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UNIVERSITY OF SOUTHAMPTON
FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES
School of Psychology

**Factors in Adult Children that Influence and Motivate Care
Giving for Parents with Dementia**

by

Suzanne Dodge

Thesis for the degree of Master of Philosophy in
Health Psychology Research and Professional Practice

September 2009

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES
SCHOOL OF PSYCHOLOGY

Master of Philosophy

SYSTEMATIC REVIEW: WHAT ARE THE MAIN PSYCHOLOGICAL
PREDICTORS OF CARER BURDEN IN ADULT CHILDREN CARING FOR
PARENTS WITH DEMENTIA?

by Suzanne Dodge

This systematic review evaluated research on adult children of parents with dementia who were primary carers and the possible psychological predictors of carer burden. Searches were undertaken from January 2004 to October 2008. Research papers using a range of different methodologies were selected. Inclusion criteria incorporated a focus on psychological predictors of carer burden and the relationship between the parent with dementia and adult child carer in the community. Trial quality was assessed and data was extracted following the Cochrane Handbook. Where it was deemed necessary researchers in the field were contacted for additional information.

Eighteen studies were included in the review. There was a great deal of quality data in the literature focusing on carers of people with dementia but far less on the parent child relationship during this complex caring dynamic. The eighteen papers clearly illustrated that family history, filial obligations and emotional issues influenced this relationship and these could be overlooked when current stress and burden were focused on by clinicians and researchers. A psycho-educational approach for adult child carers may help alleviate some motivational problems by increasing understanding of the illness. This approach may also aid identification of psychological predictors of carer burden before they reach crisis point. Further high quality research using either qualitative or quantitative methodology is required before this carer population is recognised as having specific service needs separate to that of spouse carers.

EMPIRICAL STUDY: FACTORS IN ADULT CHILDREN THAT INFLUENCE
AND MOTIVATE CARE GIVING FOR PARENTS WITH DEMENTIA: A
QUALITATIVE STUDY

Dementia results in a progressive decline in multiple areas of function, including memory, reasoning, communication skills and skills needed to carry out daily activities (Banergee & Owen, 2008). Dementia currently affects 24.3 million people world wide and 700,000 people in the UK alone. The illness is estimated at costing the UK £17 billion per year and this is likely to rise in the next thirty years to over £50 billion (National Dementia Strategy, 2008).

Carers tend usually to be either a spouse or the offspring of the individual with dementia as the majority of people with the illness live in their own homes. The aim of this study was to ascertain what motivates adult children of parents with dementia to care and what kind of a psychological and social impact caring has on them. Much of the literature focuses on the relationship between husband and wife, rather than the parent-child relationship pre and post diagnosis.

This qualitative study used thematic analysis (Boyatzis, 1998) with techniques from grounded theory (Glaser & Strauss, 1967) in order to analyse ten interviews with adult children of parents with dementia who were primary carers. It illustrates what factors influenced and motivated them to care and considered how the pre morbid relationship, type of attachment to the parent and the concept of filial duty could influence the affective environment within the care giving household. Just over a quarter of these carers were found to be struggling to cope and, although in many cases they exhibited devoted selflessness, they also experienced contradictory emotions about their parent and considered support from their family and the National Health Service (NHS) to be insufficient. Long term implications for the NHS and society as a whole are discussed.

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DECLARATION OF AUTHORSHIP

I, SUZANNE DODGE, declare that the thesis entitled "Factors in Adult Children that Influence and Motivate Care Giving for Parents with Dementia" and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- This work was done wholly or mainly while in candidature for a research degree at this University;
- Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- Where I have consulted the published work of others, this is always clearly attributed;
- Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- None of this work has been published before submission;

Signed:

Dated:

ACKNOWLEDGEMENTS

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ABBREVIATIONS

Alzheimer's Disease.....	AD
Education.....	Ed
Expressed Emotion.....	EE
General Practitioner.....	GP
Motivations in Elder Care Scale.....	MECS
Mini Mental State Examination.....	MMSE
National Health Service.....	NHS
Psychiatric History.....	PH
Relationships in Elder Care Scale.....	RECS
Social Economic Status.....	SES

1.0 CHAPTER ONE: SYSTEMATIC REVIEW

What are the Main Psychological Predictors of Carer Burden in Adult Children Caring for Parents with Dementia?

1.1 INTRODUCTION

1.1a Alzheimer's Disease and the Impact of Caring

There are approximately 700,000 people in the UK with some form of dementia (Alzheimer's society, 2009). Alzheimer's disease (AD) is the most common form of dementia and is a devastating neurodegenerative illness that affects many different aspects of cognition. Neurofibrillary tangles and senile plaques within specific areas of the brain, primarily the medial temporal lobe, are characteristic features of AD. The disease changes the chemistry and structure of the brain, causing brain cells to die. In the early stages, memory and behaviour changes may be very subtle. People often attribute these symptoms to factors such as ageing, stress or bereavement. Later, reminders may be needed to carry out activities of daily living such as eating, dressing or using the toilet. There also may be difficulties recognising familiar people or places. Over time, there is increasing dependence on others for help. Severe memory loss and possibly difficulty with eating, swallowing, incontinence and loss of communication skills may occur. The illness may last for many years with a gradual decline; thus increasing demands are placed on carers, who are often family members with health issues or young families of their own to think about (Dementia UK, 2007).

As a carer of someone with AD one may struggle to combine work and caring responsibilities. Carers may suffer from stress, depression, anxiety and lack of sleep. There is less time for other interests or for maintaining relationships with family and friends. It is difficult to plan for the future and fatigue may be an issue due to long hours of caring with no breaks combined with challenging behaviours such as aggression, disinhibition or incontinence. These psychological and physical demands often may lead to carer burden and there is a suggestion within the literature that some carers may be more at risk than others due to certain psychological predictors. The Dementia UK report published in 2007 has the

most up to date general information regarding the disease and carers. It suggests carers for people with dementia must have guaranteed access to carer support; in particular to psychological therapies including carer training and support groups as well as quality respite care.

Burden has been defined as the extent to which caregivers perceive that their health, social life, and financial status are suffering because of their care giving experience (Zarit, Todd, & Zarit, 1986). There are several stress process models that have been used to examine care giver burden in general, particularly possible psychological qualities of the individual that may predict future caregiver burden. Lazarus and Folkman (1984) describe their model and the coping process itself as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person”. They suggest the carer either regulates the negative emotions that occur due to the stressful situation, which is said to be emotion-focused coping / or change the behaviour towards the situation, which is problem-oriented coping. Those that tend to cope more effectively are able to use the latter. However, there may be psychological predictors preventing or making it more difficult for some carers to use problem oriented coping.

1.1b Pre morbid Relationship

Many psychological theories in the area of dementia have concentrated on the caring relationship generally and identified a history of conflict as an important factor in determining a potential negative impact on care giving (Gottlieb, 1989). Gilleard and Christie (1990) suggest that the attributions made by carers are affected by the past, which continue to influence the manner in which difficulties express themselves in the home, and Williamson and Shaffer (2001) comment that the extent to which pre morbid relationships were communal in nature determines whether caregivers perceive their current relationships as rewarding, which in turn predicts caregiver depression and potentially harmful behaviour.

Premorbid relationship and adult children as carers have been researched with regard to chronic illness. Simos (1973) found that when age related problems

resembled problems from early childhood, adult children were likely to express resentment regarding the problem behaviour and the parent. Whitbeck, Simons and Conger (1991) studied nine hundred and two adult children carers of elderly parents and found poorer quality caring given to parents if families had dysfunctional communication in the past. Therefore, relationships are seen as cumulative and patterns of interactions are persistently re-enacted and go on to affect parent child relationships throughout the life course.

The elder abuse literature considers the premorbid relationship as an important risk factor. Wolf and Bergman (1989) comment that the degree to which there are unresolved family conflicts and poor conflict resolution skills may affect maltreatment of the patient and Williamson (1998) found compromised care to be especially likely to appear among those who resent having to provide care to someone with whom they have not previously enjoyed an interpersonal satisfying relationship.

1.1c Emotional Responses

A way of determining the emotional response of carers towards the care recipient is to measure the affective environment in which the family lives, and this can be done by rating the carer's Expressed Emotion (EE). There are several different methods of doing this including the Camberwell assessment interview (Vaughn & Leff, 1976) and the five minute speech sample (Magana et al, 1986). Several studies have used these measures with carers of people with AD and found varied results. Vitaliano, Young, Russo and Romano (1993) used the five minute speech sample in spouses and found 22 per cent to have high EE. However, Wagner, Logsdon, Pearson, Teri and Wagner (1997) found 40 per cent of relatives had high EE and that this was related to caregiver burden and depression. Recently, Ulstein and Engedal (2007) also found 40 per cent of carers had high EE and this was correlated with increased behavioural symptoms of the patient.

These researchers suggest that intervention packages designed to help carers with high EE should differentiate between spouses and children as they have different needs. The measurement of EE in dementia carers appears to be potentially very

useful in order to ascertain emotional responses but so far studies have mainly looked at carers in general, rather than specifically looking at the adult child carer.

1.1d Filial Piety

Another area of interest relating to quality of care is filial piety which refers to the beliefs of carers regarding their responsibilities and duties towards their elderly parents. Many of the studies in this area have been carried out in non western cultures. For instance, Ho (1994) found that education and higher SES, in a Chinese population, was negatively related to strong family attitudes and values. Very little research has looked at filial values of western adult child carers, especially where dementia is concerned. Work that has been done has focused on attachment theory. For instance, Cicirelli (1983) studied 148 adult children and their elderly mothers and found feelings of attachment to a parent had a significant effect on their commitment for future help, and Blenkner (1965) suggests that a “filial crisis” occurs when an adult child realises that their parents can no longer be looked at as a rock of support and may need support themselves. This research could certainly be expanded upon.

1.1e Aims

This systematic review aimed to examine what work has been previously published regarding the relationship between adult child carers of people with dementia and their parents. It was predicted that the majority of work currently evident would focus on the spouse carer or on the current situation rather than the lifelong relationship between parent and child. It is considered that the psychological predictors of carer burden seen in the list below are all relevant issues to assess when considering what makes a successful or unsuccessful caring relationship between an adult child and a parent;

Personality characteristics

Intelligence

Guilt

Hostility

Resentment
Pre morbid relationship
Emotional responses
Filial piety

1.2 METHOD

1.2a Inclusion and Exclusion Criteria for Selecting Studies for this Review

1.2ai Types of Studies

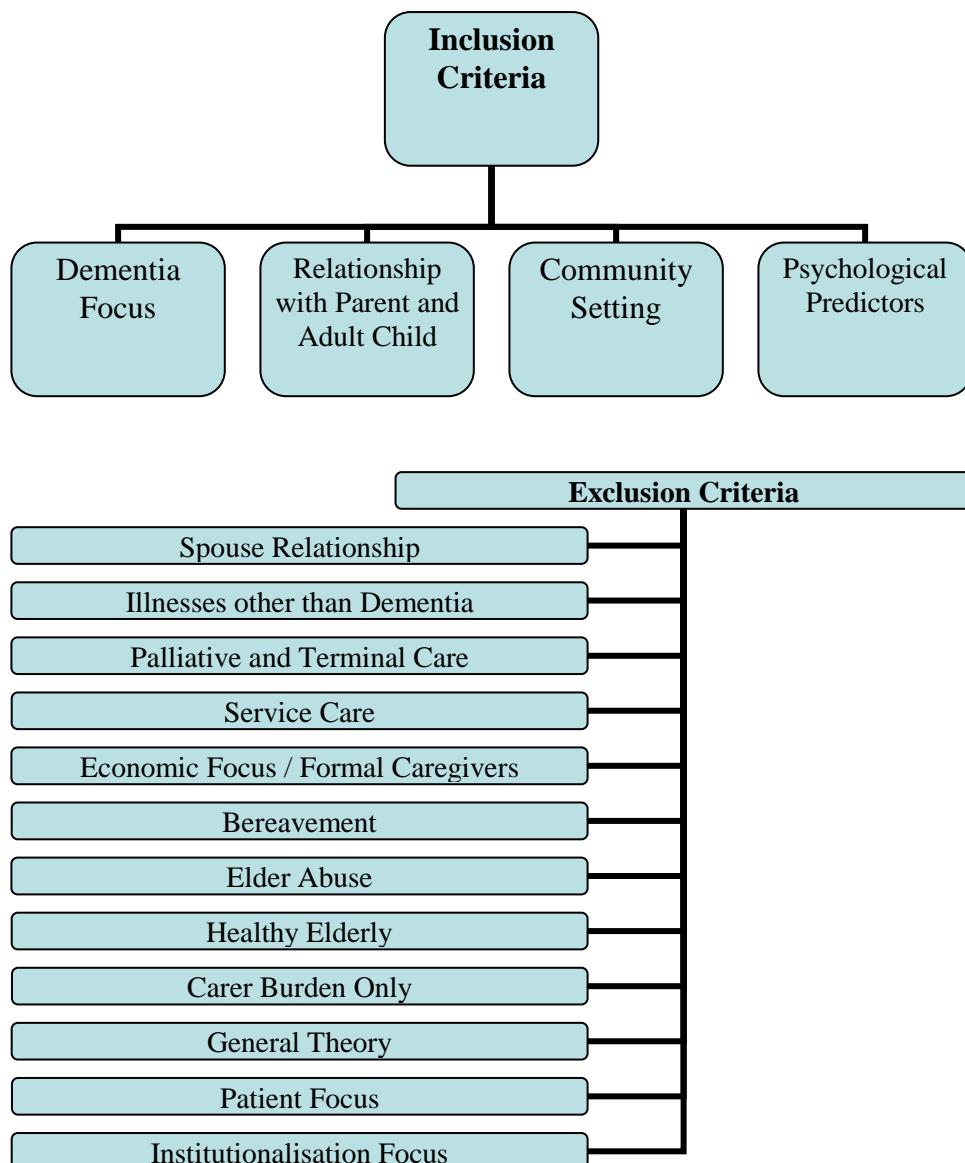
A general focus on palliative or terminal care was disallowed by the review criteria as well as any research that discussed the illness of the patient rather than the relationship between patient and carer. Any study concentrating on services, institutionalisation, economics or formal care giving were not seen as appropriate for the review, as the affiliation between carer and recipient was key, especially in terms of the pre morbid relationship. Bereavement or elder abuse studies were also excluded as these were seen as review topics in their own right. Any studies generically researching aspects of old age, although interesting, were not accepted for the review either. Research had to include psychological predictors of carer burden rather than focus on the burden itself. There is a considerable amount of literature on carer burden, as was discovered in the preliminary investigations; therefore, it was important to be selective with what could be included.

1.2aii Types of Participants

It was important for papers accepted for the review to have a dementia focus, rather than any other chronic illness. Studies looking at caring for mentally well elderly or frail parents were excluded. Studies needed to give considerable attention to the relationship between adult children and the parent they cared for. If papers discussed relationships between spouses they could be accepted for the review but not if this was a major focus of the work. It was also felt that participants should be within a community setting, as informal care was the important issue under study, rather than formal or paid care by health workers.

The diagram below illustrates the criteria used for selecting studies for this review. All types of interventions and outcome measures were considered with a predominant focus on participants who were adult child carers of their parents with dementia;

Figure 1: Diagram of inclusion and exclusion criteria used for selecting studies



1.2b Search Methods for Identification of Studies

After a general literature review several possible search terms were initially generated. These included general themes such as caring, dementia (as opposed to more specific Alzheimer's disease so as to avoid missing research that had not used this term) or adult children. An enormous amount of hits were received

using these general terms, often focusing upon current caregiver burden and issues regarding activities of daily living or memory of the parent. The exact number of hits can be seen in table one below;

Table 1 Number of hits from general terms

	Caring	Dementia	Adult Children
Allied and Complimentary Medicine 1985 to date	473	902	15
*British Nursing Index and British Nursing Index Archive 1985 to date	-	-	-
CINAHL 1981 to date	8128	8142	131
Cochrane Library	154	75	67
*DH-data 1983 to date	-	-	-
Embase 1974 to date	1665	20272	195
PsycINFO 1887 to date	2227	14963	1186
Medline 1950 to date	6535	21237	213

* These databases were not searched using general terms as it was already apparent the terms were not specific enough

It was therefore necessary to generate more specific search terms that addressed more comprehensively the areas of interest. These search terms can be seen in the tables below together with the databases searched, the amount of hits retrieved and at what stage papers were excluded from the review.

Table 2 Search terms, number of hits and stages of exclusion of studies

Database	Dementia in title	Adult children as keyword	Dementia in title & adult children as keyword	Pre morbid relation- ship as key word	Pre illness relation- ship as keyword
Allied and Complimentary Medicine 1985 to date	Hits = 863 Need to refine search	Hits = 52 Need to combine	Hits = 1 Exclude = 1	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0
British Nursing Index and British Nursing Index Archive 1985 to date	Hits = 1706 Need to refine search	Hits = 35 Need to combine	Hits = 1 Exclude = 1	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0
CINAHL 1981 to date	Hits = 706 Need to refine search	Hits = 26 Need to combine	Hits = 15 Exclude = 12	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0
Cochrane Library	Hits = 73 Need to refine search	Hits = 65 Need to combine	Hits = 5 Exclude = 5	Hits = 0 Exclude = 0	Hits = 2 Exclude = 2
DH-data 1983 to date	Hits = 706 Need to refine search	Hits = 26 Need to combine	Hits = 1 Exclude = 1	Hits = 1 Exclude = 1	Hits = 0 Exclude = 0
Embase 1974 to date	Hits = 19118 Need to refine search	Hits = 550 Need to combine	Hits = 9 Exclude = 9	Hits = 9 Exclude = 9	Hits = 2 Exclude = 2
PsycINFO 1887 to date	Hits = 14367 Need to refine	Hits = 1883 Need to combine	Hits = 18 Exclude = 16	Hits = 0 Exclude = 0	Hits = 1 Exclude = 1

Database	Dementia in title	Adult children as keyword	Dementia in title & adult children as keyword	Pre morbid relationship as key word	Pre illness relationship as keyword
Medline 1950 to date	Hits = 20323 Exclude = 3 Need to refine search	Hits = 1035 Exclude = 0 Need to combine	Hits = 25 Exclude = 23	Hits = 8 Exclude = 8	Hits = 2 Exclude = 2

Database	Filial piety as keyword	Dementia in title and Expressed Emotion as keyword	Adult children as keyword and caring as keyword	Adult children as keyword and personality as keyword
Allied and Complimentary Medicine 1985 to date	Hits = 3 Exclude = 3	Hits = 1 Exclude = 0	Hits = 1 Exclude = 1	Hits = 1 Exclude = 1
British Nursing Index and British Nursing Index Archive 1985 to date	Hits = 8 Exclude = 8	Hits = 0 Exclude = 0	Hits = 5 Exclude = 5	Hits = 1 Exclude = 1
CINAHL 1981 to date	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0	Hits = 4 Exclude = 4	Hits = 4 Exclude = 4
Cochrane Library	Hits = 0 Exclude = 0	Hits = 1 Exclude = 1	Hits = 1 Exclude = 1 Too many irrelevant hits so added dementia as a keyword	Hits = 0 Exclude = 0 Too many irrelevant hits so added dementia as a keyword
DH-data 1983 to date	Hits = 0 Exclude = 0	Hits = 1 Exclude = 0	Hits = 6 Exclude = 5	Hits = 0 Exclude = 0

Database	Filial piety as keyword	Dementia in title and Expressed Emotion as keyword	Adult children as keyword and caring as keyword	Adult children as keyword and personality as keyword
Embase 1974 to date	Hits = 2 Exclude = 0 Too many irrelevant hits so added dementia as a keyword	Hits = 5 Exclude = 2	Hits = 4 Exclude = 4 Too many irrelevant hits so added dementia as a keyword	Hits = 0 Exclude = 0 Too many irrelevant hits so added dementia as a keyword
PsycINFO 1887 to date	Hits = 9 Exclude = 9 Too many irrelevant hits so added adult children as a keyword	Hits = 5 Exclude = 1	Hits = 4 Exclude = 3 Too many irrelevant hits so added dementia as a keyword	Hits = 0 Exclude = 0
Medline 1950 to date	Hits = 1 Exclude = 1 Too many irrelevant hits so added dementia as a keyword	Hits = 9 Exclude = 6	Hits = 13 Exclude = 13 Too many irrelevant hits so added dementia as a keyword	Hits = 3 Exclude = 2 Too many irrelevant hits so added dementia as a keyword

Database	Caring as keyword and hostility as keyword	Caring as a keyword and resentment as a keyword	Emotional responses as a key word and either dementia, caring or adult children as a key word
Allied and Complimentary Medicine 1985 to date	Hits = 1 Exclude = 1	Hits = 3 Exclude = 3	Hits = 0 Exclude = 0
British Nursing Index 1985 to date	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0
CINAHL 1981 to date	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0
Cochrane Library	Hits =1 Exclude =1 Irrelevant hits so added dementia as a keyword	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0
DH-data 1983 to date	Hits = 0 Exclude = 0 Irrelevant hits so added dementia as a keyword	Hits = 0 Exclude = 0 Irrelevant hits so added adult children as a keyword	Hits = 0 Exclude = 0
Embase 1974 to date	Hits = 6 Exclude = 5 Irrelevant hits so added dementia as keyword	Hits = 0 Exclude = 0 Irrelevant hits so added dementia as a keyword	Hits = 0 Exclude = 0
PsycINFO 1887 to date	Hits = 1 Exclude = 1	Hits = 0 Exclude = 0	Hits =3 Exclude =3

Database	Caring as keyword and hostility as keyword	Caring as a keyword and resentment as a keyword	Emotional responses as a key word and either dementia, caring or adult children as a key word
Medline 1950 to date	Hits =1 Exclude =1 Irrelevant hits so added adult children as a keyword	Hits =1 Exclude =1 Irrelevant hits so added adult children as a keyword	Hits =1 Exclude =1

Database	Caring as keyword and psychological predictors as keyword	Caring as keyword and intelligence as keyword	Caring as keyword and guilt as keyword
Allied and Complimentary Medicine 1985 to date	Hits = 0 Exclude = 0	Hits = 1 Exclude = 0	Hits = 9 Exclude = 9
British Nursing Index 1985 to date	Hits = 0 Exclude = 0	Hits = 2 Exclude = 2	Hits = 5 Exclude = 5
CINAHL 1981 to date	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0
Cochrane Library	Hits = 0 Exclude = 0	Hits =1 Exclude =1 Irrelevant hits so added dementia as a keyword	Hits =0 Exclude = 0 Irrelevant hits so added dementia as a keyword
DH-data 1983 to date	Hits = 0 Exclude =0	Hits =1 Exclude =1	Hits =2 Exclude =2 Irrelevant hits so added dementia as a keyword
Embase 1974 to date	Hits = 0 Exclude = 0	Hits =1 Exclude = 1 Irrelevant hits so added dementia as a keyword	Hits =3 Exclude = 3 Irrelevant hits so added dementia

Database	Caring as keyword and psychological predictors as keyword	Caring as keyword and intelligence as keyword	Caring as keyword and guilt as keyword
PsycINFO 1887 to date	Hits = 0 Exclude = 0	Hits = 2 Exclude = 2	Hits = 1 Exclude = 1
Medline 1950 to date	Hits = 0 Exclude = 0	Hits = 1 Exclude = 1 Irrelevant hits so added dementia as a keyword	Hits = 3 Exclude = 3 Irrelevant hits so added dementia as a keyword

Database	Filial obligation	Aging parents	Filial responsibility	Parental care giving	Communal relationship theory
Allied and Complimentary Medicine 1985 to date	Hits = 1 Exclude = 1	Hits = 0 Exclude = 0 Irrelevant hits so added dementia as a keyword	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0 Irrelevant hits so added dementia as a keyword	Hits = 0 Exclude = 0
British Nursing Index 1985 to date	Hits = 1 Exclude = 1	Hits = 0 Exclude = 0 Irrelevant hits so added dementia as a keyword	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0 Irrelevant hits so added dementia as a keyword	Hits = 0 Exclude = 0
CINAHL 1981 to date	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0

Database	Filial obligation	Aging parents	Filial responsibility	Parental care giving	Communal relationship theory
Cochrane Library	Hits = 0 Exclude = 0	Hits = 2 Exclude = 2	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0 Irrelevant hits so added dementia as a keyword	Hits = 0 Exclude = 0
DH-data 1983 to date	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0			
Embase 1974 to date	Hits = 2 Exclude = 1 Irrelevant hits so added dementia as a keyword	Hits = 1 Exclude = 1 Irrelevant hits so added dementia as a keyword	Hits = 0 Exclude = 0	Hits = 0 Exclude = 0	Hits = 1 Exclude = 1
PsycINFO 1887 to date	Hits = 2 Exclude = 1 Irrelevant hits so added dementia as a keyword	Hits = 1 Exclude = 1 Irrelevant hits so added dementia as a keyword	Hits = 1 Exclude = 1 Irrelevant hits so added dementia as a keyword	Hits = 0 Exclude = 0 Irrelevant hits so added dementia as a keyword	Hits = 0 Exclude = 0
Medline 1950 to date	Hits = 2 Exclude = 2 Irrelevant hits so added dementia	Hits = 2 Exclude = 2 Irrelevant hits so added dementia	Hits = 2 Exclude = 2 Irrelevant hits so added dementia as a keyword	Hits = 0 Exclude = 0 Irrelevant hits so added dementia	Hits = 1 Exclude = 1

Two hundred and fifty one papers were reviewed and only eighteen papers were accepted as fulfilling the systematic review criteria. After reviewing eight databases using combinations of nineteen search terms it was felt that, for the purposes of this piece of work and the time constraints and limitations imposed upon it, enough of the literature had been systematically reviewed to give a flavour of what further research was needed and what had been done before. For the purposes of this review search terms have been grouped in to three over all themes. These include a) the pre morbid relationship between the parent and adult child, b) emotional responses towards the parent particularly exhibited through expressed emotion (EE) and c) filial piety.

1.2c Data Collection and Analysis

All studies were considered individually for inclusion. Some were immediately obvious as unacceptable after reading the title or abstract provided. In many other cases it was not obvious from the abstract and so the paper was either ordered from the Hampshire Partnership Trust library or found at the Southampton University Library and read in full. It was then decided as to whether the piece of work could be accepted for the review. A list of the papers accepted for the review can be found in the appendices. Other papers that were excluded immediately are referenced at the end of this review.

In addition to this search strategy, relevant researchers in the field of dementia, expressed emotion and filial piety were contacted via email to ascertain what unpublished work was currently being carried out. This included Dr. Richard Hastings from Bangor University in Wales, Prof. Mary Gilhooly at Plymouth University and Prof. Alfons Marcoen from the University of Leuven, Belgium.

Many papers were ordered and reviewed and although were interesting and contributed to knowledge of dementia care in families they could not be accepted according to the inclusion / exclusion criteria. After systematically searching the literature for some time it was acknowledged that no new studies were showing and therefore, eighteen studies were accepted as eligible for the review. Each of

these studies will be discussed, assessed for their methodological qualities and their contribution to the literature.

1.3 RESULTS

Of the eighteen studies accepted for the systematic review eleven used a quantitative methodology and seven used a qualitative methodology. The studies are grouped in this way for the reader's benefit. Each study is discussed individually regarding design; methodology; results; limitations and what gaps in knowledge this leaves for further research.

