship between daughters and mothers throughout the life span influences how daughters cope with caring for their mothers when they develop dementia.

As part of a larger study, thirty one daughters were interviewed using the Adult Attachment Interview (AAI: George, Kaplan and Main, 1996). The interviews were rated according to Main and Goldwyn's (1994) standardized classification system. Daughters' reflective functioning was also rated using the Reflective Functioning Scale (Fonagy, Target, Steele, and Steele, 1998). The participants completed a series of self report questionnaire measures including the Clinical Dementia Rating Scale (Hughes Berg, Danziger, Coben, and Martin, 1982), the Relative Stress Scale (RSS: Greene, Smith and Timbury, 1982), the General Health Questionnaire (GHQ-28:

Goldberg, 1978) and the Social Support Questionnaire (SSQ: Sarason, Sarason, Shearin and Pierce, 1987). Additionally, some of the daughter caregivers were asked how they understood their relationship with their mother to have influenced their caring role and data from the responses to these questions was analysed qualitatively.

It was predicted that daughters with secure attachment histories would be less psychologically distressed as measured by the RSS and GHQ-28 than daughter caregivers with insecure attachment histories. Using overall coherence as an indicator of attachment security, a relationship between overall coherence and psychological distress was not found. It was also predicted that high reflective functioning would serve as a protective factor from psychological distress. Conversely, it was found that daughters with higher reflective functioning scores were more psychologically distressed than daughter caregivers with lower reflective functioning scores.

The qualitative analysis revealed four clusters of themes. These were change and loss, motivational influences, coping and support and caring within the context of the wider care system. The limitations of the research design, the clinical implications of the findings and future research directions are discussed.

Chapter One

Family caregiving in dementia: The use of stress and attachment

theories in understanding caregiver burden

Overview

The importance of individual differences in personality in adaptation to life stresses has been emphasised by both theory and research in psychology. Caring for a relative with dementia has been identified as one of the most stressful events in the family life cycle (Zarit and Edwards, 1996). Most research in this area has concentrated on identifying stresses of family care and factors which are associated with individual differences in the experience of stress (Zarit and Edwards. 1996).

In this chapter, the stressors associated with caring for a person with dementia are discussed and the Aneshensel, Pearlin, Mullan, Zarit, and Whitlatch (1995) model of the stress process is outlined. Attachment theory and it's relationship to caregiving behaviour and stress is presented as well as a discussion about how attachment theory may help to understand the caregiving relationship between daughters and their mothers who are suffering from dementia. The possible role of attachment theory in explaining differential outcomes in the daughter's experience of stress is also discussed. This chapter will also briefly introduce qualitative research methodology and the advantages of using this research methodology in conjunction with quantitative methods. The chapter will finish with the aims and objectives of the study and the research hypotheses.

What is dementia?

The Diagnostic and Statistical Manual IV (DSM-IV; American Psychiatric Association [APA], 1994) defines dementia as a disorder involving impairments in memory, plus additional impairments in language, motor abilities, perception, judgement and reasoning which are sufficient to inhibit social and/or occupational functioning. Several disorders are grouped together under the label of dementia because they share the same cluster of symptoms. Among the most frequent causes of dementia are Alzheimer's Disease and Multi-infarct or Vascular dementia (Aneshensel et al, 1995). Alzheimer's Disease accounts for 50-75% of all cases of dementia (Vetter, Krauss, Steiner, Kropp, Moller, Moises, and Koller, 1999).

Estimates of the prevalence of dementia vary from one study to another. This is mostly due to the absence of clear markers to identify the underlying disease process (Aneshensel et al, 1995). Most studies however, point to a prevalence rate of between 4 and 7 % of the population over the age of 65 years for moderate to severe dementia (Aneshensel et al, 1995). The prevalence of dementia increases with age, with a prevalence rate of 20% or more for the population aged over 85 years (APA, 1994).

Dementia is frequently described as a progressive and irreversible disease. However, the rate of progression through the disease varies. Thus, severe disability and death may occur within a few years of onset. More typically, deterioration is gradual and patients survive from 10 years to as long as 20 years post diagnosis (Aneshensel et al, 1995).

The number of very old people in the British population is increasing rapidly and given the increased prevalence of dementia in the older age groups, it is therefore likely that the number of people with dementia are likely to increase (Bledin, MacCarthy, Kuipers and Woods, 1990). Furthermore, statutory facilities and services are unlikely to meet the demand and thus, increasing numbers of people in the community are going to find themselves carers of an elderly relative or parent (Bledin et al, 1990).

The context of family caregiving

It is widely recognised that the families of people with dementia provide the bulk of dementia care in the United Kingdom and in most other countries (Woods, 1997). Various researchers have found that over three quarters of the help received by impaired elderly is provided by family members (Aneshensel et al, 1995). It is well established that caring at home for somebody suffering with dementia can be a very disruptive and difficult task (Lee, 1999, Zarit and Edwards, 1996).

Who are the family caregivers?

The responsibility of caring for a family member falls most frequently on women (Lee, 1999), with approximately 70% of caregivers being women (Orbell, 1996). This has been explained in a number of ways including normative expectations of gender roles and filial obligations and economic factors (Aronson, 1992, Lee, 1999). The preponderance of female caregivers can also be linked to the suggestion that there is a genetic bias for females throughout development to be somehow more predisposed towards becoming attached and relying more on attachment figures than males and thus, more predisposed toward caregiving (Ainsworth, 1991).

Turning to kin relationships, caregiving for elderly individuals with dementia is a task primarily fulfilled by daughters and/or spouses. Adult children who provide care for an elderly parent are the largest single group of family caregivers, representing 37% of all informal caregivers for the frail elderly (Stone, Cafferata and Sangl, 1987). In line with research findings that the majority of caregivers are women, daughters outnumber sons in caregiving role by a ratio of three to one (Stone and Kemper, 1989).

Past research has shown that the kin relationship between caregiver and care recipient affects the experience of family caregiving (Li, Seltzer and Greenberg, 1999). The kin relationship between caregiver and care recipient makes a difference in terms of the feelings of commitment and obligation towards the caregiving role and how difficult or distressing this role will be for the caregiver. In turn, feelings of commitment and obligation influence how long someone is willing to provide assistance (Zarit and Edwards, 1996).

The impact on daughter caregivers, compared with other caregivers, is thought to differ in important ways. For example, female caregivers of relatives with dementia are reported to show higher levels of depression, distress and strain than other caregivers in similar situations (Livingston, Mandela, and Katona, 1996, Morris, Morris and Britton, 1988a, 1988b). Furthermore, daughter caregivers also appear to experience more subjective stress and guilt (Phibbs, Woods, Chaudhury, Walker and Rai, 1997). Nonetheless, the daughters of many parents with dementia appear to cope well. Additionally, the gender of the parent has been shown to affect the level of

----

stress in parent-child relationships, with more conflict in mother-daughter dyads than

other parent-child combinations (Seltzer and Ryff, 1996). The factors which

distinguish these different groups have yet to be established.

The decision to become a caregiver

There are many reasons why an individual may take on a caregiving role. These

reasons include to fulfil an internalised obligation, no viable alternative caregiver,

institutional care is either unavailable or unaffordable, one's parent/partner needs it or

one is convinced that if the shoe as on the other foot, the caregiver would be the

beneficiary of the care recipient's concern, and the emotional attachment and the life

long history or structural composition of relationships (Aneshensel et al, 1995).

Whatever the reason for caregiving, the decision to become a caregiver is likely to be

closely bound by the biographies of caregivers and their relationship with their family

member over many years. In the case of child-parent caregiving, the selection of the

caregiver is not only regulated by the quality of the relationship, but also by powerful

customs dictating circumstances under which one is obligated to provide care and one

is excused (Aneshensel et al, 1995). As a result of early socialisation to the norms of

expected filial behaviour, adult children come to feel that it is their duty or

responsibility to help their elderly parents. Research evidence suggests that such a

conception of filial obligation is related to adult children's behaviour and to burden

(Circelli, 1993).

Despite the wealth of literature on caregiving and the experience of caregiving, much

of the literature has either focused upon either spousal relationships or treated

caregivers as a homogeneous group. As there is research to suggest that kin relationships affect the experience of caregiving and to suggest that the closer the blood or role relationship, the greater the impact on the mental health of the caregiver (Morris et al, 1988b), it seems appropriate to investigate aspects of the caregiving role in relation to specific kin relationships.

The caregiving role

Caregiving can be defined as the interactions in which one family member is helping another on a regular basis with the tasks that are necessary for independent living (Zarit and Edwards, 1996). This includes the functional or instrumental tasks of independent living such as shopping, cooking and managing finances and, personal tasks such as bathing, dressing and toileting. In the case of a person with dementia, the care recipient may also need some on going supervision. Caregiving constitutes a change in ongoing patterns of exchange in response to a new disability, which results in one or more people providing regular help to the care recipient (Zarit and Edwards, 1996).

Some patterns of help may develop gradually over many years, thus making it difficult to establish when caregiving began. Many caregivers enter the role long before they apply the label of caregiver to themselves (Aneshensel et al, 1995) and thus people will identify themselves as caregivers in different ways and in response to different situations. Aneshensel et al (1995) suggest that the identification of oneself as a caregiver and the socialisation into this role may be a major transition for some families, with implications for how they subsequently adapt to the demands placed upon them.

Caregiving is a complex, muti-faceted process (Zarit and Edwards, 1996) and the

context in which the caregiving role is currently enacted is determined by the nature

of the needs and demands of the family member who receives care, by the other roles

and responsibilities that compete for the caregiver's time and energy, and by the

availability of support to assist the caregiver in negotiating this role (Li et al, 1999).

Dementia is a condition that diminishes memory, impairs cognitive processes and

reduces internal behavioural controls and thus, as the symptoms advance, patients

require increased supervision and assistance. The relentless demands associated with

caring for a relative suffering from dementia can stretch and overwhelm the adaptive

capacities of the family (Aneshensel, Pearlin and Schuler, 1993). As Aneshensel et al

(1995) describe;

> *"the degenerative and irreversible course of Alzheimer's Disease and*
>
> *other late life dementias typically results in family caregivers*
>
> *becoming increasingly engulfed by the needs of impaired relatives.*
>
> *The time and energies of caregivers come to be consumed in this*
>
> *single, enveloping role. Absorption into caregiving, of course is often*
>
> *at the expense of the activities and relationships across which their*
>
> *lives had been previously spread" (p.2).*

Caring for a person with dementia is assumed to be more difficult and burdensome

than caring for others suffering with other chronic conditions or illnesses. This in part

has been explained by the characteristic cognitive, behavioural and affective losses

associated with the disease (Light, Niederehe and Lebowitz, 1994), the disruption the

illness has on the relationship between the caregiver and the care recipient and the far

reaching consequences upon the caregivers' lives the caring situation has (Morris et

al, 1988b). Woods (1989) has likened the experience of being a caregiver for a

dementia sufferer to a bereavement and has thus, highlighted loss as a major feature of

the life of a caregiver.

In a large study involving over 1000 family carers, Ory, Hoffman, Yee, Tennstedt,

and Schulz (1999) found that dementia caregivers spend significantly more hours per

week providing care than non dementia caregivers. Dementia caregivers also

reported greater impacts in terms of employment, caregiver strain, mental and

physical health conditions, time for leisure and other family members and family

conflict, which were over and above the intensity of caregiving. Furthermore, the

nature of the care demands, which includes the physical requirement of providing care

and the daily management of a relative who has functional, behavioural and cognitive

impairments has been shown to be related to caregiver distress. Research has shown

that greater caregiving demands are associated with elevated caregiver burden

(Aneshensel et al, 1995).

Kitwood (1997) in his pioneering work on dementia care, highlighted the more

intrapsychic and dynamic aspects of caring for someone with dementia. He suggested

that caring for someone with dementia may be difficult as it can activate universal

fears about ageing and death which in turn, can impede caregiving. Furthermore, he

suggested that all caregivers, whether informal or formal, have a script for becoming a

caregiver which may derive from early childhood experiences. Kitwood (1997)

17

acknowledged that frequently in caregiving, the relationship with a dementia sufferer arouses emotional memories of other previous relationships. With regards to family relationships, Kitwood (1997) specifically writes that the psychodynamics of long term relationships are likely to continue and, in some cases, in an exaggerated and noxious form thus, hindering caregiving. These dynamic aspects of relationships may be particularly poignant for adult children now caring for the very person who cared for them as a child.

The concept of caregiver burden

Much of the research conducted on family caregiving has been concerned with identifying the stresses of family care and the factors which are associated with individual differences in the experience of stress (Zarit and Edwards. 1996). Research has specifically focused on the concept of caregiver burden. This is a multi-dimensional construct which includes the physical, emotional, social and financial costs to the caregiver (Lee, 1999). Most research on caregiving concludes that caregiving is associated with significant burden, although the evidence on physical health and preventive health behaviours is more mixed (Lee, 1999). Summarizing the research evidence on the negative effects of caregiving, Lee (1999) concludes that caregiving has been associated with physical and emotional strain, increased psychiatric symptoms and illness, increased physical symptoms, increased health care and medication usage, emotional exhaustion and reduced leisure time.

With regards to psychiatric symptomatology, the prevalence rates for psychiatric disorder as measured by the General Health Questionnaire for dementia caregivers range from no difference from non-dementia caregivers to 68% (Morris et al, 1988b).

Many studies report a level of depression higher than that accepted for a community sample (Morris et al, 1988b). This has been attributed to several factors including behaviour problems exhibited by the relative, role overload, role captivity, sense of mastery (feeling in control), finding personal meaning in caregiving, coping strategies and social support (Alspaugh, Zarit, Stephens, Townsend and Greene, 1999, Aneshensel et al, 1995, Li et al, 1999, Noonan and Tennstedt, 1997).

Research has suggested that daughter caregivers may experience more guilt than other family caregivers (Phibbs et al, 1997). Guilt may be thought of as the emotional state produced by the internal recognition of a violation of internalized moral standards (Woods, 1997). Woods (1997) suggests that guilt in family caregivers arises in the context of a long-standing history and will be influenced by the caregiver's propensity for self-blame and the relationship dynamic. He also suggests that a substantial proportion of caregivers will experience guilt in relation to their caregiving.

Reviewing the literature on the emotional stresses experienced by caregivers, Morris et al (1988b) concluded that there were a number of mediating variables affecting strain. These included the meaning carers attribute to the caregiving situation, the quality of the relationship to the dementia sufferer, the coping strategies employed by the caregiver and the availability of both formal and informal support. It is to understanding the stress process and the influences of mediators to which we now turn.

Understanding caregiving stress - the stress process model

Understanding caregiving and it's consequent strains has been considered using theories of stress and adaptation (Zarit and Edwards, 1996). One such approach has been the stress process model (Aneshensel et al, 1993, Aneshensel et al, 1995). Two important concepts form the basis of this model; caregiving as a career with a number of different stages and the stress process. The model consists of four factors which are stressors, mediators, outcomes and background or contextual factors. The basic model can be seen in figure 1.1 below.

Background and contextual factors
e.g. kin relationship, relationship quality, socioeconomic status

Primary Stressors; Objective
e.g.supervising relative, physical care tasks, incontinence

Primary Stressors; Subjective
e.g. role overload, loss of relationship, role captivity

Secondary Stressors: Role strains
e.g. family conflict, constriction of social/lesisure activities

Secondary Stressors: Intrapsychic strains
e.g. erosion of sense of mastery, erosion of self-concept

Outcomes
e.g. psychological well-being physical health

Mediators
e.g. social support coping strategies

Figure 1.1: Stress process model of caregiving (adapted from Zarit and Edwards, 1996)

Additionally, two concepts are important in understanding how well a caregiver copes with their caregiving role. These are stress proliferation and stress containment. Stress proliferation refers to the encroachment of care-related stress into areas of life previously insulated from hardship whereas stress containment refers to the regulation or control of the impact of care-related stressors (Aneshensel et al, 1995).

The model suggests that the stress process is driven by two major types of stressors; primary and secondary stressors. Stressors refer to the conditions, experiences and activities which caregivers find problematic. Primary stressors are made up of the objective demands and tasks anchored in daily care such as supervising the patient, performing physical care, and carrying out instrumental tasks such as paying bills (Anesehensel, et al, 1993). The objective primary stressors most likely to be considered a problem are incontinence, over demanding behaviour and the need for constant supervision (Morris et al, 1988b).

Primary subjective stressors centre around the caregiver's appraisal of how difficult they find the tasks of caring. Aneshensel et al (1995) have identified feeling overloaded by caregiving responsibilities, the loss of the relationship with the other person and feelings of being captive in the caregiver role as key variables falling into this category.

Secondary stressors develop or intensify as caregiving continues through time. They do not directly involve the tasks of providing care but emerge as problems in other social roles, network relations and feelings about the self. Among the secondary

---

stressors commonly experienced by carers are economic hardship, family conflicts, constriction of social and leisure activities and friction with work responsibilities. Other secondary stressors involve painful intrapsychic dislocations, including the erosion of a sense of mastery, doubts about one's confidence and feelings that one has become captive of an unwanted role (Aneshensel et al, 1995). These hardships may generate psychological distress among caregivers and/or lead to the institutional placement of the dementia sufferer.

Another source of stress is the gradual absorption of a person into a caregiving role (Aneshensel, et al 1993). Long before family members became caregivers they were in relationships characterised by mutual caring and reciprocal exchanges of affection and assistance. However, as the dementia progresses these qualities become less mutual and more unilateral. Thus, relationships undergo a complete metamorphosis of role-related expectations, obligations, and norms as adult autonomy is replaced by patient dependency (Aneshensel et al, 1993).

While the stress model assumes that there are multiple influences in determining, and indicators of, outcome, it focuses exclusively on an individual caregiver's coping mechanisms. The model rarely recognizes or explores positive outcomes. More importantly, care recipient characteristics are often considered to be stressors which loses sight of the dyadic relationship between caregiver and recipient, as well as other important relationships. Relationships are multi-dimensional, include past and present interactions and occur within particular cultural and historical contexts (Yates, Tennstedt and Chang, 1999).

The quality of the caregiver- care recipient relationship

The quality of the relationship between the caregiver and the care recipient has been considered as a mediator of caregiver burden. It seems that within the relationship, the closer the emotional bond, the less the strain (Morris et al, 1988a). The quality of the relationship has been found to be related to problematic behaviours in the dementia patient and the caregiver's sense of role overload and depression (Yates et al 1999).

The quality of the relationship with the dementia sufferer is likely to be closely associated to the relationship prior to the onset of dementia and may have an important impact on the caregiver's ability to find meaning from the caregiving relationship (Morris et al, 1988a, Morris et al, 1988b). The manner in which caregivers attribute meaning to their situation may in turn influence their vulnerability to stress and emotional strain.

Caregiving strain has been associated with relationship difficulties as indicated by simple ratings of the quality of the pre-morbid relationship (Morris et al, 1988) or ratings of expressed emotion in caregivers (Bledin et al, 1990, Gilleard, Belford, Gilleard, Whittick, and Gledhill, 1984, Gilhooly & Whittick, 1989, Wagner, Logsdon, Pearson and Teri, 1997). For example, Bledin et al (1990) found that daughter caregivers who scored high on a measure of expressed emotion were more likely to report increased levels of strain and distress compared with daughters who scored low on the measure of expressed emotion. Those scoring high on expressed emotion were also less likely to have siblings, which raises questions about the nature of the

---

relationship between only children and their parents and the extent to which early

patterns might persist into later life (Bledin et al, 1990).

The ratings of the pre-morbid relationship suffer from charges of being overly reliant

on retrospective report, and of reducing a complex dynamic to single ratings. The

expressed emotion measure tends to reflect the speaker's perspective on the current

relationship, as opposed to providing a comprehensive picture of the speaker's

thoughts and feelings concerning the history of the relationship. This latter focus is

central to recent advances in attachment theory and research which have provided

evidence relevant to John Bowlby's claim concerning the cross-generational

transmission of attachment patterns (Bowlby, 1973), i.e. that social learning is as

important as genetic inheritance.

Social support

Thoits (1986) conceptualized social support to include all of those activities

performed by others that help an individual to manage a stressful encounter. With

regards to caregiving, social support may either be expressed in the form of the direct

provision of tangible caregiving assistance or through the expression of concern and

compassion for the caregiver (Li et al, 1999).

Caregiver research demonstrates that social support plays an important role in the

caregiving process (Rapp, Shumaker, Schmidt, Naughton and Anderson, 1998). In

general, social support has been found to be associated with depression, with lower

support being associated with greater depression (Bodnar and Keicolt-Glaser, 1994).

Social resourcefulness is one of the many coping resources pressed into service by some people when acute and chronic demands threaten to disrupt their psychological or social equilibrium (Rapp et al, 1998). How people request, direct and maintain social support in times of need may therefore be important. Rapp et al's (1998) findings are consistent with idea that social resourcefulness leads to social support and support in turn, enhances well-being. They found that social resourcefulness was significantly associated with social support and well-being.

However, some researchers (e.g. Fisher and Lieberman, 1994, Lee, 1999) have suggested that the impact of social support may not always be a positive one. For example, the influence of a caregiver's wider family system is not always a positive one, with some family qualities serving a protective function and others exacerbating the negative aspects of caregiving by affecting personal health and well-being (Fisher and Lieberman, 1994). The relationship between social support and caregiver strain is thus argued to be a complex one which is not well understood (Morris et al, 1988b).

