

VOLUME I: RESEARCH

THE IMPACT OF DEMENTIA ON FAMILIES

By

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OVERVIEW OF THESIS

As partial fulfilment for the degree of Doctorate of Clinical Psychology (Clin.Psy.D) at the University of Birmingham, a research and clinical volume are submitted. Throughout the thesis, all identifying information has been anonymised to ensure confidentiality is maintained.

Volume I represents the research component. This is comprised of three papers which explore the impact of dementia on families. The first paper is a systematic and critical review of the literature exploring the positive aspects of caregiving for family caregivers of persons with dementia. This paper will be edited for submission to *Dementia: The International Journal of Social Research and Practice*. The second paper describes the first stage of a longitudinal study investigating the effect of having a parent with young onset dementia on young people's transitions into adulthood. This paper will be edited for submission to *Social Science and Medicine*. The third paper provides a brief summary of the literature review and the empirical paper. This is intended for dissemination to a wider audience, in particular for the young people who took part in the research.

Volume II represents the clinical volume. This is comprised of five clinical practice reports. The first presents a cognitive and psychodynamic formulation of a 44-year-old man presenting with social anxiety. A single-case experimental design is presented in the second paper. It details the case of a 39-year-old woman presenting with longstanding issues of shame. The third report describes a service evaluation which examines the extent to which the psychological needs of people with dementia and their carers are being met within an Older Adult Memory Service. In the fourth report a case study is presented. This details the

case of Jenni a 15-year-old girl presenting with low self esteem and self-critical thoughts. The fifth report is an abstract for a presentation of a 4-year-old boy engaging in 'no fear' behaviours. Attachment theory and psychodynamic perspectives were incorporated to understand, formulate and intervene.

To my fiancé James
For your love, encouragement and support

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Firstly I would like to thank the eight young people who gave up their time to be interviewed for this study. I appreciate how difficult it was for them to open up to a stranger about their experiences and I admire their courage in doing so. I hope this study collectively reflects their individual stories and that it will be of benefit to them and others in similar situations.

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LITERATURE REVIEW

Paper to be edited for submission to *Dementia: The International Journal of Social Research
and Practice*.

**WHAT DO WE KNOW ABOUT THE POSITIVE ASPECTS OF
CAREGIVING FOR FAMILY CAREGIVERS OF PEOPLE WITH
DEMENTIA?
A LITERATURE REVIEW**

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ABSTRACT

Historically dementia caregiver research has focused on experiences of burden and the negative consequences of this. However this focus has started to shift to the positive aspects of caregiving. This review presents a systematic and critical overview of research exploring the positive aspects of caregiving for family caregivers of persons with dementia. A literature search identified 20 published articles that met the inclusion criteria. To determine the quality, believability and usefulness of the articles all of the papers were critiqued using a streamlined version of Caldwell, Henshaw and Taylor's (2005) review framework. The reviewed literature focused on exploring three main areas and papers were grouped accordingly: The positive aspects experienced by caregivers, predictive factors and the impact of positive experiences on caregiver outcomes. Further research using more homogenous samples of caregivers, and focusing on young carers is recommended to flesh out current understanding.

Key words: dementia, carers, positive aspects, family caregivers, personal growth

INTRODUCTION

Dementia is an umbrella term encompassing a number of diagnoses (Knapp et al., 2007). Whilst the clinical presentations of these differ, they are all marked by progressive and largely irreversible declines in multiple areas of functioning (DoH, 2009; NICE/SCIE, 2006). With the rise in life expectancy, an increasing number of people are being diagnosed with dementia (Connell, Janevic, & Gallant, 2001). This is likely to result in an increase in the number of people who find themselves caring for a family member with dementia (DoH, 2008). In the UK it is estimated that there are 800,000 people with dementia and 670,000 family and friends acting as primary caregivers (Alzheimer's Society, 2012).

Dementia caregiving: The historical focus of research

Caring for a person with dementia is thought to be particularly challenging due to the cognitive, behavioural and affective losses associated with the illness (Ory, Yee, Tennstedt, & Schulz, 2000). Research has suggested that due to the presentation of the illness, dementia caregiving can lead to higher levels of emotional and physical strain than any other type of caregiving (Schulz, 2000). As such there is a plethora of research focusing on the negative outcomes of dementia caregiving (Etters, Goodall, & Harrison, 2008; Thomas et al., 2002).

Research has typically explored the burden experienced by family caregivers and the negative consequences of this (Butcher, Holkup, & Buckwater, 2001; Farren, Keane-Hagerty, Tatarowicz, & Scorza, 1993). Findings suggest that caregivers of people with dementia are likely to experience a variety of burdens in response to physical, psychological, social and financial stressors (Connell et al., 2001).

This burden has been associated with poorer outcomes (Schulz, Boerner, Hear, Zhang, & Gitlin, 2006) such as: Higher levels of depression, anxiety and psychotropic drug use (Schulz, O'Brien, Bookwala, & Fleissner, 1995), employment complications and increases in family strain and conflicts (Ory et al., 2000), declines in physical health (Connell, 1994; Davis, 1997), decreases in social and personal leisure activities (Almberg, Grafström, & Winblad, 1997) and reduced marital satisfaction (Baikie, 2002).

Dementia caregiving: A change in research focus

Within health and clinical psychology there is a growing interest in the strengths-based perspective and "*how people may grow stronger or gain from a stressful situation*" (Netto, Goh, & Yap, 2009, p. 246). Over the last two decades literature has started to explore the positive aspects of caregiving (PAC). Evidence has suggested that caregiving experiences include not only burden and cause psychological distress, but also have the potential to be positive and growth-enhancing (Dupuis, Epp, & Smale, 2004).

Findings suggest that PAC include: Personal growth, finding meaning and joy, improved social relationships, a sense of mastery and fulfilment, positive affect, wellbeing and satisfaction (Butcher et al., 2001; Cohen, Colantonio, & Vernich, 2002; Dupuis et al., 2004; Gold et al., 1995; Rapp, & Cho, 2000). It is thought that these experiences are shaped by caregiver and care-receiver characteristics, the past and current caregiver care-receiver relationship, illness-related variables and ways of coping (Gonçalves-Pererira et al., 2010). Research has suggested that PAC may help ameliorate stressors and negative caregiving outcomes and thus help maintain quality of life (Tarlow et al., 2004).

Rationale

With the prevalence rates of dementia rising and the increase in the number of family members finding themselves caring for a relative with dementia, understanding the experience of these caregivers is paramount. As highlighted above, a vast amount of literature explores the negative experiences associated with caregiving whilst research into the positive experiences is still in its relative infancy. To gain a rounded picture of the impact of caregiving, it is important that we develop our understanding of these positive experiences.

In 2010, Carbonneau, Caron and Desrosiers presented a conceptual framework for the positive aspects of dementia caregiving based on a review of the general caregiving literature and identified three domains: The quality of the daily relationship between the caregiver and care-receiver, the meaning of the role and feelings of accomplishment. The framework suggests that these outcomes are determined by the caregiver's sense of self-efficacy and enrichments in daily life and that they can lead to increased wellbeing and care continuity. Whilst some similarities may exist across caregiver groups, it is likely that dementia caregivers show distinct differences due to the nature of the illness itself (Ory et al., 2000). Given this, and the growing body of research investigating the positive aspects of dementia caregiving, it seems timely to review this literature.

This review aims to provide a systematic and critical overview of research concerning the PAC for family caregivers of persons with dementia. It is hoped that, through the review and integration of this research, we will be able to gain a better understanding of the complexity of the caregiver experience, inform effective interventions and shape clinical practice.

METHOD

Initially the key terms “‘positive aspects’ AND dementia AND caregiving” were used to search the PsychINFO database (1806-2011) to identify relevant articles. This yielded a total of 36 articles. Following a review of their abstracts, seven were felt to be relevant to the review question. These articles were read and their subject headings were consulted in order to refine the search strategy. The following key terms and minor variations upon them were identified: Dementia/Alzheimer’s disease, caregivers/family members, satisfaction/gain/personal growth/personal development/adversarial growth/posttraumatic growth/uplift and positive aspects/positive outcome/positive experience/positive impact.

These key words were then used to search the following databases: PsychINFO, Medline and EMBASE (See Appendix A for the full search strategy). The time frame used was 1980 to March 2012 as initial searches did not identify any relevant articles published prior to 1980. A total of 407 articles were yielded by this search. Due to the number generated, titles were reviewed and 379 papers were excluded as they focused on: Satisfaction with interventions, treatment, medication, professional care and care homes; burden in caregiving; assessment/ disclosure of diagnoses and typical caregiver characteristics. A possible 28 articles were retained and their abstracts were reviewed. Using the inclusion and exclusion criteria (Table 1) irrelevant or inappropriate articles were filtered out. Seventeen papers were accepted.

A further search using the key words above was conducted using the CINAHL database (time frame; 1980-2012. See Appendix B for CINAHL search strategy). This yielded

one further paper. Finally all references from the included articles were reviewed and two additional articles were found.

Table 1: *Inclusion and Exclusion criteria.*

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> • Data were from family caregivers (not professional carers). • Caregivers providing care for a relative with dementia/Alzheimer’s disease (not caring for people with a more diverse range of conditions). • The study explored the positive aspects of dementia caregiving. • There was a dedicated section for discussion of the positive aspects of dementia caregiving (if the article investigated both positive and negative aspects). • Quantitative articles had to include a measure of positive aspects of caregiving. 	<ul style="list-style-type: none"> • Articles not focusing on family caregivers’ experiences. • Articles focusing on the development of a measure of positive aspects of caregiving. • Articles without data collection and analysis. • Articles that did not have a dedicated section for discussion of the positive aspects of caregiving (when both the positive and negative aspects had). • Conference papers, dissertations and books.

In total 20 papers met the inclusion criteria and were included; six qualitative studies (Beach, 1994; 1997; Murray, Schneider, Banerjee, & Mann, 1999; Netto et al., 2009; Peacock et al., 2010; Sanders, 2005), thirteen quantitative studies (Andr n & Elmst hl, 2005; Baker, Robertson, & Connelly, 2010; Boerner, Horowitz, & Schulz, 2004; Gonalves-Pererira et al., 2010; Harwood et al., 2000; Hilgeman, Allen, DeCoster, & Burgio, 2007; Kinney & Stephens, 1989; Kramer, 1993; 1997; Leipold, Schacke, & Zank, 2008; Liew et al., 2010; Ott, Sanders, & Kelber, 2007; Roff et al., 2004) and one mixed methodology study (Narayan, Lewis, Tornatore, Hepburn, & Corcoran-Perry, 2001).

Ten of the articles focused solely on exploring the PAC and ten investigated both positive and negative experiences. Seven studies primarily focused on exploring the positive aspects experienced by caregivers, eleven investigated factors that are associated with these and the final two focused on the impact that these experiences can have on treatment outcomes and adaptation to bereavement.

A summary of the main characteristics and findings of the qualitative and quantitative studies is presented in Tables 2 and 3 respectively. The mixed method study conducted by Narayan et al. (2001) is reviewed in both tables. A more detailed overview of the studies is provided in Appendix C and D.

Table 2: Summary of qualitative studies (* represents mixed method studies reviewed in both tables)

Study	Country	Sample size	Rel. to care-receiver	Methodology	Themes of gain
Beach (1994)	U.S	14	Grandchildren, niece/nephew and child	Content analysis	Increased mother-daughter bonds, increased opportunities for siblings to spend time together and family bonding.
Beach (1997)	U.S	20	Grandchildren, niece/nephew and child.	Content analysis	Increases sibling activity, greater empathy for older adults, significant mother-adolescent bonding and peer selection and maintenance.
Murray et al. (1999)	14 EU Countries	280	Spouses	Content analysis	Job satisfaction, reciprocity and mutual affection, companionship and sense of duty
Narayan et al. (2001)*	U.S	43	Spouses	Approach not specified	Strengthening of relationships, new learning and feelings of confidence and enjoyment in relation to learning more about themselves.
Netto et al. (2009)	Singapore	12	Daughters, sons, spouse and niece	Grounded theory	Personal growth, gains in relationships and higher-level gains
Peacock et al. (2010)	Canada	39	Spouses, adult-child/adult in-laws, niece/ nephew and other	Interpretive descriptive qualitative approach.	An opportunity to give back, personal growth, discovering inner strengths, sense of competence in the role and opportunity for closer relationship with care-receiver.
Sanders (2005)	U.S	85	Daughters, spouses and sons	Grounded theory	Spiritual growth and increased faith, personal growth and feelings of mastery and accomplishments.

Table 3: Summary of quantitative studies (* represents mixed method studies reviewed in both tables. References for the measures can be found in the original articles)

Study	Country	Sample size	Rel. to care-receiver	Design	Gain measure	Key results
Kinney & Stephens (1989)	U.S	60	Spouses and other	Cross-sectional	Caregiving Hassles and Uplifts Scale	More uplifts were reported by those who were satisfied with support, those caring for those less impaired and those spending more time on caregiving tasks.
Kramer (1993)	U.S	72	Wives	Cross-sectional	Caregiving Satisfaction scale	Prior relationship quality and access to social resources were associated with caregiving satisfaction.
Kramer (1997)	U.S	74	Husbands	Cross-sectional	Caregiving Satisfaction scale	Gain predicted by caregiver education, satisfaction with social participation, health and problem-focused coping.
Harwood et al., (2000)	U.S	40	Adult-children, spouses and nieces.	Cross-sectional	Caregiver Satisfaction Scale	Caregiver satisfaction was predicted by perceived emotional support and caregiver age, with older age and higher levels of support being linked to greater satisfaction
Narayan et al. (2001)*	U.S	50	Spouses	Cross-sectional, mixed methods	The positive aspects of caregiving scale	Positive aspects of caregiving lead to greater caregiver competence. Positive aspects of caregiving were associated with duration of caregiving.
Boerner et al. (2004)	U.S	217	Spouses and other	Longitudinal	Caregiving Benefit Scale	Caregiving benefit was associated with higher post-loss grief and depression.

Study	Country	Sample size	Rel. to care-receiver	Design	Gain measure	Key results
Roff et al. (2004)	U.S	275	Spouses and other	Cross-sectional	Positive Aspects of Caregiving	African Americans reported more PAC than their Caucasian counterparts. Factors associated with this were; socioeconomic status, behavioural bothers, anxiety and religiosity.
Andrén et al. (2005)	Sweden	153	Offspring, spouses and other	Cross-sectional	Carer's Assessment of Satisfaction Index	Caregiver age, disease severity and caregiver-care receiver relationships influenced satisfaction. Sources of satisfaction related to the caregiver and care-receiver.
Hilgeman et al. (2007)	U.S	243	Spouses and non-spouse	Longitudinal	The Positive Aspects of Caregiving Scale	African Americans reported higher levels of PAC. Increases in PAC were associated with lower levels of depression and behavioural bother across time.
Ott et al. (2007)	U.S	201	Spouses and Adult-children	Cross-sectional	Personal growth subscale of the Hogan Grief Reaction Checklist.	Relationship to care recipient was significantly associated with personal growth. Level of social support, coping by reframing and religion significantly contributed to caregiver's personal growth.

Study	Country	Sample size	Rel. to care-receiver	Design	Gain measure	Key results
Leipold et al. (2008)	Germany	126 (study 1) and 321 (study 2)	Spouses, adult-children	Cross-sectional (study 1) and Longitudinal (study 2)	General Personal Growth Scale	Personal growth was associated with two specific caregiving demands; duration of caregiving and lack of social acknowledgement.
Baker et al. (2010)	UK and U.S	70	Husbands	Cross-sectional	Caregiver Satisfaction Scale	Higher gain scores were associated with more traditional responses about emotional closeness to other men and about success, power and competition.
Gonçalves-Pererira et al. (2010)	Portugal	116	Spouses, adult-children and other	Cross-sectional	Positive Aspects of Caregiving Scale	More positive aspects were recognised by older caregivers and those living with the patient. Caregivers from low social class and lower education evidenced higher PAC scores.
Liew et al. (2010)	Singapore	334	Spouses, adult-children, in-laws, grandchildren and other	Cross-sectional	Gain in Alzheimer's Care Instrument	Gain was positively correlated with caregiver sense of competence, positive management strategies and frequent/ close contact with the care-receiver and inversely associated with caregiver burden and mental health problems. Caregiver wellbeing, positive caregiver strategies and participation in caregiver educational/support groups were significantly associated with gain.

QUALITY REVIEW

In order to determine the quality of the studies, a critical appraisal framework was employed (Katrak, Bialocerkowski, Massy-Westropp, Kumar, & Grimmer, 2004). Whilst the importance of critical appraisal tools has been acknowledged, there is currently no 'gold standard' and there is lack of consensus over the most appropriate aspects of research to include in these tools (Katrak et al., 2004). A number of quality criteria frameworks were consulted (Caldwell, Henshaw, & Taylor, 2005; CASP, 2011; Sale & Brazil, 2004; Salter, Hellings, Foley, & Teasell, 2008). The framework described by Caldwell et al. (2005) was felt to be the most appropriate, since it addresses the quality of both qualitative and quantitative research, it was developed specifically for health-related research and it provides a simple-to-understand flow chart for the novice reviewer.

A streamlined version of this framework was developed, retaining all the key criteria but taking out three minor ones (Does the title reflect the content? Are the authors credible? Does the abstract summarize the key components?) to leave a focus on the core content. Specific questions were drawn from other appraisal tools (CASP, 2011; Sale & Brazil, 2004; Salter et al., 2008) to operationalise each criterion in Caldwell's framework. For example, the criterion 'Are all ethical issues identified and addressed?' was divided into two key points: 'Does the author(s) state that ethical approval was sought? Does the author(s) demonstrate an awareness of the ethical issues raised by the study? (E.g. informed consent, confidentiality, how the effects of the study on participants during and after are handled, withdrawal etc.). This ensured a degree of specificity and consistency when rating the articles against the criteria.

Separate templates were drawn up for qualitative (Appendix E) and quantitative studies (Appendix F). Each indicator of quality was assigned a rating (Table 4). The quality of each paper was evaluated against the respective framework (Table 5 for qualitative and Table 6 for quantitative studies). Narayan et al's. (2004) mixed method study is appraised in both tables (indicated by *).

Table 4: *Quality rating system*

Quality rating	Quality rating definition
++	All or most of the criteria have been fulfilled. Criteria that have not been fulfilled are thought very unlikely to impact on the quality or overall conclusions of the study.
+/-	Some of the criteria have been fulfilled. Criteria that have not been fulfilled or not adequately described are thought unlikely to impact on the quality or overall conclusions of the study.
--	Few or no criteria fulfilled. The unfulfilled criteria are thought likely to have an impact on the quality or overall conclusions of the study.

This framework allows clear identification of the strengths and weaknesses of each study (see Appendices G and H for an example of the decision-making process). Whilst the framework provides a guide there is inevitably an element of subjectivity in the ratings assigned. In order to reduce this bias a handful of quality checks were reviewed by the research supervisor (identified by # in the rating tables). Discrepancies were identified and a consensus reached on the quality rating assigned.