1.3a Quantitative Studies

1. Gilleard, C. J. (1986). Family attitudes to caring for the elderly mentally infirm at home. *Family Practice*, 3, 31- 36.

In this first study under discussion 129 participants were sampled with an age range from fifty eight to eighty five. Both adult child carers (n=58) and spouses (n=49) are included in the sample which allows the reader to compare similarities and differences between the two. The other twenty two carers were either related in a different way or friends of the person with dementia. Unfortunately, no information regarding gender is given, although it is suggested that there are few sons. The aim of the research was to study the attendees of four psychogeriatric day care centres in order to examine the causes and consequences of attitudes to care giving by the supporting relative. All participants were new referrals to the day centres, living in the community either with the person caring for them (n=90) or visiting at least three times a week (n=39). By using referrals of this kind a rather biased sample of carers is obtained for the study as there is usually a coping problem to require such a referral. Attitudes of these carers will perhaps have been coloured by the events leading up to the referral and may overshadow the long term relationship. Thus, attitudes of people with successful caring relationships, who are managing well, are not seen here.

There is little explanation regarding the design of the study other than it being cross sectional in nature and using various questionnaires relating to general health, ratings of burden, past and present relationships and attitudes and expectations. Follow up visits are carried out at three to four months and six to eight months. This meant that a very small amount of caring time was assessed as caring for someone with dementia can often last for years. Measures include a combination of the researchers' own design and tried and tested questionnaires and interviews. The analyses used in the study only seem to be descriptive or correlational and, therefore, no real causality can be assumed by the reader.

Results of this study are interesting as the differences between types of carers are acknowledged by the researcher. Attitudes towards caring have an obvious impact on the institutionalisation of the person with dementia. For instance, seventeen per cent of carers who had uncertainties about coping at baseline had institutionalised the person they cared for just three months later. It was found that spouses were much less likely to give up caring. Sixteen per cent of children felt unable to carry on caring compared to two per cent of spouses. For neither spouses nor children did the number or frequency of problems experienced by the person with dementia influence attitudes to care. This was also true for age of the person with dementia, length of time caring and types of services received. It seems that current emotional distress significantly influenced care giving attitudes of children but not spouses and the quality of the past relationship significantly influenced attitudes of spouses but not children. For both types of carers the decision to institutionalise the person with dementia was perhaps so uncomfortable it was externalised and attributed to outside causes, even though the event often could be predicted by attitudes at baseline.

It is apparent that this study highlights some important links between carer emotions, relationships past and present and differences between types of carers but leaves scope for researching a more representative sample of carers using a longitudinal approach.

2. Orford, J., O'Reilly, P. & Goonatilleke, A. (1987). Expressed emotion and perceived family interaction in the key relatives of elderly patients with dementia. *Psychological Medicine, 17*, 963-970.

The first quantitative study chosen for the review to use the expressed emotion method looks carefully at carers looking after four different types of patient. Sixty five carers are sampled (24 male and 41 female carers). The ages of these carers are not given but all lived with the person they cared for, with only a small minority being adult child carers.

The aim of the study was to investigate levels of expressed emotion within the different families. Twenty five of the carers were caring for patients between the ages of eighteen and forty six, twelve carers were looking after people over the age of sixty with dementia all of whom attended a day hospital, twelve carers were looking after patients over sixty who had functional health problems and twelve carers were looking after patients over sixty with physical health problems. Therefore, for the review there is obviously an issue with the fact that not enough emphasis is placed on the views of the adult child and there is a skewed picture of patients with dementia as they have been referred to a day hospital.

The researchers use the Vaughn and Leff (1976) measure of expressed emotion which involves a lengthy one and a half to two and a half hour interview with the carer. It is stated that family relationships are covered within the interviews but it is not clear whether these are past or present. It is mentioned that researchers rating expressed emotion were not overly familiar with the tool and that they had difficulty matching their results to that of trained persons. It is apparent that the cut off score of six critical comments had to be changed to two, for this study, to give a score of high expressed emotion. Emotional over involvement scoring is also queried as most of the carers of people with dementia exhibited self sacrificing behaviours indicating this to be the norm for this population rather than a warning sign. Overall, it seems that this tool was not overly sensitive to the dementia group and had to be adapted. It is however, an important study as it is the first study to attempt to do this. When cut offs had been changed results

showed seventeen per cent of carers of people with dementia had high expressed emotion.

The second outcome measure used in this study was the family interaction questionnaire which again assesses recent family interactions rather than those in the past. This tool had been adapted for the study and combines two different checklists based on Leary's (1957) and Benjamin's (1974) work. The authors give greater weight to items reflecting hostile dominance but it is not stated whether this new 48 item version of the questionnaire is validated. Carers of people with dementia scored higher on the item "dominance given" and "protection given" and less on the items "submissive" and "affection received and given" when compared to the other groups.

Therefore, this study attempts to use measures that are validated for general use but not with dementia carers and perhaps would usually be administered amongst different types of carer or different types of illnesses. There is also no real focus on the adult child relationship and the person who has dementia which means it is one of the less relevant studies of the review.

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

Using expressed emotion within the field of dementia began to be more popular in the late eighties. These researchers interview 48 carers of patients with dementia attending one of two day hospitals. The two groups were split into co resident carers, the majority of which were spouses with a mean age of 62.6 years and non co resident carers, the majority of which were adult child carers who had a mean age of 53.2 years (age ranges not available). Thus, making this a very relevant study for the review as the reader can draw comparisons.

The design of the study is sound as many well known measures are used to look at different aspects of carers' characteristics and psychological wellbeing as well as patient characteristics, thus generating some good quality data. The semi structured Camberwell family interviews (Vaughn & Leff, 1976) are again used to

measure expressed emotion and are said to take between three and twelve hours to complete. Twelve critical comments are stated as the average for the study and this is not surprising considering the length of the interviews but perhaps gives a slightly over estimated outlook regarding the stress of the carers. From a positive point of view the raters were fully trained, unlike the previous study and one of them was not directly involved in the study and therefore could be more objective. The results of this study show critical comments to be correlated with the sex of the carer, as women tended to be more emotionally involved with their caring situation and therefore more critical. Also significant correlations were found between caregivers' psychological wellbeing; the quality of their relationship with the person they cared for; the amount of contact they had with their friends and their level of expressed emotion. Interestingly, there were no significant differences between carer age and the number of critical comments, patient level of impairment or whether the family had help from services.

Unfortunately, only correlations are used so it is unknown as to whether high expressed emotion actually causes poor mental health in carers or less social contact. This study is useful as it shows the different responsibilities between the types of carers as only 25 per cent of spouse carers had jobs as opposed to 62.5 per cent of adult children and only eight per cent of spouses had other dependents compared to 50 per cent of adult children carers. Researchers have addressed both the pre morbid relationship between adult child carer and patient and the emotional responses that are generated. There is a broad consideration of what psychological predictors of carer burden may exist in this situation and expressed emotion is shown to be a useful research tool to be used in the future.

4. Bledin, K.D., 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.

Expressed emotion is also used with this small sample of 25 primary caring daughters. The researchers aimed to describe the characteristics of women caring for parents with dementia in terms of expressed emotion ratings; strain; psychiatric morbidity; coping strategies and support and also to investigate whether expressed

emotion is related to continued care in the community at a nine month follow up. These daughters are recruited via support groups, charitable organisations and psychiatric services and so are not wholly representative of the caring community as carers not involved in such areas do not participate in the study. The design of the study is cross sectional and although it is stated that participants are followed up nine months later this is only by telephone or by post in order to check whether they are still the primary carer and this would perhaps have elicited more meaningful results if there was a longer time span and the original baseline assessments were repeated.

Researchers used the brief, one hour version of the Camberwell family interview Leff and Vaughn (1985) to assess expressed emotion levels. They used the median critical comment cut off of four to divide participants in to two groups of carers with either high or low expressed emotion. These two groups were then compared regarding several other scales. The other scales included measurements of parents' behaviour and mood; carer coping strategies; stress and general health. Experienced raters were used to score the outcome measures and statistics implemented include analyses of covariance.

Results show that more efficient coping strategies are reported by people who made less critical comments. Interestingly, six of the high expressed emotion group had no siblings compared to none of the low expressed emotion group. This raises some questions regarding early relationship patterns between only children and their parents and about the reasons some of these daughters were caring. Nine of the carers expressed at least some hostility towards the person they cared for and half of the carers made no positive remarks about the person they cared for at all. It is suggested that a critical attitude can generalise to hostility and can be a risk factor for adult child carers especially when there is a poor pre morbid relationship, inadequate social support and a lack of feeling in control. It is important to recognise the uses of measuring high expressed emotion as these carers are said to be more likely to report stress and strain. In this study expressed emotion is not said to be associated with continuing care in the community but this may have been different if a longer, more comprehensive follow up had been implemented.

5. England, M.C. (1990). Test of a model for caregiver strain. *Case Western Reserve University (Health Sciences)*, 281

England's PhD thesis in 1990 relates closely to the topics relevant for this review. She sampled 168 carers of older people. The majority of carers were women, as is usual for such studies (41 males and 127 females). All of these carers are adult children of the people they care for except for two grandchildren and one younger sister. Two thirds of the women in the sample worked and 80 per cent of the men worked, which illustrates the time constraints put upon these carers.

The aim of the PhD was to examine the fit of a model for caregiver strain to try to explain offspring carer burden whilst investigating the influence of parent care plans, filial obligation, an interpersonal sense of relatedness and self coherence. The two latter concepts perhaps need further clarification as they have not been mentioned before within the review. Relatedness is said to be "a psychological sense of commonality, connectedness and continuity associated with being a person and being able to talk freely and effectively with others" (Shotter, 1986, p.200), and self coherence is "the confidence and meaningfulness with which an individual can integrate present and past experiences with the self and the environment" (Antonovsky, 1979, p.23). Both of these concepts are thought, by England, to be key when attempting to explain carer strain.

The researcher interviewed her participants twice using several different scales in order to measure the various outcome measures and in addition to this, at each interview, asked carers to write down their parent care plans. The study was exploratory and non experimental and results were ascertained using path analyses.

Recruitment of carers is again achieved via contacting different agencies such as support groups or day hospitals that carers had accessed in the last six months. This is often the method used by researchers in this field and there is a danger that a particular group of carers, who are reluctant to ask for help, may not be asked for their views. At first this study appears to concentrate on carers of people with Alzheimer's disease (eighty one per cent) but when reading more carefully there

are quite a few carers of people with different illnesses also included in the sample. Not only are carers of people with different dementias such as Huntington's chorea sampled but also other mental health problems altogether such as manic depression and schizophrenia. These differing illnesses present different issues and should perhaps not have been used for this study. Nineteen per cent of the sample had parents living in nursing homes and thirteen per cent had another parent who was still alive which again is looking at a different sort of responsibility, as others may be sharing the caring load somewhat.

Findings are interesting as a moderately strong direct linkage between caregiver burden and strain and between relatedness and self coherence is found. Greater relatedness seems to be linked to greater self coherence and lower caregiver strain. In addition to this, higher filial obligation is also correlated with lower caregiver burden. These are important results as it is evidence that perhaps an insight into the lives of the carers could equip clinicians with a more comprehensive understanding of the caring situation and could enable them to design health services that could mitigate the negative consequences of care giver strain.

6. Whittick, J.E. (1992). Expressed emotion and coping techniques amongst carers of the dementing elderly. In G.M.M. Jones & B.M.L. Miesen (Eds.), *Care-giving in dementia: Research & applications* (pp.380-397). Routledge, Taylor & Francis Ltd.

The fourth of the expressed emotion studies chosen for the review aimed to investigate differences in coping techniques amongst carers. It is unclear whether these twenty participants are spouse carers or adult child carers but as the mean age is 65 (age ranges not given) and there are resident and non resident carers one may assume that there must be a significant number of people caring for their parents.

Outcome measures for this cross sectional study include the patient rejection scale adapted from Kreisman (1979). This scale measures hostility, criticism and warmth and takes approximately one and a half to two hours to complete with the respondent. Other scales used include the ways of coping checklist (Folkman &

Lazarus, 1980) and the Beck depression inventory (Beck & Beamesderfer, 1974). These assessments were only completed at one time point and perhaps a follow up would have provided the reader with more helpful information.

Findings show the group to be scoring generally high for expressed emotion. There was a significant inverse relationship between the patient rejection scale and the quality of the pre morbid relationship but not for the current relationship quality. This is possibly because this particular carer group were seen by the author as fairly highly educated regarding dementia using information gleaned from media coverage and support groups. It is recommended by the researchers that carers are supported and educated especially with provision of information on coping techniques to combat depression in the carer as those with higher expressed emotion had higher levels of depression. What is really interesting about this study is that the results illustrate that it is not the patient problem behaviours that cause high expressed emotion. The more impaired the person with dementia is the less hostility and criticism is exhibited by the carer. Perhaps it is assumed by the carer that the patient is in more control of their negative behaviours early on in the disease and as the disease progresses the lack of patient control becomes more obvious thus causing less hostility and criticism. Thus, the importance of teaching ways of coping at every stage of the disease and increasing the carer repertoire of coping techniques is well highlighted.

7. Fearon, M., Donaldson, C., Burns, A. & Tarrier, N. (1998). Intimacy as a determinant of expressed emotion in carers of people with Alzheimer's disease. *Psychological Medicine*, 28, 1085-1090.

In the late nineties another study using expressed emotion as a research tool was published. It is difficult to ascertain the break down of types of carer sampled for the study but the age range is 50 to 77. There is a fairly even split of males and females which is rare (43 males and 56 females) and allows the reader insight into the male caring perspective which is certainly needed throughout the literature.

The aim of the study was to investigate the role of past and present intimacy in determining the level of expressed emotion in carers of people with dementia.

The premise being that if there has been a poor past pre morbid relationship then theoretically the relative will find it hard to see caring as a chance to repay their relative. Memory loss in dementia makes sharing thoughts and feelings more difficult and this compromises affection, perhaps leading carers to comment on disaffection giving rise to critical comments. Furthermore, conflict resolution skills are minimised and, therefore, the carer may then become less accepting of the person with dementia as a whole.

Researchers used the standard tool for measuring expressed emotion, the Camberwell family interview (Vaughn and Leff, 1976) as well as an adapted version of an intimacy questionnaire for elderly spouse carers originally designed by Morris (1988) utilising 22 statements covering affection, cohesion, expressiveness, compatibility and conflict resolution. Participants were asked to complete the intimacy questionnaire twice, once with the past in mind and once with the current situation in mind. The problem with this, potentially, could have been that participants were subject to a retrospective distortion regarding past relationships and therefore a clear picture may have been difficult to obtain. Additionally, this tool is usually used with older couples and has been validated for this purpose and not necessarily to investigate dementia or adult child carers. Therefore, there are some reservations regarding measuring intimacy between parent and child with a tool meant for couples. The measurement of expressed emotion, on the other hand, was conducted very professionally as consistency and reliability of ratings were checked by highly experienced raters and all raters were blinded to the intimacy questionnaire responses. A regression model was used to examine expressed emotion status as a function of intimacy scores.

Thirty four percent of the carers sampled were rated as having high expressed emotion and this was using six critical comments or four over emotional comments as a cut off. Interestingly, there were no gender, age or duration of illness differences found between high and low expressed emotion ratings. Eighteen per cent (18) of subjects previously had low intimacy levels and 82 per cent (81) previously had high intimacy levels. Current intimacy was shown to be lower as 36 per cent (36) having low scores and 64 per cent (63) having high scores thus illustrating how intimacy apparently diminishes as dementia

progresses. Current intimacy was shown to be strongly related to expressed emotion as 64 per cent of participants with low current intimacy had high expressed emotion. Significant differences were found between high and low intimacy groups on measures of hostility and criticism but not warmth. Thus, researchers suggest measuring intimacy instead of expressed emotion in order to have a quicker way of identifying critical and hostile caring environments. However, there are also contradictory results showing an increase in 24 dyads' intimacy levels which leaves the subject open to further investigation.

8. Pearlin, L.I., Pioli, M.F. & McLaughlin, A.E. (2001). Caregiving by adult children: Involvement, role disruption, and health. In R.H. Binstock & L.K. George (Eds.) *Handbook of Aging and the Social Sciences*, pp. 238–254. San Diego, CA: Academic Press.

Other studies identified for the review were difficult to reject even though they were not strictly what was being searched for. In this case, 125 adult children who had a parent with Alzheimer's disease but who also had another parent as the primary caregiver were sampled. Therefore, 100 per cent of the sample were adult child carers of a parent with dementia but they were actually secondary carers. These adult children were also identified by their caring parent as the child who would help them the most with caring tasks and this was open to the influences of family politics as it was only the opinion of the parent and not fact that was used in the selection process for recruitment to the study. The spouse, primary carers, were identified through advertisements, particularly in minority areas, which is a more representative method than only recruiting people that attend day centres etc. Therefore, this study has a different perspective to the others selected for the review as it aims to look at the involvement, role disruption and health outcomes of adult children as secondary carers for a parent with dementia.

The authors examine the Stress Process Framework (Pearlin et al, 1981) which considers stress as an unfolding process involving changes among related components. The components include primary and secondary stressors and both may affect health outcomes. Moderators are also discussed and these include

personal and social resources such as coping repertoires which are all said to be embedded in social and economic characteristics of the individual.

Participants were interviewed only once giving cross sectional data and different questionnaires were used. These cover involvement in care giving such as activities of daily living helped with, role disruption such as marital, parental or work and indicators of health and well being such as depression and self rated health. Not all of the scales used were validated for this population.

Results showed that the need and attachment of the parents did not significantly account for the differences in care giving involvement. The same was true for the quality of the past relationship before the parent had dementia as well as the present relationship. The important findings in this study were that multiple roles were the key factor in determining levels of stress and role disruption is said to potentially lead to depression as the greater the role disruption was the lower the health rating. Therefore, structural constraints made the difference to how much caring was given and how much stress was experienced. The number of major roles, the reduction of commitments and the concerns about finances contributed as stressors. Some adult children were able to access resources to restructure their lives and be quite flexible. Others may have had a clustering of stressors that developed beyond care giving and, in turn, their health and well being may have been at risk. These findings would almost certainly be magnified if the adult child were the primary carer.

9. Spruytte, N., Van-Audenhove, C., Lammertyn, F. & Storms, G. (2002). The quality of the caregiving relationship in informal care for older adults with dementia and chronic psychiatric patients. *Psychology and Psychotherapy: Theory, Research and Practice*, 75, 295-311.

The largest group of carers to be sampled within the review are in this Flemish study from 2002. Two hundred and twenty one spouse, child or child in law carers were interviewed, a large proportion of whom were male. Sixty one percent were either children of the person they cared for or a child in law and 72 per cent lived with them. The difficulty with this participant group is the relative lack of a past or childhood relationship between the impaired parents and the in law group

as quality can not be assessed. Participants were again recruited in a rather biased way using psychiatric services and perhaps neglecting those who were currently coping on their own without any interventions from formal services. The group were compared with chronically ill psychiatric patients without dementia (144 patients with dementia v 77 patients with a chronic mental illness).

The study aimed to look at the carer – patient relationship quality in carers of people with dementia compared with mentally ill persons and to explore the determinants of the relationship quality. The authors speak a great deal about expressed emotion, as if they too are measuring it, but they do not use any recognised expressed emotion tool. Instead they use the perceived criticism scale, Hooley and Teasdale (1989) together with their own five point scale to measure warmth, conflict and critique. Attributions of patient problem behaviour were measured as well as network characteristics such as formal and informal support. T tests, analyses of variance, correlational analyses and principal component analyses are used to assess whether relationship quality differs as a function of patient group.

Results showed that warmth, conflict and criticism were better in the caring dyads that were older, had female patients with dementia rather than male, had patients with a lower level of education and interestingly, were children or children in law rather than spouse carers. This last finding was only seen in patients with dementia. The key issues causing increases in criticism and a poorer relationship were disturbances in patient behaviour and the perceptions of those disturbances. Therefore, if internal attributions to the parent were that behaviours were “under their control” then carers were more critical. This was the case for both types of patient carer. It is suggested that these misattributions could be rectified with better information and support which could in turn reduce criticism levels. The results from this study differ from other similar research studies. Researchers using validated expressed emotion tools find no relationship between the problem behaviour of the patient and higher levels of criticism. Perhaps researchers should be more specific regarding which problem behaviours are most likely to cause this increase.

10. Son, G.R., Wykle, M.L. & Zausniewski, A. (2003). Global aging. Korean adult child caregivers of older adults with dementia: Predictors of burden and satisfaction. *Journal of Gerontological Nursing*, 29, 19-28.

This Korean study considers no spouse carers as all 117 participants are adult children carers for parents with dementia. However, cultural differences are evident in that more people with dementia are looked after by their family in Korea rather than in a residential setting and often when the adult child is the son then the primary carer becomes the daughter in law. This is true of this sample as 45 percent (53) of the carers are daughters in law and 82 per cent (96) of the carers are women. This makes the past quality of the relationship very different from that of people related by blood. This sample is also said to be a convenience sample and is predominantly middle class with high education and high income.

The aim of the study was to find predictors of carer burden and satisfaction in adult children caring for parents with dementia in Korea and to observe differences from Western countries. Interestingly, a positive viewpoint from other cultures is evident as researchers suggest that satisfaction; self knowledge; a better understanding of the aging process; improvement in the parent child relationship and a sense of meaning from the caring experience can be achieved by caring in some cases. Researchers use one, forty minute, face to face, structured interview and many different scales assessing demographics, involvement in activities of daily living and social support. They utilise a predictive, correlational design and a cross sectional, survey approach using multiple regression analyses to measure burden and satisfaction.

Results showed little difference between Korean and American carers. Both parent cognitive impairment and caregivers' perceived health significantly predicted burden with only the perceived health of the carer predicting satisfaction. Perceived social support was also a significant predictor of burden and satisfaction, but more strongly burden. Unfortunately, although these researchers focus completely on adult child carers of parents with dementia the study adds very little to the readers' knowledge of the importance of past

relationships, emotional responses or filial piety in determining carer burden for this population.

11. Stiens, G., Maeck, L. & Stoppe, G. (2006) Filial maturity as a predictor for the burden of demented parents' caregivers. *Zeitschrift fur Gerontologie und Geriatrie, 39, 120-125.*

The last of the quantitative studies chosen for the review is a German paper from 2006. Sixty one participants, mainly female, adult child carers of parents with dementia were recruited via newspaper advertisement, support groups or through psychiatric services. All of the carers were primary carers and, interestingly, 82 per cent of them had children of their own to look after. The aim of the study was to compare the use of the Louvain filial maturity scale (Marcoen, 1993) between adult children who care for parents with dementia and those who care for people with other illnesses and also to assess whether filial maturity can predict burden. The comparison group were sampled from another study carried out by Marcoen (1993). Filial maturity was originally conceptualised by Blenkner (1965) who stated that between forty - fifty years of age people often have what she called a "filial crisis" when they realise their parents can not be the support they always have been. If this developmental stage is accomplished successfully then filial maturity is achieved.

The Louvain filial maturity scale (Marcoen, 1993) is well validated but not specifically for use in carers of people with dementia. Because of this several statements from the scale had to be omitted as they were not appropriate; therefore, there is the underlying question of how sensitive the measure is for this population. The scale is said to measure personality, health and burden and is carried out at baseline and six months later. Unfortunately, 26 per cent of the sample were lost to follow up at six months, for various reasons, which is unusually high.

The main results of the study show a feeling of obligation to be the main reason for taking care of ones parents. Twenty five percent of the parents with dementia from this study were in a nursing home by the time of the six month follow up and

those with higher filial obligation were more likely to continue to care even if they were under a considerable amount of stress and burden. The researchers found low scores of parental consideration to be correlated with high levels of carer burden. Filial maturity had no influence on carer burden. Although there are some design issues such as the relevance of the scale used and the large drop out rate this study is useful in that it shows the importance of family dynamics through the life course in influencing the decision to care for parents.

1.3ai Overview of Quantitative Studies

It is apparent from analysing these eleven papers in detail that further research could expand on the many issues raised. Many of the samples in these studies did not represent adult child carers completely. However, no method of sampling is completely satisfactory as all have some weaknesses. Participants in these studies are often not blood related, they are spouses or not primary carers and the majority are usually female. Scales that are used are often not validated for carers of people with dementia or for adult child carers per se. The main problem, however, is that there are contradictory and inconclusive results found throughout the studies regarding the impact of parent symptoms; filial obligation; pre morbid history and emotional responses to caring on carer burden of adult child carers of parents with dementia.

1.3b Qualitative Studies

12. Blieszner, R. & Shifflett, P.A. (1989). Affection, communication, and commitment in adult child care giving for parents with Alzheimer's disease. In J.A. Mancini (Ed.). *Aging Parents and Adult Children*, (pp. 231-243). Lexington Books, MA, England.

The earliest of the qualitative studies found for this review examines the feelings of adult children regarding caring for their parents with dementia and explores the effects of the disease on the relationship with regard to affection, communication and commitment. Five adult child primary carers are sampled. Only one was male and one was a daughter in law. This study is excellent in addressing the

topics for the review as it looks in real detail at why these adult children are caring and does not concentrate on stress, strain and burden as so many other studies do.

In depth interviews were conducted, the first one beginning just after diagnosis of dementia and three further interviews continuing over eighteen months allowing researchers to hear very specific views and experiences in detail. The first interview covers the time before the parent exhibited any symptoms and is retrospective. Family roles and personalities are discussed so as to ascertain the personal and structural constructs that drive the adult child to care. As well as the four interviews researchers also measure affection and commitment. The Miller social intimacy scale, Miller and Lefcourt (1982) was used to measure affection which is well validated and has internal consistency and good test- retest reliability and the author's own commitment scale was developed for the study which is said to be both inductive and exploratory in nature.

Although there is little explanation of how the qualitative interviews were analysed the study does address why the adult children are caring, particularly when all but one of these subjects have siblings. It is concluded that generally the carers felt love for the parent they cared for and had reached some sort of filial maturity. Personal constructs included a positive attitude towards the relationship expressed by a sense of personal dedication, a wanting to repay past kindness and a personal commitment to them. Structural constructs such as social pressures are said to be important but obligation is less so. Intimacy levels tended to decline over the eighteen months but personal commitment stayed high. This study highlights the potential of how this knowledge about relationships could inform practice and how differences in reasons for caring should be taken into account rather than one approach fitting all.

13. Globerman, J. (1995). The unencumbered child: family reputations and responsibilities in the care of relatives with Alzheimer's disease. *Family Process, 34*, 7-99.

This large qualitative study of 54 carers differs from the other studies chosen for the review but has been accepted because of its interesting perspective on dementia care giving. The aim of the study was to examine differences in the

experience of burden, focus, suffering and sense of responsibility in carers and non carers; basically, to investigate how families decide who does what in the context of care giving for a relative with dementia. Of the 54 participants, 67 per cent were adult children. Thirty eight families were interviewed in total and eighteen were used for this study. Of these interviews, nine daughters and nine sons were labelled as “unencumbered”. This meant that, for some reason, certain members of families were excused from caring apparently because of childhood reputations that had followed them into adulthood. In other words, roles had become entrenched due to family legacy. Five interviewers used an ethnically homogeneous group of Jewish families to conduct the one and a half to three hour interviews with them. Using grounded theory and McCracken’s five stage long interview method (1988) data was analysed when categories became saturated.