Interventions with caregivers

It has been established that intervention in general with caregivers can improve the psychological and social well-being of both the caregivers and the people with dementia. For example, Ostwald, Hepburn, Caron, Burns and Mantell (1999) reported that a psycheducational group intervention involving education, support and skills training was successful in reducing caregivers' negative reactions to behavioural problems and in reducing caregiver burden.

The strength of this type of research depends arguably more on interventions with spousal (Brodaty et al, 1992), as opposed to daughter caregivers. Notably, the type of interventions used often follow the stress process model and are very broad in their focus, e.g. social skills and coping strategies, and are less-concerned with the specific dynamics of interpersonal relationships. While not being atheoretical, previous intervention research has not relied upon established theories of relationship dynamics. A serious consideration of relationship patterns seems particularly relevant to the situation of persons with dementia when the caregivers are adult children whose earliest and perhaps most long-lasting lessons in caregiving have come from the person who is now in need of care.

Attachment theory

Based on ethology, attachment theory is essentially a theory about relationships (Holmes, 1993). Attachment theory also has explanatory value in how individuals regulate emotions and use different coping strategies and styles in dealing with problematic situations (Markiewicz, Reis and Gold, 1997).

The caregiving relationship is widely documented as stressful which, according to Bowlby's attachment theory, should increase the salience of attachments as determinants of the caregiver's responses (Markiewicz et al, 1997). Furthermore, attachment theory and research suggests specific predictions about caregivers' reactions to caregiving stress and about their decision to continue to care or institutionalise their relative (Markiewicz et al, 1997).

Attachment across the life span

The function of attachment is to promote survival and reproductive success (Bowlby, 1969). The goal therefore, of attachment behaviour is the seeking of protection by maintaining proximity to the attachment figure in response to either perceived or real threat or danger. Bowlby (1979) maintained that "attachment behaviour is held to characterise human beings from the cradle to grave" (p.129) and thus, the goal of seeking protection remains consistent throughout the life span, though the actual behaviour may vary according to age and context (George and Solomon, 1999).

Attachment behaviour is organised around an attachment behavioural system (Bowlby, 1969). Behavioural systems comprise behaviours that are co-ordinated to achieve a specific goal and adaptive function. They are activated and terminated by internal and environmental cues and they are guided by a feedback system that monitors the aforementioned cues. Furthermore, behavioural systems can be described as involving the developmental integration of sequences of behaviour that become functional over time as the product of organism-environment interaction. Behavioural systems are organised by specific cognitive control mechanisms (mental representations; George and Solomon, 1999).

Ordinarily, the individual's ability to behave independently and to rely on themselves, not their parents, increases gradually throughout childhood and adolescence. By the early years of adulthood, most people achieve a sense of autonomy from their parents. However, their attachments to their parents do not disappear (Colin, 1996). The child's primary attachment to the mother or initial caregiver is held to continue throughout the life span (Bowlby, 1980).

During adulthood, most adult children continue a meaningful association with their parents, regardless of the fact that parents are involved with fewer aspects of their lives than they did before. However, there is little systematic knowledge of the nature of these continuing attachments to parents (Ainsworth, 1991).

During childhood attachments are ordinarily asymmetrical; the child seeks care and protection and the attachment figure provides it (Colin, 1996). It is generally believed to be maladaptive for the parent of a young child to reverse roles and to seek care, support and security from the child. However, when the parent suffers with dementia or experiences ill or failing health, the roles established in childhood may become completely reversed, with the adult-child providing security and protection to their parent and this may be considered healthy (Ainsworth, 1991). Caregiving and role reversal in these circumstances is not well understood or researched.

The caregiving system

Bowlby (1969) proposed a complementary system in the parent to the attachment system. He suggested that the behaviour of the attachment figure is organised by a caregiving behavioural system. The caregiving system and the attachment system function together to keep child safe from harm. Until recently, caregiving as an organised behavioural system had not been considered in depth (George and Solomon, 1999).

Thinking about caregiving in the context of the child-parent relationship, Solomon and George (1999) describe caregiving behaviour as arising from a "biologically based

28

---

or instinctual behavioural system that is organised around the goal of the protection of the infant" (p.172). They suggest that caregiving behaviour is organised within a behavioural system that is independent of, but linked developmentally and behaviourally to, attachment.

The consideration of a complementary caregiving system moves the focus of understanding the child-parent relationship from the perspective of being protected (child's goal) to the perspective of providing protection (parent's goal). This change of focus enables researchers to understand the meaning of, and motivation underlying, important aspects of parental behaviour, cultural differences in providing care, the development of the infant's attachment and the mechanisms of intergenerational transmission (George and Solomon, 1999). This model of caregiving also has important implications for understanding the development of caregiving behaviour throughout the life span and thus may be helpful in understanding caregiving for an elderly parent.

George and Solomon (1999) propose that the caregiving system is activated by internal or external cues which the parent perceives as frightening or dangerous in some way for the child. Once this system is activated the caregiver can call upon a repertoire of behaviours to protect the infant. The caregiver's behaviour towards the infant depends upon the conscious and unconscious appraisal of several sources of information including the cues from the child and the parent's evaluation of threat. The caregiving system is deactivated once the caregiver has the infant in close proximity.

The behavioural systems are regulated in the mind by cognitive models that organise evaluate and appraise experience. These models were referred to as internal working models (IWMs) by Bowlby (1969) and are described below. The content of these representations is thought to be organised and available in several different forms, including inferences, attitudes, goals, plans, feelings and defences that serve to organise and regulate the smooth functioning of the behavioural system.

The access to the contents of the IWMs is guided by information processing rules which include defensive processes. They regulate how information is stored and organised, what information is allowed to consciousness, and the transformation or exclusion of certain kinds of information that would otherwise cause undue distress, pain or fear (Solomon and George, 1999). Features of maternal representations of caregiving have been illustrated to be associated with childhood attachment security across early childhood (Solomon and George, 1999).

Emotional experience is also an important component of caregiving system (Pianta, Marvin, Britner, and Borowitz, 1996). Bowlby (1969) maintained that emotion is a state that serves as a signalling capacity and therefore, caregiver's emotional states such depression or anger and their representations of emotional experience affect their behaviour toward child. Researchers have also maintained that social interaction processes such as sensitivity, synchrony, and reciprocity are qualities of the caregiving system and thus play important roles in the functioning of the caregiving system (Pianta et al, 1996).

George and Solomon (1999) propose that if the caregiving system is a behavioural system in its own right then it should be guided by a set of representational schemes which are related to providing care. They further suggest that there are many influences upon these representations, including the parent's own experience of maternal care. Sroufe and Fleeson (1986) also maintained that attachment related experiences with caregivers in infancy create behavioural and internal organisations that are carried into adulthood and become the organisational core of the caregiving system. George and Solomon (1999) propose that representations of the self as caregivers become differentiated and integrated during pregnancy, at birth and post natally through both the experience of thinking about the meaning of the new infant and providing care to him/her. Additionally, Bretherton (1991) suggested that when constructing a preliminary model of the self and the baby as partners in an attachment-caregiving relationship the caregiver uses 1) a general model of the world, 2) a normative model about babies in general and 3) models of caregiving behaviour from experiences in childhood. This model is then corrected in response to the feedback from the infant. Given the implications for caregiving in alternative caregiving situations, it may be that becoming a caregiver of an elderly mother with dementia activates mental representations of self as caregiver and also those regarding more specific aspects of the mother-child relationship, which in turn may influence how well a daughter copes with the caring situation.

Furthermore, George and Solomon (1999) suggest that parents of children with differing attachment classification have different representations of themselves as caregivers. Furthermore, they have found that mothers of secure children can be characterised as flexible in their mental representations of caregiving and are both

----

positive and realistic about potential threats to child security. Furthermore, they are able to evaluate caregiving in relation to the situation, the child's personality and developmental needs, child rearing goals and their own needs. The mothers of ambivalent and avoidant children however, seem to have conditional representational models of caregiving which either emphasise rejection or promote dependency. If this model can be applied to daughters caring for their mothers, it follows that daughters with differing attachment histories and attachment relationships with their mothers are likely to respond differently when confronted with caregiving situations.

Crucial to this theory is the idea that the cargiving system functions as an organised system in which represented elements affect one another (Pianta et al, 1996). Thus, the smooth functioning of the caregiving system can be disrupted if any one of these psychological or social interaction processes become disordered and stressed beyond a limit (Main, 1991). Main (1991) also argues that parents' unresolved early loss and trauma experiences disrupt caregiving/attachment systems at least in part through the alteration of the psychological processes involved in the regulation of caregiving behaviour. When child's attachment behaviour evokes memories that are dissociated from parents' cognitive functions, it can be frightening to parents and can disrupt the caregiving system.

Internal working models

One of the cornerstones of attachment theory is the concept internal working models of relationships proposed by Bowlby (1969). Bowlby maintained that internal working models determine how the child interacts with the world and are acquired during the first few years of life based on parent-child interactions. The internal

32

----

working model can be described as a mental representation of past events and

interpersonal interactions. This concept is useful in thinking about how attachment

theory may help to understand the caregiving relationship between daughters and their

mothers who are suffering from dementia and differential outcomes in the daughter's

experience of stress.

Steele and Steele, (1994) provide a useful description of internal working models.

They note that the optimal function of internal working models is to encode

interactions in such a way that will facilitate an ability to accurately predict how

significant others will behave and how the self might feel, think and behave in

response. This view assumes an ongoing interplay among emotion, cognition and

behaviour in personality development and both cognitive and emotional processes are

seen to influence the way that events and interactions are actively represented and

appraised, both consciously and unconsciously.

Steele and Steele (1994) also suggest that although these mental representations are

perceived as organised structures resistant to change, they are open to modification

over the course of development. As these models are described as relatively fixed,

they are carried through into adulthood and influence the nature of adult relationships

(Bowlby, 1969, 1988). It has been shown experimentally that adults with different

working models of attachment are predisposed to think, feel and act differently in

relationships (Collins, 1996).

Importantly, the theory of internal working models allows for the possibility of the

individual later integrating negative experiences into a representation of the self as

---

resilient and capable of love despite past negative experiences. Thus, there is room

for the subsequent reworking of internal working models in the light of new

experiences and new ways of thinking about past experiences to accommodate more

favourable interactions (Steele and Steele, 1994).

The adult attachment interview (AAI) appears to compel the respondent to

demonstrate significant aspects of their internal working models or habitual

non-conscious strategies for dealing with distress (Steele and Steele, 1994). The

adult attachment interview is a semi-structured interview consisting of a series of

questions designed to elicit an account of childhood which is used to rate both the

interviewee's probable childhood experience with parents and the interviewee's

current state of mind concerning attachment (Hesse, 1999, Steele and Steele, 1994).

Over the past decade, it has been repeatedly demonstrated that the quality of the

relationship between child and parent is powerfully influenced by the extent to which

that parent is capable of providing a coherent narrative description, and evaluation, of

his or her own attachment history (as measured by the AAI; see Van IJzendoorn,

1995). Thus, it has been established that how you become a caregiver to your own

child is determined in large part by how you were cared for during childhood, and

more importantly by how you think and feel about that caregiving history in the

present. To date, however, this research has largely neglected questions relevant to

the situation of care giving for older people, and attachment processes in older people

themselves.

The role of coherence and reflective functioning

Main (1991) has argued that differences in attachment organizations during childhood are strongly linked to the quality of metacognition in the parent. Metacognition can be defined as the knowledge about, or of, thinking, and the regulation of thinking (Main, 1991). Specifically, Main has suggested that coherence, i.e. the internal coherence of the AAI attachment narrative and the overall plausibility of this narrative, is the strongest predictor of infant attachment security. Furthermore, it has been argued that incoherent adult attachment narratives, indicating multiple models of attachment relationships, may be a key cause of a child's insecure pattern of attachment.

In an attempt to understand individual differences in metacognitive capacity, Fonagy and his colleagues (Fonagy, Steele, Steele, Higgitt and Target, 1994, Fonagy, Leigh, Steele, Steele, Kennedy, Mattoon, Target and Gerber, 1996, Fonagy, Target, Steele and Steele, 1998) have developed the concept of the reflective self. Reflective functioning refers to the developmental acquisition of a person's capacity to mentalise or understand oneself and others in terms of mental states. Thus, reflective functioning involves both a self-reflective and interpersonal component that optimally provides an individual with a "well-developed capacity to distinguish inner from outer reality, pretend from 'real' modes of functioning, intra-personal mental and emotional processes from interpersonal communications" (Fonagy et al, 1998, p.4.).

Qualities indicative of good reflective functioning include an awareness of the nature of mental states, efforts to tease out the mental states underlying behaviour and the recognition of developmental aspects of mental states (Fonagy et al, 1998). Thus as

Slade (1999) suggests, reflective functioning is what allows the individual to make sense of his/her own experience and to enter into another person's experience. Additionally, Fonagy et al (1994) suggest that reflective function may enhance the likelihood of planning effectively, successfully eliciting support and making good use of past experiences.

Importantly, reflective functioning has been demonstrated to have a protective role. Firstly, there is evidence to suggest that secure attachment is associated with greater awareness of the mental states of others. For example, parents who were rated as high in reflective functioning were three or four times more likely to have children who were rated as secure than parents whose reflective capacity was poor (Fonagy et al, 1994). Secondly, Fonagy et al (1994) found that reflective functioning was particularly important for attachment security in the child when the parent reported adverse experiences during childhood. Thirdly, previous research has also suggested that reflective functioning and coherence may serve as protective factors from mental health difficulties (Fonagy et al, 1996). Thus, Fonagy et al (1994, 1996) argue that reflective functioning has the potential to prevent negative experiences from the past influencing the current relationship with the child and adversely affecting mental health.

Attachment and caregiving in dementia

The relevance of attachment theory and research to the situation of children caring for their elderly parents has become a recent research interest. Circelli (1991) proposed a relationship between attachment and caregiving with regards to the elderly. He suggested that adult children usually maintain regular contact with elderly parents and

36

----

tend to feel an affectional closeness towards them. Furthermore, he suggested that once attachment has been established in childhood a system of protective behaviour develops within the child's attachment system that is designed to protect the elderly parent from harm. Thus, when the attachment figure is threatened by illness, the adult child will attempt to engage in caregiving behaviours to protect his/her aging parent from harm and preserve the attachment bond.

Roland (1999) has suggested several ways in which attachment theory may be useful in understanding stress in daughter caregivers. Firstly, she suggests that it might be predicted that a daughter whose sense of self is strongly founded on identification with her mother who was both helpful and supportive of autonomy will, later in life, be well equipped to enact the role of caregiver relatively free of inhibition or undue strain. Conversely, if a mother frequently rejected or misinterpreted her daughter's bid for comfort in stressful situations, she may develop not only an internal working model of the parent as rejecting, but also one of herself as unworthy of support, and be less at ease in her role as caregiver.

Secondly, Roland (1999) suggests that daughters who are better able to moderate the impact of stress through enlisting appropriate social support might be protected, whereas daughters who cannot, are likely to be at greater risk of negative outcomes. Moreover, daughters who have had a more difficult relationship with their mothers prior to caregiving and remain angrily or passively preoccupied by unresolved issues are likely to have lower stress thresholds than those daughters who have not. Thus, they may be at further risk of becoming angry with their mothers during times of stress, possibly exacerbating existing levels of stress.

Thirdly, Roland (1999) suggests that for daughter caregivers, the current state of mind with regard to attachment to her mother (i.e. reflective functioning) may be crucial as is the daughter's ability to maintain a level of objectivity during the caregiving process. More specifically on the basis of attachment theory and research, one might predict that a daughter who is aware of her own and her mother's imperfections both now and in the past and can openly discuss these openly in a balanced and integrated way may find caregiving less stressful.

The potential relationship between attachment and caregiver burden has been noted previously by Cicerelli (1993) who distinguished between the constructs of attachment and obligation to the dependent parent. Relying on questionnaire self-report measures administered to the daughters, Cicerelli (1993) showed 'stronger' attachment was related to less subjective burden and stronger obligation was related to greater objective burden with respect to caring for a parent having a range of disabilities. The construct of attachment as used by Cicerelli was meant to capture degree of felt closeness to the dependent parent. Generally in attachment theory, and most recently demonstrated by research involving the Adult Attachment Interview, stated closeness or intimacy with a parent does not necessarily imply a secure overall attachment or coherent representation of caregiving. With respect to the current research, there are three limitations of this research: 1) the limited use of the attachment construct, 2) the exclusive reliance on questionnaires (as opposed to interview or behavioural data) and 3) the lack of attentiveness to the possibly unique stressor represented by caring for a parent with dementia.

Markiewicz et al (1997) also investigated the links between attachment and dementia caregivers. In their sample of 113 of spousal and adult child caregivers, they found that attachment was related to social support, negative emotional reactions to the patient's problems and decisions to maintain or institutionalize their relative. Specifically, they found that caregivers characterized as anxious-ambivalent on a questionnaire measure of attachment were more likely to report less social support, less satisfaction with their social support and more negative emotional reactions to the problems exhibited by their family member compared with other attachment styles. Caregivers who scored highly on avoidance were also more likely to distance themselves from their relative by deciding to place them in institutional care.

Secure attachment style as measured by self-report questionnaires, has also been found to protect adult children caregivers of parents in institutional care from psychiatric symptomatolgy and caregiver strain (Crispi, Schiaffino and Berman, 1997). Crispi et al (1997) also found that preoccupation with the current attachment relationship was related to psychological symptomatolgy, with those more preoccupied with attachment related thoughts experiencing more symptomatology.

Although the above two studies highlight the potential of an attachment approach with the caregiving population, there are several limitations to this research. Firstly, questionnaire measures of attachment style have been found have less predictive validity, are likely to mis-classify some aspects of insecure attachment as secure and may be unable to identify certain subgroups (e.g. those rated as dismissing using the AAI; Hesse, 1999, Steele and Steele, 1994). Secondly, it is likely that the attachment

----

issues are likely to be different for daughter (or adult children, more generally) caregivers compared to spousal caregivers.

Using the AAI with a sample of eighteen daughter caregivers, Roland (1999) found that daughters who had both good past and current relationships with their mothers as measured by subscales of the Adult Attachment Interview recorded significantly lower levels of stress as measured by the Relative's Stress Scale (Greene, Smith and Gardner, 1982) and General Health Questionnaire (Goldberg, 1978) and were significantly more likely to use approach rather than avoidance coping. Daughter caregivers were defined as having a good past relationship with their mother if they scored lower on the rejection and role reversal subscales of the AAI. Current relationship status was defined by the anger and idealization subscales of the AAI. Daughters with higher scores on coherence, idealization and passivity subscales of the AAI were also more likely to demonstrate significantly higher reflective functioning. Roland (1999) found no significant differences in levels of social support between those who did and those who did not have good relationships with their mothers.

Thus, the present research relies on the most up-to-date attachment research measures to investigate the possibility that attachment characteristics may predict the emotional and social well-being of daughters who are caring for their mother with dementia and extends the work completed by Roland (1999). A relationship perspective is particularly needed in the context of dementia as it was the now dependent parent who was responsible for the adult-child caregiver's early attachment experiences. This role reversal may be an important source of the distress experienced by caregivers (Aneshensel et al, 1995).

Qualitative research methodology

In some important respects, the story of each caregiver is different from that of all others (Aneshensel et al, 1995). Thompson (1981) and Taylor (1983) both argue for the importance of exploring the meaning of stressful events and situations to the person undergoing them. Thus, if the way an individual thinks about and labels a potentially stressful situation is an important factor in determining their response to the stressor, then the examination of detailed case studies of individual accounts of stressful situations should be able to enrich psychological models (Smith, 1996, Smith, Flowers and Osborn, 1997).

Morris et al (1988a, 1988b) have suggested that the ability to find a meaning from the caregiving situation is likely to have links with the historical relationship with dementia sufferer and in turn, the ability to find a positive meaning in the caregiving situation may be related to caregiver burden. Using questionnaire measures with 131 family caregivers, the ability to find personal meaning in the caregiving situation (i.e. holding positive beliefs concerning oneself and the caregiving role) was found to mediate the relationship between care-related stressors and the experience of depressive symptoms and self esteem (Noonan and Tennstedt, 1997). The findings of this study suggested that the ability to hold positive beliefs about the caregiving situation and about the self as a caregiver was associated with lower levels of depression and greater self esteem.

Quantitative research methods are useful in constructing broad models. Attachment theory can be considered as one such broad model. Attachment theory (and other

broad models) are useful in establishing general rules, but many of the individual idiosyncrasies and differences are lost using quantitative data analysis. One of the most interesting, and potentially clinically useful, aspects of research is the individual's construction of the meaning of their situation. In this case, the meaning of the situation concerns how daughter caregivers understand their caregiving relationship with their mother in the historical context of their relationship with her. Qualitative research methods are useful to this end and are able to explore the content of a particular individual's beliefs and responses and thus, illuminating the process operating within models (Smith et al, 1997). Barker, Pistrang and Elliott (1994) adopt a stance of methodological pluralism, suggesting that examining single cases within the context of a larger comparison study gives a human dimension to research that is lacking in the predominantly statistical reports from larger projects. Therefore, using both quantitative and qualitative research methodologies can enrich and inform each other.