Table 5: *Quality review of qualitative studies*

Quality criteria	Journal Article			
	Beach, 1994	Beach, 1997 #	Murray et al., 1999 #	Narayan et al., 2001*
1. Rationale clearly described?	++	++	+/-	++
2. Research aims stated?	++	++	++	++
3. Ethical issues addressed?	+/-	+/-	--	+/-
4. Methodology appropriate to the research question?	Yes	Yes	Yes	Yes
5. Philosophical background identified?	--	--	--	--
6. Study design identified and the rationale for choice evident?	+/-	++	+/-	--
7. Major concepts identified?	--	+/-	--	+/-
8. Sample population situated?	++	++	+/-	++
9. Selection of participants adequately described?	++	++	+/-	++
10. Method of data collection auditable?	++	++	+/-	++
11. Method of data analysis credible and confirmable?	++	++	+/-	++
12. Reflectivity considered and described?	--	--	--	--
13. Findings clearly stated?	+/-	+/-	+/-	+/-
14. Comprehensive discussion?	+/-	++	+/-	+/-
15. Strengths and limitations identified?	+/-	++	+/-	++
16. Justifiable conclusions made?	++	++	+/-	++

Quality criteria	Journal Article		
	Sanders, 2005	Netto et al., 2009	Peacock et al., 2010
1. Rationale clearly described?	++	++	++
2. Research aims stated?	++	++	++
3. Ethical issues addressed?	--	+/-	+/-
4. Methodology appropriate to the research question?	Yes	Yes	Yes
5. Philosophical background identified?	--	+/-	+/-
6. Study design identified and the rationale for choice evident?	++	++	+/-
7. Major concepts identified?	+/-	++	+/-
8. Sample population situated?	++	++	++
9. Selection of participants adequately described?	+/-	+/-	+/-
10. Method of data collection auditable?	++	++	+/-
11. Method of data analysis credible and confirmable?	++	+/-	++
12. Reflectivity considered and described?	--	+/-	--
13. Findings clearly stated?	++	++	++
14. Comprehensive discussion?	+/-	++	++
15. Strengths and limitations identified?	++	++	+/-
16. Justifiable conclusions made?	++	++	++

Table 6: *Quality review of quantitative studies*

Quality criteria	Journal Article				
	Kinney & Stephens, 1989	Kramer, 1993	Kramer, 1997	Harwood et al., 2000 #	Narayan et al., 2001*
1. Rationale clearly described?	++	++	++	++	++
2. Research aims clearly stated?	++	++	++	++	++
3. Ethical issues addressed?	--	--	--	+/-	+/-
4. Is the methodology appropriate to the research question?	Yes	Yes	Yes	Yes	Yes
5. Study design identified and the rationale for choice evident?	+/-	+/-	+/-	+/-	--
6. Hypotheses stated?	--	++	+/-	--	--
7. Key study variables identified?	++	++	++	++	++
8. Sample population situated?	++	++	++	++	++
9. Selection of participants adequately described?	--	+/-	+/-	+/-	++
10. Method of data collection is reliable and valid?	++	+/-	++	+/-	+/-
11. Method of data analysis is reliable and valid?	++	++	++	++	++
12. Findings clearly stated?	++	++	++	++	++
13. Comprehensive discussion?	++	++	++	++	++
14. Strengths and limitations identified?	+/-	++	++	+/-	++
15. Justifiable conclusions made?	++	++	++	++	++

Quality criteria	Journal Article				
	Boerner et al., 2004	Roff et al., 2004 #	Andrén & Elmståhl, 2005 #	Hilgeman et al., 2007 #	Ott et al., 2007 #
1. Rationale clearly described?	++	++	++	++	++
2. Research aims clearly stated?	++	++	++	++	++
3. Ethical issues addressed?	--	--	++	--	+/-
4. Is the methodology appropriate to the research question?	Yes	Yes	Yes	Yes	Yes
5. Study design identified and the rationale for choice evident?	+/-	+/-	--	+/-	+/-
6. Hypotheses stated?	++	++	--	++	--
7. Key study variables identified?	++	++	++	++	++
8. Sample population situated?	+/-	++	++	++	++
9. Selection of participants adequately described?	++	++	++	++	++
10. Method of data collection is reliable and valid?	+/-	+/-	+/-	++	+/-
11. Method of data analysis is reliable and valid?	++	++	+/-	++	++
12. Findings clearly stated?	++	++	++	+/-	++
13. Comprehensive discussion?	+/-	++	++	++	++
14. Strengths and limitations identified?	++	--	++	+/-	++
15. Justifiable conclusions made?	++	++	+/-	++	++

Quality criteria	Journal Article			
	Leipoid et al., 2008 #	Baker et al., 2010	Conçalves-Pererira et al., 2010	Liew et al., 2010
1. Rationale clearly described?	++	++	++	++
2. Research aims clearly stated?	++	++	++	+/-
3. Ethical issues addressed?	+/-	++	+/-	++
4. Is the methodology appropriate to the research question?	Yes	Yes	Yes	Yes
5. Study design identified and the rationale for choice evident?	+/-	+/-	+/-	+/-
6. Hypotheses stated?	++	--	--	--
7. Key study variables identified?	++	++	++	++
8. Sample population situated?	+/-	++	++	++
9. Selection of participants adequately described?	+/-	++	+/-	++
10. Method of data collection is reliable and valid?	+/-	+/-	++	++
11. Method of data analysis is reliable and valid?	++	++	+/-	++
12. Findings clearly stated?	++	++	+/-	++
13. Comprehensive discussion?	++	++	++	++
14. Strengths and limitations identified?	+/-	+/-	++	++
15. Justifiable conclusions made?	++	++	++	++

The ratings suggest that both the qualitative and quantitative studies were of satisfactory quality, with many meeting most of the criteria. Of the few criteria that were rated as poor, commonalities were evident. The key themes from the quality review are discussed below, highlighting some of the strengths and weaknesses of the articles. Common weakness will be discussed at the end.

Qualitative studies

All the qualitative articles chose an appropriate methodology and gave clear statements of their aims. All but one study (Murray et al., 1999) gave a clear description of their rationale; describing current literature, identifying gaps in the evidence base and justifying the need for the research. Most studies (Beach, 1994; 1997; Narayan et al., 2001; Netto et al., 2009; Peacock et al., 2010; Sanders, 2005) provided enough detail about the participants, setting and context for the reader to establish transferability. For all the studies the data analysis was rigorous enough to be rated as at least satisfactory. In addition, they all scored at least satisfactory for providing comprehensive discussions, making justifiable conclusions and discussing strengths and limitations.

In qualitative research one needs to ensure that the themes or theory produced accurately reflect the data and that it is understandable and useful (Hall & Callery, 2001). Five of the studies (Beach, 1994; 1997; Narayan et al., 2001; Peacock et al., 2010; Sanders, 2005) explicitly described the processes implemented to address the issue of validity during analysis and interpretation. The remaining researchers (Murray et al., 1999; Netto et al., 2009) did not discuss the issue of validity and as such the credibility of their results needs to be considered when drawing conclusions from these articles.

When conducting qualitative research it is important to consider reflexivity (Hall & Callery, 2001); the process whereby researchers acknowledge the influences of their prior biases, assumptions and experiences on the research process (Salter et al., 2008). Acknowledging these can increase the likelihood that bias is taken into account, meaning that the interpretations may more accurately reflect participants' experiences (Hall & Callery, 2001). All but one study (Netto et al., 2009) were rated as poor in meeting this criterion. This reduces the credibility of these articles as there is no transparency about the influence of the researchers on the interpretations made.

Due to the relative infancy of this area, there are no accepted definitions for caregivers' positive experiences. Within the literature these are conceptualised in a variety of ways including: Rewards, satisfaction, gains, uplifts and positive aspects (Carbonneau et al., 2010). Whilst all but two articles (Beach, 1994; Murray et al., 1999) were rated as at least satisfactory for defining their major concepts, variation was evident within this. Netto et al. (2009) provided clear definitions for the terms 'caregiver' and 'gains' and Sanders (2005) described her utilisation of the term 'gains'. The remaining studies provided definitions of the theories underpinning their research and the key terms within these, yet failed to define their use of the term 'caregiver' or what they considered to be the PAC (Beach, 1997; Narayan et al., 2001; Peacock et al., 2010). This makes direct comparisons difficult.

In summary the appraisal of the qualitative articles indicates that all can be judged as satisfactory. Beach et al.'s study (1997) was considered to be particularly strong as evidenced by its rating of ++ on all of the methodological quality criteria. The article by Murray et al.

(1999) was considered to be weaker as it met the majority of criteria only at a satisfactory level. As such less weight should be placed on the findings of this study.

Quantitative studies

All of the quantitative studies described their rationale and aims clearly, used appropriate methodology and clearly identified key variables. All were rated as at least satisfactory for clearly stating their findings, providing comprehensive discussions and making justifiable conclusions. In addition they all scored satisfactorily or higher on criteria assessing the reliability and validity of their data collection and analyses, suggesting that their findings are internally valid. However limitations were also evident and these are discussed below.

In terms of participants, all but six studies (Gonçalves-Pererira et al., 2010; Harwood et al., 2000; Kinney & Stephens, 1989; Kramer, 1993; 1997; Leipold et al., 2008) fully described their recruitment procedures and only two (Boerner et al., 2004; Leipold et al., 2008) failed to provide enough detail to determine transferability of the results. As the study by Leipold et al. (2008) only satisfactorily, rather than fully, met the criterion for situating the population sample and adequately describing the recruitment procedure, the generalisability of their results is reduced. In addition the external validity of Kinney and Stephens' (1989) results is reduced as they did not describe their recruitment procedure. As such more confidence can be placed on the findings of the other studies.

It is noted that over half of the studies (Andrén & Elmståhl, 2005; Baker et al., 2010; Gonçalves-Pererira et al., 2010; Harwood et al., 2000; Kinney & Stephens, 1989; Liew et al.,

2010; Narayan et al., 2001; Ott et al., 2007) failed to state their hypotheses despite their discussions often implying that they had some.

When selecting scales it is important to choose ones that are reliable and valid (Pallant, 2007). Reliability indicates the scale's consistency over time and whether its items are measuring the same construct and validity refers to whether the scale is measuring what it states it measures (Searle, 1999). Whilst the majority of the articles reported satisfactory ratings of internal consistency for their measures (evidenced by Cronbach's alpha), three (Andrén & Elmståhl, 2005; Boerner et al., 2004; Liew et al., 2010) only provided this information for some of their scales. In terms of reporting the psychometric properties of the scales, or providing references to articles where this information can be obtained, the majority of studies only reported this for some scales. The articles by Gonçalves-Pererira et al. (2010), Hilgeman et al. (2007) and Kinney and Stephens (1989) were the only three who provided this information for all scales used. Furthermore a number of the studies (Baker et al., 2010; Boerner et al., 2004; Leipold et al., 2008; Roff et al., 2004) described using modified versions of scales; however no explanation of these modifications was given.

Quality frameworks suggest that when reporting statistical findings, authors should indicate which tests were used, identify whether the data met the necessary assumptions, report levels of significance and consider the impact of extraneous variables (CASP, 2011). These factors enable the reader to make decisions about the validity of the statistical findings. All of the studies described using appropriate statistical tests for their research aims and stated significance values. Only four studies (Andrén & Elmståhl, 2005; Gonçalves-Pererira et al., 2010; Kramer, 1993; Liew et al., 2010) explicitly stated that their data met the assumptions.

However the majority of the studies provided sufficient information for the author to conclude that these had been met.

The issue of multiple terminologies to define PAC was again evident. This was evidenced through the use of a variety of scales assessing the following concepts: Uplifts (Kinney & Stephens, 1989), gains (Liew et al., 2010), satisfaction (Andrén & Elmståhl, 2005; Baker et al., 2010; Harwood et al., 2000; Kramer, 1993; 1997), personal growth (Leipold et al., 2010; Ott et al., 2007), positive aspects (Gonçalves-Pererira et al., 2010; Hilgeman et al., 2007; Narayan et al., 2001; Roff et al., 2004) and benefits (Boerner et al., 2004). Whilst all these scales demonstrated satisfactory internal consistency (Pallant, 2007), direct comparisons are again difficult to make due to the lack of consistency in definitions.

In summary the appraisal of the quantitative articles indicates that all can be judged as at least satisfactory. The articles by Hilgeman et al. (2007) and Liew et al. (2010) met most of the methodological quality criteria and as such more confidence should be placed on their findings. It is noted that more methodological flaws were evident in the article by Leipold et al. (2008) and therefore their findings should be interpreted with caution.

Commonalities

Only seven studies used single-population groups within their samples (Baker et al., 2010; Beach, 1994; 1997; Kramer, 1993; 1997; Murray et al., 1999; Narayan et al., 2001). The samples within the remaining articles included a mixture of spouse, offspring, grandchildren and 'other relatives'. Whilst this may allow generalisability of findings to generic caregiving populations, it does not allow for exploration of differences between

specific caregiver groups. As such the conclusions of these studies have been amalgamated for the purpose of this review to determine what we know about the PAC for family caregivers in general. Where there are results from the single population studies, these will be identified.

Within the reviewed studies there was a lack of consensus over the definition of 'caregivers' resulting in a variety of definitions. Only two studies (Netto et al., 2009; Ott et al., 2007) explicitly provided definitions. As a result of the lack of a consistent definition, the samples contained a mixture of primary caregivers, secondary caregivers, co-resident and non co-resident caregivers and caregivers who provided different levels of support. Therefore we cannot yet tell whether positive aspects are related to these different dimensions.

RESULTS

Findings from the reviewed papers are discussed below in relation to: The PAC, predictive factors and the impact of positive experiences. To draw out these three themes, the author read and re-read the papers to become familiar with the data. Findings across all of the studies were compared and grouped based on similarities. Illustrative extracts from the qualitative papers have been used to demonstrate themes. The weight placed on the findings should be based on the comments above.

Positive aspects of dementia caregiving

Five key areas of gain were identified within the literature: Relationships, personal growth, mastery, spiritual growth and reciprocity. It is noted that the only gain reported by adolescents in Beach's (1994; 1997) studies (the two studies focused on younger carers) was in relationships. As such only studies with adult-child, spouses and other family members contributed to the remaining four themes.

Relationships

In Beach's (1997) study 73% of adolescents described feeling that the caregiving situation had had a positive influence on family relationships. This idea was echoed in the study by Netto et al. (2010) where participants described feeling that the caregiving experience had brought their families closer. They described "*treasuring loved ones more*" and being "*united as well as being each other's support*" (p. 254). The sharing of experiences, burdens and joys appeared an important factor in strengthening these relationships. Furthermore shared coping appeared to facilitate the development of closer family bonds, especially at times when the relative with dementia was engaging in behaviours they felt

others may perceive as uncharacteristic (Beach, 1994; 1997). Adolescents reported positive changes in their relationships with siblings, stating that the caregiving situation had resulted in them spending more time together and that older siblings gravitated home more (Beach, 1994; 1997). They also described the caregiving experience leading to increased bonds and intimacy with their well mothers who were described as being the primary caregivers. A reciprocated level of empathy, trust and respect was described within these relationships. The adolescents spoke about their mothers being appreciative of their help, receiving praise and positive reinforcements for this help, being trusted with more serious aspects of caregiving and the sharing of emotions.

Caregivers also reported feeling that their relationship with the care-recipient had grown closer or stronger. Participants described “*getting closer together*” (Narayan et al., 2001, p. 24) and experiencing a greater emotional closeness (Murray et al., 1999) with their unwell partners. They felt that the increased amount of time they spent together (Peacock et al., 2010) and their constant contact and close proximity to the care-recipient (Netto et al., 2009) had brought them closer together.

Personal growth

For many, caregiving created new dimensions in their lives and revealed hidden elements of their personality. Caregivers described becoming more responsible, stronger, more self-aware and more resilient (Sanders, 2005; Netto et al., 2009). Caregivers described feeling more “*able to take hardships*” and to “*take certain crises better...[and] cope in a better way*” (Netto et al., 2009, p. 252). The successful navigation of particularly trying times appeared to facilitate these appraisals of strength and resilience. Caregivers’ increased self-

awareness enabled them to become more aware of, and to reflect upon their own strengths and weaknesses and recognise how these impacted on their feelings of burden (Netto et al., 2009). Additional gains in personal growth included: Becoming more patient and understanding of others and thus more accommodating and less judgemental; becoming more creative in their problem solving; and learning to take things as they come and accept that which cannot be changed (Netto et al., 2009).

Many appeared to appreciate the opportunity to grow as a person through caregiving. They described “*being thankful*” (Sanders, 2005, p. 69) as it had allowed them to re-evaluate their lives and what was most important to them and being “*grateful*” (Peacock et al., 2010, p. 648) for the opportunity of self-discovery.

Mastery

Caregivers described how they had acquired new skills and strengthened existing ones as a result of providing care for a relative with dementia (Andrén & Elmståhl, 2005; Narayan et al., 2001; Murray et al., 1999). Feelings of accomplishment were common in those who found themselves performing tasks that they originally felt incapable of or had concerns about (Sanders, 2005). Spouses who felt that their lives had been enriched were found to be more likely to perceive themselves as competent and confident caregivers (Narayan et al., 2001).

Mastering the caregiving role resulted in feelings of satisfaction (Peacock et al., 2010) related to both caregiver and care-recipient factors (Andrén & Elmståhl, 2005). Caregiver sources of satisfaction included: Feeling needed or wanted, observing care-receiver appreciation and feeling that the care-receiver would do the same for them if the roles were

reversed. Satisfaction relating to the care-receiver included: Maintaining their hygiene, comfort and appearance, seeing them happy and being able to maintain their dignity. In addition satisfaction was reinforced by their ability to provide a safe and loving environment (Peacock et al., 2010) and in doing their best for the care-receiver (Murray et al., 1999).

Further feelings of mastery were experienced when caregivers developed effective ways of coping with challenges and stresses associated with dementia such as difficult behaviours (Peacock et al., 2010) and as such they felt better able to handle trying situations (Netto et al., 2009). Additionally caregivers in Sanders' (2005) study described how the role had resulted in them developing new interests which, for some, resulted in changes in careers.

Spiritual growth

Some caregivers described how caregiving had resulted in changes in their beliefs and the value that they placed on relationships (Netto et al., 2009). They described feeling an increased presence of God in their lives and realising how blessed they were. This seemed to generate feelings of strength and support as they felt a greater force was aiding them in their role (Sanders, 2005). For many, their faith was perceived as being the only stable factor in their lives (Sanders, 2005). A number of caregivers described wanting to repay the gains that they had experienced by providing support and being of service to others (Netto et al., 2009).

Reciprocity

Caregiving was seen as an opportunity to give back to family members (Peacock et al., 2010) and repay spouses for past care and affection (Murray et al., 1999). Comments such as "*she took care of me now I take care of her*" were reported (p. 665). Spouses viewed

caregiving as a fundamental part of marriage, fulfilling the vow ‘for better, for worse’ (Murray et al., 1999; Peacock et al., 2010). However husbands and wives were reported to appraise their caregiving role differently; husbands seeing their caregiving as repayment to their wives for past care and wives viewing it more as a continuation of their relationship (Peacock et al., 2010).

Predictive factors

Several studies considered factors that might predict the experience of PAC. These studies primarily included adult-child, spouse and other family members together in mixed samples. For the purpose of the review, findings have been grouped into factors that were most commonly explored.

Demographics

Several studies have suggested that older age is associated with greater caregiver satisfaction (Andrén & Elmståhl, 2005; Baker et al., 2010; Gonçalves-Pererira et al., 2010; Harwood et al., 2000). This association appeared to be greatest when caregiving was perceived as having a purpose (opportunity for skill development and personal growth) or being a way to show appreciation or express love to the person (Andrén & Elmståhl, 2005). Harwood et al. (2000) suggested that this association may be affected by the relationship between the caregiver and care-receiver. They suggested that older caregivers would more likely be spouses, and derive more satisfaction providing care for a partner than adult-children who are caring for a parent. The higher levels of gains reported by older male caregivers in Baker et al.’s (2010) study were found to be associated with more traditional male responses regarding emotional closeness to other men and power, competition and success. They

suggested that men with less traditional beliefs may have dealt with domestic/caring tasks before and as such are likely to report lower levels of gain.

The role of ethnicity has also been explored. African-American caregivers were found to report experiencing more gains than Caucasians (Hilgeman et al., 2007; Roff et al., 2004). Factors such as lower socioeconomic status, lower anxiety and behavioural bother (the extent to which the caregivers were upset by or bothered by the care-receivers' behaviours) and greater religiosity were attributed to this higher reporting of gain (Roff et al., 2004). The authors contend that the correlation between lower socioeconomic status and greater caregiver benefit may be explained by African-Americans' familiarity with dealing with adversity which may help them to reframe difficulties, such as caring for a relative with dementia, more positively (Gallagher-Thompson et al., 2000, as cited in Roff et al., 2004).

Discrepancies were evident within the literature regarding the association between care-receiver's place of residence and PAC. Whilst Ott and colleagues (2007) found that the magnitude of growth was not dependent on this, findings from Gonçalves-Pererira et al.'s (2010) study suggested that co-resident caregivers recognised more caregiver benefits. Similarly Liew et al. (2010) found that those in frequent and close contact with the care-receiver reported more gains. However this relationship ceased to be significant after further analysis. Rather the authors suggested that this frequent close contact provided more opportunities for caregivers to equip themselves with strategies to cope with the demands and stressors of caregiving, hence coping mediated the relationship.

The influence of education on caregiver gains has also been explored. Kramer (1997) found that higher levels of gains were reported by those caregivers who were less educated. They suggested that those with higher education levels were likely to observe a greater discrepancy between their previous and current role and as such may not experience a sense of reward or meaning from the caregiver role (Kramer, 1997). This finding was supported by Gonçalves-Pererira et al. (2010) who found that Portuguese carers with lower levels of education scored higher on a measure of PAC.

Differences in findings have also been found in terms of the relationship between health and PAC. Kramer (1997) found that men who subjectively reported being in good health appraised higher levels of gain. However Harwood et al. (2000), Andrén and Elmståhl (2005) and Baker et al. (2010) found no association between subjective health and PAC.

In summary the above evidence suggests that a number of caregiving demographics may be associated with PAC however this evidence is contradictory.

Relationship factors

Caregivers who describe a better pre-dementia relationship reported experiencing a greater satisfaction from caregiving (Kramer, 1993). It was suggested that those who experience closer relationships may feel less burdened in the role (Williamson & Schulz, 1990, as cited in Kramer, 1993) and as such may report higher levels of satisfaction. In line with these findings, Swedish caregivers who described having a more distant relationship with the care-recipient experienced less PAC (Andrén & Elmståhl, 2005).

The relationship also appears to have an influence on the types of gain experienced. Spouse caregivers reported experiencing higher reciprocity gains than offspring caregivers (Andrén & Elmståhl, 2005). Conversely Ott et al. (2007) found that adult-children experienced more growth than spouses. Sanders (2005) identified that whilst spiritual growth was experienced by offspring and wife caregivers, it was notably absent in the accounts of husband caregivers. She also found that husbands and daughters reported experiencing more personal growth as a result of the caregiving role than sons and wives.

These findings suggest that those who report a more distant and/or strained relationship with the care-recipient prior to the onset of dementia may be less likely to experience PAC. In addition these studies propose the caregivers' relationship to the care-recipient may also have some influence on the types of gains experienced.

Social resources

Satisfaction with the frequency and quality of social activities and with social participation has been found to have positive associations with caregiver gains (Kramer, 1993; 1997). Harwood et al. (2000) found that perceived emotional support significantly impacted on PAC in Cuban American caregivers. Those who felt that others were available for support appeared to appraise the caregiving situation as more satisfying. This finding was echoed by Kinney and Stephens (1989) and Ott et al. (2007) who found that higher levels of support contributed to more uplifts and greater personal growth. In addition those who attended education/support groups were found to be more likely to experience higher levels of gain than those who did not (Liew et al., 2010). It was suggested that participation in these groups

may increase caregiver skills and knowledge which in turn may lead to more positive appraisals.

In summary the above findings offer evidence to suggest that greater social resources, such as the availability of others for support, attendance at carer groups and participation in social activities may contribute to positive outcomes for dementia caregivers.