Findings showed a real difference in how these non-caring, unencumbered adult children processed the caring situation. Five broad patterns were found. Firstly, their characterisation of themselves and by others was often described as selfish, spoiled or absent minded. This was not to say they were unsuccessful in other areas of their lives, only care giving. Secondly, the focus of the unencumbered child was more self centred, using language directed towards themselves rather than the parent, often being unrealistic and showing an avoidance of the disease. Thirdly, whereas care giving children looked at the nature of suffering in terms of the parent, the unencumbered child would concentrate on their own suffering as an “internal tearing apart”. They also had a completely different sense of responsibility, and care giving siblings tended to protect the non caring child referring to their unstable nature or lack of being able to cope. Generally, this study highlights how decisions about apportioning care are complex and often related to family legacy rather than care giving demands, proximity or gender.

14. Cahill, S.M. (1999). Caring in families: What motivates wives, daughters and daughters in law to provide dementia care? *Journal of Family Studies*, 5, 235-247.

Cahill writes with a feminist perspective and sampled 39 wives, daughters and daughters in law who cared for a relative with dementia in Australia. Thirty one

percent (12) of the sample were true adult child carers. The aim of the study was to assess to what extent women were satisfied with their pre caring relationship; what factors motivated the women to care and did they have a choice to be the primary carer. In other words, was the care given willingly or given reluctantly?

The researcher used qualitative, descriptive and exploratory methods with open ended, in depth interviews as well as fixed choice questions addressing the pre caring relationship history and reasons for care giving. Although it is not stated what sort of qualitative methods are used the researcher mentions data reduction in order to link themes together and counting themes, which seems to be a kind of content analysis.

Participants were asked what motivated them to care and were allowed more than one answer. Interestingly, the top answers were love (95 per cent) and concern (92 per cent) but also duty (74 per cent), moral obligation (49 per cent) and guilt (eighteen per cent). Two wives and three daughters were not satisfied with the caring situation and a significant twenty eight per cent (eleven) of carers reported suffering some sort of abuse at the hands of the person they cared for in the past. There were marked differences between the spouse carers and the daughters and daughters in law. For those who stated they wanted to care all but one were wives whereas for those who felt they had to care six out of nine were daughters or daughters in law. Wives perhaps saw caring as a marital obligation whereas daughters and daughters in law perhaps saw it as a moral one.

This study does not give very much information regarding the analysis of the qualitative data, therefore it would be very difficult to replicate. Cahill speaks about the open ended interviews but the paper is written in quite a simplistic fashion. It does, however, address some important issues and tackles the subject of motivations to care which is key to this review. It highlights the complexity of why adult children may become carers such as their gender, the labour market, the unavailability of others and commitments to other family care. A warning is given to health professionals regarding the importance of knowing whether someone is caring willingly or not as there may be serious repercussions on the quality of that care.

15. Sherrell, K., Buckwalter, K.C. & Morhardt, D. (2001). Negotiating family relationships: Dementia care as a midlife developmental task. *Families in Society*, 82, 383- 392.

Sherrell et al. use a case study in order to analyse the relationship between adult child carer and parent with dementia. She illustrates the journey from filial crisis to filial maturity using three unstructured, open ended interviews lasting thirty minutes each at the time points of baseline, six months and twelve months. The study is therefore longitudinal rather than cross sectional. Originally forty interviews were conducted using a written interview schedule. However, the case of “Joan” was chosen as representative of someone demonstrating filial anxiety and then filial maturity, Blenker (1965).

The researchers try to present caring as a positive, growth enhancing experience as an alternative to the burden stress model. Currently the two most prominent care giving models within the literature are those of Lazarus and Folkman’s (1984) stress burden model and the view that parent care is a role reversal in which the parent becomes a child again (Seltzer, 1990). This case study shows how “Joan” initially grieves and mourns the father she once knew and eventually releases her grip of previous rules and learns to deal with her own mortality. The three interviews, although fairly short, are broken down into stages of a growth model over the course of the year. Joan regresses to an earlier stage of psychological development which brings up unresolved issues from childhood. She manages to rework and resolve these difficulties and eventually reaches filial maturity. This positive experience of caring is said to allow her to age more successfully by creating a future based on her own identity and taking responsibility for her own life.

This case study is refreshing in that it has such a positive outlook. It allows the reader to see specific views and experiences in detail and encourages the reader to see Joan as an example of how a very common human situation can become beneficial to all involved. The study also gives useful recommendations to health professionals regarding the need to gain the trust of the caregiver so that they share relationship conflicts and difficulties and can gain support from them.

16. Perry, J. (2004). Daughters giving care to mothers who have dementia: mastering the 3 R's of (re)calling, (re)learning, and (re)adjusting, 5, 50-69.

Another study to focus on daughters only samples twenty adult child primary carers in order to examine care giving narratives. The aim was to identify the process and concepts involved in becoming and being the carer in the family. This research is important from a representative point of view as not only did the sample comprise nineteen daughters and one daughter in law but participants were either in the early, middle or advanced stages of caring for a mother with dementia which gives a full, rounded picture of their experiences. Some participants are interviewed two or three times giving 29 interviews in total and, although the participants are predominantly white European, there are some Asian participants also.

The researcher is clear about how she uses Grounded theory, Strauss and Corbin (1994) in a reflexive rather than passive manner always reframing the information that she gathers. The interviews are in depth and open ended covering how the carers assumed the care giving role in the first place, what their views and feelings are and what the day to day reality of caring involves. Perry then uses constant comparison analysis and theoretical sampling to analyse the data.

The central theme that emerges from the data is mastery and Perry describes how the carers achieve this through recalling, relearning and readjusting to the situation. Recalling involved remembering how their mothers used to be and deconstructing that image in order to reconstruct it with the impact of the disease included. The daughters certainly did not all feel love for their mothers but were bound to them in some way by rules of culture, family, social traditions or gender. Relearning involved discovering and developing new ways to be with their mothers and trying to treasure what they still had whilst trying to maintain personhood whereas readjusting involved the daughters attempting to protect themselves by using cognitive strategies, reflection and processing loss and grief. This study highlights the way dementia influences how daughters view their mothers and how carers manage to reconstruct their relationships and also how

important it is to give role specific support to adult children whilst continually exploring family relationships.

17. Ward-Griffin, C., Oudshoorn, A., Clark, K. & Bol, N. (2007) Other - adult daughter relationships within dementia care: a critical analysis. *Journal of Family Nursing*, 13, 13–32.

This Canadian study again looks at mothers and daughters in a dementia care giving setting and interviews the mothers as well as the daughters. There were ten mothers participating in the study and fifteen daughters as some sisters were also interviewed. Ward - Griffin et al. aimed to examine different types of mother daughter relationship in order to better understand their care giving and care. Two interviews were conducted for the study. The first interview served as a baseline measurement and the second interview was conducted six to nine months later. Interviewing the mothers allowed the study a different perspective. However, the researchers included a cut off score from one of the memory tests they utilised so that only people with mild to moderate dementia could participate. They continued to use this cut off for the second interview and unfortunately this meant losing two mothers' second interviews because their condition had deteriorated. This was perhaps a mistake as some valuable data could have been gained from these interviews.

The qualitative design used by researchers was said to be interpretive and descriptive. They used guidelines from Lofland and Lofland (1995) and focused on finding key defining characteristics, contextual factors and health experiences within the interviews. They followed socialist feminist theory (Stoller, 1993) in which caring is said to be an intergenerational process between two women as well as a life course perspective (Fingerman, 2001), which suggests the meaning of care is based on a life time of experiences rather than just the time of the illness.

Two dialectical dimensions were found which included a) a task focused approach - emotion focused approach and b) a deficit based approach - strength based approach. Four types of relationships were identified amongst the mother daughter dyads. Firstly, a custodial relationship in which the defining

characteristic is duty, carers are task focused and deficit based and give the minimal amount of care necessary. Here there is often objectification of the mother. Similarly, there is the combative relationship which is more emotionally charged, aggressive and controlling on the part of the daughter. Thirdly, there is the cooperative relationship which is strength based, mothers and daughters work as a team and the defining characteristic is reciprocity. Lastly, the cohesive relationship which is emotion focused and strength based. This relationship is said to have come from a positive pre morbid relationship as there is a positive, mutual emotional bond. Here the two women are said to be able to achieve self actualization and mutual growth. The four types of relationship are dynamic and the carers may move between them all.

The important issue that should be taken from this study is that again it is illustrated that health care providers should be aware of these relationship differences as they are likely to affect health outcomes for both parties in terms of strain and burden. Thus, a lot of the evidence taken from this review suggests that these psychological predictors of carer burden could be focused on more within the NHS in order to identify risk factors for certain families.

18. Tada, T., Tanioka, T., Hashimoto, F., Matsushita, Y., Yamashita, R., Kawanishi, C. & Onishi, C. (2007). Clarification of caring behaviours by the family of elderly relations living in rural Japan. *International Journal for Human Caring, 11*, 25-9.

The last of the studies for the review is a case study in Japan of a daughter caring for her mother with dementia. The aim of the study is to reflect on Mayeroff's (1971) concept of hope and commitment whilst seeing the meaning of caring as a "lived experience". The authors analyse the participant's individual expectations, faithfulness, courage and intentional relationship with her mother. This woman has four children of her own and lives in a rural, mountainous area of Japan and, therefore, is fairly isolated socially although she is said to have a very supportive family. The seven authors of the paper say they use an inductive analysis of the three one hour interviews however there is little explanation of this.

The findings from the study do seem very optimistic, focusing very much on the positive and the paper, as a whole, is very philosophical. The daughter is said to find meaning by sharing the experience of caring with others and she grows and develops through providing care achieving self awareness and self realisation. She tries to understand her mother's behaviours whilst respecting her as a member of the family and is influenced greatly by the actions of her dead father. She has "learned caring experientially" which has resulted in an intergenerational chain of caring. It is possible perhaps that Japanese cultural norms and expectations encourage a focus on the positive side of caring. It would be interesting to know whether this woman was given any choice in her situation and whether she was completely satisfied with her life.

1.3bi Overview of Qualitative Studies

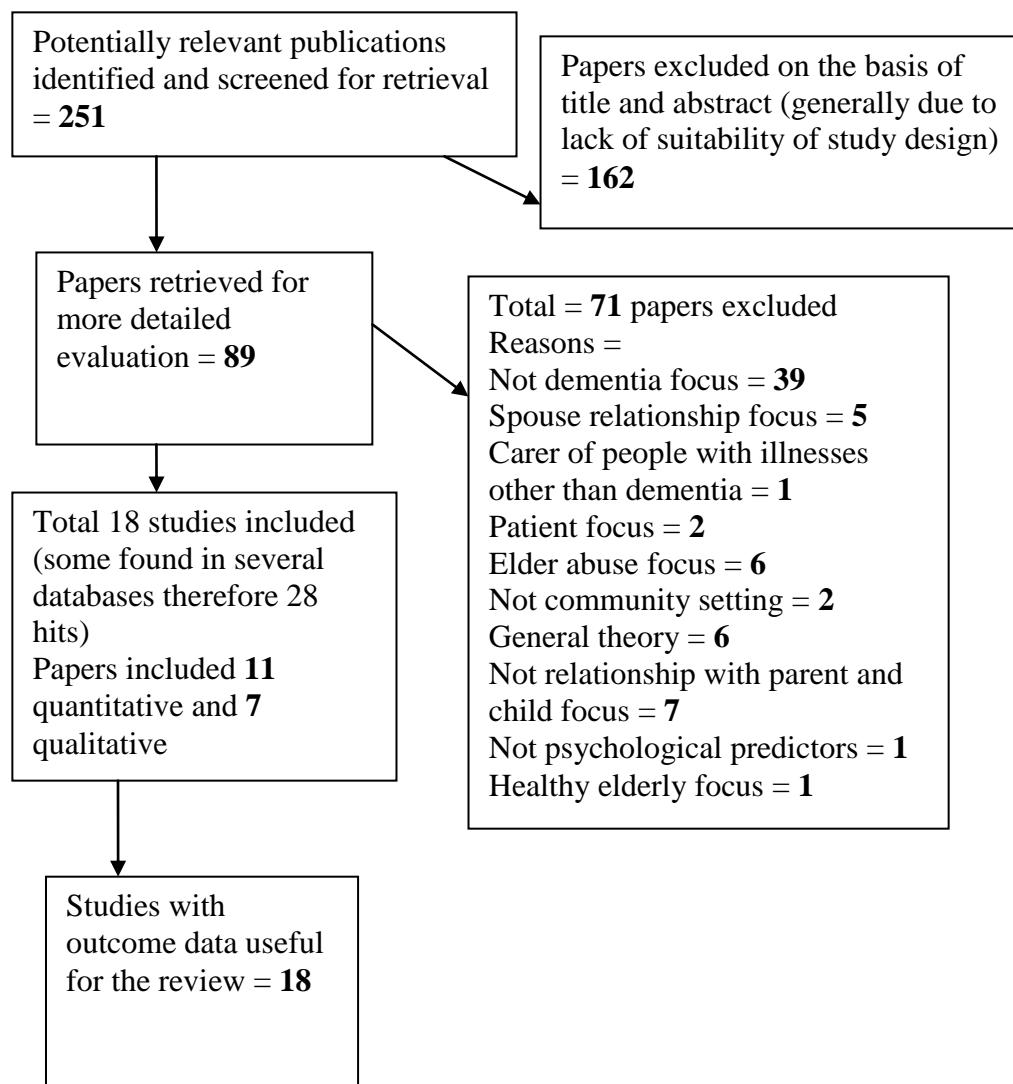
The eight qualitative studies differ considerably in their depth of analysis and perspective. Most of the qualitative studies chosen for the review highlight the importance of the relationship between adult child carer and the parent with dementia currently and before the illness, as well as the filial motivations and emotional responses to the interviews. They also recommend that health professionals attend to the different kinships of carers and their willingness to care because of the potential problems that could arise in the relationship and that this can impact on the quality of care. With regard to the methodology used within these studies some are lacking in their explanations of how they analysed their interviews (Blieszner & Shifflett, 1989; Cahill, 1999 and Tada et al, 2007). It is certainly beneficial, however, to have the qualitative detail of experience from the participants in these studies as this adds to the reader's understanding of the complexity of the caring relationship.

1.4 DISCUSSION

Eighteen studies were included in this systematic review sharing similar overall goals and objectives. However, there were multiple differences in terms of study design and outcome measures. The value of the studies varied as some were from peer – review journals and others had less methodological quality. The diagram

below illustrates how many papers were identified, why they were rejected and how many were accepted for the review;

Figure 2: Diagram to show how studies were identified, excluded and accepted



It is apparent from this systematic review that relatively few studies have attempted to address the issue of psychological predictors of carer burden in adult children caring for their parent with dementia and incorporated pre morbid relationships, emotional responses and filial piety. In fact, few have examined psychological predictors of carer burden in this population at all.

In retrospect, using different search terms such as attachment; sons; daughters; mothers; fathers or Alzheimers disease may have unearthed more valuable studies.

For instance, Steele et al. (2004) conducted research looking at different kinds of attachment types between mothers with dementia and their daughter caregivers. They found that daughters who were able to give a coherent account of their attachment histories were securely attached to their mothers. These mothers showed joy at a reunion with their daughters after being parted for forty five minutes. Daughters with an impoverished level of coherence or with unresolved mourning evident at interview had mothers who were less responsive at reunion. Unfortunately, this important and relavent study was not highlighted during this search due to the particular search terms chosen.

The research that has been conducted has often been not exclusive to adult children, incorporating spouses and other relative carers or has been very much biased towards women as carers. The studies are far from representative from point of view of gender as many have focused on daughters caring for their mothers or daughters that are collectively lumped together with wives caring for their husbands. This certainly tells us that more research is needed in the area of men caring for a parent with dementia and adult children as a single caring group. Some work by Daire (2002) is found within the literature that does consider sons and their pre morbid relationship with a parent with dementia. However, it is unfortunate that this can not be accepted for the review due to the study being based on parents with dementia who have already been institutionalised. This research highlights the fact that if sons feel their first sixteen years of life have affection, emotional warmth, empathy and closeness then they suffer less stress in the care giving role.

Generally, from conducting this review it is surprising to see the huge amount of literature on current carer burden in the dementia field, rather than research concentrating on psychological predictors to prevent burden and crises. It is apparent from considering the evidence, that from diagnoses it may be possible to predict families who will need increased support from services in the future. Research focusing on the positive and satisfying aspects of caring such as psychological growth and away from the idea of burden is refreshing. The idea that by caring for a parent one is contributing to the welfare of society, preserving values and ideas to pass on to other generations and perhaps reaching filial

maturity and resolving longstanding issues is an interesting one. Huyck (1989) comments that “the best contribution one can make to a social system is to provide care for the person who cared for you and to model that kind of caring for children and grandchildren”, thus giving adult child carers much deserved credit.

The symposium in The Gerontologist looking at the positive aspects of care giving (Miller & Lawton, 1997) is described as “a corrective focus” and signifies a move away from the traditional stress process models of Lazarus and Folkman (1984) and Zarit et al. (1986) and a move towards a focus on psychological predictors of what may cause adult children to be able to tolerate the strains associated with care giving and how health professionals can contribute to this.

1.5 CONCLUSION

Overall, this systematic review has been helpful in illustrating that there is a clear gap in the literature for further researching specifically the complex dynamics between the adult child carer and their parent with dementia. The family history, filial obligations and the emotional aspects that influence the parent child relationship are lost when current stress and burden are focused on by clinicians and researchers. Where filial piety is concerned it is apparent that cultural differences may reduce it's relevance to western carers somewhat, however it is still an interesting concept. Health psychologists must first understand what psychological predictors of carer burden there are in adult children caring for a parent with dementia before they are able to think about prevention at all. Evidently, different processes occur within the parent child relationship than when the relationship is between other family members or when the elderly person is dealing with a different chronic illness.

The implications for research and for clinical practice are that there is a great need for better understanding and more support of these carers. The proportion of research papers published since 2002 devoted to chronic disorders perhaps reveals misguided governmental or NHS priorities as 23 per cent have been in cancer; eighteen per cent in cardiovascular disease; seven per cent in musculoskeletal disorders; three per cent in stroke and only one per cent in dementia (Dementia

UK, 2007). Thus, there is a lot of scope for more research in the area of dementia care in general as it is increasingly obvious that more evidence is needed to inform clinical practice, in order for health professionals to put strategies and care plans in place for different types of informal carers of people with dementia in the community.

2.0 CHAPTER TWO: EMPIRICAL STUDY

Factors in Adult Children that Influence and Motivate Care Giving for Parents with Dementia: A Qualitative Study

2.1 INTRODUCTION

Dementia affects one person in twenty over the age of 65 and one person in five over the age of 80. Much of the caring for people with dementia has shifted from institutions to a community setting. The value of services provided by unpaid, family carers in the UK has been estimated at over £6 billion a year (Alzheimer's Society, 2007). However, these carers often have to fund their caring from their own personal assets and can experience more strain, distress and psychological morbidity than carers of other older people. A large minority of those caring for people with dementia in the UK are adult children, who often have families and responsibilities of their own. This research aims at finding out what particular psychological, familial and circumstantial factors contribute to motivate adult children to care for their parents with dementia.

2.1a The Pre-morbid Relationship

When reviewing the literature it is apparent that relatively little has been researched on how the pre morbid relationship influences the current care giving relationship, specifically where adult children as carers for people with dementia are concerned. Theories are concerned with the caring relationship generally and identify a history of conflict as an important factor in determining a potential negative impact on care giving (Gottlieb, 1989). Williamson and Shaffer (2001) comment that the extent to which pre morbid relationships are communal in nature determines whether caregivers perceive their current relationships as rewarding, which in turn can predict caregiver depression and potentially harmful behaviour. This communal relationships theory states that if a pre-illness relationship is characterised by mutual responsiveness to each other's needs it is more reciprocal and therefore more rewarding. In other words "the pre-illness experience serves

as a lens through which caregivers view and react to their current care giving circumstances" (Williamson & Shaffer, 2001).

Attachment theory focuses on the emotional or affectional bond between two people. Bowlby (1980) suggests attachment to a parent does not stop at childhood but endures throughout the life span. When the attachment bond is threatened by illness to the elderly parent, the adult child wants to maintain the emotional bond therefore provides care. If there have been interpersonal conflicts between adult children and their parents this can affect the caring relationship. If there is a history of rejection and alienation, even appeals to duty may not make much difference to the adult child. The adult attachment model of helping (Cicirelli, 1986) is based on Bowlby's life span attachment theory. It emphasizes the motivational component of the definition of attachment. Attachment is conceptualised as an internal state involving a conscious desire to be close to someone specific, whose presence elicits feelings of emotional security and comfort. This theory is important when attempting to understand why an adult child may care for their mother or father as their need to keep the relationship secure, safe and protected motivates them to devote their time and energy.

The pre morbid relationship and adult children as carers have been researched with regard to chronic illness. Many studies have highlighted the importance of the strength of the bond between the parent and child before the parent becomes more dependent on the child. Rossi and Rossi (1991) suggest affective quality of early family life is related to current assistance patterns between parents and children. Sroufe and Fleeson (1988) theorise that individuals develop an image of themselves and others in relationships, based on their experiences. These are then "represented relationships" and are carried forward into novel situations and create expectations which influence a response. Hagestad (1981) also comments that early developmental history provides a blue print for novel ambiguous relationships. Relationships generally do seem to be cumulative in nature and patterns of interactions are repeated, thus continuing to affect parent child relationships throughout the life course. When a person with dementia and their adult child carer first present at a memory clinic it seems obvious that pre morbid relationship quality should be taken into consideration by the clinician.

2.1b Elder Abuse

The elder abuse literature considers the pre morbid relationship as an important risk factor (Williamson, 1998; Wolf & Bergman, 1989). Wolf, Stugnell and Godkin (1982) identify five types of abuse and neglect. The three types of abuse consist of physical abuse, psychological abuse and material abuse. The two types of neglect include active neglect, in which there is a failure to fulfil care giving responsibilities, and passive neglect in which failure to take care of a person is neither deliberate nor conscious. Cooney and Mortimer (1995) conducted a cross sectional study by sending out an anonymous postal questionnaire to 200 members of a voluntary organisation responsible for giving help and support to carers of people with dementia. Carers were asked about the possible occurrence of verbal and physical abuse and neglect. There was only a 33 per cent response rate and this was possibly due to the sensitive subject matter. Fifty five percent of those carers who did respond admitted to some form of abuse with verbal (psychological) abuse being the most common. Verbal abuse was associated with poor pre morbid relationships and social isolation of the carer. Twenty seven percent of the carers interviewed were daughters and 50 per cent spouses. If arguments had occurred before the illness, this contributed to a higher incidence of verbal abuse in the caring relationship. However, for this to escalate to physical abuse the carer would usually additionally have mental health issues themselves.

Pillemer and Suitor (1992) found abusive carers or potentially abusive carers to be more willing than others to place their dependent in an institution. Five percent of the carers of people with Alzheimer's disease that they interviewed had actually hit or tried to hit their care recipient and seventeen per cent were afraid they might. Maltreatment became an issue if there had been a poor relationship previously as the fostering of anger, hostility and resentment could be vented via aggressive behaviour. Obligation alone is likely to result in a minimal care giving effort. Steinman (1979) labelled different types of carer that may be more or less likely to become abusive. If they had been involved in conflicts in the past with their parent they may become the "over-zealous approacher" who continues with the care giving and the conflict which results in stress and burden. On the other hand, the "active avoider" avoids care giving and conflict by getting someone else

to do it or doing nothing. The “vacillator” gives care for a while but then avoids when negative feelings build up and the “constructive approacher” recognises conflict and takes steps to resolve it. Steinman warned that the “overzealous approacher” may experience burnout and the “vacillator” is more likely to be involved in neglect during the avoidance phase. These labels are helpful when attempting to pre-empt elder abuse.

Studies concerning elder abuse in other countries and non-western cultures are interesting. Saveman and Sandive (2001) aimed to describe the awareness among Swedish GPs of elderly patients at risk of suffering abuse during the twelve month period prior to a questionnaire being sent to them. There was a 59 per cent response rate from 110 questionnaires. Results showed 77 per cent of GPs had one patient who was at risk of abuse and or neglect and 25 per cent were aware of patients subjected to verified or suspected elder abuse. The figures of elders in at risk situations were similar to those of a comparable study conducted in the UK (84 per cent) (McCreadie, Bennett & Tinker, 1998). However, the Swedish GPs only identified half as many people as the UK GPs actually experiencing abuse. Although results are interesting, in both studies researchers do not focus on dementia and again the designs were not longitudinal.

In Chinese culture there is an aging population and the policy of one child per couple has meant that family duties cannot be shared with siblings. Yan, Tang and Yeung (2002) suggest that abusers in China tend to be the adult offspring and are typically male; living with victims; married; experiencing familial conflicts or financial problems and stress or psychological disorders. The elderly often rely financially on adult offspring, as pensions are small and the government does not provide sufficiently. Interestingly, there is a higher suicide rate among elderly Chinese than any other population. Yan and Tang (2001) sampled 355 older people and asked them to respond to a questionnaire using the revised conflict tactics scale (Straus, Hamby, Boney-McCoy and Sugarman, 1996). There was an 80 per cent response rate and the sample were gleaned from community centres for the elderly. They were predominantly healthy, non random and the study was cross sectional. Two percent reported physical abuse and 21 per cent verbal abuse. Those that scored higher for abuse tended to have more overall

psychological distress and be more dependent. Seventy five percent of abusers were said to be the adult children of the respondents and the prevalence rates for verbal abuse in this study were much higher than those found in western studies. However, the issue in China is still very much a taboo as older people do not want to bring dishonour to the family. Therefore, globally, elder abuse is an extremely important topic that is relevant to us all and is substantially affected by the pre morbid relationship in the family.

2.1c Filial Piety

Another area of interest relating to motivations to care is the beliefs of carers regarding their responsibilities and duties towards their elderly parents. Filial responsibility has been defined as “a sense of personal obligation to assist with the maintenance of aging parents’ wellbeing” (Schorr, 1960, 1980). Many of the studies in this area have been carried out in non western cultures.

Historically, Confucian principles advocate reciprocity and virtue when paying parents back for their care but more recently there has been a backlash against filial piety in China. Ho (1994) reviewed the literature in this area and found education and higher SES, in a Chinese population, to be negatively related to strong family attitudes and values. He suggests that traditional filial piety is on the decline and that research in this area consistently points to negative psychological consequences on human development. Yeh (2003) agrees in stating that filial piety can have a negative affect on personal growth as it can result in an uncreative character and poor cognitive development. Finch and Mason (1991) researched 240 students in Hong Kong and found that filial piety was not a consensual norm but that family cohesion was more important. Thus, it seems that some non western countries are beginning to break away from long standing cultural traditions. However, it is still apparent that institutionalisation is viewed with contempt and there is high social pressure for daughters and daughters in law to be primary carers (Kim & Lee, 2003). When considering mental illness and filial piety in these countries, dementia is often viewed as normal aging and the behavioural disturbances in dementia can be seen as the person being half way between lives (Ikels, 2002).

