A thesis submitted in partial fulfilment for the degree of

Clinical Psychology Doctorate

# VOLUME I

# RESEARCH COMPONENT

## Adult children who care for a parent with dementia

## Literature Review and Research Paper

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## Overview

This thesis is submitted in partial fulfilment for the degree of Clinical Psychology Doctorate from the School of Psychology, the University of Birmingham.

Volume I contains the research component of the thesis; this consists of a literature review, an empirical paper and an executive summary. The two main papers focus on the lived experience of adult children who care for a parent with dementia. The first presents a meta-ethnography on the lived experience of adult sons and daughter caregivers for parents with dementia. The second, which is the empirical paper, uses qualitative methods to explore how adult-daughter caregivers make sense of relationship changes with their mother with dementia. It is intended that both papers will be submitted to 'Dementia' for publication (see appendix 1 for publication guidelines).

Volume II contains five clinical practice reports (CPRs) completed throughout the course. CPR1 presents the formulation of a 69 year old woman with symptoms of panic disorder from a cognitive behavioural and psychodynamic perspective. CPR2 reports an evaluation of staff training needs in an older adult mental health service. CPR3 presents a case study of a 25 year old female with symptoms of psychosis and anxiety.CPR4 presents a single-case experimental design of a Solihull Approach intervention used with a 13 year old girl with learning disabilities and 'angry outbursts'. CPR5 is represented in the form of an abstract outlining the case of a 14 year old girl with obsessive compulsive disorder (OCD).

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# Volume I- Contents

**Literature Review:** What do we know about the lived experience of adult-children who care for a parent with dementia? A meta-ethnography of the literature.

**Empirical Paper-**Adult-daughters who care for a mother with dementia: How do they make sense of relationship changes?

# Volume I –Appendices

# Volume II- Contents

# WHAT DO WE KNOW ABOUT THE LIVED EXPERIENCE OF ADULT-CHILDREN WHO CARE FOR A PARENT WITH DEMENTIA?

# A META-ETHNOGRAPHY OF THE QUALITATIVE LITERATURE

## LITERATURE REVIEW

**Abstract**

The aim of the review was to explore the experiences of adult-children caring for a parent with dementia. A search was conducted for literature which has been published between 1990 and 2012; exclusion criteria were applied and 15 papers were selected to be included in the review. A meta-ethnography (Noblitt & Hare, 1988) of the literature was conducted. The review identified a number of shared themes in the experiences of caregivers. These included: 'motivations/incentives to care', 'the role of a carer', 'common emotions/feelings', 'ways of coping' and 'services/systems'. The review highlighted the complexities involved when caring for a parent with dementia and the potential impact of the past relationship on the present experiences of the carer. The similarities between the findings of the current review and findings from dementia and other caregiving research are discussed as well as implications for clinical practice.

**Keywords:** Adult-children, carers, dementia, review, qualitative

**Introduction**

The number of people diagnosed with dementia is steadily increasing; due to the growth of the population and the fact that people are living for longer (Dementia, 2010). The Alzheimer's Society has recently published a major report on the social and economic impact of dementia in the UK. This report showed that there are currently 800,000 people with dementia and it is estimated that 670, 000 family and friends are acting as primary carers. The report states that although work has been undertaken to help improve the quality of life for people with dementia and their carers, many are still not living well with the condition.

Evidence suggests that caregiving between adult-children and their parents with dementia is becoming increasingly common and will continue to increase in the future (Ward-Griffin, Oudshoorn, Clark, & Bol, 2007; Parsons, 1997; Hoffman, 1998). Understanding the relationship between adult-children and their parents with dementia and understanding the psychological responses of adult-children to the caring role, are important research goals.  In a recent review, Ablitt, Jones and Muers (2009) summarised the evidence suggesting that the relationship between the person with dementia and their family carer plays an important role in moderating the impact of dementia on those involved:  Poorer quality relationships have been associated with higher levels of depression and strain, a reduced quality of life, less reward from the caring role, and a greater decline in wellbeing and cognitive functioning on the part of the person with dementia.  There are high levels of depression in family carers and depression in family carers is associated with institutionalisation (Draper, 2004). There is also evidence of the

increased risk of abuse towards the person with dementia if a family carer is suffering from anxiety and/or depression (Cooper, Blanchard, Selwood, Walker, & Livingston, 2010).

The majority of research conducted on adult-children dementia carers has been limited to quantitative methods.  Bledin, MacCarthy, Kuipers and Woods (1990) discovered that daughters who scored highly for expressed emotion, reported higher levels of strain and distress, whereas those who made fewer critical comments and more positive remarks were found to be coping more efficiently. Ott, Sanders and Kelberet (2007) explored the grief and personal growth experiences of spouses and adult children. They found that levels of grief increased as the severity of the dementia increased (for both groups). They also found that when the person with dementia lived out of the home, spouse caregivers experienced more sadness and longing, worry, isolation and personal sacrifice burden compared to adult-child caregivers. Results showed that the majority of caregivers experienced personal growth but that adult-children experienced the most. Conde-Sala, Garre-Olmo, Turró-Garriga,Vilalta-Franch and López-Pousa (2010b) conducted a cross-sectional analytic study which compared burden between spouse and adult-child caregivers. Their results showed greater burden in adult-children, who tended to experience more feelings of guilt. Conde-Sala, Garre-Olmo, Turro-Garriga, Vilata-Franch, and Lopez-Pousa (2010a) found differences in spouses and adult-children's perceptions of the person with dementia's quality of life. Spouses tended to have a more positive perception and this was linked to higher educational levels of the caregiver and more functional self-sufficiency of the person with dementia. Adult-children perceived the quality of life of the person with dementia as poorer and this was linked to greater caregiver burden and higher levels of depression in the person with dementia.

This research highlights that the experiences of adult-child carers can be different to spouses and that this relationship warrants further, more detailed exploration.  Quantitative research methods carry certain limitations: The results can be limited as they provide numerical measurement as opposed to detailed narrative; and preset answers (to questionnaires) might not reflect how people really feel about a subject and may lack depth and insight.  By contrast, qualitative approaches are well suited to exploring areas of significant complexity (such as family relationships) and to examining new areas where there is limited knowledge of the topic (Smith, 2003).  There are a small number of qualitative studies that have investigated the lived experiences of adult-children caring for a parent with dementia, with some focusing specifically on their relationship. It was considered that a review of these studies would be of some value. Care provision by adult-children is becoming increasingly common; it is important to understand more about the relationship between adult-children and their parents and about the psychological responses of adult-children to their caring role; and qualitative methodology has the potential to enhance our understanding in such a complex area

**Method**

**Synthesising Qualitative Literature**

Synthesising qualitative research is still in its infancy (Fingeld, 2003). At present, there are only a small number of papers which have attempted to synthesise qualitative research. However, this area is growing due to the increasing number of qualitative studies published in the past decade (Mays & Pope, 2000) and the need to pull together qualitative findings which can then be used in policy development and intervention recommendations. Methods used to integrate qualitative data are still relatively new and therefore not well defined (Salter, Hellings, Foley, & Teasell, 2008) and the synthesis of qualitative data has been perceived as a challenge due to the variety of different epistemologies (Murphy, Dingwell, Greatbatch, & Watson, 1998; Popay, Rogers, & Williams, 1998). 'Meta-synthesis' is a frequently used but potentially ambiguous term. It has been used to describe the different methods used to synthesis qualitative data but also for synthesising both qualitative and quantitative data (Fingeld, 2003). 'Meta-ethnography' (Noblitt & Hare, 1988) is an interpretative method which focuses solely on synthesising qualitative data and has been increasingly used in health research (Campbell, et al., 2003). This method aims to bring together and break down findings which are then examined so that the essential features are discovered, the researcher then combines concepts to form a new transformed whole (Schreiber, Cooks & Stern, 1989).  Meta-ethnography involves seven steps (Noblitt & Hare, 1988):

1. Getting started (the search)

2.  Confirming initial interest (literature screening)

3.  Reading studies and extracting data

4.  Determining how studies are related (identifying common themes and concepts)

5.  Translating studies (checking first and/or second order concepts and themes against each other)

6.  Synthesising translations (attempting to create new third order constructs)

7.  Expressing the synthesis.

Atkins et al. (2007) explains this process in more detail and shares similarities with the approach adopted for the current review.

**1. Getting started (the search)**

The following search terms were used to search PsycINFO (original time frame: 1987-2012), Medline (original time frame: 1948-2012) and EMBASE (original time frame: 1988-2012).

1.  Dementia (first search-title, second-keyword, term exploded)

2.  Alzheimer's disease (first search-title, second-keyword)

3.  ("adult daughter*" or "adult son*" or "adult child*" or "daughter*" or "mother*" or "son*" or "father*"), (first search-title, second-keyword)

4.  Caregivers (keyword search, term exploded)

5. 1 or 2

6. 3 and 4 and 5

The following search terms were used to search CINAHL (1990-2012):

1. Dementia (Title search)

2. Alzheimer's disease (Title search)

3. ("adult child*" or "adult daughter*" or "adult daughter*" or "adult son*" or
   "daughter*" or "son*" or "adult offspring" or "offspring" or "mother*" or
   "father*") (Title search)

4. 1 or 2

5. 4 and 3

**2. Confirming initial interest (literature screening)**

Once a full search had been conducted, the results were limited to peer-reviewed
journal articles published between 1990 and 2011, as initial searches did not find any
relevant articles published earlier than this period.  The results were also limited to English
journal articles. The following inclusion and exclusion criteria were then applied to filter
out the irrelevant/inappropriate articles.

**Inclusion Criteria**

- Data were only from adult-child (aged 18 or over) carers or, if using a
  mixed sample of carers, each group (e.g. spouses and adult-children) was
  analysed and results presented separately

- The study used qualitative methodology to explore the experiences of adult-children acting in a caring role

**Exclusion Criteria**

- Mixed design/methodology

- Method of data analysis not specified (i.e. whether it was grounded theory, content analysis etc)

- Person with dementia had diagnosis of 'early onset'

- Focused solely on person with dementia's experiences

- Focused on medical measures

- Focused on an intervention

- Personal accounts

14 articles were identified for inclusion in the review; reference lists were searched for potential articles and 1 further article was found, making the total number of articles 15.

Figure 1 represents the search process:
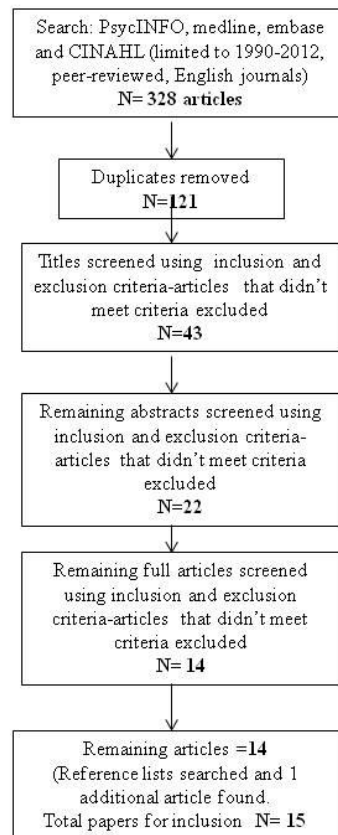
*Figure 1: Flow-chart of search process*

**Further considerations about inclusion/exclusion of papers**

There are no official definitions of 'family caregiver', one view is that it involves providing extraordinary care which exceeds the boundaries of normal family relationships (Schulz & Martire, 2004). However, the term 'family caregiver' was defined in the majority of papers as a family member who provides informal, unpaid care for the person with dementia. This care involves providing emotional support and/or personal care and/or support with daily living activities and occurs on at least a weekly basis; this definition was applied for the review. The papers included involved a mix of caregivers who provided different levels of support in different environments. Some caregivers provided

care for a parent with dementia who lived with them and so were considered primary caregivers (Perry, 2004; Saunders and McFarland, 2002). Some papers involved participants who provided care to a parent who lived separately in the community and were also considered as primary caregivers in some cases (Ward-Griffin et al., 2007; Werner, Goldstein & Buchbinder, 2010). Papers which used participants who provided care to the person with dementia while in a full-time care facility were also included in the review (Legault & Ducharne, 2009; Dupius, 2002; Kelsey, Laditka & Laditka, 2010). It was felt that the inclusion of a broad sample of caregivers would help improve understanding of the experiences of caregivers in different circumstances and would help to draw together a broad overview of this area of research.

It was decided that papers which mixed-designs (qualitative and quantitative) would be excluded as the results presented a combination of both methods, meaning that the qualitative findings could not be separated, therefore not fitting in with the inclusion criteria. There was also consideration given to how to define qualitative research and which methods would be included. The studies used a variety of approaches which included: Grounded Theory, Content Analysis, Thematic Analysis, Interpretative Phenomenological perspective, Discursive Analysis and Constant Comparative Analysis. It was decided that papers that clearly described their data analysis and resulting themes/concepts would be included so that conclusions could be drawn about the findings with more confidence and the synthesis of themes would hold some weight. Papers that had made an effort to analyse and interpret caregivers' experiences were included in the review. This included two papers that interviewed mother and daughter dyads (Ward-Griffin et al., 2007; Forbat, 2003) and one that interviewed a daughter carer and a grand-

daughter carer (Simpson, 2010). The account of the experiences of the daughters was clearly separated from that of the mothers in the dyads and from the granddaughter in Simpson's (2010) paper; thus fitting the inclusion criteria. Papers that focused on children and adult-children caring for a parent with early-onset dementia were excluded as it was felt that due to the nature of the dementia, that their experiences might be different to those caring for a parent with normal-onset dementia and that this would warrant a separate literature review. An evaluation of the quality of each paper was conducted and this may help the reader to draw conclusions about the usefulness/weight of each paper.

**Quality evaluation**

Each paper's quality was evaluated using criteria described by Murphy, Dingwell, Greatbatch, Parker and Watson (1998) and Mays and Pope (2000), (see Table 1). These criteria focused on two main areas (credibility and relevance) and were chosen due to their transparency and applicability to different qualitative approaches. The following questions were asked when scrutinising each paper (Murphy et al., 1998; Mays & Pope, 2000; Salter, Hellings, Foley, & Teasell, 2008):

*Credibility*

1. Were explanations of sampling strategies and data collection methods provided?

2. Was the method of data analysis described and enough data displayed to allow the reader to determine whether interpretations made by the researcher are supported by the data (analysis)?

3.  Did the authors acknowledge the influence of the research process and the presence

of the researcher including the role of prior biases, assumptions and experience, on

the collected data (reflexivity)?

4.  Has appropriate attention been given to contradictory data? Are negative cases

taken into account? (negative cases)

5.  Did the authors explore alternative, plausible explanations for the data collected

and incorporate a range of different perspectives (fair dealing)?

*Relevance*

1. Did the authors provide information regarding participants, setting and context so

that the reader might be able to determine the relevance of the findings to other settings

(transferability)?

2.  Did the authors discuss findings within a broader context, propose generalisation of

findings and/or suggest a direction for future research (analytic generalisation)?

| Study (Main author) | Credibility | | | | | Relevance | | Score |
| | Data collection | Analysis | Negative cases | Reflexivity | Fair dealing | Transfer-ability | General-siability | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Saunders (2002) | * | * | | | | * | * | 4/7 |
| Perry (2004) | * | * | * | | | * | * | 5/7 |
| Harris (1998) | * | * | | | * | * | * | 5/7 |
| Legault (2009) | * | * | * | | | * | * | 5/7 |
| Ward-Griffin (2007) | * | * | * | | | * | * | 5/7 |
| Dupuis (2002) | * | * | * | * | | * | * | 6/7 |
| McCarty (1996) | * | * | | | | * | * | 4/7 |
| Tan (2009) | * | * | * | * | | * | * | 6/7 |

| Wallhagen (2006) | * | * | | | * | | * | * | 5/7 |
|---|---|---|---|---|---|---|---|---|---|
| Globerman (1995) | * | * | * | | * | | * | * | 6/7 |
| Kelsey (2010) | * | * | * | | | | * | * | 5/7 |
| Werner (2010) | * | * | * | | | | * | * | 5/7 |
| Forbat (2003) | | * | | | * | | * | * | 4/7 |
| Yamamoto (1997) | * | * | * | | * | | * | * | 6/7 |
| Simpson (2010) | * | * | | | | | * | * | 4/7 |

*Table 1: Quality evaluation (* indicates paper has met criteria)*

All papers were read and re-read to draw conclusions about these criteria and checked for consistency with another reviewer on a random sample of 5 papers. Agreement on the number of criteria met by each paper was high, with only one paper's marks needing adjusting. All the studies included achieved a score of four or above (out of seven). All received full marks for auditability (as discussed in the inclusion/exclusion criteria) as well as full marks for transferability and analytic generalisation. This highlights that the papers were written in a transparent style which would enable readers to draw conclusions from the findings and use the results in a meta-synthesis. However, the majority of studies failed to consider alternative, plausible explanations for the data collected which could point to potential biases in the research process.  With all of these issues taken into consideration, all 15 papers were kept with the aim of producing a full and wide-ranging review. However, gaps highlighted by this quality evaluation should be borne in mind when considering the credibility and relevance of the current review.

**3. Reading studies and extracting data**

Each paper was read and data was extracted. Data extracted for Table 2 included the study title, sample number, analysis, the setting and methods as well as the themes proposed by the authors of the original papers. Table A1 (see appendix 2) gives examples of quotes and shows the original authors' explanatory notes for each theme.

**4.  Determining how studies are related (identifying common themes and concepts)**

All the titles of the studies were written down, along with their themes, on an A2 sheet. I then looked across the themes and started to group similar concepts into themes to by colour-coding them. This produced some draft common themes which were kept in mind during the next stage.

**5. Translating studies (checking first and/or second order concepts and themes against each other)**

The next stage (illustrated in Table 3) involved making notes based on my thoughts and interpretations of each theme; while doing this I considered the theme title, example quotes and the original authors explanations of each theme (column 4, Table 3). Appendix 2 contains the complete table.  I then looked across my comments and interpretations to check my (second order) concepts against each other; this also involved assessing the frequency of each concept so as to gauge which were common in a number of studies. Those that were only present in one or two studies were not included in the next step.

| Study | N | Analysis | Participants | Settings and methods | Themes found |
|-------|---|----------|--------------|----------------------|--------------|
| Saunders & McFarland (2002) Perceptions of Caregiving Sons caring for a parent with Alzheimer's Disease | 18 | Grounded Theory | Primary caregivers 18 sons. 14 Caring for a mother, 4 for a father. Rural area of North-East United States (known for conservatism). Caucasian. Age 35-67. Caring for between 6 months to 8 years. | Some involved in local chapter of Alzheimer's Association. Others through word of mouth. Unstructured interview outline. Interviews conducted: in homes of sons, professional offices or other public facilities. | Initial reaction to memory loss Becoming caregivers Women in the sons' world Learning new roles Conflicts Uncomfortable situations Service utilisation |
| Perry (2004) Daughters Giving Care to Mothers Who Have Dementia: Mastering the 3 Rs of (Re) Calling, (Re) Learning, and (Re) Adjusting | 20 | Constant comparative analysis | 19 daughters & 1 daughter-in-law Mothers in early, middle and advanced stages of dementia Age 43-60, mean 49 years Time caregiving: 1-11 years 18 lived with their mothers, 1 daughter in law lived with mother in law, one just placed mother in care | Recruited through staff from support groups and day centres in Pacific Northwest Most interviews took place at participants' homes In-depth interviews Some participants interviewed two or three times (29 interviews in total) | Mastery: (Re) Calling (Re) Learning (Re) Adjusting |
| Harris (1998) Listening to Caregiving Sons: Misunderstood Realities | 30 | Content analysis | 30 sons: 13 primary & 17 secondary caregivers Age 32-71, mean=50 17% African American, 83% White 26% Blue collar workers, 74% graduates | Cleveland Area Alzheimer's Association provided access to the families Recruitment done through ads in newsletter, | Common themes: Duty, Acceptance, Taking Charge, Common emotions, work flexibility. Common issues: Loss, sibling relationships, role |

| Study | N | Analysis | Participants | Settings and methods | Themes found |
|-------|---|----------|--------------|---------------------|--------------|
| | | | 33% caring for a mother, 67% caring for a father<br>23% of parents lived with their son, 23% lived in a nursing home & 27% lived in their own home<br>77% had siblings, 57% were catholic, 60% married | reviewing helpline calls over two 3-month periods and contacting support groups<br>General interview guide used<br>In-depth personal interviews<br>Average of 1.5-2 hours per interview<br>Conducted at locations selected by the sons | reversal, coping strategies, positive outcomes.<br>Types of sons: Dutiful son, the son that goes the extra mile, the strategic planner, the son who shares the care. |
| Legault & Ducharme (2009)<br>Advocating for a parent with dementia in a long-term care facility: The process experienced by daughters | 14 | Grounded Theory | 14 daughters of an institutionalised parent with dementia<br>Mean age 55.2 years (44-65 years)<br>14.5 years of education on average<br>11 took care of their mother, 3 their father<br>(sociodemographic table in paper) | Recruited in three long-term care facilities in Montreal<br>In-depth interviews (90 mins on average)<br>Conducted in daughter's home or location of their choice<br>Interview guide developed which looked at: personal, relational and contextual conditions that influence transformation of the advocacy role, actions and interactions the role entails, consequences for | 3 interrelated processes which explain the role transformation of the daughters:<br>Integration in care setting, Evaluation of quality of care & Development of trust |

| Study | N | Analysis | Participants | Settings and methods | Themes found |
|-------|---|----------|--------------|----------------------|--------------|
| | | | | carers and their parents | |
| Ward-Griffin, Oudshoorn, Clark & Bol (2007) Mother-Adult Daughter relationships within dementia care: A critical analysis | 25 | Schematic typology from outcome of NUD*IST qualitative software program<br><br>Exploratory qualitative approach<br><br>'Interpretative descriptive study' | 15 mother-daughter dyads<br><br>10 community dwelling mothers with mild to moderate cognitive impairment and their 15 caregiving daughters (some mothers had 2 or more daughters participating)<br><br>Mothers age 75-98 (mean=84.6) Mini Mental State Examination score of 17 or higher (mean 22/30) 78% widowed, 55% Canadian Mean age of daughters =49.6 (35-63), 64% married, 50% postsecondary education or higher, 50% employed fulltime Daughters had been providing daily-weekly assistance for an average of 49 months (11-72) | In-depth interviews<br><br>If both mother and daughter-separate interviews conducted<br><br>All participants asked to take part in two audio taped interviews (approx 1 hour) at intervals of approx 6 to 9 months<br><br>Two mothers could not participate in second interview due to SMMSE lower than 17.<br><br>15 Mother-daughter dyads for first interview and 13 for second | Four dynamic types of mother-daughter relationships: Custodial (tasks), Combative (emotion focused), Cooperative (tasks), Cohesive (emotion focused) |
| Dupius (2002) Understanding ambiguous loss in the context of dementia care: Adult children's perspectives | 61 | Grounded Theory-modified constant comparative method | 38 daughters 23 sons caring for a parent with dementia living in a long-term care facility Majority in 50s or older, married and working full or part-time 73% caring for mothers | Each family member participated in an in-depth active interview (more conversational in style)<br><br>6 participants were interviewed with their | Process-moving through phases-based on level of cognitive impairment<br><br>Ambiguity in each phase: Anticipatory loss Progressive loss |

| Study | N | Analysis | Participants | Settings and methods | Themes found |
|---|---|---|---|---|---|
| | | | Care receivers 66-95 years (average=84.2) 31% in early phase of institution-based caring careers (1 to 9 months), 27.9% mid-phases (10mths-2 years), 41% in later phases (over 2 years) | partners 45 mins-3 hours per interview (typical=90mins) | Acknowledged loss (coping: acceptance, avoidance) |
| McCarty (1996) Caring for a parent with Alzheimer's disease: process of daughter caregiver stress | 17 | Grounded theory | 16 Daughters and 1 daughter-in-law carers (direct caregiver, allied caregivers to a spouse caregiver or direct or allied caregiver advocates for in-patient parents) | Semi-structured interviews 3 daughters interviewed during the initial caregiving phase, 9 during middle caregiving phase, 5 during terminal caregiving phase Interviews held in a place of daughters' choice (Private meeting room at hospital, homes) Interviews 50 to 120 mins (average=60 mins) | Substantive theory and 13 hypotheses Core category: Coping with the 'living death' of a parent with AD Beliefs Perceptions Transactions and relationship patterns Categories inferred from data: Negotiation styles Decision making criteria and processes Direct and indirect parent caregiving Negotiation of self-care and stress Loss and grieving Pattern of vacillation (attaching and detaching) |

| Study | N | Analysis | Participants | Settings and methods | Themes found |
|-------|---|----------|--------------|----------------------|--------------|
| Tan & Schneider (2009) Humour as a Coping Strategy for Adult-Child Caregivers of Individuals with Alzheimer's Disease | 6 | Content Analysis<br><br>Patton's method of phenomenological analysis | 6 adult-children caregivers<br>Provided some sort of care to parent at least twice a week<br>Age 39-59 (mean=50.7)<br>5 females, 1 male<br>One parent had mild AD, 2=mild-to-mod, 2=mod-severe, 1 parent had passed away 1 year before the study<br>One adult-child caregiver was caring for her mother-in-law<br>1 parent lived with a spouse, 2 in long-term care, 1 lived independently, 1 lived with adult-child | Background questionnaire completed-this information was used to individualise semi-structured interview guide<br><br>Field notes were compiled (comfort level of participant, emerging insights)<br><br>Participants were emailed transcripts of the interview to clarify and edit information provided<br><br>Data triangulation achieved through concomitant analysis of multiple sources of data (field notes, background questionnaires, transcripts and member checks) | Main themes:<br><br>Experience of young adult-child caregivers<br><br>Determinants of effective humour<br><br>Factors influencing use of humour<br><br>Perceived benefits of humour |

| Study | N | Analysis | Participants | Settings and methods | Themes found |
|---|---|---|---|---|---|
| Wallhagen & Yamamoto-Mitanni (2006) The Meaning of Family Caregiving in Japan and the United States: A Qualitative Comparison Study | 16 | Constant comparative analysis | 9 Japanese & 7 American caregivers Majority married and daughters of care recipients<br><br>One Japanese caregiver was a niece-in-law (lived with care recipient for 25 years)<br><br>Mean age of Japanese caregivers: 53.9, American: 49.4<br><br>Mean age of care recipient: Japan=82.0, America=80.4 | Semi-structured interviews<br><br>Each participant interviewed twice at 6 month intervals (interview guide provided in appendix)<br><br>Interviews lasted between 1 ½ and 2 hours and took place at caregivers home or research office | Two universal/overarching themes: Moral obligation & Intense loss<br><br>Themes that highlight cultural differences:<br><br>Reasons for caregiving<br><br>Caregiving as a career<br><br>Caregiving as a life phase or detour |
| Globerman (1995) The Unencumbered Child: Family Reputations and Responsibilities in the Care of Relatives with Alzheimer's Disease | 36 | Grounded Theory | 18 families 54 individuals (3 spouses, 36 adult children and 11 of their spouses, 4 grandchildren)<br><br>All quotes in paper come from adult-children<br><br>Multiservice site for Jewish Elderly was selected to allow for an ethnically homogenous sample. | Interview guide used with open-ended questions about respondents experience, involvement of others, impact of AD on their lives, family patterns.<br><br>Family members interviewed individually in a location of their choice (usually own home). Interviews lasted between 1 ½ and 3 hours | Characterisation (of the unencumbered child)<br><br>Focus (on experiences)<br><br>Nature of suffering<br><br>Different sense of responsibility.<br><br>Protection & Entitlement |

| Study | N | Analysis | Participants | Settings and methods | Themes found |
|-------|---|----------|--------------|----------------------|--------------|
| Kelsey, Laditka & Laditka (2010)<br><br>Caregiver Perspectives on Transitions to Assisted Living and Memory Care | 15 | Grounded theory and thematic analysis | 15 caregivers<br>11 women: 2 spouses, 1 sibling, 8 daughters.<br>4 men: 2 spouses, 2 sons<br><br>Adult children average age=58.1<br>Spouses average age=84.0<br><br><br>10 parent-child pairs: 1 father-daughter, 2 mother-son and 7 mother-daughter dyads. | Participants recruited through referrals from ADRD* support group leaders and a recruitment notice in the South Carolina Alzheimer's Association<br><br>In-depth interviews Interview script consisted of open-ended and semi-structured questions<br><br><br>First 7 interviews face to face, remaining 8 over the telephone | Reasons for the ALF* move and experiences with it. Reasons for selecting a particular ALF. Recognised need for future dementia care on admission to ALF. Transfer policy from ALF described on admission. Informing caregivers of the need for a MCU* move. Caregiver reaction to transitioning from ALF to MCU. Expectations of transitioning to MCUs. Suggestions for moving a family member with ADRD*. Concern about greater costs of MCUs. Suggestions to improve |

| Study | N | Analysis | Participants | Settings and methods | Themes found |
|---|---|---|---|---|---|
| | | | | | move from ALF to [1]MCU |
| Werner, Goldstein & Buchbinder (2010) Subjective Experience of Family Stigma a Reported by Children of Alzheimer's Disease Patients | 10 | Content Analysis | 10 adult-children caregivers 8 women, 2 men PWD*-community dwelling Mean age=52.9 (SD=8.5, range 42-67) Been involved in care for an average of 4.4 years (SD=3.9, range=0.5-13) 1 lived with parent, 4 lived in same neighbourhood, 4 lived in same city, 1 lived in a different city | Data collected from a non-probabilistic purposive sample who was participating in support groups conducted by the Israel Alzheimer's Association in northern part of Israel.<br><br>In-depth semi-structured interview in participants' homes.<br><br>Interviews conducted in Hebrew using an interview guide | Caregiver stigma Cognitive attributions, emotional reactions and behavioural reactions<br><br>Lay public's stigma Cognitive attributions, emotional reactions and behavioural reactions<br><br>Structural stigma Cognitive attributions and behavioural reactions |

[1] *ARRD: Alzheimer's Disease or a related disorder
*ALF: Assisted living facility
* MCU: Memory Care Unit

| Study | N | Analysis | Participants | Settings and methods | Themes found |
|---|---|---|---|---|---|
| Yamamoto & Wallhagen (1997) The Continuation of Family Caregiving in Japan | 26 | Constant comparative analysis | 13 Japanese daughter and 13 daughter-in-law caregivers Age range 32-63 PWD age range 63-99 18 living with caregivers 5 living independently 3 in long-term care setting | Recruited through several senior service organisations in Japan. Interviews lasted 1-4 hours (average=2) Non-structured approach with follow-up probe questions. | Reasons for care continuation: Value of care (Societal norms & attachment) Maintainers of value. Reinforcers of care continuation. |
| Simpson (2010) Case Studies of Hispanic Caregivers of Persons With Dementia: Reconciliation of Self | 1 | Interpretative phenomenology perspective | 2 Hispanic female caregivers (identified themselves as primary caregivers of a community-dwelling PWD) One was a granddaughter and one a daughter of PWD Cecelia-48 year old, worked full-time and been caring for her grandmother for 1 ½ years, grandmother=87 years old. Diana=63 years old and retired, been caring for her mother for 13 years, mother=97 years old | Study conducted in an urban setting in South central US. Participants recruited from a geriatric psychiatric practice Interviews conducted using combination of unstructured and semi-structured questions. One conducted at participant's home and one in a medical office. One lasted 45 mins, the other lasted 2hours | Common themes: Parent/child role reversal. Needing to maintain respect. Self as caregiver. Disruption of self. Unique to adult-daughter: Self as caregiver-expectation that siblings would participate in care-reconciling herself as sole caregiver Disruption of self-fear of mother's death brings fear of loss of self |

*Table 2: Summary of studies*

| Paper | Theme | Quote(s) | Paper's author's notes | Review author's commentary/interpretations |
|---|---|---|---|---|
| Harris (1998) | Duty | "You got to do what you got to do." "What kept me going was my devotion to her. I saw how they (his parents) treated me over my lifetime, the loyalty they felt. I learned. I learned that's what you do with family. You don't moan and groan about them; you take care of them. You do what you have to do." | Filial obligation. Sense of duty to care for their ill parents. | Duty/filial obligation and responsibility. Family expectations, family culture. Repaying. |

*Table 3: Example of author's interpretations of a theme*

**6. Synthesising translations (attempting to create new third order constructs)**

The second-order concepts (produced in stage 5) were all written down on post-its and placed on an A2 sheet of paper. I then grouped similar concepts together (e.g. those that showed examples of reasons for caring). I then attempted to create new constructs that became the title of a cluster of concepts (e.g. motivations to care). The clusters of concepts were discussed with my research supervisors and the final new themes and subthemes were agreed.