Coping strategies

Husband caregivers who reported using problem-focused coping also reported higher levels of gain (Kramer, 1997). As these strategies focus on managing the stressors of dementia caregiving, such as behaviours, the authors suggest that use of problem-focused coping is likely to engender feelings of mastery. Echoing this, Liew et al. (2010) found that the use of active management and encouragement were linked with PAC. It was felt that these strategies created more structured environments which reduced care-receiver distress and therefore benefitted the caregiver.

Illness severity

Research suggests that duration of caregiving is significantly associated with PAC where those who had been caregiving longer reported experiencing more PAC (Liew et al., 2010; Narayan et al., 2001). This increase appeared to be triggered by caregiving demands as, once caregiving tasks were controlled for, caregiving duration ceased to be associated with personal growth (Leipold et al., 2008). Their findings suggest that personal growth increases as caregiving tasks increase. Similarly Kinney and Stephens (1989) found that more

caregiving uplifts were reported by those who spent a greater proportion of time per day on caregiving activities.

The care-recipients' level of functioning has also been associated with PAC. Those caring for individuals with greater limitations in daily functioning reported higher levels of satisfaction (Kramer, 1993). It was suggested that those who help care-receivers with physical functioning may experience more satisfaction as they can clearly see the rewards of their work. This finding was echoed in the Kinney and Stephens (1989) study where greater uplifts were reported by caregivers of those who were more physically disabled and less cognitively/behaviourally impaired. However whilst Andrén and Elmståhl (2005) found a positive association between satisfaction and disease severity, this correlation was more significant when the care-receiver had impairments in intellectual functioning compared with those presenting with impaired emotional or motor functioning.

Behavioural bother has also shown some association with PAC, with more gains being reported by caregivers who experience less problematic behaviour (Roff et al., 2004). In support Boerner et al. (2004) found that fewer benefits were described by those who cared for a relative presenting with more behavioural and memory problems. In contrast findings from Hilgeman et al.'s (2007) study did not support this association. However they did find an association between daily care burden and PAC, with higher gains being reported by caregivers who experienced less daily care burden.

To summarise there is some evidence to suggest that lower levels of problematic behaviour and daily care burden may be associated with PAC.

The impact of positive experiences of caregiving

The impact of PAC on caregiver outcomes has been investigated in a handful of studies, which focused on outcomes such as post-loss experiences of grief and depression, treatment benefit and adverse effects of caregiving.

Caregivers who experienced more gains prior to the loss of the person with dementia were found to report higher levels of post-loss grief and depression (Boerner et al., 2004). The authors suggest that these caregivers may have been closer to the care-recipient and/or perceived caregiving as a more meaningful and important role. They propose that the loss experienced may be greater and consequently higher levels of depression and grief may be reported (Boerner et al., 2004).

Several studies have proposed that PAC may buffer caregivers against the adverse effects of caregiving such as burden and depression (Hilgeman et al., 2007; Liew et al., 2010; Peacock et al., 2009; Sanders, 2005). Lower levels of depression, daily care burden and behavioural bother were found to be reported by caregivers who identified more PAC over time (Hilgeman et al., 2007). The authors suggest that these negative outcomes may be reduced as a result of the caregiver's positively reappraising their situation over time. In support of this, Liew et al. (2010) found evidence to suggest that caregivers who experienced more PAC reported less burden and greater mental well being and Sanders (2005) identified that spiritual growth appeared to create a sense of comfort in caregivers which seemed to help reduce feelings of strain. However Kinney and Stephens (1989) found that more uplifts were associated with greater feelings of distress.

In terms of intervention benefit, Hilgeman et al. (2007) noted that those who reported less PAC appeared to benefit more from their intervention. The authors proposed that this benefit may have been related to the intervention focusing on building caregiver skills in managing stress. Taking into consideration other findings identified within this review it could be suggested that the intervention may have resulted in increased feelings of mastery which in turn may have lead to increased feelings of benefit (Sanders, 2005).

DISCUSSION

The findings of this systematic review suggest that dementia caregivers can experience PAC across five key areas. Evidence from the reviewed studies suggests that all caregiver groups may experience gains in family relationships such as closer bonds, strengthened relationships with the care-recipient and, for adolescents, positive changes in their relationships with siblings and well mothers. Adult caregivers within these studies described having the opportunity to grow as a person and develop a greater self awareness; experiencing feelings of accomplishment and mastery related to the successful undertaking of caregiving tasks and their ability to cope with difficulties they initially felt unsure of; spiritual growth; and having the chance to repay the care-recipient for previous care. Factors that were proposed to facilitate these gains included: Caregiver age, level of education and ethnicity, quality of the pre-dementia relationship, frequency of contact, perceived support, satisfaction with social activities and participation, attendance at educational/support groups, the use of problem-focused coping strategies, the number of caregiving tasks and behavioural bother/daily care burden. Whilst less research has focused on the impact of gains on caregiver outcomes, findings suggest that grief, burden and wellbeing and the benefit gained from skill-based interventions may be influenced by the amount of PAC reported by caregivers.

As previously discussed, Carbonneau and colleagues (2010) produced a conceptual model of the positive aspects of dementia caregiving based on a review of the generic caregiving literature. Whilst the three pertinent themes identified within this review echo those presented in their model, some differences were found. In terms of the domains of PAC, Carbonneau et al.'s model acknowledges personal growth and reciprocity, however these appeared more central in the dementia caregiving literature than in their broader review.

Additionally their model focuses on the quality of the caregiver/care-receiver daily relationship whereas the dementia literature suggests that gains can also be experienced in other familial relationships. While similar outcomes were described in both reviews, the current review also considered the impact of PAC on caregiver grief. Finally whilst they identified two main determinants of PAC, this review found that the picture was less clear, with multiple factors being identified as potential predictors. As so many disparate predictors have been explored in the dementia research, we need further studies that replicate the findings before we can be more definite about some of these.

Review limitations

A number of studies highlight that PAC can occur simultaneously alongside negative aspects of caregiving (Baker et al., 2010; Gonçalves-Pererira et al., 2010; Harwood et al., 2000; Kramer, 1993; 1997; Murray et al., 1999; Narayan et al., 2001; Sanders, 2005). However the association between positive and negative experiences remains unclear. Narayan et al. (2001) found no significant correlations between negative and positive subjective responses, whereas Gonçalves-Pererira et al. (2010) found that higher levels of burden were reported by those who experienced less PAC. Due to the co-existence of these experiences, the findings of this review need to be considered alongside the literature on the negative consequences of dementia caregiving in order to gain a rounded view of the caregiving experience.

Limitations of the reviewed studies

The framework described by Caldwell et al. (2005) was used to assess the quality of the articles contained within this review. Whilst the quality of all the papers was deemed to be

at least satisfactory, a number of limitations were evident. The majority of studies employed cross-sectional designs with few controlling for confounding variables thus causality cannot be assumed. For example there is evidence to suggest that PAC may reduce the experience of burden and depression however, it may also be plausible that depression and burden are likely to prevent the carer from experiencing PAC. Most of studies used heterogeneous samples and did not differentiate between findings in terms of the caregiver's relationship to the care-receiver. There was a lack of consensus regarding the definition of 'caregivers' and what constitutes PAC. The variations in the terminologies and scales used make direct comparisons between studies difficult. It is noted that the majority of studies were conducted in America and as such the transferability of data to other population groups may be reduced. Finally, despite an extensive range of predictive factors being investigated, very few studies have explored the same factors. Whilst this is likely to be a result of the relative infancy of this area of research, it makes comparisons across the literature in terms of support and contradictions difficult.

Clinical implications and future research

Whilst drawing substantial conclusions and recommendations are difficult based on the design limitations of the studies there is some evidence to suggest that the experience of PAC may reduce the impact of negative consequences associated with caregiving such as burden and depression (Hilgeman et al., 2007; Liew et al., 2010; Peacock et al., 2009; Sanders, 2005; Tarlow et al., 2004). Additionally findings also propose that the experience of PAC may help motivate caregivers to continue in their roles (Murray et al., 2001; Peacock et al., 2009). As such ascertaining information about the pre-dementia relationship, their involvement in and satisfaction with social activities, and how they experience the role may

help identify those 'at risk' of experiencing greater feelings of burden, depression and post-loss grief (Boerner et al., 2004; Netto et al., 2009). Findings offered evidence to suggest that factors such as social support, attendance at educational groups, the development of effective coping strategies, experiencing feelings of accomplishment, learning new skills and satisfaction with social activities and/or participation may impact on PAC (Andrén & Elmståhl, 2005; Harwood et al., 2000; Kramer, 1993; 1997; Liew et al., 2010; Netto et al., 2009; Peacock et al., 2010). In light of these findings it is suggested that caregiver interventions focusing on refining and developing skills, teaching problem-focused coping and active management strategies and increasing caregiver's social involvement may help enhance PAC (Harwood et al., 2000; Narayan et al., 2001; Ott et al., 2007).

This area of research is still in its relative infancy and further exploration is need to develop our understanding further and offer support for, or contradictions to, initial findings. In order to build a more comprehensive picture, the following recommendations for future research are suggested. To determine whether the types of gains experienced differ between caregiver groups, it is suggested that future research draws on homogeneous samples or differentiates findings according to specific groups. Additionally, further research focusing on predictive factors would add to the strength of the present findings and establish whether these are common across caregiver groups. Whilst the impact of PAC on caregiver outcomes has received some attention, further research is needed to build upon these findings. Finally, this review highlighted the lack of research investigating the experiences of young children involved in caregiving with only one study including this population group in their sample (Beach, 1997). The experiences of these young children are likely to differ from those of older caregivers and as such further research is warranted in this area.

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EMPIRICAL PAPER

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**YOUNG PEOPLE'S EXPERIENCES OF HAVING A PARENT WITH
YOUNG ONSET DEMENTIA:**

**Stage one of a longitudinal study investigating the effect of these
experiences on their transitions into adulthood.**

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ABSTRACT

Although dementia is often thought to be an illness of old age, over 17,000 people develop it before the age of 65. This is known as young onset dementia (YOD). With people starting families later in life it is likely that many of these people will still have children who are reliant on them. Despite this very little research has explored these children's experiences of having a parent with YOD and the impact that this may have on their development. This is the first stage of a longitudinal study which aims to explore the effects of having a parent with YOD on young people's transitions into adulthood. Eight young people aged 14 to 23 years took part in the study. They were recruited via NHS services across the west midlands and through voluntary organisations. The young people's experiences were ascertained through semi-structured interviews. Interviews were recorded, transcribed and analysed using grounded theory methodology. The author proposes a model to describe the experiences of these young people. This model consists of nine categories: 'Something's wrong', 'discovering dementia', 'stepping up, role reversal', 'maturity and changes in self-concept', 'stress and strain of the illness', 'reconfiguring relationships', 'loss', 'coping' and 'sense making'. Whilst stepping up into adult roles appeared to impact on the young person's ability to separate from the family, thus impacting on their transition into adulthood, it also appeared to accelerate growth with many of the young people describing increases in maturity. Many of the young people described how they felt 'forgotten' by services who typically focus on the person with YOD and their spouse. It is recommended that information and interventions specific to young people are developed and provided, alongside family interventions that promote open communication.

Key words: young onset dementia, children, personal growth, stepping up, burden

INTRODUCTION

A significant number of people develop dementia under the age of 65 (van Vliet et al., 2010). These people are referred to as having young onset dementia (YOD). It is estimated that over 17,000 people in the UK suffer with YOD (Alzheimer's Society, 2012). However many believe that this figure is likely to be an under-representation with some reports suggesting that the figures are closer to 64,000 (SCIE, 2010).

Younger people with dementia

It is suggested that the needs of people with YOD vary from those who develop dementia later in life, due to differences in the social and psychological context of older and younger people (Beattie, Daker-White, Gilliard, & Means, 2002; Pison-Young, Lee, Jones, & Guss, 2011). They are more likely to still be in paid work, have heavy financial responsibilities and be physically fit and healthy (DoH, 2009; Luscombe, Brodaty, & Freeth, 1998). Additionally due to the age of onset and the increasing number of couples having offspring later in life, many people diagnosed with YOD are likely to have children who are still reliant on them and living at home (Keady & Nolan, 1999).

Children of young people with dementia

Whilst a number of studies have investigated the impact of YOD on the person and their families, very little research has been conducted to explore the experiences of these children and the possible impact on their development (Roach & Keady, 2008; Svanberg, Spector, & Stott, 2011; van Vliet, de Vugt, Bakker, Koopmans, & Verhey, 2010). Over the past two decades there have been seven published studies which have included children who have parents with YOD (Allen, Oyebode, & Allen, 2009; Beach, 1994; 1997; Davies, Clovis,

Ingram, Priddy, & Tinklenberg, 2000; Robertson, 1996; Svanberg, Stott, & Spector, 2010; Szinovacz, 2003). In addition the author is aware of one unpublished study (Lord, Oyebode, Allen, & Allen, 2010).

Changes in relationships are described in most of the studies. Robertson (1996) found that children experienced a loss of relationship with the unwell parent and that they often struggled to mourn this loss. In regard to their relationship with the well parent, findings varied. Young people have described stronger, closer relationships with the well parent (Beach, 1994; 1997; Robertson, 1996; Szinovacz, 2003). Conversely others reported a deterioration in this relationship, related to: Having to compete for their caregiving parent's attention; their parents taking their stress out on them and being absorbed in care activities; and the enforcement of stricter rules/curfews (Beach, 1994; Szinovacz, 2003).

Illness acceptance and grief have been explored by Davies and colleagues (2000). They described how the young people have to concurrently "*redefine the parent as a patient with dementia, mourn the loss of the person that was and adjust to changes in the family system*" (p.54). A four-stage model was proposed to describe the processes children go through before they can accept the illness: Awareness; explanation; attribution and; integration. For healthy adjustment they state that children must simultaneously tackle several tasks: Adjust to changes in the family system; redefine their relationship with the unwell parent and; mourn the loss of the person that was. Once they have accepted and recognised the illness, then grief can begin.

Young people who had fathers with YOD described coping with the illness ‘one day at a time’ (Allen et al., 2009). The young person’s wellbeing was found to be affected by the illness, reconfiguration of relationships, strain, caring and coping. They described experiences of facing the loss of their ‘real’ father, taking on adult responsibilities, worries for the well parent and adapting to changes in family role. These young people were re-interviewed 4 years later (Lord et al., 2010), at which point it was suggested that they experienced four different process during their ‘journey’: Coping, grieving, questioning and growing. Movement between these stages was thought to be influenced by their parent’s position on the illness trajectory, demands placed upon them and the occurrence of specific events.

Finally Svanberg et al. (2010) proposed a three-stage process model for young people adapting to having a parent with YOD: Grieving for the ‘lost parent’, emotional detachment and becoming grown up. The young people in her study described how they ‘just got on with it’ and felt that they had no choice but to help care for their parent.

Children of parents with YOD: Adolescent development

Most children who have a parent with YOD are likely to be approaching, entering or already navigating adolescence; a critical time period where children grow into young adults, assisted by their parents who provide a secure base and modelling (Carr, 2006). During this period adolescents start to discover themselves and make sense of how they fit into the world through self-exploration and greater autonomy.

Research suggests that a number of factors can affect the successful negotiation of this life-stage. These include parental illness, taking on caregiving tasks, the unavailability of

parents due to the illness or being heavily involved in caregiving and the stresses associated with caring for a family member with YOD (Becker, 2007; Compas, Hinden, & Gerhardt, 1995). Additionally children within caregiving families may find themselves 'forced' into assuming adult roles and responsibilities prematurely at a time when they are trying to seek separation and individualisation (Davies et al., 2000). Whilst the young people are navigating adolescence and making sense of their own identity, research has described how they are simultaneously witnessing and making sense of the progressive decline of their parent's cognitive function and self-care abilities (Rosenthal Gelman, & Greer, 2011). At the same time the young people are coping with the demands placed upon them and the losses that they were faced with over the illness trajectory (Lord et al., 2010). It is suggested that this further hinders their transition to adulthood.

Rationale

Only three of the studies described above have explicitly explored the young person's perceptions (Allen et al., 2009; Lord et al., 2010; Svanberg et al., 2010). However it is noted that a number of the unwell parents in Lord et al.'s (2010) and Svanberg et al.'s study were deceased at the point that the young person was interviewed and this may have impacted on the findings. Whilst other studies have included children who have a parent with YOD, their perceptions have been combined with the views of young people caring for other relatives with dementia, such as grandparents (Beach, 1994; 1997; Szinovacz, 2003) or with those of parents and professionals (Robertson, 1996). As such their unique experiences cannot be unequivocally drawn from the data. Whilst Davies et al. (2000) looked specifically at children of parents with dementia, the mean age of the children in their sample was 28 years and only 10% of them were living with the parent. It is likely that their experiences may differ from

children who are younger and who are living with the parent with YOD. It has been suggested that further research is needed in this area due to the unique progression of the illness and the significant effects it has on young people. Previous studies highlight the need for longitudinal research to explore the continuing impact of having a parent with YOD, the inclusion of children who have a mother diagnosed with YOD and for samples to include younger children.

The overall aim of the current study is to explore the ongoing experiences of having a parent with YOD; and to increase our understanding of the difficulties faced by these young people and their continuing impact as they simultaneously navigate adolescence and develop into young adults whilst witnessing the deterioration of their parent. This study attempts to address the limitations described above and expand on the findings of the three earlier studies (Allen et al., 2009; Lord et al., 2010; Svanberg et al., 2010) by recruiting young people who have mothers diagnosed with YOD and including only those who are currently living with or in regular contact with the unwell parent. Additionally this study aims to address the need for longitudinal studies by gaining consent from the young people to interview them at regular intervals to explore the ongoing affect of having a mother or father with YOD.

The study aims to address the following question: What is the ongoing impact of having a parent with YOD? This aim will be addressed using a two stage design. In the first stage a cross sectional design will be employed to explore the young people's current perceptions and in stage two the ongoing impact of these experiences will be explored through the use of a longitudinal methodology. This research constitutes stage one and thus describes the findings of the cross sectional element of the study.

METHOD

Design

A longitudinal qualitative methodology, incorporating two stages, was adopted to address the overall aim of the study. As previously stated this study describes the initial interview conducted at stage one, the cross sectional element of the study. Findings from stage two will be amalgamated and compared with those from stage one as the young people are interviewed at intervals of no less than a year until they reach the age of 25 to inform our understanding on the ongoing effects of having a parent with YOD.

The young people's experiences were elicited through semi-structured interviews. Using the grounded theory framework proposed by Corbin and Strauss (2008), data were collected and analysed. Grounded theory aims to generate a theory, which is "grounded" in the data, to explain the phenomena being studied (Barker, Pistrang & Elliot, 2005). When relatively little is known about an area of interest, grounded theory is advocated as a method of choice. To ensure that the proposed theory was based on the young people's subjective reality and reflected their experiences, a constructivist approach was taken (Charmaz, 2006).

Procedure

Ethical approval was originally granted by Coventry and Warwickshire Research Ethics Committee in June 2009 (Appendix A). However an opportunity arose for the original chief investigator to pursue an alternative project and as such the project was put on hold. In January 2011 a change in investigator was approved and the project commenced (Appendix B).

Services across seven NHS Trusts within the West Midlands were approached to act as participant identification centres. Research governance approval was granted from each Trust's Research and Development department (Appendix C). The original target for the sample size was approximately 15. This figure was determined based on the following. Firstly, grounded theory methodology advocates that data collection should continue until no new categories emerge, thus it was hoped that this sample size would allow saturation to be reached. Secondly, due to the longitudinal element of the study loss of participants may occur as a result of drop out or loss of contact and therefore this sample size would allow for this loss whilst still allowing the researcher to obtain meaningful and useful results. However this target was not reached due to a number of difficulties encountered in the recruitment process. These difficulties included: Given the rarity of the intended participant group, a large number of sites were contacted at the outset of the study, however this inevitably meant it was hard to have frequent personal contact with potential referrers at each and every site; there were increasing pressures on services to meet targets limiting the time professionals had available to push the project; and some services that agreed to identify participants were being re-organised during the recruitment period. To increase the sample size, additional ethical approval was obtained to access participants through national voluntary agencies such as the Alzheimer's Society (Appendix D). In addition advertisements were placed on the Alzheimer's society 'Talking Point' website (Appendix E) however none of the current participants was recruited via this method.

Participants

Eight participants were recruited through Specialist Young Onset Dementia Services and Older Adult Services across the West Midlands area and locally through the Alzheimer's Society. These participants met the following inclusion criteria: (1) Aged between 13 and 24

years, (2) had a mother or father who had been diagnosed with young onset dementia at least three months previously and (3) live with or are in regular contact with this parent. Four males and four females were recruited from five families (Table 1). All were white British and their ages ranged from 14 to 22 years. Of the five parents with dementia, three were female. All but one parent lived in the family home. The wide age band within the inclusion criteria was chosen for two reasons. Firstly, due to the recruitment difficulties described above the age range was adopted to increase the sample pool and thus the potential sample size. Secondly, the transition from adolescence to adulthood was thought to occur between the ages of 13 and 18. However it has been suggested that due to societal changes, this journey into adulthood now occurs over a longer period of time continuing up to the age of 25 (Arnett, 2000). As such young people up to the age of 25 were included in this study.