Very little research has looked at filial values of western adult child carers, especially where dementia is concerned. Finley, Roberts and Banahan (1988) interviewed adult children with elderly parents in the USA to investigate motivators and inhibitors of attitudes of filial obligation. These researchers used a random digit dialling sampling technique in their telephone interviews in order to gain 1760 useable interviews. From these households, 38 per cent (n=667) had a parent over 70 years of age. Females were over represented in this sample; they did not focus on dementia at all and the study was cross sectional. However, the sample was random and these adult children carers were then interviewed extensively regarding their care giving responsibilities, affective relationships with parents and attitudes of family obligation. Findings showed that obligation was not simply a product of affection but the degree of obligation could be explained by structural and demographic factors such as the distance they lived from the parent and role conflict. Gender differences showed that for daughters, but not for sons, affection was a predicting variable for filial obligation to parents.

For the first time in history an individual is said to be likely to spend more years as an adult child with living parents than as a parent with a child under twenty, (Hagestad, 1990). Perhaps one should advocate greater emphasis on the entire family history rather than examining filial responsibility in isolation. Studying several generations of families, whilst asking questions about characteristics of parent child relationships prior to parent dependency, is crucial (Brubaker, 1990; Gubrium, 1988). A more holistic view of the family situation could then be seen.

Several theories of care giving have been put forward regarding the importance of how the adult child rationalises their feelings of filial piety and obligation. Lyonette and Yardley (2003, 2006) conducted a longitudinal study investigating the influence of work related, care related and personal factors on carer outcomes among 204 working female carers. This sample was self selecting and therefore not representative of all carers as only people working for the NHS were approached. The older people being cared for also did not necessarily have dementia. However, after initial qualitative interviews with fourteen female working carers were analysed using thematic analysis (Boyatzis, 1998), seven key important areas for carers were identified. Two of these (motivations for caring

and quality of the relationship with the older person) had no existing measures available and so the Motivations in Elder Care Scale (MECS) and the Relationships in Elder Care Scale (RECS) were developed by these researchers. These new measures, used in the larger sample of 204, predicted carer stress at baseline and at a one year follow up. Many working carers took on caring for an older person as a result of feelings of guilt, duty, responsibility and lack of choice which were said to be extrinsic motivations. Intrinsic motivations were matters such as living up to one's principles and having a caring nature. Extrinsic motivations to care and a poorer quality of relationship were the highest predictors of carer stress.

Nydegger (1991) suggests the filial role is easier if it comes about through gradual change and not through crisis. Therefore, there is a period of adjustment to the new role identity. Adult children may then begin by "anticipatory care giving" or "hovering behaviour". This then moves on to the "urging" stage (urging parents to adopt certain behaviour) and then eventually the "action" stage (Bowers, 1987). Other theories include social identity theory in which people are said to care because they are avoiding the cost of social disapproval (Seelbach, 1984) and normative socialisation theory, when one is socialised to act according to social norms based on traditional influences, determined by norms rather than rationally weighing up pros and cons (Bush and Simmons, 1981).

2.1d Demographic Factors

Demographic factors impinge on the caring process. Of particular interest to this study are gender and the sibling system as this seems to have a substantial affect on caring. For instance, Dwyer and Coward (1991) used data from the longitudinal file of the 1982-1984 National Long-Term Care Survey. From this, they found brothers provided less help when in mixed gendered relationships with siblings. If all the care giving responsibility falls to one adult child this may have detrimental affects on the family. Mathews and Rosner (1988) identify that two sister families tend to share the caring role responsibility but that daughters and sons were reluctant to help a parent if they perceive another sibling had been a favourite. Additionally, the sex of the parent needing care is said to be related to

the sex of the child who provides it (Stoller, 1990). Aldous (1987) found that elderly mothers are most likely to choose daughters as confidants when they live nearby, are early born and have interests similar to their own. With sons and mothers, the sons' marital status is an important factor. Fathers are more likely to choose sons rather than daughters as confidants. Therefore, these demographic factors influence the caring situation as well as the quality of the relationship.

Men and women seem to have different attitudes towards caring, and therefore involve themselves in different care giving activities. Seelbach and Sauer (1977) conducted a tabular analysis of responses from 595 elderly parents and showed filial responsibility expectations to be inversely associated with morale of the parent. Attitudes of the elderly parents regarding adult child responsibilities to care illustrated that 51 per cent of females felt that every child should be willing to share their home with aging parents compared to 46 per cent of males, and 60 per cent of females felt that, when at all possible, aged parents should be taken care of by their children rather than a social agency (compared to 49 per cent of males).

Stein et al. (1998) suggest that men and women have different thresholds of obligation that they must feel before they become caregiver and that women feel more obligation than men. They suggest that women are more likely than men to take the care giving role when one parent dies. Himes (1994) projects that roughly half of all adult women will provide care to an elderly parent at some point in their lives, most likely before the age of 55. Sons are said to be more involved in decision making and financial support (Stoller, 1982) and devote less time than women when they are primary caregivers (Horowitz, 1985). Women in modern society often have multiple roles. Stephens and Townsend (1997) remark that many women juggle potentially stressful work and family commitments, in addition to parent care. This social pressure for women to fit in to the care giving role, regardless of the relationship quality, has the potential to cause considerable problems with regard to burden and quality of care for the parent.

2.1e Expressed Emotion

A way of measuring the affective environment in which a family lives is rating the caregiver's expressed emotion. Expressed emotion is a method of calculating the nature of the emotional relationship between patient and carer. High expressed emotion is shown when the carer is critical about the person they are looking after or emotionally over-involved when they are asked to talk about the person for a set period of time.

Originally, Brown, Carstairs and Topping (1958) used this method with schizophrenic patients. They found that prognosis for the patient was, to an extent, related to the emotional atmosphere within the family. The initial lengthy Camberwell family interview assessment tool measured criticism, hostility, emotional over involvement, warmth and positive remarks. The rating of expressed emotion has now been used to examine a multitude of different illnesses including asthma; depression; obsessive compulsive disorder; attentional deficit hyperactivity disorder; eating disorders and conduct disorder, (Hastings, Daley, Burns and Beck, 2006). The shortened way of measuring expressed emotion, developed by Magana et al. (1986) is the five minute speech sample. This is far more practical for the researcher. It is said to have good reliability, concurrent validity and inter-rater reliability across measures (Moore and Kuipers, 1999), and the carer is asked to express their thoughts and feelings about the patient whilst uninterrupted by the researcher for five minutes.

Several studies have used this measure with carers of people with dementia and found varied results (Orford et al, 1987; Gilhooly and Whittick, 1989).

Barrowclough, Johnston and Tarrier (1994) suggest attributions and expressed emotion are relevant as they found carers rating highly for criticism gave causal explanations for patient's behaviour as controllable by the patient. These carers saw abnormal behaviours as the fault of the dependent. The high expressed emotion group were more likely to consider the idea of permanent institutionalisation and the low expressed emotion group were more likely to have regular breaks or use services such as day centres. These studies warn that a critical attitude can generalise to resentment and, therefore, high expressed

emotion can be added to the list of risk factors for poor quality of care along with a poor pre morbid relationship, feelings of obligation and inadequate support.

Whittick (1992) used the concept of expressed emotion when she sampled a mixture of twenty spouse and adult child carers of people with dementia. Outcome measures for this cross sectional study included the patient rejection scale adapted from Kreisman (1979). This scale measured hostility, criticism and warmth. This and additional assessments were only completed at one time point and perhaps a follow up would have provided the reader with more helpful information. However, findings show a significant inverse relationship between the patient rejection scale and the quality of the pre morbid relationship but not for the current relationship quality. It is recommended by the researchers that carers are supported and educated especially with provision of information on coping techniques to combat depression in the carer as those with higher expressed emotion had higher levels of depression. The illness process for dementia seems to be often poorly understood which can create unrealistic expectations for the carer. Evidently, the idea of expressed emotion allows researchers to focus on the emotional state of the carer and their feelings towards the person they are caring for.

2.1f Overview

It is apparent from the literature reviewed so far that there has been a lot of work in the area of dementia and carers of people that have the illness. Many studies have highlighted the importance of the past quality of the relationship, the current emotional state of the carer, and the motivations they have to care. Sibling systems and family dynamics have been addressed as well as gender differences in attitudes to caring. However, many studies tend to sample carers of healthy elderly people rather than looking at the dementia caring relationship, which of course is very different. Studies are often focused on one point in time rather than longitudinal and this perhaps does not give a full picture of the caring experience, particularly in dementia, as the disease may last for many years. Much of the research is biased towards women carers and the views of male carers are ignored. Most importantly, all carers tended to be grouped together within samples so that

the spouse, adult child and in-laws' views could not be separated. There is a clear gap in the literature for more longitudinal research focusing on the views of both male and female, adult child carers of parents with dementia in order for clinicians to understand more clearly their motivations to care and the potential risk factors for carer burden.

2.1g Aims and Objectives

The aim of this study is to develop methods that could be used within memory clinics to identify those adult child carers of people with dementia that may be at risk of developing difficulties with caring. In order to do this it is necessary to try to uncover what influences and motivates adult children to be a primary carer for a parent with dementia and to look at the different sorts of relationships within families. This exploratory study has the objective of examining in detail the pre morbid relationship between parent and child. There is particular interest to investigate how this relates to any feelings of resentment between siblings or other family members. Issues of filial piety, obligation and duty will be addressed as well as demographic or circumstantial factors to uncover implicit, deep rooted feelings within the relationships. Semi structured interviews will be conducted and thematic analyses (Boyatzis, 1998), along with techniques from grounded theory (Glaser and Strauss, 1967), used to interpret the data. This exploratory study is a precursor to a larger piece of work and therefore will be used to gather information on these dynamic, complex and broad topics so as to inform researchers of possible areas to focus on more closely when identifying risk factors for carer burden.

2.2 METHOD

The focus of this qualitative study was to investigate the experiences of adult child carers of parents with dementia whilst concentrating on issues such as family structure; the sibling system; pre morbid and current relationships; power dynamics and concepts of motivation and filial piety. Ten interviews were conducted with this in mind and during their analyses the major themes that underpinned the interviews were identified.

2.2a Participants and Recruitment

Ten adult child carers of patients who attended a memory and research clinic in the south of England were approached to take part in the study. This NHS department consists of a team of psychiatrists, nurses and psychologists. The memory clinic part of the unit provides an outpatient service and outreach community team to three Primary Care Trusts. When patients and their carers initially attend the clinic they are asked by one of the team of psychiatrists for their generic consent to take part in research. Their response is then recorded within their patient notes, which researchers have access to. When an appropriate study starts patients and carers who have expressed an initial interest and given their generic consent are then approached by one of the team and asked whether they would be interested in a particular study.

To source the particular carers needed for this study the three memory nurses working within the unit were approached regarding their caseload. Memory nurses were asked if they knew of any adult child who was the primary carer for their parent with dementia and who would be prepared to be involved in the study. A mixture of carers who were seen as either coping or not coping were identified.

Before contacting any carer the patient database was utilised and patient records were investigated to glean as much information as possible about their parent, the family situation and their social circumstances. It was necessary for inclusion criteria to be fulfilled. Therefore, participants had to be the primary carer of the parent, although not necessarily living with them, have contact with them every day and for the other parent to be either deceased or not in any contact with the family. The Mini Mental State Examination (MMSE) score (Folstein, Folstein, and McHugh, 1975) was recorded as well as patient medications and information about the family system.

Once the review process was complete the participant was telephoned in order to invite them to take part in the study. A brief outline of the study was given over the phone and it was explained that the interview could take place either in their home or at the hospital, whichever they were more comfortable with. In all cases

the carers agreed to take part and an appointment was made for a meeting. Information sheets were then posted to the participant so that they had time to digest the information and had the opportunity to change their minds about participating in the study if they so wished.

Of the ten participants who agreed to take part four were male and six were female. The carers' age ranged from 35 years to 70 and they all lived in and around the Hampshire area. Eight cared for their mothers and two cared for their fathers. All of the parents had Alzheimer's disease but they differed in the severity and stage of the disease.

On meeting the adult child carer an explanation of what would be involved during the visit was given detailing the participant information sheet and clarifying any points that seemed unclear. Particularly important to the study was the fact that interviews would be tape recorded for transcription purposes and the confidentiality of this procedure needed to be highlighted as sensitive issues were to be discussed. Once the carer was happy with what was being asked of them and they understood how long the process would take, the consent form was signed.

Before the semi structured interview began a five minute speech sample (Magana et al, 1986) from the participant was taken in order to assess whether they were exhibiting high or low expressed emotion. As previously highlighted, expressed emotion can be a risk factor for carer burden in dementia. Therefore, the sample was used as a check to confirm that purposive sampling had succeeded in getting a range of people who varied on this important dimension. This process required the participant to speak for five minutes without any interruption from the researcher about their current relationship with the person they cared for. The researcher instructed the participant as follows:

I'd like to hear your thoughts and feelings about (your relative), in your own words and without my interrupting with any questions or comments. When I ask you to begin I'd like you to speak for five minutes, telling me what kind of person (relative's name) is and how the two of you get along together. After you

begin to speak, I prefer not to answer any questions until after the five minutes are over. Do you have any questions before we begin?

This continuous sample of speech was tape recorded and coded later. The researcher was accustomed to using the five minute speech sample coding manual and felt confident when using it here. After the speech sample had been recorded the interview began.

The key topics covered during the interview can be seen in figure three;

Figure 3: Carer interview

- 1. Could you tell me about your family? Who they are, where they live, what they do?**
- 2. Could you describe to me the relationships you had with your mother and father when you were younger and before they were elderly?**
- 3. Were there any relevant events before your mother / father's illness that caused any problems in your relationship? Any significant life events or arguments?**
- 4. How do you feel about looking after your mother / father and how does this affect your life?**
- 5. How do you feel your relationship between you and your mother / father has changed since they became ill?**
- 6. How would you have described your mother / father before they were ill and how would you describe yourself?**
- 7. How would you describe your brothers/sisters or other members of your family and what is your relationship with them like?**
- 8. What do you think other members of your family feel about you being the main carer for your mother / father?**
- 9. What are the main reasons for you caring for your mother / father?**
- 10. If you could have any help in looking after your mother / father what would it be and who would it be from?**

The interview was designed after searching the literature for possible relevant factors that may influence and motivate adult child carers to care for their parent. The first question aims to elicit a general picture of the family system and the kind of support the carer is receiving from them. Information about siblings, age differences and birth order, education and marital status as well as health problems of the carer and the parent is paramount. Questions two and three focus on the pre morbid relationship between the parents and children in the family and guide the carers to consider potential important life events that may have shaped the relationships in the past. Questions four and five look more at current feelings of the carer and whether they have changed since their parent became ill. Questions six and seven consider the dynamics and power relationships between different members of the family so as to identify whether there is any resentment apparent and the remaining questions look at the strength of the feelings of filial piety, obligation or duty. Ideally these issues emerged through discussion spontaneously. The interview took between one and two hours with each participant. After the interview had been conducted it was ensured that the participant had not been distressed in any way by the topics discussed. The participant was then thanked for their time, informed of how they had helped and what research may come from this exploratory study in the future.

2.2b Ethical Considerations

Participant information sheets and consent forms were submitted to the Southampton and West Hampshire NHS local research ethics committee and Southampton university research ethics committee . Approval from the committee's were received in May 2005 after some additional information were requested. The additional information included matters such as enquiring what mechanisms had been put in place to deal with distressed participants, ensuring the researcher clarified the recruitment process and how the interviews could be conducted or managed at home if the parents needed to be looked after. Approval was also required from the research and development department of the Hampshire Partnership Trust, the Data Protection Officer for the Trust and a full risk assessment was carried out.

2.2c Preparation and Analysis of the Interview Data

All of the audio tapes were transcribed in full including speech samples and the interviews. The speech samples were coded for each participant and assessed as to whether the initial statements were positive, neutral or negative. The same was assessed for the overall parent - child relationship. Critical and positive remarks were counted as well as instances of dissatisfaction and emotional over involvement in order to assess whether the participant could be rated as having high or low expressed emotion.

2.2d Thematic Coding Procedures

The transcriptions from the interviews were analysed using thematic analysis, (Boyatzis, 1998), along with techniques from grounded theory (Glaser & Strauss, 1967). Transcripts were read and re-read whilst notes were made. Theoretical sensitivity, the ability to perceive variables and relationships, was attained by recording themes, concepts and properties throughout the whole process. Memos were used to connect interrelationships between the interviews. Field notes and code notes were constructed for important parts of text within each interview, thus developing a coding manual for each participant. By utilising various different forms of coding techniques, themes were split in to subthemes, whilst thoughts and ideas were formed. Gradually different concepts, properties, themes and core dimensions began to emerge.

Thematic analysis was used in order to attain a comprehensive picture of the carers' experiences and to try to create a "storyline". Although grounded theory techniques are used here it is not a grounded theory study as the aim was never to develop a 'theory' as such. With grounded theory the researcher approaches the subject matter deliberately with limited prior knowledge of the subject matter, which is also not the case here. Other qualitative methods were considered by the researcher. However content analysis was not used as a more semantic analysis was needed, and a phenomenological analysis was rejected because this study did not have an idiopathic approach as it was searching for similarities and differences between carers' experiences rather than one common experience.

Three core dimensions seem to incorporate the general feelings conveyed in the interviews. These dimensions encompass several themes and subthemes. It is hoped that this study will in some way reveal what motivates the adult child carer to care for their parent with dementia.

2.3 RESULTS

The results section of this report is divided into several sections. Firstly, a description of the demographic data relating to the parents in the study (such as age; gender; marital status; MMSE score; pre morbid psychiatric history and number of children) will be given. Secondly, demographic information regarding the adult child carer is reported, which in addition to the above incorporates social economic status and self – reported childhood happiness. The main body of the results section will explain the themes and sub-themes underpinning the interview transcripts and will give examples of text from the participants.

2.3a Demographic Information

2.3ai Parents

Of the ten parents who were being cared for in the study their age ranged from 71 to 95 years. Eight were female and eight had a deceased spouse, with two having a living spouse separated from them due to infidelity. The mean MMSE score of the parents was 19/30 (moderate dementia) and two had a pre morbid history of psychiatric problems as noted from their patient records. The sibling system of the families consisted of two of the parents having four children; one having three children; five having two children; one having one child and one having had two children originally but one had died. This demographic information can be seen more fully in Table Three;

Table 3: Parent demographics

No.	Age	Gender	Spouse status	Mini Mental State Exam	Psychiatric History of parent	Number of children
001	86	Female	Divorced	18/30	Yes	4
002	92	Male	Dead	26/30	No	2
003	95	Male	Dead	19/30	No	2
004	73	Female	Dead	27/30	Yes	3
005	83	Female	Dead	22/30	No	2
006	81	Female	Divorced	24/30	No	2
007	87	Female	Dead	24/30	No	2
008	71	Female	Dead	7/30	No	4
009	77	Female	Dead	2/30	No	1
010	79	Female	Dead	19/30	No	2

2.3aii Carers

Of the ten carers who were interviewed their ages ranged from 35 to 70 years old.

Six were female and seven carers in this sample were married, two were single and one was divorced. Two had a University education and eight had left school at fifteen or sixteen. Three had no children of their own, one had one child co-habiting with them and six had two children, the majority of whom were co-habiting with them. Six did not feel that they had a good childhood where as four had enjoyed their childhood. Seven had a past psychiatric history involving a diagnosis of depression or anxiety.

From the expressed emotion speech samples it was evident that purposive sampling had achieved its purpose as there was a representative range of carers with high and low expressed emotion. The sample had been chosen deliberately and non-randomly in order to elicit a range of adult child carer experiences.

Overall, three carers were rated as having high expressed emotion and seven had low expressed emotion. Expressed emotion ratings were classified using the detailed instructions from the coding manual supplied by the University of Southampton. Thirty per cent exhibiting high expressed emotion is a distribution

one would expect from reading the literature. This demographic information can be seen in more detail in Table Four;

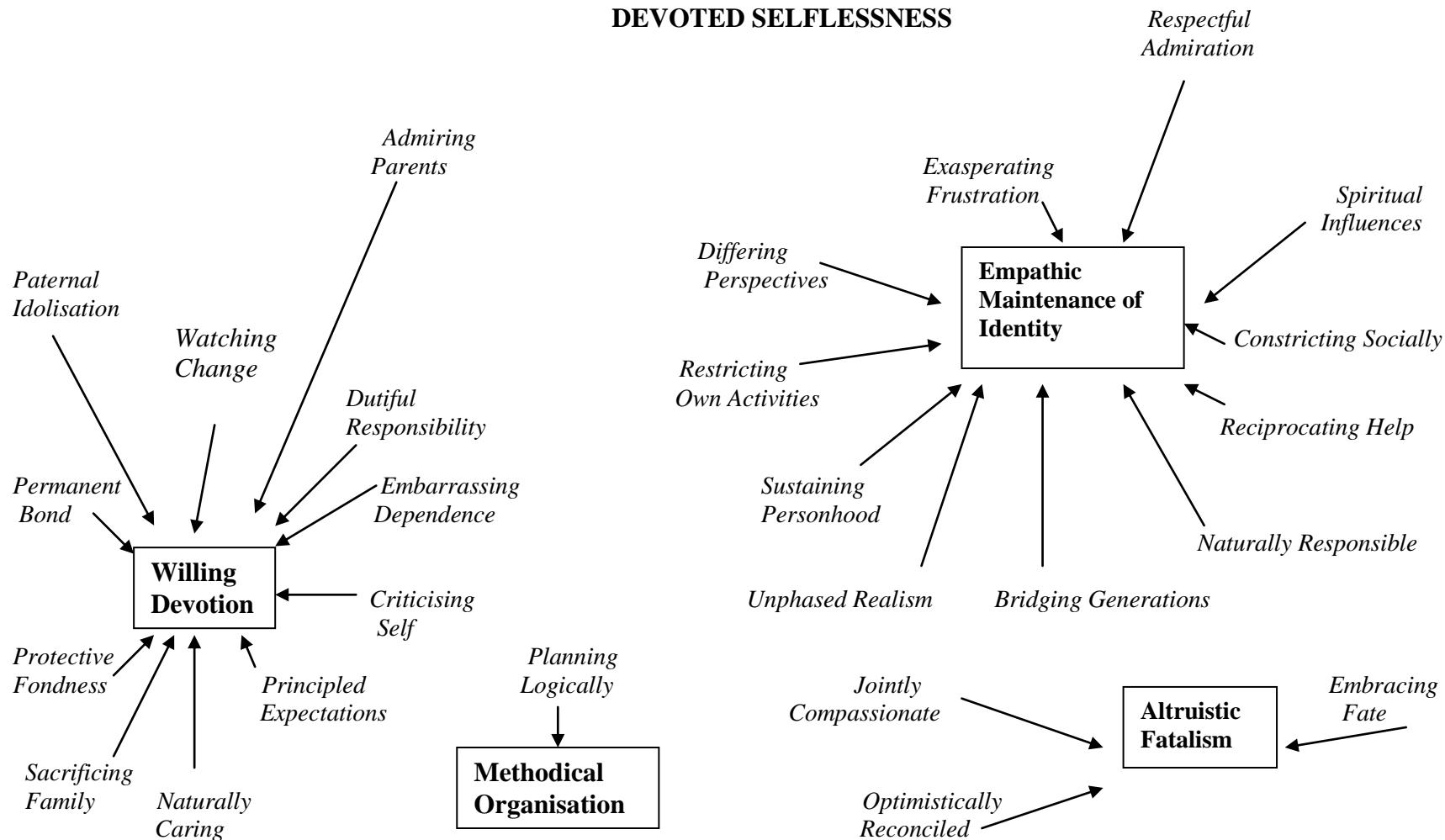
Table 4: Carer demographics

No	Age	Gender	Marital status & no. of children	Education	Childhood of carer (self-reported)	Psychiatric History and Expressed Emotion
1	50	Male	Single 0	11	Poor	Yes (Low EE)
2	60	Female	Married 2 not co-habiting	11	Poor	Yes (High EE)
3	70	Male	Single 0	10	Good	No (Low EE)
4	37	Female	Married 2 co-habiting	16	Good	No (Low EE)
5	52	Male	Divorce 2 not co-habiting	11	Good	Yes (High EE)
6	53	Male	Married 0	11	Poor	No (Low EE)
7	60	Female	Married 2 not co-habiting	16	Poor	No (Low EE)
8	35	Female	Married 1 co-habiting	11	Poor	No (Low EE)
9	50	Female	Married 2 co-habiting	11	Poor	No (High EE)
10	44	Female	Married 2 co-habiting	11	Good	No (Low EE)

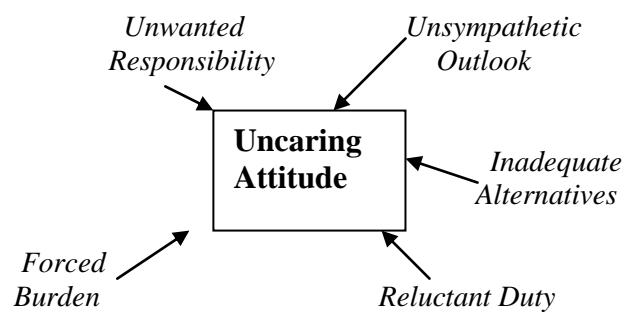
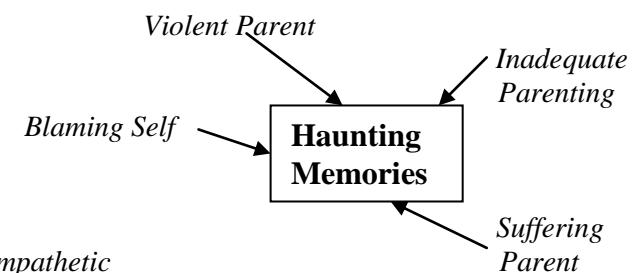
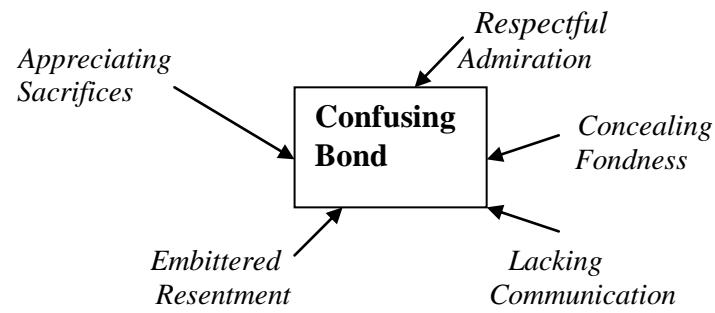
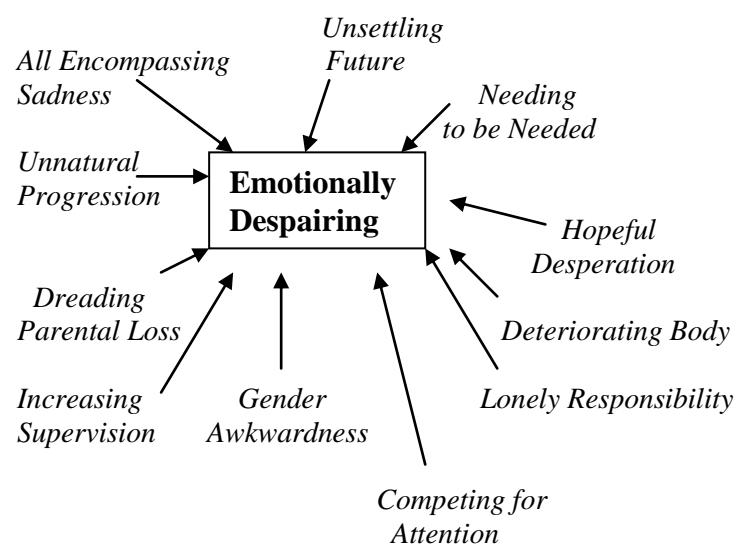
2.3b Interviews