Research aims and hypotheses

The current research aims to extend previous research on attachment and caregiving in dementia care. Specifically, the primary aim was to explore the possible associations between daughter-caregivers' narratives concerning their relationship history and their self-reported levels of psychological well-being. It also aimed to explore whether adult attachment helps to explain adult experiences and reactions in the prolonged, intimate caregiving relationship in which an adult daughter provides essential care to her mother while simultaneously observing the decline of her mother and the inevitable loss of the original relationship.

In addition to using attachment theory to understand the caregiving relationship and in line with qualitative research ideology, the second aim of the study was to explore the daughter caregivers' current thoughts and feelings about their relationship with their mother using qualitative analysis.

Hypotheses

1. The severity of the dementia and the nature of the caregiving relationship will be associated with levels of psychological distress

2. Even after controlling for the influence of demographic variables, the security of attachment will be associated with levels of psychological distress. Specifically, security of attachment will predict lower levels of psychological distress.

3. More specifically, reflective functioning will be associated with psychological distress. The predicted direction is that the lower the reflective function score, the higher the psychological distress.

4. Social support will influence the relationship between attachment and psychological distress, either directly through mediation or indirectly through moderation.

Chapter Two

Method

Overview

This study formed part of a larger study carried out by Dr Howard Steele, Professor Robert Woods and Emily Phibbs which was investigating attachment relationships in daughter caregivers and their mothers with dementia using observational, interview and questionnaire data. In this chapter details pertaining to the recruitment of the sample, the sample itself, the measures used in the study, the procedure and the data analysis will be outlined.

Design

Within the context of a single visit (2-3 hour) laboratory visit, semi-structured interviews were collected from, and questionnaire information was administered to, a sample of daughters who were caring for their mothers with dementia using a correlational research design.

Participants

Recruitment

Volunteers from the population of daughters caring for a mother with dementia were solicited via invitations placed in national and southeast regional and local newspapers, ADS newsletters, and publicity to carers' groups. Interested daughter caregivers were asked to contact the project at University College London for information about the study.

Initial telephone contact with respondents included screening questions to establish agreement with inclusion criteria. These were competence in the English language, a documented dementia in the mother, the ability to travel to the university laboratory in London or the hospital setting in Harlow, Essex and a full understanding of what was being asked of them and their mothers.

Fifty two daughter caregivers responded to the request for participation. Of these twenty one (40.4%) did not take part in the study. Of those who did not take part in the study, twelve declined to take part after their inquiry, five did not meet the study's inclusion criteria and four women cancelled after making appointments.

Sample

The decision to request detailed demographic information about the participants was only taken after some eight to ten participants had been seen. While telephone contact with the first eight to ten participants successfully obtained some of the demographic information, the demographic information provided below is incomplete.

Thirty one daughter caregivers participated in the study. Twenty seven of these caregivers provided information regarding about their age. The age range of the daughter caregivers who participated in the study was 31 to 64 years with a mean of 50.4 years (SD 7.47). Twelve (38.7%) daughters were not currently living with a partner, twelve (38.7%) daughters were living with a partner and seven (22.5%) daughters did not provide this information. Of the twenty five participants who

provided information regarding siblings, seven (22.5%) had no siblings, eleven (35.9%) had one sibling and seven (22.5%) had more than one sibling.

Of the twenty six participants who gave information about where their mother lived, thirteen (41.9%) reported that their mothers were currently residing with them. Thirteen (38.7%) said that their mothers lived away from them, with three (9.7%) of these mothers having been recently placed in residential care. In these three cases the daughters still considered themselves main caregivers and reported frequent contact with their mother which involved caregiving duties.

Only seventeen daughters provided information regarding the length of time they had been caring for their mothers. The length of time participants had been caring for their mothers ranged from 1 to 96 months with a mean of 30.6 months (SD 23.5) For the twenty two daughters who provided information regarding diagnosis, the length of time since their mother had been diagnosed with dementia ranged from 6 to 108 months with a mean of 29.8 months (SD 25.5) The number of months which daughters had noticed problems with their mother's cognitive functioning differed from that of diagnosis, ranging from 24 to 156 months with a mean of 59.3 months (SD 34.5). The number of hours per week spent caring for their mothers for the fifteen daughters who provided information ranged from 10 to 84 hours with a mean of 39.3 hours (S.D. 25.6). Fourteen (45.3%) participants were currently receiving help with caring for their mother from services, five (16.2%) were not and eleven (35.5%) daughters did not give this information.

Twenty six participants gave their mothers age. The age range of the mothers the daughters were caring for was 70 to 93 with a mean of 82.4 years (SD 5.5). For twenty four of the cared for mothers the diagnosis was available. Fourteen (45.2%) mothers had a diagnosis of Alzheimer's Disease, four (12.9%) had a diagnosis of Vascular Dementia and six (19.3%) had a mixed diagnosis or other type of dementia.

Procedure

Prior to conducting the study ethical approval was sought and granted from two sources: the ethical committee at University Hospitals London (appendix 1) and the ethical committee at West Essex Mental Health Trust (appendix 2).

Daughter caregivers who met the inclusion criteria and who agreed to participate in the study were sent detailed information outlining the study and what would happen during their visit in more detail, the contact names and address for the study and an appointment letter (see appendix 3 for a copy of the information sheet sent to participants). The women were advised that they could contact the project before their appointment if they had any queries or concerns.

Visits took place at University College London or at a local hospital in Essex. The visits took part in the morning or afternoon, lasting approximately 2.5 hours. Travel expenses were reimbursed to participants. On arrival the participants were advised of the study's interest in observing respondents' thoughts and feelings about family relationships, and that primarily the mode of inquiring about relationships would be interview-based questions about the daughter's and mother's family of origin. They were told what would happen during their visit and asked to sign a consent form (see

appendix 4). Participants were told that if they decided to take part in the study they did not have to answer all the questions and that they could withdraw at any time. The participants were also assured of the confidentiality and anonymity of their responses.

The procedure started with the Adult Attachment Interview (AAI: George, Kaplan and Main, 1996; see below) and was then followed by the interviewer collecting demographic information about the daughter and her mother and completing the Clinical Dementia Rating Scale (Hughes et al, 1982). The participants were then asked to complete three self-report questionnaires aimed at assessing the respondent's psychological well-being and social support. The materials were administered in this order for two main reasons. Firstly, George et al (1996) suggest that should the AAI follow other interviews or tasks involving the description or the evaluation of a stressful life event, there is a risk that the ability of the AAI to "surprise the unconscious" will be compromised and thus lead to problems in the coding of interview material. Secondly, placing the questionnaires at the end of the study enabled the interview to be drawn to a close gradually, allowing the participant time before leaving the study, especially if she had been upset by the interview. Finally the daughter was debriefed and any questions were answered.

The participants were contacted within one to two weeks following the interviews to ask for their comments about the study and to discuss whether there had been any after effects or concerns about taking part in the study. In only two cases interviewees reported that they were greatly perturbed by the experience when

contacted by telephone. These daughters discussed their concerns with a member of

the research team and following this, decided that they did not need further support.

Measures

The measures used in the study are described below in the order that they were

administered, along with the scoring guidelines and why they were selected.

Adult Attachment Interview (appendix 5)

Overview

The Adult Attachment Interview (AAI: George, Kaplan and Main 1996). is a

semi-structured interview consisting of eighteen questions with a series of follow- up

probes, which focus upon early attachment experiences and their effects.   The

interview lasts approximately one hour and all interviews are tape recorded and later

transcribed for subsequent scoring.

The interview begins with asking the respondent to give a general description of their

family background and their relationship to their parents or caregivers. Respondents

are then asked for five adjectives to describe their relationship to each parent during

childhood and then for memories which support the choice of each adjective. During

the interview respondents are also asked to recall what they did when they were upset

or ill and how their parents responded, separation experiences, possible experiences of

rejection, threats regarding discipline and any experience of abuse. There are also

questions in the interview which explore the respondent's experience of loss through

death, both as a child and an adult. Finally, the respondent is asked about their

current relationship with their parents and how their experiences of being parented have influenced their adult personality.

Hesse (1999) suggests that the central task presented to the respondent by the interview is to produce and reflect upon memories relating to attachment while simultaneously maintaining coherent discourse with the interviewer. The technique has been described as one of "surprising the unconscious" (George et al, 1996).

Reasons why the AAI was selected for the study

The AAI was chosen for use in this study because it provides a comprehensive measure of relationship patterns with parental figures across the life span, from early childhood through to the current day. It was also considered superior to self-report questionnaires which measure attachment styles. Questionnaires measuring attachment styles have not been found to be predictive of infant-parent attachment, have been unable to capture the current state of mind regarding attachment and are at risk of misjudging some aspects of attachment (Hesse, 1999, Steele and Steele, 1994).

Notably, the psychometric qualities of the AAI classification system have been thoroughly tested (George et al, 1996). The major categories of the AAI have been found to be stable over time, unrelated to most measures of intelligence and long and short term memory, unrelated to social desirability and not attributable to interviewer effects (Bakersman-Kranenburg and Van IJzendoorn, 1993, Steele and Steele, 1994). Furthermore, inter-rater reliability on the major classifications are typically very high, circa 90 per cent across numerous studies (Steele and Steele, 1994). The major

----

classifications of the AAI have also been found to be predictive of infant attachment classification (Van IJzendoorn, 1995).

Modifications made to the AAI for this study

The AAI was initially designed to be used with mothers who had young children to examine the relationship between their own experiences of being parented and how they parent their own children. Therefore, two questions, 17 and 18, which focus on the respondent's relationship with their child and their wishes for their child were omitted from this study as they were redundant in this sample of daughters caring for their mothers with dementia.

Six questions were added to the end of the AAI (see appendix 6) which aimed to explore the participants thoughts regarding how their relationship with their mother over time had influenced their caregiving role and ability to cope and thus enrich the information gathered from the AAIs. These questions were adapted from Roland (1999) and were added approximately half way through the study. This was in response to the observation that many of the daughter caregivers reflected upon the caregiving relationship with their mother after the Adult Attachment Interview had finished. It was hoped that these questions would capture some of the caregivers' thoughts about their understanding of the relationship with their mother over time and their caregiving role. Although these questions were added to the end of the AAI, they were analysed separately using qualitative methods (see below).

Coding of the AAI

The attachment interviews from the daughters were classified using the adult attachment scoring and classification systems (Main and Goldwyn, 1994) and rated according to the previously validated reflective functioning scale (Fonagy, Target, Steele and Steele, 1998).

Adult Attachment Scoring and Classification Systems

Each of the transcripts was analysed and coded individually by Dr Howard Steele, Director of the Attachment Research Unit at University College London, according to the methods and coding criteria outlined in the Adult Attachment Scoring and Classification System (Main and Goldwyn, 1994). Dr Steele was personally trained by Main in scoring AAIs and has been classified as a reliable rater for the AAI.

The coding of each transcript involved three phases. Firstly, the transcript was rated on the participant's probable experiences with each parent. Secondly, the transcript was rated on various aspects of the respondent's present state of mind with regards to attachment. Finally, the transcript was assigned an overall attachment classification.

The five scales used for rating a participant's probable experiences are as follows;

1) **Loving versus unloving** - this scale refers to the extent to which the interviewee experienced their parents as loving and supportive during childhood.

2) **Rejection** - this scale refers to the extent to which the parents have actively rejected and/or avoided the child during childhood.

----

3) **Involving/role reversal** - the aim of this scale is to assess the extent to which the

parent involved the child in maintaining their own well-being rather than the parent

looking after the child's well-being.

4) **Neglect** - this scale assess the extent to which the parents, who were physically

available, were inattentive, preoccupied or otherwise occupied, uninvolved or

psychologically unavailable to the child.

5) **Pressured to achieve** - this scale measures the extent to which the child was

pressured to achieve some status during childhood or was pushed to succeed.

Each parental figure is rated separately on a nine point scale, based on the rater's

judgment of the transcript as a whole. The anchor points for these scales can be seen

in table 2.1 below.

Table 2.1: Scoring guidelines for probable experiences with each parental figure

during childhood

Scale	Scoring		
	1	**5**	**9**
Loving vs. unloving	very lacking in love	neither unloving or actively loving	very loving
Rejection	not at all rejecting	moderately rejecting	extremely rejecting
Role reversal	parent's well-being not made a concern	parent seeks attention from child	role reversal
Neglect	not inattentive	inattentive	strongly neglecting
Pressured to achieve	not pushed or pressured to achieve	moderately pushed to achievement	pushed to achieve without concern for child

----

Another eight scales assess the current state of mind with regards to attachment. The scales refer to the mental representation of attachment-related experiences and to the organization of information relevant to attachment (Main and Goldwyn, 1994). Of these eight scales three are parent specific, while the other five are non-parent specific. The eight scales are briefly outlined below;

Parent-specific state of mind scales.

1)   **Idealisation of the parent** - this scale assesses the degree to which the participant's description of their experiences with their parents are objective and consistent with the evidence presented in the transcript.

2) **Involved/involving preoccupying anger** - this scale assesses the extent to which the interviewee expresses current anger towards the parent during the interview.

3) **Active dismissal/derogation of attachment experiences or relationships** - the aim of this scale is to measure the extent to which the interviewee presents evidence that undermines the importance and influence of childhood history and attachment history.

Non-parent specific state of mind scales

1)   **Coherence of transcript** - this scale sets to assess the degree to which the discourse is flowing. Thus, the scale assesses the ability of the interviewee to present and assess the past and it's influences in a way which seems reasonable and understandable to the reader.

---

2)   **Insistence upon the inability to recall childhood experiences** - this scale measures the degree to which the participant repeatedly and strongly reports an inability to recall childhood experiences.

3)   **Passivity of discourse** - this scale aims to assess the passivity of the thought processes related to attachment. It is observed in unfinished sentences, lapses into silence, repeated vague intrusions and overtly vague expressions. It is said to be indicative of a mind that has great difficulty using words to specify meaning.

4)   **Overall coherence of mind** - this scale assesses the nature of the respondent's apparent attachment-related beliefs and belief systems in comparison to the rater's own assessment of reality. This scale is particularly useful where the interview transcript may seem incoherent to the reader but where the reader has a feeling that the participant is still in balance with his or her childhood experiences.

5)   **Unresolved (disorganised/disoriented) states of mind with respect to experiences of loss or abuse** - this scale is a specific index of unresolved loss resulting from the death of significant others and/or the experience of abuse.

The anchor points for scoring these scales can be seen in table 2.2 below.

Table 2.2:   Scoring guidelines for current states of mind with respect to attachment scales

Scale	Scoring		
	1	**5**	**9**
Coherence of transcript	highly incoherent	neither coherent or incoherent	highly coherent
Idealisation of the parent	no idealisation of the parent	moderate idealisation of the parent	very strong idealisation of the parent
Insistence upon inability to recall childhood	no insistence upon inability to recall childhood	some insistence upon inability to recall childhood	very frequent/strong insistence upon inability to recall childhood
Involve/involving anger	no direct expressions of anger	moderate expressions of anger	extreme expressions of anger
Passivity of discourse	no evidence of passivity	moderate passivity	habitually passive discourse
Dismissal/ derogation of attachment	no dismissal or derogation	some dismissal or derogation	strong derogation or dismissal
Overall coherence of mind	very incoherent	neither coherent or incoherent	very coherent
Unresolved states of mind (re: loss or abuse)	no evidence of disorganisation or disorientation	unsettled but definitely not disorganised or disorientated	marked disorganisation or disorientation

Finally, the transcript is given an overall attachment classification based the rater's overall judgment of the transcript as a whole. The transcript is given one of three classifications; secure-autonomous, dismissing of attachment or preoccupied with, or by, early attachments or experiences. Each major classification group has several subtype classifications. In addition the transcript may also receive a classification of

---

unresolved with respect to loss or abuse. In rare cases the transcript may be given a

cannot classify classification if the rater is unable to categorize a transcript. The

major classifications, their characteristics and a description of the typical transcript

can be seen in table 2.3 below.

Table 2.3: Characteristics of major attachment classifications (after Main and Goldwyn, 1994, Steele and Steele, 1994).

Attachment classification	Typical characteristics	Interview description
Free autonomous (F)	value attachment experiences and regard attachment experiences as influential. (50-60% of non clinical samples)	coherent, free flowing style of discourse, relative absence of self deception, acceptance of need to depend of others, realisation that self and others are not perfect
Dismissing of attachment (D)	current attempt to limit the influence of attachment in thought, feeling and daily life (25-30% of non clinical samples)	denial of painful affect or experience, inability to recall, strong idealisation of the parents, information related report
Preoccupied or entangled (E)	confused, unobjective, and preoccupied by past attachment experiences (10-15% of non clinical samples)	overinvolved with childhood attachment experiences, experiences not located in the past, confusing speech, run-on sentences, long and difficult to follow
Unresolved (U)	disorganisation/disorientation in thinking or discourse regarding loss or abuse	unsuccessful denial, disbelief, disorientation to space/time, confusing statements, feelings of being casual, unusual attention to detail

Reflective Functioning Scale

The Reflective Functioning (RF) Scale is a nine-point scale developed by Fonagy,

Target, Steele, and Steele (1998) which assesses the extent to which the respondent

---

can coherently refer to mental states as motivators and consequences of interpersonal behaviour as measured by the AAI. Qualities which suggest moderate to high reflective function include an awareness of mental states, efforts to tease out mental states underlying behaviour, the recognition of the developmental aspects of mental states and an awareness of mental states in relation to the interviewer (Fonagy et al, 1998).

Responses to questions in the transcript that are identified as permit or demand questions are scored using the RF Scale. Permit questions can be defined as those which allow the speaker to demonstrate their reflective-self abilities. Example of permit questions in the AAI are *can you orientate me to your family background?* and *what did you do when you were upset as child?* Demand questions can be defined as those that demand from speakers a demonstration of their capacity for reflective self function. For example, *why do you think your parents behaved as they did during your childhood?* or *have there been any changes in your relationship with your parents since childhood?*. Each response passage is scored before an overall reflective function score is given on the basis of the best fit. The anchor points for scoring reflective function can be seen in table 2.4 below.

Table 2.4: Scoring guidelines for the Reflective Functioning Scale (Fonagy et al,

1998)

Scoring			
-1	**1**	**5**	**9**
Reflective Function (RF) Rejection of RF or unintegrated, bizarre or inappropriate RF	Lacking in RF	Ordinary or inconsistent RF	Exceptional RF

The Reflective Functioning Scale is said to have good inter-rater reliability and has

been shown to be unrelated to vocabulary skills, general intelligence, age and social

class (Fonagy et al, 1998). The scale has been argued to be particularly predictive of

secure attachments in infants with their mothers (Fonagy et al, 1998).

Demographic Questionnaire (appendix 7)

The demographic information collected was broadly divided into two parts;

information about the caregiver herself and information about the caregiver's mother.

Data collected on the caregiver included her age, marital status, number of siblings

and length of time she had been caring for her mother.

Data collected on the caregiver's mother included the mother's age, who the mother

lived with, the diagnosis and when the diagnosis was received. The amount and type

of formal care services the mothers' received in addition to their daughter's help was

also recorded.

Clinical Dementia Rating Scale (appendix 8)

The severity of dementia of the caregiver's mothers was assessed using the Clinical Dementia Rating Scale (CDRS; Hughes, Berg, Danziger, Coben & Martin, 1982). This scale provides a guide to the global level of dementia severity, taking into account both cognitive and behavioural decline. The scale is able to distinguish among older adults with a wide range of cognitive function, from healthy to severely impaired (Hughes et al, 1982).

The scale assesses memory, orientation, judgment and problem solving, community participation, home and hobbies and personal care. Each item is scored on a four point scale from healthy (score of 0) to severely impaired (score of 3). The overall severity of dementia is decided by firstly, the respondent's score on the memory item and secondly, the remaining responses.

The questionnaire has good inter rater reliability (alpha = 0.89) and good correlations with other scales measuring severity of dementia. It is also able to accurately predict subsequent ratings and therefore has predictive validity (Hughes et al, 1982). This measure was also chosen because of it's simplicity, accuracy and quickness.

General Health Questionnaire - 28 item version (appendix 9)

The General Health Questionnaire (GHQ-28; Goldberg, 1978) is a widely used instrument for screening psychiatric disorder in patient and community samples and has been used in many studies with carers of dementia sufferers (Morris et al, 1988). It has been shown to be accurate in detecting major depression and anxiety in community samples (Goldberg, 1978). The 28-item version was chosen as the

----

primary measure of overall caregiver distress, as its sub-scales allow assessment of anxiety and depression in addition to the overall rating.

The GHQ-28 has four subscales. These are somatic symptoms, anxiety and insomnia, social dysfunction and severe depression. As well as a score for each of these subscales, an overall score can be calculated. Scoring for each item on the questionnaire is on a four point Likert scale.

Relative Stress Scale (appendix 10)

The Relative Stress Scale is a fifteen item questionnaire providing an index of caregiver stress when caring for a relative with dementia (Greene, Smith and Timbury, 1982). It is a widely used standardized scale with good test-retest reliability and validity figures (Greene et al, 1982).