Table 1: *Participant demographics (Family identification letters and pseudonyms have been used. YOD = young onset dementia, AD= Alzheimer's disease).*

N ^o	Pseudonym	Family	Gender	Age	Parent with dementia	Age of parent	Type of dementia	Duration of dementia diagnosis	Family configuration
1	Jack	A	Male	22	Mother	48	YOD	1 year (symptoms present for 7 years)	Lives with mother, maternal aunt and 6 yr old cousin.
2	Claire	B	Female	14	Father	45	AD	5 years	Lives with mother. Father in care home.
3	Thomas	C	Male	17	Father	60	AD	4 years (only made aware 2yrs ago)	Lives with mother, father and twin siblings.
4	George	C	Male	15	Father	60	AD	4 years (only made aware 2yrs ago)	Lives with mother, father, older brother and twin sister.
5	Hayley	D	Female	14	Mother	55	YOD	3 years (in end stages)	Lives with mother, father and 4 older brothers.
6	Jessica	E	Female	20	Mother	47	AD	1.5 years	Lives with mother, father, younger brother and sister.
7	Sally	E	Female	17	Mother	47	AD	1.5 years	Lives with mother, father, younger brother and older sister.
8	Paul	E	Male	15	Mother	47	AD	1.5 years	Lives with mother, father and two older sisters.

Families with a young person meeting the inclusion criteria were initially approached by a familiar professional from their service provider. Those who expressed an interest were provided with an information pack containing: An invitation letter (Appendix F; young person's version, Appendix G; parent/guardian version) and information about the study (Appendix H; young person's version, Appendix I; older child's version, Appendix J; parent/guardian version). Those who consented to take part were then contacted by the author to discuss the study further, answer any questions and if appropriate arrange an interview date. Interviews took place at their venue of choice. To ensure that all the young people were aware of the aims of the study and their right to withdraw, the author read through the information sheet with them before obtaining their consent (Appendix K; young person's version, Appendix L; older child's version). Parental consent was obtained for all young people under the age of 16 (Appendix M).

Interviews ranged in length from 60 to 115 minutes and were digitally recorded. All but one participant, who chose to be interviewed at the university, were interviewed in their home. Following the interview participants were debriefed and details of support services were provided if needed. All participants received a gift voucher as a token of appreciation after their interview. Immediately following the interview the author recorded her reflections about the interview content and process (Appendix N).

Interview schedule

A semi-structured interview guide (Appendix O) was developed based on themes from previous studies (Allen et al., 2009; Lord et al., 2010; Svanberg et al., 2010). The following topic areas were covered: Dementia, changes within the family home, relationships, personal

changes, coping, support and the wider impact of the diagnosis. Examples of opening questions included: ‘What was it like for you when you found out that your mom/dad was unwell?’ and ‘What impacts do you feel your mom/dad’s illness have had on you as a person?’ In accordance with grounded theory (Corbin & Strauss, 2008) data collection and analysis were carried out iteratively with new themes and lines of enquiry being incorporated into the interview schedule. These included worries about having dementia in the future, feeling different to peers and positive changes in the self.

Analysis

Interviews were transcribed verbatim and analysed by the author. Analysis followed Corbin and Strauss’ (2008) methodology. In vivo and descriptive labels were applied to units of data, often sentences or utterances (open coding: Appendix P), thus allowing the author to stay close to the data (Charmaz, 2006). Conceptually similar labels were then grouped together into focused codes (Appendix Q). As each transcript was analysed these codes were reviewed and reorganised to incorporate new data. For example the code ‘seeing changes in Mom/Dad’ was initially developed to incorporate the young people’s experiences of noticing differences in the unwell parent. As the analysis progressed this category was reorganised and relabelled to illustrate two key processes of ‘noticing’ and ‘realising’. Further alterations were made through discussions with research supervisors. These focused codes were grouped into categories which were then linked through the process of axial coding to produce a plausible explanatory framework about the experiences of these young people. Constant comparisons were made between transcripts to compare data for similarities and differences. Memos were kept throughout the analysis process where the author recorded her thoughts on the data, comparisons between transcripts and emerging themes (Appendix R).

Credibility and reflexivity

It is important that qualitative researchers ensure that the proposed theory accurately reflects the data and that it is understandable and useful (Hall & Callery, 2001). Transcripts were analysed independently by the author and research supervisors. Assigned codes were reviewed, discrepancies discussed and a consensus reached. In addition a section of the analysis was reviewed and commented on by peers. Initial thoughts relating to emerging themes and model development were discussed in research meetings (Appendix S). The proposed model was then discussed with a Clinical Psychologist who works with older adults and one who works with young people to ensure that it was deemed understandable and useful. Ideas offered by these consultees were used to further develop the model and refine its diagrammatical representation (Appendix T).

Being aware of and acknowledging one's own influence on the research process increases the likelihood that the model accurately reflects the participant's experiences (Salter, Hellings, Foley & Teasell, 2008). Whilst an interview guide was consulted, the researcher was mindful of allowing the young people to direct the content of the interview and also to check out with them if there was anything else they wanted to discuss that had not been covered. Additionally reflective diaries and memos were kept throughout for the author to 'park' her thoughts and ideas to help her remain 'close' to the data.

RESULTS

The proposed grounded theory is based on the initial interviews of the young people and as such portrays their current perceptions. Data collected in stage two will be used to build on the current model to illustrate the ongoing impact of these experiences as they grow up.

Nine main categories transpired from the data analysis (Table 2). Figure 1 captures the young people's experiences of having a parent diagnosed with YOD. The model suggests that initially the young people progressed through a linear process of sensing that 'something was wrong' with their parent and finding out that they had 'dementia'. In response to changes in their parent pre and post diagnosis, they described taking on increasing responsibilities and 'stepping up' into adult roles which resulted in changes in their 'maturity and self-concept'. These increases in responsibility and living with a parent with YOD generated feelings of 'stress and strain'. This, coupled with stepping up, resulted in the 'reconfiguration of relationships' particularly with family members. As a result of the changes in the parent and the family home, the young people described experiencing a 'loss' of past life, their parent and their future. They described employing a number of strategies in order to 'cope' with hearing the diagnosis and the stress and strain of the illness. Finally the young people described their attempts to 'make sense' of and understand the changes in their parents and the diagnosis.

Each category will be presented in turn. Sub-categories within these, and the links between categories, are described and supporting quotes offered.

Table 2: *Categories and sub-categories*

Categories	Subcategories
Something's wrong	<ul style="list-style-type: none"> • Noticing • Realising
Discovering dementia	<ul style="list-style-type: none"> • "They have dementia" • "They won't get better"
Stepping up, Role reversal	
Maturity and changes in self-concept	<ul style="list-style-type: none"> • Growth • Changes in me • Out of step with peers • Decisions based on illness
Stress and strain of the illness	<ul style="list-style-type: none"> • Changes in behaviour • Emotional strain • Reminders • Sense of burden • Well parent's coping • Worry for well parent • Own future
Reconfiguring relationships	<ul style="list-style-type: none"> • Family closeness • The unwell parent • The well parent • Other family members
Loss	<ul style="list-style-type: none"> • Past life • Parent and future
Coping	<ul style="list-style-type: none"> • Blocking • Confiding in others • Understanding the illness • Distraction • Distancing self • Support
Sense making	

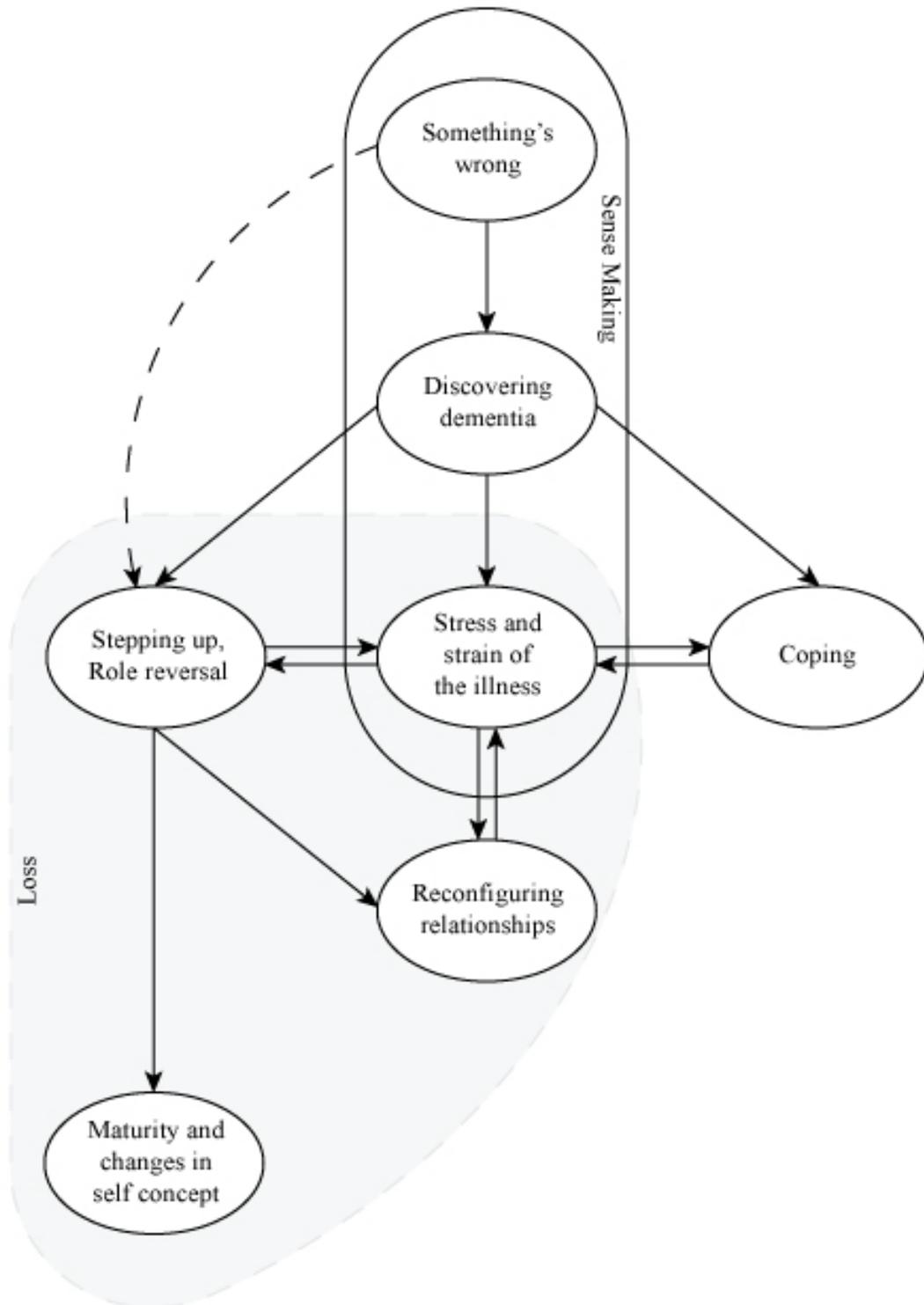


Figure 1: The proposed ground theory of young people’s experiences of having a parent with young onset dementia. (Sense making: Over arching theme which encompasses three of the main categories. Loss: While feelings of loss were present within the young people’s stories it was felt that this loss was emerging rather than prominent within their accounts. As such this category is represented within the model as a shaded circle encompassing the categories that influence this. Arrows: Indicate the links between the main categories).

Something's wrong

This category reflects the young people's experiences of feeling that something "*isn't quite right*" (**Jessica**). Two processes appeared to be present: Noticing and realising. Whilst these processes emerged strongly in the majority of transcripts they were notably absent from one young person's account; "*I didn't really see anything different coz I always had fun with dad and that carried on through...and that's why I didn't notice, everything seemed normal to me*" (**George**).

Noticing

Prior to learning about the diagnosis the young people described observing 'unusual' behaviours in their parents. These were often described as "*subtle changes*" (**Jack**) in the way the parent functioned in daily life and were likely to have gone unnoticed by those outside the family home:

It was just like little every day things that weren't huge and you wouldn't know about if you weren't living with her. Like if you would have come in you wouldn't have noticed. You wouldn't have known anything was up really. Sally

Most described noticing things such as slowing down, forgetfulness, increased irritability and language difficulties:

Just forgetfulness of where things were really were mostly...the occurrences and stuff and she was losing quite a lot of stuff from her handbag and stuff like that we all definitely noticed something. She'd forget things like her mobile phone, her house keys, lose her house keys quite a lot, she'd forget certain things like where things were in the kitchen and stuff in the different drawers and things like that and different washing loads and stuff. Paul

Another described observing changes in his father's behaviours around routine tasks, for example, noticing he needed a list of what to buy at the shops:

*He always had a small list with like little stuff he wouldn't normally get. But this time he had to write everything out. You know I need bread, I need milk, I need this, I need that. I was just thinking why does he need that? **Thomas***

For some, thoughts of something being 'wrong' were triggered when they were away from the familiar home environment. In these unfamiliar environments their parent's cognitive impairment appeared to show up in a way that it had not when they were at home:

*The first thing that I...like see like different changes was when we went on holiday. We literally just got in the room and me and my mom went and just jumped on the bed and just lay there and all of a sudden my dad...my dad just went...as he just put the suit cases down he went 'we've slept in this bed before'. We went 'no we haven't we've just got here'. He goes 'no we've slept in this room before'. I said 'no we haven't'. So we had...We were going 'no we haven't'. We were just joking about it coz we thought he was being stupid like silly and you know how he is. But that's the first like change that I remember. I just thought it was my dad being silly. **Claire***

Whilst many of the young people mentioned being confused or worried about these behaviours, they did not initially raise these concerns with the well parent. This appeared to be related to not wanting to add to the well parent's stress or upset them. Instead they described checking out with siblings and external family whether they too had noticed anything:

*I sort of mentioned a few things to my sister like going, have you noticed things like...like just taking her aside one day and saying have you noticed that Mom's doing this or that she forgot this or something. I didn't actually go to my Dad first. **Jessica***

In response to these changes, a couple of the young people described 'stepping up' and taking over some of the ill parent's jobs to protect their reputation:

*Then I started to kind of started to take over what was going on in the house. I kind of felt it was my responsibility to make sure that Dad wasn't noticing that the house isn't getting cleaned and things like that. **Sally***

Realising

There appeared to be a point in time where the young people 'realised' that the changes they had been witnessing were a sign of something more serious:

*There's an incident that's fairly memorable and that's when we realised there was something seriously wrong[...]...because they never received the form they stopped all of her benefits including rent...rent that was being paid on the house at the time[...] And then she er...breaks down, starts crying and having a bit of a ...urm...quite emotional and I finally got after quite a while of talking to her I finally got through to her what had happened, that she hadn't done these forms and things. And she couldn't explain why she couldn't do the forms...there was about three weeks, three and a half weeks where we had absolutely nothing and I couldn't go to school for those three and a half weeks erm...but there's no rent being paid on the house those three and a half weeks, there's...we had no er...we had some electric, we didn't have any gas which meant no hot water, no heating. We had minimal food (laughs)...that was a difficult three weeks. **Jack***

For Thomas this realisation came when his father spoke to him about how he would be responsible for looking after the family when he was no longer around:

*And then I come outside and I'm sitting with dad and I think I was playing with my DS or something. And then er he goes...he looks at me and goes 'Thomas, you know you're going to look after the family when I'm gone don't you'. And I thought hang on a minute that's a bit strange and I was like 'yeah why'. He was just like 'nah I'm just saying and making sure you will'. And I was like 'right'. And little stuff like that like he'd do it again and then he'd have a proper talk with me and say 'no I'm being deadly serious now you need to make sure you look after the family especially your mom. You know if I go it's going to hurt her the most'. **Thomas***

Others described realising when their observations, worries and concerns were acknowledged by other family members. This seemed to act as a confirmation that their worries were justified:

*I can remember her (aunt) saying something like, yeah she rang us one day and urm...she rang her and left a message on the answer machine and then like literally 10 minutes later rang her again and left exactly the same message but didn't even know she'd done it twice. That was the sort of day when I sort of realised that actually no something isn't right. **Jessica***

Discovering dementia

Within their accounts the above process of noticing and realising preceded the acquisition of answers and in some cases the seeking of medical opinions. This category describes the young people's reactions to hearing the news that their parent has dementia and that the illness is irreversible. Phrases such as 'you're hit with it' were commonly used within this category.

“They have dementia”

All the young people vividly recalled the moment that they became aware of their parent's diagnosis. Typically this occurred when they were told by the well parent once it had been confirmed. However two of the older children talked about their active involvement in the diagnostic process. As an only child in a single parent family, Jack described accompanying his mother to medical appointments and experiencing feelings of frustration at the prolonged diagnostic process and the lack of answers as to what was wrong:

*They had absolutely no clue. They...they thought at one point she was making it up because they...so they kept testing and couldn't find anything and so they concluded there is nothing wrong erm...when clearly there was. I mean looking at her, and the neurologist er...he said er...commented on how he didn't er...my mom was wasting his time and wasting everyone's time and er...and er essentially I suppose he was implying she was faking it. **Jack***

In addition Jessica described the process creating feelings of frustration and uncertainty as she and her family 'treaded water' waiting for clarification of what was wrong with her mother;

It was just such a long time to wait coz it...when you're so...when something like that's going on you get so wrapped up about it and everything then becomes really tense because everybody's thinking 'Oh God something's wrong? What is it going to be?' and it took...it seemed to take forever to get a diagnosis.....you don't really sit with it

*because you try not to think about it because otherwise it just eats you up inside because you're just sitting there thinking 'what's going to happen'. You know things like that. 'Is she...is it one of those things where it's curable or what really'. Yeah you can't really get your head around it at that time because it's sort of...everything's so up in the air and you don't actually know what's going on because you're waiting for some sort of correspondence from the doctors and things like that to find out what the blood tests said and then what the brain scan said and all that sort of rubbish. **Jessica***

Feelings of shock and disbelief were typically encountered when the young people were informed of the diagnosis: “*Oh my God...Mom's not 65...that's not even possible*”

(Sally). Others expressed conflicting feelings; relief at having answers but devastation at the implications of this:

*I think it was like devastation relief. The relief the thought of actually knowing what it was because it had been six months and it just takes over your life really not knowing what it is. It just takes over like your whole thoughts and things. Urm...I think I was just devastated because...this is going to sound rude but she's my Mom. So it's like...she's my Mom. She's not supposed to...I think I always thought of my Mom as a bit invincible...like when you're two you think your Mom is the best person in the world coz she's this person who does everything for you and I always thought she was going to be like invincible. I always thought she was going to be just around forever...er...but I think that was the moment when it's like Oh God, she's actually not going to be. **Jessica***

In addition some of the younger participants talked about having little/no understanding of what dementia was which seemed to create feelings of anxiety: “*it was quite stressful to know that my Mom had an illness but not know anything about that illness*”

(Paul). This often facilitated the process of searching for information which frequently led to further feelings of shock and disbelief when they learnt about the progression of the illness:

*It was shocking reading some of it... Just like forgetting who people are and stuff and shocking things like later care as well going into homes and stuff is quite shocking to see my Mom...I think about what if my Mom was in that sort of state that would be pretty frightening. **Paul***

“They won’t get better”

Coupled with hearing the diagnosis the young people described having to also come to terms with the irreversibility of the illness. Most of the young people describe hearing/reading that there was no cure as being the thing that hit them the most: “...and I found out that he couldn’t get any better. That’s what really like hit me” (**Claire**). Being heavily involved in the diagnostic process Jack described the moment he found out from the doctors that his mother’s illness was permanent:

*Erm...but yeah I er...the, the moment it really kind of...urm...was made clear it was, it really erm struck me was, so she went to the neurologist, brain scanned [...] I vaguely remember 2008 [...] and then they compared them with the prior tests when she’d first gone for the tests I was mentioning urm six years ago say. [...] I remember he said...he showed me on the computer the images...the two images compared urm...the brain had shrunk and it was currently...it was currently what would have been a 65-70 year old patient with dementia rather than 46. So she was about twenty, twenty-five years before. Urm...yeah it was...and you could see the brain had shrunk, although...when I realised what shrunk meant it was a bit weird erm...but er yeah that was when it, that was when it hit that it was...(long pause)...irreversible. It was...yeah there was no helping her. **Jack***

Many of the young people spoke openly about their disbelief when they heard that the illness was irreversible and were faced prematurely with their parent’s mortality:

*I didn’t want to believe it. So I was kind of in denial. I didn’t want to accept the fact that in a couple of year’s time my Mom wouldn’t know my name. I didn’t want to do that so I kind of didn’t take it to heart then...like I didn’t want to think about it too much.... I didn’t believe the fact that she had this illness and this disease coz I was so young. When I say I was so young it was only a couple of years ago but I wasn’t...matured and I was still a child and I didn’t want to believe the fact I wasn’t going to have my Mom to grow up with. **Hayley***

For most the news of the dementia, the permanency of the illness and the knowledge that their parents may not share key moments in their life occurred at times of transition. The

young people spoke about their experiences of hearing this news on top of these transitions and negotiating adolescent life:

*Probably the most horrible experience of my life because it was June...I was doing my exams...literally I had fallen out with my closest friend from school, she wasn't talking to me, didn't really have anyone to turn to at the time...was trying to get exams done and just kind of trying to get things sorted. **Sally***

Strong links are evident within the young people's accounts between 'Discovering dementia' and 'coping', which are described further in the section on coping below.