**Results**

**Expressing the synthesis (step 7)**

The majority of papers explored the role and identity of being a caregiver as well as managing the challenges of the role. Some papers focused on the less researched areas of prior relationship with the parent and the positive outcomes of being a carer. The main themes are: Motivations/incentives to care, the role of the carers, common emotions/reactions, ways of coping, and services/systems. Each theme has a number of related sub-themes. The presented themes were found to be common across a range of studies and therefore likely to be representative of the experiences of adult-children who care for a parent with dementia. The themes and subthemes generated by the synthesis are presented in Table 4, along with the main author for each paper represented in the subtheme and example quotes.

| Main theme | Sub-themes | Papers (Main author) | Key Quotes |
|---|---|---|---|
| **Motivations/incentives to care** | Filial obligation/Repaying | Saunders (2002), Perry (2004), Harris (1998), Ward-Griffin (2007), McCarty (1996), Wallhagen (2006), Werner (2010), Yamamoto (1997) | "She cared for me when I was sick. I owed this to her." "I just owe her so much that, uh, I don't even really think about it like I don't, I'm not doing it to be a martyr or anything." "You got to do what you got to do." "It is my job, or rather a part of my job." |
|  | Attachment/prior relationship | Ward-Griffin (2007),  McCarty (1996), Tan (2009), Wallhagen (2006), Yamamoto (1997), Forbat (2003), Perry (2004) | "I wonder why I want to take care of her. I guess this stems from my relationship with my mother from my childhood. Although it was only a short while that I lived with her, but how do you say, I guess I was closest to her (quietly crying)...So I think I kept that feeling all along" |

| Main theme | Sub-themes | Papers (Main author) | Key Quotes |
|---|---|---|---|
| | Expectations about becoming a carer | Saunders (2002), Perry (2004), Harris (1998), McCarty (1996), Wallhagen (2006), Globerman (1995), Werner (2010), Yamamoto (1997), Simpson (2010) | "Rather than making a fuss saying 'caregiving, caregiving,' it is just a part of life. They are all a part of life." "It's just something we don't ever prepare for. It's something we get thrown into." |
| **The role of a carer** | Role reversal | Saunders (2002), Perry (2004), Harris (1998), Ward-Griffin (2007), McCarty (1996), Tan (2009), Globerman (1995), Kelsey (2010), Yamamoto (1997), Simpson (2010) | "She was my mother, and she did all this stuff for me and now it's slowly reversing." "My wife refused to provide any care for my mother. Therefore, I bathed her, changed her, toileted her and got her ready for day care every day..." |
| | Identity as a caregiver/expectations of the role | Saunders (2002), Perry (2004), Legault (2009), Dupius (2002), Kelsey (2010), Simpson (2010) | "Who am I now I look after her? Am I still a daughter? Is she still my mother if she doesn't look after me?" |

| Main theme | Sub-themes | Papers (Main author) | Key Quotes |
|---|---|---|---|
| | Siblings | Saunders (2002), Harris (1998), McCarty (1996), Globerman (1995), Dupius (2002). | "I had always thought my sister would be the caregiver for my mom or dad. But, my sister and her family moved out of the state and suddenly when my dad dies, there was no one who could care for mom. So, I became her caregiver....certainly not planning on that." "I'm talking more to my brother than I ever did before" |
| **Common emotions/reactions** | Thoughts and feelings about continuity of personhood | Saunders (2002), Dupius (2003), McCarty (1996), Kelsey (2010) | "...once I didn't want to come because I had had such a terrible visit with my mother the week before. I can't even explain, it was just a feeling I had that it was hopeless. It was just the most useless time I've ever had in my life and that we we all kidding ourselves, and that has she really in reality died. And these are negative, negative thoughts that I hadn't even thought before. Like have we all been pretending that this woman is even alive?" |

| Main theme | Sub-themes | Papers (Main author) | Key Quotes |
|---|---|---|---|
| | Negative feelings about the parent (Guilt, anger/resentment, shame/embarrassment) | Saunders (2002), Perry (2004), Harris (1998), Ward-Griffin (2007), McCarty (1996), Tan (2009), Globerman (1995), Kelsey (2010), Werner (2010), Forbat (2003) | "There was never enough time to do what I felt I should have done. I let my mother carry too much of it (the caregiving responsibility for his father), because she was strong, and so in my case I went to the point of path of least resistance."<br><br>"I hollered at her! I hollered at her!"<br><br>"She was a very difficult person to be around..." |
| | Loss and sadness | Saunders (2002), Perry (2004), Harris (1998), Dupius (2002), McCarty (1996), Yamamoto (1997), Werner (2010) | "You could actually see the decline because she was getting sort of more in, you know, um, inward and not so, um friendly toward people and outgoing like she used to be, and it was really a shame because, um, people couldn't talk to her anymore"<br><br>"The emotional sense of sadness...it's just overwhelming. I can't describe it. |

| Main theme | Sub-themes | Papers (Main author) | Key Quotes |
|---|---|---|---|
| | | | It's just so sad to see these competent capable people-they were so successful." |
| | Stress and burden | Harris (1998), Kelsey (2010) Saunders (2002), Tan (2009) | "Well from a professional standpoint, it was very difficult to balance all my responsibilities with her and then of course, all of the unwritten professional development expectations, and still give attention to my mom." |
| | Rewards of caring | Tan (2009), Perry, 2004; Ward-Griffin, 2007; Yamamoto, 1997 , Harris (1998), Saunders (2002). | "Recently, mother often says 'Oh, I took a bath today, thanks to you. I appreciate that.' It may sound strange, but I am glad I am told such a thing. When I see mother like that, I strongly feel like responding to her and I can be very honest about such a feeling. Yeah, a quite sincere and straightforward feeling. She is trusting me that much, 100 percent..." "Reminiscing about something-that's a big thing for humour. If you start reminiscing about crazy |

| Main theme | Sub-themes | Papers (Main author) | Key Quotes |
|---|---|---|---|
| | | | things you've done together of things you've laughed over...that's the most fun." |
| **Ways of coping** | Acceptance vs. avoidance | Saunders (2002), Harris (1998), Tan & Schneider (2009), Wallhagen (2006), Globerman (1995), Kelsey (2010), Werner (2010), Dupius (2002), McCarty (1996) | "You remember how sweet and compassionate your mom was and you look at the disease and it's totally out of character, but you might as well come out of your denial you're in. You have to recognise the fact that she has a serious problem and begin to help her and help yourself dealing with it." "Being able to get lost in the pressures of work with nothing else to distract you; it's all consuming. It's a great sucking tunnel- and if you like it, you don't pull that hard away from it. You can fill all your available time with work." |

| Main theme | Sub-themes | Papers (Main author) | Key Quotes |
|---|---|---|---|
| **Services/Systems** | Utilisation/access | Kelsey (2010), Tan (2009), Saunders (2002), Yamamoto (1997), Legault (2009) | "When we walked in, it was bright. It was sunny. There were activities. It was a happy place." "I could go over there in five minutes and take care of him. Convenience was very important." |
| | Relationships with Care Homes/staff | Kelsey (2010), Legault (2009), McCarty (1996) | "What I've told staff is: 'I'm not against you, I'm with you. I'm here to lend a hand, to take care of my mother, first of all, but to also help you. So if there's anything I can do or cannot do, just talk to me." |
| | | | "There wasn't the clear connect between where I placed her and what the next step would entail...Maybe somebody mentioned it, but it certainly wasn't clear to me." |

*Table 4: Themes and sub-themes*

**Motivations/incentives to care**

*Filial obligation/paying them back*

A number of studies found that carers felt it was their duty or felt obliged to care for their parent (Saunders and McFarland, 2002; Perry, 2004, Harris, 1998, Ward-Griffin et al., 2007, McCarty, 1996, Wallhagen & Yamamoto-Mitani, 2006, Werner et al., 2010; Yamamoto & Wallhagen, 1997). This was explained by many carers in terms of the idea that, because their parent had cared for them as a child and/or supported them in their adult life, they owed it to them to care for them. Harris (1998) referred to this concept as 'filial obligation' which is the idea that, due to early socialisation to norms of expected behaviour towards a parent, adult-children come to feel that it is their obligation to help their parents. Harris (1998) also found that being able to 'pay their parents back' was seen as a positive aspect of caring (see rewards of caring subtheme for more detail). Saunders and McFarland (2002) provided a quote which illustrates this subtheme well: "She cared for me when I was sick. I owed this to her". The general sense from the papers was that carers saw caring as something they had to do.

*Attachment style/prior relationship*

Ward-Griffin et al. (2007) pointed to the fact that caregiving is relational and therefore cannot be separated from people's experiences of and feelings towards each other in the past. Some adult-children referred to their childhood relationship/attachment with their parent and how this impacted on their current relationship. Some daughters described how they deconstructed their pre-morbid relationships with their mothers and then built new understandings (Perry, 2004). This involved recalling memories of their mother and their

relationship in order to come to terms and make sense of the changes they saw in their mother and to make the decision to become the carer. Some daughters reported interacting with their parent in a way that they had interacted with her in the past: "She was a very difficult person to be around. Even when I was a little girl, I knew I never wanted to be like her. And I told my kids, if I ever get like grandma, just shoot me!" This daughter described how she was currently finding her mother difficult. This highlighted continuity in past and current ways of relating to her mother (Ward-Griffin et al., 2007; McCarty 1996). Past feelings towards the parents appeared to impact directly on the current relationship with the parent (Forbat, 2003). Yamamoto and Wallhagen (1997) found that a strong sense of attachment led carers to give high value to caregiving.

*Expectations about becoming a carer*

Caregivers from different cultures talked about their expectations around taking on the caring role and their understanding of these expectations. Wallhagen and Yamamoto-Mitani (2006) found a distinct difference between American and Japanese carers. They found that Japanese women saw caring as a 'matter of course' and that it was their position in the family to take care of the elderly whereas American women often felt being a carer was unexpected and not prepared for: "It's just something we don't ever prepare for. It's something we get thrown into". Yamamoto and Wallhagen (1997) found that caregiving in Japan is highly valued due to societal norms regarding filial caregiving. Other studies focused on family values and expectations around caring for a parent in the community, as opposed to the carer and their parent choosing for the parent to move into a care home (Perry, 2004).

**The role of the carer**

*Role Reversal*

Caregivers described taking on a parental role for their parent and how they felt they had switched roles from being taken care of as a child/young adult to taking on new roles such as providing personal care and managing inappropriate behaviour (Saunders and McFarland, 2002; Tan & Schneider, 2009; McCarty 1996; Simpson, 2010): "She was my mother, and she did all this stuff for me and now it's slowly reversing." Carers talked about the issue of power and having to take charge of the situation as well as facing power struggles with their parent (Harris, 1998; Ward-Griffin et al., 2007; McCarty 1996; Yamamoto & Wallhagen, 1997). Another common way of making sense of this role reversal was describing the parent as a child or that the parent had been seen as independent but then in need of care, causing a change in roles (Perry, 2004; Tan & Schneider 2009).

*Identity as a caregiver/expectations of the role*

Questions about the identity of the caregiver were brought up: "Who am I now I look after her? Am I still a daughter? Is she still my mother if she doesn't look after me?" (Perry, 2004) as well as acknowledging the impact caregiving has on their life and their identity (Simpson, 2010). The participant in Simpson's (2010) paper talked about the self being disrupted or threatened by the caregiving role. Caregivers also reported having thoughts about the expectations of the role as well as thoughts of the future and when to stop being the primary caregiver (Kelsey et al., 2010; Saunders and McFarland, 2002; Perry, 2004). Legault and Ducharme (2009) explored the role of the carer when their parent was in a care home and how this became more focused on being an advocate for their parent.

*Siblings*

Globerman (1995) focused on why some adult-children take on the caregiving role and why some of their siblings become the 'unencumbered child'. The study found that the adult-children 'returned to family of origin reputations' (p.7) which meant fulfilling similar roles to those they fulfilled in the past. The study also found that different siblings felt different senses of responsibility and those that took on the caring role experienced negative feelings towards the siblings who did not help with caregiving. Saunders and McFarland (2002)), McCarty (1996) and Dupius (2002) found similar negative feelings towards siblings who did not help out. Harris (1998) found a mixture of positive and negative experiences and feelings between siblings, with some feeling closer to a sibling as a result of the caring role, while others felt the caring role reawakened old sibling rivalries which pushed siblings further apart.

**Common emotions/reactions**

*Thoughts and feelings about personhood*

Carers talked about feelings of ambiguity, especially during the middle and later stages of dementia were regarding the psychological existence of their parents, one day being psychologically present, one day not (Dupius, 2002). McCarty (1996) also found that carers experienced feelings of ambivalence; this was related to multiple sayings of goodbye to the parent. This gave a sense of carers not being sure if their parent was still their parent and at times experiencing discontinuity of personhood: "She doesn't know anybody, she doesn't respond to anything other than her own name. I don't call her mom anymore" (Werner et al., 2010). Some carers described how they still saw their parent as their parent and wanted to

maintain their personhood by protecting their identity through thinking about what their parent would have wanted before developing dementia (Perry, 2004; Ward-Griffin et al., 2007; McCarty 1996; Kelsey et al., 2010; Werner et al., 2010; Simpson 2010).

*Negative feelings about the parent (guilt, anger/resentment, shame/embarrassment)*

Adult-children described a mixture of negative feelings towards the parent or about caring for the parent. Carers often reported feeling guilty for reasons such as considering discussing (with their parent) a move into a care home, getting angry and not doing enough in their caring role and/or letting others take over: "There was never enough time to do what I felt I should have done. I let my mother carry too much of it (the caregiving responsibility for his father), because she was strong, and so in my case I went to the point of path of least resistance." (Perry, 2004), (see also Harris 1998; Globerman et al., 1995). Some carers talked of uncomfortable situations such their mother displaying disinhibited behaviour towards them and a sense of embarrassment over this (Saunders and McFarland, 2002), while others talked of the stigma associated with dementia and feeling embarrassed due to their parents' inappropriate behaviour and appearance (Werner et al., 2010). Anger and resentment were other common emotions described by carers (Forbat, 2003; Harris, 1998; Ward-Griffin et al., 2007; McCarty 1996).

*Loss and sadness*

Feelings of sadness and loss were experienced throughout the different stages of dementia. Saunders and McFarland (2002)) found that carers felt a sense of sadness in response to the initial memory loss and to receiving the diagnosis. More papers found that carers experienced these feelings during the middle and later stages of dementia. This was

linked to the 'psychosocial death' of the parent with regards to their personality changing and their level of disability (Dupius, 2002; McCarty 1996; Harris 1998; Yamamoto & Wallhagen, 1997). Some carers described the pain of still seeing their parent as their parent but having to develop new ways to be with them (Perry, 2004). Some adult-children talked about a sense of loss for the person they loved, but also loss of their own personal space, prior lifestyles, life consistency and job opportunities (Harris, 1998; McCarty 1996). Feelings of sorrow were described to lead to an increase in instrumental involvement such as taking care of their parent's finances or hiring a caregiver to provide extra help (Werner et al., 2010).

*Stress and burden*

Many carers talked about having to balance different roles, especially with regards to work and how this caused feelings of stress; this was particularly pertinent to the male caregivers. Saunders and McFarland (2002)) found that adult-sons experienced professional conflict that jeopardised employment and future professional growth. Carers also reported that due to balancing responsibilities, they felt they were doing nothing well. Harris (1998) produced the theme 'work flexibility' which referred to the ability to control their working hours so as to allow time for the caring role. One son described how "there's no way you can run a job and deal with this at times". Sons in this study talked of experiencing stress and burden and one son described the exhaustion of going through lots of different emotions: "It's like being on an emotional rollercoaster, and in a 24 hour period, you experience about every emotion known to mankind". A predominant factor in the development of stress and feelings of exhaustion was the lack of support, especially those without the support of siblings (McCarty, 1998; Globerman, 1995).

*Rewards of caring*

Some studies have explored positive outcomes for the carer and the parent with dementia. The positive outcomes could also be seen as reinforcements for caring (Yamamoto & Wallhagen, 1997). Tan and Schneider (2009) looked at adult-children's use of humour to help them "get away from it", as a stress reliever and for moments of enjoyment with the parent. Some adult-children talked about participating in new and enjoyable activities such as going to dance school, painting or outings with the family, as well as focusing on the financial benefits of caring for their parent at home (Yamamoto & Wallhagen, 1997). Some studies found that carers felt closer to their parent as a result of caring and appreciated being appreciated by them (Perry, 2004; Ward-Griffin et al., 2007; Yamamoto & Wallhagen, 1997). Another reward involved carers reflecting on how they had developed and grown since becoming a carer, including what they had learned about themselves and their relationship with their parent (Perry, 2004; Harris, 1998), learning new skills and new roles (Saunders and McFarland, 2002; Harris, 1998) and new ways of seeing the world (Tan & Schneider, 2009; Yamamoto & Wallhagen, 1997).

**Ways of coping**

*Acceptance versus avoidance*

There appeared to be a distinct split between those carers who accepted the situation and their role as opposed to those who used strategies to avoid it; however it is likely that this was affected by the stage of dementia and could fluctuate over time. Some adult-children described accepting the diagnosis of dementia (Harris, 1998), while others talked about 'just getting on with it', being open about the difficulties and having an attitude of 'do what you

have to do to provide care for mum or dad', especially the more challenging parts of the role such as intimate care (Saunders and McFarland, 2002; Tan & Schneider 2009; Wallhagen & Yamamoto-Mitani, 2006). Another aspect of acceptance involved taking charge of the situation and pushing their families to make necessary decisions (Harris, 1998). Dupius (2002) found that some carers were able to acknowledge and accept the psychological loss or psychosocial death of their parent during the later stages of dementia whereas some used avoidance which led to pain and distress. Other carers used avoidance (of the situation, of thinking about it, minimising feelings of distress) to cope with the difficulties of caring and to stay with feelings of denial (McCarty, 1996; Wallhagen & Yamamoto-Mitani, 2006, Globerman, 1995; Kelsey et al., 2010).

**Services/systems**

*Utilisation/access*

Some adult-sons described how they accessed support groups but that they found them unhelpful as the majority of the group was women. They talked about having different needs with regards to these types of services (Saunders and McFarland, 2002). On the other hand, some carers reported finding support groups helpful and valuable (Kelsey et al., 2010; Tan & Schneider, 2009; Yamamoto & Wallhagen, 1997). Experiences of utilising care homes/assisted living facilities and specialist dementia/memory units arose for some caregivers as their parents' needs changed. They described how they became familiar with the new setting (learning the home's operating rules and constraints) and evaluated the quality of care their parent received (Legault & Ducharne, 2009). Others talked about reasons for selecting particular homes/units, which included liking the facility and the proximity and

convenience (Kelsey et al., 2010). Further considerations and decisions to be made by carers involved recognising the need for future specialist dementia care and the expectations around this form of care (such as how well the parent will adapt to the change), (Kelsey et al., 2010).

*Relationships with staff/professionals*

A predominant theme that arose when talking about accessing and utilising care homes, specialist dementia services/units and other care services was that of the importance of building a relationship with staff. Many carers reported learning ways to communicate with nursing staff such as being diplomatic and encouraging reciprocity, thereby setting up a partnership between carers and staff. They also reported how an important part of their advocacy role was the development of trust with staff (Legault & Ducharne, 2009; McCarty 1996). Difficulties arose when staff failed to communicate effectively with carers which left them feeling confused about issues such as transfer policies (to another unit). Some carers talked about how useful it was when staff initiated conversations about future decisions/moves (Kelsey et al., 2010). The issue of being provided with the relevant information came up when talking about relationships with staff. Carers talked of needing to be informed of what care is available now and in the future, and being told about which facilities matched their parent's needs (Kelsey et al., 2010). Some participants described how some staff/professionals had insufficient knowledge about dementia and how to manage some of the symptoms; this led to tensions in the relationship with professionals due to carers and their parent feeling discriminated against and lost with regards to what to do next (Werner et al., 2010; Saunders and McFarland, 2002).

**Discussion**

The results highlight the complex and multi-faceted nature of the experience of adult-children who care for a parent with dementia (either in the community or while the parent stays in a nursing or care home). The variety of psychological responses to the caring role highlights that there does not seem to be a clear pattern to the way of responding to the role over time and models of grief such as Kubler-Ross' (1969) grief cycle do not necessarily fit this population. The results point to the importance of the prior relationship and how this might impact on the adult-child's way of making sense of their reasons for caring for their parent. Other relationships that seemed significant to carers' and their experiences included siblings and care professionals. The concept of paying a parent back for caring for them as a child is a key factor and shows a distinct difference in the experience of caring compared to spouse carers. Another key concept which was common across studies was role reversal which linked to adult-childrens' sense of identity and potential confusion around this. A further key finding was the use of avoidance and acceptance as coping strategies and some of the rewards of caring. The relationship of each of the themes to broader psychological theory and evidence will now be discussed.

*Motivations/incentives to care*

The prior relationship (including attachment) figured in the participants' accounts of their motivations to care for a parent with dementia. Bowlby's theory of attachment (Bowlby, 1969; 1982) and the succeeding research on attachment across the life cycle can be a valuable lens through which to view relationships between older adults and their caregivers. Cicirelli (1993) used quantitative methods to investigate the effects of attachment and filial obligation

on adult-childrens' motives for caregiving. Cicirelli's results suggested both attachment and obligation were related to the amount of help provided. Stronger attachment was related to less subjective burden whereas a stronger obligation was related to greater burden. Carpenter's (2001) quantitative study looked at the attachment bonds of adult daughters caring for elderly mothers. Carpenter found that daughters who were securely attached provided more emotional care than insecurely attached daughters. Securely attached daughters also reported less caregiver burden.

*The role of a carer*

Role reversal (Seltzer, 1990) refers to the adult-child taking on a parental role, while viewing the parent as taking on a more child-like role.  This process was frequently reported in the studies reviewed here.  Blenkner (1965) has proposed that role reversal is not a normal developmental phase and represents a 'pathological relational development' between a small number of adult children and their parents.  Psychodynamic thinking proposes that adult-children defend against hidden fears about their parent  no longer being 'all powerful' and that adult-children cope with these fears by trying to provide 'perfect' care for their parent (Jarvik, 1990). This particular theory about role reversal was not highlighted in this review but could be hypothesised to link to the adult-children's motivations to care for their parent as their motivation to care might be driven by their hidden fears.  These hidden fears could also be hypothesised to be underlying the adult-children's common emotions such as guilt around not providing the best care.

*Common emotions/reactions*

Quantitative research has reported on high levels of stress and burden in family members caring for a person with dementia (Ory, Hoffman, Yee. Tennstedt & Schulz, 1999; Schulz, O'Brien, Bookwala & Fleissner, 1995; Burton, Zdanuiuk, Schulz, Jackson & Hirsh, 2003) and more specifically in adult-child carers (Conde-Sala et al (a), 2010). Other common experiences include feelings of guilt (Conde-Sala et al (a), 2010) and loss or grief (Chan, Livingston, Jones & Sampson, 2012; Ott et al, 2007). There were similarities with the literature on continuity and maintaining personhood of the person with dementia (Chesla, 1994; Walters, 2010; Perry, 2002). Cohen, Colantonio and Vernich (2002) explored the positive aspects of caregiving for an elderly relative and how this was linked to caregiver outcomes. Two hundred and eleven caregivers (73%) could recognise at least one specific positive aspect and an additional 20 (6.9%) could identify a second positive aspect. Positive feelings about caregiving were found to be linked to lower depression and burden. Netto, Jenny and Phillip (2009) conducted a qualitative study and found that all caregivers reported having gained from caregiving. The most common gain was personal growth (more patient /understanding, becoming stronger/more resilient and increased self-awareness/more knowledgeable). Other gains were in their relationship with the person with dementia, existential gains such as spirituality and a 'more enlightened perspective on life'.

*Ways of coping*

Some studies have found that dementia carers use a mixture of acceptance and avoidance to cope with caring. This can involve emotional avoidance (i.e. detachment) as well as avoiding spending time with the person with dementia (Sun, Kosberg, Kaufman &

Leeper, 2010). This may be a way of trying to manage painful feelings around seeing their

parent deteriorate and could link to the experiences of role reversal. A systematic review

found that the use of more 'dysfunctional coping' such as avoidance was linked to higher

rates of anxiety and depression in family carers (Li, Cooper, Bradley, Shulman, Livingston,

2012, pg 10). Sun et al. (2010) found that 'deliberate' coping which was perceived as

acceptance was related to higher life satisfaction scores; whereas an avoidant coping style

was related to lower life satisfaction scores and higher caregiver burden scores. The carers in

this literature review that tended to use more avoidant coping strategies may have

experienced more difficult emotions as a result.