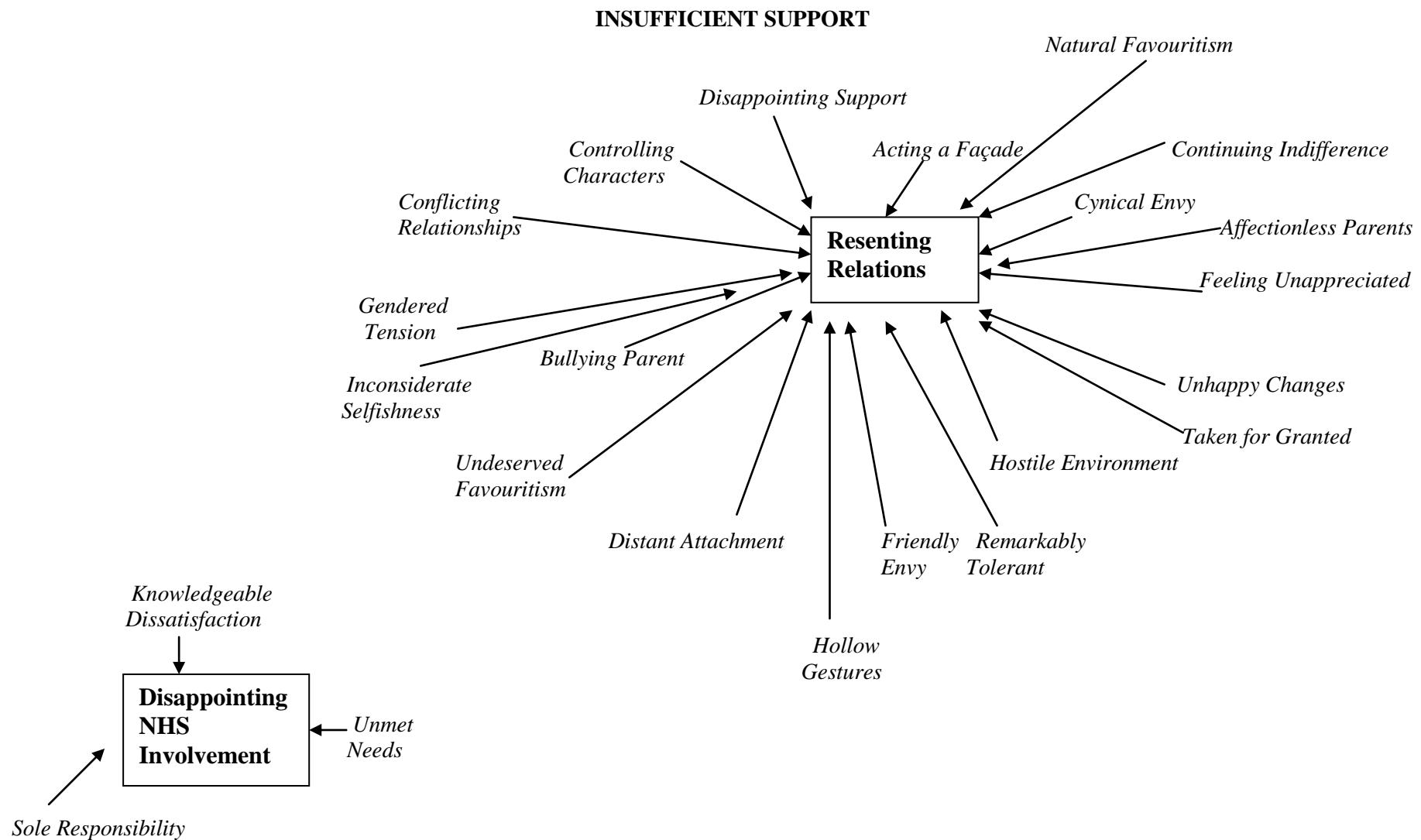
The following reports the dimensions and themes that were generated whilst using thematic analysis. Three main dimensions are described 1) Devoted Selflessness 2) Contradictory Emotions and 3) Insufficient Support. Each dimension is divided into several themes and subthemes and examples are given to show how they relate. Figure Four illustrates how each dimension, theme and subtheme are connected.

Figure 4: Coding diagram



CONTRADICTIONARY EMOTIONS





2.3bi Devoted Selflessness

The dimension “Devoted Selflessness” comprises four themes. These themes are a) Willing Devotion, b) Altruistic Fatalism, c) Empathic Maintenance of Identity, and d) Methodical Organisation. The main idea running throughout this dimension is the overwhelming feeling of attachment and love towards the parents being cared for.

Willing Devotion

The majority of participants exhibited willing devotion towards the parent they were caring for. They felt caring was a natural progression of events as they had been cared for as a child and it was their turn to be carer. Many carers felt no bitterness or bad feeling, rather that the situation was reciprocal and was a fair repayment.

Cause I realised I suppose he looked after me all these years and um it's reciprocal I - my thinking now is that my duty now is to look after my father. (See participant 003, field note 3.3a, coding manual p.165).

It is important for this carer that the parent is protected and has the best care for as long as is realistically possible from him. Most participants felt fully responsible for this.

An idea running through a lot of the interviews were clear principles as to what was right and wrong with regards to caring. There was no question in some carer's mind as to what the “right” thing to do was;

I think people should – not should that's... I find it difficult to understand people not caring for their parents. Unless I suppose they've had a particularly difficult childhood. (See participant 004, field note 4.3c, coding manual p.170).

There is almost an ethical obligation that this carer feels not only applies to her but is extended to all individuals who have parents needing care and an air of

judgement regarding those who do not take on this responsibility. Similarly, another carer relays a conversation she has had with her brother.

He said 'you know I think the time has come maybe for mum to go in to somewhere' and I said to him 'Really? Then the years we were growing up and mum could have just walked out and left us or put us in care. Would it have been alright if she had just sent us somewhere? Would that have been alright?' (See participant 008, field note 8.5b, coding manual p.204).

The intensity of the feelings these two women have about care coming from outside the family is remarkable and, interestingly both these carers are young and mums with school aged children to look after therefore had incredibly busy lives. The idea was that of a balance of care through the life course, a natural progression that was expressed by male carers too.

She spat and wet my mouth - I hated that. But she did. It was my mum these... things in your life you know? She is the one who knitted me stupid balaclavas to go to school in - an embarrassment - but that is what mums do and this is just - this is not a paying back situation it is just - it is not duty, it is not payback – it is just a natural thing people should do. (See participant 006, field note 6.6e, coding manual p.193).

The differences between the adult children in the study who had high EE and those who did not were highlighted when “natural caring” was discussed. For some, caring was second nature but for others to look after their parent, as if they were a child, went against all their instincts.

You have children and it is natural that they would move on. It's instinctive inside you, what they can do next, which it is not instinctive to undo backwards. It is not instinctive to be dressing your mother. It is ... it goes against all your natural instincts and your responses. (See participant 009, field note 9.6a, coding manual p.221).

This lady was horrified at what had happened to her mother and felt no control over the situation that she was faced with. She was rated as having high expressed emotion and found a lot of issues difficult to talk about. When one compares her with another adult child carer in a very similar situation, caring for her mother at the end stages of her illness, the contrast is very evident.

I'm not joking I can get her in and out of that shower in about seven minutes. Social services – when we were timing her and everything to see how much we need her carer (not that I'd let her do that because she's got her dignity) um they said to me they couldn't believe how quick I was. (See participant 008, field note 8.4i, coding manual p.203).

This carer uses humour to cope with the circumstances she finds herself in and does not think twice about changing her mother's incontinence pad or getting her dressed. Humour is seen throughout many of the interviews and is used to deal with embarrassing situations that otherwise would be quite distressing.

I wash his back and do his hair and then getting on to hygiene, personal habits if you like, he has become incontinent at times. The first time was last week I cleaned the sheets and I noticed upstairs the carpet had taken a bit of a battering (laughs). It was an old carpet. (See participant 003, field note 3.5c, coding manual p.167).

The willing devotion from the adult child carers is seen more in those that have had a good pre morbid relationship and in those who have shared a bond throughout life and not simply come back in to contact with their parent out of necessity. One of the participants interviewed had always been very close to his mother, partly because they had shared the experience of living with his abusive father. As a child he and his mother had done everything together.

Yes – absolutely and you forget the woman there is still my mum and it don't matter what she will ever be like. She is the same woman who used to take me up to the fair every Easter and wipe my mouth with a dirty tissue at the bus stop. (See participant 006, field note 6.6d, coding manual p.193).

The bond between mother and son, in this case, is so strong he can see past the dementia to the woman that has been there all his life. This bond makes the decision to care an obvious one for him.

Altruistic Fatalism

One participant in particular had been through a very difficult childhood coping with a violent, mentally ill father and now faced the caring responsibilities of someone she loved dearly having dementia.

I'm trying to look after my mum. I'm trying to train the new carer. We had one start last week but at the end of the day it's just got to be done. There's no point worrying about it or getting upset. You've just got to get up and get on with it.
(See participant 008, field note 8.10d, coding manual p.208).

This lady had to give up a job that she really enjoyed to become a full time carer for her mother and she had made that sacrifice for apparently selfless reasons. However, one must acknowledge the complex and dialectical nature of these relationships. What seem to be altruistic gestures and of no benefit to the carer perhaps feed a greater wish or need to be close to that parent at a time when they are ill and questions of mortality are being realised. Therefore, caring often could be fulfilling a need within the carer as well as the physical needs of the parent.

It is obvious that having a strong relationship with a partner who is fully committed to caring for their mother or father in law helps a great deal. The responsibility involved has implications for the whole family.

Because when I'm upstairs trying to get Jake's teeth brushed, pyjamas on – you know what five year old children are like aggggg...It's Dave who's down here with my mum and says 'look Val that programme we like's on'. (See participant 008, field note 8.13c, coding manual p.211).

If the partner is not completely supportive, the affective environment within the household can be very different, as was seen during other interviews.

My husband has no time at all for him now. He'll go round and mend the tap if it's broken and sit and have a cup of coffee but he won't offer any conversation. He sits there fairly silent and he won't laugh at dad's jokes. (See participant 002, field note 2.4e, coding manual p.158).

This lack of interest in a partner's parent is bound to add to an unpleasant atmosphere that makes the carer's life more difficult.

Whilst talking to the carers who were reconciled in their role and seemingly fully comfortable with their lives, it was apparent that some felt it was "meant to be" and there was no point in feeling that they were missing out on life.

Whatever you're doing at that time in your life is right and it's all happening for a reason. (See participant 008, field note 8.11a, coding manual p.209).

This fatalistic belief system enables this carer to cope and make the best of her situation. Without this belief carers tended to feel life was unfair, which seemed to make coping with being a primary caregiver for a parent with dementia much harder.

Empathic Maintenance of Identity

Carers that were managing well with their caring role had great empathy with their parent. They knew what sort of a life they had had, whether they had suffered in the past or whether they had made sacrifices for their children and they respected that. They saw life through their parent's eyes.

I love her very much and she, I think, had a difficult time bringing us up, which she could have done differently. She could have been you know she could... she gave up a lot of her life for us so there is that sort of repay bit but it's not... it's not a duty thing. I just think it is the right thing. (See participant 004, field note 4.14c, coding manual p.181).

These empathic carers knew how their mother or father would feel if they were still as mentally aware as they had been and they were keen to preserve their dignity and ensure matters were taken care of in a way they would have approved of. In their mind, the illness and the person are separated and the carers remember the character their parent had.

I am not sure what we will do about that. Angela did say about maybe one of the neighbours popping in but then I don't think that... I am almost sure that mum wouldn't want that. She wouldn't want them to know her business. That she has got... that she wouldn't want them to think that she has got a problem, she can't look after herself.... (See participant 010, field note 10.5c, coding manual p.229).

This carer is realistic when considering what her mother will need but is mindful to what she would want outsiders knowing.

The carers that understood what dementia entails seemed better equipped to cope with their ill parent. Those that knew their parent's uncharacteristic behaviour was not due to the individual but because of a degenerative disease were more able to detach themselves when the parent acted out of character.

This is part of life as we see it. This is not unusual for us, so we are not scared of what might happen. (See participant 006, field note 6.7c, coding manual p.194).

This carer has experienced dementia before with another relative and therefore, has a sort of “unphased realism” that allows him to take uncharacteristic behaviour in his stride. However, in cases where this does not happen and behaviours are entrenched within the pre-existing character of the parent, the carer cannot disassociate the illness from the person.

When she is manic and she is pulling at cushions and walking up and down, she is a walker...I can walk away quite happily. She is in very good hands and I can walk away. When she turns to me and says 'don't go and leave me in here, take me home with you mum'...or whatever ... for days I could be at rock bottom. (See participant 009, field note 9.5c, coding manual p.221).

This is extremely difficult to deal with and has a profound affect on this carer who, incidentally, had a very difficult and confusing pre morbid relationship with her mother.

Although realism as to what their parent can still do is important it is also evident that sustaining the personhood of the parent is imperative (Kitwood, 1997). Adult child carers often spoke about how they would take their parent shopping or to the cinema and that this was “their time”. Those carers who had a strong bond seemed to find this comforting, possibly because they were seeing their parent in familiar situations and were doing activities that they would have done with them pre illness.

I think it's nice that as adults, and she is still an adult and it's important that she feels like it, we sit down and watch a movie at the end of the evening together. The three of us or a comedy or something that she likes and we try - you know to chat a bit – doesn't really happen but we try. (See participant 008, field note 8.14a, coding manual p.211).

This carer was adamant that her mother did not “vegetate” and that the family enjoyed quality time together. She made the most of the situation and tried not to exclude her severely impaired mother from any activities that the family were involved in.

Methodical Organisation

The carers that were devoted to caring for their ill parent and were managing their role well were noticeably more methodical and organised than carers who resented caring and were trying to do so in a chaotic fashion.

I think although I'm quite shy, people do say that I'm quite bossy. I suppose it's about being organised as well. I know what I want and how I want it and if nobody else is going to stand up and take the lead I will do that in sort of family things. So I will get on and organise it if nobody else is doing it. (See participant 004, field note 4.4b, coding manual p.171).

It was noticeable that these people seemed to have more calm and stable characteristics when compared to the rest of their siblings. They were also often the youngest member of the sibling system. This caring style enabled them to look after their parent and the rest of their family and gave them a feeling of being in control.

I wrote to all my brothers and I said 'look I think it's our duty to sort this out now because we're all working at the moment' and I sorted it out with Help the Aged – very good plan and we paid it monthly for a year. All of us, the four of us, so it's all sorted out but you see they'd never think of something like that. (See participant 008, field note 8.18h, coding manual p.215).

These carers wanted issues to do with their parent dealt with in a particular way and the only way to ensure that this is done to their liking is to do it themselves.

2.3bii Contradictory Emotions

The dimension of “Contradictory Emotions” also comprises four themes. These themes are a) Emotionally Despairing, b) Confusing Bond, c) Haunting Memories, and d) Uncaring Attitude. The general idea that runs throughout this dimension is disharmony in the family and a sense of life being unfair.

Emotionally Despairing

Although there were many positive sides to caring apparent throughout the interviews a lot of carers exhibited contradictory emotions when the thought of what was happening to their loved one became overwhelming. Some carers were more balanced than others in their outlook. In one particular case a bachelor who had never moved away from the family home was dreading the loss of his parent because she was all he had known. He seemed terrified of what his life would become after the death of his mother, as he had nobody else.

You know I feel like I need to see her even though the conversation is very limited. I just feel I've got to see her. It makes me feel better. (See participant 001, field note 1.3c, coding manual p.145).

He is desperately hopeful that his mother will miraculously recover from the recent deterioration in her illness. Caring has become his whole life and he has given up his job to spend more time with her. It is useful to consider the literature on attachment in this case and the work of Mary Ainsworth in the 1960's. She defined the concept of different attachment styles as secure; insecure- avoidant and insecure - ambivalent or resistant. This carer seems to have an insecure - ambivalent attachment to his mother as he seeks proximity to her before they have been separated. This attachment style has endured throughout his lifetime and he is fully aware that his lack of alternative companions limits what options he has after her death.

A feeling of loneliness is also described by other adult child carers, even those who are surrounded by their siblings, partner or own children. There is always ultimately one person on whom the responsibility or burden of caring for a person with dementia falls and that can be overwhelming for the individual.

When that happens I do fall apart and when those times come every so many months, it's been more this year, those times I go a bit mental and I cry a lot and I get upset and I find it difficult to eat and function really but I just keep going because I have to. (See participant 008, field note 8.9a, coding manual p.207).

Everyone in this carer's family is helpful in their own way but she is the person who feels completely responsible.

The issue of gender is discussed during the interviews. It seems that when the carer and parent are opposing genders this makes personal matters more awkward, particularly if there is a male caring for a female.

As I say I try and buy mum clothes. I mean I've got a job to buy clothes for myself (laughs). I go in the shops and I have a panic attack and I leave with nothing. (See participant 001, field note 1.7b, coding manual p.147).

It is apparent that often the women carers in this sample were more comfortable with the “hands on” approach that is often required when caring for someone with dementia.

Obviously I groom her every day and shower her and help her wash. So I'm showering her, I'm patting her and everything and I'm saying do this, do this, do that and I show her. (See participant 008, field note 8.4h, coding manual p.203).

Each caring situation is different and the past and present dynamics between the caregiver and recipient are bound to affect both parties.

Confusing Bond

Some of the carers in this sample had simple and straightforward relationships with their parent but for others negative past events and feelings had led to a confusing bond being formed which continued into adult life and, in some cases, had created an embittered resentment of the parent they had to care for.

That is water under the bridge and I shouldn't be thinking about that now and I wouldn't be if daily I didn't have to go and be nice (laughs). I don't like people who do things unwillingly and that's what I...I don't ever behave like that but that's how I feel. (See participant 002, field note 2.1g, coding manual p.154).

This carer had a very difficult upbringing which she totally blamed on her father, whom she cares for. Daily she had to bottle up her feelings causing her to feel hypocritical, as she knew her caring actions towards her father were not completely genuine. This led the carer to feel badly about herself and affects her continuously. The carer speaks as if there is no choice in her situation as if she is caring for her father against her wishes. The truth is likely to be more complex than this as the feelings she had for her father are rather ambiguous. She has

resented him and yet craved his attention all her life. These circumstances contributed detrimentally to her physical and mental health as she suffered from hypertension and depression.

The natural thing for me to have done would have been to have had nothing to do with him because of all the things that have happened in the past. (See participant 002, field note 2.1k, coding manual p.155).

Again natural versus unnatural was a theme that was important for all the carers in this sample. This carer knew that her situation felt wrong but she felt pressured by her family to continue caring. Other carers felt their love had not been reciprocated by the parent in the past and perhaps had been one way. These feelings of rejection never seemed to disappear and although the carers were now in their fifties and sixties the feelings were very much present.

I was sent to people to be looked after - nothing like there is now - and because I was an only child I think I was very lonely. I had, obviously looking back, my mum was my whole world and I think I had this grudge against her because of that. (See participant 009, field note 9.8b, coding manual p.222).

This feeling of neglect as a child seems to have become an issue throughout her adult life as the carer always craved attention from her mother and was never satisfied with their relationship. This dissatisfaction in their relationship is reflected in her high expressed emotion rating.

When the bond between parent and child has been confused and conflicting in the past it seems that the carer experiences turmoil and these uncomfortable emotions are difficult to ignore. The nature of the illness contributes to the confusion, as often the parent forgets there has ever been a problem.

Yeah but he only focuses on me. It's like looking down the wrong end of a telescope and all he can see is baby girl at the other end. (See participant 002, field note 2.2a, coding manual p.155).

In some ways this carer seemed secretly pleased that she was finally getting the attention she had always craved from her father but on the other hand was still incredibly angry at him. These hostile emotions must have an influence on the affective environment within which the person with dementia lives and thus have an impact on their quality of life.

Haunting Memories

A large percentage of the sample did not have an enjoyable childhood for reasons such as inadequate parenting, poverty, alcohol dependence, mental illness or negligence. This affected carers differently depending on where the blame lay.

So my home life was very horrible. It's hard to describe now because now you get these support workers and the teachers move in and so forth but there was no support at that time. (See participant 002, field note 2.6f, coding manual p.159).

This carer blamed her father's negligent parenting for her mother's illness and eventual death and the mental illness and demise of her younger brother. He had not cared for them as he should and it was ironic to her that she was now responsible for this man who had let her down so badly. The carer was constantly haunted by the death of her younger brother, whom her father did not remember because of his illness but in her eyes had conveniently forgotten and this forgetfulness was absolutely deliberate to her.

It was me that forced him... (Choking tears) my brother in to care. (See participant 002, field note 2.7b, coding manual p.160).

Partly her sadness was mixed with self blame as she felt she had let her brother down too. When she had little contact with her father these emotions had been buried but constant contact with her father meant she was reminded every day and she could not forgive him.

Other carers, although appreciative of their parents' sacrifices for them, remembered their childhood as a difficult time.

People were not welcome in our house because that was considered to be a waste of time – leisure was something we didn't know about. We had to be working, because that was the thing that was perceived to be most important by my father.
(See participant 007, field note 7.4d, coding manual p.198).

This lady came from a very poor background but because of her good education became a head teacher and enjoyed relative wealth. When she spoke of her childhood her voice lacked emotion. Her father had been a very dominant man and there was a degree of blame for her mother, whom she cared for, for being “weak” when not standing up for herself or her daughters. This carer felt caring had been forced upon her and she certainly was not happy about the situation.

Some participants were haunted by memories of their parents’ suffering which had scarred them deeply. One man had witnessed his father’s death and this had contributed to him having a nervous breakdown.

He fell down the steps from the top to the bottom of the staircase and he had a stroke. When he fell he hit his forehead on the corner of the steps like that and it hit him in the forehead like an axe and just cleaned his head apart. (See participant 005, field note 5.4b, coding manual p.184).

The son could not believe his father died in this way and constantly played the scene back in his mind. When this is combined with the illness of his much loved mother the carer found it hard to cope with the present situation and throughout the interview seemed on the edge of tears.

When there has been violence in the home the adult child carer grieved for the parent who has suffered.

I think he had just worn the life right out of her. I mean she lived every day thinking she wasn't going to get through to the end of the day – beating her up. The mental abuse was terrible. She didn't think anything of herself by the end of it all. (See participant 008, field note 8.16b, coding manual p.213).

This carer was empathic towards her mother and because she knew what she went through whilst the family were growing up was especially adamant that she deserved the best care whilst ill. In contrast to others, this traumatic childhood seemed to have made the family closer. The father was not blamed because the carer understood he was mentally ill and therefore she was able to cope with these awful memories because of her insight.

Uncaring Attitude

Carers who felt their role towards their parent was a burden to them exhibited a somewhat uncaring attitude and were unsympathetic in their outlook and in the terminology they used to refer to them.

Ohhhh this is what I can't get across to people – as long as I can remember um when he came here it was considered bad enough to go in to residential and previous to that he'd been wacky for quite a few years maybe six - eight years easily. (See participant 002, field note 2.8a, coding manual p.161).

This lady did not experience any sorrow for her father as she saw his dementia as another way of avoiding responsibility, something she feels he has always done. The difference between this carer and the ones who showed empathy is a lack of understanding about the disease, as she simply sees her father as someone who is continuing to manipulate the people around him, including herself.

When there has been a lack of a bond the caring situation becomes more a filial obligation and a relentless tie that prevents the person from doing what they want.

We share it, but we both find it a considerable burden. (See participant 007, field note 7.2c, coding manual p.196).

Because of a lack of adequate alternatives this unwanted responsibility fell to two sisters that felt equally forced into the caring role. They were reluctantly dutiful as they knew their parents would have expected nothing less and when the residential

homes they had initially attempted to use were found to be below standard there seemed no other option but to become joint primary carers.

With my sister and myself, if I have her Saturday my sister has her Sunday and vice-versa. So you see our weekends are not free either and I mean nobody could be more dutiful than we are, believe me. (See participant 007, field note 7.3b, coding manual p.197).

There was a tinge of sarcasm as this lady described what her life was like. She resented the fact that her retirement, which she was so looking forward to, had been spoiled by this woman that she was never particularly close to in the first place. Again it was apparent that the pre-morbid relationship played a huge part in influencing the current care giving arrangement.

2.3biii Insufficient Support

The dimension “Insufficient Support” had two themes. These themes were a) Resenting Relations and b) Disappointing NHS Involvement. The general idea throughout this dimension is that of not wanting to be taken for granted and a general wishing for appreciation from others.

Resenting Relations

Possibly one of the most common issues that emerged from the interviews was that of insufficient support, particularly from siblings. Many of the participants felt that they were taken for granted by the rest of the family.

They know someone's there being with mum. I said to them a while ago 'I can't remember volunteering for all this'. You know we discussed mums future a few years ago when she broke her pelvis but nothing came of it. (See participant 001, field note 1.8c, coding manual p.148.).

This man had two brothers that lived very locally but played no part in the care of their mother. Although the adult child was happy to play the role of primary carer,

he had not been given a choice and would have very much appreciated some help, particularly from his sister in laws, as he was finding the personal hygiene of his mother difficult to cope with. He was desperately disappointed for himself and his mother that his brothers were so disinterested. There was also a sense of regret, as this man had fallen into the carer's role and in doing so has missed any opportunities to have a family of his own. He did not feel appreciated by his brothers as they had made the assumption that he would take full responsibility for care and this unfairness angered him.

This disappointing support is echoed throughout the interviews and where perhaps siblings had not been close in the past; it was highlighted when care for a parent becomes necessary. Family dynamics often showed sibling tension and conflict.

There is actually quite a lot of tension I think it would be fair to say, between me and my brother (laughs). I try to let it sort of wash over me. (See participant 004, field note 4.8e, coding manual p.176).

Again, this carer was happy to take the majority of the responsibility for her mother, even though she worked and had a young family, but resented the fact that her brother lived around the corner and did not help at all or rarely even visit. The tension this strained relationship between brother and sister create caused major disharmony within the family. The caring daughter was highly protective of her ill mother and was watchful that her seemingly uncaring brother did not upset her.

Sometimes he 'll be fine and other times he 'll be really curt and short and that – that hurts her. She 's very hesitant about ringing him and asking for anything or she would always ask me before him and you know would always ask my sister even though she 's in Wales, before him. (See participant 004, field note 4.9a, coding manual p.176.).

Some of the adult child carers were remarkably tolerant of their siblings, especially when they lived locally and could have lent a hand. One carer highlighted the lack of help her brothers gave her and yet she refused to show criticism or blame.