Stepping up, Role reversal

In response to their awareness of the diagnosis and its implications, all the young people spoke about taking on increasing responsibilities. These included providing physical care, taking on an adult/parental role and providing support to the well parent. As the only female Hayley explained how she was responsible for her mother's personal care:

*I actually used to have to bath her and clean her and shower her and all this and urm...we would...if she were to like wet herself like for example coz I being a girl I would have to do that. Obviously the lads would help but that makes them feel uncomfortable coz they're obviously lads and this is our Mom. So like if it was our Dad then the brothers, the boys would do it but coz it's the Mom and she's a woman and I'm a girl I was responsible. **Hayley***

The older siblings in the families specifically spoke about taking on a more 'parental role' thus suggesting that family positions have an impact on the roles they step into. Taking on this role appeared to be influenced by the well parent's coping. Thomas's account portrays how he would take charge and ask his younger siblings to help out more when their mother was struggling:

*And then I spoke to [siblings] and said ‘moms not feeling at the best at the moment you need to help her out as much as you can around the house or whatever while I got to work. It’s a harsh thing to say because I’m at work but you know you’re going to have to help her out a bit more. **Thomas***

Whilst Sally described taking on the role of helping her younger brother understand and come to terms with the diagnosis due to her father having not accepted the illness:

*That was the first time anyone had spoken to him about what was happening with Mom and I told him all the things that I read that I thought he should know and said to him if you ever want to talk to anybody...like this is the time when we all talk to each other [...] I’ll give you the books. You read what you want to do and that type of thing, and he did. He came home and we sat and we read them together. **Sally***

Their narratives illustrated how at times they felt as though they had swapped roles with their unwell parent:

*...before she was looking after me but now it’s the other way round and we’re all kind of looking after her coz before she obviously used to do the housework and clean up after us but now we clean up after her. **Hayley***

*Well at that point I just took over so to speak. I...so as I say I sorted everything out erm on the bureaucracy front and from that point on I er took over every other sort of paperwork, things like that. So that was the point that marked me in a sense taking over in the house. **Jack***

Two participants described how their responsibilities had reduced since their parent was receiving professional care. Claire talked about her father going into a care home and how “literally the only responsibility that we both have now is feeding him” (**Claire**). This reduction in responsibilities was also echoed in Hayley’s account after carers started to come into their home:

*Well I don’t have them same responsibilities as before so...like before I had to do all the hygiene stuff and stuff like that. I no longer have them responsibilities because we obviously have the carers coming in now and doing that. **Hayley***

There was notably less discussion of this theme within the accounts of the younger siblings. It was felt that this was influenced by the tendency of either older siblings or sisters to 'step up'. In a sense they appeared to be shielding the younger siblings from having to take these on; "*And [brother] seems to have stepped up and taken...taken a little bit of the role of dad. So he'll kind of look after us and help us with stuff*" (George).

Links were evident within the transcripts between 'stepping up, role reversal' and 'stress and strain of the illness'. For many, stepping up and taking on more responsibilities resulted in feelings of burden (discussed in the section on 'sense of burden' below). These changes in responsibilities also appeared to impact on their relationships with family members. Jessica described how she is often in conflict with her father over who 'runs the house' since she took over her mother's role:

We have quite an ongoing battle at the moment that he thinks that he runs the household. And I'm like OK... you fill in the board then and you then plan the week to fit in with everybody else, so that you know where everybody else is and what meals we're going to have and whose doing what when and he just couldn't do it and I was like well, how can you be running a household if you don't know what's going on in the household. So that's a bit of an ongoing battle at the moment. Jessica

Maturity and changes in self-concept

Stepping up appeared to engender personal growth in terms of maturity and self-concept. Growth, changes in self and feeling out of step with peers were mentioned by all of the young people. In addition most spoke about making decisions based on the illness as a result of this growth. Whilst the young people attributed this personal growth to their parent's illness, a number of them also felt that some of these changes were in part a consequence of natural adolescent development.

Growth

As a result of taking on more adult roles and responsibilities, the young people felt that they had had to grow up quickly and had become “*a lot more mature*” (**Claire**). Jack and Hayley both described how taking on ‘adult’ responsibilities facilitated this premature growth:

There was...I think er...because of having to take over at 16, 17, and...having to just...deal with this...deal with my mom's illness for the past 6 or 7 years urm...I think it forced me to grow up a lot younger. **Jack**

Coz urm...coz all these responsibilities that have made me grow up that little bit faster. And coz obviously I had to wash my Mom and stuff like that...that's...I wouldn't say it's given me the experience coz that not the right word but it's kind of gave me that boost that I needed that if my Mom wasn't ill that she would give me if you know what I mean...urm so urm...that's kind of how I have matured. **Hayley**

Many described how this growth was a result of the situation rather than an active choice. One young person vividly illustrated this lack of choice and how this growth has resulted in her aligning herself more with being an adult:

I see myself as an adult now definitely. Everything with Mom has kind of been a massive boot to say grow up and not just please grow up... you've got to grow up right now and there wasn't really much progression of teenager slowly build it up turned into like an adult slowly it was like teenager adult. **Sally**

The young people felt that this increased maturity enabled them to work better together as a team and provide support for their well parents:

We've started to act more mature and take...and do more jobs more, and try and help mom more because she's got a lot of stuff to do...like we don't fight as much or we don't argue as much or stuff like that...and we don't get into as much trouble as we used to. **George**

Changes in me

All of the young people described experiencing changes in the person they were. These changes were influenced by their stepping up and the subsequent growth that they experienced. Many felt that through their experiences they had become better people:

*Urm...because it's happened I think it's made me a better person because I'm not me me me and I'm not ungrateful to my mom because I do appreciate her and I do try and help her as much as I can. **Claire***

Predominantly these changes were considered to be positive outcomes of their experiences such as having a greater work ethic, having more empathy and consideration for others and becoming more self-aware, independent and stronger as a person:

*Urm...I think I'm more aware of other people now. Urm...yeah more aware of how things, how my actions affect other people I suppose because it makes you...you have to think about it in that if I do this how's it going to affect that and the circle that continues. **Jessica***

However some spoke of how they felt that their experiences had simultaneously resulted in negative changes:

*In one sense I've become more sensible. Not just coz having to take over things like that but...responsible in that... urm...urm...It's made me more sensitive to that I think urm...yeah so...but I know er...sadly on the opposite hand it's made me quite hard hearted. **Jack***

The negative changes experienced included an increase in drinking, getting angry more quickly and feeling as though they can take life too seriously. Paul described how he felt that the experience had reduced his confidence around other people as he worries about them finding out about his mother's illness:

*I was probably a lot more confident back then...urm I would have been probably...I would have talked to a lot more different people whereas now I sort of don't really talk to anyone different...I've got my group of friends and mainly just talk to them. So I guess that's sort of changed a bit. I would have talked...I would have been happy to talk to anyone before but [...] like I find it more difficult now to go and talk to someone that I don't know as well now... I rather they didn't know [about Mom's illness]...it's just easier if you don't talk to them. **Paul***

Out of step with peers

As a consequence of facing their parent's premature mortality, stepping up and their subsequent growth, the majority of the young people described feeling 'out of step' with their peers in terms of their worries, stresses and the things that they deem to be important:

*Urm...I think it's partly accepting urm...my mom's imminent decline and mortality but hard hearted in regards to...in regard to other people somewhat because I think it's quite frustrating. Because I can sit there, and again I'm reserved and don't talk but other people are not quite the same and so they'll sit and talk about...talk about their problems and I don't know, they've just had an argument with their parents or...you know just general, I think I do them a disservice. But you know the general problems they have, which are very serious to them, but then er...I'm always slightly detached in that I just think 'well at least you don't er...have that...have this rather'. **Jack***

Feelings of frustration and annoyance were common when talking about the seemingly insignificant and petty arguments and stresses to which their peers devoted a lot of energy and concern:

*...what they think of a disaster or a horrible thing to happen is...their hairs horrible, they've got no makeup on or they've ripped their tights or they haven't get their favourite shoes on say or something like that. Whereas mine is like oh dad's gone into hospital. Oh dad's lost like...whatever's happened that's probably...I think I've...when they're having petty arguments I'm thinking there's no point in this little argument coz there's a lot more important things. You're just wasting your breath on nothing. That's what I'm...that's why I'm thinking you've got to grow up coz you're like fourteen and you haven't...grown up to your age. You're still acting like a ten year old. You're still having petty arguments. You're still like...you're still worrying about your appearance...that kind of stuff. Whereas some days I go into school with no make-up on, my hair's up in a bun, and I really don't care what I look like coz at the end of the day I couldn't give a monkey's what people think about me no more (laughs). **Claire***

Decisions based on illness

Many of the young people described being at key transition points at the time when their parents were showing signs of, or diagnosed with, YOD. These transitions included taking exams, moving to college and considering future options. Others talked about how they were now approaching these. A number of the young people spoke about how their well parent had encouraged them not to make decisions based on their parent's illness:

*Because he's always said to us right from the beginning of getting Mom's diagnosis he's always said I don't want this to affect your lives, I want you to live your lives, you know, it should never affect you. You should go off and do whatever you want to do...don't feel like it should hold you back. **Jessica***

However as a result of taking on adult roles and responsibilities within the family and the increase in maturity and consideration for others that this brought, many of the young people described how their parent's illness had played a role in the decisions that they have made. Jack's account illustrates his desire to be able to provide for his mother in the future:

*School yes. It was a major factor for me dropping out of A-levels initially. Urm...I rather idiotically thought what am I doing here I need to be getting a job, doing various things. Urm...I...but then a year later I'd realised my mistake. Now if I actually...looking ahead if I actually do need to erm...eventually look after her, put her in a...whether that involves getting carers or putting her in a home or anything like that...urm...No I...I should probably get qualifications, get a better job than what I would have done without the A-levels. **Jack***

Whilst Sally described wanting to remain close to the family to help support them and spend as much time with her mother whilst she is relatively well:

Well I want to go to University, I have applied to University. I've looked at Universities in the area that I can come back at weekends and that is because of Mom, because I know that the family's going to need my support... and I want to spend the time with Mom when she's good as much as I can because who knows what's it going to be like in 5 years time...if Mom wasn't like she is I would probably looking at

moving there and living in but because she is as she is I'm looking at staying at home instead. Sally

Stress and strain of the illness

This category portrays the stresses and strains that the participants experienced. It encompasses accounts of primary (changes in behaviour, the emotional strain of these, everyday reminders and a sense of burden) and secondary stresses (worry for the well parent and their own future) associated with the illness.

Changes in behaviour

All the young people spoke about the deterioration that they had seen in their parent's functioning. For many this deterioration meant that their parents were no longer able to continue in their 'role' in the family:

Mom was kind of like the pivotal point of the household. Like she used to do all the cooking, cleaning, she used to transport people urm...organise who was doing what, what day. Basically just know where everybody was...just run the house and the family...but not anymore. Jessica

One young person described seeing psychological changes in his father that were out of character to the person he knew before:

You know he's...you know he's more aggressive when he's driving. If someone annoys him he snaps at them. You know he's actually properly swearing. He never would've swore. Never heard my dad swear...lot different now. In the car it's a lot different. Thomas

Emotional strain

Accounts of the emotional strain of living with the parent's illness and the changes in their behaviours were littered throughout the transcripts. Many described feelings of distress when they saw their unwell parent upset and were unable to comfort them:

*I just don't like it when she cries... It's just the sound of her coz that's normally the only sound that actually does come out of her now. But it's just before when she wasn't ill she didn't used to cry and urm...it's just the sound hearing her coz it feels like she's in pain and there's nothing we can do about it. **Hayley***

Others spoke about how their parent's memory loss created feelings of sadness and worry, especially when the things forgotten were related to the young person themselves:

*Urm when she forget my birthday that was quite difficult coz it was just something for me that put a bit of strain on me to think she can't even remember my birthday and stuff... like you feel that she's like forgetting you as a person...but then you know she's not but it's just the condition and stuff, it's quite scary and upsetting. **Paul***

For some, changes in the parent's behaviours also resulted in feelings of anger and frustration. This was particularly evident in the accounts of the older males. Thomas spoke about how he became frustrated with his father's endless questioning:

*I do get frustrated with him. I do end up shouting at him. You know not shouting but getting very agitated with him telling him 'dad stop being stupid now'... We go shopping and it's like 'have you got a list? Have you got a pen?' We always have to bring a list. I could do the shopping on my own without a list but I always have to bring a list because he needs to know that he's got a list. And when we get there he's like 'do we need a trolley'. 'Have we got the bags in the car?' **Thomas***

Whilst Jack described his feelings of irritation at his mother's desire to be close to him and his frustration at not knowing how to deal with this:

*She wants to spend time with me [...].she just sits there for hours. Like next to me but she doesn't say anything and she just looks into space...It's just so frustrating at the moment because I don't know what to do about it. **Jack***

Feelings of embarrassment were also described by the young people due to their parent's behaviours when out in public:

*We put it on the counter and the woman said that will be £2.99...£1.99 whatever it was. And he goes that's a rip off...that's a rip off...that's ridiculous, I can get it from down the road for whatever price he said. I'm thinking 'oh my gosh dad just... just give the woman the money'. I'm thinking 'it's not a rip off just give the woman the money'. In the end I had to give her my money and go 'come on let's just go.' **Claire***

For the majority of the young people this emotional strain centred on the unwell parent and the manifestation of the illness. However some also spoke about the strain of witnessing the impact of the illness on their well parent: *"to see him that heartbroken and upset I was just like...that got to me (**Jessica**)*. Hayley described the impact of her mother's hospital admissions on her father and the psychological distress this triggers in her:

*When Mom goes into hospital he is constantly urm...constantly down. He's upset and he doesn't like to cry in front of us. He tries his best not to. He does try to be really strong in front of us but when he just breaks down it just makes me really upset knowing that there's nothing we can stop...we can't stop him feeling like that. **Hayley***

Reminders

Whilst most of the young people described coping with the changes in their parent by blocking thoughts and emotions and *"just getting on with things"* (**Claire**), many described being faced with constant reminders of their parent's illness. For some these reminders were the behavioural symptoms:

*...everything she forgot or didn't do or whatever was difficult to cope with because it's just like a constant reminder of what is happening. It's just like it keeps smacking you in the face like Oh my god it's not ever going to go. **Jessica***

For others these were differences in how they were treated compared to their peers:

*If I get a phone call I'm allowed to walk out of the room and take it I don't have to explain or anything like that and it's just little things like that that sometimes hit home that Mom's not right as she should be coz I'm the only person who'll walk out of my biology lesson just so I can answer my phone to my Mom to tell her where something is. **Sally***

Sense of burden

Coping with the changes in their parent's behaviours, the constant reminders and the emotional strain, combined with taking on more responsibility, resulted in feelings of burden for many of the young people:

*I can't physically manage to cook and like every night and keep up with everything else that I'm doing because I'm vegetarian and they all eat meat so I was cooking 2 meals every night and trying to keep up college work and trying to clean and trying to do like the ironing and everything else and it just wasn't going to happen at all and I was trying to fit in being an emotional teenager and having a boyfriend and all that type of stuff and it just wasn't working. **Sally***

In addition they spoke about not wanting to add to the burden of family members and as such described seeking advice and help from others:

*Coz I can tell her [sister] anything I'll go to her first. Because mom has all this pressure on her I don't wana put more pressure on her coz of what's happening in her own life. Coz she's got her own worries to worry about. So I'll go to her after I've gone to [twin]. **George***

To cope some of the young people described trying to reduce the pressures that they felt by stopping activities or eliminating aspects of their lives:

I had a long term girlfriend at the time. I was at university. Start of the second year. Start of the year that matters. Er...there was my mom obviously er...her going downhill at speed. There was er...there was another issue to do with er...financial issues. There was...there was also erm...an unrelated issue, to this anyway...urm...regarding my...regarding my mom being a single parent but anyway. And I mean as I was saying

*some people, some of the students were throwing...their life crisis was just their exams. Their university... I had that and...there was my mom and there was potentially a problem with my father. There was er...I had a girlfriend at the time. There were financial issues. And yeah it got so bad er...and...and I got so bad that I just thought I have to drop a few of these things. **Jack***

Well parent's coping

For some a great source of strain was the way the well parent coped with the illness.

Siblings from one family described how their father would take out his feelings on them and how his lack of acceptance of the diagnosis triggered feelings of distress:

*He told me that he would never be able to accept Mom's diagnosis and we had a very emotional chat on the way home and it plays on my mind some of the things he said because it is hard to hear your parent get upset as anyone would be you don't want to see your parent upset because they're someone you look up to and respect. **Sally***

Siblings from another family described how their mother pushes them to spend time together to create memories for them to remember:

*She tries and creates memories and stuff like that. She always trying to think how am I going to create a memory... You know my dad's...give him memories and stuff like that you know. Create some memories so he you know...we can...remember stuff and so we have good memories as well as just bad ones of him sitting around doing nothing...she's like 'shall we sit round and play a game' and you're like 'no I'm not feeling that'. And she's like 'no I think we should sit down and play like monopoly or something like that'. You're like no but it's 'we're sitting down and playing'. **Thomas***

Worry for well parent

Most of the young people voiced concerns for their well parents. Many talked about fears for their physical health due to the stress that they were under: "*he does get very very stressed out and that really worries me because his Dad had heart problems, his brother's got heart problems, his sister's got heart problems, so it worries me that he's going to...*" (**Sally**).

For others these worries were related to the coping strategies the well parent utilised:

*...and when he goes out drinking every night. He goes out every night. And I know that's his time and that's why I sit in here with Mom and he does urm... I know he's...it's understandable that he does go out every night and that he does have that little time to himself coz obviously everyone is entitled to have that little time...and we all do understand that but I'm afraid that he's drinking that little bit too much. And that's going to affect him in some way, if you know what I mean. **Hayley***

Some described worrying about the amount of pressure the well parent was under.

This worry appeared to be related to the multiple roles that the parent took on:

*She's got a load of pressure on her...she's got to go to work...she's got to work. She's got to come home. She's got to do all that kind of stuff. And then she's got to take care of us" (**George**).*

For others it was about the parent's attempts to compensate for the 'loss' of the unwell parent:

*Urm...well my mom said to me that she always thinks that she had to be the mom and the dad of the...the like family because he's not here anymore even though he is here. If you get what I'm saying (smiling). So...urm. I think...I agree with what she's saying but she doesn't have to be both. She can just be one. Coz we...she doesn't have to be the fun one and the caring one at the same time. She can just be her. And we can still have a laugh. I think she's putting too much pressure on herself just to be the two. **Claire***

Finally a number of the older siblings expressed worries about how their well parent will cope when the unwell parent is no longer here:

*Especially as they've been together for so long it must you know...and when Mom's gone really. Not in a horrible way but I don't know what he will do when she's not around anymore. That's another thing that worries me sometimes but I...I don't think we're a long way of tackling that one, but yeah it's just the whole when we're not here and when Mom's not here, what is he doing to do then. **Jessica***

Own future

Whilst all the young people acknowledged that they had wondered whether they may develop YOD in the future, the extent to which they reported being affected by this varied. Although most of the young people described checking this concern out with other family members, two of the younger participants stated that they had not done anything about this thought yet: “*I thought it would run in the genes or something but I haven’t followed that up yet*” (**Hayley**). Some of the young people spoke about their reactions to finding out that the illness may be inherited:

*Then...then when I, when the diagnosis kind of came through I realised that...the illness was hereditary...urm...yeah. That affected me (holding back tears, removed eye contact)... And it didn’t help on hearing that early onset dementia...so my mom so it hit my mom about 44. It didn’t help hearing that...and also from what I’ve read online, that it can hit people in their twenties, thirties...urm...yeah...so that kind of...yeah...it just kind of made me think. **Jack***

Claire spoke about how her experiences had made her determined to be tested for the illness so that she could make choices about having children in the future:

*Urm probably because it ran in the family. That’s when I got quite worried coz I was like I don’t want to get it and stuff. But my mom said it only ran in the male genes. So hopefully it doesn’t like just go through everybody. So my mom...we’re going to have like a test to make sure I’m not going to get it or I’m just a carrier so I make sure that I don’t have any boys or anything like that. So...so I spare them that [...] I’d rather not know that my future son is gona be, potentially be by themselves in their care home. Nobody visiting them so... **Claire***

Others described how they were not going to let this possibility affect their lives. They appeared to live with this uncertainty by “*dealing with what’s happening now*” (**Sally**) and not wasting their lives:

So it goes back to what I sort of said, why sit and cry about it when you can laugh and have a bit of fun. I think I take on the you might as well laugh because it’s not going to

get you anywhere if you're crying, so if it happens to me, it happens to me and there's nothing I can do about it anyway really coz there's no cure for it and they can't do things to stop it so if it happens it happens then that's just life really isn't it. [...]
what's the point in sitting here worrying about it, when you're just going to waste your life when you could be out doing things like making new experiences for yourself to remember rather than sitting here wondering about what you are not going remember.
Jessica

Within the young people's accounts links were apparent between 'stress and strain of the illness' and a number of categories. As a result of the unwell parent being unable to effectively continue in their roles many of the young people described 'stepping up': "*I'm the sort of...taken on the pivotal point that Mom used to be*" (**Jessica**). Stress and strain was felt by the young people in relation to their well parent's coping and the changes in their unwell parent. This appeared to impact on their relationships with them. In addition all of the young people described employing strategies such as distraction, actively blocking thoughts and feelings and "just getting on with it" to cope with the impact of the illness.

Reconfiguring relationships

Changes in the unwell parent and the well parent's coping, coupled with the taking on of 'adult' responsibilities, appeared to result in the reconfiguration of family relationships. This category describes the young people's views on family closeness and their relationships with the unwell and well parent and other family members since their parent has had YOD.

Family closeness

The majority of the young people described feeling that their family had grown closer as a result of their parent's illness. One person described how her mother's illness resulted in her older siblings gravitating home more often:

I think we wouldn't be as close as we were. I think we would all go our separate ways if Mom wasn't ill because...we urm...we like my sister she comes down and brings the kids down to see Mom and [brother] comes down to see Mom and [brother] comes down to see Mom. They all come back here at one point and like if Mom wasn't ill maybe they wouldn't come back and they would just go their separate ways and stuff.