The scale is divided into three sub scales. These are 1) personal distress experienced by the relative in relation to the person with dementia (6 items) 2) the degree of life upset produced by having to care for the relative (5 items) and 3) negative feelings (4 items). Each question is rated on a five point Likert scale from rarely to always/considerably. Scores are calculated by adding the 0-4 rating for each question on each sub scale and then across all scales, giving a total score.

Social Support Questionnaire (appendix 11)

The Social Support Questionnaire (Sarason, Sarason, Shearin & Pierce 1987) is a questionnaire measuring both the availability of social support and satisfaction with this support.

The questionnaire has six items, each with two parts. The first part of the item asks

the respondent to list all the people s/he feels she can turn to in times of need in each

of a variety of situations. The scale is called number of perceived available support.

The second part of the item measures the individual's degree of satisfaction with the

perceived support available in that particular situation. Respondents indicate how

satisfied they are on a six point Likert scale from very dissatisfied to very satisfied.

This scale is called satisfaction.

The questionnaire has good internal and test-retest reliability (Sarason et al, 1987).

Data Analysis

The data collected from this study was analysed using both quantitative and

qualitative methodology.

Quantitative data analysis

The data was summarized via the calculations of the measures of frequency, central

tendency and dispersion of the scores on the Adult Attachment Interview and the

self-report questionnaire measures.

Pearson's Product Moment Correlations were then conducted to examine the

relationships between the various variables collected in the study and also to test the

hypotheses concerning the relationships between psychological distress, the

demographic variables and attachment (hypotheses one to three). Finally linear

----

regression analyses were conducted to explore the influence of social support upon the relationship between attachment and reflective functioning and thus test hypothesis four.

Qualitative data analysis

The data from the transcripts from the AAI and the six additional questions (see appendix 6) added to the end of the AAI were analysed separately.

The additional questions were analysed using Interpretative Phenomenological Analysis (IPA). IPA aims to allow participants to tell their own story, in their own words, about the topic under investigation (Smith et al, 1997). IPA is concerned with cognitions, that is what the particular respondent thinks or believes. However, it also acknowledges that the research process is a dynamic one, which is to some extent influenced by the interests of the researcher. The analytic process involved a series of steps according to Smith, Jarman and Osborn (1999):

1. Firstly, the transcript was read several times so that the researcher became familiar with the content of the interview. Notes were made in the left hand margin of any interesting or significant remarks. The example below shows how this was done with an excerpt of an interview with one of the daughter (D) caregivers:

	I. Do you think your relationship with your mother has influenced the way that you are now in that you care for her?
Role reversal	D. The way I am with her - it's well it's like role reversal now (*right*) it it was it's not so much
Suddenness of change	now because there's but I we I was suddenly

---

	like the one who had to be umm -- not in
Taking charge	control but looking after her and that telling
Mothering	her what she should do and shouldn't do and
Mother - childlike = regression	her being like a child and refusing to do it and
	me not behaving like a child and insisting that
Difficult ground - role reversal	she did it you know I had to be very careful in
	my in what I said and did and uhh ......

2. Secondly, notes are made in the right hand margin to document emerging theme titles and keyword which capture the essential quality of the text. From the above account the following themes were noted;

I. Do you think your relationship with your mother has influenced the way that you are now in that you care for her?

D. The way I am with her - it's well it's like role reversal now (*right*) it it was it's not so much now because there's but I we I was	Relationship change Role reversal
suddenly like the one who had to be umm -- not in control but looking after her and that telling her what she should do and	Difficulties with role change
shouldn't do and her being like a child and refusing to do it and me not behaving	Changes in mother
like a child and insisting that she did it you know I had to be very careful in my in what I said and did and uhh	Difficulties with role change

3. Thirdly, concepts which seemed to relate to each other were grouped together and the way in which they were related to each other considered. This lead to the creation of superordinate and subordinate categories. The following themes were identified from this caregiver's account and clustered under the domain of "change";

Change

- ◆ Change in relationship with mother

- ◆ Role reversal

- ◆ Difficulties with coming to terms with role change

- ◆ Changes in mother

4. This process was repeated for each transcript, noting both consistent and new themes. Although each interview was read with an open mind, the sequential nature of this process may have primed the researcher to certain aspects of the data.

5. The themes and clusters from all the interviews considered in the analysis and the relationships between them were then considered. The aim was to look for clusters of themes which reflected shared aspects of the caregivng relationship for a number of participants.

6. Finally, the clusters and themes were translated into a narrative account in order to make consistent and meaningful statements about the participants' experiences which was rooted in their own words.

As a check on the analysis in the present study, three of the transcripts were read by an independent person who was not involved in the project and discussed with the author. This person was a mental health professional working with people with dementia and their caregivers. The interpretation of the interviews were discussed and the themes and categories agreed upon. At later stages of the analysis, the

----

emerging narrative account was discussed with the second person and members of the

research team.

Chapter Three

Results of the quantitative data analyses

Overview

This chapter provides the results of the statistical analyses of the data gathered from the project. It is divided into three parts. In part one the descriptive statistics on the Adult Attachment Interview (AAI) classifications and the self report measures are presented. Part two examines the statistical correlations between various aspects of the variables collected in the study. Finally, in part three the hypotheses presented in the introduction are tested.

Descriptive statistics

This section summarizes the data via presentation of information regarding the frequency, central tendency and dispersion of the scores on the Adult Attachment Interview and the self-report questionnaire measures.

The mean and standard deviation (SD) were chosen for the self report measures because a sample mean and standard deviation give the most reliable estimates of central tendency and dispersion in the population and are considered to be robust (Rowntree, 1981). They are also the most common methods used by other researchers, thus allowing comparisons between data sets.

Adult Attachment Interview Classifications

The adult attachment interviews were classified on the basis of the rater's overall judgment of the transcript as a whole. The classification of the adult attachment

interviews administered to twenty eight of the daughter caregivers can be seen in

Table 3.1.

Table 3.1: Daughter caregiver adult attachment interview classifications (n=28)

Daughter Caregivers' Adult Attachment Classifications	Number of Caregivers (n=28)	%
Free autonomous (secure)	8	28.6
Dismissing (insecure)	10	35.7
Entangled (insecure)	10	35.7
Unclassifiable	0	0
Unresolved regarding loss or abuse	6	21.4

Table 3.1 shows that only eight daughter caregivers were classified as being securely attached, whilst the majority, twenty, were classified as being insecurely attached. Additionally, six interviews were judged to be unresolved with respect to either loss or trauma.

Given the high proportion of caregivers judged as insecurely attached (71.4%), there is insufficient statistical power to compare securely versus insecurely attached caregivers. Thus, attention was turned to the 9 point dimensional rating scales as highlighted in the method. Coherence (both the coherence of transcript and coherence of mind subscales) is argued to be the strongest predictor of infant security of attachment to their parent (Main, 1991). Still perhaps more indicative of infant security is the Reflective Functioning (RF) Scale. This scale assesses the extent to which the respondent can coherently refer to mental states as motivators and

----

consequences of interpersonal behaviour and has been found to be related to the

quality of an infant's attachment to their parent (Fonagy et al, 1998). Table 3.2

shows the means, standard deviations and ranges for these scales for twenty eight

daughter caregivers.

Table 3.2: Means, standard deviations and range of caregivers' score on reflective function, coherence of transcript and coherence of mind

Attachment Domain	Mean (n=28)	SD	Range	Possible Range
Reflective function	3.14	1.73	0.5-8	-1-9
Coherence of Transcript	4.04	1.65	1-8	1-9
Coherence of mind	4.04	1.85	1-8	1-9

The above table shows that daughter caregivers from this sample, scored on average

in the lower half of all three subscales The lowest mean score was for Reflective

Functioning (mean 3.14, SD 1.73).

Daughter caregivers' current levels of psychological distress and social support

A summary of caregivers' scores on the General Health Questionnaire (GHQ),

Relative Stress Scale (RSS) and Social Support Questionnaire (SSQ) can be seen in

table 3.3 below.

Table 3.3: Means, standard deviations and range of caregivers' scores on stress

and social support measures

Psychological Distress	Mean	SD	Range	Possible Range
GHQ total score	25.63	15.34	0-72	0-84
Anxiety and insomnia	7.67	5.86	0-20	0-21
Somatic symptoms	7.40	5.38	0-21	0-21
Severe depression	2.87	3.73	0-13	0-21
Social dysfunction	7.70	3.24	0-20	0-21
RSS total score	22.80	11.28	6-46	0-60
Personal distress	10.80	5.18	2-21	0-24
Negative feelings	4.41	2.80	0-12	0-16
Life upsets	8.35	5.27	0-17	0-20
SSQ				
Number of perceived social supports	17.83	8.66	0-45	N/A
Satisfaction with social support	5.34	0.79	2.60 -6.00	1-36

Note: Anxiety and insomnia, Somatic symptoms, Severe depression, Social dysfunction are

subscales of the GHQ; Personal distress, Negative feelings, Life upsets are subscales of the

RSS; Higher scores on both scales indicate more distress. Number of perceived social

supports and Satisfaction with social support are subscales of the SSQ. Higher scores

indicate more supports and more satisfaction.

The ranges on both the GHQ and the RSS indicate that there is a large amount of

variability in the amount of psychological distress reported by the caregivers in this

study. The number of social supports reported by participants also varied widely.

As the table shows, the mean GHQ total score was 25.63 (SD 15.34) The mean score was 22.80 (SD 11.28) on the RSS total scale.

The distribution of scores on all the above measures were tested for normality using the significance of skewness. This calculation involves dividing the skewness statistic by the standard error of the skewness statistic. This provides a z statistic. Satisfaction with social support was skewed to the right (satisfied; significant at p<0.05) and was transformed in order to complete the data analyses. When distributions have skewness in this direction, the best strategy is to reflect the variable and then apply an appropriate transformation (Tabachnick and Fidell, 1996). Thus, satisfaction with social support was transformed using reflect and square root functions. This new variable was not significantly skewed and thus, was used in further analyses.

Level of impairment of daughter caregivers' mothers

The mean, standard deviation and range of the mothers' score on the Clinical Dementia Rating Scale can be seen in table 3.4

Table 3.4: Mean, standard deviation and range of mothers' score on the clinical dementia rating scale

Level of impairment	Mean	SD	Range	Possible Range
Clinical Dementia Rating Scale	2.02	0.86	.50-3.00	0-3

The above table shows that the severity of the dementia ranged from questionable to severe impairment as measured by the Clinical Dementia Rating Scale (Hughes et al, 1982). The majority of the mothers had a moderate level of impairment.

Statistical correlations between the variables used in this study

Statistical correlations using Pearsons Product Moment Correlation were performed to examine the strength of the relationship between different variables used in the study. Firstly, the relationship between attachment classification (grouped into secure and insecure attachment classifications), coherence and reflective functioning was examined. The results can be seen in table 3.5

Table 3.5: Correlation coefficients between attachment classification, reflective function, coherence of transcript and coherence of mind (n=28).

	Attachment classification *(secure vs insecure)*	Coherence of mind	Coherence of transcript	Reflective Function
Attachment classification *(secure vs insecure)*	1	.640**	.672**	.633**
Reflective function	.633**	.799**	.767**	
Coherence of transcript	.672**	.960**		
Coherence of mind	.640**			

** *correlation significant at p<0.01 (two tailed).*

The above table shows that the three indicators of attachment (reflective function, coherence of transcript and coherence of mind) are significantly correlated with each

---

other at the p<0.01 level. Cronbach's alpha for the three attachment variables was

calculated to be 0.88, indicating that the three variables were measuring the same

dimension of attachment. Given the high correlation between coherence of transcript

and coherence of mind (r = .96, p<0.01), these variables were summed together to

form a new variable of overall coherence. This new variable was used in further data

analyses.

The General Health Questionnaire (GHQ) and the Relative Stress Scale (RSS) were

significantly correlated at (r = .567, p< 0.01 (two tailed); 30 cases). As both

measures were used in this study as global measures of psychological distress, they

were summed together to form a new variable of psychological distress which was

used in further analyses.

The relationship between eleven demographic variables collected in the study and the

two attachment variables (reflective functioning and overall coherence) were also

explored using Pearson's Product Moment Correlation. The results of the

correlations indicated that there were no significant correlations between the

demographic variables and the attachment variables. However, there was a significant

trend regarding daughters scores on the attachment scales and whether or not they

were receiving help from services. Based on only seventeen cases the result

suggested that there was a tendency for daughters who scored higher on the

Reflective Functioning Scale and on overall coherence to be more likely to be

receiving help from services (r = .492 and r = .582, respectively; significant at p<0.05

(two tailed)).

Hypotheses Testing

Hypothesis 1: *The severity of the dementia and the nature of the caregiving relationship will be associated with levels of psychological distress.*

The demographic variables collected during the course of the study were correlated with psychological distress using Pearsons Product Moment Correlation. It was considered that these demographic characteristics may confound the relationship between attachment and psychological distress. The results of these correlations can be seen in table 3.6.

Table 3.6: Correlation coefficients between demographic variables and psychological distress

Demographic variable	Psychological distress
Mothers' age *(n=26)*	0.34
CDR score *(n=30)*	-0.19
Number of months since diagnosis *(n=22)*	0.28
Number of months since family noticed problems *(n=23)*	0.14
Daughter caregivers' age *(n=27)*	0.34
Number of siblings *(n=25)*	0.06
Marital status *(n=24)*	-0.15
Number of hours of care provided per week by daughter *(n=15)*	-0.07
Number of months care has been provided by daughter *(n=17)*	0.14
Mother and daughter living together *(n=25)*	-0.17
Daughter receiving help from services *(n=20)*	0.40

All correlations = non-significant (two tailed)

Table 3.6 shows that none of the demographic variables collected in this study were significantly correlated with psychological distress. The strongest correlations however, were for mother's age, daughter caregiver's age and whether the daughter

74

----

received help from services (r = 0.34, , r = 0.34 and r = 0.40 respectively). As these

variables were not significantly correlated with psychological distress, they were not

controlled for in further analyses.

Hypothesis 2. Even after controlling for the influence of demographic variables,

the security of attachment will be associated with levels of psychological distress.

Specifically, security of attachment will predict lower levels of psychological

distress.

Originally a sample size of 60 was originally chosen following consideration of the

likelihood (based on previous attachment research involving non-clinical participants)

that at least one third of these 60 daughters would present with insecure attachment

narratives. Further, power analyses suggested that with a sample of this size,

moderate to large effects would be readily observed (p < .05).

Due to the difficulties in recruiting daughter caregivers to participate in the study, the

sample size was limited to 27 caregivers who completed both the AAI and the self

report measures, with only 28.6% were classified secure. Thus, hypothesis two was

not directly tested because of the small overall sample size and the high number of

insecurely rated interviews, thus meaning insufficient statistical power to detect

differences between secure and insecure groups.

Overall coherence (coherence of transcript and coherence of mind) was considered as

an indicator of attachment security. Overall coherence was scored on a continuous,

interval scale, thus allowing correlation to be performed. Using Pearsons Product

----

Moment Correlation, the relationship between overall coherence and psychological

distress was found to be non significant (r = .31, non significant at p<.12).

Hypothesis 3.   More specifically, reflective functioning will be associated with psychological distress.   The predicted direction will be that the lower the reflective function score the higher the psychological distress.

Hypothesis three was tested using Pearsons Product Moment Correlation. Reflective

function was significantly and positively correlated with psychological distress (r =

0.380, p< 0.05 (two tailed)). Thus, the higher the score on the reflective function

scale, the higher the score on the measures of psychological distress. This

relationship is in the opposite direction to the direction stated in the hypothesis.

Hypothesis 4.   Social support will influence the relationship between attachment and psychological distress, either directly through mediation or indirectly through moderation.

Hypothesis four was tested using linear regression. Regression analyses were used to

explore the influence of social support upon the relationship between attachment and

reflective functioning. It has previously been established (see above) that only

reflective functioning affects the dependent variable (psychological distress) and thus,

is the only independent variable considered in the regression analyses. Furthermore,

as none of the demographic variables were correlated with both attachment and

psychological distress, they were not controlled for in the analyses.

Cooks Distance was calculated to assess the influence of single observations. To test

the possible assumptions of normality, linearity and homogeneity of variance were

---

calculated by plotting the standardized residuals against the standardized predicted

values of the dependent variable generated for each regression equation. A

cumulative normal probability of residuals was also generated to provide a second test

of normality. These results confirmed the appropriateness of each regression design.

Social Support as a mediator

Firstly, social support as a mediator of the relationship between reflective functioning

and psychological distress was assessed. To establish mediation, three conditions

must hold (Baron and Kenny, 1986);

1. The independent variable must influence the mediator.

2. The independent variable must affect the dependent variable.

3. The mediator must affect the dependent variable.

The Social Support Questionnaire (SSQ) provides two indicators of social support;

number of supports and satisfaction with support. Both indicators were considered as

potential mediators of the relationship between reflective function and psychological

distress. The results of the regression analyses can be seen in table 3.7 below.

Table 3.7: Regression coefficients for reflective functioning with number of and satisfaction with social supports

	Step One	
	IV = reflective function DV = number of social supports	**IV = reflective function DV = satisfaction with social supports**
Beta	0.145	0.192
t	0.717	0.949
p	0.481	0.352
R	0.145	0.190
R Square	0.021	0.036
Adjusted R Square	-0.020	-0.004

Table 3.7 shows that the both the number of social supports and the satisfaction with social supports only account for a very small proportion of the variance in each regression equation (less than 3 and 4%). Both regressions were found to be non significant. Thus, the results show that neither number of social supports nor satisfaction with social supportss mediate the relationship between reflective functioning and psychological distress.

Social Support as a moderator

Moderation implies that the casual relation between two variables changes as a function of the moderator variable (Baron and Kenny, 1986). Three casual paths feed into the moderator hypothesis;

1. The independent variable's relationship with the dependent variable

2. The moderator's relationship with the dependent variable

3. The impact of the interaction of the independent variable and the moderator upon the dependent variable. The moderator hypothesis is supported if this interaction path is significant.

In addition to these considerations, it is desirable that the moderator variable be

uncorrelated with both the independent variable and the dependent variable. Using

Pearsons Product Moment Correlations, this was found to be the case for both

number and satisfaction with social support and psychological distress as can be seen

in table 3.8.

Table 3.8: Correlation coefficients for social support and reflective functioning

	Reflective functioning	Psychological distress
Number of social supports	0.15	-0.28
Quality of social supports	-0.20	0.19

All correlations non significant (two tailed)

The regression analyses below consider the number of social supports as a moderator

of the relationship between reflective functioning and psychological distress. The

interaction variable was created by multiplying the reflective functioning variable and

the number of social supports. The results of the regression analyses for number of

social supports can be seen in table 3.9.

Table 3.9: Regression analyses for number of social supports as a moderator

	Model One IV = rf DV= psychological distress	Model Two IVs = rf No of supports DV= psychological distress	Model Three IVs= rf no of supports rf x no of supports DV= psychological distress
Beta: rf no of support rf x no	0.382	0.431 -0.332	0.896 -0.720 -0.580
t: rf no of support rf x no	2.023	2.368 1.820	1.348 0.178 0.727
p: rf no of support rf x no	0.036*	0.027* 0.082	0.192 0.860 0.475
R	0.382	0.503	0.520
Adjusted R Square	0.110	0.188	0.171
R Square change (calculated against R Square)	0.146	0.108	0.018

significant at p<0.05. All other findings = non significant

The results of the regression analyses suggest that reflective functioning is a significant predictor of psychological distress accounting for 11% of the variance, when considered on it's own (significant at p<0.05). Reflective functioning is also a significant predictor of psychological distress when accounting for number of social supports (model two), accounting for 18.8% of the variance (significant at p<0.05). The magnitude of the Beta value indicates that the predictive effect of reflective functioning was increased in model two compared with model one, although this was non significant (F change = 3.314, p<0.08). Reflective functioning was not a significant predictor of psychological distress when the interaction of the two variables is considered (model three). Thus, number of social supports does not moderate the relationship between reflective functioning and psychological distress.

The regression analyses below considers satisfaction with social supports as a moderator of the relationship between reflective functioning and psychological distress. The interaction variable was created by multiplying the reflective functioning variable and satisfaction with social supports. The results of the regression analyses for satisfaction with social supports can be seen in table 3.10.

Table 3.10: Regression analyses for satisfaction with social supports as a moderator

	Model One IV = rf DV= psychological distress	Model Two IVs = rf satisfaction with supports DV= psychological distress	Model Three IVs= rf satisfaction with supports rf x satisfaction DV= psychological distress
Beta: rf **satis. with** **support** **rf x satis.**	0.382	0.434 0.265	0.001 0.110 0.434
t: rf **satis. with** **support** **rf x satis.**	2.023	2.301 1.407	0.001 0.205 0.307
p: rf **satis. with** **support** **rf x satis.**	0.054	0.31* 0.17	0.999 0.839 0.762
R	0.382	0.461	0.465
Adjusted R2	0.110	0.144	0.109
R2 change	0.146	0.067	0.003

significant at p<0.05. All other findings = non significant

The table shows that reflective functioning alone accounts for 11% of the variance, but when considered alone is not a significant predictor (although approaching significance). However, reflective functioning is a significant predictor of psychological distress, accounting for 14% of the variance, when the effect of

---

satisfaction with social supports is accounted for, (significant at $p<0.05$), but not when the interaction of the two variables is considered (model three). However, the significance of F change is non significant for model two (F change = 1.773, $p<0.17$). Thus, satisfaction with social supports does not moderate the relationship between reflective functioning and psychological distress.