*Services/Systems*

*Utilisation/access (support groups, care nursing homes, specialist dementia units)*

Dementia and non-dementia research has found that carers value meeting others in a

similar situation, either for social or for learning needs purposes, and that this can be done by

accessing support groups (Stoltz, Ullman & Willman, 2004; Thomson et, al., 2007). This

links with the adult-children's stories about accessing support groups, with some finding

them useful, while others less so. The evidence for the efficacy of support groups is mixed

and some studies have not found a significant difference in wellbeing between attendees and

non-attendees (Gage and Kinney, 1995). Carers' need for relevant information about

available services has been found in other studies (Brodaty, Thomson, Thompson & Fine,

2005). Some studies have focused on family carers' experiences of moving a family member

with dementia into a care or nursing home. Family carers have been found to experience

emotion such as guilt, anger, despair, resentment and general psychological distress (Ryan,

2002). This highlights that carers continue to experience difficult emotions following care or nursing home placement. Non-dementia research has highlighted the importance of the relationship between family members and care staff. One particular study has looked at the relationship in assisted living facilities and the findings point to the need for care staff and family members to be empathic of each other and see each other as partners in care (Kemp, Ball, Perkins, Hollinsworth & Lepore, 2009). This links to the subtheme of 'relationships with staff/professionals'. Difficulties communicating with care home staff and its importance to carers have been identified in Ryan & Scullion's study (2000). This paper explored the opposing perceptions of carers and staff about their respective roles once the person with dementia has been admitted to a care home.

**Methodological considerations**

There are limitations to the studies that were reviewed. Only a small number of papers reported on negative cases and only one considered alternative interpretations of their data. The majority of carers were white adult-daughters from westernised cultures. Although female carers are likely to be representative of the caring population in England (Ward-Griffin et al., 2007; Brody, 1981), the studies may be missing different experiences and ways of making sense of these experiences that could be useful in developing one to one and family interventions. Some studies included male carers as well as carers from different cultures (Japan, Israel) and this is likely to have had an effect on the ways the participants in these studies made sense of their experiences. For example, the sense of stigma may be very different for those living in Israel compared to those living in England; extrapolating from the themes produced needs to be done cautiously as there are likely to be some cultural differences. Participants were self-selected, meaning that the themes found might not

represent some of the experiences of carers who were difficult to recruit, such as those who might find it too difficult to participate in such emotive and challenging research.

The methodology used in this review has both strengths and weaknesses. The literature search aimed to be inclusive and covered a range of databases and terms. However, some relevant studies may have been omitted as some authors may have used keywords and titles which did not fully represent the content of the study. The method of analysis meant that the papers' themes were explored in great depth and the results formed a new, cohesive group of themes that covered a large area of research. The subjectivity involved in the process of interpreting the original authors themes could be perceived as a weakness of the review.

It is important to acknowledge and reflect on the author's influence on the meta-ethnography synthesis. Throughout my career in psychology, I have been interested in family relationships, and attachment more specifically, as well as the ways that people try to manage difficult/unwanted feelings. My interest in these areas is likely to have had an impact on my thinking while conducting the meta-ethnography and had some influence when deciding how to group subthemes. The potential bias was reduced by discussing my thinking about the themes and subthemes with my research supervisors to reach an agreement on the evidence for the themes produced; however, the credibility of the review could be further improved by using more than one person to code the themes in the literature. It was also likely that work on a concurrent research project which looks at daughters who care for a mother with dementia, and uses IPA to produce themes of common experiences, affected my style of interpretation and grouping themes together.

**Clinical implications**

Adult-children may benefit from therapeutic interventions which focus on the history between them and their parent with dementia as a means of making sense of current feelings between them, ways of caring they have adopted, and the coping strategies that they are using. Ward-Griffin's (2007) paper opens up some interesting ideas around caring style and the potential motivations for the different styles of interacting with a parent. If therapists can help adult-children to process unresolved feelings may make the caring role less stressful and distressing and may encourage more positive ways of seeing their parent and looking after them. Other areas to focus on could include the cultural expectations placed on people to care for a parent and issues with identity linked to potential experiences of role reversal. It is hoped that by aiding a better understanding in the caregiver, that the care recipients will also benefit, hence reducing their levels of distress and possibly also reducing the need for extra input from care services.

Other professionals such as inpatient and community nurses, nursing assistants and doctors (who have input with people with dementia and their adult-child carers) could use the findings from this study to help them name and validate the different experiences adult-children carers may have. Again, there could be some focus on helping the carer to use acceptance as a coping strategy more often than avoidance. These approaches could be used in a one to one or group setting in hospitals, clinics and in the community and could also be used in carer support groups. It is hoped that carers will feel that their experiences are understood and this might help to reduce any negative impacts of caring on the carer and encourage a culture of talking about their experiences and considering their own needs as

well as their parents'. There is also a chance that this process will encourage more positive relationships between carers and services.

*Future research*

Future research could benefit from a better, more detailed understanding of different motivations to care. A more specific focus could be on different cultural factors that impact on expectations about taking on the caring role for a parent. The different coping strategies used and the subsequent distress experienced needs further exploration as interventions to be used with adult-children carers and their family need to be relevant to their situation. More grounded theory research would be useful in attempting to formulate the combination of factors (i.e. prior relationship/attachment, personality, resilience, stage of dementia/type of dementia) which lead to different styles of caring and subsequently varying levels of distress and/or positive feelings in the carer and the person with dementia. It would be useful to increase research focus on the positive aspects of caring, for adult-children and their parent as well as looking at whether some adult-children are able to repair their previous difficult relationship with their parent while caring for them. This links to the concept of filial maturity (Blenkner, 1965) which appears to be an important stage to be reached so that adult-children can process previous conflicts and move on to provide a positive caring style. This research could point to potential therapeutic interventions that would help the adult-child move to this developmental stage and potentially reduce the risk of unwanted feelings towards their parent and potential emotional and/or physical abuse.

## References

Ablitt, A., Jones, G.V., & Muers, J. (2009). Living with dementia: A systematic review of the

influence of relationship factors. *Aging and Mental Health, 13,* 497-511. doi:

10.1080/13607860902774436

Atkins, S., Lewin, S., Smith, H., Engel, M., Fretheim, A., & Volmink, J. (2008)  Conducting

a meta-ethnography of qualitative literature: Lessons learnt. *BMC Medical Research

Methodology,* 8 (21), doi:10.1186/1471-2288-8-21.

Alzheimer's Society (2012). *Alzheimer's Society Dementia 2012 Report*.  Retrieved from:

http://alzheimers.org.uk/site/scripts/download_info.php?fileID=1390

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,

221-257.

Blenkner, M. (1965). Social work and family relationships in later life with some thoughts on

filial maturity. In E Shanas & G. Streib (Eds.), *Social structure and the family:

Generational relations*

Bowlby, J. (1969). Attachment and loss: Volume 1. *Attachment*. New York: Basic books.

Bowlby, J. (1988). *A secure base*. London: Routledge.

Brodety, H., Thomson, C., Thompson, C., & Fine, M. (2005). Why caregivers of people with

dementia don't use services. *Geriatric Psychiatry,* 20 (6), 537-546.

Brody, E.M (1981). "Women in the middle" and family help to older people. *The Gerontologist*, 5., 471- 479.

Burton, L.C., Zdaniuk, B., Schulz, R., Jackson, S., & Hirsch, C. (2003). Transitions in spousal caregiving. *The Gerontologist*, 43, 230-241.

Campbell, R., Round, P., Pope, C., Britten, N., Pill, R., Morgan, M., & Donovan, J. (2003).

Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social Science and Medicine*, 56 (4), 671-684.

Carpenter, B. (2001). Attachment bonds between adult daughters and their older mothers: Associations with contemporary caregiving. *The Journals of Gerontology and: Psychological Sciences*, 56B (5), 257-266

Chan, D., Livingston, G., Jones, L., & Sampson, E. (2012).Grief reactions in dementia carers: a systematic review. *International Journal of Geriatric Psychiatry*. Downloaded from http://onlinelibrary.wiley.com/doi/10.1002/gps.3795. doi: 10.1002/gps.3795.

Cicirelli, V. G. (1993). Attachment and obligation as daughters' motives for caregiving behaviour and subsequent effect on subjective burden. *Psychology and Aging*, 8 (2), 144-155.

Cohen, C. A., Colantonio, A. & Vernich, L. (2002). Positive aspects of caregiving:

Rounding out the caregiving experience. International *Journal of Geriatric Psychiatry*, 17, 184-188.

Conde-Sala, J. L., Garre-Olmo, J., Turro-Garriga, O., Vilata-Franch, J., & Lopez-Pousa, S.

    (2010a). Quality of Life of Patients with Alzheimer's Disease: Differential

    perceptions between Spouse and Adult Child Caregivers. *Dementia and Geriatric*

    *Cognitive Disorders*, 29, 97-108.

Conde-Sala, J.L., Garre-Olmo, J., Turró-Garriga, O., Vilalta-Franch, J., López-Pousa, S.

    (2010b). Differential features of burden between spouse and adult-child caregivers of

    patients with Alzheimer's disease: an exploratory comparative design. *International*

    *Journal of Nursing Studies*, 47 (10), 1262-1273

Cooper, C., Blanchard, M., Selwood, A., Walker, Z., Livingston, G. (2010). Family carers'

    distress and abusive behaviour: longitudinal study. *The British Journal of Psychiatry*,

    196, 480-485.

Dementia, 2010. *The prevalence, economic cost and research funding of dementia compared*

    *with other major diseases*. A report produced by the Health Economics Research

    Centre, University of Oxford for the Alzheimer's Research Trust. Retrieved from:

    http://www.dementia2010.org/

Draper, B. (2004). *Dealing With Dementia: A Guide to Alzheimer's Disease and Depression*

    *in Caregivers of Patients with Dementia*. Allen & Unwin: Crows Nest, New South

    Wales.

Dupius, S. L. (2002). Understanding Ambiguous Loss in the Context of Dementia Care:

    Adult Children's Perspectives. *Journal of Gerontological Social Work*, 37 (20), 93-

    115.

Fingeld, D. L. (2003). Meta-synthesis: The State of the Art- So Far. *Qualitative Health Research*, 13, 893-904

Forbat, L. (2003). Relationship difficulties in dementia care. A discursive analysis of two women's accounts. *Dementia*, 2 (1), 67-84.

Gage, M. & Kinney, J. (1995). They aren't for everyone: The impact of support group participation on caregivers' wellbeing. *Clinical Gerontologist,* 16, 21-34.

Globerman, J. (1995). The Unencumbered Child: Family Reputations and Responsibilities in the Care of Relatives with Alzheimer's Disease. *Family Process*, 34, 87-99.

Harris, P. B. (1998). Listening to Caregiving Sons: Misunderstood Realities. *The Gerontologist*, 38 (3), 342-352.

Hoffman, R.L. (1998). Caregiver Burden: Historical Development. *Nursing Forum*, 33 (4), 5-11.

Jarvik, L. F. (1990). Role reversal: Implications for therapeutic intervention. *Journal of Gerontological Social Work*, 15 (1/2), 23-34.

Kelsey, S. G. Laditka, S. B., & Laditka, J. N. (2010). Caregiver Perspectives on Transitions to Assisted Living and Memory Care. *American Journal of Alzheimer's Disease & Other Dementias*, 25 (3), 255-264.

Kemp,C. L., Ball, M. M., Perkins, M. M., Hollingsworth, C., & Lepore, M. (2009) "I Get Along With Most of Them": Direct Care Workers' Relationships With Residents' Families in Assisted Living. *The Gerontologist,* 49 (2), 224-235.

Kubler-Ross, E. (1969). *On Death and Dying*. New York: Macmillan.

Legault, A., & Ducharme, F. (2009). Advocating for a Parent with Dementia in a Long-term Care Facility. *Journal of Family Nursing*, 15 (2), 198-219.

Li, R., Cooper, C., Bradley, J., Shulman, A., & Livingston, G. (2011) Coping strategies and psychological morbidity in family carers of people with dementia: A systematic review and meta-analysis. *Journal of Affective Disorders*, 139 (1), 1-11.

Mays, N., Pope, C. (2000). Qualitative research in health care. Assessing quality in qualitative research. *British Medical Journal*, 320 (7226), 50-52.

McCarty, E. F. (1996). Caring for a parent with Alzheimer's disease: process of daughter caregiver stress. *Journal of Advanced Nursing*, 23, 792-803

Murphy, E., Dingwell, R., Greatbatch, D., Parker, S., & Watson, P. (1998). Qualitative Research Methods in Health Technology Assessment: a review of the literature. *Health Technology Assessment*, 2(16), 1-274

Netto, N., Jenny, G., Philip, Y. (2009). Growing and Gaining Through Caring for a

Loved One with Dementia. *Dementia*, 8(2), 245-261

Noblitt, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative methods*. Newbury Park, CA: Sage.

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

Ott, C. H., Sanders, S., & Kelber, S. T. (2007). Grief and Personal Growth Experience of Spouses and Adult-Child Caregivers of Individuals With Alzheimer's Disease and Related Dementias. *The Gerontologist*, 47 (6), 798-809.

Parsons, K. (1997). The male experience of caregiving for a family member with Alzheimer's disease. *Qualitative Health Research*, 7, 391-498.

Perry, J. (2004). Daughters Giving Care to Mothers Who Have Dementia: Mastering the 3 R's of (Re) Calling, (Re) Learning, and (Re) Adjusting. *Journal of Family Nursing*, 10 (1), 50-69.HeH

Popay, J., Rogers, A., & Williams, G. (1998). Rationale and standards for the systematic review of qualitative literature in health services research. *Qualitative Health Research*, 8(3), 341-351

Ryan, A.A., Scullion, H.F. (2000) Nursing home placement: an exploration of the experiences of family carers. *Journal of Advanced Nursing*;, 32 (5), 1187-1195.

Ryan, A. (2002). Transitions in Care: Family carers' experiences of nursing home placement. *Journal of research in nursing,* 7 (5), 324-334.

Salter, K., Hellings, C., Foley, N., & Teasell, R. (2008). The experience of living with stroke: A Qualitative Meta-Synthesis. *Journal of Rehabilitation Medicine*, 40, 595-602

Saunders, S., & McFarland, P. (2002). Perceptions of Caregiving Role by Son's Caring for a parent with Alzheimer's Disease: A Qualitative Study. *Journal of Gerontological Social Work*, 37 (2), 61-76.

Tan, T., Schneider, M. A. (2010). Humor as a Coping Strategy for Adult-Child Caregivers of Individuals with Alzheimer's Disease. *Journal of Family Communication*, 10 (1), 7-23HeH

Schreiber, R., Crooks, D., & Stern, P. N. (1989). Qualitative meta-analysis. In J. M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 311-327). London: Sage

Schulz, R., Martire, L. M. (2004). Family Caregiving of Persons With Dementia. Prevalence, Health Effects, and Support Strategies. *American Journal of Geriatric Psychiatry*, 12, 240-249.

Schulz, R., O'Brien, A.T., Bookwala, J., Fleissner, K. (1995). Psychiatric and physical morbidity effects of Dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist*, 35, 771-791.

Seltzer, M. M. (1990). Role reversal: You don't go home again. *Journal of Gerontological Social Work*, 15 (1/2), 5-14.

Simpson, C. (2010). Case Studies of Hispanic Caregivers of Persons With Dementia: Reconciliation of Self. *Journal of Transcultural Nursing*, 21 (2), 167-174.

Smith, J. A. (2003). *Qualitative Psychology: A practical guide to research methods*. London: Sage.

Sun, F., Kosberg, J. L., Kaufman, A. V., & Leeper, J. D. (2010) Coping strategies and caregiving outcomes among rural dementia caregivers. *Journal of Gerontological Social Work*, 53(6), 547-67.

Wallhagen, M. I., & Yamamoto-Mitani, N. (2006). The Meaning of Family Caregiving in Japan and the United States: A Qualitative Comparative Study. *Journal of Transcultural Nursing*, 17 (1), 65-73

Ward-Griffin, C. Oudshorn, A. M., Clark, K. & Bol, N. (2007) Mother-Adult Daughter Relationships within Dementia Care. A Critical Analysis. *Journal of Family Nursing*, 13 (1), 13-32.

Werner, P., Goldstein, D., & Buchbinder, E. (2010). Subjective Experience of Family Stigma as Reported by Children of Alzheimer's Disease Patients. *Qualitative Health Research*, 20 (2), 159-169.

Yamamoto, N., & Wallhagen, M.I. (1997). The Continuation of Family Caregiving in Japan. *Journal of Health and Social Behaviour*, 38 (2), 164-176.

# ADULT DAUGHTERS WHO CARE FOR A MOTHER WITH DEMENTIA: HOW DO THEY MAKE SENSE OF RELATIONSHIP CHANGES?

## EMPIRICAL PAPER

**Abstract**

This study aimed to explore adult-daughter's perceptions of changes in their relationship with their mother with dementia using an interpretative phenomenological approach (IPA). Five participants, caring for a mother with dementia, took part in two interviews. The first focused on the relationship prior to the dementia, the second on the relationship since the dementia. Six main themes emerged from the data: Power and control, motivations to care, lenses to view personality and relationship changes, negative aspects of the relationship, performativity, and attachment/quality of relationship. Interconnections between the themes appeared for each participant. These interconnections are discussed along with hypothesised links to related theories, such as attachment, role reversal, continuity and discontinuity as well as relevant research. Clinical implications include suggestions around offering adult-children one to one therapeutic support which could focus on the past as well as the current relationship.

**Keywords:** Adult-daughters, dementia, carers, qualitative

## Introduction

Dementia poses challenges to family relationships. Family members show considerable individual variation in how they respond to these challenges (Schulz & Martire, 2003; Haley et, al., 1996). Whilst some take on the role of carer, others do not, with some adult children tending to provide care for a parent when there is no spouse available (Schulz & Martire, 2003). Some carers experience negative feelings towards the person they are looking after and their role, but others less so and positive experiences are reported (Schulz & Martire, 2003; Netto, Jenny, & Philip, 2009). Negative feelings include guilt, anger and embarrassment (Conde-Sala et al., 2010a; Harris, 1998; Ward-Griffin 2007; McCarty 1996; Werner, Goldstein & Buchbinder, 2010). Positive experiences include learning new skills and personal (psychological) growth (Perry, 2004; Harris, 1998). The quality of the relationship between the family member and the person they are looking after inevitably also varies (Schulz et, al., 1995; Ward-Griffin, 2007; Chelsa, Martinson & Muwaswes, 1994).

*Adult children and aged parents: Key theories and research*

Various theories have been proposed to attempt to explain why family (non-dementia) carers respond to the caring role in different ways. The life-course perspective views the relationship between an adult child and an aged parent using a developmental view. Three key theories have been proposed: role reversal (Seltzer, 1990), filial maturity (Blenkner, 1985) and attachment theory (Bowlby, 1969;1982).

Role reversal refers to the adult-child taking on a parental role, while the parent is seen as taking on a child-like role. The underpinning psychodynamic theory proposes that adult-children experience  hidden fears linked to admitting that their parents are no longer 'all powerful' and they cope with these fears by trying to provide 'perfect' care for them ( Jarvik, 1990). It has been suggested that  adult-children need to work through unresolved conflicts so as to avoid feeling driven to care, with consequent feelings of guilt, exhaustion and stress (Jarvik, 1990). Blenkner (1965) has argued that role reversal is not a normal developmental phase but represents 'pathological relational development'. Brody (1990) suggested that caregiving for a parent may be perceived as role reversal due to the superficial similarities to caring for a young child. She described how some of the obvious similarities, included feeding and toileting, might mask the more subtle differences between the two roles. Some argue that role reversal beliefs may be potentially damaging for parents and their adult children (Brody, 1990; Selzter, 1990).  Albert (1990) found that adult-child carers were more likely to view caring for their parent as similar to childcare when they thought that only they could care for their parent due to their 'special' parent-child bond.

Filial maturity (Blenkner, 1985) is seen as a developmental stage in which the adult-child comes to see their parent as an individual with needs and an identity  separate from the parental role.  This allows a midlife opportunity for personal growth which can change caregiving from an experience of burden to one with positive rewards (Sherrell, Buckwalter, & Morhardt, 2001). It has been proposed that caring for a parent provides opportunities for psychological growth in parallel with other challenges of midlife. However, where filial maturity is not achieved,

unresolved conflicts from the adult-child's childhood can resurface and lead to 'repeating patterns' in the current relationship (Sherrell & Newton, 1996; Sherrell et al., 2001).

Bowlby's (1969;1982) theory of attachment and research on attachment across the life cycle highlight the usefulness of using this lens to view relationships between older adults and their caregivers. Cicirelli (1993) found that both attachment style and sense of obligation were related to the amount of help provided. Stronger attachment was related to less subjective burden whereas a stronger obligation was related to greater burden. Filial obligation refers to the idea that due to early socialisation, adult-children feel that it is their obligation to help their parents. Carpenter (2001) found that daughters who were securely attached provided more emotional care to mothers and reported less burden than insecurely attached daughters. Whitback, Hoyt and Huck (1994) established that negative family histories adversely affected the degree of concern adults felt towards their aging parents. In particular, memories of early rejection were found to reduce adult-children's concern about parental wellbeing, that is, they had a lower sense of obligation.

It has been proposed that daughters may be particularly vulnerable to feelings of burden when care giving, due to the unique and potentially intense nature of their prior relationship with their mothers (Jordan, 1991). Donorfio and Kellett (2006) used grounded theory to examine the concept of 'filial responsibility' between caregiving daughters and frail mothers. They produced a framework of four intrapsychic caregiving and care-receiving transitions: 1) Realising I am a caregiver/receiver, 2) Defining the caregiver/care-receiver roles, 3) Redefining the caregiving

relationship and 4) Relationship acceptance. These transitions were all influenced by different levels of filial responsibility and the one factor mentioned by all was: 'Personal', which included: love, respect, guilt, power, obligation, being responsible, companionship, fear of being alone, being able to live with oneself, feeling good, modelling for own children and inheritance promises.

*Dementia and family carers :Theories and research*

The majority of past dementia-carer research has focused on experiences of stress and burden on the family carer (Schulz & Martire, 2004). Studies that have explored the relationship between carers and care recipients have tended to explore the current relationship (Ablitt, Jones, & Muers, 2009). However, 'continuity' and 'discontinuity' have been put forward to explain how family carers may perceive relationship changes when a family member develops dementia (Chesla, Martinson, & Muwaswes, 1994). Continuity and discontinuity are viewed as opposite ends of a spectrum, with continuity referring to the carer viewing the person with dementia and/or their relationship as the same as prior to the dementia, discontinuity as different. This dimension may link to the family member's need/motivation to maintain or pull away from the 'personhood' of the family member as a means of coping with the illness (Chesla, 1994; Lewis, 1998). Walters, Oyebode and Riley (2010) found a core category of continuity-discontinuity which pervaded all of their themes. This study focused on spouse carers; the concepts of continuity and discontinuity have not yet received specific focus with regards to adult-children carers.

Increasingly, adult children (the majority female), are caring for a parent with dementia (Brody, 1981; 1991; Schulz & Martire, 2004). This is likely to continue to increase in the future (Ward-Griffin, Oudshoorn, Clark, & Bol, 2007; Parsons, 1997; Hoffman, 1998). Much of the research conducted in this area has been quantitative, though some studies have used qualitative methods. Saunders and McFarland (2002)) derived the following themes that summarised caregiving sons' experiences: 'Initial reaction to memory loss', 'Becoming caregivers', 'Women in son's world', 'Learning new roles', 'Conflicts', 'Uncomfortable situations' and 'Service utilisation.' Harris (1998) also looked at sons' experiences and found themes of: 'Duty', 'Acceptance', 'Taking charge', 'Common emotions' and 'Work flexibility'. The themes in both papers were linked to motivations to care, the concept of role reversal, negative feelings towards the parent, and loss and sadness, as well as different ways of coping.

Ward-Griffin (2007) found that prior relationship patterns impacted on the caregiving role and the current relationship. She found four dynamic categories of relationship: Custodial (task and deficit focused), Combative (emotion and deficit focused), Cooperative (task and strength focused) and Cohesive (emotion and strength focused). These highlighted how daughters viewed their style of relationship (amount of focus on emotions, feelings towards their mother) as consistent across time. Forbat (2003) found that the past difficulties in the relationship impacted on the current relationship between a daughter caring for a mother with dementia. Perry (2004) described three stages that daughters went through when caring for their mother. The first stage '(Re)calling' referred to the daughters using their memories of their mother as well as other family knowledge to adjust to their mother's presentation. This stage also involved making the

decision to take on the caregiving role.  Motivations for becoming the carer included love and commitment, promises to the family and/or cultural, family or social traditions. The stage of '(Re) learning' required the daughters to re-learn who their mother had been, who she currently was and to work out ways to be with her and care for her in public and in private. The final stage '(Re) adjusting' involved the daughters changing their lives by trying to care for themselves as well as making some sense of their caring role and considering the future.

Expectations about caring for a parent with dementia in different cultures have been explored.  Wallhagen and Yamamoto-Mitani (2006) found that American daughters felt morally obliged to care for their mother, whereas Japanese women saw it as expected. Japanese women saw caregiving as an expected career whereas American women did not anticipate the role and experienced more negative feelings.  Yamamoto and Wallhagen (1997) looked at the continuation of caregiving in Japan and suggested that caregiving is highly valued due to societal norms regarding filial caregiving and attachment to the care recipient. Those with negative feelings towards the care recipient gave the role of caregiving lower value. Caring was viewed as the role of women in the family. Factors which maintained the value of caregiving included: Encouragement and appreciation from the mother; having a desire to live life free of regret in the end; societal value of caregiving; and gaining new insights into human aging and dying. Predictors of care continuation included new activities, financial benefits, situational determinants (i.e. absence of siblings) and personal style or behaviour.

*Rationale*

In summary, evidence suggests that intergenerational care giving between daughters and mothers is likely to become increasingly common (Ward-Griffin, 2007). The well-being of adult-daughter carers and their parents might be at risk if their relationship is put under strain when the parent develops dementia. Unresolved conflicts, attachment styles and family roles may influence the coping strategies used by the adult-child, further impacting on the relationship. So that this complex relationship is better understood, further research needs to be done. This study builds on research by Walters, Oyebode and Riley (2010) and Ward-Griffin (2007). It is hoped that an interpretative study examining the experiences of daughters in relation to their perception of their life-long relationship to their parent, may further our understanding of some of the factors that impact on the current relationship and subsequent emotions and difficulties/satisfactions attached to this. An interpretative phenomenological analysis (IPA) approach was employed to provide an in-depth and detailed study of daughters' experiences.

The aim of the present study is to investigate how adult-daughter carers make sense of the relationship they had with their mother prior to the development of dementia and how they make sense of any relationship changes that may arise after dementia. The research sought to explore attachment/quality of the relationship and continuity-discontinuity, by looking at the similarities and differences in the descriptions of the mothers and the relationships before and after dementia. It is hoped that, by understanding more about how the prior relationship impacts on the current relationship and the caregiving role, the research can help to inform professionals;

enabling them to provide appropriate support to help manage difficulties which may lead to

strain in the relationship and distress on the part of the carer and person with dementia.

**Method**

**Design**

A qualitative research methodology was used to explore adult-daughter caregivers' understanding of any changes that occurred in their relationship with their mother since the perceived onset of dementia. Interpretative phenomenological analysis (IPA) sits within social constructionism as which holds the view that people participate in the construction of their perceived social reality. IPA. has origins in phenomenology (philosophical approach to the study of experience) and hermeneutics (theory of interpretation) and key concepts have come from Husserl, Heidegger and Merlau-Ponty (Smith, Flowers, & Larkin, 2009). .IPA aims to explore how participants make sense of something major in their lives by engaging with participants' reflections of the significance of what is happening; this is usually done via interviews, diaries or focus groups in order to gather in-depth data. The process enables individuals to express their experiences through their own words. The researcher aims to get close to the individual's inner world, to explore the 'insider's perspective' (Conrad, 1987, cited in Smith, Jarman & Osborn, 1999,p53) through interpretation.

Data collection does not aim to test hypotheses and this approach is maintained in data analysis. A small homogenous sample is chosen so as to focus on particular people in a particular context. IPA is idiographic, meaning that it explores individuals' perspectives while acknowledging and reflecting on their context. The researcher examines each case in order to elicit key themes and then moves on to more general claims. Analysis and interpretation are

carried out by the researcher, who aims to be mindful of their part in the process of the interviews as well as the analysis of the data (Smith, Flowers, & Larkin, 2009).

Face-to face interviews were conducted for a pilot interview and the main study. The transcripts from main study interviews were analysed using IPA methods (Smith, Flowers & Larkin, 2009). The study received approval from the University of Birmingham, Life and Health Sciences Ethical Review Ethics Committee (see appendix 4).

**Participants**

*Pilot interview*

An email was sent out to all staff and students in the University psychology department, explaining the study and inviting a volunteer to take part in a pilot interview so that the interview guide could be informally tested and feedback could be gained on the experience of the participant. One adult daughter (non-caregiver) with a parent with dementia was identified. The participant was informed that her interview would be transcribed and used to adapt the interview guide but that her data would not be used in the analysis in the main study.