Hayley

In contrast others felt that their family had become less close. However this was felt to be a result of external pressures which impacted on the amount of time they had to spend together and not solely a result of the illness:

Well there's less...like coz [brother] is working and we've got studying and stuff to do for school and mom's working so it's kind of difficult to get us all together as a family. And to sit down and say like talk about stuff or watch a film or play a game. And mom...mom does try to do that but we've always got stuff to do. **George**

The unwell parent

Variation was evident within this theme. Most of the young people felt that their relationship with the unwell parent had deteriorated. This appeared to be due to the loss/reduction in the interaction and communication between them as a result of the illness:

We aren't as close...coz she obviously doesn't interact with us anymore. I talk to her but she obviously she can't talk back and it's brought a whole new urm...I look at...a whole new aspect of looking at things and urm...a kind of...it's different to how other people would be like urm...now she's ill we obviously don't talk as...talk much. Well we obviously don't talk much and urm. **Hayley**

Conversely others felt that the illness had resulted in their relationship becoming closer. They felt that this improved closeness was a result of spending more time with the parent and helping to provide their care:

Urm...Mom and I are a lot closer now than we used to be...urm...just because I think it's...I don't know why really but I don't know...I think it's because I look after her...well not look after her but I'm here with her and we spend more time than we used to really. Yeah we're closer now than we used to be. Still wouldn't like go to her with a problem because she wouldn't understand it really but yeah I mean I take her

*out for lunch and do things like that and we do things like mother daughter stuff together now that whereas we never used to before. **Jessica***

The well parent

Most of the young people also felt that their relationship with the well parent had deteriorated. Some felt that this was due to their well parent needing to work more in order to provide for the family and therefore not having as much time to spend with them. For others this deterioration was linked to how their well parent was coping:

*Urm I don't get on with my Dad as well as I used to coz he's quite stressed and things and he's not as laid back as he used to be. So he gets quite stressed at little things and stuff but there was a point when he took a lot of anger and stuff out on me, and on my sisters as well. **Paul***

One young person described how her relationship with her mother got worse as all their conversations had become about her father and his dementia:

*But sometimes I do think we talk about it too much. Coz there was a point when, when, about a year ago eighteen months ago when that was the only thing we talked about. And I felt like we didn't have any relationship we just had conversations about what we were...what we had in common. It was...I felt like our whole relationship had broken down. We had nothing to talk about apart from dad [...] I felt like we had nothing in common. I felt like we had, we didn't know anything about each other. **Claire***

The unwell parent's place of residence appeared to influence the changes in this relationship. From Claire's account her relationship with her mother has improved since her father has been looked after and they have had more time together 'free' from some of the strains of the illness: "*Urm, it's a lot stronger. We are like best friends (laughs)... So I think that's how our relationship has got better coz we have had a lot more time to ourselves*" **Claire.**

Other family members

In contrast to the other themes within this category, most of the young people felt that their relationships with other family members had improved, particularly with siblings: “*I know now that they are there for me and that if I need them they’re there...so that’s kind of brought us a little bit closer*” (**Hayley**). Whilst these changes were associated with their parent’s illness, some of the young people acknowledged that they felt ‘normal’ adolescent growth had also influenced these changes:

Urm...[sister] and I are a lot closer...like we’re inseparable now...going out together and things like that. Best friends. Like we tell each other absolutely everything now, whereas like I said when we were little, we used to beat each other up. But I think that’s also come with growing up not just because of the situation...like the situation like has influenced it more but we tell each other absolutely everything right...inseparable now. **Jessica**

In contrast one young person felt that his relationship with his brother had deteriorated. However he felt that this was due to his brother working more rather than the illness per se: “*We’re probably less close. He’s working a lot more or studying a lot more so...that has affected like the time that we’ve spent together*” (**George**).

Links were present between this category and ‘stress and strain of the illness’. The deterioration of relationship with the well/unwell parent and the dynamics between them appeared to add to the emotional strain that the young people experienced:

He vented quite a lot of his frustrations out on us and there was a lot of stress in the house over the summer and it wasn’t a nice place to be...so I think I took that quite personally and that was hard for me. It was really tough. **Sally**

Loss

Feelings of loss were present within the young people's accounts. Commonly the young people reflected on the loss of their past life due to the changes that had occurred. In addition some spoke about the loss of their parent and of the future they had envisaged. The losses that they experienced were felt to be influenced by their 'stepping up' and thus becoming more responsible, their consideration for others, the changes in their relationships and factors associated with the stress and strain of the illness.

Past life

Within the young people's accounts a sense of longing for their past life was evident. They spoke about how their parent's illness had become the focus and that this had impacted on the activities that they previously did:

*Because we obviously don't do them things now and everything revolves around Mom. So we don't go out for meals much now...well we don't go out for meals at all now. So everything kind of revolves around here and staying in and who's looking after Mom and stuff like that. **Hayley***

For many life had become more restrictive. They could no longer be spontaneous in making decisions as things had to be planned in advance. Jessica's account illustrates how the focus on the unwell parent and the need to plan in advance impacted on her social life:

*Yeah it's yeah...it affects like your social life in that if you want to go out. We always make sure that we plan in advance what we are doing and so that we don't ever let Mom be in the house on her own. So if we wanted to go out we make sure nobody else is out that night as well so that Mom's with someone. Urm...yeah coz it's not fair to leave her on her own and she doesn't like being on her own so...yeah it's just you have to have organised fun (laughing). **Jessica***

Parent and future

Five of the young people talked about the ‘loss’ of their parent and anticipated future. Interestingly this theme was mentioned by all of the female participants and/or those without siblings, four of whom had a mother diagnosed with YOD. As the illness progressed they acknowledged how their mother was becoming less like the person they once knew:

*I've accepted the idea that she's no longer my mother. She's not that person anymore and...(sighs)...well the mind's almost gone, its only the body now. Depending on how you feel about that urm...yeah I...I've almost accepted that. She's gone now. **Jack***

For Hayley the ‘loss’ of her mother triggered feelings of regret as she felt that she had not appreciated the time that she had with her; *“I took advantage that she was there...I did not really know that it was going to end... so it wasn't as important to me then but obviously I was wrong”* (**Hayley**). The girls spoke about how they felt saddened that their mothers had not seen them grow up and may not be around to share key moments in their lives:

*She might not see me get married, have kids and met her grandchildren and then see the rest of my life and all that sort of stuff, like watch me leave home and things...the things that Moms are supposed to be involved in.. They're supposed to be involved in picking your wedding dress and all that sort of stuff and it's just like well what if she can't do that and what if she like...what if when I get married she doesn't actually know what's going on and she doesn't know who I am when I get married and things like that. **Jessica***

Coping

To cope with ‘discovering dementia’ and the ‘stress and strains of the illness’, the young people described utilising a variety of coping mechanisms.

Blocking

The blocking of thoughts and emotions was described by all as an active decision that they had made to help them cope with the situation and continue in daily life. Many described how they did not let themselves think about things;

*You just don't really know so you can't really think about it too much because if you do then it just gets to you and it doesn't keep things normal really...I don't want to think of my Mom as somebody who doesn't know who I am because well why wouldn't she know who I am really. You don't let...I don't let myself think about it because it's just easier that way. **Jessica***

Whilst others described blocking out their thoughts and feelings through the use of alcohol:

*The thing which helps me get through it is having a nice...like at the end of a shift at work or at the end of the day or the end of the week if I get Friday or Saturday night off just got to the pub and have a couple of beers. I enjoy that. Come back on the Sunday and I'll be more refreshed. Not refreshed on the morning but you know what I mean. Mentally more refreshed. It's just a place where I can go like a sanctuary. I can go there and just chill. **Thomas***

Confiding in others

Within the young people's accounts there was a divide in terms of whether they talked to others as a means of coping. Some of the young people described talking to family members such as siblings and aunts about things that were worrying them: "*Like [sister] and I used to have a few conversations about it and just say well...just have a bit of conversation about how we thought Mom was doing*" (**Jessica**). It was noted that the young people rarely described talking to their well parent about what was happening. Others described how their family only talked when incidents or professionals prompted this:

She was like 'if what [name] is saying is true he's getting more aggressive. We need to start...stop getting so wound up with him. You know calm ourselves down. It's going to

*be easier said than done but calm ourselves down'. And we've only done that I think once, twice. It's only when we see significant...his getting frustrated and its fine. We know he's going to get frustrated. But when he goes over the top frustrated. **Thomas***

Differences were also evident in the young people's accounts in terms of whether they confided in their peers. Some of the young people described how they have "*been constantly lying to cover up so I don't have to tell them (peers) the truth*" (**Claire**). They described being worried about their friends' reactions and not wanting to be treated differently:

*I just I don't want anyone else to treat me differently...so I'd rather be the same as I was like to them coz it's just better if they don't know so that they don't have to change themselves to consider me and stuff. **Paul***

Others described how they had confided in a few peers:

*...I haven't actually like told a lot of people. My close friends they all know but I don't...it's not like everybody I know knows. Urm...I don't really know why but I just don't feel that they need to know. **Jessica***

The amount the young people confided in their peers appeared to be influenced by the extent to which they talked about things with their family. Those who described talking about the illness regularly with family members did not seem to discuss the situation with their peers as much as those who did not talk with family.

Understanding the illness

Some of the young people described wanting to find out more about the illness so that they were aware of what might happen. Knowing what to expect seemed to create a sense of comfort and allowed them time to prepare for what might happen:

There's stages to it and he's literally gone down those stages. It's only now that he's starting to go down a different path. Because there's nowhere for him to go in the

*stages he's going...he's leaving food in his mouth. He can't walk. He's going off his legs. We really don't know where he's going to go because there's no more stages there. Whereas before we knew oh ok stage 5 this is going to happen and we could prepare ourselves. **Claire***

However others described preferring to take each day as it comes rather than knowing what could happen:

*I don't really wana know what's going to happen... Coz I don't wanna like set myself set up. I don't want get upset about stuff that might not happen so I'd rather not know about it. Just take it as it comes. **George***

Distraction

Most of the young people described utilising distraction as a coping mechanism.

Jessica's account illustrates how taking on 'adult' roles distracted her from wondering what might happen:

*I think that's when I sort of stepped into the role of running the house. Thinking right I'm not going to let this get to me because I don't know what's going to happen so I'm just going to carry on and keep things going for everybody else. So I think that's when I stepped into the whole...the role. **Jessica***

One young person described how she had places/activities which acted to distract her from what was happening and then places where she allowed herself to think about her father:

*I have a distraction. Urm...I er throw myself into school and my dance and things. So either way I have a lot of things to do. When I'm at dance I'm not always thinking oh what's going to happen in the future. I've got something to distract me. Then as soon as I get home or I can go to the care home I can think about those things. **Claire***

Distancing self

In order to cope, the older participants and those whose parents were in the later stages (e.g. Hayley and Jack) described physically distancing themselves from the situation. They

spoke about going to college, work or friends' houses in order to get a break from the emotional stress of the home environment:

*But I think hang on a minute why was I wanting more work?...I think it was because I wanted a break from here. So I was wanting more hours so it give me a break from here... I mean coz when you're on shift you're having a laugh as well as doing something which can keep your mind off things. **Thomas***

*But I've got this one friend she's really understanding about it. She doesn't judge me at all. No matter what I say she's always there for me. And if I ever need anything or if too much is here at home I will go to her house. **Hayley***

Support

The majority of participants spoke about how they themselves had not been offered much support and how they felt alone in their experiences. Many believed this was because they did not fit into a particular service: "*I'm in the bracket in between being a child and being an adult carer so I don't get anything*" (**Jessica**). Jessica spoke about some of the support she would have liked as her father was not in a place to help her:

*At the beginning when we were getting the diagnosis because like we were kept in the dark. I didn't know what was going on and I think there should have been someone from the doctors or the hospital or somewhere just to come over to the house and just explain things because Dad wasn't in the situation to explain things to us because he was going through exactly what we were going through [...] Then after the diagnosis for maybe 3months or so just to help, like help us get into some sort of family routine or something because we had a lot...like once you got the diagnosis, you get a diagnosis and you're like right got to sort out the legal stuff, like wills and things like that and urm...and then it's disability allowance and Mom's...stupid things like drivers licenses...stupid little things like that really and things like just getting everything else in place. **Jessica***

Where support or information was available, some of the young people felt that this was aimed at an older audience and was not specific to them or their needs:

I think the main thing is something like being a child and having a parent to be diagnosed with Alzheimer's is really hard. To be a child and to be a teenager and to

*be like...your parents to be diagnosed like that, there was no one to explain to me and all of the things that I read were aimed at older people, there was nothing aimed at a 16 year old, it was all aimed at if your parent but obviously aimed like 25, 30, 35 year olds. **Sally***

A minority of the young people described being offered support from external agencies but stated that they declined these. For some this was a personal choice of not wanting to talk to unfamiliar people and for others it about the timing of this. One young person stated that he did not want to accept the offer of support too soon:

*No not at this moment in time coz I don't want to use it too soon. Coz I know we're all gonna need it at one point. We are all gonna need it unless...they are amazingly strong mentally. We'll all need it mentally but if you use it too soon you're not going to feel the benefits later on...a lot later on. **Thomas***

Sense making

This process describes the young people's attempts to make sense of and understand the situation. Within the transcripts this process appeared to encompass three of the main categories: 'Something's wrong', 'Discovering dementia' and 'Stress and strain of the illness'.

Something's wrong

When the young people described noticing that something was not quite right they described making sense of these occurrences by attributing them to other causes: "I just personally put it down to stress" (**Jessica**) and:

*I just thought it was... do you know as people get older they start to lose their memory a bit as part of old age I just thought it was that really so...it just happened to everyone when they got older" **Hayley***

Discovering dementia

As they discovered that their parent had dementia, they described questioning why this had happened and realising that there are no answers:

*So I suppose it goes back to me thinking its unfair really doesn't it. Urm...not really because...I mean when you first get the diagnosis you're like why us, why did it have to happen to us and things like that but you then realise that actually there's nothing you can do about it. **Jessica***

One young person described how she and her siblings had attributed the blame for their mother's illness to their father:

*Well at first we thought it was something we did...and so like...like at first my brothers blamed my Dad for it. They thought it was because he wasn't...he was at work all the time and not spending as much time as he could have with her that it was his fault. So at one point...it didn't last long [...]We knew that it wasn't that and it wasn't anything to do with what we did or stuff like that or our actual life it was just natural causes really. **Hayley***

Facing their parent's premature mortality led some of the young people to make sense of more existential issues. Realising that his mother had dementia and facing the irreversibility of this, Jack described questioning his own existence and choices:

*I er would sit there in class surrounded by the other students and just think it's...not only stupid but...not futile but...I...I think it was more of a urm...it's what I sometimes call in philosophy an argument from outrage [...]it was sort of it was almost an insane feeling that you know we're doing this, we're sitting here doing this whilst er...things like what are happening to my mom, and in my case obviously my mom, were happening over there and it led I think...it still strikes now and again...to a certain apathy regarding the studies. It's like...yeah I realise it was a means to an ends eventually in the future but that doesn't help the fact that while I'm there at that moment you know 'what am I doing here? This isn't helping at all'. **Jack***

Stress and strain of the illness

Witnessing the changes in their unwell parent's behaviour resulted in further questioning. Some of the young people described trying to make sense of how their parent had gone from the person they had been to the person they were now:

*I mean how does a [job role] of a [company] all of a sudden just go 'arh can't remember that'. You know I just...you know you wonder how's it start...how does someone go from that to this...sitting on a sofa playing on a palm twenty-four hours a day. **Thomas***

Whilst others tried to make sense of specific behavioural changes, particularly those directed at them:

*I think it was because he was frustrated because I could do things that he couldn't do. I could figure out how to turn the telly on. I could wash up. I could do most things that he couldn't do and I think he got quite frustrated. When he was driving he would never let me touch anything on the dash board. He would be like 'no you can't touch that, no you can't touch that'. Because I think if I'd done anything that he couldn't have done he would have been really frustrated with himself because I don't think...because he very rarely touched the dash board at all. He just left it on one station whereas before he always used to flick on it and make sure he had the right song on it. **Claire***

DISCUSSION

This study aimed to identify the processes that young people may go through when discovering that their parent has YOD and the impact that this has on them. A number of key categories emerged from the grounded theory; 'Stepping up, Role reversal', 'Maturity and changes in self concept', 'Reconfiguring relationships', 'Sense making', 'Stress and strain of the illness', 'Coping' and 'Loss'.

The majority of stresses that the young people described encountering were consistent with previous findings (Allen et al., 2009; Beach, 1994; Davies et al., 2000; Lord et al., 2010; Svanberg et al., 2010; Szinovacz, 2003). In addition they identified feelings of strain related to their well parent's coping. Research suggests that adolescents' adaptation to the situation is influenced by the caregiving parent's ability to cope (Szinovacz, 2003). Allen and colleagues (2009) noted the parallels between their findings and the stress-burden model proposed by Pearlin, Mullan, Semple and Skaff (1990); parallels that were also evident in this study.

Echoing past research (Allen et al., 2009; Lord et al., 2010; Svanberg et al., 2010) and findings within the parental illness literature (Helseth & Ulfsaet, 2003; Valiakalayil, Paulson, & Tibbo, 2004), absenting and distraction were the main coping strategies utilised. Additionally the young people also described consciously deciding to avoid thinking about their parent's illness and 'just get on with it'. Their accounts suggested that if they allowed themselves time to think then they might not be able to continue functioning as they were. The concept of 'just getting on with it' resonated with Allen et al.'s (2009) overarching theme of 'one day at a time'.

Consistent with past findings (Allen et al., 2009; Davies et al., 2000; Lord et al., 2010; Svanberg et al., 2010) participants talked about ‘stepping up’, role reversal and embracing ‘parental roles’. The concept of parentification (Broszormenyl-Nagy & Spark, 1973, as cited in Early & Cushway, 2002) has been used to describe the premature assumption of adult roles (Stein, Riedel, & Rotheram-Borus, 1999). Whilst parentification has been identified in previous research (Allen et al., 2009; Lord et al., 2010; Svanberg et al., 2010) this study found it to be more pronounced in the accounts of the older siblings. Caregiving research suggests that involvement in caregiving and parentification can result in difficulties pursuing separation from the family unit (Becker, 2007; Mayseless, Bartholomew, Henderson, & Trinke, 2004); difficulties which were evident in the young people’s accounts. Many described the increase in responsibility, alongside worries for their well parent, influencing decisions such as where to go to university with many choosing to remain close to the family home in order to continue providing support. However, the process of stepping up also appeared to result in accelerated growth; echoing previous research (Lord et al., 2010; Svanberg et al., 2010). Growth and development occur throughout the lifespan (Charles & Carstensen, 2010) however adversarial growth can occur where difficult or traumatic life events act as a catalyst for increased/premature growth (Linley & Joseph, 2005; Tedeschi & Calhoun, 2004). Although some associated their growth with ‘normal’ adolescent development, all of the young people reported feeling different to their peers in terms of their maturity, priorities and concerns. Research suggests that, while parentification is associated with the neglect of developmental tasks, it can also result in feelings of mastery and increased confidence (Stein et al., 1999). Through the development of new skills and the successful negotiation of stressful and challenging times, the young people seemed to gain greater self-

awareness and resiliency and compassion to others (Milam, Ritt-Olson & Unger, 2004) thereby enhancing personal growth.

As stated above previous caregiving research has suggested that parental illness, the premature assumption of caregiving roles and the unavailability of a parent due to illness or their heavy involvement in caregiving can hinder the transition to adulthood (Becker, 2007; Compas et al., 1995; Lord et al., 2010). Whilst the young people's accounts suggested that they may experience difficulties in separating from the family unit due to the roles that they have assumed, their accounts also indicate that taking on these 'adult' roles and responsibilities may facilitate the development of more adult characteristics. For example many of the young people described a loss of the egocentricity of adolescence stating that they had more empathy and consideration for others. As such it could also be suggested that caregiving may also facilitate adolescent development and the transition to adulthood.

Although the majority of participants felt that their parent's illness had brought their family closer together, most described experiencing deterioration in their relationships with their parents. Similar findings were identified in Beach's (1994) and Szinovacz's (2003) studies. The decline in their relationship with the unwell parent was attributed to the reduction in the parent's language skills which affected communication. Echoing Szinovacz's (2003) findings, participants described having less time with their well parents and being the 'sounding block' for their stresses and frustrations; factors which impacted negatively on the quality of these relationships and added to the stress and strain the young people experienced. Therefore whilst the young people were attempting to make sense of and come to terms with

their parent's illness, they were simultaneously experiencing strains in their relationships with both parents.

A sense of longing for past lives was evident in all of their accounts. The young people describing experiencing restrictions on social lives and family time as their unwell parent became the primary focus. Though some did not explicitly acknowledge the loss of their parent, their accounts suggested that feelings of grief may have been present. Many spoke about what their parent "was" like, implying the parent was already gone (Adams & Sanders, 2004), although this loss appeared to be less prominent compared to the other themes and findings from previous studies. The young people may have been denying their feelings of grief; a strategy that can enable caregivers to continue functioning (Meuser, Marwit, & Sanders, 2004). Furthermore while the parent that they knew is fading, they are still physically present, leading to a sense of ambiguous loss (Dupuis, 2002). Consequently the young people may not have felt it was appropriate to express their grief (Doka, 2004). Davies and colleagues (2000) propose that only after the illness and the 'loss' of a parent is accepted can the grieving process start; thus it could be suggested that the young people in this study may not have reached this acceptance. Finally Lord et al. (2010) found loss to be more prominent than in their original study (Allen et al., 2009) suggesting that grief may not be acknowledged or expressed until further along the illness trajectory.