Chapter Four

Results of the qualitative data analysis

Overview

This chapter outlines the results of the analysis of six interview transcripts using Interpretative Phenomenological Analysis (IPA). The domains, clusters and themes gathered from this analysis are presented and discussed. Quotations from the transcripts are used to illustrate the various themes.

Daughter caregiver perceptions of the influence of their past relationship with their mother upon the caring role

At the end of the Adult Attachment Interview (AAI), daughters were asked six questions (see appendix six) relating to whether they considered their relationship with their mother over time to have influenced their caregiving role. These questions were adapted from Roland (1999) and were added approximately half way through the study. This was in response to the observation that many of the daughter caregivers reflected upon the caregiving relationship with their mother after the Adult Attachment Interview had finished. The responses to these questions were analysed separately from the AAI data using interpretative phenomenological analysis (IPA).

Fifteen daughters were asked these questions and twelve interview transcripts contained responses to all of the six questions. This section reports the clusters and themes gathered from six interviews, (six being half of the available data set and thus thought to be a representative number) chosen at random. Quotations from the participants are indicated by D plus a number (the identification number of the

participant). Four domains of themes emerged from the accounts of these daughter

caregivers. These can be seen in table 4.1 below.

Table 4.1: Summary of the domains, clusters and themes from the analysis of

daughter caregivers' perceptions of their caregiving role

Change and Loss	**Motivational influences**

◆ Changes in their relationship with their mother
  - role reversal
  - changes in their mother's personality/abilities
  - glimpses of pre morbid personality
 	
◆ Loss
  - coming to terms with changes
  - loss relating to other aspects of life
  - caring for your mother who no longer seems like your mother
	◆ Comparison with others
	  - other caregivers
	  - other mother-daughter relationships
	
	◆ Making sense of the motivation
	  - finding a reason why
	  - obligation
	  - lack of alternatives
	  - role of other people

Coping and support	**Caring within the context of the wider care system**

◆ The learning process
 	
◆ Sources of support
  - friends and family
  - carers organisations
 	
◆ Strategies for coping
  - needing time and space
  - specific strategies
  - childhood memories
	◆ The struggle to obtain appropriate services
	  - service inadequacies
	  - learning through experience
	
	◆ Service ideals
	  - support for carers
	  - resources for people with dementia

Change and loss

It became evident that change, both within the relationship with their mothers and within their mothers' personalities and abilities, and loss were key themes in the accounts of the daughter caregivers.

Changes in the relationship with their mother

Some of the caregivers talked about how their mother had changed through having dementia and how this had impacted on their relationship with their mother. For example one daughter caregiver (D18) said:

> *"I think it's made a bit more difficult because all the time you're thinking she shouldn't be like this she didn't used to be like this you know uh like when you try and give her food she'll really go for you I'm not eating a lump of shit not eating it and you think -- you know I I really could do something..." (D18).*

The daughter caregivers talked about how their mothers had become childlike through having dementia. References made by the daughters to their mothers in this way included *"naughty"*, *"childlike"*, and *"when she's a child"*. The identification of their mothers as childlike seemed to lead daughters into conversations about role reversal, taking charge and the need to protect their mothers.

A recurrent theme in the accounts of the daughters was the reversal of roles between mother and daughter, with the daughter taking charge and looking after the mother. For example;

"The way I am with her - it's well it's like role reversal now (right) ....

I I was suddenly like the one who had to be umm -- not in control but

looking after her and that telling her what she should do and

shouldn't do and her being like a child and refusing to do it and me

not behaving like a child and insisting that she did it you know...."

(D14).

Coming to terms with the reversal of roles was generally considered difficult by participants. For example as the above participant later explained:

"Yeah, it's just I think the role reversal is the hardest thing to accept

and it's the right thing to be you know you at the time it feels wrong it

feels completely alien to suddenly be the mother and the mothering ...

but it's fine now I feel that what I did and what I said it's like at the

time I felt very guilty every feeling of guilt that felt wrong at the time I

now feel was justified..." (D14).

Furthermore, one participant highlighted the difficulty of the transition for her mother as well as herself;

".......my mother's view of me was not as a daughter who could offer

care my mother's view of me was sort the daughter who visited you

know who when when I came I could take her out to lunch ... but I

couldn't do jobs for her like I couldn't clean the house or do her

----

shopping or sort practical things out so she wouldn't let me (umm)

and so it was a terribly difficult transition and I didn't I don't think

my mother ever took it into her mind that I was had become the

carer...." (D28).

Some of the caregivers seemed to give importance to the moments when their mother was able to remember or was more like the person they remembered. For these caregivers, these glimpses of "normality" appeared to be linked to the motivation to be able to continue caring, by being able to join with their mother in some way. For example, one caregiver (D18) describes these glimpses like so;

"..........but every so often she has patches of good and you say to her

do you remember so and so mum she'll say oh yeah we had a good

time then you dirty sod because her mind's gone again and that's how

it is ...... " (D18).

Loss

Many of the participants commented on at least one aspect of loss during their accounts. At times, this loss was concerned with the loss of the relationship that they had shared with their mother. This theme was closely related to the daughter's accounts of how their mother and their relationship had changed since the onset of the dementia. For example daughter caregiver 27 said:

"...because I loved her so much and she I was very close to her and I

considered her my friend I really miss her now I really miss having

---

her as somebody that I can talk to tell her about Naomi all sorts of

things like that plan things we always had you know Christmases

together and we did have a few holidays together..." (D27).

The participants also commented on the loss of their mother as a person and the depersonalisation of their mother through the onset of dementia. One daughter caregiver (D18) spoke of her mother becoming a stranger;

> *"Yeah what you've got to remember is that is isn't your mother is not*
>
> *your mother once it gets to stage uh past the memory loss and*
>
> *confusion once it gets to a stage like mum is now you which is what*
>
> *we're beginning to do now is to stand back and think we'll that's not*
>
> *my mother my mother went two years ago and this is a stranger in my*
>
> *mother's body um because it isn't your mother any more uh well it*
>
> *looks like your mother um and it knows your name it isn't your*
>
> *mother..." (D18) .*

The above account highlights the caregiver's perceptions about the loss of her mother as she once was and also the perception of the dementia progressively taking over her mother's body. The caregiver refers to her mother several times as "*it*", stressing the loss of the concept of her mother as a person. It perhaps also indicates the difficulty of coming to terms with the reality that this person was once very different to how she is now. For this caregiver, it seemed useful to think about her mother in this way as it seems to make it easier to continue with her caregiving role as she says it allows her to "*stand back*" from the situation.

Some of the caregivers referred to other losses they had experienced or could potentially experience because of their decision to become a caregiver. For example, one caregiver (D18) who had recently reached retirement age commented: *"... can I really give up my life for the next so many years to to look after somebody ... cos you think to yourself um I'm sixty and I'm retired I've got plans that we've made which is had to been put on hold ..."* . Other caregivers talked about the impact upon their careers, social life, hobbies and other relationships.

Motivational influences

Comparison with others

A number of participants described the reason they care for their mother by comparing and contrasting it with other peoples' relationships. For example, one caregiver compared her reasons for caring with her experiences of other carers at the local support group:

> *"... I've spoken to lots of people sort of at the Alzheimer's meeting...*
>
> *caring for mum I never ever wanted it to, some people do it's become*
>
> *chore to look after her or duty to look after her, it was always I*
>
> *looked after cos we wanted to look after her ..." (D14).*

Another caregiver compared her reasons for caring with her mother with those of a hypothetical person who hadn't had a close relationship with their mother: *"...... how could you umm suddenly bring yourself to care for somebody who you hadn't had a good life with I wonder and hadn't sort of close and got on well with .." (D27).*

Making sense of the motivation

Many of the caregivers suggested why they were currently caring for their mother. The theme of duty or obligation was a strong one in the accounts of the participants. Many likened it to "returning the favour". One daughter caregiver (D16) said: *"...some of it is obligation that because I feel that I was cared for (uh) therefore I would want to care for her"*, suggesting that she saw her caring role stemming from a concept of duty. Another daughter also referred to "returning the favour", this time seemingly based on a close childhood relationship *".....mum is the most important thing in our life um but then as I said she's my mum she looked after me when I was a child and now I'm looking after her when she's a child ... "* (D18).

One caregiver (D24) referred to the sense of satisfaction and achievement she felt in caring for her mother, suggesting another reason why some caregivers both decide to become a caregiver and continue with caring. The following excerpt suggests that this caregiver sees her caregiver role as her current employment:

> *"......I find it quite interesting umm that there's certain things that I found out that are in her mind and make her do things and I've I've found out why umm and I find that each day is so different and its an interest to me of how the mind works and why it works like that um and what you can do you know it's become my job now if I can find something that'll calm her down or stop her worrying it's an achievement for me..... " (D24).*

The importance of factors other than the relationship between mother and daughter were apparent in the accounts of the participants. These factors included the lack of appropriate alternatives as explained by one caregiver (D28) *"....I mean partly the reason I care for now is because nobody else will (uh huh) and so I suppose I could have chosen that route to ...".* The lack of choice was also expressed by one caregiver (D16) as the motivation behind her decision to become a carer, this time by referring to inadequate services for people with dementia *"...I would not leave her in the hands of the social services home care service which have not succeeded more in washing and dressing her properly and happily more than perhaps ten or fifteen times since Christmas ...".*

One participant (D24) however highlighted the impact of perceiving choice in her decision to care for her mother *"... at the back of my mind I've always known the money's that there via if I need to get mum into a home privately ...".* This comment suggests that the perception that there is an alternative to caring for mother at home, may be important for at least some caregivers in the decision to care or continue caring.

Some participants talked about the role of other family members, such as siblings or partners and their decision to become a caregiver. One caregiver (D28) summarized this as: *"...the story if you like is is obviously directly about me and her but it can't ignore those other players in in in the story".* The accounts suggest that family members can be a positive influence on the daughter's caregiving role. For example, the accounts described other members of the family such as husbands, siblings or off spring helping the daughter caregiver practically e.g. *"my daughter comes round you*

---

know umm once a week umm and my son pops in nearly every day cos he works in the area" (D24) and/or emotionally *e.g. "my daughter .. she's got a very adult head on her for fifteen and she's very caring and when I get upset and go home and cry about my mum she really helps me get through it"* (D27) with their caregiving duties.

However, the accounts also suggested that the decisions of other family members can influence the decision to care in a more negative way, by leaving one member of the family feeling as though they carry the responsibility for ensuring their mother is adequately cared for. For example, one caregiver recalled how she became a caregiver for her mother *"...my sister decided um about five years ago that my mother was becoming difficult and she was there was the first signs of dementia and she moved away .... I thought if you've got to go you've got to go you know and I'll do more visiting and my mother did kind of tip my mother into a major depression and dementia was there ..."* (D28).

Coping and support

One of the questions which the daughter caregivers were asked was " in difficult times what sources of strength do you draw upon to help you get through the day?". Some of the participants responded to this question by referring to members of their social network who gave them support while others referred to more specific strategies that they had found useful over time. The theme of coping and support also came up at other points in the interview and was often linked to the question which asked whether their relationship with their mother over time had influenced the way in which they coped with their caregiver role.

The learning process

Some participants talked about the process of learning to cope with the ever changing

dementia patient. For example:

> *"Everybody willl find it different and they seemed to go through*
>
> *different stages as well so you just get over one stage and you think*
>
> *ohh okay I've dealt with that and then a different thing happens and*
>
> *how have to start learning to deal with that you just have to try to*
>
> *keep as calm as possible ..." (D27).*

Strategies for coping

Daughter caregivers often cited specific strategies they used in order to cope. Many

of these involved creating time and space for themselves. For example one caregiver

(D16) said *"...I know I've got to get stress relief so I go home and play solitaire on*

the computer for perhaps a couple of hours......". Another caregiver (D24) outlined

several strategies she used in which to create some time and space for herself. She

also recognized the importance of maintaining other relationships:

> *"..I just ohh I got to go the loo and go off and have a cigarette when*
>
> *she's naughty ... I might just go out in the garden or just say ooh you*
>
> *know I'm going in the garden and cut the grass an something like that*
>
> *I just move away myself ... I do a bit of painting ... you've got to have*
>
> *a cut off point where you stop being a carer and be a wife and mum*
>
> *.." (D24).*

Interestingly, some of the participants referred to stories from their childhood as a way of thinking about how they coped with caring for their mother. These stories perhaps highlight the powerful nature of events in childhood upon current life. Two examples of this can be seen below;

> *"... we used to have this funny old aunt who wasn't actually dementia but she was always a little bit slow ..... and she used to say to me if I ever get like sis push me down the stairs so if she's playing up too much I say you know who you're getting like don't you aunt sissy she went ohh I'm not am I umm you know so I think that's how we cope that's that we've always had that relationship (yeah) umm you know as I say we have been close and confided in each other and I think that's helped how we care now" (D24).*

and

> *"I can remember there was a boy at school um I think he must have be must have been spastic and of course you know what kids are like and I know my mum said to me you mustn't do that just because he's got something wrong with him doesn't mean that he's not as good as you are um you know God made everybody and I think that's why I can can cope with the way my mum is ...." (D018).*

Sources of support

Many of the participants cited other family members such as siblings, partners and offspring as sources of support. Participants also frequently mentioned the voluntary carers' organizations as valuable sources of both information and advice, suggesting that contact with other carers is important. One caregiver (D24) talked about the training she had received from her local carers' group which focused on useful strategies in managing various aspects of dementia. This she described as a *"real boon".*

Caring within the context of the wider care system

Caring for their mothers in the context of service provision was a strong theme for many participants. They referred to inadequacies in the services for people with dementia, their struggles to gain more suitable and higher quality care and their vision of ideal services.

The struggle to obtain appropriate services

Many of the participants referred to the difficulties they had encountered in obtaining appropriate care for their mother from formal services. Some of the concerns related to the financial arrangements of the system. For example, one caregiver (D18) said;

> *".. the only problem is is money you see everything you have to pay*
>
> *for she owns half of her house that we've been in since she became ill*
>
> *moved in with us umm and of course it costs five hundred pounds a*
>
> *week so you can't do it.." (D18).*

Other concerns were about the lack of services or inadequate services for people with dementia and their relatives. For example caregiver 27 said *"...certain days I feel I can cope and other days I just cannot cope and I think there's no help out there for us there's no one to talk to..."*. Another caregiver (D16) commented on the lack of beds available in her local area for people with dementia. Some daughters believed that their mother's would receive better care if they remained with them, suggesting perceptions of poor services. As one daughter caregiver (D24) explained *"..there's a few things that I kind of found out what irritates her and what I can do to keep her amused umm that I've worked out that I know she wouldn't get in a home.."*

Caregivers also commented about the level of care they currently received;

> *"....home care will put two hundred different women in in to look after mum without thinking of my father's feelings that all these strange people coming in to the house (um) and making mom burst into tears because there not her friends that I think the actual feelings of the family are not taken into account by the social services...."*
> *(D16).*

With regards to their struggles to gain more appropriate services, caregivers commented on learning from experience; *"... I think I would be a bit more dominant three years ago (right) in trying to get the right services from day one now I know what exists or what could have existed ..." (D016).* Another caregiver (D18) similarly commented *"... you can't tell what's in the future can you but if I'd had any inkling this was going to happen I would have made her sold the house and give*

----

it to my brother um so that she hadn't got any money then the State would have

kicked in ... " The caregivers frequently used battle analogies, such as *"you're*

fighting the whole time" to describe their experiences.

What carers are looking for from services

Some of the caregivers talked about what they would like from services for

themselves, their mother and for people with dementia more generally. With regards

to themselves, caregivers stressed the need for someone to talk to and the need for

information and advice. One participant (D27) talking specifically about her needs

from services as a caregiver said:

> *"......sometimes all you want is to talk to somebody and ask them*
>
> *questions so they can give you an answer how do you deal with*
>
> *certain things, what can we do to help ... sometimes I want to be*
>
> *taught how to deal with her ... I wish there was somewhere you could*
>
> *go to get advice on how to deal with this ..."* (D27).

Some participants also commented on the needs of their mother or more generally,

people with dementia. For example, one caregiver (D16) said *"...its really much*

more understanding of dementia by the services that are looking after them...." .

Furthermore, this caregiver said that people with dementia *".. respond to being cared*

for and loved they don't respond to being told what to do ... they need more love

much more love than I think we can understand because they're frightened...".

Chapter Five

Discussion

Overview

This final chapter of the thesis provides a summary and evaluation of the main findings of the study. These findings are discussed in light of previous research in the field. The chapter also provides an account of the limitations of the current research. Finally, the clinical implications of the research and directions for future research are discussed.

Summary and evaluation of the main findings

The aim of this study was to extend previous research on attachment and caregiving in dementia care. Specifically, the primary aim was to explore the possible associations between daughter caregivers' narratives concerning their relationship history and their self-reported levels of psychological distress. Additionally, via qualitative analysis, the study aimed to explore daughter caregivers' current thoughts and feelings about their relationship with their mother. The main findings of the study and their relationship to the hypotheses stated in the introduction, as well as novel features of the observed results, are reviewed below. The findings from the qualitative analysis are also briefly summarized.

Distribution of adult attachment classifications

An interesting observation from this study is the finding that only eight daughter caregiver participants were classified as being securely attached according to Main and Goldwyn's (1994) classification system, whilst the majority, twenty, were

---

classified as being insecurely attached. Additionally, six interviews were judged to be unresolved with respect to either loss or trauma.

The attachment classifications found in this study are dissimilar to the ones demonstrated in other attachment research with non-clinical populations. In a meta-analytic review of over six hundred Adult Attachment Interviews involving non-clinical samples, Van IJzendoorn (1995) found 56% were classified as secure, 27% dismissing and 17% preoccupied, compared to 28.6%, 35.7% and 35.7% respectively for this study. The low percentage of secure individuals is similar to that found with a clinical population of psychiatric patients (Fonagy et al, 1996). Curiously, previous research by Roland (1999) using the AAI with a small sample of eighteen daughter caregivers, observed proportions of security much more in keeping with the normal range as reported by Van IJzendoorn (1995).

This finding that over 70% of the sample were classified as insecurely attached is an interesting one. One can speculate why this may be the case. Given Roland's (1999) findings, it seems that the distribution of AAIs for this sample is not necessarily representative of all daughters caring for their mothers with dementia. It may be that this particular study and the way in which participants were recruited, attracted daughter caregivers who had an insecure attachment history who felt that they needed an opportunity to tell and reflect upon their narrative histories. This is in part is reflected by the fairly large proportion (21.4%) of interviews rated as unresolved with regards to loss or trauma. Only one (3.6%) of these interviews classified as unresolved was rated as secure. Unfortunately, Roland (1999) did not report classifications regarding unresolved loss or trauma.

Furthermore, it may be that daughters caring for their mothers with dementia with secure attachment histories did not feel that they needed an opportunity to tell their attachment narratives. One further consideration, is that daughter caregivers with secure attachment histories are more likely to be able to negotiate issues such as the decision to place their mother in residential care or enlist others to help care for their mother. Clearly, these hypotheses require further exploration and empirical testing.

Overall coherence and reflective functioning

With regards to the subscales of the AAI and the Reflective Functioning Scale (Fonagy et al, 1998), the daughter caregivers from this sample scored low on all three core dimensions of attachment under consideration (reflective functioning, coherence of transcript and coherence of mind). The participants in this sample scored lower than non-clinical populations on the subscales of the adult attachment interview pertaining to coherence. The mean score reported for a non-clinical sample on overall coherence (coherence of transcript and mind) is 5.50 compared to the current sample mean of 4.04 (Fonagy et al, 1996). Roland's (1999) reported sample mean for overall coherence was 5.56.

The participants also scored low on the Reflective Functioning Scale, with the mean being 3.14. This indicates that on average the sample were scoring within the lacking to low reflectivity range. The mean score on the Reflective Functioning Scale was found to be 5.50 in a non-clinical sample (Fonagy et al, 1996). Comparing the current sample mean with Roland's (1999) study of daughter caregivers, the current sample scored lower on average than her sample of daughter caregivers (mean 3.94, SD

1.73). Interestingly, Roland's (1999) sample mean for reflective functioning is also lower than non-clinical samples. The mean scores obtained by the current sample on both overall coherence and reflective functioning more closely resemble mean scores obtained by a psychiatric sample (4.10 and 3.70 respectively; Fonagy et al, 1996).

Although the range of scores on the reflective functioning scale was varied (1-8), the mean score was low in comparison with other non-clinical populations. It was similar however, to the mean score obtained in Roland's (1999) study of daughter caregivers. The mean score on overall coherence was also lower than reported by Fonagy et al (1996) for non-clinical populations. The results suggest that with regards to overall coherence and reflective functioning, the current sample shared more similarities with clinical populations than with non-clinical populations. This finding shares some similarities with research findings of increased psychiatric difficulties in caregiver samples (Morris et al, 1988b). Notably, Morris et al (1988b) observe up to 68% psychiatric caseness in their narrative review of eleven studies.