You know it's not like I'm asking – they've never had her round weekends or anything like that. I don't ask them and I don't expect them to. (See participant 008, field note 8.19e, coding manual p.216).

It is confusing as to why this carer did not expect any of her three brothers to help with their own mother. Throughout the interview she referred to the situation as if it were of her own making and therefore she needed to cope practically on her own.

I've been doing this for nearly six years. I've only had one week holiday in six years. I'm shattered you know. (See participant 008, field note 8.6e, coding manual p.205).

As this lady had made the decision to be a full time carer she felt as if this was her job and that she was in some way not entitled to receive support. The brothers in this family were fortunate to have such an altruistic sister as all their filial responsibility was channelled through her.

It was apparent that some of the offers of help or feelings of regret from the siblings who did not care for their parent were not seen as genuine by the primary carers.

I think she found it very tiring having her with her. Um... sometimes she apologises for being away and sometimes... and sometimes she actually means it... and sometimes it is a hollow gesture, which I fully understand. She has never had to do that. (See participant 006, field note 6.5e, coding manual p.192).

These “hollow gestures” were from an older sister that had emigrated many years ago to Canada. The participant felt that his sister was saying what she thought she should but in reality would not want the situation any other way. He laughed off the lack of support but there was the undercurrent of resentment, as he felt abandoned by her and had been left to pick up the pieces of their mother’s broken and violent marriage and now her dementia. There were a couple of instances from the interviews, like this, where the one and only sibling had emigrated and

this had exonerated them from their duty as a caring adult child. The sibling that was left behind had very little choice but to look after the parent.

Many of the parents that had dementia were seen as having a “favourite sibling” and this sometimes caused ill feeling, especially when it was seen as undeserved.

Steve, the youngest... he was actually mum's favourite cause there was a bit of a gap between us. That's what I said to Phil 'Steve's the favourite and he don't want to see his mother. He can't be bothered' (Disbelief) Nothing wrong! I was doing all the running around or whatever and Steve's getting all the praise. (See participant 001, field note 1.12a, coding manual p.152).

The parent was perhaps so familiar with the caring child that she showed less feeling for him and more for the non caring child, which was upsetting and felt unfair for the carer.

Although he does very little she has got this thing about not wanting him to feel left out. Wanting him to be involved in making the decisions and I know he actually half the time doesn't give a toss to be honest but you can't really say that to her. (See participant 004, field note 4.10b, coding manual p.178).

These carers, who were doing everything they possibly could to make sure their parent was safe and comfortable and happy, felt envious about this apparent favouritism. It perhaps their efforts seem under valued.

Disappointing NHS Involvement

Another type of support that was needed by these families was from the NHS and it was noticeable that carers felt more could be done for them and their parent with dementia. It was difficult to ascertain whether the criticism that was aimed at professional services stemmed from the obvious distress involved at the time of diagnosis of dementia and throughout the illness. Perhaps venting distress through criticism was therapeutic for them or perhaps the criticism was deserved, it is difficult to assess on such a subjective and emotive issue.

I think he thought we were making a fuss about nothing. I think he wasn't sure the assessment was necessary. Between that and the diagnosis mum wanted me to go to her appointments with her and sit in, (which I wouldn't have done before) because she forgot things and he seemed to not like that. (See participant 004, field note 4.7a, coding manual p.173).

This carer was angry that she was seen by her GP as interfering and hysterical regarding her mother's illness. In this particular case the carer had a professional mental health background, as did some of her family, and this previous knowledge seemed to increase her expectations of the health service, rather than being satisfied with an unprofessional attitude.

I find it annoying and frustrating when the physical health side are not...It doesn't seem to be integrated and I don't think it's to do with... I mean we see it when our residents have physical health problems and have to go in to General hospital, the lack of understanding around mental health. (See participant 004, field note 4.7i, coding manual p.175).

This lady has a professional insight that helped her deal with mistreatment within the NHS and enabled her to protect her mother's rights. There seemed to be a gap in the health service for a psycho-educational approach to help carers understand what dementia involved and how to best cope with it.

Just to phone up and say this has now happened. What can I do? Even just to talk to somebody. Talking ... I just firmly believe that talking is just ... just talking...just crying... you know? But I can't talk about those people... But I am quite ... I battle on, but every now and then you have just got to vent it. You can't necessarily vent it to your family because you are hurting them. (See participant 009, field note 9.10b, coding manual p.224).

This lady felt her needs had not been met and that she would benefit from counselling. She obviously did not want her family to become too involved in her mother's care and therefore need outside emotional support. This is perhaps evidence that a professionally trained person such as a Health Counsellor or

Psychologist could be used as a source of reassurance and perhaps, in some cases, crisis prevention.

2.3c Follow Up of Interviewees and their Parents

Eighteen months after the first interview the researcher returned to the patients' psychogeriatric notes and memory nurses to ascertain what the situation was now like for the ten interviewees. Three of the ten parents had died, four were in rest homes or nursing homes and only three female parents were still at home and being cared for by their family. Interestingly, the adult children who were still caring were the three young women with young families of their own who had close relationships with their mothers.

This follow up finding did not seem to be related to the severity of the parents' dementia or the physical frailty of the individual. One of the most profoundly impaired parents, who was unable to be examined cognitively even when the interviews were being completed because of her lack of comprehension, was still being cared for at the eighteen month follow up. Therefore, this seemed to imply that these three carers had a stronger motivation and ability to continue caring and this seemed to be at least partly related to the lifelong quality of their parent child relationship.

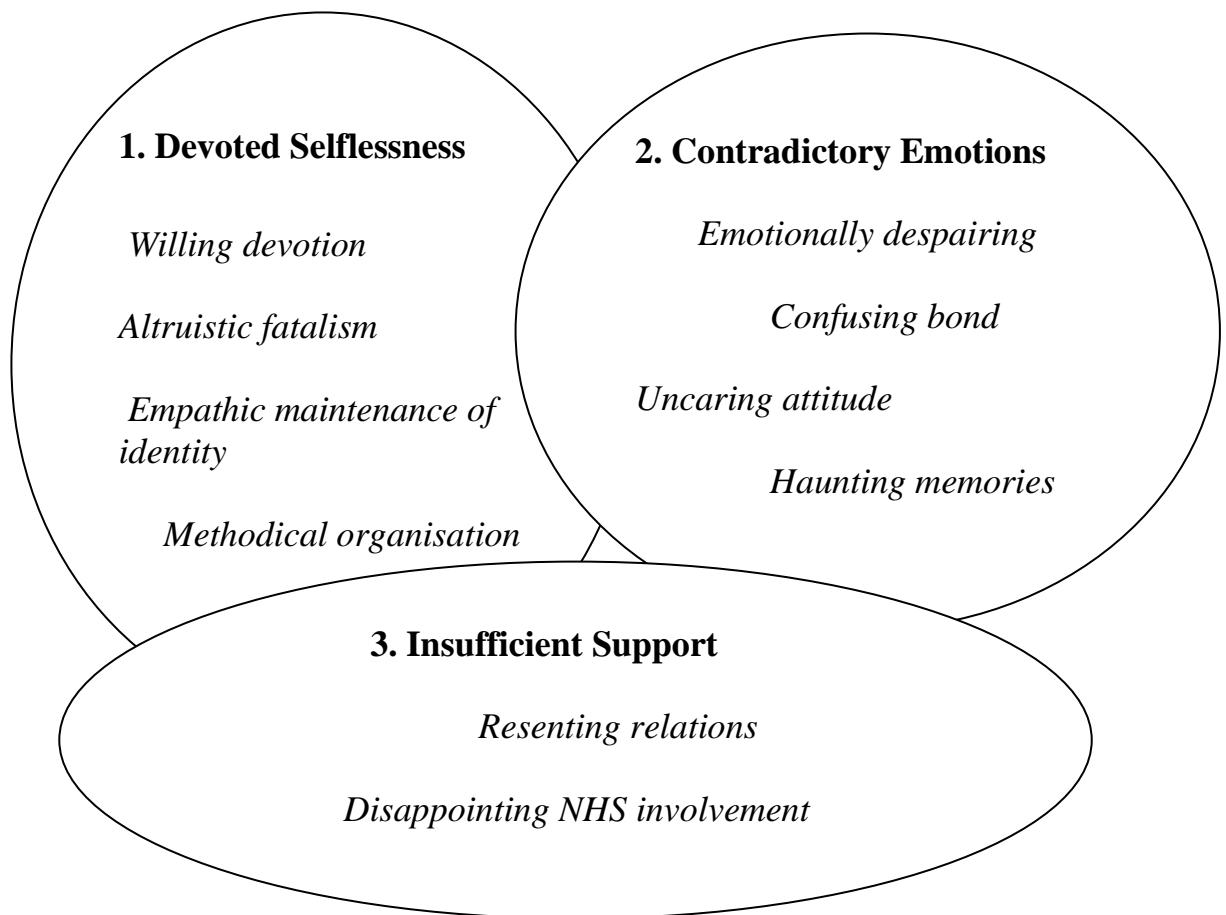
2.4 DISCUSSION

2.4a Introduction

The discussion section is divided in to several parts. The initial diagram in Figure Five aims to illustrate what motivates adult children to care for parents with dementia and exhibits how the three main dimensions interlink. There is then discussion as to whether the three dimensions 1) Devoted Selflessness, 2) Contradictory Emotions, and 3) Insufficient Support concur with previous literature on issues such as the pre-morbid relationship, attachment theory, expressed emotion, elder abuse, filial piety and family demographics. Finally,

limitations of the study are presented and possible future research ideas are considered.

Figure 5: A diagram to show themes influencing motivations for adult children to care for parents with dementia



The three dimensions are representations of important issues affecting an adult child caring for a parent with dementia. The themes overlap with each becoming more or less important to a carer at any one time. Those people with high expressed emotion, who were not necessarily coping as well as others, tended to have an imbalance. Thus, carers whose contradictory emotions overwhelmed them or who felt unappreciated and unsupported the majority of the time found it more difficult to experience the positive, selfless or altruistic aspects of caring.

2.4b Previous Literature

Many of the themes that have been drawn from the interviews with adult children caring for their parent with dementia concur with the existing literature. However, there are some limitations as to how one may generalise the results of the research further and these will be discussed.

2.4bi The Pre-morbid Relationship

The pre morbid relationship between parent and child is a major focus for the study and adult attachment theory is important when considering how these carers feel. Cicirelli's (1986) expansion of Bowlby's (1980) life span attachment theory conceptualising attachment as an internal state involving a conscious desire to be close to someone whose presence elicits feelings of emotional security very much describes many of the participants from this study.

The three young daughters who truly respected their mothers for bringing them up in the face of adversity all had a strong bond with their parent, and they wished to maintain that bond, thus nurturing the parent and reversing the initial parent child role. The parent becomes quite dependent and the relationship comes full circle. It is interesting that it was these daughters who continued to care eighteen months later, when the participants with insecure attachment styles felt unable to carry on in the role.

Those adult child carers who had high expressed emotion or who were perhaps particularly unfeeling when discussing their association with their parent often had difficult previous relationships with their parent and frequently attributed negative actions from the elderly individual as attributable to the person and not the disease.

Participant 002 had a very difficult childhood and she resented her father immensely, seeing him as "negligent" and "irresponsible". She had made these attributions towards her father and blamed him for her poor childhood. This continued to influence how difficulties expressed themselves in the caring

relationship between her and her father. Similarly, participant 009 felt she had been unloved as a child and this was reflected in her expressed emotion ratings. The unresolved issues from her childhood haunted the current relationship. Thus, Williamson and Shaffer's (2001) communal relationship theory is supported here in that the extent to which pre-morbid relationships were communal in nature determines whether caregivers perceive their current relationships as rewarding. At the eighteen month follow up of the three carers and their parents who were rated as having high expressed emotion at interview one had died and two were in rest homes.

2.4bii Elder Abuse

There were no obvious signs of elder abuse when conducting the interviews, so it is hard to make inferences from the data. It is evident that even if there were abuse within a family it would be difficult to explore it in a single interview with a stranger as the carer no doubt would be reluctant to do this and a rapport would need to be built between carer and interviewer first.

It is interesting to think of Steinman's (1979) theory of elder abuse when considering the ten participants within this research. Participant 009 perhaps could be labelled the "over zealous approacher" as she continued to give a large amount of care with past conflicts very much at the forefront of her mind, causing her stress and strain that could have impacted on her mother. Alternatively, participant 002 could be labelled the "vacillator" as she gave care for a while but then avoided it when negative feelings built up. This lady spent a great deal of time in France with her husband which she called her "escape" and this is evidently the time that her father's care suffered and he was perhaps somewhat neglected. It is useful to have Steinman's theory in mind when considering the different individual circumstances and relationships.

2.4biii Filial Piety

When considering filial piety the research conducted by Ho (1994), suggesting that families with higher social economic status and education levels were less

likely to have strong family attitudes, was not supported. Mixtures of families from different backgrounds were included in this study and there was no obvious trend to show more or less care, although the numbers in the study are very small. The majority of carers that were coping well denied a feeling of duty but rather a “natural repayment”, often for bringing the carer up in difficult circumstances. Those that felt their relationship was unnatural and were unhappy with the caring situation felt a lack of control and that parental expectations were the reason for caring. These carers were in the minority however.

It is interesting that the carers who were comfortable with their caring role were quite judgemental of those that would perhaps put their parents in to residential care and those that felt forced to care were well aware of those moral judgements made by others thus supporting social identity theory, (Seelbach, 1984), in that they are avoiding the cost of social disapproval.

2.4biv Demographic Factors

When considering family demographic factors influencing motivations to care for parents with dementia, particularly gender, the interviews did not show agreement with the literature but again the sample size was far too small to make generalizations. Dwyer and Coward (1991) found brothers provided less help when in mixed gendered relationships with siblings and this was evident with some families but equally there were a couple of families that had male and female siblings where the male had become the primary caregiver. Thus, the Stein et al. (1998) theory that men have different thresholds of obligation is not supported here. What was evident was that those caregivers who had supportive partners, whether they were male or female, did not have high expressed emotion. Those that did have high expressed emotion were either separated from their partner or had a partner who had very much stood back from caring, thus leaving the adult child carer alone in their role. This highlights the importance of a good support network for the carer so that they do not become overwhelmed with their situation.

2.4bv Expressed Emotion

The five minute speech sample (Magana et al, 1986) and expressed emotion rating was a good indication for how the mood of the interview would flow. It was interesting to see how those people who had high or low expressed emotion elicited similar themes to one other. For instance, those participants with high expressed emotion often had many haunting memories and those with low expressed emotion ratings were often methodical and organised in their caring style. One noticeable factor was that the adult child carer who focused on what their parent could not do was far more stressed than those who focused on what their parent could do.

The three carers with high expressed emotion used negative attributions regarding the causality of their parents actions, considering their behaviour to be somewhat controllable and part of their continuing personality rather than part of the illness process. These negative attributions of causality in carers with high expressed emotion were also found by Barrowclough, Johnston and Tarrier (1994) when they considered carers of patients with schizophrenia and are indeed an aspect that may be worked on clinically when teaching coping techniques to carers.

The main difference between adult child carers who had high or low expressed emotion scores was that those with low scores found the experience “natural” whereas those who had high scores felt their situation was “unnatural” in some way. Two of the three carers with high expressed emotion in this study had a strained pre-morbid relationship but the third simply found the transition of his mother from a capable, independent, immaculately dressed woman to an unpredictable, behaviourally disturbed person, unbearable. This indicated that the pre morbid relationship is not the only issue to consider when predicting expressed emotion levels. The study is in agreement with several authors (Blieszner & Shifflett, 1989; Gilleard, 1986; Bledin, MacCarthy, Kuipers & Woods, 1990) in that intervention packages designed to help carers within this situation should differentiate between spouses and children as they obviously have very different needs.

2.4c Limitations

There are obvious drawbacks to the study design used for this piece of research. As only a pilot study with few participants and using qualitative methodology, generalisations of frequency of attitudes within the general population of carers are not possible. There are further limitations to the sample used. The participants were self-selecting not only with regard to the memory clinic, as they would have requested a referral initially but also to the study itself. Offspring who were not caring for whatever reason were not represented and therefore it cannot be concluded that the members of this sample were typical of all adult children with a parent with dementia.

It must also be mentioned that the researcher for this study held the additional position of study co ordinator at the memory and research clinic and there was perhaps a clash of roles. There are different procedures used to recruit participants within the clinic when compared to the University and there may perhaps have been a different response from participants if the researcher had not worked at the clinic.

A particular bias of helpful carers agreed to participate in the study, as the memory nurses were consulted as to who would be likely to agree to be interviewed before the families were approached. Perhaps those families more in danger of elder neglect or abuse would not be so keen to speak with a researcher. In hindsight it may have been interesting to interview comparison samples as well, for instance, those carers who were in similar circumstances but who decided not to attempt or to continue caring.

It could be argued that the use of a semi structured interview, such as the one used in this study, would be too time consuming for clinical use. However, this has been taken into consideration and the aim is to use the semi structured interview as a research tool only and perhaps utilise the data from the interviews to create a more user friendly questionnaire format in the future. This would be used to establish indicators of pre-morbid relationship quality, filial piety, elder abuse and expressed emotion, and any additional factors that may be helpful in an initial

assessment at a memory clinic. It is hoped that by understanding the family dynamics in a more comprehensive manner the clinician has a better chance of preventing crises.

2.4d Future ideas

It is apparent that this research has been applied to a very specific population, adult children carers and parents with dementia. However, there is no reason why this design could not be used in other caring situations. Adult children may care for elderly parents without dementia but with multiple physical problems who require a great deal of aid with activities of daily living or who have chronic illnesses that impact on the mental health of the parent and cause illnesses such as depression and anxiety.

The five minute speech sample (Magana et al, 1986) has been utilised to research the affective environment of families caring for people with many different illnesses such as Diabetes (Anderson,1990); Schizophrenia (Bebbington & Kuipers,1994); Asthma (Hermanns, Florin, Dietrich, Rieger & Hahlweg,1990); Rheumatoid Arthritis (Manne & Zautra,1989); Anorexia (Szmukler, Eisler, Russell & Dare,1985) and Post Traumatic Stress Disorder, (Tarrier,1996) to name but a few. The key aim of this study was to develop methods that could be used within memory clinics to identify those adult child carers of people with dementia that may be at risk of developing difficulties with caring. It is conceivable that the interview used in this study could be used in such a way not only in dementia but also with a multitude of different illnesses to ascertain the quality of adult children carer - parent relationships, with a view to crisis prevention.

To conclude it seems that all ten participants from this study, although very different in their circumstances, elicited some similar themes and subthemes that could be used when considering future research in this field. Many of the carers showed devoted selflessness that encompassed feelings of willing devotion and altruism. They empathically felt for their parent and wanted to maintain their identity for as long as humanly possible, but in order to cope sufficiently needed to keep routine and a methodical organisation within the household. Some carers

were hindered in their caring efforts by contradictory emotions caused by a confusing parental bond and haunting memories from the past. This sometimes led the adult child participants to be emotionally despairing or to have an uncaring attitude towards their parent. All carers spoke of some areas where there had been insufficient support, whether this had been disappointing NHS involvement or led to resenting relations for not doing their fair share.

The eighteen month follow up of these families supported the idea that a healthy, loving relationship between parent and child may be the key contributing factor to motivate continuing care at home. When this has not been the case it is important for health services to be aware of the situation in order to make a risk assessment and to put support structures in place. The National Dementia Strategy (2008) report states that early provision of support at home can decrease institutionalisation by 22 per cent and that carer support and counselling at the stage of diagnosis can reduce care home placements by 28 per cent. The issues discussed in this paper were repeatedly referred to throughout the interviews and were therefore very important to the carers. It seems that this information would be helpful in a clinical setting to inform professionals regarding the background of families who enter the Older People's Mental Health service in the future.

It is recommended that more research is carried out in this area as, with the growing elderly population, we as a society will depend more and more on informal carers, a large minority of whom will be adult children. It is paramount that the emotional and physical needs as well as the past circumstances of the parent and the carer are fully considered in dementia care in order to ensure these families are able to cope appropriately and not be left until it is too late for them to manage at all.

APPENDIX A

Table Five; Studies accepted for the systematic review

No.	Title	Reference	Year	Author
1	Family attitudes to caring for the elderly mentally infirm at home.	<i>Family Practice</i> , 3, 31-36.	1986	Gilleard, C.J.
2	Expressed emotion and perceived family interaction in the key relatives of elderly patients with dementia.	<i>Psychological Medicine</i> , 17, 963-970.	1987	Orford, J., O'Reilly, P. & Goonatilleke, A.
3.	Expressed emotion in caregivers of the dementing elderly.	<i>British Journal of Medical Psychology</i> , 62, 265-272.	1989	Gilhooly, M.L. & Whittick, J. E.
4.	Daughters of people with dementia: Expressed emotion, strain and coping.	<i>British Journal of Psychiatry</i> , 157, 221-227.	1990	Bledin, K.D., MacCarthy, B., Kuipers, L. & Woods, R.T.
5.	Test of a model for caregiver strain.	<i>Case Western Reserve University (Health Sciences)</i> , 28.	1990	England, M.C.
6.	Expressed emotion and coping techniques amongst carers of the dementing elderly.	In G.M.M Jones & B.M.L Miesen, (Eds.), <i>Care-giving in dementia: Research & applications</i> (pp.380-397) N.Y: Tavistock / Routledge.	1992	Whittick, J.E.
7.	Intimacy as a determinant of expressed emotion in carers of people with Alzheimer's disease.	<i>Psychological Medicine</i> , 28, 1085-1090.	1998	Fearon, M., Donaldson, C., Burns, A. & Tarrier, N.
8.	Caregiving by adult children: Involvement, role disruption, and health.	In R.H. Binstock & L.K. George (Eds.) <i>Handbook of Aging and the Social Sciences</i> , pp. 238-254. San Diego, CA: Academic Press.	2001	Pearlin, L.I., Pioli, M.F. & McLaughlin, A.E.

No.	Title	Reference	Year	Author
9.	The quality of the care giving relationship in informal care for older adults with dementia and chronic psychiatric patients.	<i>Psychology & Psychotherapy: Theory, Research & Practice</i> , 75, 295-311.	2002	Spruytte, N., Van-Audenhove, C., Lammertyn, F. & Storms, G.
10.	Korean adult child caregivers of older adults with dementia.	<i>Journal of Gerontological Nursing</i> , 29, 19-28	2003	Son, G.R., Wykle, M.L. & Zausniewski, A.
11.	Filial maturity as a predictor for the burden of demented parents' caregivers	<i>Zeitschrift fur Gerontologie und Geriatrie</i> , 39, 120-125.	2006	Stiens, G., Maeck, L. & Stoppe, G.
12.	Affection, communication, and commitment in adult child care giving for parents with Alzheimer's disease.	In J.A. Mancini (Ed.). <i>Aging Parents and Adult Children</i> , (pp. 231-243). Lexington Books, MA, England.	1989	Blieszner, R. & Shifflett, P.A.
13.	The unencumbered child: Family reputations and responsibilities in the care of relatives with Alzheimer's disease.	<i>Family process</i> , 34, 7-99.	1995	Globerman, J.
14.	Caring in families: What motivates wives, daughters, and daughters-in-law to provide dementia care?	<i>Journal of Family Studies</i> , 5, 235-247.	1999	Cahill, S.M.
15.	Negotiating family relationships: Dementia care as a midlife developmental task.	<i>Families in Society</i> , 82, 383-392.	2001	Sherrell, K., Buckwalter, K.C. & Morhardt, D.
16.	Daughters giving care to mothers who have dementia: mastering the 3 R's of (re)calling, (re)learning, and (re)adjusting.	<i>Journal of Family Nursing</i> , 10, 50-69.	2004	Perry, J.
17.	Mother-adult daughter relationships within dementia care: a critical analysis.	<i>Journal of Family Nursing</i> , 13, 13-32	2007	Ward-Griffin, C., Oudshoorn, A, Clark, K & Bol, N.

No.	Title	Reference	Year	Author
18.	Clarification of caring behaviours by the family of elderly relations living in rural Japan.	<i>International Journal for Human Caring</i> , 11, 25–9	2007	Tada,T., Tanioka,T., Hashimoto, F., Matsushita, Y., Yamashita, R., Kawanishi, C. & Onishi, C.

APPENDIX B

Papers fully reviewed and excluded

Baikie, E. (2002). The impact of dementia on marital relationships. *Sexual & Relationship Therapy. Special Issue: Sex & intimacy in older people*, 7, 289-299.

Reason for exclusion: Spouse relationship focus

Ballard, C.G., Saad, K., Coope, B. & Graham, C. (1995). The aetiology of depression in the carers of dementia sufferers. *Journal of Affective Disorders*, 35, 59-63.

Reason for exclusion: Carers of people with illnesses other than dementia.

Beck, A., Daley, D., Hastings, R.P. & Stevenson, J. (2004). Mothers expressed emotion towards children with and without intellectual abilities. *Journal of Intellectual Disability Research*, 48, 628-638.

Reason for exclusion: Not dementia focus.

Blieszner, R. & Hamon, R.R. (1992). Filial responsibility, attitudes, motivators and behaviours. *Gender, Families & Elder Care* (pp. 105-119). C.A: Sage Focus Editions, Sage Publications, Inc, Thousand Oaks.

Reason for exclusion: Not dementia focus.

Braudy-Harris, P., Orpelt - Long, S. & Fujii, M. (1998). Men and elder care in Japan: A ripple of change? *Journal of Cross Cultural Gerontology*, 13, 177-198.

Reason for exclusion: Not dementia focus.

Browne, C.J. & Shlosberg, E. (2006). Attachment theory, ageing and dementia: A review of the literature. *Ageing and Mental Health*, 10, 134-142.

Reason for exclusion: Patient focus

Cheung, C.K., Lee, J.J. & Chan, C.M. (1994). Explicating filial piety in relation to family cohesion. *Journal of Social Behaviour & Personality*, 9, 565-580.

Reason for exclusion: Not dementia focus.

Christensen, K.A., Stephens, M.A.P. & Townsend, A.L. (1998). Mastery in women's multiple roles and well being: Adult daughters providing care to impaired parents. *Health Psychology*, 17, 163-171.

Reason for exclusion: Not dementia focus.

Cicirelli, V.G. (1983). A comparison of helping behaviour to elderly parents of adult children with intact and disrupted marriages. *Gerontologist*, 23, 619-625.

Reason for exclusion: Not dementia focus.

Cicirelli, V.G. (1983). Adult children's attachment and helping behaviour to elderly parents: A path model. *Journal of Marriage & The Family*, 45, 815-825.

Reason for exclusion: Not dementia focus.

Cicirelli, V.G. (1984). Marital disruption and adult children's perception of their siblings' help to elderly parents. *Family Relations: Journal of Applied Family & Child Studies*, 33, 613-621.

Reason for exclusion: Not dementia focus.

Cicirelli, V.G. (1986). The helping relationship and family neglect in later life. *Elder abuse: Conflict in the Family* (pp.49-66). Auburn House Publishing Co, N.Y.

Reason for exclusion: Not dementia focus.

Cicirelli, V.G. (1990). Relationship of personal and social variables to belief in paternalism in parent care giving situations. *Psychology & Ageing, 5*, 458-466.