Lord et al. (2010) noticed in their study that the young people made sense of their parent's illness, their own identity and their futures through a process of questioning. Although this process was present, it appeared to be more specifically associated with noticing something was wrong, discovering dementia and their parent's behaviours. The

young people described dismissing or attributing changes to other causes such as stress, looking for someone or something to blame and attempting to make sense of how their parents had gone from working to 'just being' around the house. Neimeyer (2000) acknowledges that finding meaning can help reduce psychological suffering and assist people in coping and adjusting to the loss.

Previous studies have questioned the influence of gender on the young people's experiences. Gender differences were evident in this study within the loss theme. All of the female participants, three of whom had a mother with YOD, described sadness and regret that they had not appreciated their mothers more and that their mothers would not witness them growing up and might not be involved in future key events. Drawing on past research (Allen et al., 2009; Lord et al., 2010) it is hypothesised that gender differences may become more important as the young people grow up. Whilst gender differences were not prevalent in this study, findings suggested that the young person's position in the family significantly influenced the impact of the situation. Older children tended to 'step up' and take on a more adult/parental role within the family thus protecting their younger siblings from some responsibilities and truths.

Limitations and implications for future research

There are a number of limitations to this study. All of the participants were of white British origin. Consequently their experiences may not be representative of the experiences of young people of other cultural backgrounds thus reducing the generalisability of findings. In grounded theory data collection should continue until no new categories emerge. Whilst data

collected during the eighth interview did not alter the emerging categories an additional interview would have helped clarify that data saturation had been reached.

The inclusion of young people from other cultural backgrounds in future studies would allow the plausibility of the model to be determined in regard to other population groups. In addition future studies may benefit from exploring further the impact of the young person's position in the family unit and possible gender differences. Within the current study adolescent development and adversarial growth appeared to be interrelated. Research exploring the young people's growth over the illness trajectory may help to further clarify the impact that their parent's illness has on their personal growth.

Clinical implications

YOD impacts on the whole family and therefore it is imperative that services consider all those within this system. The young people's accounts highlighted how were often 'forgotten' by services and where support was available they felt that this was aimed at older audiences. Drawing on the above findings, and the ideas suggested by the young people taking part in the study, a number of clinical recommendations are suggested regarding the ways in which services could support this population group. Mechanisms to implement these recommendations are also suggested. In order to transfer the knowledge gained, the findings and recommendations below will be reported back to the services involved in identifying participants via the following mechanisms: A brief written report of the study's findings; and presentations at young onset dementia forums and/or service meetings.

Discovering the diagnosis was a time of uncertainty, which was exacerbated by the well-parents' emotional unavailability to cascade information down. The young people felt that having information specifically aimed at their age group would aid their understanding of the diagnosis and its implications, and that staged information would allow them to be in control of the amount of information that they wished to know. Additionally support should be available to help alleviate any worries or concerns that may arise from the acquisition of this information. To address this need services could identify a named point of contact who has responsibility for providing the young people with this information and a space to discuss any worries or concerns that they may have. Furthermore offering young people a space to talk would also provide them with opportunities to explore the illness further and discuss its impacts on them. In addition, interventions centring on meaning-making may assist the young people to cope and adjust to the losses experienced. The need to provide age specific information may also be addressed through consultation with these young people. Some of the young people spoke about how they had felt alone in their experiences and would have welcomed the opportunity to meet people in similar situations. Through the provision of forums aimed at young people with a parent with YOD and/or the development of 'safe' social media environments, such as chat rooms, experiences and information could be shared and peer support offered. Services could also direct young people to chat forums that are already established such as 'talking point' which is run by the Alzheimer's Society. In terms of the wider family unit, interventions that promote communication and offer information regarding the impact of YOD on children may help family members come together and share experiences, concerns and worries and identify ways in which the young people can be supported.

Summary and Conclusions

In summary, whilst the current findings offer support for many of those described in the previous three studies which explicitly explored the young people's experiences of having a parent with YOD there were also a number of additional findings. These included: The strain experienced by the young people in relation to their well parents coping; the influence of the young person's position in the family in relation to stepping up and taking on a more parental role; feeling out of step with their peers due to the personal growth they experienced; and the deterioration of their relationship with the well parent. In addition whilst some themes echoed those of previous studies a number of these differed in terms of their prominence within the transcripts. Although growth has been described in these studies this appeared to be more prominent in the current study. All of the young people spontaneously spoke about how they felt they had not only matured as a result of the situation but how these experiences had also facilitated personal growth in terms of their own self-concept. Furthermore whilst loss appeared to be less prominent in the accounts of the young people, especially in relation to the loss of their parent, it was noted that this loss was more present in the female participant's accounts, three of whom had mothers with YOD; thus suggesting that gender of the young person and the parent may have some influence on their experiences. Finally, although the use of strategies to block out thoughts and feelings echo those described by previous studies this decision appeared to be a more conscious and active decision.

The young people's accounts illustrate the pervasive impact of having a parent with YOD. Their accounts illustrate a sense of isolation from peers, a desire to provide for and/or remain close to the family unit, deterioration in family relationships, feelings of loss, uncertainty, regret and sadness and experiences of burden and emotional strain. Whilst the

findings of this study suggest that the wellbeing and development of these young people may be hindered experiences of adversarial growth were evident. This suggests that their transition to adulthood may also be facilitated and their lives enriched.

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PUBLIC DOMAIN BRIEFING DOCUMENT

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THE IMPACT OF DEMENTIA ON FAMILIES

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PUBLIC DOMAIN BRIEFING DOCUMENT

The Impact of dementia on families

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This research was submitted as partial fulfilment for the degree of Doctorate in Clinical Psychology at the University of Birmingham. The research is comprised of two parts. Paper one reviews the literature exploring what we currently know about the positive aspects of caregiving for family caregivers of persons with dementia. The second paper explores the experiences of young people who have a parent with young onset dementia.

What do we know about the positive impacts of caregiving for family caregivers of people with dementia? A literature review.

Within the UK it is estimated that there are 800,000 people with dementia and 670,000 family and friends acting as primary caregivers (Alzheimer's Society, 2012). Providing care for a relative with dementia can be challenging and as such research has often focused on caregiver burden. However over the past two decades research has started to consider how people may grow or gain from caregiving.

Over a third of dementia caregivers report experiencing gains from the caregiving role such as a strengthening of family relationships, opportunities to develop and grow as a person, feelings of accomplishment through learning new skills and developing effective coping strategies, spiritual growth and having an opportunity to give back to the family member. Factors thought to influence the experience of gains included caregiver demographics such as age, ethnicity and education, the quality of the relationship between the caregiver and care-receiver before dementia, the amount of contact the caregiver has with the care-receiver, the

availability of support and the care-receiver's level of functioning. Caregiver gains have been associated with increased feelings of grief following the loss of the person with dementia, less burden and greater mental wellbeing.

Findings suggest these gains may reduce the negative effects associated with caregiving. As such it is recommended that caregiver interventions focus on increasing these feelings of gain by developing and refining caregiver skills, fostering problem-focused coping and increasing caregiver's social involvement. Gathering information on the factors associated with gains may help clinicians identify caregivers who may benefit the most from these interventions. To develop our understanding of caregiver gains it is suggested that future research explores the possible gains experienced by young caregivers.

Young people's experiences of having a parent with young onset dementia

Although dementia is often associated with old age a significant number of people develop it under the age of 65, when it is known as young onset dementia (YOD). In UK it is estimated that over 17,000 people have YOD (Alzheimer's Society, 2012). Many of these people will have children who are still reliant upon them and living at home (SCIE, 2010). Whilst a few studies have included these children in their samples, only two published studies (Allen, Oyebode & Allen, 2009; Svanberg, Spector & Scott, 2010) and one unpublished study (Lord, Oyebode, Allen & Allen, 2010) have overtly explored young people's perceptions.

The study aimed to expand on the previous studies by exploring the ongoing impact of having a parent with young onset dementia. This is the first stage of a longitudinal study exploring the impact of these experiences as the young people move into adulthood. Eight

young people aged 14-23 years consented to be interviewed about their experiences.

Interviews were analysed using grounded theory.

Initially the young people described going through a process of sensing that something was wrong with their parents and finding out that they had YOD. In response to the changes in their parent and finding out the diagnosis they described taking on additional responsibilities to help out within the home. They felt this had forced them to grow up quickly and they described experiencing positive changes in themselves. Living with a parent with YOD and the increase in responsibilities also resulted in feelings of stress and strain and changes in family relationships. The changes within the home often resulted in feelings of loss: Of past life, their parent and their imagined future. They described using a number of ways of coping such as distraction, blocking thoughts and feelings and distancing themselves. They also described trying to make sense of the changes in their parents and the diagnosis.

The young people described often feeling ‘forgotten’ by services and identified ways in which services could support them more. They suggested having information specifically aimed at their age group, being supported and/or involved in setting up family routines and having the opportunity to meet people in similar situations. Services should also consider offering the young person opportunities to talk about the illness and its impact on them and providing interventions centred on helping people cope with and adjust to the losses experienced. Additionally family interventions that promote communication and provide information on the impact of YOD on young people may help family members share experiences and identify ways to support the young people.

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The author would like to thank the eight young people who gave up their time to be interviewed for this study. I am aware of how difficult it was for them to open up to a stranger about their experiences and admire their courage in sharing their stories.

Further contacts

For further information, please contact Sue Tolley, Trainee Clinical Psychologist, or Dr Jan Oyebode, Consultant Clinical Psychologist, at the School of Psychology, University of Birmingham, Edgbaston, Birmingham, B15 2TT. Tel: 

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APPENDICES
LITERATURE REVIEW

APPENDIX A:

SEARCH STRATEGY FOR PSYCHINFO, MEDLINE AND EMBASE DATABASES

Search strategy for PsychINFO, Medline and EMBASE databases.

1. Dementia (subject heading, exploded).
2. Alzheimer's disease (subject heading, exploded).
3. Caregivers (subject heading).
4. Family (subject heading).
5. Family members (subject heading, exploded to include; adopted children, adult offspring, ancestors, cousins, daughters, foster children, grandchildren, grandparents, parents, siblings, sons, spouses or stepchildren).
6. 1 or 2
7. 3 or 4 or 5
8. 6 and 7
9. Satisf* or gain* or "personal growth" or "personal development" or "adversarial growth" or "posttraumatic growth" or uplift (title, abstract, keyword search).
10. "Positive aspect" or "positive outcome" or "positive experience" or "positive impact" (title, abstract, key word search).
11. 9 or 10
12. (Satisf* or gain* or "personal growth" or "personal development" or "adversarial growth" or "posttraumatic growth" or uplift or "Positive aspect" or "positive outcome" or "positive experience" or "positive impact") adj5 (caregiv* or carer* or family*) (abstract search).
13. 11 and 12
14. 8 and 13
15. Limit 14 to English language
16. Remove duplicates from 15

APPENDIX B:
SEARCH STRATEGY FOR CINAHL DATABASE

Search strategy for the CINAHL database.

1. Dementia (mapped heading, exploded).
2. Alzheimer's disease (mapped heading).
3. 1 or 2
4. Caregivers (mapped heading).
5. Family (mapped heading, exploded).
6. 4 or 5
7. 3 and 6
8. Satisf* or gain* or "personal growth" or "personal development" or "adversarial growth" or "posttraumatic growth" or uplift (abstract search).
9. "Positive aspect" or "positive outcome" or "positive experience" or "positive impact" (abstract search).
10. 8 or 9
11. (Satisf* or gain* or "personal growth" or "personal development" or "adversarial growth" or "posttraumatic growth" or uplift or "Positive aspect" or "positive outcome" or "positive experience" or "positive impact") N5 (caregiv* or carer* or family*) (abstract search).
12. 10 and 11
13. 7 and 12

APPENDIX C:

DETAILED OVERVIEW OF QUALITATIVE STUDIES

(* represents mixed method studies reviewed in both tables)

Author	Purpose of study	Participants	Methodology	Themes of gain	Positive aspects of caregiving identified
Beach (1994)	To examine the experiences of caregiving adolescents of family members with Alzheimer's disease.	14 adolescents. <i>(Gender: 55% female and 45% male. Average age; 19. Ethnicity: 64% Caucasian, 18% African American, 9% Native American and 9% Pacific Islander. Rel. to care receiver: 44% grandchildren, 28% niece/nephew and 28% child)</i>	Semi-structured interviews: Questions focused on the inevitability of the elder's death, interactions with the ill elder, positive and negative caregiving consequences, patient and family denial, previous patterns of family interactions, social support and perceptions of parental stress. Data analysed using content analysis. Analysis was verified by 3 of the participants and adolescent caregivers and professionals were asked to comment on the findings.	3 main themes within the gain category. 1. Increased mother-daughter bonds and reliance. 2. Created opportunities for siblings to spend time together. 3. Facilitated use of humour amongst family members as coping mechanism.	<ul style="list-style-type: none"> • Caregiving resulted in a number of positive relationship building opportunities. • Adolescents grew closer to the primary caregiver (most often their mother). • They reported engaging in more activity time with siblings. • Greater family bonding via the use of humour as a coping mechanism.

Author	Purpose of study	Participants	Methodology	Themes of gain	Positive aspects of caregiving identified
Beach (1997)	<p>To examine the potential positive caregiving experiences of adolescents and their perceptions of relational enhancement as a result of caregiving.</p> <p>Specific research questions: <i>How does the caregiving environment alter adolescent-older adult relationships?</i> <i>Does the caregiving context have a positive influence on adolescent-mother (primary caregiver) relationships?</i> <i>How do sibling associations weather the caregiving situation?</i> <i>Do caregiving responsibilities influence peer selection?</i></p>	<p>20 adolescents, aged 14-18 years. <i>(Gender: 55% female and 45% male. Ethnicity: 64% Caucasian, 18% African American, 9% Native American and 9% Pacific Islander. Rel. to care receiver: 60% grandchildren, 20% niece/nephew and 20% child. Primary caregiver: 82% mother).</i> Recruited via local Alzheimer's Associations, U.S.</p>	<p>Semi-structured interviews: Questions focused on their thoughts and feelings regarding Alzheimer's disease, dementia, intergenerational relationships and elder care (question areas given).</p> <p>Data analysed using content analysis. Each category had to be mentioned at least three times within each interview to be considered. Data analysis was verified by 5 respondents, caregiving adolescents (not participants in study) and 2 colleagues who work with young adults.</p>	<p>4 main themes:</p> <ol style="list-style-type: none"> 1. Increased sibling activity/sharing (73%). 2. Greater empathy for older adults (73%). 3. Significant mother-adolescent bonding. 4. Peer relationship selection and maintenance. 	<ul style="list-style-type: none"> • Increased opportunity for more productive sibling interactions and the gravitation of siblings home. • Increased empathy for and positive relationships with their ill elders. • Greater intimacy and closeness within the mother-adolescent relationship. • Greater family fusion within the caregiving environment appeared to facilitate from the adolescents identity exploration.

Author	Purpose of study	Participants	Methodology	Themes of gain	Positive aspects of caregiving identified
Murray, Schneider, Banerjee & Mann (1999)	<p>To investigate whether qualitative differences exist in the subjective experiences of spouse caregivers who live in countries with statutory rights and those who are bound by duty of care across 14 EU countries, and also whether there are gender differences.</p> <p>Four open ended questions focusing on the main difficulties in coping with dementia, rewards of caring, perceived social reactions and subjective appraisals of support.</p>	<p>280 spouse caregivers of individuals who were diagnosed with dementia within the past 12-36 months.</p> <p><i>(Overall Mean Carer age: 71 years. Overall carer gender: 58% female. Overall mean spouse age: 73. Overall mean number of years living together: 43 years)*</i>.</p> <p>Sample recruited by professional experienced in dementia care and research.</p>	<p>A content analysis approach was employed.</p> <p>Semi-structured interviews. Questions devised by authors.</p> <p>Data analysed using content analysis. Interview transcripts were translated into English before analysis. Responses to each topic were listed verbatim. Similar statements were assigned to categories. Themes were coded so that findings could be compared with responses to structured instruments used in other studies.</p>	<p>4 main themes:</p> <ol style="list-style-type: none"> 1. Job satisfaction. 2. Reciprocity and mutual affection. 3. Companionship. 4. Sense of duty. 	<ul style="list-style-type: none"> • 82% reported experiencing some rewards. • Commonality in experiences was found across countries and gender. • Job satisfaction gained from: Making spouses comfortable, the acquisition of new skills, achievements and ‘doing their best’. • Reciprocity and mutual affection gained from: Returning past care/affection and a greater emotional closeness. • Companionship gained from: Staying together, feeling efforts were appreciated and the experience of pleasant moments. • Sense of duty gained from: Obligation of marriage.

Author	Purpose of study	Participants	Methodology	Themes of gain	Positive aspects of caregiving identified
<p>Narayan, Lewis, Tornatore, Hepburn & Corcoran-Perry (2001)*</p>	<p>To examine the relationship between and among spouse caregivers' positive and negative subjective responses to caregiving and increase understanding of the experience of spouse caregivers'.</p> <p>Part of a wider 3-year study designed to test interventions targeted at family caregivers.</p> <p>Interview consisted of open ended and specific questions about various aspects of caregiving.</p>	<p>43 spouse caregivers (data was missing from seven of the participants).</p> <p>Demographic data only available for the whole sample group. No revised demographics available for those included in qualitative element.</p> <p>First 50 spouses recruited for wider study via Alzheimer's association-affiliated support groups, physicians, day centres & other agencies working with population group, USA.</p>	<p>Mixed methods design: Semi-structured interviews and questionnaires.</p> <p>Interview data was analysed to illustrate caregiver experiences as they related to the quantitative measures: Positive aspects of caregiving, caregiver competence, relational deprivation, role captivity and loss of self. Data was coded by four research team members, with two team members coding each variable. Coding reviewed and consensus agreed.</p>	<p>The main qualitative themes are not explicitly stated within the article.</p>	<ul style="list-style-type: none"> • Spouse's responses suggested a strengthening of relationship with the care receiver and others. • Responses implied new learning from the caregiving experience. • Caregiver's responses indicated feelings of confidence and enjoyment in relation to learning more about themselves.

Author	Purpose of study	Participants	Methodology	Themes of gain	Positive aspects of caregiving identified
<p>Netto, Goh & Yap (2009)</p>	<p>To explore the possible gains in the caregiving experience of family caregivers of persons with dementia using a strength based perspective (focusing on positive psychology).</p> <p>Gains were defined as ‘any positive affective or practical return of a reciprocal nature that is experienced as a direct result of becoming a caregiver’ (Kramer, 1997).</p>	<p>12 primary caregivers of those diagnosed with dementia under follow-up in a dementia care clinic</p> <p>(<i>Gender</i>: 10 females and 2 males. <i>Ethnicity</i>: 11 Chinese and 1 Indian. <i>Relationship status</i>: 8 married, 3 single and 1 widowed. <i>Rel. to care receiver</i>: 8 daughters, 2 sons, 1 spouse (wife) and 1 niece).</p> <p>Purposive sampling (guided by theoretical sampling) from three institutions in Singapore.</p>	<p>Design was guided by grounded theory methodology.</p> <p>Semi-structured interviews consisting of open-ended questions. Developed in consultation with staff experienced in dementia care.</p> <p>Selective transcription was used where responses specific to the research question or dementia caregiving were provided.</p> <p>Data analysed through the use of a coding paradigm: open, axial and selective coding.</p>	<p>3 main themes:</p> <ol style="list-style-type: none"> 1. Personal growth. 2. Gains in relationships. 3. Higher-level gains. 	<ul style="list-style-type: none"> • More patient/ understanding, becoming stronger/ more resilient, increased self-awareness/ insight into selves and being more knowledgeable and therefore more able to make informed decisions. • Other personal gains included: Being more creative in problem solving, a sense of mastery in trying situations, increased humbleness and attaining selflessness. • Improvements in relationship with care recipient, others in family and improved interaction with older persons. • Positive change in philosophy in life, spiritual growth and altruism.

Author	Purpose of study	Participants	Methodology	Themes of gain	Positive aspects of caregiving identified
Sanders (2005)	<p>To identify and compare the various types of strain and gain that are experienced by caregivers of individuals with Alzheimer's disease.</p> <p>Gain was defined as "the extent to which the caregiving role is appraised to enhance an individual's life....Gain may include any positive affect or practical return that is experienced as a result of becoming a caregiver" (Kramer, 1997, p.219).</p> <p><i>Specific questions: What would you describe as your main caregiving problem right now? How do you feel you have changed as you have taken on the caregiving role?</i></p>	<p>Urban sample of 85 caregivers (spouses and adult-children).</p> <p><i>(Gender: 69% female and 31% male. Average age: 60 years (range: 28-89). Rel. to care receiver: 33% daughters, 15% wives, 14% husbands and 8% sons. Ethnicity: 54% Caucasian, 31% African American, 11% Hispanic and 5% Asian).</i></p> <p>Recruited via the local Alzheimer's Association, East Coast, U.S.</p>	<p>Asked to respond to a series of open ended qualitative questions that were incorporated into a survey.</p> <p>Analysis was guided by grounded theory. The researcher and a colleague independently identified preliminary themes by content analysis using line by line coding. These were grouped together in common thematic areas and then reviewed to create the final themes. Final themes were presented to outside individuals for input on validity of findings and interpretation of results.</p>	<p>3 main themes associated with gain:</p> <ol style="list-style-type: none"> 1. Spiritual growth and increased faith. 2. Personal growth. 3. Feelings of mastery and accomplishments. 	<ul style="list-style-type: none"> • Spiritual growth and faith combated inherent strains, buffered adverse effects, enabled the caregiver role to be assumed and increased inner strength. • Created new dimensions in caregiver's lives, revealed hidden aspects of personality and encouraged individuals to re-evaluate life and what is important. • Feelings of personal accomplishments from fulfilling the role and conquering element initially concerned about, developing new skills and creating new interests.