Levels of psychological distress and social support

The means, standard deviations and range of scores were reported for each of the self report measures. The ranges on both the General Health Questionnaire (Goldberg, 1978) and the Relative Stress Scale (Greene et al, 1982) completed by the participants indicate that there was a large amount of variability in the amount of psychological distress reported by the caregivers in this study. The descriptive statistics also suggest that on average, the daughter caregivers were experiencing a considerable amount of psychological distress at the time they completed the questionnaires.

The GHQ total score (mean 25.63, SD 15.34) is similar to that reported by Roland (1999; mean 23.89, SD 4.79), suggesting similar levels of psychological distress. The mean score of 22.80 (SD 11.28) on the RSS scale was lower than that reported by Roland (1999; mean 31.78 SD 9.76) and also lower than that reported by Greene et al (1982; mean 27.22, SD 10.33), suggesting less stress as measured by this particular questionnaire.

The number of social supports reported by participants as revealed by the Social Support Questionnaire (Sarason et al, 1987) varied widely. However, the participants reported that they had on average 18 social supports upon whom they could call for support in times of need. According to scores on the satisfaction with social supports sub-scale, the participants reported high levels of satisfaction with the support they were receiving.

The relationship between psychological distress and demographic variables

The relationship between various demographic variables collected in the study and psychological distress was explored. Based on previous research (e.g. Aneshensel et al, 1995), hypothesis one predicted that the severity of the care recipient's dementia and the nature of the caregiving relationship (i.e. number of hours care provided by the daughter, number of months daughter had been caring for her mother) would be related to the amount of psychological distress experienced by the daughter caregivers. It was found that none of the demographic variables collected in this study were significantly correlated with psychological distress. However, the

strongest correlations were reported for mother's age, daughter caregiver's age and whether or not the daughter received help from services.

In previous research, the nature of the care demands, including the physical requirement of providing care and the daily management of a relative with dementia have been shown to be related to caregiver distress. For example, in a longitudinal study, Aneshensel et al (1995) found that greater caregiving demands were associated with elevated caregiver burden. It may be that no statistically significant associations were found in this study because of the small overall sample size and also because of the significant amount of missing information.

The relationship between attachment and psychological distress

Hypotheses two and three predicted relationships between attachment status and psychological distress. Given that there were only twenty seven available data sets and that over seventy per cent of these interviews were classified as insecure (and thus insufficient statistical power), the relationship between security of attachment and psychological distress was not investigated.

Instead, the dimension of coherence was explored as an indicator of attachment security. Main (1991) has previously argued that coherence (both the coherence of transcript and coherence of mind subscales of the AAI) is the strongest predictor of an infant's security of attachment to his/her caregiver. The results of this study found that overall coherence was not significantly related to levels of psychological distress.

Hypothesis three suggested a relationship between reflective functioning as measured by the Reflective Functioning Scale and levels of psychological distress. Specifically, this hypothesis predicted that high reflective functioning would act as protective factor from psychological distress. Thus, it was expected that daughter caregivers scoring high on this scale would score lower on the measures of psychological distress. It was found however, that reflective functioning was significantly and positively correlated with psychological distress: the higher the score on the Reflective Functioning Scale, the higher the score on the overall measure of psychological distress. This finding is in the opposite direction to the one proposed in hypothesis three.

The finding that daughters with higher scores on the Reflective Functioning Scale were more psychologically distressed is worthy of attention. Some support for the current finding regarding reflective functioning comes from Roland's (1999) study. She found that daughters who were more reflective reported significantly higher scores on the life upsets sub scales of the Relative Stress Scale. However, previous research has suggested that reflective functioning and coherence may serve as protective factors from mental health difficulties (Fonagy et al, 1994, 1996). Furthermore, Fonagy et al (1998) have argued that reflective functioning in the parent is the best predictor of attachment security in the infant.

With regards to the caregiving situation in question, it had been suggested (e.g. Roland, 1999) that the current state of mind with regard to her attachment to her mother (i.e. coherence and reflective functioning) may be crucial. More specifically, on the basis of attachment theory and research it has been suggested that one might

predict that a daughter who is aware of her own and her mother's imperfections both now and in the past and who can openly discuss these in a balanced and integrated way would find caregiving less stressful.

The assumption that findings from infant-caregiver studies demonstrating the protective nature of reflective functioning could be translated across the life span may have been naive. Reflective Functioning enables an individual to "read" another persons mind through the ability to attribute mental states and feelings to others (Fonagy et al, 1998). As Slade (1999) suggests, reflective functioning is what allows the individual to make sense of his/her own experience and to enter into another person's experience. Thus, in the context of this study, daughters scoring higher on the reflective functioning scale may be better able to attribute mental states to their mothers and so empathize with their mother's difficulties. This ability to empathize and "put oneself in mother's shoes" may lead to greater psychological distress. Importantly, the high reflective functioning score itself is likely to reflect earlier childhood adversities that have been largely overcome (Fonagy et al, 1994).

Conversely, a daughter scoring low on the Reflective Functioning Scale is lacking in the ability to make sense of her experience and other's psychological experience and thus less able to "put herself in her mother's shoes". Therefore, it may be that these daughter caregivers do not experience the same levels of distress. Another plausible explanation for the finding that daughters with lower reflectivity were less distressed as measured by the self-report measures, is that these daughters were less open and more defensive about the distress they were experiencing. Reflective functioning is

----

associated with the ability to fully experience, express and regulate a range of both

positive and negative affects (Slade, 1999).

To date, reflective functioning has been connected with observable behaviour i.e. an

infant's behaviour towards their caregiver (Fonagy et al, 1994). It may be that

although daughters with higher reflective functioning are more distressed, they may

demonstrate different observable behaviour patterns towards their mothers than

daughters with lower reflective functioning. Fonagy et al (1998) maintain that

reflective functioning provides the individual with a "well developed capacity to

distinguish inner from outer reality, pretend from real modes of functioning and

intra-personal mental and emotional processes from interpersonal communications"

(p.4). Thus, reflective functioning has been argued to enhance communication

(Fonagy et al, 1998). To date, data collected from the larger Caregiving and

Dementia study at UCL has demonstrated links between unresolved loss and role

reversal with respect to overall communication quality and emotional attunement

(Woods et al, 2000).

The role of support in relation to attachment and psychological distress

The role of social support in the relationship between reflective functioning and

psychological distress was investigated. It was predicted in hypothesis four that

social support would influence the relationship between attachment and psychological

distress, either through mediation or moderation. The role of social support was

investigated through two means; the number of perceived social supports reported by

the participants and their satisfaction with these supports. It was found that neither

the perceived number of social supports nor the reported satisfaction with these supports as measured by the Social Support Questionnaire (SSQ; Sarason et al, 1987) mediated the relationship between reflective functioning and psychological distress. Furthermore, the two social support variables were found not to moderate the relationship between reflective functioning and psychological distress. Thus, hypothesis four was not supported.

However, an interesting observation was made regarding the relationship of reflective functioning and overall coherence and professional help. Based on limited numbers, there was a significant trend towards relationships between carers' score on the Reflective Functioning Scale and on the Overall Coherence dimension and whether or not a daughter received help from services with regards to caring for their mothers. These findings suggested that the higher the score on Reflective Functioning Scale and the higher the score on the Overall Coherence dimension, the more likely the daughter caregivers were to be receiving help from services.

The finding that social support did not mediate or moderate the relationship between attachment and psychological distress was unexpected. However, accounting for social support (both number of available supports and satisfaction with current support) in regression analyses suggested a trend for both number of social supports and satisfaction with social support to be independent predictors of psychological distress, accounting for an additional 7% and 3% of the variance respectively.

Conversely, previous caregiver research has demonstrated that social support plays an important role in the caregiving process, with lower levels of social support being

---

associated with greater levels of depression (Rapp et al, 1998, Bodnar and

Keicolt-Glaser, 1994). Specifically, previous research had indicated that attachment

style (as measured by self report measures) contributed to the prediction of the total

number of social supports and the satisfaction with these social supports as measured

by the SSQ (Markiewicz et al, 1997). However, the current research did not find a

statistically significant association between overall coherence and reflective

functioning and either sub-scale of the SSQ.

Interestingly, the qualitative analysis carried out on a sub group of the current sample,

suggested that social support was an important theme for the participants in thinking

about coping with the stress associated with caring for their mother. In attempting to

understand the relationship between psychological distress and support, Morris et al

(1988b) maintain that the relationship between social support (both informal and

formal) is a complex one. They summarize research findings which indicate that

support may not be so beneficial in alleviating caregiver burden for women and

suggest that this may be related to gender role expectations.

Of particular note, was the trend observed towards an association between a

daughter's level of reflective functioning and whether or not they received help from

services. The daughters with higher reflective functioning were more likely to be

distressed than daughters with lower reflective functioning. This may mean that these

reflective daughters were therefore more likely to be receiving help because of their

levels of distress. Alternatively, it could also be that these daughter caregivers were,

in some way, more able to ask for or seek appropriate sources of help. Social

resourcefulness is one of the many coping resources pressed into service by people

when acute and chronic demands threaten to disrupt their psychological or social equilibrium (Rapp et al, 1998). How people request, direct and maintain social support in times of need has been found to be important. Rapp et al's (1998) findings were consistent with the idea that social resourcefulness leads to social support and support in turn, enhances well-being. It is possible therefore, that with a larger sample size, a link between attachment, social support and well-being may be more robustly highlighted.

Qualitative analysis

In response to the participants reflecting upon their relationship with their mother over time and the influences upon their caregiving role after the AAI interviews had finished, several questions were added to the end of the AAI to capture these comments. These questions were adapted from Roland (1999). The responses to the questions were analysed separately from the AAIs, using interpretative phenomenological analysis.

From the analysis of six interviews, four categories of themes were identified. These categories were change and loss, motivational influences, coping and support and caring within the context of the wider system. These categories will be discussed in turn below.

Change and loss

Many of the daughter caregivers talked about their experiences of change in their mother's personality and in their relationship with their mother, and the associated feelings of loss. A recurrent theme in the accounts of the daughters was the reversal

----

of roles between mother and daughter, with the daughter taking charge and looking after the mother. Coming to terms with the reversal of roles was generally considered difficult by participants.

The theme of role reversal is an interesting one. It is generally considered in attachment theory that it is maladaptive for the parent of a young child to reverse roles and to seek care, support and security from the child. However, when the parent suffers with dementia or experiences ill or failing health, the roles established in childhood may become completely reversed, with the adult-child providing security and protection to their parent (Colin, 1996). Caregiving and role reversal in these circumstances is not well understood or researched. More specifically, it is not known whether the occurrence of role reversal in childhood makes it easier or more difficult to adjust to such changes in later life.

Many of the participants commented on at least one aspect of loss during their accounts. The losses the daughters described concerned the loss of the relationship that they had shared with their mother, the loss of their mother's pre-morbid personality, and losses in other aspects of their life they had experienced or could potentially experience because of their decision to become a caregiver.

The theme of loss was a particularly strong one for these caregivers. Woods (1989) has likened the experience of being a carer for a dementia sufferer to a bereavement. Furthermore, he highlights loss as a major feature of the life of a caregiver. The accounts of the daughter caregivers highlighted several aspects of loss experienced by this group of caregivers. Interestingly, many aspects of loss discussed by the

participants were related to the change in the structure of the relationship between mother and daughter.

Motivational influences

Researchers have noted several reasons why a relative may take on a caregiving role. These have included the lack of viable alternatives, to fulfil an internalised norm of duty, emotional attachment and the life long history of relationships (Aneshensel et al, 1995). These reasons are consistent with some of those discussed by the daughter caregivers in this study. The study also supported the idea that the selection of a caregiver is regulated not only by the quality of the relationship, but also by powerful customs dictating circumstances under which individuals feel obligated to provide care (Aneshensel et al, 1995). However, of note were the attempts made by these caregivers to understand why and search for the reason why they had taken on the role of caring for their mother.

A number of participants described the reason they care for their mother by comparing and contrasting it with other peoples' relationships. The explanations discussed by the daughter caregivers included duty or obligation, the relationship they had had with their mother over time and the sense of satisfaction and achievement they felt in caring for their mother.

The importance of factors other than the relationship between mother and daughter were apparent in the accounts of the participants. These factors included the lack of appropriate alternatives, inadequate service provision and the role of other family

---

members, such as siblings or partners, in their decision to become a caregiver and to continue in their caregiving role.

Family members were seen by the participants as either positive or negative influences upon their current caregiving role. Likewise, some researchers (e.g. Lee, 1999, Fisher and Lieberman, 1994) have suggested that the impact of the family is not always a positive one, with some family qualities serving a protective function and others exacerbating the negative aspects of caregiving by affecting personal health and well-being.

Coping and support

Daughters were explicitly asked about their coping strategies in times of difficulty. Some of the participants responded to this question by referring to members of their social network who gave them support while others referred to more specific strategies that they had found useful over time. The theme of coping and support also came up at other points in the interview and was linked to the question which asked whether their relationship with their mother over time had influenced the way in which they coped with their caregiver role. Some participants also talked about the process of learning to cope with the ever changing dementia patient.

Interestingly, some of the participants referred to stories from their childhood as a way of thinking about how they coped with caring for their mother. Finding personal meaning from the caregiving situation (i.e. holding positive beliefs concerning one's caregiving role) has been identified as an important mediating variable in the relationship between care-related stressors and well-being (Noonan and Tennstedt,

----

1997, Morris et al, 1988a). Furthermore, Morris et al (1988b) have suggested that the ability to find a meaning from the caregiving situation is likely to have links with the historical relationship with dementia sufferer.

Many of the participants cited other family members such as siblings, partners and offspring as sources of support. Participants also frequently mentioned the voluntary carers' organizations as a valuable source of both information and advice, suggesting that contact with other carers is important.

Coping and support have been previously argued to be linked to levels of psychological distress. For example, Aneshensel et al (1995) maintain that social, personal and material resources may moderate the relationship between stress and it's outcome. Research investigating the role of coping in caregiving for an elderly relative has suggested that perceived ability to cope may be an important factor in determining the level of psychological distress (Morris et al, 1988b). As discussed previously, the relationship between social support and distress is a complex one, with at least some research suggesting that social support plays an important role in the caregiving process (Rapp et al, 1998). The interviews analysed qualitatively highlighted the importance for these caregivers of several aspects of coping and support; the need for both support from family members and professional help (in terms of help with the more practical aspects of caring and emotional support) and of finding ways which allowed the caregiver to have some time to themselves.

Caring within the context of the wider care system

Caring for their mothers in the context of service provision was an important theme for many participants. They referred to inadequacies in the services for people with dementia, their struggles to gain more suitable and higher quality care and their vision of ideal services.

Many of the participants referred to the difficulties they had encountered in obtaining appropriate care for their mother from formal services. Other concerns were about the lack of services or inadequate services for people with dementia and their relatives, such as the lack of emotional support for carers and the lack of respite care beds. Consequently, some daughters believed that their mother's would receive better care if they remained with them. Furthermore, the participants commented on their struggles to gain more appropriate services, which were often described using battle analogies.

Some of the caregivers talked about what they would like from services for themselves, their mother and for people with dementia more generally. With regards to themselves, caregivers stressed the need for someone to talk to and the need for information and advice.

The participants highlighted the importance of considering the wider context in understanding their caregiving role in several ways. Firstly, through their reasons for caring for their mother. Secondly, through their discussion of the role of significant others in their caregiving duties and finally, through their discussion of service related issues. Their accounts demonstrate the complexity of understanding the decisions to

care and whether to continue to care for their mother. As one caregiver succinctly put it *"...the story if you like is is obviously directly about me and her but it can't ignore those other players in in in the story"* (D18). The accounts also highlight how several theories (e.g. stress process model, attachment theory) may be useful in understanding the complex nature of caregiving relationships.

Limitations of the study design

Sample size

A considerable limitation of the current study was the sample size. Thirty one daughter caregivers participated in the research, with only twenty seven of these providing complete data sets including the AAI and self report measures. One daughter caregiver did not complete the AAI, one daughter caregiver did not complete the self report measures and for the remaining two caregivers, the AAIs could not be coded because of poor recording quality. The sample size is thus small and restrictive.

The original aim of the study was to recruit sixty daughter caregivers following consideration of the likelihood (based on previous attachment research involving non-clinical participants) that at least one third of these 60 daughters would present with insecure attachment narratives. Further, power analyses suggested that with a sample of this size , moderate to large effects would be readily observed.

Recruitment of daughter caregivers proved very difficult, even though several means to do so were tried (advertisements in the national and local press, advertisements via voluntary organizations, face to face contact with several carers groups and contact

----

with local clinicians). Although fifty two daughter care givers contacted the study, twenty one (40.40% of all inquiries) did not take part in the study. Of those who did not take part in the study, twelve declined to take part after their inquiry, five did not meet the study's inclusion criteria and four women cancelled after making appointments. Sixteen out of the twenty one caregivers declining to participate suggests a high refusal rate. Unfortunately, demographic data about those who did not take part, allowing comparisons with those who did, was not available.

However, the daughter caregivers who did take part in the study came from a range of recruitment sources (although many of them were already receiving support from services). There was also some variability in the demographic variables collected in the study such as the daughter caregivers age, the number of hours they spent caring for their mother and the length of time they had been caring for her. The daughter caregivers were in the main similar to other samples of caregivers with regards to the levels of psychological distress they were experiencing (see Roland, 1999, Greene et al, 1982).

The lack of observed associations between attachment status (e.g. reflective functioning, coherence), psychological distress, social support and the demographic variables may be related to the sample size. It is possible that with a larger sample size, the trends observed in the data would reach levels of significance (because of greater power). Presuming that a larger sample size would lead to a higher proportion of securely rated individuals, a larger sample size would also mean that attachment security could be investigated as a predictor of psychological distress.

The use of a smaller sample in this study allowed for the use of both qualitative and quantitative research methodology. The sample size specifically allowed the author to conduct some qualitative research, which was not planned at the start of the project. The qualitative findings have helped to think about the broader context of caring for a relative with dementia and to think about possible future research directions.

Generalisability

A further limitation to the current study with respect to the sample size, was the distribution of adult attachment classifications. The lack of securely attached daughter caregivers in the current sample suggests some caution should be taken before generalizing the findings to other daughter caregivers who may more closely resemble the sample of Roland (1999).

Additionally, the sample was restricted to daughter caregivers only and thus the findings may only apply to this specific group of caregivers. Furthermore, the daughter caregivers came from the urban south east of the country and were predominately from white, middle class backgrounds.

Measures chosen

The Adult Attachment Interview

The AAI was chosen for use in this study because it provides a comprehensive measure of relationship patterns with parental figures across the life span, from early childhood through to the current day. Notably, the psychometric qualities of the AAI classification system have been thoroughly tested (George et al, 1996). It was also considered superior to self-report questionnaires which measure attachment styles.

Questionnaires measuring attachment styles have not been found to be predictive of infant-parent attachment, have been unable to capture the current state of mind regarding attachment and are at risk of misjudging some aspects of attachment (Hesse, 1999, Steele and Steele, 1994).

However, the Adult Attachment Interview was originally developed to specifically understand parent-child relationships in context of understanding a young child's attachment to his/her parents (Hesse, 1999). Although the AAI has been used in many research studies and it's use with differing populations has widened, it has not been widely used with older people. Furthermore, the AAI has not been extensively used to explore other types of caregiving relationship, such as caregiving in dementia.

This study raises an interesting question regarding the use of the AAI in this type of research. It is currently unknown whether the experience of caring for your mother with dementia and coming to terms with the diagnosis of dementia can impact upon the attachment narrative and the daughter's current state of mind regarding attachment. Ideally, the adult attachment interview would have to be carried out prior to the onset of the mother's difficulties, and at some point after the onset, to explore the influence of the caregiving relationship on the attachment narrative.

Until recently, caregiving as an organised behavioural system has not been considered in depth (George and Solomon, 1999). George and Solomon (1999) suggest that caregiving behaviour is organised within a behavioural system that is independent of, but linked developmentally and behaviourally to, attachment. The consideration of a complementary caregiving system moves the focus of understanding the child-parent

----

relationship from the perspective of being protected to the perspective of providing

protection. Furthermore, George and Solomon (1999) suggest that parents of

children with differing attachment classification have different representations of

themselves as caregivers. The consideration of a specific caregiving system perhaps

lends itself to the development of specific measures to explore caregiving behaviour.

Solomon and George (1999) have made some attempt to develop an interview

measure of caregiving behaviour in adults for use with mothers of young infants.

Self-report measures

The self report measures chosen for this study allowed the testing of the hypotheses

stated in the introduction. However, it can be argued that a study is only as good as

the measures it has employed.

The General Health Questionnaire (GHQ-28; Goldberg, 1978) and Relative Stress

Scale (Green, Smith and Timbury, 1982) were chosen as measures of psychological

distress because they are both standardized scales which have been widely employed

in caregiver studies. For the purposes of this study, the scores of both questionnaires

were summed to form an overall score of psychological distress. While this approach

has it's advantages, for example, it may lead to less risk of type one error, it can be

argued, despite the strong and positive correlations, that the questionnaires measure

different aspects of psychological distress. In line with this argument, it could be

argued that attachment may influence different aspects of psychological distress (i.e.

psychiatric problems vs. specific caregiver stress) in different ways.