Reason for exclusion: Not dementia focus.

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

Reason for exclusion: Not dementia focus.

Cicirelli, V.G. (1995). A measure of care giving daughters' attachment to elderly mothers. *Journal of Family Psychology, 9*, 89-94.

Reason for exclusion: Not dementia focus.

Cicirelli, V.G. (1998). A frame of reference for guiding research regarding the relationship between adult attachment and mental health in aging families. J. Lomranz (Ed.) *Handbook of Ageing and Mental Health: An Integrative Approach* (pp. 341-353). N.Y: Plenum Press.

Reason for exclusion: Not dementia focus.

Cicirelli, V.G. (2000). An examination of the trajectory of the adult child's care giving for an elderly parent. *Family Relations: Interdisciplinary Journal of Applied Family Studies, 49*, 169-175.

Reason for exclusion: Not dementia focus.

Compton, S.A., Flanagan, P. & Gregg, W. (1997). Elder abuse in people with dementia in Northern Ireland: Prevalence and predictors in cases referred to a psychiatry of old age service. *International Journal of Geriatric Psychiatry, 12*, 632-635.

Reason for exclusion: Elder abuse focus

Cooney, C. & Howard, R. (1995). Abuse of patients with dementia by carers – out of sight but not out of mind. *International Journal of Geriatric Psychiatry, 10*, 735-741.

Reason for exclusion: Elder abuse focus

Cooney, C. & Mortimer, A. (1995). Elder abuse and dementia: A pilot study. *International Journal of Social Psychiatry, 41*, 276-283.

Reason for exclusion: Elder abuse focus

Coyne, A.C., Reichman, W.E. & Berbig, L.J. (1993). The relationship between dementia and elder abuse. *The American Journal of Psychiatry, 150*, 643-646.

Reason for exclusion: Elder abuse focus

Daire, A.P. (2002). The influence of parental bonding on emotional distress in care giving sons for a parent with dementia. *The Gerontologist, 42*, 766-771.

Reason for exclusion: Not community setting

Daire, A.P. (2004). Investigating caregiver distress with the parental bonding instrument (PBI). *Dementia: The International Journal of Social Research and Practice, 3*, 83-94.

Reason for exclusion: Not community setting

De Vugt, M.E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., Winkens, I., Jolles, J. & Verhey, F.R.J. (2003). Behavioural disturbances in dementia patients and quality of the marital relationship. *International Journal of Geriatric Psychiatry, 18*, 149-154.

Reason for exclusion: Spouse relationship focus

Ferraro, K.F. (2001). Ageing and role transitions. In R.H. Binstock (Ed.) *Handbook of Ageing and the Social Sciences. 5th Edition* (pp.313-330). C.A :Academic Press.

Reason for exclusion: General theory

Finley, N.J., Roberts, D. & Banahan, B.F. (1988). Motivators and inhibitors of attitudes of filial obligation toward aging parents. *The Gerontological Society of America, 28*, 73 - 78.

Reason for exclusion: Not dementia focus.

Gilleard, C. J. (1984). Emotional distress amongst the supporters of the elderly mentally infirm. *British Journal of Psychiatry, 145*, 172-177.

Reason for exclusion: Not relationship with parent and adult child focus

Gold, D.P., Cohen, C., Shulman, K. & Zuccher, C. (1995). Care giving and dementia: Predicting negative and positive outcomes for caregivers. *International Journal of Aging & Human Development, 41*, 183-201.

Reason for exclusion: General theory

Golimbet, V. & Trubnikov, V. (2001). Evaluation of the dementia carer's situation in Russia. *International Journal of Geriatric Psychiatry, 16*, 94-99.

Reason for exclusion: General theory

Hastings, R.P, Daley, D, Burns,C & Beck, A. (2005). Maternal distress and expressed emotion: Cross sectional and longitudinal relationships with behaviour problems of children with intellectual disabilities. *American Journal of Mental Retardation, 111*, 48-61.

Reason for exclusion: Not dementia focus.

Ho D.Y. (1994). Filial piety, authoritarian moralism, and cognitive conservatism in Chinese societies. *Genetic, Social, & General Psychology Monographs*, 120, 347-365.

Reason for exclusion: Not dementia focus.

Ho D.Y. (1996). Filial piety and its psychological consequences. In M.H. Bond (Ed.) *The Handbook of Chinese Psychology* (pp.155-165) N.Y: Oxford University Press.

Reason for exclusion: Not dementia focus.

Horowitz, A. (1985). Sons and daughters as caregivers to older parents: Differences in role performance and consequences. *The Gerontologist*, 25, 612-617.

Reason for exclusion: Not dementia focus.

Hubley, A.M., Hemingway, D. & Michalos, A.C. (2003). A comparison of older informal caregivers and non-caregivers living in non-metropolitan areas. *Social Indicators Research*, 61, 241-258.

Reason for exclusion: General theory

Ikels, C. (2002). Constructing and deconstructing the self: Dementia in China. *Journal of Cross Cultural Gerontology*, 17, 233-251.

Reason for exclusion: Not dementia focus.

Kim, I. K. & Kim, C. S. (2003). Patterns of family support and the quality of life of the elderly. *Social Indicators Research*, 62, 437.

Reason for exclusion: Not dementia focus.

Kim, J.S. & Lee, E.H. (2003). Cultural and non cultural predictors of health outcomes in Korean daughter and daughter in law caregivers. *Public Health Nursing, 20*, 111-119.

Reason for exclusion: Not dementia focus.

Kramer, B.J. (1993). Marital history and the prior relationship as predictors of positive and negative outcomes among wife caregivers. *Family Relations: Interdisciplinary Journal of Applied Family Studies, 42*, 367-375.

Reason for exclusion: Spouse relationship focus

Kramer, B.J. & Lambert, J.D. (1999). Care giving as a life course transition among older husbands: A prospective study. *Gerontologist, 39*, 658-667.

Reason for exclusion: Spouse relationship focus

Lawrence, R.H., Tennstedt, S.L. & Assman, S.F. (1998). Quality of the caregiver – care recipient relationship. Does it offset negative consequences of care giving for family caregivers. *Psychology and Aging, 13*, 150-158.

Reason for exclusion: Not relationship with parent and adult child focus.

Lee, M.Y. & Mjelde, M.L.A. (2004). Cultural dissonance among generations: A solution-focused approach with East Asian elders and their families. *Journal of Marital & Family Therapy, 30*, 497-513.

Reason for exclusion: Not dementia focus.

Lee, Y.R. & Sung, K.T. (1998). Cultural influences on caregiving burden: Cases of Koreans and Americans. *International Journal of Ageing & Human Development, 46*, 125-141.

Reason for exclusion: Not psychological predictors

Lyonette, C & Yardley, L. (2003). The influence on carer wellbeing of motivations to care for older people and the relationship with the care recipient. *Ageing & Society*, 23, 487-506.

Reason for exclusion: Not dementia focus.

Lyonette, C. & Yardley, L. (2006). Predicting mental health outcomes in female working carers: A longitudinal analysis. *Aging and Mental Health*, 10, 368-377.

Reason for exclusion: Not dementia focus.

McLaughlin, L.A. & Braun, K.L. (1998). Asian and Pacific Islander cultural values: Considerations for health care decision making. *Health & Social Work*, 23, 116-126.

Reason for exclusion: Not dementia focus.

Marcoen, A. (2005). Parent care: The core component of intergenerational relationships in middle and late adult hood. *European Journal of Ageing*, 2, 208-212.

Reason for exclusion: Not dementia focus.

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

Reason for exclusion: Spouse relationship focus

Ng, S.H. (2002). Will families support their elders? Answers from across cultures. In T.D. Nelson (Ed.) *Ageism: Stereotyping and prejudice against older persons* (pp. 295-309). The MIT Press, Cambridge, MA, US.

Reason for exclusion: Not dementia focus.

Pang, E. C., Jordan-Marsh, M., Silverstein, M. and Cody, M. (2003). Health seeking behaviours of elderly Chinese Americans: shifts in expectations. *The Gerontologist*, 43, 864-874.

Reason for exclusion: Not dementia focus.

Pruchno, R. & Rosenbaum, J. (2003). Social relationships in adulthood and old age. In R.M. Lerner (Ed.) *Handbook of Psychology: Developmental Psychology* (pp.487-509). Easterbrooks, M.A.

Reason for exclusion: Not dementia focus.

Pyke, K. (1999). The micropolitics of care in relationships between ageing parents and adult children: Individualism, collectivism and power. *Journal of Marriage and the Family*, 61, 661-672.

Reason for exclusion: Not dementia focus.

Rahman, N. (1993). Conflict and care giving: Testing a social-psychological model. *Australian Journal on Ageing*, 12, 16-19.

Reason for exclusion: General theory

Sadler, P., Kurrie, I. & Cameron, I. (1995). Dementia and elder abuse. *Australian Journal on Aging*, 14, 36-40.

Reason for exclusion: Not relationship with parent and adult child focus

Saveman, B. & Sandvide, A. (2001). Swedish general practitioners' awareness of elderly patients at risk of or actually suffering from elderly abuse. *Scandinavian Journal of caring sciences*, 15, 244-249.

Reason for exclusion: Elder abuse focus.

Shaffer, D.R. & Williamson, G.M. (2006). Shall we select Selective Investment Theory? A viewpoint from the informal care arena. *Psychological Inquiry*, 17, 51-55.

Reason for exclusion: Not dementia focus

Siegler, I.C., Dawson, D.V. & Welsh, K.A. (1994). Caregiver ratings of personality change in Alzheimer's disease patients: A replication. *Psychology & Aging*, 9, 464-466.

Reason for exclusion: Patient focus

Stein, C.H., Wemmerus, V.A., Ward, M., Gaines, M.E., Freeberg, A.L. & Jewell, T.C. (1998). Because they're my parents": An intergenerational study of felt obligation and parental care giving. *Journal of Marriage & the Family*, 60, 611-622.

Reason for exclusion: Healthy elderly focus.

Sung, K.T. (1995). Measures and dimensions of filial piety in Korea. *The Gerontologist*, 35, 240 – 247.

Reason for exclusion: Not dementia focus.

Tarrier, N., Barrowclough, C., Ward, J., Donaldson, C., Burns, A. & Gregg. (2002). Expressed emotion and attributions in the carers of patients with Alzheimer's disease: The effect on carer burden. *Journal of Abnormal Psychology*, 111, 340–349.

Reason for exclusion: Not relationship with parent and adult child focus

Wearden, A.J., Tarrier, N., Barrowclough, C., Zastowny, T.R. & Rahill, A.A. (2000). A review of expressed emotion research in health care. *Clinical Psychology Review*, 20, 633-666.

Reason for exclusion: Not relationship with parent and adult child focus

Wenger, G.C., Scott, A. & Seddon, D. (2002). The experience of caring for older people with dementia in a rural area: Using services. *Aging & Mental Health, 6*, 30-38.

Reason for exclusion: General theory

Whitbeck, L.B., Simons, R.L. & Conger, R. D. (1991). The effects of early family relationship on contemporary relationships and assistance patterns between adult children and their parents. *Gerontology: Social Sciences, 46*, 330-337

Reason for exclusion: Not dementia focus.

Wijeratne, C. & Lovestone, S. (1996). A pilot study comparing psychological and physical morbidity in carers of elderly people with dementia and those with depression. *International Journal of Geriatric Psychiatry, 11*, 741-744.

Reason for exclusion: Not relationship with parent and adult child focus

Wijeratne, C. (1997). Review: Pathways to morbidity in carers of dementia sufferers. *International Psychogeriatrics, 9*, 69-79.

Reason for exclusion: Not relationship with parent and adult child focus

Williamson, G.M., Shaffer, D.R. & Schulz, R. (1998). Activity restriction and prior relationship history as contributors to mental health outcomes among middle aged and older spousal caregivers. *Health Psychology, 17*, 152-162.

Reason for exclusion: Not dementia focus.

Williamson, G.M. & Shaffer, D.R. (2001). Relationship quality and potentially harmful behaviours by spousal caregivers: How we were then, how we are now. *Psychology & Aging, 16*, 217-226.

Reason for exclusion: Spouse relationship focus

Yan, E., Tang, C. & Yeung, D. (2002). No safe haven. A review on elder abuse in Chinese families. *Trauma, violence and abuse*, 3, 167-183.

Reason for exclusion: Elder abuse focus

Yeh, K.H. & Bedford, O. (2003). A test of the Dual Filial Piety model. *Asian Journal of Social Psychology*, 6, 215-228.

Reason for exclusion: Not dementia focus.

Yeh, K. H. (2003). The beneficial and harmful effects of filial piety: An integrative analysis. In K.S. Yang, K. Hwang-Kwang, P.B. Pederson and I. Daibo (Eds.) *Contributions in Psychology. Progress in Asian Social Psychology: Conceptual and Empirical Contributions* (pp.67-82). C.T: Greenwood Publishing group.

Reason for exclusion: Not dementia focus.

Zhan, H.J. & Montgomery, R.J.V. (2003). Gender and elder care in China: The influence of filial piety and structural constraints. *Gender & Society*, 17, 209 -229.

Reason for exclusion: Not dementia focus.

Zhang, J. & Harris-Bond, M. (1998). Personality and filial piety among college students in two Chinese societies. *Journal of Cross- Cultural Psychology*, 29, 403-417.

Reason for exclusion: Not dementia focus.

APPENDIX C

Participant Information Sheet

Factors in children that influence and motivate caregiving for parents with memory problems

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether you would like to take part. Thank you for reading this.

What is the purpose of the study?

The aim of the study is to find out what influences and motivates adult children to be the primary carer for a parent with memory problems. To do this we need to talk to people that are in that situation and to ask them about their relationship with their parent in the past, how or if it has changed and whether other factors in the family have contributed to circumstances as they are now.

The study will involve an interview of approximately 1- 2 hours either at your home or at the -----, which ever is more convenient for you. The interview will be recorded on to an audiotape so that no information is forgotten. The tape will be anonymous.

Approximately 15 participants will be recruited in to the study and only one interview is necessary.

Why have I been chosen?

You have attended the Memory Assessment and Research Centre -----as a caregiver of a parent with memory problems.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign the consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part will not affect the standard of care you or your parent receives.

What will happen to me if I take part?

The research will only involve one visit which should take no more than 1-2 hours. When you have consented to take part in the study the interview will begin.

What are the possible disadvantages and risks of taking part?

There is a possibility that topics discussed may be sensitive and emotional for participants. The researcher is aware of this and participants will not be expected to talk about anything they are not comfortable with.

What are the possible benefits of taking part?

Although there is no intended clinical benefit to you or your parent it is hoped that the information gathered about adult children caring for their parent with memory problems will contribute to improving services for people in this situation in the future.

Will my taking part in the study be kept confidential?

All information that is collected about you and your parent during the course of the research will be kept strictly confidential. Any information about you or your parent that leaves the hospital will have your name and address removed so that you can not be recognised from it.

As a Health Psychology student my research is supervised by a Clinical Psychologist (Professor Peter Coleman) and by a Consultant in Old Age Psychiatry (Dr.Clive Holmes). Both of these supervisors will keep any information I need to discuss with them entirely confidential.

What will happen to the results of the research study?

The results of the study will be recorded, without mentioning your identity. They may be published in a scientific journal or presented at scientific meetings.

Who is organising and funding the research?

The University of Southampton and the -----

Who has reviewed the study?

The Southampton and West Hampshire Local Research Ethics Committee have reviewed this study.

Contact for further information?

If you have any questions please ask them now or contact Suzanne Wilkinson at the --

Thank you for taking the time to read this participant information sheet.

APPENDIX D

Participant Identification Number :

Consent Form

Title of project: Factors in children that influence and motivate caregiving for parents with dementia

Name of researcher: Suzanne Wilkinson

Please initial box

- 1. I confirm that I have read and understand the information sheet dated..... for the above study and have had the opportunity to ask questions.**

- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.**

- 3. I understand that sections of my parent's medical notes may be looked at by responsible individuals from ----- or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to these records.**

- 4. I agree that the interview may be audiotaped for transcription purposes and that my identity will be confidential.**

- 5. I agree to take part in the above study.**

Name of participant (BLOCK CAPITALS) **Date** **Signature**

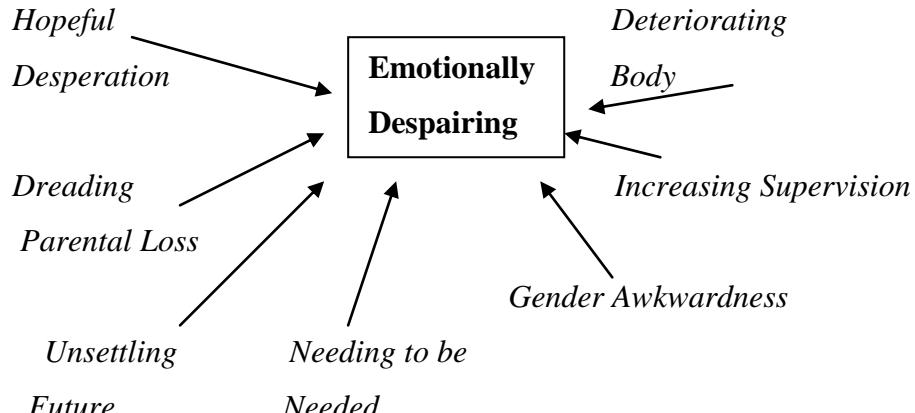
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Name of researcher (BLOCK CAPITALS) **Date** **Signature**

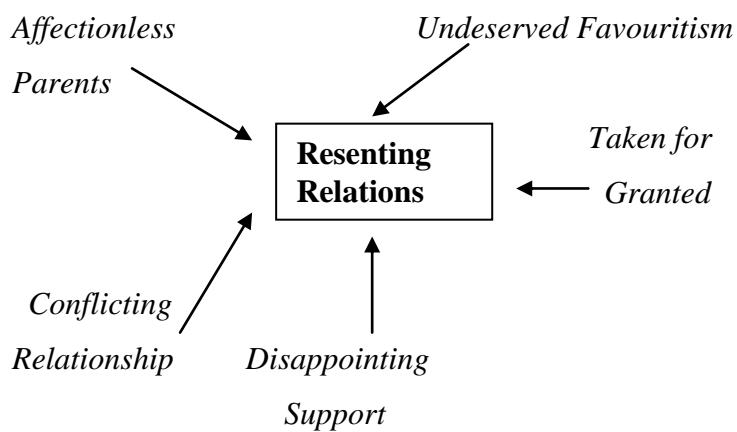
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APPENDIX E
CODING MANUAL SUMMARY
PARTICIPANT 001

Dimension two - CONTRADICTORY EMOTIONS



Dimension three - INSUFFICIENT SUPPORT

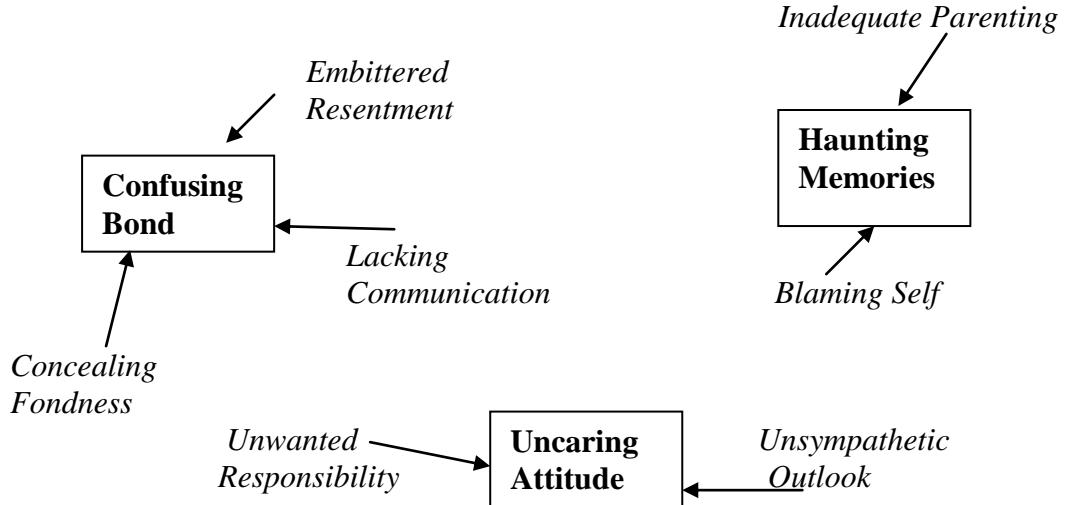


Explanation: This participant exhibited feelings representing two of the three dimensions – contradictory emotions and insufficient support. The themes of emotionally despairing and resenting relations point to real isolation from the family. This participant is not satisfied with how life has turned out and he sees life as unfair considering he has only ever tried to do the right thing for his mother.

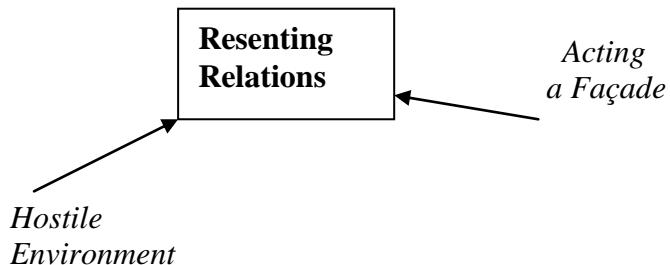
CODING MANUAL SUMMARY

PARTICIPANT 002

Dimension two - CONTRADICTORY EMOTIONS



Dimension three - INSUFFICIENT SUPPORT

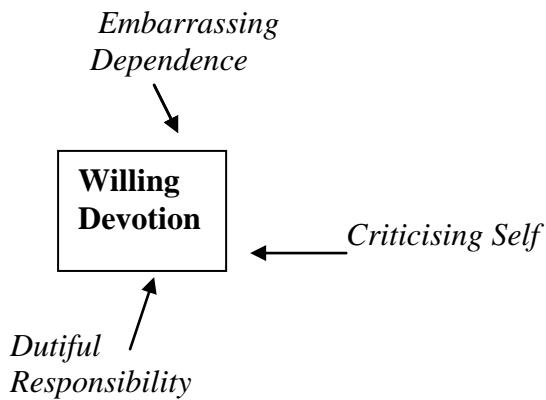


Explanation: This participant exhibited feelings representing two of the three dimensions – contradictory emotions and insufficient support. The four themes of confusing bond, haunting memories, uncaring attitude and resenting relations give's the reader a true picture of the turbulence this woman feels inside and towards her family. She rated high on expressed emotion and one can see how inevitably this constant pent up frustration and ill feeling could lead to crisis in the future.

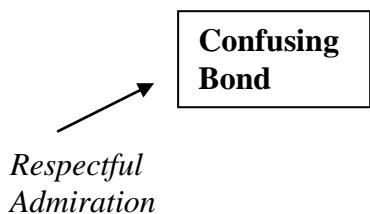
CODING MANUAL SUMMARY

PARTICIPANT 003

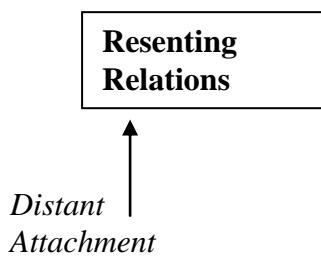
Dimension one – DEVOTED SELFLESSNESS



Dimension two - CONTRADICTORY EMOTIONS



Dimension three – INSUFFICIENT SUPPORT

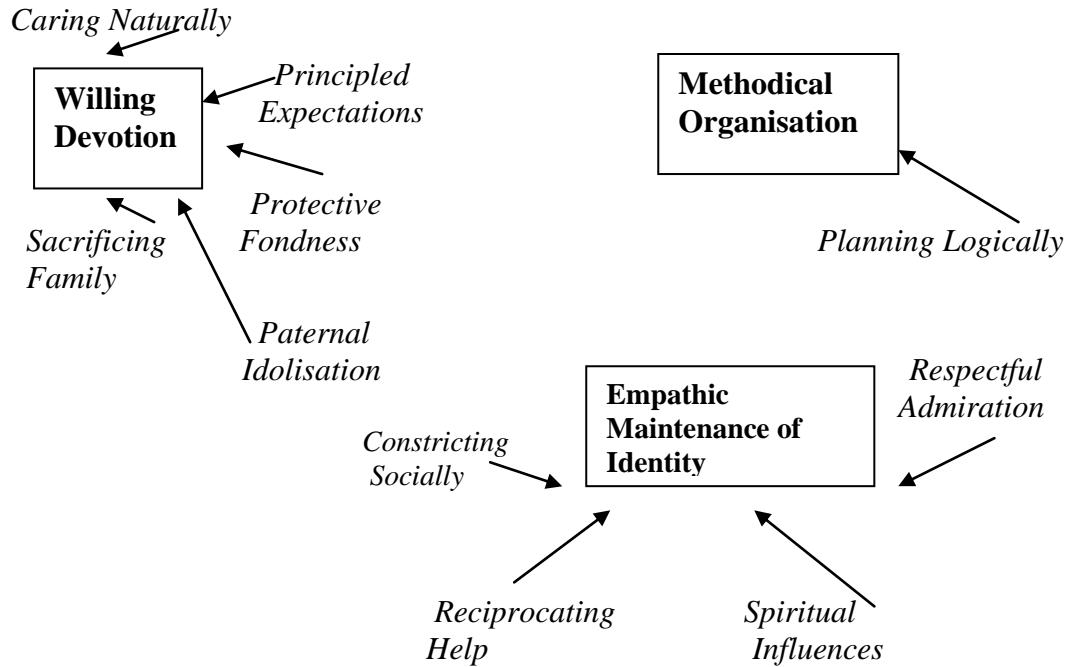


Explanation: This participant exhibited feelings representing all three dimensions – devoted selflessness, contradictory emotions and insufficient support. The themes of willing devotion, confusing bond and resenting relations were evident. He is content with the caring situation, feels it is his duty but also wants to care for his dad.