*Main study*

Adult-daughter caregivers were identified through 2 local carer support groups run by the third sector. Participants were required to be: 1) Aged 18 years or older, 2) a female providing care for their biological mother with dementia, 3) to have been providing care for at least 12 months (Carers self-identified as providing instrumental and/or emotional support to their

mother), 4) the mothers' primary problem needed to be dementia. The two exclusion criteria were: 1) The mother resided in a care-home, 2) the daughter was unable to speak and understand English. The inclusion and exclusion criterion were used to maintain the focus of the study so as to adhere to IPA methodology (Smith, Flowers, & Larkin, 2009).

Five adult-daughter caregivers were recruited and each was interviewed twice. It is recommended that a sample size of between 4 and 10 participants is used for IPA projects (Smith, Flowers & Larkin, 2009) and as each participant would be interviewed on two occasions, it was felt that 10 interviews would produce sufficient rich data for analysis. Four of the adult-daughters lived separately from their mothers, one lived with her mother. Wendy and Janet were sisters who both provided care for their mother separately (they coordinated their caring roles over the phone and face to face when together). All were white British, with English as their first language. (See Table 1 for demographics).

| Participant alias | Caregiver age (yrs) | Care-recipient age (yrs) | Length of time caring (yrs) | Ethnicity |
|---|---|---|---|---|
| Lynn | 53 | 76 | 5 | White British |
| Beverley | 48 | 85 | 5 | White British |
| Wendy | 55 | 82 | 4 | White British |
| Janet | 45 | 82 | 4 | White British |
| Anne | 52 | 80 | 6 | White British |

*Table 1: Participant demographics*

**Procedure**

The managers of the local support service and groups were contacted, and informed about the research and the researcher arranged to attend a support group meeting and talk about the study. Following these talks, the main researcher was available to answer questions. Posters were handed at out the meetings and placed in the support services so that potential participants could contact the main researcher. Individuals who were interested contacted the researcher or gave permission to be contacted and were sent copies of the participant information sheet (appendix 5) and the recruitment poster. Following a phone conversation with interested individuals, which clarified that they met the inclusion criteria, a convenient time and place were arranged for the first interview, at which written informed consent was taken (appendix 6)  .

Ten face-to face, semi-structured interviews were conducted. Each participant was interviewed on two separate occasions, with each interview lasting 50 to 80 minutes. All interviews were audio-taped. The interviews followed a semi-structured schedule (see appendix 7). The questions in the schedule were developed and edited by drawing on themes of  previous research with a similar focus or approach, discussion between the researcher and two research supervisors and piloting the interview questions with an adult-daughter who had a mother with dementia (non-caregiver). The schedule listed questions and prompts for interview A and interview B. Interview A explored the participant's relationship with their mother from their early childhood up until the mother starting showing signs of dementia. The aim was to open up

conversations about attachment (i.e.containment of emotions), family dynamics, what they talked about, time spent together, relationship ups and downs and significant incidents/memories. Interview B focused on the participant's role of caregiver and what had changed and not changed in their relationship with their mother. Both interviews explored the participant's feelings towards their mother at different stages in their life and the last part of interview B invited the participant to reflect on the parallels and connections between the past and the present. The discussions during each interview were led by the participants and so the interview schedule was not followed in the same order for every participant. The majority of questions were open and non-leading, with prompts used to encourage further detail as necessary.

Four of the participants were interviewed at their homes and one was interviewed, at her request, in a NHS building. Once each interview was completed, the researcher asked each participant if there was anything they felt had been missed and if there were any parts of the conversation they were not comfortable with being used for the study. The participants were also given time to talk about any difficult and/or interesting issues that had been raised and how they found the interview. The main researcher transcribed verbatim from the audio-tapes and included laughter, crying and pauses, along with speech in the analysis. A reflective log was completed after each interview; this described the interviewer's thoughts and feelings during the interview and was kept in mind during the analysis (see example in appendix 8)

**Analysis**

Each participant's transcripts for interview A and B were combined to make one longer document and each of these was analysed fully before moving on to the next. Step 1 involved reading and re-reading each transcript and paying attention to what appeared to be important to the participant; these areas were underlined during this phase. This step required the researcher to become immersed in the original data and meant that the participant became the focus of analysis (Smith et.al, 2009). Step 2 was called initial noting; this stage was the initial level of analysis and explored semantic content and language use (see appendix 9 for example). The researcher wrote down exploratory notes in the right-hand margin of the transcript and these were broken down into three different types: Descriptive, linguistic and conceptual. Descriptive comments described the content, linguistic comments focused on the specific use of language (which could also involve repetition of words, hesitations) and conceptual comments looked at engaging at a more 'interrogative and conceptual level' and was more interpretative (Smith et.al, 2009, p84). Step 3: Developing emergent themes, involved the researcher looking for themes among the initial notes by attempting to reduce the amount of detail, at the same time 'mapping' the interrelationships, connections and patterns between exploratory notes. In step 4 the researcher searched for connections across emergent themes for each participant. The researcher compared the emergent themes arising from interviews A and B, and noted similarities and differences between them (see appendix 10 for example). She then grouped these into over-arching themes, each of which was then given a title. Step 5 involved moving onto the next case and repeating steps 1-4. Step 6 was: Looking for patterns across cases (see appendix 11 ).

Frequent discussions took place with research supervisors to ensure plausibility and trustworthiness of initial notes and themes as well as discussing connections and contradictions across cases. This was also done with peers in an IPA support group to provide further feedback on the plausibility of emergent themes. See Appendix 3 for author's reflections on the whole process.

**Results**

Six main over-arching themes were derived and are presented in Table 1. Not all participants

contributed to all sub-themes; however, this is not a requirement of IPA (Smith, 2003). The final

themes were chosen for their prevalence and also the strength of their place within the

participants' accounts.  The over-arching themes and their sub-themes are discussed in more

detail below;

| Over-arching theme | Sub-theme |
|---|---|
| 1) Power and control  (discontinuity) | a. Role reversal/parental role/ taking charge<br>b. Power struggles |
| 2)Motivations to care (discontinuity) | a. Paying her back/Duty/responsibility/obligation<br>b. Appreciating being appreciated |
| 3)  Lenses to view personality and relationship changes (discontinuity) | a. Medical model/us and them<br>b. Personality changes<br>c. Strong then weak/Independent then dependent |
| 4) Negative aspects of the relationship (discontinuity & continuity) | Discontinuity<br><br>a. Frustration/burden<br>b. Shame/guilt/uncomfortable situations<br>c. Loss/grief/thoughts of future<br>Continuity<br><br>a. Unsaid things/unresolved feelings |

| 5) Performativity (discontinuity & continuity) | Discontinuity<br>   a. Avoidance<br>   b. Caring as a job/being professional<br>Continuity.<br>   c. Maintaining personhood/mum's wishes |
|---|---|
| 6) Attachment/quality of relationship (continuity) | a. Ways of responding to mum<br>b. Repeating patterns of care<br>c. Small moments of closeness |

Table 2: Over-arching themes and sub-themes

NB In Table 2, the labels in brackets of discontinuity and continuity refer to the researcher's interpretation of whether each theme appeared to illustrate perceived change or perceived continuity in the daughters' views of their mothers and their relationship with them.

**Theme 1: Power and control (Discontinuity)**

The theme of power and control looks at the significant changes in power dynamics and feelings of responsibility for each other's wellbeing as a result of a daughter becoming a carer for her mother.

*Role reversal/parental role/taking charge*

All five caregivers described feeling as if they had switched places with their mother as they felt they had to take on a parental role while seeing their mother in a childlike role. Some actually used the phrase 'role reversal' to describe how the dynamics had changed. A common way of describing their mothers was 'like a child' and this seemed to be a way of making sense

of their behaviour since developing dementia as well as stemming from their needs being very

basic such as being bathed and fed and dressed.  This description was also used when describing

challenging or new behaviours that mothers displayed such as repeated questioning or socially

inappropriate behaviour. This way of describing their mothers may have been a way of

depersonalising them or detaching from the situation in some way.

Lynn briefly summarised her relationship with her mother since her mother developed

dementia: "Erm I suppose mum sums it up when she says: "When did we swap over places

Lynn?" I suppose that sums it up really." Janet and Beverley described their caring roles and

how they saw their mother as a child.

> "I have all the dealings with social services, with carers, erm medical appointments, all
> the arranging really, all the organising...I go and give her a bath (laughs) and that sort of
> thing...and I sort of fell into the paperwork, finances...I think she could probably do with
> more care but unless you're that way inclined, it's very hard really, as it's like looking
> after a child..."(Janet)

This quote also highlights motivations to provide care and the caring style, which will be

discussed in more detail in the next theme. Beverley stated that: "It's just like having a three-

year-old."

All of the participants talked about times when they had needed to take charge of a

situation. Some described this as being a necessary way to manage situations and something they

'just had to do'. Others described how their mother seemed to be happy with them taking control

and did not  resist in any way. The participants made sense of this by seeing it as part of their

role to parent their mother, thus invoking the concept of role reversal. At the end of Beverley's

second interview, she seemed to summarise the change in power between her and her mother:

> " Erm, it's her healthcare you see, when we're going to the doctors now she just lets me, she is happy for me to discuss with the doctor and yet sometimes when we go out she will say 'why did he say that?' But while we were at the doctors she will let me take over so it seems as though she is happy enough for me to make decisions about her healthcare...so she's sort of relinquishing control of herself...so I suppose in some ways she sees me, in charge of her really...almost a role reversal because when we were children she would decide what we did and if the doctor wasn't available, what to give us, whereas now it's the other way round." (Beverley)

Beverley appears to have made sense of taking charge by focusing on her mother's acceptance of

the role reversal. She also gave a specific example of a role that her mother used to have; this

came up with other participants (for example, bathing their mother who used to bath them). It

was interesting that Beverley used the word 'almost' when talking about the role reversal; this

highlighted that she might not have felt that she had taken on the parental role completely. Lynn

described how she felt she had to take charge quickly, as her mother was drinking heavily since

developing symptoms of dementia and she felt a sense of urgency to look after her wellbeing.

> "I took her to the doctors and she had a blood count and whatever the blood count should be for alcohol should've been sort of 90 and it was 900, 10 times what it should have been....so I thought we've got to try and sort this out but this was when she would still go shopping with me..but you know I try to cut the drinking down, I would go around the house and find bottles hidden in the cupboard, the best one was in the wheelbarrow in the outhouse (laughs)...I suppose the personality I am instead of doing it gently I was like 'Right mum we're doing this, we are doing that'..." (Lynn)

It felt as if Lynn felt a sense of panic when she found out how much her mother had been drinking and immediately took charge of the situation in a parental manner.

*Power struggles*

Power struggles and battles were experienced as some daughters described their mothers as not wanting to let go of some of their power; these battles could also be linked to the caring style used by the daughter as some described trying to tell their mother what to do rather than making decisions in a more collaborative way. Janet talked about having a battle over power and control with her mother.

> "I can tell her what to do and she does generally accept things, sometimes she will say 'no I don't want to, I don't want to go out, I don't want to eat something'...her biggest control is over what she eats and I realise it's sort of, it's the power thing, it's her little bit, clinging onto something that she can actually control...because you can't force someone to eat something..." (Janet)

Janet's experience of her mother trying to regain some control over her life, and her acknowledgment that you cannot force someone to do something, highlights a dilemma that was shared by Beverley, Wendy and Anne. Wendy stated that it was 'always a battle' with her mum and that her mum was 'always being difficult' with regards to making decisions about going out, what to eat and so on. She explained how she manages her mother's resistance to going to a lunch club; by reminding herself of the benefits of the club and how she feels it is important for her mother to get out of the house.

> "…I hate saying, you know, 'I'm taking you to the lunch club,' because she'll just say, 'don't want to go' and she loves it when she gets there and she has a good dinner, you know, and she mixes with people and it's a day out for her, well lunch out. So it's good

for her because she needs to get out of the house. So it's the right approach but it's very difficult to do that." (Wendy)

Lynn, on the other hand, talked about taking control quickly but not facing any power struggles or battles with her mother. She had described her relationship with her mother as non-confrontational throughout her life so this may have impacted on their current way of relating. A contrast to this was found in Anne's story. Anne talked about there being little confrontation in her earlier life with her mother but that there were often power struggles currently.

> "It's quite difficult because she wouldn't change her clothes regularly, but you couldn't actually grab them off her back! So yes a little bit of washing, I mean earlier I would go with her to the shops, help her with the shopping and it would go much easier if I did the shopping for her, which she was a bit resistant to but it did get difficult. She would pick up fresh cakes and I would say put them down (laughs), it wasn't quite like that but I would say 'Mum please don't touch the cakes'..she would say 'Well I've got to see what they feel like', and I would say 'Well it's not very nice for other people' and she couldn't understand.." (Anne)

She described how difficult it could be to reason with her mother even though she tried to explain things to her in a straightforward way. She also talks about her mother's resistance to some of her input which made it easier for her to take over some activities her mother would previously have done. Anne's story gives a sense of managing and/or reducing power battles through careful use of language and trying to manage her own feelings of frustration.

**Theme 2: Motivations to care (Discontinuity)**

This theme includes the different reasons that had motivated the adult-daughters to care for their mother.

*Repaying her/duty/responsibility/obligation*

This topic came up when the participants were asked about how they became a carer and also when asked to consider the links between their earlier and current relationship with their mother. Each of the adult-daughters described how they felt they needed to care for their mother as their mothers had cared for them when they were children. They described how they felt they owed it to their mothers and had to take it on. Some were more comfortable with this than others and this seemed to be linked to whether or not there were past difficulties in the relationship. Janet described a difficult past relationship with her mother and during the second interview reported that she finds caring 'gruelling' and that she 'never fancied doing it'. She went on to state that: "When it's your parent, you feel like its payback time and you just have to do it" as well as:

> "Well you got a choice, there is a choice but you feel, it's not even a duty really, you just feel that, you know, she's sacrificed and done things for me so I feel like I have to do that for her really." (Janet)

Lynn described how without thinking about it, she became the carer as she felt it was the natural thing to do:

> "I just automatically presumed that was it, it wasn't a major decision, I just did it so like when somebody falls over in front of you, you automatically go and help them up, it was just something that you do, that's how I looked at it." (Lynn)

Anne talked about her motivations for caring based on a mixture of feelings: "Well I find it hard work, I mean obviously I do it because she's my mother.."

*Appreciating being appreciated*

Four of the five daughters reported that there were some positives that revolved around their mother showing appreciation for their care which appeared to reinforce their behaviour and kept them motivated to continue:

> "I went and did her shopping yesterday, went to Tescos and came back and she's always pleased to see you there, you could have been five minutes or five years but she's always pleased to see you.." (Lynn)

> "She's always been appreciative of everything you do you know, it sounds daft but manners, please and thank you's and we will go out and she will say 'thank you for a lovely morning Lynn' and I mean I could have taken her to the dentist and had her tooth pulled but she would say 'thank you for taking me out and the lovely morning, I don't think she's realised what she's done but she always says thank you." (Lynn)

Lynn seems to be describing significant reinforcement from her mother's gratitude. It felt important for Lynn to repeat her point that although her mother might not realise what they were doing together or that they could have been doing something unpleasant, she still appreciates what Lynn has done. The use of the dentist analogy is an interesting way of portraying this. Janet also talked about similar experiences: "She's really pleased to see you and makes you feel very welcome and is always grateful for everything you do..she sort of thanks for everything.."

**Theme 3: Lenses to view personality and relationship changes (Discontinuity)**

This theme explores the different lenses or frameworks used to make sense of changes in mothers and subsequent changes in the relationship. Role reversal could also be seen as a lens but it was felt that it warranted a section on its own as it was such a prominent narrative.

*Personality changes-*

Anne described how her mother's confusion and agitation meant that she was 'difficult' to be around at times. This felt like a distinct change from her earlier warmer descriptions of her mother and pointed to a change for the worse in the relationship. On the other hand, some daughters talked about positive changes. Wendy and Janet described how their mothers had each become 'nicer' and showed their emotions more; which they saw as a positive.

> "But my relationship with mum has changed dramatically now because she forgets to be nasty now, so she's very nice to me and I know she loves me to go and see her, um she says things like 'You're the best of the bunch'......it's more pleasant because she's not being nasty of saying horrid things" (Wendy)

> "She has become a much nicer person (laughs), she sort of thanks you for everything, in fact it's a bit over the top really, she's so gushing and nice and friendly, it's quite strange really, she's actually much nicer...she is less guarded, she's able to let her feelings out a lot more...and she seems more happy, pleased with little things..she is much easier to be with." (Janet)

These quotes show how Wendy and Janet appear to appreciate the changes in their mother's presentation and this may point to experiences that they felt they missed out on before the dementia. As sisters, they reported that their mother was 'nasty' and said 'horrid things' in the past and they seem to share the opinion that the dementia has caused a dramatic change in these behaviours as well as improving their relationship. Beverley also talked about how she felt closer to her mother due to her mother displaying her emotions more.

> "I think actually in some ways I do feel a bit closer to her now than I did because of the way she is emotionally, I remember when my father died she didn't discuss that with me at all, she didn't say how upset she was, she wouldn't discuss it, whereas now, in some ways I suppose I do feel a little a bit closer to her because when she's frightened she says she is frightened."(Beverley)

*Medical model/us and them*

All of the adult-daughters seemed to refer to the medical model as a means of making sense of changes in their mum's behaviour and impact on their relationship. Some caregivers referred to medical terms and procedures; Anne was a good example of this.

> "So I say this is a shock change, that, you know an intelligent person and now garbled conversations we hold now...so her brain has atrophied further as far as I can make out, she had a fall and she was in hospital for two days, they did another CT scan, she wouldn't lie still so it wasn't ideal but they did say there was evidence of brain atrophy.." (Anne)

It seemed that Anne felt it was important to understand the biology behind her mother's change in presentation as she witnessed a dramatic movement from an 'intelligent' mother to one that couldn't hold conversations and didn't make any sense. It appeared that she saw her mother as a very different person and that this greatly impacted on the relationship, thus highlighting the concept of discontinuity.

Some of the daughters used the word 'they' when talking about people with dementia and when referring to their mother's behaviour. This was interpreted to be a way of grouping people with dementia together and felt depersonalising at times. It was felt it might have been used to give distance, perhaps as a means of coping with the difficult feelings triggered off by witnessing the change in their mother.

> "She had her jumper or something on back to front you see they, they don't, they all do it apparently, with dementia they dress themselves inappropriately." (Beverley).

> "You know it's only lately that she's gotten really really bad, you know, it's been a...they say they drop down in steps don't they and once they've dropped down they never go back up again" (Wendy)

Wendy also described how she saw her mother's personality changes being wholly due to the dementia.

> " She's always saying she's got a cold and I was saying, you know, 'You haven't got a cold you just feel cold,' because she hasn't got any weight on her, you know you get annoyed with her and it's pointless, it's pointless because it's the illness.....I like to treat her as normal but she's not normal.." (Wendy)

The use of the word 'illness' is interesting as it implies a medical lens with which to view her mother. This quote also highlights Wendy's attempts to treat her mother as 'normal' but then deciding she is not. This links to the concept of discontinuity as Wendy seems to view her mother and their relationship as different.

*Strong then weak/Independent then dependent*

All five participants described how their mothers had been strong, independent women prior to the dementia but they now saw them as weak, frail, vulnerable and dependent on them.

"She's always been so, strong, I think I mentioned that before...that whenever anything, if she had a problem, because she's had, she did very good with her health, she's had hip replacements and different things and erm, she's never been particularly needy, she's always 'oh I'm fine'..."Janet

Janet described her mother as a "tragic figure" who is "pathetically grateful" and "very fragile and thin" since developing dementia. There was an obvious contrast between the before and after dementia descriptions.

**Theme 4: Negative aspects of the relationship (Discontinuity & continuity)**

The subthemes that seem to convey discontinuity will now be described, followed by those

interpreted to convey a sense of continuity.

<u>Discontinuity</u>

*Frustration/burden*

Caregivers described feeling frustrated and at times overwhelmed.  Four of the daughters

gave the sense that they felt burdened with having to care for their mother.

> "I went round yesterday and couldn't get in because the mortise lock was in there and
> there is only one person that could've done that, it was mum so of course I was going
> 'Who left the lock in?' because I'm so angry she's done it and I'm like 'So who the
> bloody hell has put the key in?' And I get silly and stupid and sarcastic and then it's only
> me that gets upset..." (Lynn)

Lynn had not described these kinds of feelings prior to her mother developing dementia and they

appeared to be linked to her mother's confusion and her dependence. When asked how she felt

toward her mother when she is around her, Anne replied:

> "It's not the same relationship...frustrated, erm I don't enjoy it quite honestly...I find it
> difficult making conversation because she doesn't really take in what you're saying she
> just comes up with a comments like 'well we will just have to do what they want us to
> do' I don't know who they are so I just said 'yes we will have to won't we' so it's just
> making replies and not questioning her closely.." (Anne)

The carers appeared to struggle with the loss of ordinary conversation with their mothers and

often linked this to their feelings of frustration.

*Embarrassment/ guilt/ uncomfortable situations*

Feelings of embarrassment were experienced by four of the adult-daughters. This was related to their mothers' behaviour when in public and the daughters' fears about what others might think. Anne talked about an incident which seemed to make her feel uncomfortable:

> "We went to my aunt's funeral and I had to take her to the toilet at the service station on the way and then she needed help pulling her pants and tights up afterwards, thankfully there was a very sympathetic lady there that watched out for me when she realised what was going on..." (Anne)

Janet appeared to feel similar feelings in her story about taking her mother to see her grand-daughter in a concert:

> "I still take her now but she wouldn't realise it was my daughter performing and she can be quite embarrassing because she doesn't realise she has to be quiet so she will try and talk to you, instead of being quiet and watching what's going on...so she will be quite insensitive to anybody around, she will carry on talking or will start singing (laughs) so it can be embarrassing.." (Janet)

*Loss/grief/thoughts of future*

A very frequent experience felt by all caregivers involved feelings of loss of who their mother was, a loss of two-way conversation and thoughts about potential further loss in the future, of both their mother's personality as well as her physical death. When asked about what aspects of their relationship had stayed the same, Beverley talked about the loss of her mother's help and advice:

"None, none, because you see my mother was quite a positive person and if I was thinking of doing something, changing something in the house I would get her to come along and help or ask for her advice..She was used to managing a house and she would let people in as well if I was at work, she was a big help to me, if they had to come round to do anything she would let them all in, there's nothing like that anymore" (Beverley)

Beverley seemed to be making sense of the current situation by seeing her mother as completely different with respect to the amount of help or advice she could provide, which felt like a definite discontinuity in her narrative. The others told similar stories about the loss of reciprocal communication. Anne appeared to experience this loss intensely as she made reference to these feelings on several occasions during the interview: "The change now is I find it difficult communicating with her and tiring and frustrating and something I don't enjoy doing." When describing her prior relationship with her mother, Anne described how she felt she could talk to her mother about almost anything:

" Right erm whereas I said I got married quite young, erm, we had my son three years later, erm I had trouble conceiving a second one and she was very supportive, so yes I did confide in her over that.." (Anne)

The daughters talked about the loss they felt due to the times their mother does not seem to recognise them or realise who they are:

"and I'm thinking she doesn't really know who I am really sometimes, that's really hard."(Janet) The carers also described their fears of future losses:"I suppose deep down, I hope, I know about Alzheimer's where everything closes down, I hope she doesn't go like that, I hope she falls over or has a nasty accident, it sounds awful but you know what I mean, you know it would be horrible if mum goes to that, it would save her from diminishing just to her bodily functions." (Lynn)

The other carers seemed to share this fear and having knowledge about dementia appeared to make this fear more prominent. The adult-daughters compared dementia to physical illnesses or injuries and said that dementia felt tougher due to the potential for complete loss of their mother's personality.

*Continuity*

*Unsaid things/unresolved feelings*

Three of the daughters described negative feelings towards their mother that had been present since before the dementia. The carers described how they had not talked about these feelings with their mothers and gave the sense that they were unresolved and were still being processed. These feelings seemed to impact on the daughters' feelings around caring for their mother and the ways they made sense of the caring role.

> "My sister organised for this calm you down tablet in the morning because she was getting so, you know, agitated and unreasonable and but that's (laughingly) what mum's always been like her whole life so, you know...but it's difficult to deal with.." (Wendy)

When Wendy was asked what things have stayed the same with her mother since the dementia she stated:

> "Cantan-cantankerous ((laughs)), argumentative, she likes to, she's always enjoyed heated discussions so she'll throw something in just to get you going, you know, um , so and she's the same now you know, 'Oh it's all right for you going away on holiday' you know, or you know just silly things that really irritate you, you know, she's still the same" (Wendy)

Although Wendy was referring to her mum's personality and identity, there appeared to be negative feelings attached to her story. She gave the impression that she has found her mother's behaviour to be difficult and irritating both before and after the dementia, but had not discussed these feelings with her mother. The past difficult feelings seemed to impact on her current feelings towards her mother; this was also found with the other two daughters. This highlights that although the daughters viewed significant changes in their mothers' personality, there were some underlying feelings that had not changed.

**Theme 5: Performativity (Discontinuity & Continuity)**

This theme refers to the daughters' ways of performing the role as carer. As with theme 4, the subthemes that appear to convey discontinuity will now be described, followed by those that were interpreted to convey a sense of continuity.

*Avoidance (Discontinuity)*

Caregivers listed the different strategies they used to avoid aspects of the caregiving role as well as feelings associated with these.

> "So now the thought of sitting down with her and making conversation for two hours, erm, you know, I don't relish it I'm afraid I put the television on or glance at the newspaper and try and comment about something I read in the newspaper, I really don't relish doing a one-to-one, talking you know going round and round in circles.." (Anne)

Participants also described emotionally detaching from their mother at times, as a means of getting through the day and managing the uncomfortable feelings towards their mother and the role.

"I mean bathing is one, I know she can't wash herself..I find it really sad..erm, one that she was quite happy to allow me to bathe her and erm, and is more like she's gone back to being a child, so I think it's really sad, I mean a bit unpleasant really, doing that for a parent but I just have to sort of mentally detach...I just sort of think about other things while I'm doing it.." (Janet)

This highlights the uncomfortable feelings attached to the role reversal and seeing their parent in a childlike way and the wish to not think about certain aspects of the role. This was experienced by all the adult-daughters.

*Caring as a job/being professional.(Discontinuity)*

All five daughters described the role of being a carer as being like a professional job. The role was described as involving liaison with professionals and speaking on behalf of their mother.

"… and I knew there was the memory clinic at Bloxwich and Alzheimer's so I took her to the doctors, a very good family doctor that we've had for years and erm I think I might have gone in first on my own to talk about mom and then I had an appointment with mom a day later or whatever...and explain to him, my mom was brilliant she's always been very cooperative and I explained to him I said 'I think there's problems here could we have a referral to the memory clinic?' He said 'Yeah no problems.' Obviously this physical tests, blood tests they do anyway, just to rule out other things which is what we did. Mom got into the system and went to the memory clinic, and I think it was 2003 which was three years after we moved in that she got the Alzheimer's diagnosis so I took her to all the appointments and everything." (Lynn)

In this quote, Lynn describes her mother as being 'cooperative' and she gives a sense of her mother as a service user and Lynn as the professional caregiver. She used the word 'we' when referring to getting her mother's blood tests done, giving the impression that she has a significant role in managing her mother's health. She also highlights that she has some knowledge and awareness of dementia and that she knows what service her mother needs.

It seemed important for the daughters to come across as competent carers. Wendy talked about doing her best as a carer: "You know, you've done your best and that's all you can do isn't it, through..through their life. That's what I'm trying to do." Both Lynn and Anne talked about making sure that paid carers 'did things properly.' Lynn described how she likes the care to be done a certain way and gives the impression that she feels the paid carers aren't doing enough:

> "  Well homecare go in three times a day. I bet they're not in for an hour but it's fine for what we want and I get mum up in the morning and make sure she's washed and dressed because she wouldn't wash and she certainly wouldn't change her clothes, and then they go back in a lunchtime, I sort out the following foods and homecare go back in at lunchtime and give her a meal, and then I'm there every afternoon. Although homecare come in to do her tea I like to get her tea ready and I just leave a note there...and it works really well. I just leave them a note. Things have changed a bit now. Obviously you know I would like mom to have her tea at about five o'clock but they've got another call at five o'clock so sometimes they don't get to mom until six o'clock well if she's had her lunch at 12 o'clock that's a long time. That's why I go in every afternoon, leave her her tea so she can get it if she wants if she wants to eat it at five" (Lynn)

All the daughters talked about their caring role as consisting of many parts which at times felt like a juggling act. The daughters appeared to be making sense of their role by viewing it as one similar to a managerial position in a company as they felt responsible for communicating with all services/professionals and making sure that the system ran smoothly. It could be hypothesised that this way of viewing the role could be a way of distancing themselves from the difficult feelings attached to seeing their mother with dementia.

*Maintaining personhood/mum's wishes (Continuity)*

Three of the caregivers described their intention to maintain their mother's personhood. This involved thinking about what their mother would have wanted before she developed dementia and trying to keep certain aspects of her life the same.