The Social Support Questionnaire (Sarason et al, 1987) was chosen because it is possible to measure both the availability of social support and satisfaction with this support. The questionnaire has good internal and test-retest reliability (Sarason et al, 1987). Although this questionnaire is a popular measure of social support, an interesting observation about the use of SSQ was made during the study. Many of the participants who took part in the study found the instructions for the questionnaire difficult to understand and needed further explanation. The confusion about the demands of the questionnaire may have influenced the accuracy of the responses. It could also be argued that the satisfaction sub-scale of the questionnaire contains elements of social desirability, especially as most participants reported that they were very satisfied with the support they had listed.

The use of quantitative and qualitative research methodology

The use of both qualitative and quantitative research methodology is worthy of mentioning. It may be argued that treating the Adult Attachment Interview narratives and the narratives regarding daughter caregivers perceptions of the influences on their current caring role separately is a methodological weakness. However, in the light of the above discussion regarding the applicability of the AAI to older populations and other caregiving situations the methodological stance taken may be considered as a strength of this particular study.

Smith et al (1997) have suggested that the way an individual thinks about and labels a stressful situation may be important in determining their response to the stressor. Thus, the detailed examination of individual accounts of stressful situations will enrich the understanding of the factors and processes involved. Additionally, Barker et al

(1994) adopt a stance of methodological pluralism, suggesting that examining single cases within the context of a larger comparison study gives a human dimension to research that is lacking in the predominantly statistical reports from larger projects. In this case, the use of a separate qualitative analysis, although limited in its numbers, has highlighted specific relationship changes which may be associated with difficulties and also influences on the caregiving relationship other than attachment.

Clinical implications

Given the lack of alternative good quality formal services and the social pressure and moral obligation which carers feel to care for their relatives (Circelli, 1993), it is likely that carers will continue to take on the role of caring for their elderly relatives irrespective of the quality of their relationship with that person. This study has highlighted the importance of understanding both the historical context and the wider context of the caregiving relationship.

This study has implications at a service level. Firstly, services need to acknowledge the impact of a caregiver's relationship history and current state of mind regarding their relationship with their mother. This means that assessments should routinely ask about the nature of the relationship over time and their current relationship. Assessments should also consider the wider context such as family relationships and financial and practical resources. The research also suggests that services also need to address the lack of the good quality resources currently available to caregivers and people with dementia. As the participants themselves highlighted, emotional, as well as practical, support should be routinely available for caregivers. The participants

----

also indicated the need for education about dementia and formal training to help

caregivers cope with the difficulties they face.

Thinking about caregivers on an individual level, attachment theory provides guidance

as to how a therapist might best intervene to support these caregivers. A

consideration of attachment theory in preparing formulations regarding individuals

can be useful in helping the clinical psychologist decide whether an intervention is

needed and devising the most appropriate intervention. One further strength of

attachment theory its' application to the understanding of current relationships,

including the therapeutic relationship. Attachment theory can be applied to the

thinking of transference and devising therapeutic strategies (Bowlby, 1988, Holmes,

1996). According to attachment theory the patient will attach him/herself to the

therapist during the course of treatment. The nature of this attachment, the

transferential feelings and therapeutic strategies will differ according to the type of

attachment link (Holmes, 1996).

More specifically, Steele and Steele (in press) maintain that the Adult Attachment

Interview has potential clinical applications in the diagnosis, treatment and outcome

evaluations of clinical work. Slade (1999) suggests that the AAI classification system

may help the therapist to navigate a therapeutic path that might assist the patient

toward noticing the connections between conscious, verbally articulated patterns of

behaviour and earlier experiences of rejection, separation and loss and unmet

attachment needs.

The finding that daughters with higher reflective functioning are likely to be more psychologically distressed needs consideration. Although these daughters are likely to be more distressed, they are also inclined to be more open about this distress and perhaps more able to ask for support, implying that reflective functioning may not mean that these daughters, (and their mothers) are at increased risk of experiencing difficulties in their caregiving role. Moreover, as these daughters are likely to be more communicative about their distress, they may respond well to therapeutic input. Reflective functioning is indicative of the ability to regulate and thus fully experience a range of affects (Slade, 1999). Thus, daughter caregivers with good reflective functioning may be able to make good use of therapy through the open expression of a range of emotions and states associated with their caregiving role. Furthermore, these daughters may be more able to listen, contemplate and use specific therapeutic interventions.

For daughters who scored lower in reflective functioning, therapeutic interventions may be particularly important if levels of distress are being masked (see above) through defensive processes. Clinicians should be aware that these daughters and in turn, their mothers, may be at increased risk of experiencing difficulties. Main (1991) has drawn attention to the structure of the attachment narrative. Main suggests that experiences that cannot be known or spoken about are at the root of incoherence in discourse. Through careful attention to the narrative process, clinicians can gain insight into how the patient defends him/herself against the intrusion of unacceptable feelings or memories into conscious thought (Slade, 1999).

Directions for future research

Given the limited sample size, it is appropriate to suggest that more research with bigger sample sizes is required to assess the generalisability of these findings to other daughter caregivers. A bigger sample would also facilitate the exploration of attachment security, and more specifically, attachment classification, and it's relationship to psychological distress. Furthermore, an increased sample size would allow more sophisticated statistical analyses to be performed on the data.

It may also be useful to explore the effects of other familial relationships, attachment, caring for an elderly relative with dementia and psychological distress. For example, previous research (Bledin et al, 1990) has highlighted potential differences between adult child caregivers who have siblings and those who do not. Further research investigating this aspect may prove fruitful.

Given that daughter caregivers bought specific attention to the concept of role reversal and the difficulty in adjusting to this change of roles, this area would be an interesting area of further investigation. The Adult Attachment Interview has a specific scale relating to this concept which may be useful to use. Similarly, other specific experiences during childhood may also be worthy of attention.

Attachment theory predicts how individuals regulate emotions and use different coping styles in dealing with problematic situations (Markiewicz et al, 1997). The link between attachment and coping style was not explicitly explored in this study. Roland (1999) found some evidence that reflective functioning may be related to coping style. Her results specifically suggested that a greater use of cognitive

---

approach coping was associated with higher reflective functioning scores. The association between attachment dimensions and coping styles deserves further attention. It would also be of great interest to consider whether attachment can help predict how caregivers respond over time to their mother's decline and her eventual death.

The understanding of caregiving has been concentrated upon the parent-child relationship. Research which extends the understanding of caregiving to other caregiving relationships would increase our understanding of the caregiving system originally proposed by Bowlby (1969). This research may involve the development of alternative measures and rating scales to the Adult Attachment Interview. Furthermore, investigation into understanding the impact of receiving a diagnosis of dementia upon the attachment narrative would also be useful. This would perhaps involve longitudinal studies.

Finally, more qualitative research may also add to our understanding of how different factors affect an individual's response to the caregiving situation and also in deriving individual case formulations. Qualitative research may also contribute to the development of standardized rating scales which specifically address the caregiver's views on their current relationship with their relative.

Concluding remarks

The aim of this study was to extend previous research on attachment and caregiving in dementia care. Specifically, the aims were to explore the possible associations between daughter-caregivers' narratives concerning their relationship history and

125

---

levels of psychological distress. The findings suggest that reflective functioning is predictive of psychological distress. The qualitative analysis highlighted several important aspects of the caregiving relationship such as role reversal, support, and services for people with dementia. Further research is required with larger samples to confirm these findings. Research with larger sample sizes would also allow the exploration of specific attachment experiences, as well as current states of mind concerning attachment in general, psychological distress and social support.

References

Ainsworth, M.D.S. (1991). Attachments and other affectional bonds across the life cycle. In Parkes, C.M., Stevenson-Hinde, J. and Marris, P. (Eds). Attachment Across the Life Cycle. (pp33-51). London: Routledge.

Alspaugh, M.E.L., Zarit, S.H., Stephens, M.A.P., Townsend, A.L., and Greene, R. (1999). Longitudinal patterns of risk for depression in dementia caregivers: Objective and subjective primary stress as predictors. Psychology and Aging, 14, 34-43.

American Psychiatric Association (1994). The Diagnostic and Statistical Manual of Psychiatric Disorders, fourth edition. Washington, DC: APA.

Aneshensel, C. S., Pearlin, L. I. and Schuler, R.H. (1993). Stress, role captivity and the cessation of caregiving. Journal of Health and Social Behaviour, 34, 54-70.

Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H. and Whitlatch, C. J. (1995). Profiles in Caregiving: The Unexpected Career. San Diego: Academic Press.

Aronson, J. (1992). Women's sense of responsibility for the care of old people: 'But who else is going to do it?'. Gender and Society, 6, 8-29.

Bakermans-Kranenburg, M.J. and Van IJzendoorn, M.H. (1993). A psychometric study of the adult attachment interview. Developmental Psychology, 29, 870-879.

Barker, C., Pistrang, N. and Elliott, R. (1994). Research Methods in Clinical and Counselling Psychology. Chichester: Wiley.

Baron, R.M. and Kenny, D.A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic and statistical considerations. Journal of Personality and Social Psychology, 51, 1173-1182.

Bledin, K., MacCarthy, B., Kuipers, L., & Woods, R. T. (1990). Daughters of people

with dementia: Expressed emotion, strain and coping. British Journal of

Psychiatry, 157, 221 227.

Bodnar, J. and Keicolt-Glaser, J.K. (1994). Caregiver depression following

bereavement: Chronic stress isn't over when it's over. Psychology and Aging, 9,

372-380.

Bowlby, J. (1969). Attachment and Loss (Vol. 1): Attachment. New York; Basic

Books.

Bowlby, J. (1973). Attachment and Loss (Vol. 2): Separation, Anxiety and Anger.

New York: Basic Books.

Bowlby, J. (1979). The Making and Breaking of Affectional Bonds. London:

Tavistock Publications.

Bowlby, J. (1980). Attachment and Loss (Vol. 3): Loss, Sadness and Depression.

New York: Basic Books.

Bowlby, J. (1988). A Secure Base: Clinical Applications of Attachment Theory.

London: Routledge.

Bretherton, I. (1991) The roots and growing points of attachment theory. In Parkes,

C.M., Stevenson-Hinde, J. and Marris, P. (Eds). Attachment Across the Life

Cycle. (pp9-32). London: Routledge.

Brodaty, H. (1992). Carers: training informal carers. In T. Arie (Ed.). Recent

Advances in Psychogeriatrics Vol 2 (pp.163-171). Edinburgh: Churchill

Livingstone.

Circelli, V. (1991). Attachment theory in old age. In K. Pillemer and K. McCartney

(Eds.) Parent-Child Relations Throughout Life (pp25-42). Hillsdale: Erlbaum.

Cicerelli, V. (1993). Attachment and obligation as daughters' motives for care giving behaviour and subsequent effect on subjective burden. Psychology and Aging, 8, 144-155.

Colin, V.L. (1996). Human Attachment. New York: McGraw Hill.

Collins, N.L. (1996). Working models of attachment: Implications for explanation, emotion and behaviour. Journal of Personality and Social Psychology, 71, 810-832.

Crispi, E.L., Schiaffino, K., and Berman, W.H. (1997). The contribution of attachment to burden in adult children of institutionalized parents with dementia. The Gerontologist, 37, 52-60.

Fisher, L. and Lieberman, M.A. (1994). Alzheimer's Disease: The impact of the family in spouses, offspring and in-laws. Family Process, 33, 305-325.

Fonagy, P., Steele, M., Steele, H., Higgitt, A.C. and Target, M.. (1994). The Emmanuel Miller memorial lecture 1992: The theory and practice of resilience. Journal of Child Psychology and Psychiatry, 35, 231-257.

Fonagy, P., Leigh, T., Steele, M., Steele, H., Kennedy, R., Mattoon, G., Target, M. and Gerber, A. (1996). The relation of attachment status, psychiatric classification, and response to psychotherapy. Journal of Consulting and Clinical Psychology, 64, 22-31.

Fonagy, P., Target, M., Steele, H, and Steele, M., (1998). The Reflective Functioning Manual (version 5). Unpublished document, University College London.

George, C., Kaplan, N., and Main, M. (1996). The Adult Attachment Interview (third edition). Unpublished manuscript, University of California at Berkeley.

George, C. and Solomon, J. (1999). Attachment and caregiving: The caregiving behavioural system. In J. Cassidy and P. Shaver (Eds.). Handbook of Attachment Theory and Research (pp649-670). New York: Guildford Press

Gilhooly, M. L. M., and Whittick, J. E. (1989). Expressed emotion in caregivers of the dementing elderly. British Journal of Medical Psychology, 62, 265-272.

Gilleard, C.J., Belford, H., Gilleard, E., Whittick, J.E. & Gledhill, K. (1984). Emotional distress amongst the supporters of the elderly mentally infirm. British Journal of Psychiatry, 145, 172-177.

Goldberg, D. (1978). Manual of the General Health Questionnaire. Windsor: NFERNelson.

Grant, L. (1998). Remind me who I am, again. London: Granta.

Greene, J.G., Smith, R., & Timbury, G.C. (1982). Measuring behavioural disturbance of elderly demented patients in the community and its effects on relatives: A factor analytic study. Age and Ageing, 11, 121-126.

Hesse, E. (1999). The adult attachment interview: Historical and current perspectives. In J. Cassidy and P. Shaver (Eds.). Handbook of Attachment Theory and Research (pp395-433). New York: Guildford Press.

Holmes, J. (1993). John Bowlby and Attachment Theory. London: Routledge.

Holmes, J. (1996). Attachment, Intimacy, Autonomy: Using Attachment Theory in Adult Psychotherapy. New Jersey: Jason Aronson.

Hughes, C.P., Berg, L., Danziger, W.L., Coben, L.A., Martin, R.L. (1982). A new clinical scale for the staging of dementia. British Journal of Psychiatry, 140, 566-572.

Kitwood, T. (1997). Dementia Reconsidered. Buckingham: Oxford University Press.

Lee, C. (1999). Health, stress and coping among women caregivers: A review. Journal of Health Psychology. 4, 27-40.

Li, L.W., Seltzer, M.M., and Greenberg, J.S. (1999). Change in depressive symptoms among daughter caregivers: An 18-month longitudinal study. Psychology and Aging, 14, 206-219.

Light, E., Niederehe, G. and Lebowitz, (1994). Stress Effects on Family Caregivers of Alzheimer's Patients: Research and Intervention. New York: Springer

Livingston, G., Mandela, M. & Katona, C. (1996). Depression and other psychiatric morbidity in carers of elderly people living at home. British Medical Journal, 312, 153 -156.

Main, M. (1991). Metacognitive knowledge, metacognitive monitoring and singular (coherent) v. multiple (incoherent) models of attachment. In Parkes, C.M., Stevenson-Hinde, J. and Marris, P. (Eds.). Attachment Across the Life Cycle (pp127-159). London: Routledge.

Main, M. and Goldwyn, R. (1994). Adult Attachment Scoring and Classification Systems (version 6). Unpublished document: University College London.

Markiewicz, D., Reis, M. and Gold, D.P. (1997). An exploration of attachment styles and personality traits in caregiving for dementia patients. International Journal of Aging and Human Development, 45, 111-132.

Morris, L.W., Morris, R.G. & Britton, P.G. (1988a). The relationship between marital intimacy, perceived strain and depression in spouse caregivers of dementia sufferers. British Journal of Medical Psychology, 61, 231 236.

Morris, R.G., Morris, L.W. and Britton, P.G. (1988b). Factors affecting the emotional well-being of the caregivers of dementia sufferers. British Journal of Psychiatry, 153, 147-156.

Noonan, A.E., aand Tennstedt, S.L. (1997). Meaning in caregiving and its contribution to caregiver well-being. The Gerontologist, 37, 785-794.

Orbell, S. (1996). Informal care in social context: A social psychological analysis of participation, impact and intervention in care of the elderly. Psychology and Health, 11, 155-178.

Ory, M.G., Hoffman, R.R., Yee, J.L., Tennstedt, S. and Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. The Gerontologist, 39, 177-185.

Ostwald, S.K., Hepburn, K.W., Caron, W., Burns, T. and Mantell, R. (1999). Reducing caregiver burden: A randomized psychoeducational intervention for caregivers of persons with dementia. The Gerontologist, 39, 299-309.

Phibbs, E., Woods, R.T., Chaudhury, S., Walker, J. & Rai, G. (1997). Guilt and Relationship Change in Caregivers of Older People with Dementia. Paper presented at 1st Bologna International Meeting on Cognitive & Affective Disorders in the Elderly, Bologna, Italy.

Pianta, R.C., Marvin, R..S., Britner, P.A. and Borowitz (1996). Mothers' resolution of their children's diagnosis; Organised patterns of caregiving representations. Infant Mental Health Journal, 17, 239-256.

Rapp, S.R., Shumaker, S., Schmidt, S., Naughton, M. and Anderson, R. (1998). Social resourcefulness: It's relationship to social support and well-being among caregivers of dementia victims. Aging and Mental Health, 2, 40-48.

Roland, L. (1999) Attachment and Caregiver Stress: Utilizing Attachment Research to Identify Risk and Protective Factors in Daughters Caring for their Mothers with Dementia. Unpublished D.Clin.Psy. thesis, University of East Anglia.

Rowntree, D. (1981). <u>Statistics Without Tears: A primer for Non-Mathematicians</u>. London: Penguin.

Sarason, I.G., Sarason, B.R., Shearin, E.N., & Pierce, G.R. (1987). A brief measure of social support: Practical and theoretical implications. <u>Journal of Social and Personal Relationships, 4</u>, 497-510.

Seltzer, M.M. and Ryff, C.D. (1996). The parental experience in mid-life: Past, present and future. In C.D. Ryff, and Seltzer, M.M. (Eds.) <u>The Parental Experience in Mid-life</u> (pp. 641-661). Chicago: University of Chicago Press.

Slade, A. (1999). Attachment theory and research: Implications for the theory and practice of individual psychotherapy with adults. In J. Cassidy and P. Shaver (Eds.). <u>Handbook of Attachment Theory and Research</u> (pp575-594). New York: Guildford Press.

Smith, J.A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. <u>Psychology and Health, 11</u>, 261-271.

Smith, J.A., Flowers, P. and Osborn, M. (1997). Interpretative phenomenological analysis and the psychology of health and illness. In L.Yardley, (Ed.). <u>Material Discourses of Health and Illness</u>. (pp68-91). London: Routledge.

Smith, J.A., Jarman, M. and Osborn, M. (1999). Doing interpretative phenomenological analysis. In M.Murray and K.Chamberlain (Eds.) <u>Qualitative Health Psychology; Theories and Methods</u>. (pp218-240). London: Sage

Solomon, J. and George, C. (1999). The caregiving system in mothers of infants: A comparison of divorcing and married mothers. <u>Attachment and Human Development, 1</u>, 171-190.

Sroufe, L.A. and Fleeson, J. (1986) Attachment and the construction of relationships. In W. Hartup and Z. Rubin (Eds.) The Nature and Development of Relationships (pp51-71). Hillsdale, NJ: Earlbaum.

Steele, H. and Steele, M. (1994). Intergenerational patterns of attachment. Advances in Personal Relationships, 5, 93-120.

Steele, H. and Steele, M. (in press). Clinical uses of the adult attachment interview. In G. Gloger-Tippelt (Ed.) Attachment in Adolescents and Adults.

Stone, R., Cafferata, G.L., and Sangl, J. (1987). Caregivers of the frail elderly: A national profile. The Gerontologist, 27, 616-626.

Stone, R., and Kemper, P. (1989). Spouses and adult children of disabled elderly: How large a constituency of long term care reform? The Milbank Quarterly, 67, 485-506.

Tabachnick, B.G. and Fidell, L.S. (1996). Using Multivariate Statistics (3rd edition). New York; Harper Collins Publishers.

Taylor, S. (1983). Adjustment to life threatening events: A theory of cognitive adaptation. American Psychologist, 38, 1161-1173.

Thoits, P. (1986). Social Support as coping assistance. Journal of Consulting and Clinical Psychology, 54, 416-423.

Thompson, S. (1981). Will it hurt less if I can control it? A complex answer to a simple question. Psychological Bulletin, 90, 89-191.

Van IJzendoorn, M.H. (1995). Adult attachment representations, parental responsiveness and infant attachment: A meta-analysis on the predictive validity of the Adult Attachment Interview. Psychological Bulletin, 117, 387-403.

Vetter, P.H., Krauss, S., Steiner, O., Kropp, P., Moller, W.D., Moises, H.W. and Koller, O. (1999). Vascular Dementia versus Dementia of Alzheimer's type: Do

----

they have differential effects on caregivers' burden. <u>Journal of Gerontology:</u>

<u>Social Sciences, 54B,</u> S93-S98.

Wagner, A.W., Logsdon, R.G., Pearson, J.L. & Teri, L. (1997). Caregiver expressed

emotion and depression in Alzheimer's disease. <u>Aging & Mental Health, 1,</u> 132 -

139.

Woods, R.T. (1989). <u>Alzheimer's Disease: Coping with a Living Death.</u> London:

Souvenir Press.

Woods, R.T. (1997). Why should family caregivers feel guilty? In Marshall, M. (Ed.)