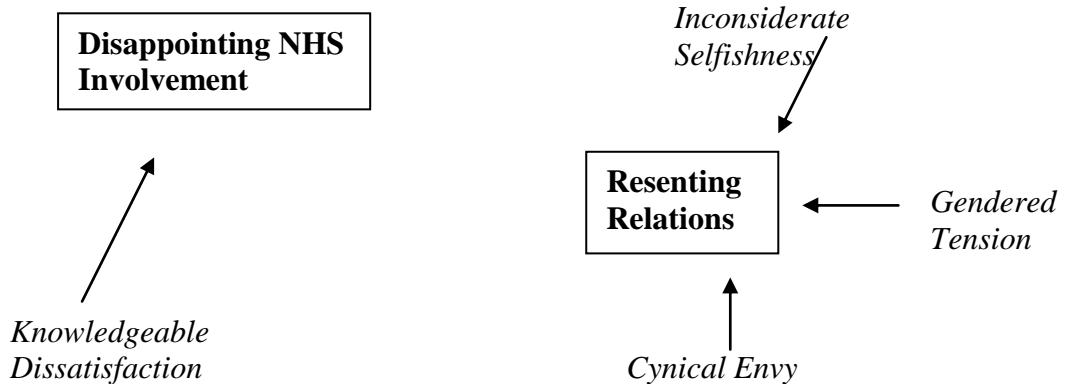
CODING MANUAL SUMMARY

PARTICIPANT 004

Dimension one – DEVOTED SELFLESSNESS



Dimension three – INSUFFICIENT SUPPORT

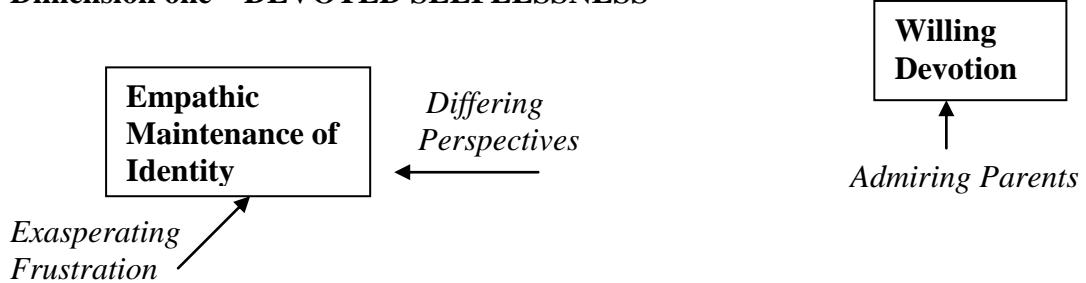


Explanation: This participant exhibited feelings representing two of the three dimensions – devoted selflessness and insufficient support. The five themes of willing devotion; methodical organisation; empathic maintenance of identity; disappointing NHS involvement and resenting relations pictures a natural carer who would welcome more support if it were available.

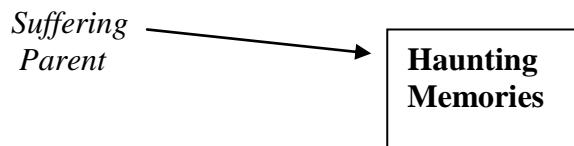
CODING MANUAL SUMMARY

PARTICIPANT 005

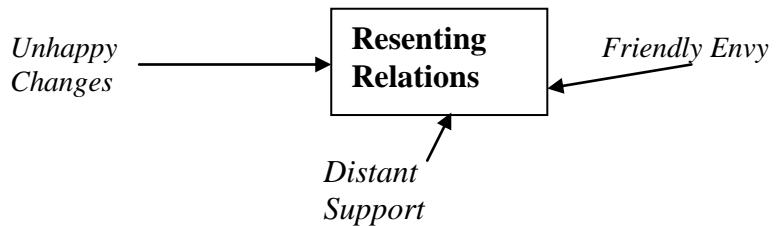
Dimension one – DEVOTED SELFLESSNESS



Dimension two – CONTRADICTORY EMOTIONS



Dimension three – INSUFFICIENT SUPPORT

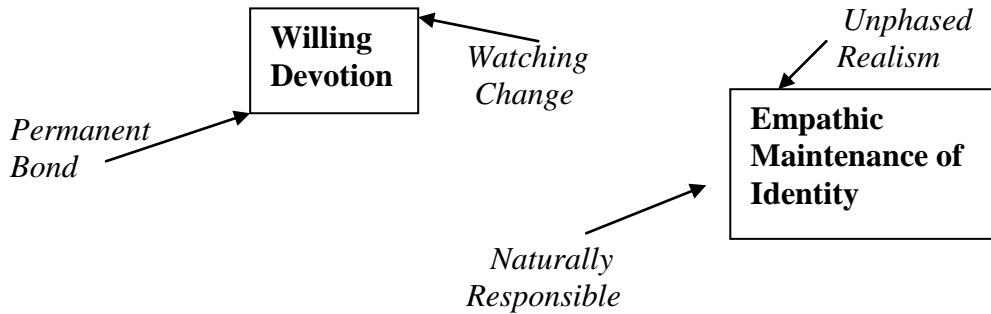


Explanation: This participant exhibited feelings representing all three dimensions – devoted selflessness, contradictory emotions and insufficient support. The themes of willing devotion, empathic maintenance of identity, haunting memories and resenting relations were illustrated. This participant rated high on expressed emotion. He had had a good relationship with his parents but was struggling to cope with their decline and had no real support around him as his brother had emigrated and his wife had left him.

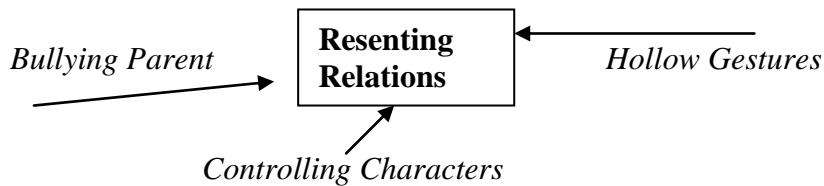
CODING MANUAL SUMMARY

PARTICIPANT 006

Dimension one – DEVOTED SELFLESSNESS



Dimension three – INSUFFICIENT SUPPORT

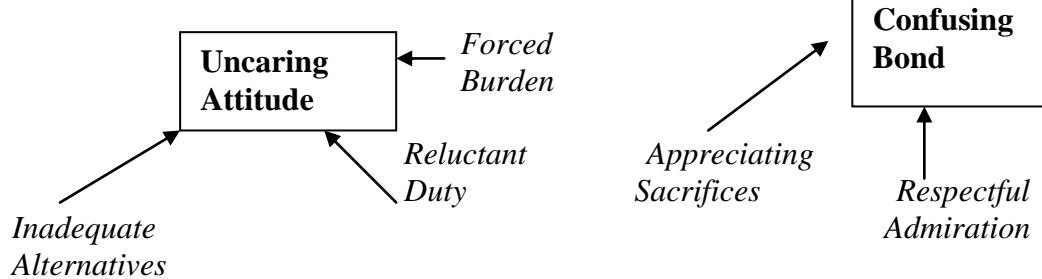


Explanation: This participant exhibited feelings representing two different dimensions – devoted selflessness and insufficient support. The three themes of willing devotion, empathic maintenance of identity and resenting relations are exhibited. This carer had a slightly passive aggressive manner and what he said did not correspond with his non verbal cues. He said he was coping well but was very controlled possibly hiding feelings of resentment and anger.

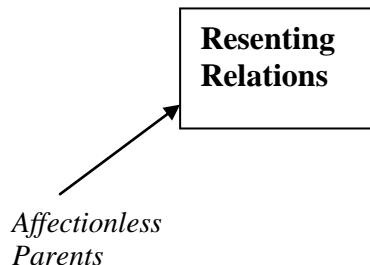
CODING MANUAL SUMMARY

PARTICIPANT 007

Dimension two – CONTRADICTORY EMOTIONS



Dimension three – INSUFFICIENT SUPPORT

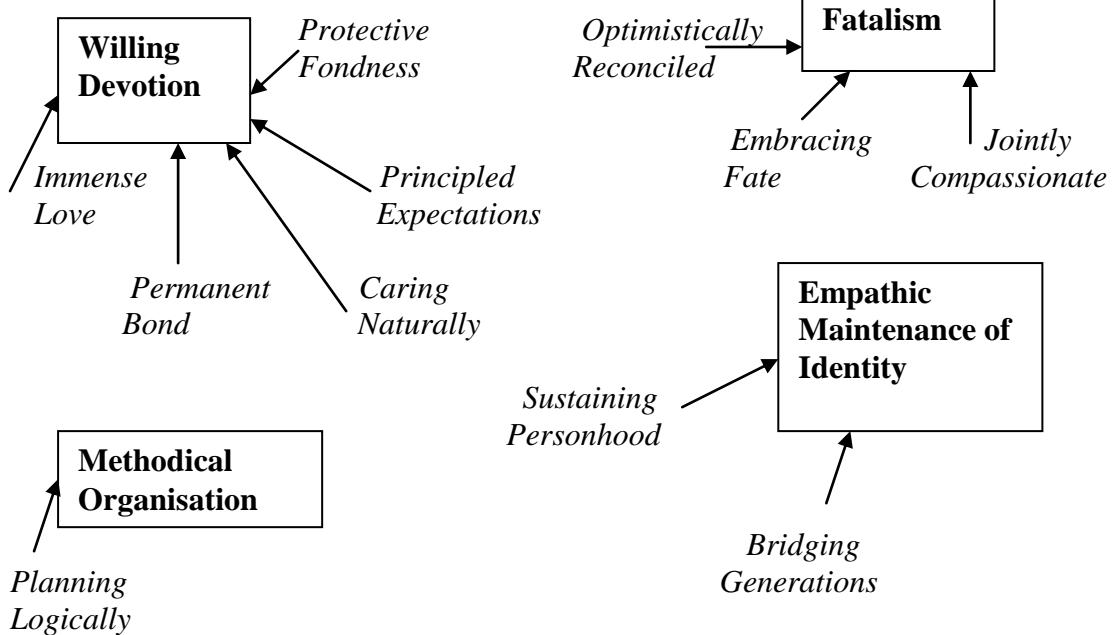


Explanation: This participant exhibited feelings representing two of the three dimensions – contradictory emotions and insufficient support. The themes of uncaring attitude, confusing bond and resenting relations highlight the fact that this participant was never particularly close to her mother and therefore does not feel attached. As the bond is not strong between mother and daughter resentment has developed within the relationship.

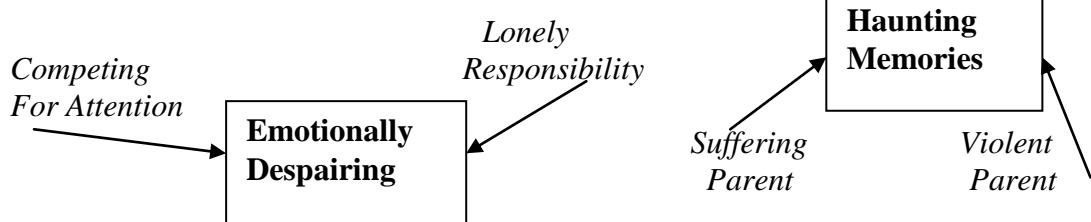
CODING MANUAL SUMMARY

PARTICIPANT 008

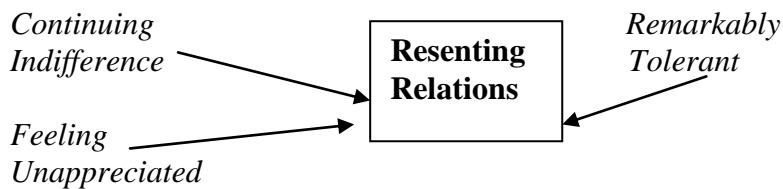
Dimension one – DEVOTED SELFLESSNESS



Dimension two – CONTRADICTORY EMOTIONS



Dimension three – INSUFFICIENT SUPPORT

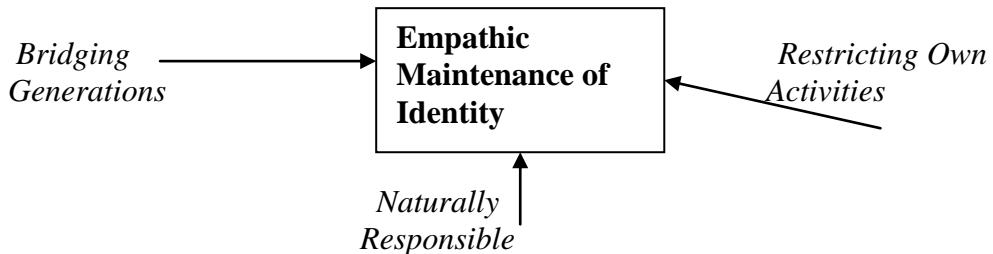


Explanation: This participant exhibited feelings representing all three dimensions – devoted selflessness, contradictory emotions and insufficient support. The themes show how dedicated this carer is to ensuring her mother is happy even though this is obviously a strain at times. She shoulders the majority of responsibility in the family.

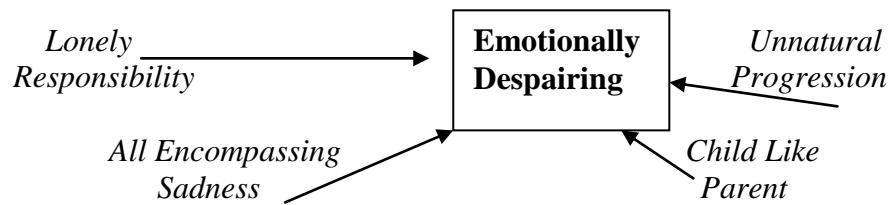
CODING MANUAL SUMMARY

PARTICIPANT 009

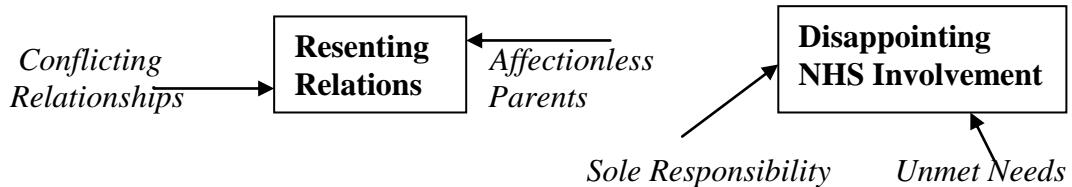
Dimension one – DEVOTED SELFLESSNESS



Dimension two – CONTRADICTORY EMOTIONS



Dimension three – INSUFFICIENT SUPPORT

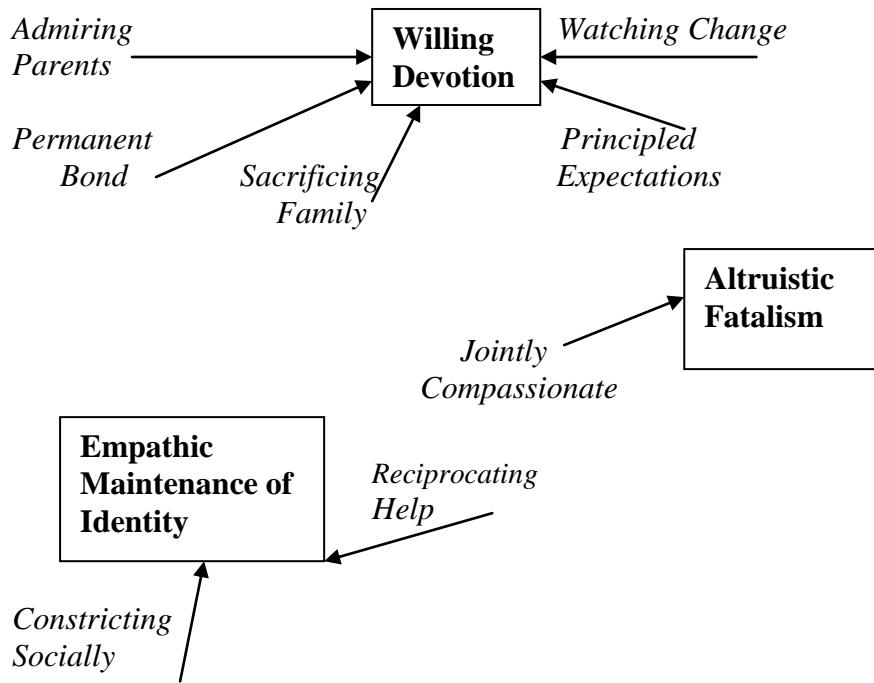


Explanation: This participant exhibited feelings representing all three dimensions and was rated high on expressed emotion. Unresolved issues with her mother were evident throughout the interview and she was obviously traumatised by the experience of looking after someone with dementia. Support seemed to be lacking from both the family and health professionals alike and consequently the participant felt very alone in her role.

CODING MANUAL SUMMARY

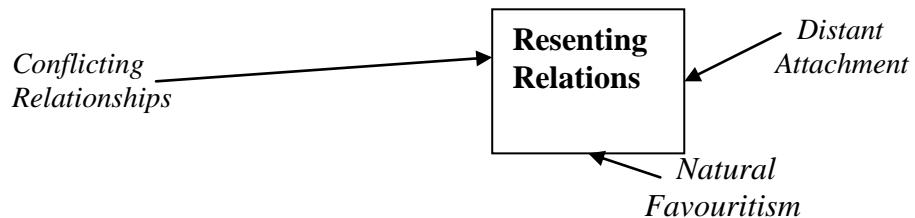
PARTICIPANT 010

Dimension one – DEVOTED SELFLESSNESS



Dimension three – INSUFFICIENT SUPPORT

RESENTING RELATIONS



Explanation: This participant exhibited feelings representing the dimensions devoted selflessness and insufficient support. On the whole this carer was more than happy to repay her mother for past kindness by caring for her but she did worry what the impact would be on her own children.

APPENDIX F
SUMMARY OF CODES

Participant No.	Dimensions	Themes	Subthemes	Codes
001	Contradictory Emotions Insufficient Support	Emotionally Despairing Resenting Relations	12	1.1 – 1.12

Text used;

You know I feel like I need to see her even though the conversation is very limited. I just feel I've got to see her. It makes me feel better. 1.3c

As I say I try and buy mum clothes. I mean I've got a job to buy clothes for myself (laughs). I go in the shops and I have a panic attack and I leave with nothing. 1.7b

They know someone's there being with mum. I said to them a while ago 'I can't remember volunteering for all this'. You know we discussed mums future a few years ago when she broke her pelvis but nothing came of it. 1.8c

Participant No.	Dimensions	Themes	Subthemes	Codes
002	Contradictory Emotions Insufficient Support	Confusing Bond Haunting Memories Uncaring Attitude Resenting Relations	9	2.1 – 2.9

Text used;

My husband has no time at all for him now. He'll go round and mend the tap if it's broken and sit and have a cup of coffee but he won't offer any conversation. He sits there fairly silent and he won't laugh at dad's jokes. 2.4e

*That is water under the bridge and I shouldn't be thinking about that now and I wouldn't be if daily I didn't have to go and be nice (laughs). I don't like people who do things unwillingly and that's what I...I don't ever behave like that but that's how I feel. **2.1g***

*The natural thing for me to have done would have been to have had nothing to do with him because of all the things that have happened in the past. **2.1k***

*Yeah but he only focuses on me. It's like looking down the wrong end of a telescope and all he can see is baby girl at the other end. **2.2a***

So my home life was very horrible. It's hard to describe now because now you get these support workers and the teachers move in and so forth but there was no support at that time.

2.6f

*It was me that forced him... (Choking tears) my brother in to care. **2.7b***

*Ohhhh this is what I can't get across to people – as long as I can remember um when he came here it was considered bad enough to go in to residential and previous to that he'd been wacky for quite a few years maybe six - eight years easily. **2.8a***

Participant No.	Dimensions	Themes	Subthemes	Codes
003	Devoted Selflessness Contradictory Emotions Insufficient Support	Willing Devotion Confusing Bond Resenting Relations	5	3.1 – 3.5

Text used;

*Cause I realised I suppose he looked after me all these years and um it's reciprocal I - my thinking now is that my duty now is to look after my father. **3.3a***

*I wash his back and do his hair and then getting on to hygiene, personal habits if you like, he has become incontinent at times. The first time was last week I cleaned the sheets and I noticed upstairs the carpet had taken a bit of a battering (laughs). It was an old carpet. **3.5c***

Participant No.	Dimensions	Themes	Subthemes	Codes
004	Devoted Selflessness Insufficient Support	Willing Devotion Empathic Maintenance of Identity Methodical Organisations Disappointing NHS Involvement Resenting Relations	14	4.1 – 4.14

Text used:

I think people should – not should that's... I find it difficult to understand people not caring for their parents. Unless I suppose they've had a particularly difficult childhood. 4.3c

I love her very much and she, I think, had a difficult time bringing us up, which she could have done differently. She could have been you know she could... she gave up a lot of her life for us so there is that sort of repay bit but it's not... it's not a duty thing. I just think it is the right thing. 4.14c

I think although I'm quite shy, people do say that I'm quite bossy. I suppose it's about being organised as well. I know what I want and how I want it and if nobody else is going to stand up and take the lead I will do that in sort of family things. So I will get on and organise it if nobody else is doing it. 4.4b

There is actually quite a lot of tension I think it would be fair to say, between me and my brother (laughs). I try to let it sort of wash over me. 4.8e

Sometimes he'll be fine and other times he'll be really curt and short and that – that hurts her. She's very hesitant about ringing him and asking for anything or she would always ask me before him and you know would always ask my sister even though she's in Wales, before him. 4.9a

Although he does very little she has got this thing about not wanting him to feel left out. Wanting him to be involved in making the decisions and I know he actually half the time doesn't give a toss to be honest but you can't really say that to her. 4.10b

I think he thought we were making a fuss about nothing. I think he wasn't sure the assessment was necessary. Between that and the diagnosis mum wanted me to go to her appointments with her and sit in, (which I wouldn't have done before) because she forgot things and he seemed to not like that. 4.7a

I find it annoying and frustrating when the physical health side are not...It doesn't seem to be integrated and I don't think it's to do with... I mean we see it when our residents have physical health problems and have to go in to General hospital, the lack of understanding around mental health. 4.7i

Participant No.	Dimensions	Themes	Subthemes	Codes
005	Devoted Selflessness Contradictory Emotions Insufficient Support	Empathic Maintenance of Identity Willing Devotion Haunting Memories Resenting Relations	7	5.1 – 5.7

Text used;

He fell down the steps from the top to the bottom of the staircase and he had a stroke. When he fell he hit his forehead on the corner of the steps like that and it hit him in the forehead like an axe and just cleaned his head apart. 5.4b

Participant No.	Dimensions	Themes	Subthemes	Codes
006	Devoted Selflessness Insufficient Support	Empathic Maintenance of Identity Willing Devotion Resenting Relations	7	6.1 – 6.7

Text used:

*She spat and wet my mouth - I hated that. But she did. It was my mum these... things in your life you know? She is the one who knitted me stupid balaclavas to go to school in - an embarrassment - but that is what mums do and this is just - this is not a paying back situation it is just - it is not duty, it is not payback – it is just a natural thing people should do. **6.6e***

*Yes – absolutely and you forget the woman there is still my mum and it don't matter what she will ever be like. She is the same woman who used to take me up to the fair every Easter and wipe my mouth with a dirty tissue at the bus stop. **6.6d***

*This is part of life as we see it. This is not unusual for us, so we are not scared of what might happen. **6.7c***

*I think she found it very tiring having her with her. Um... sometimes she apologises for being away and sometimes... and sometimes she actually means it... and sometimes it is a hollow gesture, which I fully understand. She has never had to do that. **6.5e***

Participant No.	Dimensions	Themes	Subthemes	Codes
007	Contradictory Emotions Insufficient Support	Uncaring Attitude Confusing Bond Resenting Relations	6	7.1 – 7.6

Text used;

People were not welcome in our house because that was considered to be a waste of time – leisure was something we didn't know about. We had to be working, because that was the thing that was perceived to be most important by my father. 7.4d

We share it, but we both find it a considerable burden. 7.2c

With my sister and myself, if I have her Saturday my sister has her Sunday and vice-versa. So you see our weekends are not free either and I mean nobody could be more dutiful than we are, believe me. 7.3b

Participant No.	Dimensions	Themes	Subthemes	Codes
008	Devoted Selflessness Contradictory Emotions Insufficient Support	Willing Devotion Altruistic Fatalism Empathic Maintenance of Identity Methodical Organisation Emotionally Despairing Haunting Memories Resenting Relations	18	8.1 – 8.19

Text used;

He said 'you know I think the time has come maybe for mum to go in to somewhere' and I said to him 'Really? Then the years we were growing up and mum could have just walked out and left us or put us in care. Would it have been alright if she had just sent us somewhere? Would that have been alright?' 8.5b

I'm not joking I can get her in and out of that shower in about seven minutes. Social services – when we were timing her and everything to see how much we need her carer (not that I'd let her do that because she's got her dignity) um they said to me they couldn't believe how quick I was. **8.4i**

I'm trying to look after my mum. I'm trying to train the new carer. We had one start last week but at the end of the day it's just got to be done. There's no point worrying about it or getting upset. You've just got to get up and get on with it. **8.10d**

Because when I'm upstairs trying to get Jake's teeth brushed, pyjamas on – you know what five year old children are like agggggh...It's Dave who's down here with my mum and says 'look Val that programme we like's on' **8.13c**

Whatever you're doing at that time in your life is right and it's all happening for a reason. **8.11a**

I think it's nice that as adults, and she is still an adult and it's important that she feels like it, we sit down and watch a movie at the end of the evening together. The three of us or a comedy or something that she likes and we try - you know to chat a bit – doesn't really happen but we try. **8.14a**

I wrote to all my brothers and I said 'look I think it's our duty to sort this out now because we're all working at the moment' and I sorted it out with Help the Aged – very good plan and we paid it monthly for a year. All of us, the four of us, so it's all sorted out but you see they'd never think of something like that. **8.18h**

When that happens I do fall apart and when those times come every so many months, it's been more this year, those times I go a bit mental and I cry a lot and I get upset and I find it difficult to eat and function really but I just keep going because I have to.

8.9a

Like obviously I groom her every day and shower her and help her wash. So I'm showering her, I'm patting her and everything and I'm saying do this, do this, do that and I show her. **8.4h**

*I think he had just worn the life right out of her. I mean she lived every day thinking she wasn't going to get through to the end of the day – beating her up. The mental abuse was terrible. She didn't think anything of herself by the end of it all. **8.16b***

*You know it's not like I'm asking – they've never had her round weekends or anything like that. I don't ask them and I don't expect them to. **8.19e***

*I've been doing this for nearly six years. I've only had one week holiday in six years. I'm shattered you know. **8.6e***

Participant No.	Dimensions	Themes	Subthemes	Codes
009	Devoted Selflessness Contradictory Emotions Insufficient Support	Empathic Maintenance of Identity Emotionally Despairing Disappointing NHS Involvement Resenting Relations	11	9.1 – 9.11

Text used;

*You have children and it is natural that they would move on. It's instinctive inside you, what they can do next, which it is not instinctive to undo backwards. It is not instinctive to be dressing your mother. It is ... it goes against all your natural instincts and your responses. **9.6a***

*When she is manic and she is pulling at cushions and walking up and down, she is a walker...I can walk away quite happily. She is in very good hands and I can walk away. When she turns to me and says 'don't go and leave me in here, take me home with you mum' ...or whatever ... for days I could be at rock bottom. **9.5c***

*I was sent to people to be looked after - nothing like there is now - and because I was an only child I think I was very lonely. I had, obviously looking back, my mum was my whole world and I think I had this grudge against her because of that. **9.8b***

*Just to phone up and say this has now happened. What can I do? Even just to talk to somebody. Talking ... I just firmly believe that talking is just ... just talking...just crying... you know? But I can't talk about those people... But I am quite ... I battle on, but every now and then you have just got to vent it. You can't necessarily vent it to your family because you are hurting them. **9.10b***

Participant No.	Dimensions	Themes	Subthemes	Codes
010	Devoted Selflessness Insufficient Support	Willing Devotion Altruistic Fatalism Empathic Maintenance of Identity Resenting Relations	11	10.1 – 10.11

Text used;

*I am not sure what we will do about that. Angela did say about maybe one of the neighbours popping in but then I don't think that... I am almost sure that mum wouldn't want that. She wouldn't want them to know her business. That she has got... that she wouldn't want them to think that she has got a problem, she can't look after herself.... **10.5c***

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