> "I still make sure she has a glass of wine every night, I give her her tablets and then she has a glass of wine. Perhaps it's not very conducive but hey ho she loves her red wine, we go out at lunchtimes she will always have a glass of wine at lunchtime." (Lynn)

This highlights how caregivers sometimes had to make difficult decisions about maintaining their mother's personhood, which brought up ethical dilemmas; these dilemmas tended to be about personhood versus considerations of mum's health or needing to take control for their mother's best interests. Anne talked about trying to preserve her mother's dignity and seemed to make sense of this by considering what her mother would have wanted before she developed dementia:

> "Because she is talking gibberish, sometimes inappropriate behaviour and I feel, we've got a family party coming up and I'm not going to take her because I think my mother of all would have been mortified at possibly behaving in an embarrassing way in front of, it's not just our relatives it's the other side of the family I haven't even met." (Anne)

**Theme 6: Attachment/ Quality of relationship (continuity)**

*Ways of responding to mum*

Three of the carers talked about the ways they had managed to avoid conflict with their mother in the past as well as currently. They described the techniques they had been using throughout their life, which ensured that they did not upset or annoy their mother. The carers

gave a sense of fearing the consequences if they were not successful with their usual strategy.

Wendy talked about her relationship with her mother when she had two young children:

> "I used to go visit her for the day, she used to say 'you've come here and I'm feeding you and that's saving you money...so she had this weird idea, you know really selfish idea and hurtful you know very hurtful but she was my mum and we'd fallen out once so I didn't want to fall out again, so you know, I've always kept my mouth shut, so I just don't argue with her, because the type of person mum has been she would usually say something and I just don't want to fall out with her ever again.." (Wendy)

During the second interview, Wendy talked about her ways of managing her mother's mood and behaviour currently: "I'd never...I'd never get to the stage where we fell out again. So I don't, you know take anything to heart." These carers tended to describe more difficult feelings towards their mother in the past and present and told stories of how past conflict, when younger, had made them fearful of future conflict. They seemed to be boxing off their own feelings at times, to make sure that they didn't fall out with their mother. It could be hypothesised that these three daughters continued to have an avoidant attachment style with their mothers.

Beverley portrayed a sense of sadness and slight resentment towards her mother throughout her life as she seemed to feel like she had missed out on the closeness she had wanted; especially with regards to talking about her emotions. She described how she relied on others for feelings of closeness and containment of her difficult feelings throughout her life.

> "No, even as a teenager I never felt I could discuss a lot, I didn't feel close to my mother no we didn't discuss anything emotional...no, no, no we weren't, no, definitely weren't close, as my sister got older, it was more my sister I shared more with...more emotional things with her and some of my friends.." (Beverley)

She reported similarities in her relationship with her mother since the dementia:

> "She gets frightened and I have to try and find out what frightened her. She doesn't know what is frightening her 'I don't know' she says 'ooh I'm just frightened..so I have to sit and hold her to reassure her..erm, so as for mine, no, no, she just wouldn't understand, it's more her emotions now..." (Beverley)

These quotes imply a level of continuity in the ways Beverley's mother has responded to her emotional needs and how Beverley has in turn, responded to her mother.

Lynn talked about her mother using warm and positive language with regards to before and after the dementia. She seemed to be portraying unconditional support and positive regard of her mother and this seemed to link to her positive story of what her mother was like when Lynn was a child.

> "erm just the loving mum, I always felt loved, I could remember feeling I could do anything, I could have killed someone and mum would always be there for me, no matter what, mum would always be there...I never thought about that years ago but things have gone on, things have happened over the years....she's always been there, almost always been there....I just felt so secure..." (Lynn)

During the second interview Lynn continued with the positive story of her mother when asked to describe her:

> "Lovely lady because she would still do anything to help you now she would, you know just a lovely lady...I don't know, everybody thinks she's lovely, everybody thinks she's a good laugh and she likes a glass of wine but she's always pleasant, always pleasant..." (Lynn)

It felt important for Lynn to continue to view her mother in such a positive light and she displayed genuine feelings of warmth and fondness of her mother when talking about her in the past and present.

*Repeating patterns of care*

Interestingly, caregivers described patterns of caring for their mother that seemed to emulate the style of parenting they had experienced as a child. These patterns or ways of parenting their parents (i.e. role reversal) picked up on the concept of containment (helping their mother to understand and manage their feelings). Lynn and Anne both described positive and containing relationships (interpreted as secure attachments) with their mothers before the dementia and described how their role as a carer sometimes involved helping their mother to contain their feelings:

> "I was very close to my mother, she was a very good mother, she was a very warm, kind person, I have the greatest of respect for her...a doting mother, a kind mother, always took an interest in whatever you were doing, and supported us in whatever we were doing...loving kind, understanding, empathetic..."(Anne)

When asked if she remembered what her mum was like when she was upset, Anne replied:

"Very comforting." During the second interview she talked about her mother's emotions:

> "Obviously I was available if she was worried about something. One night she rang me up because she was worried about the levels of carbon monoxide, her carbon monoxide alarm was beeping away luckily it was just the battery running out.." (Anne)

Here, Anne seemed to be providing the comfort her mother provided for her when she was young.

Beverley, Wendy and Janet described how their mothers had not always been emotionally available to them and had not been able to help them contain their feelings when younger. These carers did not describe containing their mother's feelings and tended to focus

their caring on more practical care, using a more avoidant attachment style, similar to the care

they had received as a child.

> "Like to think back on how close I was to my mum I think she was a really good mum but I don't know if I felt, like I do with my daughter where we cuddle a lot and kiss a lot and tell each other we love each other a lot but I don't think I've ever been like that with my mum or mum has ever been like that with me. She was...she cared but it wasn't a very, um, outwardly emotional relationship...she was just a good housewife, and a good mother in all be making sure you've got clean clothes, the you've got meals on the table that sort of thing.."

> "erm I've taken over all the paperwork so all her finances, erm paying bills, appointments you know all her day-to-day things really......and I'm saying you must eat this, you must eat that, you must do this..you know wash her hair, let me do this for you" (Janet)

During her second interview Janet summed up her relationship with her mother:

> "I don't think I'm closer mentally with her at all, really, I've never been, when I see some people with their mothers I think 'oh they've got a really strong bond, I don't think I've ever felt that...I'm tied to her because she's my mother but wouldn't spend time with her if she wasn't, probably not really, I wouldn't choose to be with her if she wasn't my mother so, I don't think the bonds got any stronger.." (Janet.)

These examples highlight a sense of sadness felt by the daughters who felt that there was not a

strong emotional attachment to their mother throughout their life. Some referred to cultural

factors when explaining that their mother focused on the practical side of care when they were

younger.

*Small moments of closeness*

All of the participants talked about times (albeit rare for some) when they experienced

positive feelings towards their mother both before and after the dementia. These were interpreted

as small but significant moments of closeness. Beverly talked about small moments of physical touch and affection:

> "I was probably about 12, she used to take me, her and aunty used to go to the pictures a couple of times a week....but yeah I used to enjoy it, because even then 12, she always used to hold my hand, I remember her holding my hand and she used to erm somehow she used to stroke my wrist as a sort of comforting thing" (Beverley)

This seemed to be a highly significant memory for Beverley as she described her mother as not being very tactile or showing affection when she was younger. The other carers talked about similar moments when they felt particularly close to their mother; the situations usually involved their mother showing that she cared for them in some way. Beverley talked of small moments of closeness after her mother was diagnosed with dementia and how these changed due to her mother losing some of her sight due to macular degeneration:

> "If I had her out with me or if I bought something new, I would say 'what do you think, how do you think it looks?' and she would give an opinion but not anymore you see, I still say if I buy something, I will say 'do you like my jumper?' and she will get up close and will be like 'oh yes that's nice' but she can't see the colour, she can't see any detail or anything..." (Beverley)

The caregivers gave a sense of there still being some kind of bond present with their mothers, despite physical and mental difficulties. Even when the relationships felt strained and distant, there were rare moments which highlighted a very human need for making this kind of connection and showing care, as if the daughters are still looking for maternal warmth.

*Connections between themes*

A thematic presentation of the data can sometimes obscure an understanding of how the themes are linked, particularly when, as in the present case, the links are idiosyncratic and particular to individual participants. To remedy this, thematic connections for individual participants are presented in this section.

Generally, Lynn seemed to display a sense of continuity with regards to her feelings towards her mother and who her mother was as a person. Lynn described a positive early relationship with her mother and this seemed to link with her motivations to care for her, which were generally based on feelings of love and wanting to pay her mum back. The positive early relationships also seemed to link to Lynn's ability to empathise with her mother and experience few negative feelings towards her mother or the role. The early relationship appeared to be impacting positively on Lynn's motivations to maintain her mother's sense of personhood. Lynn did describe taking on a parental role and having to take charge of her mother (i.e. role reversal, Seltzer,1990) which she considered as a change in the relationship, however, she didn't experience power battles as the other carers did. It could be hypothesised that her caring style was replicating her mother's parenting style and that this positive way of caring meant that the change in power dynamics wasn't a strong negative experience for Lynn or her mother.

In contrast to Lynn, Anne appeared to experience more of a dramatic change from being in a nurturing close relationship to one where she saw her mum and the relationship very differently. Interestingly, when caring for her mother, Anne was able to contain her mother's

feelings as her mother had hers prior to the dementia. However, she talked more about using avoidance to cope with the changes and/or role of caring. She seemed to view her mother as a different person and used lenses such as the medical model and personality changes to view her mother; she also experienced a lot of negative feelings such as embarrassment and frustration. It could be that Anne was defending against the pain and loss associated with her mother's deterioration by distancing herself from her and the relationship. It felt as though she had got to a point where she couldn't bear the sense of loss and so coped by emotionally pulling away from the relationship.

Janet, Wendy and Beverley all described generally more difficult early relationships with their mothers. They all talked about a consistent sense of missing something they had never had, with regards to emotional closeness with their mother; this gave a sense of continuity. These women seemed to be describing insecure (avoidant) attachments with their mothers and this linked to the caring style they used which tended to focus more on practical rather than emotional caring. The avoidant attachment style is hypothesised, in the present study, to link to the use, by these three daughters, of strategies to emotionally distance themselves from their mothers, such as using 'us and them' language.

The concept of role reversal in these particular relationships appeared more negative as it was linked to viewing their mother's behaviour as childlike and taking charge very firmly. Wendy, Janet and Beverley experienced negative feelings associated with caring such as frustration and resentment of the role and this may be linked to their unresolved difficult feelings

from the past. The daughters' attachment style with their mother, their ways of making sense of relationship changes and their subsequent caring styles could be interpreted as evidence that they were struggling to reach the stage of filial maturity due to unprocessed/unresolved feelings (Blenkner, 1965; Stiens, Maeck & Stoppe, 2006; Sherrell & Newton, 1996; Sherrell et al., 2001). These carers also talked about a sense of duty or obligation to care for their mother, which gave the impression that they had no choice about becoming and remaining a carer; this may be linked to the difficult early relationship and struggling with motivation to provide care for their mothers.

Janet, Wendy and Beverley also referred to a sense of discontinuity with regards to their mothers displaying more positive behaviour towards them (such as physical affection) since developing dementia and they felt this was a good outcome. It was felt that the daughters appreciated that their mothers' defences seemed to be reduced and that there was increased physical contact. These experiences seemed to reassure the daughters, albeit very late in their mother's life, that they were loved by their mothers.

**Discussion**

The aims of this study were to investigate how adult-daughters make sense of any changes that occurred in their relationship over time, with a mother with dementia and to explore what their accounts conveyed about attachment, continuity, discontinuity and personhood. For all carers, the prior relationship affected the current and this impacted on the carers' ways of making sense of their experiences of being a carer and their caring style. More difficult early relationships which could be viewed as avoidant attachment styles, tended to link with more negative feelings towards their mother and caring role and repeating patterns or care with regards to focusing more on practical rather than emotional care. For these carers, their mother showed more warmth and affection and these changes were attributed to some of the effects of dementia. However, for those with more positive early relationships and a secure attachment, the current responses to their mother and the caring role differed significantly. These findings highlight the complexity and potential unpredictable nature of the life-long mother-daughter relationship, especially when a daughter takes on the caring role.

The experiences of the participants in this study are consistent with some findings from previous research. Spouse carer research has led to the suggestion that continuity is associated with the carer deriving more positive meaning and gratification from the caring role (Chesla et al., 1994) as seems to be the case here for Lynn. Wendy, Janet and Beverley all showed how an insecure (avoidant) attachment can sometimes lead to more difficult feelings around the caring role as well as repeating attachment patterns as an adult carer. This has also been found in the

studies of Ward-Griffin (2007) and Whitback, Hoyt and Huck (1994). Carpenter (2001) found that a secure attachment can be associated with lower levels of burden; this link appears to be relevant for all participants apart from Ann. Ann's experiences appear to highlight that a positive prior relationship does not necessarily mean that a carer is at less risk of burden when caring for their mother. Lynn and Ann highlight how secure attachments are not always associated with similar outcomes in terms of the emotional reaction to the caring role. Ann's experience is consistent with research from non-dementia care that has found that stronger prior relationships were linked with greater distress (Hunt & Smith, 2004). Other dementia research has also found that a sense of discontinuity is linked to negative emotions associated with the caring role (Walters et al., 2010). This way of coping through distancing has been found in spouse-carer dementia research (Chesla et al., 1994; Lewis, 1998; Walters et al., 2010) where it has also been hypothesised that it has a protective function. Wendy, Janet and Beverley all seemed to make sense of their mothers' changes in behaviour (being more positive and warm towards them) as being due to dementia. This links to Kitwood's (1997) ideas of people with dementia experiencing reduced inhibitions which leads to opportunity for growth. However, they also seemed to experience negative feelings attached to taking on a parental role and this links to hypotheses about role reversal being harmful (Brody, 1990; Selzter, 1990). This way of behaving may unconsciously be associated with feelings of resentment about how they were parented. These concepts have been found elsewhere in the literature (Harris 1998; Perry, 2004).

There are some other factors which are likely to have affected the daughters' ways of making sense of their experiences which need to be considered. The mothers' stages of dementia

and their current level of functioning varied. Different health problems were also present; for example, one mother had macular degeneration which meant that her sight had deteriorated a significant amount. Carers whose mothers had more severe symptoms and/or physical health difficulties may have been more likely to view their mother and the relationship as more different than those with less severe difficulties. Another factor to bear in mind is the cultural differences between the participants. Some needed to work part-time, with some working more days than others and two of the participants no longer worked as they had financial support from a partner or an ex-partner. The work-life balance was not the same for all participants which might have had an effect on levels of stress, negative feelings, ways of coping, intensity of current relationship etc. This could be different for sons caring for a parent with dementia due to different gender norms and expectations around males working and financially supporting a household. Another cultural factor is that all of the mothers grew up during world war two which is likely to have impacted on the mothers' cultural norms with regards to parenting (e.g. showing affection). If this study was repeated in the future, the experiences of carers may be very different due to these types of cultural differences.

*Clinical Implications*

The results from this discussion point to a potential need to focus on the relationship between an adult-daughter and her mother with dementia and more specifically the attachment style. Daughters could be interviewed using attachment focused questions or using attachment assessment tools such as the Adult Attachment Interview (AAI; George, Kaplan, &

Main, 1985) as a means of opening up discussions about the early relationship and how this might link to the current. This form of therapy could be used to help adult-child carers explore their prior relationship with their mother and how this may have led to any negative feelings around care. Cognitive analytic therapy (Ryle, 1990) could be used to explore and name potential repeating patterns within the relationship which may be impacting on the daughters' caring style and the mothers' experiences of being cared for. Another potential intervention could be one-to-one psychodynamic therapy for the adult-daughter. The daughters in the study described the links between their past and current relationship with their mother and at times experienced distress and/or negative feelings towards their role and their mother as a result. One-to-one psychodynamic therapy might help adult-daughters to work through difficult (unconscious) feelings from the past (Rautman, 1962, cited in Jarvik, 1990), thus enabling them to make sense of their history with their mother so that they feel fewer difficult feelings and are able to reach filial maturity; this may reduce the chance of distress in them and their mother as well as having a positive impact on the daughter's caring style.

Family interventions with families caring for a person with dementia, which could also include the person with dementia, could explore the different family members' responses to dementia as well as ways of communicating difficult feelings to each other. The theme entitled 'negative aspects of the relationship' could be a point of focus for these family intervention sessions as the therapist could attempt to help facilitate constructive communication and explore more collaborative and adaptive ways of being together

*Limitations*

There are some limitations to this study. There were only 5 participants, although, each participant was interviewed on two occasions, meaning that there was a large amount of in-depth data about the relationship before and after dementia. Two of the participants were sisters which may have reduced the diversity of the accounts, however, the sisters talked about the large age gap between them, and were of course in different positions in the family so actually had unique experiences. All the participants were white females which limited the diversity of the sample. All participants attended support groups organised by the Alzheimer's society and so may be particularly motivated to seek support, whereas other carers may take a more self-sufficient position or may be more isolated, and their experiences have been missed out from the study.

*Future research*

Future research may benefit from further qualitative studies focused on particular areas of the mother-daughter relationship in dementia caregiving, such as unresolved conflicts or attachment. Use of grounded theory might allow a more detailed formulation of the links between the different aspects of the relationship and the current experiences of the carer. Other research could look at the mother's experiences of the past and present relationship; building on this study, as well as those by Ward-Griffin (2007) and Forbat (2003). There has been limited research focusing specifically on adult sons caring for a parent with dementia and this may also be a fruitful area for future research. Furthermore, the concepts of continuity and discontinuity

and personhood, could also be explored in a variety of caregiving populations, (such as carers of those with psychosis).

*Conclusion*

In summary, the type of attachment a daughter forms with her mother as a child is likely to impact on their life-long relationship. The attachment style may become activated if the adult-daughter takes on the role of carer, especially if the mother develops dementia, as the daughters' secure base may be threatened, provoking feelings of insecurity. There is a risk of unresolved feelings or conflicts from the past impacting on the adult-daughters' style of caring and the role may be experienced more negatively. For those that have a more secure attachment, the trajectory is less clear and may potentially involve strong motivations to be a good carer as well as attempts to maintain continuity of their mothers' personhood, or the changes in their mother and the relationship could be experienced as too much to bear and so could result in the carer viewing higher levels of discontinuity and emotionally withdrawing. This highly complex relationship still warrants much more investigation as this paper has highlighted that more linear ideas about relationships and outcomes, may be not be telling the full story.

## References

Albert, S. M. (1990). Caregiving as a cultural system: Conceptions of filial obligation and

parental dependency in urban America. *American Anthropologist,* 92, 319-331.

Blenkner, M. (1965). Social work and family relationships in later life with some thoughts on

filial maturity. In E Shanas & G. Streib (Eds.), *Social structure and the family:*

*Generational relations.* Englewood Cliffs, MJ: Prentice-Hall.

Bowlby, J. (1969). Attachment and loss: Volume 1. *Attachment*. New York: Basic books.

Bowlby, J. (1988). *A secure base*. London: Routledge.

Brody, E.M (1981). "Women in the middle" and family help to older people. *The*

*Gerontologist*, 5, 471- 479.

Brody, E. M. (1990). Role reversal: An inaccurate and destructive concept. *Journal of*

*Gerontological Social Work*, 15 (1/2), 15-22.

Brody, E. M. (1991). *Women in the middle: Their parent-care years*. New York: Springer

Publishing Co.

Carpenter, B. (2001). Attachment bonds between adult daughters and their older mothers:

Associations with contemporary caregiving. *The Journals of Gerontology: Psychological*

*Sciences*, 56B(5), 257-266

Chesla, C., Martinson, I. & Muwaswes, M.  (1994). Continuities and Discontinuities in Family

Members' Relationships with Alzheimer's patients. *Family Relations*, 43, 3-9

Cicirelli, V. G. (1993). Attachment and obligation as daughters' motives for caregiving

behaviour and subsequent effect on subjective burden. *Psychology and Aging*, 8 (2), 144-

155.

Conde-Sala, J. L., Garre-Olmo, J., Turro-Garriga, O., Vilata-Franch, J., & Lopez-Pousa, S.

(2010a). Quality of Life of Patients with Alzheimer's Disease: Differential perceptions

between Spouse and Adult Child Caregivers. *Dementia and Geriatric Cognitive*

*Disorders*, 29, 97-108.

Donorfio, L.K.M., & Kellett, K. (2006). Filial Responsibility and Transitions Involved: A

qualitative Exploration of Caregiving Daughters and Frail Mothers. *Journal of Adult*

*Development*, 13, 158-167.

Dementia, 2010. *The prevalence, economic cost and research funding of dementia compared*

*with other major diseases*. A report produced by the Health Economics Research Centre,

University of Oxford for the Alzheimer's Research Trust. http://www.dementia2010.org/

Center, New York: Guilford Press.

Fingerman, K.L. (1996) Sources of Tensions in the Aging Mother and Adult Daughter

Relationship.  *Psychology and Ageing*, 11(4), 591-606

Forbat, L. (2003). Relationship difficulties in dementia care. A discursive analysis of two
women's accounts. *Dementia*, 2(1), 67 – 84.

George, C., Kaplan, N., & Main, M. (1985). *Adult Attachment Interview*. Unpublished
manuscript, University of California, Berkeley.

Haley, W. E., Roth, D. L., Coleton, M. I. (1996). Appraisal, coping, and social support as
mediators of well-being in black and white family caregivers of patients with Alzheimer's
disease. *Journal of Consulting and Clinical Psychology*, 64, 21–129

Harris, P. B. (1998). Listening to Caregiving Sons: Misunderstood Realities. *The Gerontologist*,
38 (3), 342-352.

Jarvik, L. F. (1990). Role reversal: Implications for therapeutic intervention. Journal of
*Gerontological Social Work*, 15 (1/2), 23-34.

Jordan, J. (1991). Empathy and self boundaries. In J. Jordan, A Kaplan, J. Miller, 1.
Stivers & J. Surrey (Eds.) *Women's growth in connection: Writings from the Stone
Center*. New York: Guildford Press

Kitwood,T. (1997) *Dementia Reconsidered The Person Comes First*. Buckingham: OU Press

Lewis, R.D.H. (1998). The impact of the marital relationship on the experience of
caring for an elderly spouse with dementia. *Ageing and Society*, 18(2), 209- 231.

McCarty, E. F. (1996). Caring for a parent with Alzheimer's disease: process of daughter caregiver stress. *Journal of Advanced Nursing*, 23, 792-803

National Institute for Health and Clinical Excellence (NICE), 2011. *Dementia. Supporting people with dementia and their carers in health and social care.* http://www.nice.org.uk/CG42

Ory, M.G., Hoffman, R.R., 3rd, Yee, J. L., Tennstedt, S., & Schulz, R.(1999).Prevalence and impact of caregiving: A detailed comparison between dementia and non-dementia caregivers. *The Gerontologist*,39, 177-185

Perry, J. (2004). Daughters Giving Care to Mothers Who Have Dementia: Mastering the 3 R's of (Re) Calling, (Re) Learning, and (Re) Adjusting. *Journal of Family Nursing*, 10 (1), 50-69.

Ryle, A (1990) *Cognitive Analytic Therapy: Active Participation in Change*. Chichester: John Wiley & Sons.

Saunders, S., & McFarland, P. (2002). Perceptions of Caregiving Role by Son's Caring for a parent with Alzheimer's Disease: A Qualitative Study. *Journal of Gerontological Social Work*, 37 (2), 61-76.

Schultz, R., & Martire, L. M. (2004). Family Caregiving of Persons With Dementia Prevalence, Health Effects, and Support Strategies. *American Journal of Geriatric Psychiatry*, 12 (3), 240-249.

Schulz, R., O'Brien, A.T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of Alzheimer's disease caregiving: prevalence, correlates, and causes. *The Gerontologist*, 35, 771–791.

Seltzer, M. M. (1990). Role reversal: You don't go home again. *Journal of Gerontological Social Work*, 15 (1/2), 5-14.

Sherrell, K. & Newton, N. (1996). Parent care as a developmental task. Families in Society: *The Journal of Contemporary Human Sciences*, 174-181.

Sherrell, K., Buckwalter, K.C., & Morhardt, D. (2001). Negotiating Family Relationships: Dementia Care as a Midlife Developmental Task. Families in Society: *The Journal of Contemporary Human Services*, 82 (4), 383-392.

Smith, J. A. (2003). *Qualitative Psychology: A Practical guide to research methods.* London: Sage.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage.

Stiens, G., Maeck, L., & Stoppe, G. (2006). Filial maturity as a predictor for the burden of demented parents' caregivers. *Gerontology and Geriatrics,* 39, 120-125

Wallhagen, M. I., & Yamamoto-Mitani, N. (2006). The Meaning of Family Caregiving in Japan and the United States: *A Qualitative Comparative Study. Journal of Transcultural Nursing*, 17 (1), 65-73

Walters, A, H., Oyebode, J., & Riley, G. (2010) The Dynamics of Continuity and Discontinuity for Women Caring for a Spouse with Dementia. *Dementia*, 9 (2), 169-189

Ward-Griffin, C. Oudshorn, A. M., Clark, K. & Bol, N. (2007) Mother-Adult Daughter Relationships within Dementia Care. A Critical Analysis. *Journal of Family Nursing*, 13 (1), 13-32.

Whitbeck. L., Hoyt, & Huck, S. (1994). Early family relationships, intergenerational solidarity, and support provided to parents by their adult children. *Journal of Gerontology: Social Sciences*, 49 (2), S85-S94

Yamamoto, N., & Wallhagen, M.I. (1997). The Continuation of Family Caregiving in Japan. *Journal of Health and Social Behaviour*, 38 (2), 164-176.

**Public domain briefing paper**

**THE LIVED EXPERIENCE OF ADULT-CHILDREN WHO CARE FOR A PARENT WITH DEMENTIA**

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This document provides an overview of the research conducted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology programme at the University of Birmingham. This document summarises the literature review and a research paper both written in preparation for submission to peer-reviewed journals.

**Literature review: A meta-ethnography of the qualitative literature on the lived experience of adult-children who care for a parent with dementia?**

*Background*

Evidence suggests that caregiving between adult-children and their parents with dementia is becoming increasingly common and will continue to increase in the future (Ward-Griffin, Oudshoorn, Clark, & Bol, 2007).   Understanding the relationship between adult-children and their parents with dementia, and understanding the psychological responses of adult-children to the caring role, are important research goals.  The majority of research on adult-children caring for a parent has been quantitative, with some studies comparing adult-children and spouse carer outcomes. These studies have found that adult-childrens' experiences are different to spouses', highlighting that more research needs to be done so that the complexities faced by adult children

are better understood. A small number of qualitative studies have begun to explore adult childrens' experiences in more depth. Therefore a meta-ethnography was conducted to break down, interpret and the pull together these interpretations to produce new themes. These themes aimed to summarise findings from a broad range of studies.

*Conclusions*

The review produced five over-arching themes which summarised the researcher's interpretation of the main experiences, these were: Motivations/incentives to care, the role of the carer, common emotions/reactions, ways of coping, and systems/services. Table 1 shows the further break-down of the themes.

| Over-arching theme | Sub-themes |
|---|---|
| Motivations/incentives to care | • Filial obligation/Repaying<br>• Attachment/prior relationship<br>• Expectations about becoming a carer |
| The role of the carer | • Role reversal<br>• Identity as a caregiver/expectations of the role<br>• Siblings |
| Common emotions/reactions | • Thought and feelings about continuity of personhood<br>• Negative feelings about the parent (Guilt, anger/resentment, shame/embarrassment)<br>• Loss and sadness<br>• Stress and burden<br>• Rewards of caring |
| Ways of coping | • Acceptance vs. avoidance |

| Services/Systems | • Utilisation/access<br>• Relationships with Care Homes/staff |
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Table 1: Table of over-arching themes

The review highlighted how important it is to understand the nature of the relationship between the adult-child carer and the person with dementia. The concepts of role-reversal and re-paying a parent for caring for them as a child/young-adult stood out as a distinctly different experiences compared to spouse carers. Some studies found that the past relationship with the parent with dementia impacted on the current relationship and was used to explain motives for providing care. The variety of psychological responses to the caring role highlights that there does not seem to be a clear pattern to the way of responding to the role over time and models of grief such as Kubler-Ross' (1969) grief cycle do not necessarily fit this population. A further key finding was the use of avoidance and acceptance as coping strategies and some of the rewards of caring. The themes identified in the review shared some similarities with themes produced in family dementia carer research as well as the broader carer literature.

**Research paper: Adult-daughters who care for a mother with dementia: How do they make sense of relationship changes?**

*Background*

It has been proposed that daughters may be particularly vulnerable to feelings of burden when care giving, due to the unique and potentially intense nature of their prior relationship with

their mothers (Jordan, 1991). Different theories have been used to attempt to explain adult-children's experiences of caring for an elderly parent. These theories propose that the early relationship with a parent has an impact on the current and this will affect the caring style of the adult-child. Some research has looked into adult-daughters caring for a parent with dementia and has found some evidence to support the idea of the links between the past and present relationship. Other dementia family carer research has led to the concepts of 'continuity' and 'discontinuity' which refer to the carer's perception of change in the person with dementia and/or change in their relationship. This study hoped to explore how adult-daughters made sense of changes in their relationship since the onset of dementia, using one-to-one interviews with carers, with the secondary aim of understanding the relationship from childhood right up until present day.