<u>State of the Art in Dementia Care.</u> (pp39-45). London: Centre for Policy on

Ageing (CPA).

Woods, R.T. (2000). <u>Attachment and Caregiving in Dementia.</u> Paper presented at

conference on Attachment and Older adults; Contemporary Research and Clinical

Applications, London.

Yates, M.E., Tennstedt, S. and Chang, B.H. (1999). Contributors to and mediators

of psychological well-being for informal caregivers. <u>Journal of Gerontology:</u>

<u>Psychological Sciences, Vol 54B,</u> P12-P22.

Zarit, S.H. and Edwards, A.B. (1996). Family caregiving: Research and clinical

intervention. In Woods, R.T., (Ed.). <u>Handbook of the Clinical Psychology of</u>

<u>Ageing.</u> (pp333-368). London: John Wiley.

Appendices

Appendix 1

Ethical approval of the University College London Hospitals Ethics

Committee

UCL
HOSPITALS

The University College London Hospitals

The Joint UCL/UCLH Committees on the Ethics of Human Research

Committee Alpha Chairman: Professor André McLean

Please address all correspondence to:
Mrs Iwona Nowicka
Research & Development Directorate
9th Floor, St Martin's House
140 Tottenham Court Road, LONDON W1P 9LN
Tel. 0171- 380 9579   Fax 0171-380 9937
e-mail: i.nowicka@academic.uclh.nthames.nhs.uk

Professor H Steele
Sub-Department of Clinical Health Psychology
UCL
Gower Street

February 22, 1999

Dear Professor Steele

Study No: 99/0020 *(Please quote in all correspondence)*
Title: **Attachment and caregiving in daughters and their mothers with dementia.**

Thank you for your e-mail dated 3rd February addressing the issue of informed consent for the above.   I am pleased to let you know that this application is now agreed and you may proceed with your research.

Please note that it is important that you notify the Committee of any adverse events or changes (name of investigator etc) relating to this project. You should also notify the Committee on completion of the project, or indeed if the project is abandoned. **Please remember to quote the above number in any correspondence.**

Yours sincerely

Professor André McLean, BM BCL PhD FRC Path
Chairman

Appendix 2

Ethical approval of the West Essex Mental Health Trust

WEST ESSEX
LOCAL RESEARCH ETHICS COMMITTEE

Parndon Hall , The Princess Alexandra Hospital NHS Trust, Hamstel Road, Harlow, ESSEX, CM20 1QX

Tel:	**01279 827082**
Fax:	**01279 429371**

Our ref: JT/sj

28 June 1999

Dr Howard Steele
Clinical Health Psychology
University College London
Gower Street
London WC1E 6BT

Dear Dr Steele
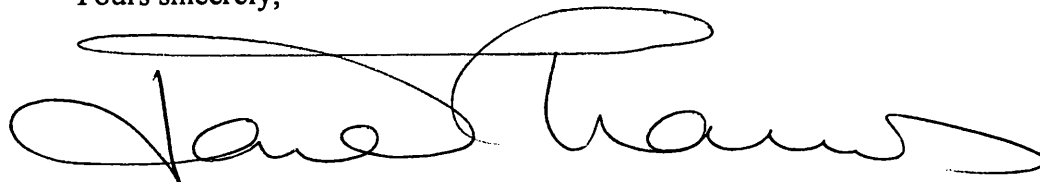
1266A ATTACHMENT AND CAREGIVING IN DAUGHTERS AND THEIR MOTHERS WITH DEMENTIA (Dr Howard Steele)

I write to confirm that the West Essex Local Research Ethics Committee met on 17 June 1999 and noted that this project has been approved by way of Chairman's Action.

Please note that I may be contacting you from time to time for information on the progress of the project. I would also grateful if you would notify me when the project is completed, or if it is terminated for any reason prior to completion, and if there are any material changes to the protocol for the project perhaps you will advise me accordingly.

May I take this opportunity to wish you every success with the project.

Yours sincerely,

Jane Thomas
Secretary to the West Essex Local Research Ethics Committee

Appendix 3

Caregivers' information sheet

Caregivers' information sheet

ATTACHMENT AND CAREGIVING PROJECT

INFORMATION SHEET

The attachment and caregiving project at UCL is concerned with the relationships between people who give and receive care in families. Caregiving in families takes many forms the earliest being that of mother and child. There are, of course, many other types of caregiving relationship and recently a focus of much interest and research is the relationship between an elderly member of the family and the person who supports and cares for them. Often this type of relationship may be between an adult daughter and her mother, whose memory and other abilities may be showing signs of decline.

Caring for such a parent who is confused can be for some a rewarding experience, but at times, it may be a difficult and even thankless task. We are interested in the levels of stress that caregivers feel, and how they cope with difficult situations that can arise. Sometimes problems that arise in caregiving have their roots in past relationship difficulties. By asking carers and those who receive care about their own childhoods, we may be able to learn more about how current caregiving relationships work. By observing interactions between daughters and mothers we also hope to examine whether any of the patterns developed earlier in life carry through into to this phase of life.

We hope that with your help we can examine in more detail the complex nature of caregiving in families. This may eventually lead us to a greater understanding of some of the rewards, and the difficulties, experienced by those who give and receive care.

Taking part in this study involves one visit to UCL. We will discuss with you transportation and meet your expenses in travelling to our centre. The visit will be in three parts:

In the first part of our study we would like to observe you and your mother engaged in carrying out a straight forward task . This is not a test, but it will allow us to broadly establish how much help your mother needs with certain tasks and how she responds to you. This will be video-taped , so that we can look in depth at the way the task was tackled later.

In the second part of the visit, we would like to ask you some questions about caring for somebody with memory problems. We would also like to ask you some questions regarding your thoughts and feelings about your relationship with your parents when you were a child. These questions take the form of an interview which will be tape recorded. All information which you give us is strictly confidential. At the same time, in an adjacent room, your mother will be encouraged to talk about her memories and feelings about her own childhood by another member of the team. These thoughts and feelings will be tape-recorded for later analysis. All information your mother gives us will be strictly confidential.

During the third and final part of the visit, you will re-join your mother, and we will video-tape the final discussion which will round off the visit. This will enable us to see how your mother responds to being re-united with you after a little time apart.

If you have any further questions about the project please contact Emily Phibbs on (0171) 504 5933.

Appendix 4

Caregivers' consent form

Sub-Department of Clinical Health Psychology

UNIVERSITY COLLEGE LONDON

GOWER STREET LONDON WC1E 6BT

ATTACHMENT & CARE-GIVING PROJECT, UCL

General Enquiries: 0171-380 7897
Clinical Tutor Team: 0171-391 1258
UCL: 0171-387 7050
Code from overseas: +44 171
Fax: 0171-916 1989

CONFIDENTIAL CONSENT FORM

To be completed by the volunteer: **Delete as necessary:**

Have you read the information sheet about the study?   Yes/No

Have you had an opportunity to ask questions and discuss the study?   Yes/No

Have you received satisfactory answers to all your questions?   Yes/No

Have you received enough information about this study?   Yes/No

Do you understand that you are free to withdraw from this study at any
time and without giving a reason for withdrawing and without affecting
your care in any way?   Yes/No

Do you agree to take part in this study?   Yes/No

Are you willing to be audio & video-recorded during your interview?   Yes/No

Which researcher have you spoken to about this study?   ....

Signature of volunteer (daughter) ....

Name ....   Date ....

Address ....

....

Signature of volunteer (mother) ....

Name ....   Date ....

Address ....

....

Signature of researcher ....

Name ....   Date ....

Appendix 5

Adult Attachment Interview

Adult Attachment Interview (George, Kaplan and Main, 1996)

1. **Tell me a bit about your family when you were a child....** *(who lived in the family home, what did your parents do for a living, did you have much contact with grandparents, extended family, did you have any siblings/other people living at home).*

2. **I'd like you to try and describe your relationship with your parents..... from as far back as you can remember.**

3. **Choose five adjectives that reflect your relationship with your mother...** *(once 5 or as many as the speaker can come up with, probe each in sequence. Ask for specific memories or incidents that describe the relationship as the chosen word. Well-elaborated specific incident given - very briefly inquire about a second. Poorly elaborated specific incident - ask for a second. When another adjective is used - repeat with reference to original adjective. When general or scripted memories are given - ask for a more specific incident).*

4. **Choose five adjectives that reflect your relationship with your father...** *(as above).*

5. **To which parent did you feel closest to, and why? Why not the same feeling with the other parent.**

6. **When you were upset as a child, what would you do?** *(specific incidents for all)*
    When you were upset emotionally, what would you do? When you were physically hurt, what would you do? Were you ever ill as a child? What would happen? *If not mentioned* **were you ever held as a child by your parents when you were upset or ill?**

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? How old were you and what did you do? Why did you think your parents did those things, do you think they realised they realised they were rejecting you?** *(if no examples, did you ever feel pushed away or ignored?).* **Were you ever frightened or worried as a child?**

9. **Were your parents ever threatening with you in any way - may be for discipline/jokingly? Some people have told us for example that their parents would threaten to leave them or send them away from home. Some people have memories of threats of some kind of behaviour that was abusive. Did anything like this ever happen to you/in your family? How old were you? Did it happen frequently? Do you feel this experience affects you now as an adult? did you have any such experiences involving anyone outside of the home?** *(same probes).*

10. In general, how do you think your overall experiences with your parents have affected your adult personality? Are there any aspects of your early experiences that you feel were a setback in your development? *(any other aspects or is there anything about your early experiences....).*

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

12. 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?

13. Did you experience the loss of a parent or other close loved one while you were a young child? Could you tell me about the circumstances and how old you were at the time? How did you respond? Was this death sudden/expected? Can you recall your feelings at the time? Have your feelings about this death changed much over time? *If not covered* did you attend the funeral and what was this like for you? *If parent or sibling* what would you say was the effect on ? and your household and how did this change over the years? Would you say this loss has had an effect on your adult personality?

Did you lose any other important persons during your childhood? *(same probes, up to 5).*
Have you lost other close persons, in adult years? *(same probes).*

14. Other than any difficult experiences you have already described, have you had any other experiences which you regard as potentially traumatic?
clarify - any experience which was overwhelmingly and immediately terrifying.

15. Were there many changes in your relationship with your parents between childhood and adulthood?

16. What is your relationship with your parents like for you now as an adult? *(current relationship).* Do you have much contact with your parents at present? What would you say your relationship with your parents is like currently? Could you tell me about any other sources of dissatisfaction in your current relationship with you parents? Any special sources of satisfaction?

Appendix 6

Additional questions asked to daughter caregivers at the end of the

Adult Attachment Interview

Additional questions asked to daughter caregivers at the end of the

Adult Attachment Interview

(analysed qualitatively)

1. How do you think your relationship with your mother has influenced the way you care for her now?

2. Has it influenced the way you cope with caring for her?

3. Do you think that your relationship with your mother over time has made it easier or more difficult to care for her?

4. In difficult times what sources of strength do you draw upon to help get you through?

5. Given all the same circumstances again, would you take on the role of caring for your mother?

6. Is there anything you wanted to add that you think is important for somebody like me trying to understand what its like for daughters caring for their mothers?

Appendix 7

Demographic Questionnaire

.

<u>Demographic Information</u>

Participant number: Date:

1. Daughter's age:

Number of siblings:

Marital status:

2. Mother's age:

3. Mother's diagnosis (if any).

4. When was the diagnosis received by the family?

5. When did the family notice problems beginning?

6. Where does mother live? (i.e. on her own, with daughter, with other)

7. Does the family receive any formal services and or respite to help in caring for mother; if so what and how often?

8. How long has the daughter been caring for mother?

9. How much contact does the daughter have with mother in a caring capacity?

10. Any additional/important information?

Appendix 8

152

Clinical Dementia Rating Scale

Clinical Dementia Rating (CDR) - Hughes et al (1982)

	Healthy [CDR 0]	Questionable dementia [CDR 0.5]	Mild dementia [CDR 1]	Moderate dementia [CDR 2]	Severe dementia [CDR 3]
Memory	No memory loss or slight inconsistent forgetfulness	Mild consistent forgetfulness; partial recollection of events; benign forgetfulness	Moderate memory less, more marked for recent events; defect interferes with everyday activities	Severe memory loss; only highly learned material retained; new material rapidly lost	Severe memory loss; only fragments remain
Orientation	Fully oriented		Some difficulty with time relationships; oriented for place and person at examination but may have geographical disorientation	Usually disoriented in time, often to place	Orientation to person only
Judgement and problem solving	Solves everyday problems well; judgement good in relation to past performance	Only doubtful impairment in solving problems, similarities, differences	Moderate difficulty in handling complex problems; social judgement usually maintained	Severely impaired in handling problems, similarities, differences; social judgement usually impaired	Unable to make judgements or solve problems
Community affairs	Independent function at usual level in job, shopping, business and financial affairs, volunteer and social groups	Only doubtful or mild impairment, if any, in these activities	Unable to function independently at these activities though may still be engaged in some; may still appear normal to casual inspection	No pretence of independent function outside home	
Home and hobbies	Life at home, hobbies, intellectual interest well maintained	Life at home, hobbies, intellectual interest well maintained or only slightly impaired	Mild but definite impairment of function at home; more difficult chores abandoned; more complicated hobbies and interests abandoned	Only simple chores preserved; very restricted interests, poorly sustained	No significant function in home outside of own room
Personal care	Fully capable of self care		Needs occasional prompting	Requires assistance in dressing, hygiene, keeping of personal effects	Requires much help with personal care; often incontinent

Score as 0, 0.5, 1, 2, 3 only if impairment is due to cognitive loss

----

Appendix 9

General Health Questionnaire - 28 item version

THE GENERAL HEALTH QUESTIONNAIRE (28 ITEM)

Please read this carefully:

We should like to know if you have had any medical complaints , and how your health has been in general, *over the past few weeks*. Please answer ALL the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about the present and recent complaints, not those you had in the past.
It is important that you try to answer ALL the questions.
Thankyou very much for your cooperation.

HAVE YOU RECENTLY:

A1.	Been feeling perfectly well and in good health ?	Better than usual	Same as usual	Worse than usual	Much worse than usual
A2.	Been feeling in need of a good tonic ?	Not at all	No more than usual	Rather more than usual	Muchmore than usual
A3.	Been feeling run down and out of sorts ?	Not at all	No more than usual	Rather more than usual	Much more than usual
A4.	Felt that you are ill ?	Not at all	No more than usual	Rather more than usual	Much more than usual
A5.	Been getting pains in your head ?	Not at all	No more than usual	Rather more than usual	Much more than usual
A6.	Been getting feelings of tightness or pressure in your head ?	Not at all	No more than usual	Rather more than usual	Much more than usual
A7.	Been having hot or cold spells ?	Not at all	No more than usual	Rather more than usual	Much more than usual

B1.	Lost much sleep over worry ?	Not at all	No more than usual	Rather more than usual	Much more than usual
B2.	Have difficulty staying asleep once you are off ?	Not at all	No more than usual	Rather more than usual	Much more than usual
B3.	Felt constantly under strain ?	Not at all	No more than usual	Rather more than usual	Much more than usual
B4.	Been getting edgy and bad tempered ?	Not at all	No more than usual	Rather more than usual	Much more than usual
B5.	Been getting scared and panicky for no good reason ?	Not at all	No more than usual	Rather more than usual	Much more than usual
B6.	Found everything getting on top of you ?	Not at all	No more than usual	Rather more than usual	Much more than usual
B7.	Been feeling nervous and strung up all the time ?	Not at all	No more than usual	Rather more than usual	Much more than usual
C1.	Managing to keep yourself busy and occupied ?	More so than usual	Same as usual	Rather less than usual	Much less than usual
C2.	Been taking longer over the things you do ?	Quicker than usual	Same as usual	Longer than usual	Much longer than usual
C3.	Felt on the whole you were doing things well ?	Better than usual	About the same	Less well than usual	Much less well
C4.	Been satisfied with the way you've carried out your task ?	More satisfied	About same as usual	Less satisfied than usual	Much less satisfied
C5.	Felt you were playing a useful part in things ?	More so than usual	Same as usual	Less so than usual	Much less useful
C6.	Felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable

C7.	Been able to enjoy normal day -to-day activities ?	More so than usual	Same as usual	Less so than usual	Much less than usual
D1.	Been thinking of yourself as a worthless person ?	Not at all	No more than usual	Rather more than usual	Much more than usual
D2.	Felt life is entirely hopeless ?	Not at all	No more than usual	Rather more than usual	Muchmore than usual
D3.	Felt that life isn't worth living ?	Not at all	No more than usual	Rather more than usual	Much more than usual
D4.	Thought of the possibility that you might do away with yourself ?	Definitely not	I don't think so	Has crossed my mind	Definitely have
D5.	Found at times you couldn't do anything because your nerves were too bad ?	Not at all	No more than usual	Rather more than usual	Much more than usual
D6.	Found yourself wishing you were dead and away from it all ?	Not at all	No more than usual	Rather more than usual	Much more than usual
D7.	Found that the idea of taking your own life kept coming into your mind ?	Definitely not	I don't think so	Has crossed my mind	Definitely has

A_____   B_____   C_____   D_____   TOTAL_____

Appendix 10

Relative Stress Scale

RS SCALE

Please think about how often/how much each of the statements below applies to you during the past two weeks.

(Rating scale as follows)
0 = not at all
1= rarely/a little
2= sometimes moderately
3= frequently/quite a lot
4= always/considerably

1. Do you ever feel that you can no longer cope with the situation ?

0   1   2   3   4

2. Do you ever feel that you need a holiday ?

0   1   2   3   4

3. Do you ever get depressed with the situation ?

0   1   2   3   4

4. Has your own health suffered at all ?

0   1   2   3   4

5. Do you worry about accidents happening to your relative ?

0   1   2   3   4

6. Do you ever feel that there will be no end to the problem ?

0   1   2   3   4

7. Do you find it difficult to get away on holiday ?

0   1   2   3   4

8. How much has your social life been affected ?

0   1   2   3   4

9. How much has the household routine been upset ?

0   1   2   3   4

10. Is your sleep interrupted by your relative ?

0   1   2   3   4

11. Has your standard of living been reduced ?

0   1   2   3   4

12. Do you ever feel embarrassed by your relative ?

0   1   2   3   4

13. Are you prevented from having visitors ?

0   1   2   3   4

14. Do you ever get cross and angry with your relative ?

0   1   2   3   4

15. Do you ever feel frustrated with your relative?

0   1   2   3   4

From Greene J.G et al Age and Ageing (1982) 11,121-126

Appendix 11

Social Support Questionnaire

Name: _____

Student Number: _____

Age: _____ Sex: _____ Date: _____

INSTRUCTIONS: The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give the persons' initials, their relationship to you (see example). Do not list more than one person next to each of the numbers beneath the question.

For the second part, circle how <u>satisfied</u> you are with the overall support you have.

If you have had no support for a question, check the words "No one," but still rate your level of satisfaction. Do not list more than nine persons per question.

Please answer all the questions as best you can. All your responses will be kept confidential.

EXAMPLE

Who do you know whom you can trust with information that could get you in trouble?

No one	1) T.N. (brother)	4) T.N. (father)	7)
	2) L.M. (friend)	5) L.M. (employer)	8)
	3) R.S. (friend)	6)	9)

How satisfied?

| 6-very satisfied | 5-fairly satisfied | 4-a little satisfied | 3-a little dissatisfied | 2-fairly dissatisfied | 1-very dissatisfied |

Whom can you really count on to be dependable when you need help?

No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

How satisfied?

| 6-very satisfied | 5-fairly satisfied | 4-a little satisfied | 3-a little dissatisfied | 2-fairly dissatisfied | 1-very dissatisfied |

Whom can you really count on to help you feel more relaxed when
you are under pressure or tense?

No one 1)   4)   7)
        2)   5)   8)
        3)   6)   9)

How satisfied?

very   5-fairly   4-a little 3-a little 2-fairly   1-very
tisfied satisfied satisfied   dissatisfied dissatisfied dissatisfied

Who accepts you totally, including both your worst and your best
points?

No one 1)   4)   7)
        2)   5)   8)
        3)   6)   9)

How satisfied?

very   5-fairly   4-a little 3-a little 2-fairly   1-very
tisfied satisfied satisfied   dissatisfied dissatisfied dissatisfied

Whom can you really count on to care about you, regardless of
what is happening to you?

No one 1)   4)   7)
        2)   5)   8)
        3)   6)   9)

How satisfied?

very   5-fairly   4-a little 3-a little 2-fairly   1-very
tisfied satisfied satisfied   dissatisfied dissatisfied dissatisfied

Whom can you really count on to help you feel better when you are
feeling generally down-in-the-dumps?

No one 1)   4)   7)
        2)   5)   8)
        3)   6)   9)

How satisfied?

very   5-fairly   4-a little 3-a little 2-fairly   1-very
isfied   satisfied satisfied   dissatisfied dissatisfied dissatisfied

Whom can you count on to console you when you are very upset?

No one 1)   4)   7)
        2)   5)   8)
        3)   6)   9)

How satisfied?

very   5-fairly   4-a little 3-a little 2-fairly   1-very
isfied   satisfied satisfied   dissatisfied dissatisfied dissatisfied