*Design*

Interpretative phenomenological analysis (IPA:Smith, 2003) which is a qualitative approach, was used to explore how adult daughter caregivers made sense of relationship changes with their mother from before to after the onset of dementia. IPA aims to understand individuals' experiences and enables individuals to express their experiences through their own words.

*Participants*

A total of 5 adult-daughters who had been providing care for their mother with dementia took part in the research. This sample size was viewed as appropriate for this type of project due to the detailed analysis to be undertaken on the transcripts of each interview.

*Procedure*

Caregivers were contacted through two local third sector support groups. The managers of each local Alzheimer's Society support group were asked if the main researcher could talk about the study at carer meetings and a recruitment poster was also put up at the groups' meeting place. Those who were interested in taking part in the study were given a participant information sheet to read before they agreed to take part. Those who still wanted to take part contacted the main researcher to ask further questions about the study and so that the researcher could double check that they met the inclusion criteria of the study. A time and a place were then arranged for the two interviews. Each participant was interviewed on two occasions. The first interview focused on the daughter's perception of their relationship with their mother before the onset of dementia, the second on the relationship since the onset.

*Analysis*

The recorded interviews were anonymised and then verbatim were transcribed. The researcher read and re-read each transcript while making notes of things of interest in the accounts as well as noting emerging themes. A list of themes was produced for each participant

and for each of the two interviews. Similarities and differences between the themes in each

interview were noted and then themes of continuity and discontinuity were put together for each

participant. All participants themes were then explored together and a final list of themes which

covered the broad range of experiences of the participants was compiled.

*Findings*

There were 6 over-arching themes which emerged from the data. The concepts of

continuity and discontinuity refer to participants' sense of change in their mother and the

relationship.

1. Power and control (discontinuity): Carers talked about significant changes in power

   dynamics and taking on a more parental role

2. Motivations to care (discontinuity): Motivations included paying their mother back for

   caring for them as a child and appreciating that their mother was grateful for the help.

3. Lenses to view personality and relationship changes (discontinuity) : Participants used

   certain lens which included 'personality changes', 'the medical model' and 'strong then

   weak/independent then dependent'.

4. Negative aspects of the relationship (discontinuity & continuity): Caregivers described

   negative aspects which had developed since the dementia (frustration/burden,

   shame/guilt/uncomfortable situations, loss/grief/thoughts of future). Carers also described

   negative aspects that had remained from before the dementia (unresolved feelings).

5. Performativity: (discontinuity & continuity) Participants talked about the different ways they managed to perform the role of carer, this included avoidance, maintaining personhood/mum's wishes and caring as a job/being professional

6. Attachment/quality of relationship (continuity): Carers described some of the aspects of the early relationship that were similar to the current relationship.

*Conclusions*

The study highlighted how the daughters' early relationship with their mother impacted on the current relationship and more specifically on the daughters' experiences of the caring role. There were interconnections between the themes for each participant; these were linked to attachment and the continuity-discontinuity dimension. Some of the findings were found to link to other carer-dementia and non-dementia research. The study provided a new insight into the complex relationship between an adult-daughter carer and her mother with dementia and shows that previous quantitative research which has found linear relationships between relationship and carer outcomes might not be telling the full story. Clinical implications include offering adult-children one to one therapeutic support which could focus on the past as well as the current relationship.

# References

Jordan, J. (1991). Empathy and self boundaries. In J. Jordan, A Kaplan, J. Miller, 1.

Stivers & J. Surrey (Eds.) Women's growth in connection: Writings from the Stone

Center, New York: Guilford Press.

Kubler-Ross, E. (1969). On Death and Dying. New York: Macmillan.

Smith, J. A. (2003). *Qualitative Psychology: A Practical guide to research methods*. London:

Sage.

Ward-Griffin, C. Oudshorn, A. M., Clark, K. & Bol, N. (2007) Mother-Adult Daughter

Relationships within Dementia Care. A Critical Analysis. Journal of Family Nursing, 13

(1), 13-32.

Appendix 1: Notes for contributors

(Not available in electronic copy)

Appendix 2: Literature Review-Table A1-Expansions and interpretation of themes-

| Saunders and McFarland (2002) Perceptions of Caregiving Role by Son's Caring for a Parent with Alzheimer's Disease | | | |
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| **Main Themes** | **Sample Quote(s)** | **Authors' Notes on the theme** | **Reviewers' commentary & Interpretation** |
| Initial reaction to memory loss | "We go through life thinking that our parents are invincible. We may not always agree or understand their points of view, but we listen to them because they are our parents. So, when you have a parent with memory loss and she says she is fine, you tend to believe her. Not because you truly believe she is fine, but because she is your mother and you do not challenge what she has to say." | Not always aware parents experiencing a problem until a major event occurred (wandering, being informed by others). Initially blaming memory loss on other psychosocial issues. Response to memory loss and diagnosis: relief, sadness, fear, frustration, anxiety, loss and ambivalence (most common=shock) Sense of responsibility. | Expectations about parents aging. 'Normal' forgetfulness Urgency to do something. Didn't see it coming. Reaction to diagnosis-relief to have an answer. Mixture of emotions experienced. |
| Becoming caregivers | "I had always thought my sister would be the caregiver for my mom or dad. But, my sister and her family moved out of the state and suddenly when my dad dies, there was no one who could care for mom. So, I became her caregiver....certainly not planning on that." "She cared for me when I was sick. I owed this to her" | How the sons became primary caregiver. None of the sons considered becoming the primary caregiver for a parent with Alzheimer's Disease. Assumed other siblings or other parent would assume this role. Sense of commitment to the parent, sense of duty, obligation. | Concept of IOU. Stigma not caring for parent and putting them in a care home-guilt. Waiting for someone else to take on the role but being left to do it. Gender expectations/roles |
| Women in Sons' world | "My wife didn't want to step in and say this is what mom needs or what has to be done with mom. She said something had to be done as far as not living by herself. So, I went and visited facilities trying to determine what was out | Majority of sons indicated that they did not receive caregiving support from female relatives. 13 of sons had women in their lives that provided emotional support but | Clear expectations for caregiving role, women offering emotional support but less hands-on caregiving. |

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| | there."<br>"I don't think my sister-in-law or my wife ever had to actually take time off work to do a doctor's appointment, but they have done things with her when they had a day off." | set clear boundaries about amount of "hands-on" caregiving they would perform. | Being there for the men if necessary. |
| Learning new roles | "My wife refused to provide any care for my mother. Therefore, I bathed her, changed her, toileted her and got her ready for day care every day. I did this all before I went to work. Some people may think that I am crazy for doing this, but what is the difference...she did it for me." | Very willing to discuss this area and went into great detail about new responsibilities.<br>Attitude of: 'do what you have to do to provide care for mom or dad'.<br>New roles such as personal care-didn't expect it.<br>Strengthening interpersonal skills.<br>More work around the house | Duty, responsibility, filial obligation.<br>Positives of being a caregiver, pride.<br>Just getting on with it.<br>Stigma of being thought crazy? |
| Conflicts | "Well, if she needs a doctor's appointment, first you check the schedule. If you can't do it, you'd have to call and see if Tim could do it. If Tim couldn't do it, you'd have to call Tom. Regardless of the system that we thought we had in place, we still got angry with each other because one of us always thought we were doing more than others."<br>"Well from a professional standpoint, it was very difficult to balance all of my responsibilities with her and then of course, all of the unwritten professional development expectations, and still give attention to my mom." | Two main areas: Interpersonal and professional.<br>Interpersonal-sharing the role of primary caregiver with siblings or trying to balance time between caring and meeting needs of their own family.<br>Professional conflict-jeopardizing employment and future professional growth.<br>Balancing responsibilities, feeling they were doing nothing well | Juggling time between caring, family and work. Impact on relationships.<br>Impact on job and future career.<br>Expectations of those at work?<br>Conflicts in families, it not feeling fair. |
| Uncomfortable situations | "Within the first several months I think she knew me, and then I became her husband. It | Emotional and psychological struggles. | Sexual advances specific to son-mother |

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| | became very uncomfortable when she would be making sexual advances towards me. How does one respond to that?" | Embarrassed by personality changes (rudeness of loud outbursts). Struggled with role reversal and sexual advances by mothers. | relationship. Role reversal. Personality changes and embarrassment in front of others. |
| Service utilisation | "I joined and Alzheimer's support group to try to find out how to deal with the disease and it turned out that the entire support group was women. I don't think it was overly helpful to me. In this group there was no agenda. Everyone just sat around and shared feelings. I left with nothing." "We called a crisis line because mom was wandering around a bad section of town trying to find her husband who had been dead for 50 years. The crisis workers did not know what to do and the police just told us to get her under control." | Would not have been able to provide care for their parent if it had not been for the utilisation of a variety of community services. Services utilised include: adult day care, in home aides, respite, office of aging, support groups, Alzheimer's association and long-term care. Many felt services did not meet their needs-groups predominantly female. Service providers not knowing how to handle crises. Wished they could have learned about services before their parent needed assistance. | Male experiences of support groups-gender bias. Usefulness of support but support not meeting all their needs. Need for information. Need for staff to have greater knowledge of dementia and its management. |

Perry (2004)
Daughters Giving Care to Mothers Who Have Dementia: Mastering the 3R's of (Re)Calling, (Re)Learning and (Re)Adjusting

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| (Re)calling | "You could actually see the decline because she was getting sort of more in, you know, um, inward and not so, um, friendly toward people and outgoing like she used to be, and it was really a shame because, um, people couldn't talk to her anymore" "I just love her so much that, uh, I don't even really think about it like I don't, I'm not doing | Daughters used memories of their mother and other family knowledge to come to terms with what they saw happening and to make the decision to take on responsibilities of caregiving. Saw or heard things that were inconsistent with recalled and remembered images of her. Becoming | Changes in personality, loss of parts of mother. Memory loss initially attributed to other factors (links to Saunders, 2010) Marker events which were interpreted as |

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| | it to be a martyr or anything"<br>"I mean at this point if she was in a home I'd feel so guilty, I'd just keep her at home just because it would kill me, not her." | watchful of their mother's behaviour. Particular events (i.e. leaving stove on), viewed as catastrophic. Exploring possible services and finding them wanting. Love and commitment for mother, promises to family. Bound by 'rules' or culture and family or social traditions and bonds of gender or love. | memory impairments that can no longer be ignored.<br>Mother being seen as independent then in need of care. Change in roles.<br>Sense of duty/filial responsibility to care to mother. Culture, family expectations. Feelings of guilt. Parent being like a child. |
| (Re)learning | "It's so hard because she's still my mum, you know, and so maybe that it why (drifting). Because she's my mother I can do some stuff easily like let go of, um, arguing with her or something or trying to make her see, see reason where there is none. She's not going to see any reason, you know, like I just have to accept it."<br>"And we've gotten closer because the relationship between her and I has been more intimate in a way because like, you know with her bathing like at first I was very uncomfortable to do that but then after she had her first bath and she says, 'Oh, that felt good!' It made me feel even better to know I was able to do that for her.." | Daughters had to re-learn who their mother had been, who she currently was and how to be with the mother and look after her in private and in public.<br>Discovery (finding out things not previously known).<br>Development of new ways to be together.<br>Pain and awareness of loss during (re)learning.<br>Reviewed what they thought their mother would want<br>Learning to treasure what was left, becoming closer<br>Protective of mother in terms of safety and mother' interface with public. | Continuity-still seeing her as their mum whatever they do.<br>Pain and loss.<br>Adapting relationship style.<br>Trying to maintain personhood, continuity<br>Focusing on positives, closeness in relationship<br>Public impression. |

| (Re)adjusting | "I'm learning a bit of what it means to be really humble," "to have hope," to learn "about your frailties and your weakness and your, um, the things that are nasty about oneself." <br><br> "Who am I now that I look after her? Am I still a daughter? Is she still my mother if she doesn't look after me?" <br><br> "I've done everything I can do. And I take, I take all that but that's all, Yeah I cannot take any more. That's why I blow up, you know, I would scream and, and now I feel more quiet now because I don't have to worry too much, I just worry about her health." | Daughter's feelings and thoughts. After learning how to be with and care for their mothers, daughters changed their lives by trying to care for themselves, to make sense of what they were doing and to consider the future. <br><br> Some created private physical space, some respite. <br><br> Cognitive strategy mothers 'couldn't help' doing some things. <br><br> Reflection on experience, gaining personal insight, identity and family issues, thoughts about own aging. Thoughts about separating from their mothers-end point. Plan to continue to provide care when their mother is placed in a care home. | Ways to cope, difficult feelings. <br> Self-care, boundaries, space. <br> Identity issues linked to caring for a parent. <br> Reframing mother's behaviour. <br> Learning more about yourself, developing insight. <br> Thoughts about the future, when to stop being the primary caregiver. |
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| Harris (1998) <br> Listening to Caregiving Sons: Misunderstood Realities | | | |
| Duty | "You got to do what you got to do." <br><br> "What kept me going was my devotion to her. I saw how they (his parents) treated me over my lifetime, the loyalty they felt. I learned. I learned that's what you do with family. You don't moan and groan about them; you take care of them. You do what you have to do." | Filial obligation. Sense of duty to care for their ill parents. | Duty/filial obligation and responsibility. <br> Family expectations, family culture. <br> IOU. |
| Acceptance | "You remember how sweet and compassionate your mom was and you look at the disease and it's totally out of character, but you might as | Being more readily able to accept the diagnosis of dementia in their parents at earlier stages in the illness than | Coping style, acceptance of reality, making plans. |

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| | well come out of your denial you're in. You have to recognise the fact that she has a serious problem and begin to help her and help yourself dealing with it. | other family members were. Didn't mean they weren't upset but they accepted reality and started to make plans. | |
| Taking charge | "There always seems to be a family captain in a situation like this and no one else was doing it so I just did it. I called a family meeting. And I said, if you want me to take responsibility, fine." | Major role of taking charge of the situation, pushing their families to make the necessary decisions. Many viewed taking charge as a natural extension of their role as sons. Frustrating aspect of taking charge was that there were no good answers. | Original role as a son, natural extension-taking charge. Just doing it. |
| Common emotions | "It's like being on an emotional roller-coaster, and in a 24-hour period, you experience just about every emotion known to mankind." "The emotional sense of sadness...it's just overwhelming. I can't describe it. It's just so sad to see these very competent capable people-they were so successful." "There was never enough time to do what I felt I should have done. I let my mother carry too much of it (the caregiving responsibility for his father), because she was strong, and so in my case I went to the point of path of least resistance." | Five common emotions: Love, pain and anguish, anger and/or resentment, sadness mingled with compassion and guilt. Fifteen sons also expressed caregiver stress and burden. Emotionally invested and involved in caregiving process. | Love, pain and anguish, anger and/or resentment, sadness and guilt. Some stress and burden. Positive-love, negative feelings towards the parent and towards themselves. |
| Work flexibility | "I would have to take weeks off to resolve this (problem for his father who had dementia), but in my position I don't need to worry about that because I am covered, but I can see where control over yours hours is necessary because there's no way you can run a job and deal with | Control and flexibility over work hours. Seniority of work roles meant they could take time off to assist their ill parents. | Gender differences? Job roles allowing men time to care for their parent. |

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| | this at times." | | |
| Loss | "I miss the person she was; she was somebody you could confide in-you could be yourself" | Loss of the person they loved, loss of personal space and freedom, loss of job opportunities. | Different types of loss-loss of part of parent/personality, loss of personal space/freedom and loss of possible job opportunities. |
| Sibling relationships | "I am talking to my brother more than I ever did before"<br>"Finally I got hold of him (brother) late one evening and I told him, 'I need help.' He said 'yes, yes I'll be there.' Wednesday, Thursday, Friday went by, and I would call him every night..." | Becoming closer to siblings, more contact.<br>Reawakening old sibling rivalries, sibling refusal to take responsibility.<br>Pushing siblings further apart.<br>Some able to put past relationship behind them for sake of parent, others could not let go. | Past relationship impacting on current difficulties. Some positives for some siblings, some negatives for others. |
| Reversing roles | "He hated me, just hated me," "He saw me as the bane of his entire existence, the root of all his troubles" | Expressed difficulty in accepting the fact they had to take on roles and tasks that their parents had performed for them as children. Bathing and driving (taking keys away) most difficult. | Role reversal, some tasks harder than others. Having to take control, negative consequences for actions. Difficulties in relationship. |
| Coping strategies | "I did the research, proposed the solutions, and then guided the decisions, but the problem with this disease if there are no good answers."<br>"Being able to get lost into the pressures of work, work with nothing else to distract you; it's all consuming. It's this great sucking tunnel-and if you like it, you don't pull that that hard away from it. You can fill all your | Four main strategies: Problem solving approach, immersing themselves in work, confiding in their wives and finding solace and support in their religious convictions. | Ways of coping, gender specific?<br>Avoidance, getting support from partners |

| | available time with work." | | |
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| Positive outcomes | "Repaying". <br> "Its just that I was pleased that I was able in some small way to be able to pay her back. I think if she had died of a heart attack, I would never have the chance to say to myself in some small way I had repaid her for what she did. Not that she ever made me feel like I had to, but I did." <br> "After being in this for a while, you start thinking what is the purpose (in life), and maybe the purpose is giving instead of getting. And so you give in some small way to somebody else who's important to you." | Chance to pay their parents back for their care, sense of purpose and sense of growth, being a role model for their children. | IOU. <br> Learning new skills/knowledge, developing the self. |
| Legault & Ducharme (2009) <br> Advocating for a Parent with Dementia in a Long-term Care Facility <br> The Process Experienced by Daughters | | | |
| Development of trust | "...because I lost confidence in the staff there...management too. It means I'll never be able to trust them completely again." <br> "Me, I can honestly say that I have confidence in them, but I still supervise things....Hey, this is no blank check!" <br> "I'll stay with her for half hour, an hour, and then when I head home, I'm at ease knowing she's safe, whereas when she was still living on her own, I would leave and I did nothing but worry about her...all the time." | Core of transformation of advocacy role that carers experienced. Dynamic process, lack of trust leads to more supervision when visiting the nursing home. Different levels of trust. Five factors associated with establishment of trust: First impressions of nursing home, comparisons with other nursing homes, interest shown by nursing staff, staff responsiveness, and transparency in event of incidents. | Links to other two themes. <br> Different factors affect development of trust. Caring role when parents in care home-advocacy role. Differences between experiences when parent was at home and now in care home. Relationships with care home and staff, |

| | | | communication, reciprocity. |
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| Integration in care setting | "What I've always told staff is: 'I'm not against you, I'm with you. I'm here to lend hand, to take care of my mother, first of all, but to also help you. So t, if there's anything I can or cannot do, just talk to me."<br>"So my sister says to herself: Alright, then, let's take a softer approach, a different approach, because there's no use in antagonising them. What we need to do is obtain their collaboration in order to make sure that our mother receives proper care." | When admitted to nursing home, daughters began process of integrating the new setting. Learning to communicate with nursing staff, learn home's operating rules and constraints. Three strategies to foster integration process: Establishing relationship of reciprocity with staff, collaborating with staff and using diplomatic communication style. | Ways of coping. Relationship and communication styles with staff<br>Being diplomatic. Reciprocity paved a way to a partnership between carers and staff. |
| Evaluation of quality of care | "You can't let your guard down ever. It's appalling! You can't take anything for granted. You can never take anything for granted."<br>"Her basic needs are not being met..her needs for drink, food, warmth...These needs are not being met satisfactorily. It's behind the threshold of acceptability." | Carers felt invested in evaluating the quality of care provided and intervening to improve it if necessary. Three stage process: Exercising judgment on quality of care, weighting the judgment and acting to change the situation. | Evaluation based on personal criteria. Feeling responsible for making sure their parent received adequate care. Taking action to change the situation. Relationship with care home and staff. Feeling invested. |
| Ward-Griffin, Oudshoorn, Clark & Bol (2007)<br>Mother-Adult Daughter Relationships Within Dementia Care<br>A Critical Analysis | | | |
| Custodial relationship (Task focused, deficit based) | "I usually take care of what needs to be done...it's just to make sure she's eating and getting her medicine, but other than that...To | Defining characteristic is duty, familial caregiving expectations main motivator and reason for interactions. | Duty, family expectations/culture. Business-like, problem |

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| | sit and talk, like there's no conversation...we don't really have a social relationship..I don't want to do it. It's not that I don't want any contact with her, I'm just tired of being a babysitter..It feels like a chore sometimes and I feel bad about that because it shouldn't, but I just figured it's my mom, and someone's got to look after her." | Daughters provide the minimal amount of care deemed necessary for their mother's survival. Daughter in charge. Notable absence or emotional attachment. Objectification of the mother-leading to potential caregiver and/or care-recipient burden. | solving style. No emotional attachment. Prior relationship. |
| Cooperative relationship (Task focused, strength based) | "I notice that our relationship is very, very comfortable. Very relaxed, very you know, mom and I are just totally in sync with one another." | Defining characteristic is reciprocity. Attempt to work together as a team, flexible and attentive to each other's needs. Tend to have a strong family network of support. Belief: "families can take care of their own". High level of satisfaction and gratification with care provided and received. | Reciprocity, working together. Family network for support. Positive outcomes for both. |
| Combative relationship (Emotion focused, deficit based) | "She was a very difficult person to be around. Even when I was a little girl, I knew I never wanted to be like my mother. And I grew up knowing that I never wanted to be like her. And I told my kids, if I ever get like grandma, just shoot me!" | Exists primarily to address cognitive deficiencies of the mother. Emotionally charged. Mother and daughter compete for control. Conflict usually been dominant force throughout their lives. Interactions shaped by previous contentious mother-daughter relationship. Increasing hostility between mother and daughter coupled with high caregiving demands and limited formal support may link to elder neglect and/or abuse. | Strong emotions. Power and control. Prior relationship, consistent over time, attachment. |
| Cohesive relationship | "Oh, my mother and I have always been good | Positive mutual bond or attachment | Attachment/bond. |

| (Emotion focused, Strength based) | friends..I'd do anything for my mom, but would like her to be as independent as possible. And occasionally she will say to me, 'I can take care of myself.' I say, 'Of course you can. Of course you can.' | exists between mother and daughter. Focuses on strengths and need for independence. Time spent together is rewarding for both. Power with not power over. | Strengths and independence. Positive time spent together. Power dynamics. |
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| Dupuis (2002) <br> Understanding Ambiguous Loss in the Context of Dementia Care: Adult Children's Perspectives | | | |
| Anticipatory loss | "Well there's nothing really difficult other than the anticipation of what's going to happen, when it's going to happen, and, you know, will I be prepared to handle it." <br> "When you come in and you visit and you see people that have been there longer and what happens as they go through this...and you know what's ahead for her, it's distressing." | Loved on is still psychologically present and remains in the family unit. Ambiguity centred around what the future holds. Unpredictability and uncertainty of future. Anticipating psychological loss of parent and how they will be able to cope with it. | Ambivalence about the future and how they will cope/manage. Awareness of future psychological loss. |
| Progressive loss | "...once I didn't want to come because I had had such a terrible visit with my mother the week before. I can't even explain, it was just a feeling I had that it was hopeless. It was just the most useless time I've ever had in my life and that we we all kidding ourselves, and that has she really in reality died. And these are negative, negative thoughts that I hadn't even thought before. Like have we all been pretending that this woman is even alive?" | As level of cognitive impairment progresses, family members moved into this phase. Pain of watching deterioration of parent and the experience in the role becomes more difficult. Sense of helplessness. Attempts to get a connection with parents, trying to maintain the image of the parents. Ambiguity regarding existence of their parents-one day psychologically present, the next day not. | Role as a caregiver, child. Watching their parent 'die mentally'. Distress and devastation. Trying to make a connection. Personhood-maintaining image of parent. Dramatic changes in parent's presentation. Ambiguity. |
| Acknowledged loss | "She doesn't know anybody, she doesn't respond to anything other than her own name. I don't call her mom anymore." | Later phases of institution-based caregiving. Realisation that parent no longer exists for them. Acknowledge | Discontinuity? Loss of role identity. Ambiguity of parent's |

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| | "He is not my father anymore. He is a man who is sweet and looks like my father but he is not my father, he is not at all." | psychological loss. Coping: Acceptance and reframing, avoidance which leads to pain and distress. Continue to deal with ambiguity of parent's existence. Struggle to decide if their visits are necessary. Being ready for parents to die physically. | existence. Differences between siblings view of parents, strain on sibling relationship. Ways of coping-acceptance or avoidance. Wanting it to all be over. |

McCarty (1996)
Caring for a parent with Alzheimer's disease: Process of daughter caregiver stress

**Core categories**

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| Coping with 'living death' | None available | Variations of coping processes and caregiver stress reactions<br>Process-change that occurs over time<br>Basic social process<br>Accounts for large variation in daughters' behaviours<br>Coping affected by beliefs and perceptions<br>Self-efficacy in the caring role<br>'Living death'<br>Management of multiple roles seen as primary issue in caregiver stress process | Coping style<br>Stress reactions<br>Self-efficacy in caring role<br>'Living death' like 'psychosocial death'?<br>Management of multiple roles-linked to stress process |
| Beliefs | "I wanted to be able to do everything; to be able to work, take care of my home, my mom, and my family and not feel any stress. We should be enjoying our life I think at this stage | Perceptions are driven by beliefs. Beliefs about control, cause and effect, power, time, self-efficacy, possibility and importance | Expectations about being able to cope<br>Juggling different roles<br>Prior beliefs affecting |

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| | of the game; it's just not like that anymore; it's scary...especially after my husband's heart attack; life is passing us by, and everyone is feeling it more." | (Self/other). Discrepancy between expectations and personal capacity Beliefs about roles, ability to cope Simultaneous life events Necessity of working Relationship between personal and situational factors | current thoughts and feelings Wanting things to be different Roles, coping |
| Perceptions | "...choice to do this job. My mother and I were close and I miss being able to call her for some advice or even ask her how to cook something. She was wonderful and always watching over everyone. The other morning it was cold, and I was putting her socks on, and she said to me, 'How am I ever going to repay you for this' and I said, 'I should be the one repaying you!'...Imagine she was able to think that...I drove to work crying and thinking it was very special moment that we had together." "she's done so much for everyone...she's wonderful....' | Transactions are driven by perceptions. Perceptions may be considered a person's cognitive appraisals. Drawing on positive parental identity Perception of caregiver role-paying mum back Perception focusing on loss as duration of caregiving increased 'should be' expectations changed to 'what is life' Perceptions of using external agencies Reappraisal of perceptions Change in life perception New information | Sense of loss, missing things Role reversal, IOU, repaying them Sadness, special moments/closeness Positive parental identity, prior personality Love Perceptions changing with time, changes, different stages Coping style 'Shoulds' and acceptance Reappraisal of perceptions/judgments Service utilisation |
| Transactions and relationship patterns | "..total care for my mother in my own home for the past 3 years and have a family and work full-time." | Transactions or 'the carrying on with others, lead to interpretation or definition of roles. | Roles. Phases of caregiving (Beginning, middle, |

| | "Mother mentions him (brother) a lot; he is very important to her. There are times when he could stop by and spend a few hours with her and he never does and she still talks about him." | Some relationships strained, some distant, relationship dominant with mother<br>Relationship with family, mother, home care.<br>Transactions or caregiving negotiations drove the patterns of relationships | end)<br>Siblings not helping out/making an effort<br>Anger at siblings<br>Differences in relationships as a result of dementia<br>Juggling different roles<br>Having to go to work and be a carer, mother etc |
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| **Categories inferred (dynamic and mediators linking beliefs, perceptions, transactions and patterns of relationship)** | | | |
| Negotiation styles | "I knew my mother for 15 years before she developed a drinking problem. My sister and I talked about that; she only knew her for a shorter time...My mother gave us as much that was positive that oddly enough we feel this Alzheimer's disease and what we both did and how we came to terms with this, helped us to close out other painful parts of the alcoholism...That was the precipitating factor for my sister moving out and starting her own life. I felt a lot of feelings of being stuck. And even my mother...interestingly enough said to me, 'She really left you. She really stuck you with me...' | Ways in which daughters' perceptions of the past parent identity and filial roles impacted on their caregiving exchange between themselves, parents and others.<br>Prior filial relationship<br>Evolving image of caregiving situation.<br>Reciprocal, unilateral and conflictual negotiation styles.<br>Daughters who drew on prior ambivalent parent identities and perceived conflictual transactions were the most vulnerable caregivers. | Parental identity<br>Filial roles<br>Prior filial relationship<br>Reciprocal, unilateral and conflictual negotiation styles (links to Ward-Griffin paper).<br>Siblings input |
| Decision –making criteria and processes | "I just went to my boss and told him I would take a day off. That was it. I knew I had to do it. I didn't talk to my mother beforehand. I knew that other family members expected that | Problem solving<br>Underlying beliefs and perceptions affect the process<br>Problem orientated coping | Problem solving<br>Coping<br>Filial relationship<br>Parental identity |

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| | I would do this. And they were right! I would do it myself." | Decision making multi-faceted (motivation, criteria and process) Beliefs and perceptions of parent identities, filial relationships, self concepts, perceptions of caregiver roles, balancing their choices with others-affected decision making Power struggles detaching (problem-focused) and distancing (emotion focused)during decision-making issues Cognitive styles of daughter Emotion focused coping (avoidance, selective attention and minimization). Self acceptance from self and others | Self concepts Caregiver roles Balancing choices with other's choices. Power struggles Cognitive styles of daughter Emotion focused coping (avoidance, selective attention and minimization) Self acceptance from self and others |
| Direct and indirect parent caregiving | None available | Direct and indirect services, emotional support and mediation with formal organisations. Dual parent caregiving role for parent with AD and primary spouse caregiver Trying to balance respect and autonomy Beliefs and perceptions about parent identities and filial relationships drove caregiving activities Prior relationship =not close, more direct instrumental and less emotional caregiving. Both emotional and instrumental for those that had close | Prior relationship Parental identity-personhood Affects on types of caregiving activities Continuity? Juggling roles The other parent/mum's partner Balancing respect and autonomy |

| | | and/or ambivalent relationships. | |
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| Negotiation of self-care and stress | None available | Those that felt alone without support from siblings were more vulnerable to stress. Perceptions of parental identities and caregiver roles affected levels of stress. Coping by handling situations day by day, finding meaning in caregiver roles, teaching family values and taking time for oneself was linked to less intense stress. | Sibling support/input Parental identities Perceptions of caregiving role important. Finding meaning in caregiving role Family values Taking time for oneself (self-care) Coping strategies linked to amount of stress experienced. |
| Loss and grieving | "He doesn't know us anymore. But every time I go to say goodbye it kills me. I'm so sick of saying goodbye. I hate it, so that is really hard on me. Every time he gets pneumonia, we go to see him. One time when the doctor told us he wouldn't make it through the night, my mother and I actually made funeral arrangements. She called the funeral home. It was so hard. I grieved. I mourned. He didn't die...And I actually got angry. I was like when is this going to end? Of course I felt guilty." | Multiple losses during caregiving phases Adjusting lives and relationships with others to accommodate caring for the parent. Own mortality, fear of inheriting AD Multiple changes and adjustments Initial phase: Loss of life consistency, parents' identities, filial roles, parents' former lifestyle. Middle: Loss of own prior lifestyles, social relationships, sibling and family relationships, efficacy in caregiver role. Terminal phase: Ambivalence related | Multiple losses Caregiving phases Own mortality Fear of inheriting AD Sadness, fear, anger Multiple changes and adjustments Loss of parent's identities, filial roles, former lifestyle. Own losses Sibling relationships Family relationships Ambivalence |

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| | | | to multiple sayings of goodbye and a desire of life continuation. | |

**Tan & Schneider (2009)**
**Humour as a Coping Strategy for Adult-Child Caregivers of Individual's with Alzheimer's Disease**

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| Experience of young adult-child caregivers | Challenge of prioritising and balancing 139commitment with parent's needs | "Basically you just put things aside. And you do what has to be done." | Reorganising other responsibilities Caregiving being consuming, significant change to time spent with family, in solitude, work and personal hobbies. Significant challenge Parent top priority | Putting mum/dad first Juggling responsibilities Work/family/hobbies being affected Significant challenge |
| | Stress experienced over healthy parent | "I think a lot of our stress is making sure that my mum's still ok." | 2 participants indicated that the vast majority of stress attributed to parent that didn't have AD* | The other parent The 'healthy' parent being the secondary carer |
| | Role reversal associated with caring for a parent | "She was my mother, and she did all this stuff for me and now it's slowly reversing." | Parent being more like a child, participant being like the parent | Role reversal Parent being like a child, being like a parent |
| Determinants of effective humour | Timing | "It has to be the right time and you're not making fun of him." | Needs to be used at the right time and in appropriate situations for it to be an effective coping mechanism Used to lighten mood and provide relief e between appropriate and inappropriate | Timing Appropriate situation Can be an effective coping strategy |
| | Topic | "Reminiscing about something-that's a big thing for humour. If you start reminiscing | Sources of humour-personal experiences or memories of the parent | Personal experiences, memories |

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| | | about crazy things you've done together of things you've laughed over...that's the most fun." | Making light of the situation to cope<br>Brief reprieve from serious situation<br>Humour should never be at the expense of parent | Brief reprieve<br>Never at their expense, respect |
| | Witnesses to humour | "People would share funny things even in our support group. You're sharing, you're not just bringing each other down, you're lifting each other up. You're helping each other." | Appropriate and appreciated in support groups, AD seminars and family and friends<br>Shared and reciprocated, making it cathartic for everyone<br>Staff can play a role<br>Right witnesses | Useful in support groups<br>Benefitting others<br>Shared humour, cathartic<br>Staff being part of it<br>If not with right witnesses, can be unhelpful |
| Factors influencing use of humour | Perspective on life | "It's not easy to be optimistic. If you're not an optimistic person to begin with you're going to have a bigger struggle." | Optimistic disposition<br>Attention to positive aspects of a grim situation<br>Humour used to avoid potential bouts of depression that could result from a predominantly negative attitude | Positive outlook<br>Ways of coping |
| | Recognition of humour as a coping strategy | "[Humour is] my way of coping." | Individuals may be able to use humour in other aspects of their life, recognition of humour as a coping strategy in this situation allowed caregivers to target their use of humour to maximise benefits.<br>For some, it wasn't their normal style but they worked hard to use humour to cope as they saw its healing qualities | Recognising that humour can be used as coping strategy.<br>Natural style for some, some having to work hard to use it<br>Use of humour can be learned |
| | Openness about | "A lot of people are embarrassed by it and don't want to talk about it." | Ability of the parent and caregiver to maintain open dialogue with friends | Openness about AD important |

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| | Alzheimer's disease | | and others was also a key determinant in whether humour was used by caregiver.<br>If caregiver was able to talk easily about the parent's illness, easier to use humour with that parent and others. | Openness makes it easier to use humour<br>Coping styles<br>Communication |
| | Family upbringing | "[Humour is] a fairly engrained part of who we are." | Parent who had humorous disposition, adult-child caregiver more prone to using humour | Intergenerational humour/coping<br>Similar ways of being/coping |
| Perceived benefits of humour | Escape | "A big help for me...to get away from it." | Concept of escape=prominent coping strategy, gather their thoughts and emotions during difficult times, regain composure<br>"way out" from reality of situation | Escaping reality<br>Gathering thoughts and emotions<br>Coping/managing difficult feelings |
| | Uplifting | "It really just lifts your spirits, I find." | Improved spirits and increased general happiness | Improving mood, lifting spirits |
| | Stress relief | "It's a stress reliever-I can just let it out." | Release from stress and burden<br>Helps to gain perspective on situation by relieving stress associated with caregiving responsibilities | Break from stress and burden<br>Gaining perspective<br>Managing difficult feelings |
| Wallhagen & Yamamoto-Mitani (2006)<br>The Meaning of Family Caregiving in Japan and the United States: A Qualitative Comparative Study | | | | |
| Overarching/universal themes<br>'Moral Obligation' &<br>'Intense loss' | | | | |
| Reasons for caregiving | | "I just think it's the right thing to do. You know, and I think that, that's it's what she | Moral obligation-America<br>Matter of course-Japan | Reciprocity<br>Paying them back |

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| | wants, and it's what I want for her." "Because they gave me life, with healthy body and I didn't have to worry about anything...it is reciprocity, and it's a matter of course, I think. It is not because it is very hard, or it is not because others around me all do the same. It just comes from my heart." | Reciprocity Attachment Japan-Their position in the family to take care of the elderly Cultural differences-Japan-social expectedness of caregiving | Obligation, doing the right thing Attachment, prior relationship Matter or course Cultural differences Social expectations Women's roles/duties |
| Caregiving as a career | "Well I guess it was like, 'oh it finally came.' No particular feeling Right. It was like, 'Oh she's getting that, senile.' More or less...We had thought about it and were kind of ready for it. So it was no surprise or anything like that." (Japan)

'It's just something we don't ever prepare for. It's something we get thrown into." (America) | Significant differences between Japanese and American women Japan-expected career America-not expected career Societal norms around life course Roles of women, daughters Anticipating the role vs. unexpected career Perceptions of aging | Cultural differences in expectations of women Perceptions of aging Impact of expectations/values on experience of being a caregiver Coping Common emotions Roles, duty, responsibility Adjusting to the role |
| Caregiving as a life phase or detour | "That's what my social worker always says. She says, you'll eventually get to go see movies again. And I go, 'oh, yeah? I'll be able to go to the movie festival again one day?' And she'll say, yeah." "Rather than making a fuss saying, 'caregiving, caregiving,' it is just a part of life. They are all a part of life. All as parts of my life journey and caregiving just happened to be | Americans talked of putting everything on hold and foregoing long-standing activities. They wanted caregiving to end and return to normalcy. Japanese women saw caregiving as a phase one component of expected life trajectory, even if it was viewed as disruptive or difficult. | Different perceptions on impact of caregiving on own life Expectations, cognitions, values Ways of coping Acceptance vs. fighting |

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| | in my schedule. Into my life journey. It is one of your schedules, and you can accept it without special emphasis on it." | | |
| Globerman (1995) The Unencumbered Child: Family Reputations and Responsibilities in the Care of Relatives with Alzheimer's Disease | | | |
| Characterisation | "Even growing up, I could see her getting out of things around the house, like the household things" "I was the kind of kid who would let something go...and eventually mom would [look after it]." "It was always like that, always like that. Even as teenagers. I remember my mother had given me chores or something, and my sister always liked to read. I tend to do more of the hands-on things, whereas my sister tends to do a lot of reading and things like that." | Uninvolved described themselves as successful, caregivers described them as 'absent minded', 'emotional', 'selfish' Unencumbered child stood out from the family and also saw themselves this way. Roles within the family Negative feelings to sibling not caregiving | Negative feelings towards siblings that don't help with caregiving Unencumbered adult-child's acceptance of their role/reasons for not caregiving Identity of caregiver and non-caregiver Coping style |
| Focus | "I really don't know where I get all the time, or where I get the ability to handle it, and now I'm feeling the stress and strain of it all." | Caregivers focused on burdens of caregiving, their developmental tasks and their responsibilities and the need to balance activities. Unencumbered children didn't speak of burden or responsibilities, focus was more self-centred, personal loss | Burden Siblings not helping with caregiving Balancing activities, time Ways of coping Focus of distress/difficulties |
| Nature of suffering | "That's the frustration. We can't do anything. It could be very long-lasting. If you get a disease that is terminal, you cry. You know it's going to end at a point in time and it's | Unencumbered children focused on the self and the loss of one's identity, an internal tearing apart They didn't focus on role strain, role | Ways of coping Cognitions Focusing on me or focusing on mum/dad |

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| | over. She could live for another fifteen years, and this gets progressively worse and I probably will get progressively more impatient." (Involved adult-child)<br><br>"I will either fall totally apart and that will be it, or I will be strong in front of them and behind the scenes I will fall apart, I most probably will have a hard time relating to my sister who is much like my mother, that would be painful for me." (Unencumbered adult-child) | conflict, difficulties in negotiating with others, exhaustion as the other siblings did | Loss of identity<br>Role conflict<br>Difficulties negotiating with others<br>Exhaustion<br>Different experiences/feelings among siblings<br>Different family roles/personalities |
| Different sense of responsibility | "My brother is more selfish than I am. His problems are of utmost importance to him, and everybody else's problems and all other problems are secondary..That's the way he views life, and maybe that's important and he needs that. I am more aware of all the problems and how they will ultimately impact on me, and maybe I'm more defensive about it and therefore I get more involved." | Involved siblings apportioned care and divided responsibilities according to how they viewed themselves and were viewed by others in family.<br>Attributed problems in apportioning care to real events, the disease and to family issues. Setting limits, feeling guilty, making decisions and choices<br>Unencumbered children had different notions of responsibility-saw involvement as others' responsibility | Being in charge of managing care, delegating<br>Guilt<br>Setting limits, making decisions and choices<br>Role within the family<br>Difficulties due to real events, the disease and family issues<br>Motivations to care<br>Responsibility |
| Protection and Entitlement | "It might be a little bit different if she had a husband. She goes around n her social activities, so her activities take care of her...There's only so much time in the day, and you've got to attend to your personal things aswell." | Struggled apportioning care<br>Returned to family of origin reputations<br>Tendency to excuse or protect the unencumbered children more than others | Family roles, scripts<br>Excusing/protecting the unencumbered child<br>Responsibility/duty<br>Family obligations<br>Cultural aspects |

| | | Family obligations, Jewish culture Birth order and gender not explanations for unencumbered status or protection from responsibility | Motivations for care (not birth order or gender) |
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| Kelsey, Laditka & Laditka (2010) Caregiver Perspectives on Transitions to Assisted Living and Memory Care | | | |
| Reasons for the ALF* Move and Experiences With it | "I think it became safety and health-related as to why I needed to move her." "We weren't comfortable with her giving herself meds and cooking for herself." | Adult children concerned with their parents' safety regarding medication management, bill paying, meal preparation, anxiety, and forgetfulness. Spouses spoke of increased burden leading to ALF move and cognitive decline Only a few adult children mentioned that moving their parents was extremely difficult for them. All spouses said the move was emotional. | Concerns about safety Differences in spouse and adult-child perspectives, feelings Some difficult feelings When to stop being the main caregiver Motivations to stop being the main caregiver Worry, concern |
| Reasons for Selecting a Particular ALF | "When we walked in, it was bright. It was sunny. There were activities. It was a happy place." "I could go over there in five minutes and take care of him. Convenience was very important." | Liked the facility Proximity Convenience | Choosing the right place for mum/dad to live/be cared for Being able to visit quickly/easily Thinking about parents' needs and own needs Still wanting to care for them |
| Recognized Need for Future Dementia Care on | "But it came down to, I think, for me, number one, knowing that I would move her one place | Recognising there might be a need for specialised dementia care | Thinking about the future Needing specialised care in |

| Admission to ALF | and it was an option that she need to go into more care that it would be available." | Some not knowing what care is available | the future<br>Thinking about things getting worse<br>Knowledge of facilities/needs |
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| Transfer Policy from ALF Described on Admission ** | "There wasn't that clear connect between where I placed her and what the next step would entail...Maybe somebody mentioned it, but it certainly wasn't clear to me." | Majority not informed about policy for transferring residents with advancing dementia | Not being informed<br>Not knowing what care is available/what will happen in the future<br>Communication with staff |
| Informing Caregivers of the Need for the MCU Move | "They talked to me about it, but ultimately decided to move her mainly for her own safety, because she was getting dressed in the middle of the night and thinking she had to go to work..and trying to get out of the building. So it was for her own safety, but it was the initiation mostly from the staff." | Assisted living facilities staff members initiated the conversation | Communication with staff<br>Staff informing you of the need to move the PWD* to specialised care<br>Staff initiating the conversation, taking the lead |
| Caregiver Reaction to Transitioning from ALF to MCU* | "It was like somebody slapped me in the face, okay? Because I had not really projected [the move into a MCU]." | Adult children said that thought of moving family member from ALF to MCU was traumatic<br>Experienced denial, anger<br>Spouses had diverse reactions-most felt it wasn't as traumatic as the move into ALF | Moving parent to specialised unit traumatic<br>Denial, anger<br>Differences between adult-child and spouse reactions |
| Expectations of Transferring to MCUs | "They've met or exceeded the expectations that I had."<br>"It was early on....a difficult transition for my mother. But it really didn't take very long for her to adapt." "I guess my mother handled it better than I thought she would." | Compared expectations to actual experience<br>Satisfied with care provided by MCU<br>Retrospectively recognised the MCU was the correct decision | Comparing expectations to actual experience<br>Turned out better than expectations<br>Satisfied with care<br>Looking back and thinking |

| | | Family member adjusted well | it was the correct decision<br>Family member adjusted well to MCU<br>Positive feelings |
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| Suggestions for Moving Family Members With ADRD Into an ALF | "I'm really so grateful there were in one building. The trauma of having to think about picking my mum up and moving her to another whole faculty....I think it would be so hard and so overwhelming. And s, if at all possible, that's exactly how I would do it again." | One third of adult children said there was an advantage to ALFs with attached MCU-ease of transitioning. Some determined this before ALF admission, others understood this retrospectively | Transitions<br>Thinking about the future/future care<br>Thinking about parents' needs<br>Learning through experience<br>Knowledge of services/care available<br>Managing their care<br>Making decisions/choices |
| Concern About Greater Costs of MCUs | None available | Concerns about extra cost | Money, worries/concerns |
| Suggestions to Improve the Move from ALF to MCU | "I've been going to an Alzheimer's support group that's sponsored through the state and the local association, and I think that's extremely valuable for people...support groups are really helpful because they prepare you for the next step."<br>"I guess number one there is the care. By the time they reach that point, I believe the care is number one and a staff that is really trained and understands Alzheimer's." | Needing to prepare, support and educate caregivers about stages of ADRD* with support groups<br>Care staff important<br>Presence of meaningful and stimulating activities | Coping/support<br>Knowledge of stages of ADRD<br>Preparing for the move/transitions<br>Shared coping<br>Managing change<br>Importance of quality of care/others caring<br>Importance of meaningful and stimulating activities<br>Parents' needs, quality of |

| | life |
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**Werner, Goldstein & Buchbinder (2010)**
**Subjective Experience of Family Stigma as Reported by Children of Alzheimer's Disease Patients (cultural influences-study done in Israel)**

| Caregiver's stigma | "He has physical and mental problems...he is unable to go to the toilet by himself. After a minute, or even after a second he does not remember, he remembers nothing, a total erasing of the information he got."<br>"One day I came in and saw her...what can I say..everything around was messy she was messy, disgusting...as a person from the slums, filthy, dirty, totally soiled."<br>"My mother was always very well groomed and dressed. She always received compliments about her appearance. Suddenly [after she got AD*], she puts on clothes that don't fit her. She looks neglected. I'm sort for her and try to groom her and keep her clean." | <u>Cognitive Reactions</u><br>Functioning level<br>Aesthetics<br><u>Emotional Reactions</u><br>Negative: Shame, embarrassment, disgust<br>Positive: Compassion, sorrow, guilt<br>Positive emotions led in increase in instrumental involvement-taking care of finances, hiring caregiver for extra help.<br><u>Behavioural Reactions</u><br>Discriminatory: Concealment, Less caregiving<br>Helping: Instrumental involvement | Severity of disease, parent's physical and mental functioning.<br>Parents looks and unattractive appearance, difficult feelings?<br>Shame, embarrassment, disgust-negative feeling s towards the parent<br>Positive feelings: Compassion, sorrow, guilt<br>Concealing the diagnosis from others, physically concealing/hiding the parent<br>Decline in involvement |
| Lay public's stigma | "People relate to an AD patient as one that has difficulties with his physical, mental and cognitive functions. They think he is always confused, forgetful, irresponsible, and a boring man. They only concentrate on how he repeats the same sentence again and again."<br>"While my mother was hospitalised in a nursing home..her friend came to visit her, but she didn't enter the room and stayed outside because she was so afraid to meet her." | <u>Cognitive Reactions</u><br>Functioning level<br>Aesthetics<br><u>Emotional Reactions</u><br>Negative: Fear, disgust<br>Positive: Pity<br>Other peoples' positive emotions resulted in decreased discrimination and desire for increased proximity and contact | Focusing on difficulties, decline, what he/she can't do<br>Judging on appearance, difficulties with personhood<br>Fear, disgust<br>Pity-increased contact<br>Avoiding contact<br>Discrimination affecting parent and adult-child |

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| | | Behavioural Reactions<br>Discriminatory: Avoidance<br>Helping: Closeness | |
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| Structural stigma | "My father has aphasia, he can't talk and feels depressed. His family physician told us that all elderly persons suffer from it, and it has no cure."<br>"My mother had hallucinations. I told her family physician about it and she answered that there was nothing to be done. Finally, only after I pressured her, she gave me a medicine that helps, but her treatment was rude and unprofessional." | <u>Cognitive attributions</u><br>Insufficient knowledge among professionals<br>Inadequate range of available services and/or access to services<br><u>Behavioural reactions</u><br>Flawed health service<br>Limited access to services | Attributed stigma to lack of knowledge and inadequate range of services<br>Institutional stigma, discrimination<br>Limited access<br>Discrimination<br>Dealing with systems/services<br>Flawed health service<br>Ageism?<br>Not being treated fairly/properly<br>Difficult feelings<br>Blame |
| Forbat (2003)<br>Relationship difficulties in dementia care: A discursive analysis of two women's' accounts | | | |
| Impact of past relationship on current relationship- | "Not really..no. She didn't have no time for any of us no. Not really not really, no. I can say that honestly. But..." "Maybe the boys, it was always HER boys it was always so good, whenever said about my sister and I it was always about HER boys, ;oh the boys need this and the boys need that' and it was never, you know yourself and Maureen, never." | Difficult early relationship-difficult current relationship<br>Daughter positioning mother as powerful and bad in past and present<br>Longstanding difficulties<br>Never close<br>Care as a constant theme-for | Care before dementia<br>Continuity of person and attachment/relationship quality, difficult feelings, caring style, unresolved feelings, impact of early relationship on current experience of caring role, |

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| | "anger...it does, yep absolutely. I know nobody's robbed her nobody's got in...nobody's broken any windows I said 'well show me where they've got in show me where they've broken a window.....'" | daughter<br>Caring style-challenging mum's presentation rather than trying to understand it-moving into arena of 'malignant care', invalidation | difficulties using person centred thinking |
| **Yamamoto & Wallhagen (1997)**<br>**The Continuation of Family Caregiving in Japan** | | | |
| Value of care | "It [caregiving] is my job, or rather a part of my job. We split the work [between the caregiver and her husband."<br>"I wonder why I take care of her. I guess this stems from my relationship with my mother from my childhood. Although it was only for a short while that I lived with her, but how do I say, I guess I was closest to her, (quietly crying)...So, I think I have kept that feeling all along." | Caregiving in Japan highly valued due to: Societal norms regarding filial caregiving and attachment to the care recipient.<br>Three societal norms: Filial responsibility, beliefs regarding role of women in family, history of primogeniture (inheritance law, successor son). Concept of 'on' (social debt)<br>Strong sense of attachment gave high value to caregiving. Those with negative emotions towards care recipient-caregiving was not given high value<br>Cycles of loss, grief, gradual adaptation, final stage of detachment<br>Care recipient seen as childlike, power relationship shifted<br>Some parts of mother-daughter relationship staying the same | Societal norms, role of women, history of roles, law, tradition<br>Caregiving by women, especially daughters-in-law<br>Expectations about looking after elders<br>Filial responsibility, duty, paying them back ('on')<br>Culture<br>Strong attachment and high value of caregiving<br>Poor attachment-low value<br>Prior relationship<br>Loss, grief, adaptation, detachment<br>Attachment changing over time<br>Childlike<br>Power changes, role reversal<br>Continuity |

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| Maintainers of value | "I have experienced a lot so far. I sometimes wonder what my life is all about, or who I am. I really hope to lead such a life that I would contently say as M (a woman who became princess of Japan) might do that I had a wonderful life when looking back at the end of my life (laugh). Therefore, even if I didn't take care of her, I would find something I feel I should do. I consider taking care of her as part of my job I should do."<br><br>"Recently, mother often says 'Oh, I took a bath today, thanks to you. I appreciate that.' It may sound strange, but I am glad I am told such a thing. When I see mother like that, I strongly feel like responding to her and I can be very honest about such a feeling. Yeah, a quite sincere and straightforward feeling. She is trusting me that much, 100 percent. I guess our relationship of parent and child has been reversed completely." | Maintained by: caregiver herself, the care recipient, social environment and consequential gains.<br>Desire to live a life free of regret in the end, caregiving has fundamental value<br>Life principle-remaining committed to decisions made in life<br>Pity and sympathy<br>Encouragement from care recipient-gratitude and appreciation<br>Difficult words/behaviours discouraged the caregiver<br>Encouragement, understanding and appreciation from spouse, other family members , neighbours ,staff<br>Sharing difficulties with other carers<br>Resentment towards others (family members)<br>New insights into human aging and dying, becoming more tolerant and generous<br>Positive effects on caregiver's children-living with grandparent | Positive outcomes, reasons for caring, motivations for care, motivations for continued care.<br>Free of regret, clear conscience<br>Support, coping, shared coping<br>Pity and sympathy<br>Values, principles<br>Encouragement, appreciation<br>Gratitude<br>Negatives and discouragement<br>Resentment towards family members not helping<br>Positives-insights, improving yourself |
| Reinforcers of care continuation | "To begin with, I think, I have been like that all my life. Since I was a small child, I have been doing what others don't like to do...I did what others don't want to do..By doing it, if the other person felt good, I felt good, too." | Rewards that came from sources other than caregiving-Diversionary activities (dance school, outings with family).<br>Financial benefits-not having to pay | Rewards, positives<br>New activities<br>Saving money<br>Knowing that there's support out there |

| | | for institutionalisation.<br>Knowledge of available resources<br>Situational determinants-absence of other siblings<br>Personal style of behaviour | Having to do it, no choice?<br>No siblings<br>Personal style of behaviour, coping, cognitions, values |
|---|---|---|---|
| Simpson (2010)<br>Case Studies of Hispanic Caregivers of Persons With Dementia: Reconciliation of Self | | | |
| Parent/child role reversal | "Sometimes I have to be firm with her, and so it's like with a child, being consistent with her and being firm with her without being mean.." | Acting as parental figure toward PWD based on their behaviours and needs | \|Role reversal, being the parent, parent as a child-more negative connotations, focusing on practical care, power/control<br>Caring style |
| Needing to maintain respect | "I've always talked to her like she is a real person. I don't ever talk to her like she is a baby or talk to her like she is less of a person. Like she doesn't know because she knows. She may not remember, but I mean, later, but she knows what's going on. She knows." | Caregiver's need to be in the traditional parent/child dyad and the respectful, maintaining identity of self as respectful daughter. | Continuity of personhood, wanting to maintain respect, seeing changes, mum's identity, maintaining ways of responding to mum, thinking of mum's wishes |
| Self as caregiver | "I worry about my mother's emotional needs. I worry about, did my sister giver he a hug today. Did she take the time to sit with her and talk to her? Does she take the time to go chit chat with her or tuck her in at night instead of just saying, okay mother, good night."<br>"And I don't feel the burden. I feel it as a gift and I thank the lord so many times that she gives me the privilege to be able to care for my | Expectations about siblings caring, being the carer, worrying about emotional needs, positives of caring, teamwork, caring bring a full-time job, identity as carer | Taking on the role, expectations about siblings roles, uplifts of caring, moments of closeness |

| | | | |
|---|---|---|---|
| | mother because when she's gone. I realise how much I appreciate her. | | |
| Disruption of self | None available | Seeing her mother, who had always been strong and capable, appear suddenly frail and vulnerable. Fear of mother's death brings on fears of loss of self, being a daughter and a caregiver | Seeing changes in personality, sense of discontinuity Identity of carer Fear of loss |

*Table A1:Expansion and interpretation of themes*

Appendix 3: Author's reflections on the process

**The author's reflections on the whole process (Empirical paper)**

When conducting qualitative research, it is especially important to acknowledge the role of the participant and researcher in the re-construction of data. Interpretative phenomenological analysis (IPA) allows for this consideration and is referred to as the double hermeneutic (Smith, 2003), which describes the multiple levels of interpretation and analysis. The following section presents an account of my experiences and reflections of the research process.

Throughout the project, discussions were had with my research supervisors, about my thoughts, feelings and values and how these might impact on the style of questions in interviews, responses to answers and the analysis of data. It was acknowledged that the participants' mothers were from the 'war baby' generation and that the styles of parenting may have been different to those of today. My expectations about attachment and communicating about emotions came from my own experiences as well as today's cultural norms. I had expectations about mothers showing physical affection and this didn't seem to be the norm for this generation of mothers. Some of my motivation for conducting this study came from my own experiences of witnessing the effects of dementia on a family system and my observations of the different responses different family members exhibited. It is likely that my hypotheses about what might be going on in my family, impacted on the way I designed and undertook this study. Discussions were had with my research supervisors about trying to suspend my own ideas about potential links between early relationships and current relationships so that the impact of this on the interview questions and analysis of the data could be minimised.

I tend to have a more psychodynamic way of thinking about emotions and relationships and so often think about unresolved feelings between a child/adult-child and their parent and that this might be played out in the current relationship. I naturally interpret what people are saying as meaning that something else might be going on under the surface and find myself wondering about unsaid things. I found myself interpreting the scripts in this way and had conversations with my research supervisors as to whether I was jumping to conclusions and interpreting at too high a level. I adjusted my interpretations to focus more on the actual text and then hypothesised about what might be going on after the main themes and subthemes were created (see discussion section). It is likely the relational focus of my findings and clinical implications were affected by my style of thinking and that I veered away from a more cognitive behavioural therapy focus as I felt that the relationship was the key to helping the adult-child and the parent to experience less difficult feelings.

I found the interviews to be full of difficult feelings and I found myself feeling really sad after each one. I found myself imaging what it would be like to have a mother with dementia and how traumatic it would be for me, my mother and our relationship. When participants became more emotional, I felt helpless to change things for them. I sometimes struggled when participants talked about less emotion focused care with their mother as I felt a sense of empathy for both the daughter and their mother and felt an urge to want to help them improve their relationship. This may have come from a mixture of factors such as my personality and upbringing but also from my role as a clinical psychologist.

Appendix 4: Letter of ethical approval

Appendix 5: Participant information sheet

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**PARTICIPANT INFORMATION SHEET**

**Daughters who have cared for a mother with dementia: What happens to their relationship?**

Hi, my name is Joanna Ward-Brown, I am a trainee Clinical Psychologist at the University of Birmingham. As part of my studies, I am carrying out a research project on family relationships in dementia. I am interested in talking to women who have cared for a mother with dementia for a minimum of one year. Before you decide if you want to talk to me or not, please read this leaflet. If you have any worries or questions you can get in touch with me, or my supervisor on the numbers or address below.

*Researcher:*    Joanna Ward-Brown, Trainee Clinical Psychologist

Supervisors:    Gerry Riley (Senior Academic Tutor) & Jan Oyebode (Course Director)

**What is the purpose of this research?**

The purpose of this research is to investigate what happens to the relationship between a mother and a daughter when the mother develops dementia. I am interested in hearing about what your relationship was like with your mother before she developed dementia as well as your relationship with your mother since she developed dementia.

**Why have I been invited to take part?**

You have been invited to take part because you have provided practical help and support to your mother with dementia, for at least 12 months.

**Do I have to take part?**

It is your decision whether or not you take part. If you decide to take part you are still free to change your mind and withdraw at any time without giving a reason. If you decide not to take part or to withdraw at any time, this will not affect the support you receive.

**What will happen to me if I agree to take part?**

We will meet twice to talk about your relationship with your mother – how it was in the past and how it has been since she developed dementia. These meetings will be more like a conversation than a formal interview. Although I will ask you some questions, I am more interested in your thoughts about the relationship and so you will have the freedom to talk about what you want to talk about. The meetings will last between 60-90 minutes. Unless you specifically request it, they will not last longer than 90 minutes. We can take a break at any time during the meeting.

**What will happen if I do not want to carry on with the study?**

You can stop the meeting or change your mind about taking part at any time, just let me know. This will have no effect on the services you receive. No records will be kept of what you said to me and nothing about you, or said by you, will be included in the write-up of the study.

**What happens if I get upset when we are talking?**

There may be times when we are talking that you feel upset, or find it difficult to talk about certain things. If at any time you feel upset or find a subject difficult, we can take a break or stop the interview. You do not have to talk about anything that is too upsetting or that you don't want to talk about.

If you have been particularly upset during the interview, I will advise you to contact the centre manager whose contact details are given at the end of this leaflet. If I am concerned about your well-being, I will discuss this with my supervisors before advising you what to do. I will discuss this with you if this were to happen.

**What will happen as a result of our meeting?**

I will make an audio recording of our meetings. Within a few days, I will listen to this and type out an exact record of our conversation (i.e. make a transcript). In this transcript, I will not use your real name or the names of anyone else you might mention. I will use pseudonyms instead. As soon as the transcript is complete, I will destroy the audio recording.

I will then read through the transcript several times, comparing it with the transcripts of the meetings I have with other participants. My supervisors will also read through the transcripts. We will then try to draw out some common themes and ideas. I will then write this up in a report which I will submit as part of my degree. The report will be held in the University of Birmingham Library. As part of my write-up, I will include quotes from the transcripts, again using pseudonyms. No personal information would be included that would allow a member of the public to identify you.

I will also write a brief summary of the research findings. I will send a copy of this to you if you would like to see it. This summary will not contain any quotes from the transcripts.

I also hope that I will publish the report in an academic journal and give presentations about the research to academic audiences. Quotes from the transcripts would be used in these, but only pseudonyms would be used and no personal information would be included that would allow a member of the public to identify you.

.

**Will anyone else know what we talked about?**

I will be the only person who listens to the audio recording. The transcripts (in which no real names will be used) will be read by my supervisors and by other members of the research team investigating this issue. They may also be seen by officials authorized by the University to check that research is being conducted properly. The final report that I write, together with any academic papers or presentations, will contain quotes from the transcripts, but no real names will be used in these quotes and no information will be included that would allow a member of the public to identify you.

The audio recording will be kept securely until the transcript is completed within a few days of our meeting. Once the transcript is completed, the audio recording will be destroyed. The paper version of the transcript will be stored in a locked cabinet when not in use. An electronic version will also be stored on a password-protected computer. The transcript will not contain your name or other identifying information. The consent form will contain your name, but this will be kept in a locked cabinet at the University separately from the transcripts and, other than myself, no one will be able to connect the consent form with a transcript. University regulations require that the consent forms and a paper copy of the transcript are kept for 10 years. After the 10 years have expired, these will be destroyed.

If you tell me something that raises serious concerns about your well-being or the well-being of anyone connected with you, I will be obliged immediately to discuss this with my supervisors and, if appropriate, pass on this information to your G.P. or to Social Services. I would inform you that I was going to do this before going ahead.

**Will I get any benefit from taking part?**

You may find it helpful to talk about your relationship with your mother, but this is not necessarily the case.

I hope that this research may eventually help to improve the way in which services provide support for women who look after their mothers.

**What should I do if I have a complaint or other concern about the way this research has been conducted?**

If, after the interview, you have any complaints or concerns, then you can talk to the member of the Alzheimer's society whose contact details are given at the end of this leaflet. Alternatively, you can contact my supervisor at the University (Gerry Riley, whose contact details are given at the end of this leaflet).

**What will happen if I say something that I regret or regret taking part?**

At the end of each meeting, I will ask you if there is any part of what you have said that you do not want me to use in the study. If there is, I will not include this in the transcript and it will not be used in any part of the study.

If, after taking part in the study, you regret this, please contact me (contact details below). I will destroy the audio recording, consent form and transcript immediately, and I will not include anything of what you told me in my write-up of the research. If you wish me to do this, you must tell me before I complete the write-up of the study (1st May 2012).

**I'm interested in taking part. What do I do next?**

If you are interested in taking part, please give the centre manager your name and phone number. She will pass these on to me and I will then phone you to answer any questions you might have, and, if you are still interested, to arrange a time to meet up with you. If you prefer, you can contact me using the details below

Appendix 6: Consent form

**UNIVERSITY** OF
**BIRMINGHAM**

**CONSENT FORM**

Daughters who have cared for a mother with dementia: What happens to their relationship?

*Researcher:* Joanna Ward-Brown

Please tick box

1. I confirm that I have understood the information sheet dated 24th September. (Version 1) for the above study.  I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time during the research interview, without giving any reason.

3. I give permission for my meeting with the researcher to be audio-recorded

4. I understand that the data collected during this study will be looked at by the researcher and relevant others at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data. ☐

5. I give permission for direct quotes from my interview to be published in any write-up of the data, on condition that my name and any other information that may identify me to a member of the public are not included. ☐

☐

6. I agree to take part in the above study.

..............................        ..................        ....................................

Name of participant        Date        Signature

..............................        ..................        ....................................

Name of researcher        Date        Signature

If you would like to be sent a summary of the study, please tick here

and write down your name and address here:

.............................................................................................................................

Appendix 7: Interview schedule

## Interview Schedule

**Your relationship with your mother before she developed symptoms of dementia**

**Interview A: The prior-relationship-concrete examples of good times/bad times etc**

Early relationship (childhood)
Teenage years
Early adulthood (twenties)
Thirties and forties
Relationship prior to the development of symptoms of dementia

**Prompts/Specific questions/Areas of interest**
When you were hurt/upset who did you go to as a child?
What was your mother like with rules, boundaries and punishment?
Did you keep secrets from her?
Did you talk about key things (i.e. puberty)?
Was your relationship different or similar to your siblings (with your mother)?
Family dynamics
Could you give me five words that would describe your mother (childhood)?
How often did you see her?
What did you tend to do together?
What did you talk about together?
What did you do for each other?
Relationship ups and downs
Can you give me an example of a time when you felt very close/had difficulties?
Significant incidents/events and impact on relationship

(Other areas of interest: Talking about emotions, physical affection, how their mother saw the relationship, expectations and values)

**Your relationship with your mother since she developed symptoms of dementia**

**Interview B: The relationship since the onset of dementia-concrete examples of good times/bad times etc**

When did your mother start to develop symptoms of dementia/when was she diagnosed?
Do you live with your mother?
What kind of care do/did you provide? How often?
Describe the relationship since your mother became unwell/symptoms started/using 5 words
What aspects have changed and what aspects have stayed the same?
What do you miss/not miss?
Could you give me five words to describe your mother?
What do you talk about to each other now?
Do you still do the things you did before?
How would you describe your mother?
Relationship ups and downs
Feelings towards your mother
Can you give me an example of a time when you felt very close/had difficulties?
Significant incidents/events and impact on relationship
Does your mother do anything for you now?

(Other areas of interest: Choice in becoming a carer, coping style, future)

Time for reflections-parallels between past and present, how does the past impact on relationship now?

Appendix 8: Example of reflective log

**Reflective Log-Participant 3**

I noticed how P3 seemed to be in a different sort of mood during this interview. She seemed to see her mother in a very different light since the dementia, although she talked about how she is still a 'difficult' woman. P3 seemed to talk about her mother in a warmer way; talking about how her mother forgets to be nasty and how she enjoys spending time with her now. It felt like there were some unresolved feelings towards her mother which she had boxed off since her mother became unwell-it felt like two very distinct periods in her life-well mum, unwell mum. Her thinking seemed to be quite black and white when thinking about her mother; this also seemed to be the case when she compared her mother and father in childhood. I found it sad when I asked P3 what she missed about her mum since she developed dementia and she said 'nothing'. It felt like P3 feels sorry for her mother now she is unwell but struggled to empathise with her mother before the illness. It seemed that she hadn't considered her mother's point of view and didn't see her as a woman with her own history and difficulties-she didn't seem to have reached a stage of filial maturity. P3 had clearly thought about the future and how she wanted to make sure her mum was looked after properly from now until the end. When asked about why she became a carer to her mother she reported that it was just something she had to do, it wasn't really a choice. I thought that as two of her siblings were also caring for her mother that it might be linked to them all feeling responsible and/or guilty. P3 reflected on the fact that her mother is still a difficult woman and still doesn't talk about her emotions it felt sad that the only way she could feel close to her mother was for her mother to change as a result of dementia. P3 continued

to use humour throughout the interview as she did in her first interview-I wondered if she realised how she really felt or whether she was so defended from it she didn't feel the underlying feelings.

Appendix 9: Example of initial noting for participant 1-section of interview 2 (Relationship since

dementia)

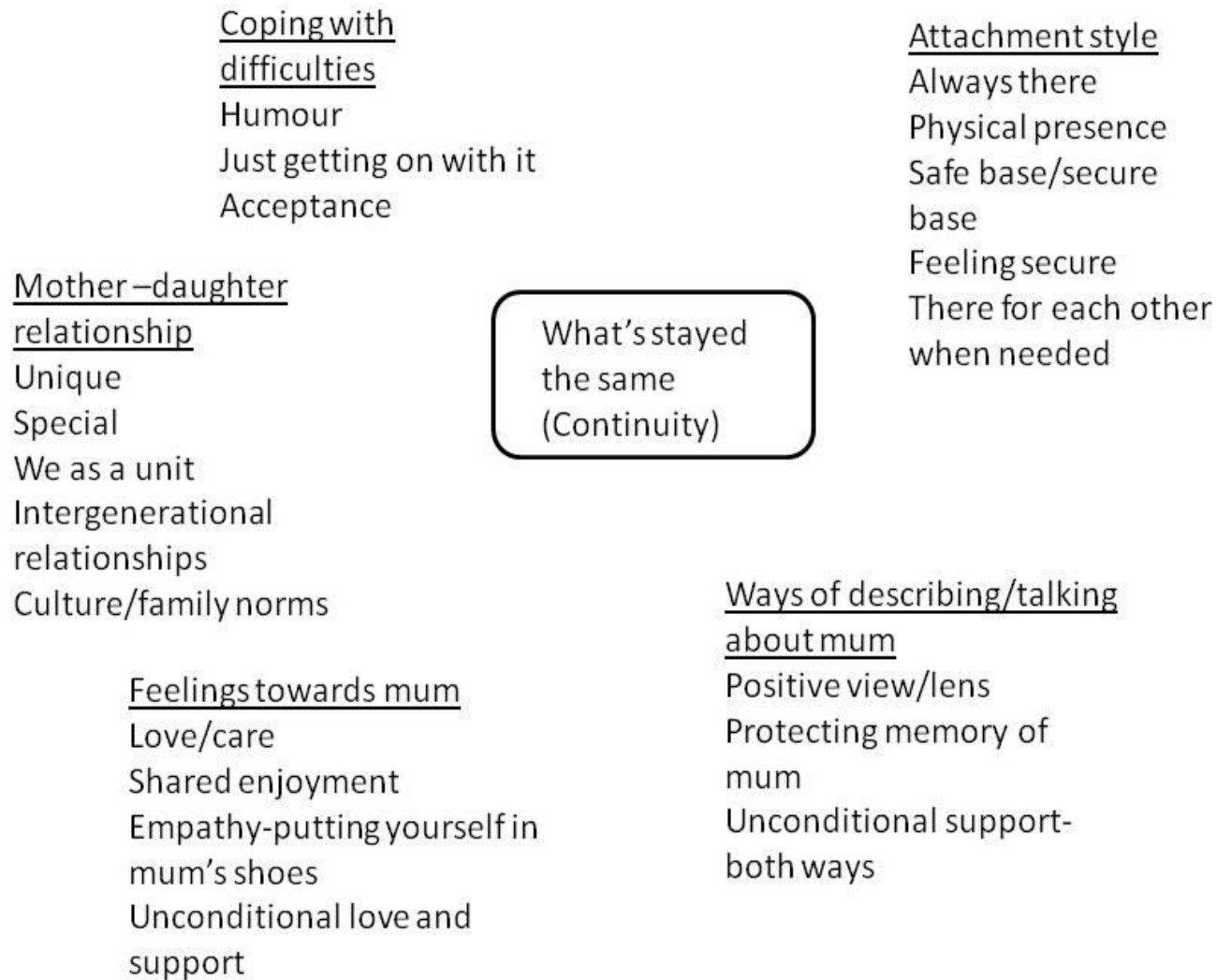| Emerging Themes | | Exploratory comments |
|---|---|---|
| Role reversal<br>Being the parent<br><br>Carer versus daughter<br><br><br>Mum versus mum with dementia<br>Special/unique relationship | P: Erm I suppose mom sums it up when she says it she says when did we swap over places Lynn? I suppose that sums it up really erm I mean she is good she is very compliant with me she is I've never seen her get nasty or sort of arsy or shitty which you know they can do erm but the simple things like Homecare will go to change her clothes but she won't change her vest and refused to do it but she will do it with me<br>I: Ok | 'Swap over places' –concept of role reversal<br>Is this also Lynn's experience?<br><br>'Compliant' sounds clinical like being a carer, not a daughter<br><br>Use of the word 'they'-referring to people with dementia-grouping us and them<br>Seems important that she won't do it for homecare but will do it for Lynn<br>Feels like an underlying fear of mother's potential difficult behaviour, grateful she's not difficult |
| Good things about caring/positive outcomes<br><br><br><br><br><br>Mum's happiness in seeing me<br>Special relationship | P: like the pensioners club she sometimes doesn't want to go but when she's there she enjoys it erm and is brilliant at taking her tablets will always take tablets but you know she's very very co-operative she's golden you go to see her ago summer evenings some mornings I was there yesterday morning yeah I when and did her shopping yesterday went to Tesco's and came back and she's always pleased to see you there could have been 5 min or five years but she's always pleased to see you<br>I: Mmm | 'Cooperative'-positives about her mother<br>'golden' very positive picture-consistencies with early relationship?<br><br><br><br>'always please to see you' emphasising how often she sees her mum, how she helps her<br>*Repetition of 'pleased to see you'* highlights mother's happiness in seeing her daughter-special relationship<br>Unconditional positive regard |
| Positive view of mum with dementia<br><br><br><br>Comparing personalities | P: erm I know all the homecare ladies think she's lovely I know I'm saying that because she is my mom but she is a pleasant soul she's always got smile on her face I'm the miserable so-and-so if I've got one on me or | Sense of importance of what homecare think of her mum<br>'Saying nice thing because she's my mum'-obligation?<br>*Repetition of pleasant soul*-positive story of mum, feels gentle, not passionate |

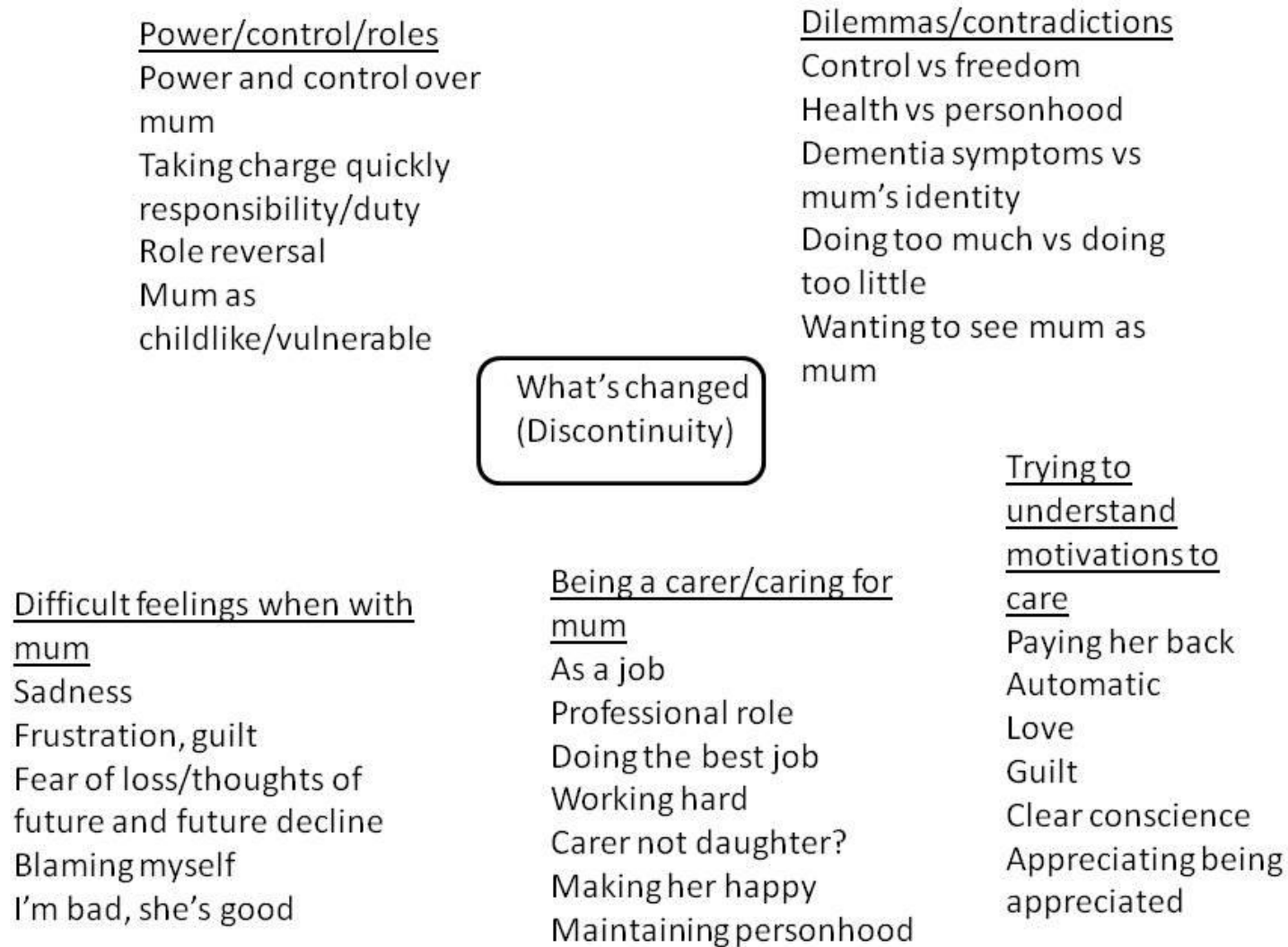| | | |
|---|---|---|
| | I'm not very happy, mom is always happy, you give her a cup of tea and you think you'd given her a bag of sovereigns she really is a pleasant soul to be around she is | Comparison of personalities-hard on herself |
| | I: so has that stayed the same do you think from before the dementia to now? That kind of personality? | *'Bag of sovereigns'* to emphasise mum's reaction |
| Appreciating being appreciated | P: Yeah, she's always been appreciative of everything you do you know it sounds daft but manners pleases and thank you's and we | Mum grateful for help/care |
| | will go out and she will say thank you for a | Manners important-reinforce sense of appreciation-values |
| Motivations for caring | lovely morning Lynn and I mean I could've taken to the dentist and had her teeth pulled | |
| | but she would say thank you for taking me out | *'Dentist'* analogy-unconditional positive regard |
| Showing care/love | and the lovely morning I don't think she has realised what we've done but she always says thank you | Sense of sadness 'I don't think she has realised what we've done..' Repetition of mum's memory loss |
| | I: Right | What does please and thank you mean to Lynn? Feels |
| | P: or whatever I take to see local productions | important-sign of love? |
| Role reversal | like we used to do when we were kids | |
| | I: right | Fond memories of childhood? Maintaining some sense of |
| Continuity | P: you know and/or the kind of things she likes | continuity, thinking of mum's wishes |
| | I: so you still do nice things together? | |
| | P: Oh yeah lunch at least once a week | Emphasises amount of time they spend together 'at least' |
| Time together | preferably twice like I say couple of tea and a | Seems to enjoy spending time with her, sense of warmth |
| Encouraging mum | piece of cake in the garden centre just simple things like that if the weather is nice take her | towards mum |
| | out for a ride in the sun it makes you sound | |
| Being a professional | awful but I make her walk just to keep her | 'It makes you sound awful' sense of guilt due to pushing |
| carer/new roles | mobile because if she was off her feet but | mum? Justifying actions, thinking about mum not coping |

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| | | |
|---|---|---|
| Knowing what's best for mum | couldn't cope there are some films at the back of his houses and make a push the wheelchair along the cycle track to Pellsall when the weather was nice in June last year and then we would go to Pellsall would have an ice cream and I would have water and we would sit and watch the world go by for half an hour sitting in the sun and then I will just push her back | Making sure she gets out of the house, thinking of mum's needs |
| Encouraging mum | | |
| Pleasant time together | | Positive, warm story, sense of mutual enjoyment |
| | I: Mmm | 'we would sit and watch the world go by' strong image, poignant moment? Sense of love? |
| | P: just to get her out for a couple of hours in the afternoon | |
| | I: so there are still lots of nice time together? | |
| Mum's identity | P: Yeah yeah because like I say moms always had cats and dogs so many people use to stop me and ask when mom was in hospital and she had two dogs then and I was taking the dogs out so many people would stop and ask me where is the old lady that used to take these dogs out I didn't know all these people | Referring back to mum having pets, people interested in her mum-seems important to portray this, others caring 'So many people' emphasises that lots of people worried about her mum |
| Mum as an important person | | |
| New roles-filling in the gaps | I: Mmm | |
| | P: they all knew mum she had been there every afternoon for God knows how many years with the dogs so when they saw me with the dogs they wanted to know what had happened to mum | Why is it important that she didn't know these people? |
| | | 'They all know mum' sense of who mum was before the dementia |
| | I: right | |
| Wanting to have a sense of continuity of personhood | P: there's quite a few old ladies along here that I know only because they will stop and ask me how my mum is and what ever | |
| | I: how is that you when that happens? | Lots of old ladies interested in how her mum is doing *Repetition* of this point, seems very important part of the story |

| | | |
|---|---|---|
| Being an advocate? | P: It's lovely<br>I: Right<br>P: it really is nice<br>I: okay | It's lovely, nice, likes it when the women ask after her mum, <u>secondary gains</u>? |
| Positives of being mum's carer/daughter | I: so what aspects of the relationship do you think have stayed the same with you and your mom since before the dementia Intel now, is there anything you think has stayed the same?<br>P: She is still very pleasant lady | |
| | I: how about the way the way that you two get on is anything that has stayed the same? | *Repetition of 'pleasant lady'* important to portray her mum in this way |
| Continuity of person/personhood<br><br>Still mum | P: Erm I don't know I don't know that's an awkward on that is I mean she still my mom she will always be the okay the mental capability is not there to sort practical things out or whatever but you know she's still my mom you know you're she's still my mom really | Sense of confusion about the relationship, feels like she's not thought about this until now<br>Wanting to see mum as separate to dementia? |
| | I: okay | |
| Thoughts of the future | P: which is a nice thing to say because she's not that far down the Alzheimer's line you know she's still my mom she knows who all the kids are she knows my two brothers wives names no way does she remember her grandchildren's names but I think she recognises them when that there is someone she knows | *Repetition of 'she's still my mum'*<br>'Down the line' –thinking about the future? |
| Continuity of relationship | | Focusing on what mum can do<br>Trying to hold on to a sense of who she is, still functioning in some ways, <u>sense of fear of future loss</u>? |
| Dilemma-dementia symptoms vs. mum's identity | I: uh huh<br>you know erm it's typical Alzheimer's in the fact but then again everybody with Alzheimer's is totally different she can tell | Typical Alzheimer's but everyone is different-contradiction<br>Dilemma of trying to understand mum's symptoms but retain a sense of mum's identity |

| Focus on memory loss | you what she did perhaps the night her mum died but she couldn't i.e. what she had dinner | |

Appendix 10: Emergent themes for participant 1

Coping with
difficulties
Humour
Just getting on with it
Acceptance

Attachment style
Always there
Physical presence
Safe base/secure
base
Feeling secure
There for each other
when needed

Mother –daughter
relationship
Unique
Special
We as a unit
Intergenerational
relationships
Culture/family norms

What's stayed
the same
(Continuity)

Feelings towards mum
Love/care
Shared enjoyment
Empathy-putting yourself in
mum's shoes
Unconditional love and
support

Ways of describing/talking
about mum
Positive view/lens
Protecting memory of
mum
Unconditional support-
both ways

Power/control/roles
Power and control over
mum
Taking charge quickly
responsibility/duty
Role reversal
Mum as
childlike/vulnerable

Dilemmas/contradictions
Control vs freedom
Health vs personhood
Dementia symptoms vs
mum's identity
Doing too much vs doing
too little
Wanting to see mum as
mum

What's changed
(Discontinuity)

Trying to
understand
motivations to
care
Paying her back
Automatic
Love
Guilt
Clear conscience
Appreciating being
appreciated

Difficult feelings when with
mum
Sadness
Frustration, guilt
Fear of loss/thoughts of
future and future decline
Blaming myself
I'm bad, she's good

Being a carer/caring for
mum
As a job
Professional role
Doing the best job
Working hard
Carer not daughter?
Making her happy
Maintaining personhood

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Appendix 11: Emergent themes for all transcripts (draft before revised to make final over-

arching and subthemes)

Caring as a
job/Identity of a
carer
Types of care, fear of
not doing
enough/doing too
much, working hard,
devotion vs own life

Ways of coping
Avoidance, acceptance
Maintaining personhood
Humour, distraction,
pretending

Seeing mum differently
Confused/agitated, strong
then weak, independent
then dependent, 'us and
them', medical model,
mum as a child,
personality changes

**Discontinuity**

Motivations to care/not
care
Paying her back,
duty/responsibility/
obligation ,
questioning/justifying
caring style, love,
thoughts of future,
barriers to care

Difficult/negative
feelings towards/with
mum
Frustration,
uncomfortable
situations,
embarrassment, loss

Power/control/roles
Role
reversal/parental
role, taking charge,
power
struggles/battles,
protecting mum

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Attachment/quality
of relationship
Practical care/basic
care
Parenting style
Containment
Wanting
more/missing
something

Ways of coping
Avoidance, acceptance
Humour, distraction,
pretending

Being a
carer/managing the
role
Maintaining
personhood
Caring as a job/being
professional

Continuity

Feelings towards mum
Love/care
Small moments of closeness
Small but significant moments
Negative feelings/unresolved
feelings
Managing mum's
mood/behaviour