APPENDIX D:

DETAILED OVERVIEW OF QUANTITATIVE STUDIES

(* represents mixed method studies reviewed in both tables)

Author	Purpose of study	Participants	Design	Gain measures	Other measures	Analysis	Key results
Kinney & Stephens (1989)	To examine sources of caregiving hassles and uplifts, identify caregiver and care-recipient factors associated with these hassles and uplifts and determine the effect of these on caregivers social and psych. wellbeing.	60 family caregivers. (Gender; 82% female. <i>Rel. to care-recipient</i> ; 50% spouses. <i>Mean age</i> ; 58 years. <i>Mean caregiving duration</i> ; 4.1 years. <i>Average hours of caregiving per day</i> ; 12.4hrs). Recruitment procedure not defined.	Cross-sectional design.	Caregiving Hassles and Uplifts Scale ($\alpha = .71-.90$).	Symptom Check List-90 Revised ($\alpha = .90$). Caregiver Social Impact Scale ($\alpha = .78-.86$)	Frequencies. Stepwise Multiple Regression analyses. Bivariate correlations.	<ul style="list-style-type: none"> • Bothe hassles and uplifts were reported by caregivers. • Uplifts were associated with care-recipients behaviour and practical/logistical aspects of caregiving (e.g. satisfaction with support from friends and family). • More uplifts were described by those caring for those less impaired. • More uplifts reported by those spending more time on caregiving activities. • Those reporting more uplifts related to care-recipient behaviours tended to report more distress.

Author	Purpose of study	Participants	Design	Gain measures	Other measures	Analysis	Key results
Kramer (1993)	<p>1) To investigate interpersonal vulnerability variables, such as marital history and the quality of the relationship pre-dementia, as predictors of positive and negative outcomes.</p> <p>2) To examine the contribution of personal resources and appraisals of stressors.</p>	<p>72 wife caregivers.</p> <p>(Age range; 57-82 years. Ethnicity; 99% Caucasian. Duration of marriage; 2-64 years (mean = 45)).</p> <p>Recruited from 12 organisation sites such as adult day health centres, home health agencies and information and referral agencies, across a US state.</p>	<p>Cross-sectional design.</p> <p>Face-to-face interviews were used to administer measures and quantify caregiver characteristics.</p>	Caregiving Satisfaction Scale ($\alpha = .90$).	<p>Short version of the Memory and Behaviour Problems checklist ($\alpha = .76$).</p> <p>Katz Index of Activities of Daily Living ($\alpha = .77$).</p> <p>Instrumental activities of daily living ($\alpha = .78$).</p> <p>Quality of the prior relationship ($\alpha = .80$).</p> <p>Satisfaction with Social involvement ($\alpha = .72$).</p> <p>Centre for Epidemiological Studies-Depression Scale ($\alpha = .864$).</p> <p>Quality of Life Index ($\alpha = .87$).</p>	<p>Frequencies.</p> <p>Histograms.</p> <p>Descriptive statistics.</p> <p>Bivariate analysis.</p> <p>Multivariate analysis.</p> <p>Hierarchical multiple regressions.</p>	<ul style="list-style-type: none"> • Poor quality of the prior relationship was significantly associated with caregiving satisfaction ($r = -.34$, $p < .01$). Those reporting poor prior relationships reported less satisfaction. • Social resources (frequency and quality of social/recreational involvement) correlated with caregiving satisfaction. • Financial resources and appraisals of stressors were not associated with satisfaction. • 31% of the variance in caregiver satisfaction was accounted for by; quality of relationship (16%, $\beta = -.29$, $p < .05$) and ADL's (9%, $\beta = .27$, $p < .05$).

Author	Purpose of study	Participants	Design	Gain measures	Other measures	Analysis	Key results
Kramer (1997)	To investigate the differential predictors for appraisals of strain and gain among husbands caring for wives with dementia while controlling for contextual variables.	74 husbands caring for wives with dementia. <i>(Age range; 51-86 years. Ethnicity; 100% Caucasian. No. years married to care-recipient; 2-66 years (mean = 45)).</i> Multi-method recruitment; community agencies, geriatric evaluation services and notices in the public media, in the USA. "Snowball" sampling also used.	Cross-sectional questionnaire design. Face-to-face interviews were used to administer measures and quantify caregiver characteristics.	Caregiving Satisfaction Scale (derived from interviews with caregivers and relevant caregiving literature. $\alpha = .90$).	Short version of the Memory and Behaviour Problems checklist ($\alpha = .76$). Katz Index of Activities of Daily Living ($\alpha = .88$). Instrumental Activities of daily Living ($\alpha = .88$). Satisfaction with Social Participation ($\alpha = .78$). Revised version of the Ways of Coping Checklist ($\alpha = .80- .84$). Screen for Caregiver Burden ($\alpha = .86$). Health	Hierarchical multiple regression.	<ul style="list-style-type: none"> • Significant predictors of caregiver gain included caregiver education, satisfaction with social participation, health and problem focused coping. • Husbands who were less educated, more satisfied with their social participation, in better health and who reported greater use of problem focused coping appraised the highest levels of gain. • Stressors were not associated with caregiver gain. • Regression equations explained 38% of the total variance in gain. Education explained 11% and resources explained 26% of the variance.

Author	Purpose of study	Participants	Design	Gain measures	Other measures	Analysis	Key results
Harwood, Baker, Ownby, Bravo, Aguero & Duara (2000)	To investigate the predictors of satisfaction and burden (positive and negative caregiving appraisal) among Hispanic caregivers of patients diagnosed with Alzheimer's disease.	40 Hispanic Cuban American family caregivers. (<i>Gender</i> ; 75% female. Mean age; 60.9 years. <i>Rel. to care receiver</i> ; 45% adult daughters, 23% wives, 18% husbands, 8% sons, 5% sisters and 2% niece's. Purposive sample of those being evaluated by a university-affiliated outpatient's clinic, USA.	Cross-sectional questionnaire design	Caregiver Satisfaction Scale.	Caregiver Burden Scale. Perceived Emotional Support (Pearlin et al., 1990). General Health Index. Mini Mental State Examination. Blessed Dementia Scale. Behavioural Pathology in Alzheimer's Disease Rating Scale.	Hierarchical multiple regressions. Pearson's correlation coefficients.	<ul style="list-style-type: none"> • 42% of the total variance was predicted by the model: Caregiving stressors explained 6% of the variance, caregiver demographics explained an additional 11% and caregiver resources accounted for 25% of the variance. • Caregiver satisfaction was predicted by perceived emotional support and caregiver age, with older age and higher levels of support being linked to greater satisfaction.

Author	Purpose of study	Participants	Design	Gain measures	Other measures	Analysis	Key results
Narayan, Lewis, Tornatore, Hepburn & Corcoran-Perry (2001)*	To examine the relationship between and among spouse caregivers' positive and negative subjective responses to caregiving and increase understanding of the experience of spouse caregivers' (part of a wider 3-year study designed to test interventions targeted at family caregivers).	50 spouse caregivers. <i>(Gender; 74% female & 26% male. Ethnicity; 100% white. Average age; 73yrs (range 60-88)).</i> First 50 spouses recruited for wider study via Alzheimer's association-affiliated support groups, physicians, day centres & other agencies working with population group, USA.	Mixed methods cross-sectional design; postal questionnaire and semi-structured interviews. Data was collected during the initial data collection phase of the wider study.	The Positive Aspects of Caregiving Scale ($\alpha = .88$). Caregiver competence scale ($\alpha = .74$).	The Relational Deprivation Scale ($\alpha = .67-.77$). The Role Captivity Scale ($\alpha = .83$). Loss of Self Scale ($\alpha = .76$).	Descriptive statistics. Pearson's product-moment correlations.	<ul style="list-style-type: none"> • One third felt they had experienced good things from caring for their spouse with dementia. • Positive aspects of caregiving and caregiving competence were significantly related ($r = .46, p < .01$) suggesting that spouses who view caregiving as having enriched their lives tend to view themselves as competent and confident caregivers. • Duration of caregiving was significantly related to positive aspects of caregiving ($r = .33, p < .05$) and caregiver competence ($r = .35, p < .05$). • Positive and negative subjective responses to caregiving are not significantly correlated and can co-exist.

Author	Purpose of study	Participants	Design	Gain measures	Other measures	Analysis	Key results
Boerner, Horowitz & Schulz (2004)	To explore how positive aspects of caregiving affect adaptation to bereavement, in terms of depression and grief, among older adults who care for a family member with dementia (subsection of the wider REACH study, a multisite caregiver intervention trial).	217 bereaved caregivers. <i>(Gender; 84% female and 16% male. Average age; 64 years old. Rel to care receiver; 50% spouses and 50% other-not stated).</i> Recruited from multiple sites of the REACH project, USA.	Longitudinal questionnaire design. Data collected during the year prior to (M = 15.7 weeks, SD = 9.9 weeks) and after bereavement (M = 15.4 weeks, SD = 10.1 weeks).	Caregiving Benefit ($\alpha = .74$).	Centre for Epidemiological Studies-Depression (CES-D) Scale ($\alpha = .74$). Texas Revised Inventory of Grief ($\alpha = .87$). The Index of ADL's ($\alpha = .96$). Revised Memory and Behaviour Problem Checklist. ($\alpha = .86$).	Descriptive statistics. Multivariate analyses. Multiple regression analyses. Blockwise hierarchical regressions.	<ul style="list-style-type: none"> • Caregiving benefit showed significant positive links with higher post-loss grief (.47, $p < .001$). • Those with more pre-loss benefits were likely to show more depressive symptoms within a year following the death of a family member with dementia (.15, $p < .05$). • Caregiving benefit accounted for a significant proportion of the variance in depressive symptoms and the direction of this effect was positive. • In predicting grief, caregiver benefit accounted for 20% of the variance (when pre-loss depression was removed from the equation).

Author	Purpose of study	Participants	Design	Gain measures	Other measures	Analysis	Key results
Roff, Burgio, Gitlin, Nichols, Chaplin & Hardin (2004)	<p>1) To determine whether African Americans express more positive feelings about Alzheimer's disease caregiving than Caucasian caregivers.</p> <p>2) To explore variables that might contribute to this difference, if found (Part of the REACH study).</p>	<p>275 self-identified African American (AA) & 343 Caucasian (C) caregivers.</p> <p>(AA's: <i>Rel. to care receiver</i>; 7% husband, 20% wife & 73% other. <i>Average age</i>; 58.</p> <p>C's: <i>Rel. to care receiver</i>; 20% husbands, 41% wives & 39% other. <i>Average age</i>; 66).</p> <p>Recruited from a 3 sites of the wider REACH study, USA.</p>	<p>Cross-sectional design.</p> <p>Data collected as part of baseline phase of the wider study.</p> <p>Measures collected via in-home interviews.</p>	<p>Positive Aspects of Caregiving ($\alpha = .88$).</p>	<p>Caregiver Anxiety (Modified version of the Spielberger State-Trait Personal Inventory. $\alpha = .86$).</p> <p>Centre for Epidemiological Studies-Depression (CES-D) Scale ($\alpha = .86$).</p> <p>Religiosity (Assessed using three items; importance of faith/spirituality, attendance at religious services and frequency of prayer/meditation. $\alpha = .80$).</p> <p>Revised Memory and Behaviour Problem Checklist. ($\alpha = .87$).</p> <p>Social support ($\alpha = .80$).</p>	<p>Descriptive statistics.</p> <p>Correlations.</p> <p>Multiple regression equations.</p> <p>Sobel tests (Sobel, 1982).</p> <p>Four-step logic outlined by Baron & Kenny (1986).</p>	<ul style="list-style-type: none"> • Statistically significant correlations between race and positive aspects of caregiving. African American participants scored higher than their Caucasians counterparts on the positive aspects of caregiving scale ($F(1,616) = 30.07, p < .001$). • Socioeconomic status ($r = 0.25$), religiosity ($r = -0.28$), behavioural bother ($r = 0.16$) and anxiety ($r = 0.15$) had statistically significant relationships with race. • Factors associated with more favourable appraisals of caregiving in the African American participants were; lower socioeconomic status, lower behavioural bother, lower anxiety and higher religiosity.

Author	Purpose of study	Participants	Design	Gain measures	Other measures	Analysis	Key results
Andrén & Elmståhl (2005)	To examine the characteristics of caregivers caring for those with dementia at home, to measure rewards experienced by caregivers and to determine the factors associated with satisfaction amongst these caregivers.	153 main caregivers <i>(Gender: 61% women & 39% male. Mean age: 62 years (range = 27-90). Rel. To care-recipient: 60% off spring, 24% spouses & 16% other relatives or family friend).</i> Recruited via letters sent to all those, in one county in Sweden, who were receiving any form of social services.	Cross-sectional questionnaire design. All care-recipients underwent an assessment of dementia before the primary family caregiver participated. Care givers completed questionnaires in their own homes. Registered nurses completed the Katz, Berger and GBS scales.	Carer's Assessment of Satisfaction Index (CASI-reduced to be more specific to dementia caregiving; $\alpha = .78$).	Katz Index of ADL. Berger Scale. Gottfries-Bråne-Stein Scale (GBS). Caregiver Burden Scale ($\kappa = 0.89-1.00$). Sense of Coherence Scale (SOC; $\alpha = .82 - .95$). The Nottingham Health Profile Scale.	Factor analysis of the CASI. Multiple regression analysis. Chi-square test. Mann-Whitney U-test.	<ul style="list-style-type: none"> • Sources of satisfaction relating to the care-recipient; maintaining their hygiene, comfort and appearance (74%); seeing care give the care receiver pleasure (67%); seeing the care receiver happy (65%) and; maintaining their dignity (65%). • Sources of caregiver satisfaction; feeling needed/ wanted (55%) and; seeing appreciation from the care receiver for what they do (52%). • Caregiver age, disease severity and caregiver-care receiver relationships influenced satisfaction. • Those reporting high levels of satisfaction tolerated care giving longer.

Author	Purpose of study	Participants	Design	Gain measures	Other measures	Analysis	Key results
Hilgeman, Allen, DeCoster & Burgio (2007)	To examine the influence of positive aspects of caregiving as a moderator of treatment outcome across 12 months. (Part of the REACH study).	243 caregivers (121 African American caregivers & 122 White caregivers) (<i>Gender</i> ; 75% female. <i>Mean age</i> ; 61 years. <i>Rel. to care-recipient</i> ; 39% spouse, 61% non-spouse). Recruited from 1 site in the REACH study.	Longitudinal design (data collected at baseline, 6 months and 12 months). Measures completed at baseline, 6 and 12 months. Needs assessment and specific interventions were tailored to meet these needs. These focused on strategies to modify the physical, social and task dimensions of the home environment.	The Positive Aspects of Caregiving Scale ($\alpha = .89$).	Centre for Epidemiological Studies-Depression (CES-D) Scale ($\alpha = .86$). Revised Memory and Behaviour Checklist. Mini Mental State Examination (test retest correlations = .80-.95). Activities of Daily Living Scale ($\alpha = .83$). Katz Index of ADL.	Multi-level random coefficients regression analysis.	<ul style="list-style-type: none"> •African American caregivers reported higher levels of PAC ($F(1, 104) = 4.12, p=.0448$). •Decreases in daily care burden across time were associated with increases in PAC. •Higher values of PAC were associated with lower levels of depression across time ($F(1, 447) = 17.12, p<.0001$). •Those reporting higher PAC reported lower levels of behavioural bother across time ($F(1, 463) = 4.35, p=.0375$). •Those identifying more PAC were less upset by providing assistance with daily care ($F(1, 148) = 23.59, p<.0001$).

Author	Purpose of study	Participants	Design	Gain measures	Other measures	Analysis	Key results
Ott, Sanders & Kelber (2007)	To describe the grief and personal growth experience of spouses and adult children and the factors contributing to these experiences.	201 caregivers (90 spouses and 111 adult children). <i>(Gender; 81% female & 19% male. Age range; 20-93.).</i> Recruited via support groups sponsored by the Alzheimer's Association, memory loss clinics, community caregiver support networks, extended care facilities and by word-of-mouth.	Cross-sectional questionnaire design. Convenience sample. Questionnaires & Interviews (not described or discussed in study).	Personal Growth subscale of the Hogan Grief Reaction Checklist. ($\alpha = .881$).	Marwit & Meuser Caregiver grief Inventory-short form ($\alpha = .915$). Inventory of Social Support ($\alpha = .881$). Functional Assessment Staging of Dementia. Positive states of Mind Scale ($\alpha = .885$). Brief Cope Inventory ($\alpha = .682$ to $.870$). CES-D Scale ($\alpha = .889$). Revised Dyadic Adjustment Scale ($\alpha = .872$).	Descriptive statistics. Independent chi-square tests. Group t-tests Analyses of variance. Multivariate analyses of variance. Correlations. Hierarchical regression analyses.	<ul style="list-style-type: none"> Relationship to care-recipient was significantly associated with personal growth ($F(1,197) = 4.05, p = .046$) with adult children experience more growth than spouses. No significant difference in the magnitude of personal growth based on the care-recipients place of residence ($F(1,197) = .026, p = .873$). 46% variance in personal growth was explained by the modified Marwit-Meuser-Sanders Caregiver Grief Model. Level of social support, coping by reframing and religion significantly contributed to caregiver's personal growth.

Author	Purpose of study	Participants	Design	Gain measures	Other measures	Analysis	Key results
Leipold, Schacke & Zank (2008)	<p>Two parts;</p> <p>1) To examine the relationship between personal growth and care-related stressors.</p> <p>2) To investigate the development of personal growth over time</p> <p>Part of 'The Longitudinal Dementia Caregiver Stress Study' in Germany.</p>	<p><u>Study 1:</u> 126 relatives of dementia patients recruited via support groups in Germany (<i>Gender:</i> 94 women & 32 men. <i>Age range:</i> 32-84yrs. <i>Rel. to care-recipient;</i> 80% spouses/children).</p> <p><u>Study 2:</u> 321 caregivers from the LEANDER study, recruited via news paper announcements (<i>Gender:</i> 79% female & 21% male. <i>Average age:</i> 59.5 yrs).</p>	<p><u>Study 1:</u> Cross-sectional design using Questionnaires and structured interviews (# = measures used).</p> <p><u>Study 2:</u> Longitudinal design (over 27 months). Telephone interviews and self-completed questionnaires (* = measures used).</p>	<p>General Personal Growth Scale ($\alpha = .91$).^{##}</p>	<p>Sentence Completion Test-Short form ($\alpha = .71$).[#]</p> <p>Berlin Inventory of Caregivers' Burden with Dementia Patients - subscales.[#]</p> <p>ADL, IDAL, supervision & emotional support ($\alpha = .77$).^{##}</p> <p>Loss and Grief ($\alpha = .84$).^{##}</p> <p>Lack of Social Acknowledgement ($\alpha = .87$).^{##}</p> <p>Restrictions in Personal Need ($\alpha = .94$).^{##}</p> <p>Vocabulary test.[#]</p> <p>Demographic Indices.[#]</p>	<p><u>Study 1:</u> Correlations. Hierarchical regression.</p> <p><u>Study 2:</u> Repeated measure ANOVA's. Latent growth modelling techniques.</p>	<p><u>Study 1</u></p> <ul style="list-style-type: none"> • Duration of caregiving and lack of social acknowledgement were identified as significant care predictors of personal growth. <p><u>Study 2</u></p> <ul style="list-style-type: none"> • Caregiving tasks mediated the effect of caregiving duration on personal growth. • Increases in personal growth through caregiving were found to be predicted by increased caregiving tasks ($\beta = 0.42$, $t=2.86$). • Personal growth was associated with two specific caregiving demands; duration of caregiving and lack of social acknowledgement.

Author	Purpose of study	Participants	Design	Gain measures	Other measures	Analysis	Key results
Baker, Robertson & Connelly (2010)	To investigate whether measures of gender identity and gender role conflict contributed to prediction of husband caregiver strain and gain.	70 husband carers of wives with dementia. <i>(Mean age: 68.6 yrs (range = 43-83). Mean length of marriage: 42.9 yrs (range = 5-62). Mean duration of caregiving: 5.6 yrs (range = 1-24)).</i> Recruited via NHS day hospitals and community teams across 2 counties and via internet bulletin boards run by the Alzheimer's Society and Alzheimer's Association.	Cross-sectional survey design. Data collected via postal or internet questionnaires. Questionnaires were piloted and adapted for brevity.	5 items from the Caregiver Satisfaction Scale ($\alpha = .84$).	Short form of the Personal Attributes Questionnaire ($\alpha = .82-.85$). Brief Zarit Burden Interview ($\alpha = .85$). Adapted version of the 37-item Gender Role Conflict Scale ($\alpha = .75-.85$). Revised Memory and Behavioural Problems checklist ($\alpha = .78-.87$). Self rating of health.	Correlation matrix. Multiple regression analysis using variables that showed a significant relationship with the dependent variables.	<ul style="list-style-type: none"> • Gender role conflict had a significant positive association with gain. Higher gain scores were associated with more traditional responses about emotional closeness to other men and about success, power and competition. • Gender role conflict variables accounted for the largest proportion of variance in the final regression equation at 19.2% suggesting that they play an important role in explaining appraisals of gain in older male caregivers. • Gender identity was not a significant predictor of gain in male caregivers.

Author	Purpose of study	Participants	Design	Gain measures	Other measures	Analysis	Key results
Gonçalves-Pererira, Carmo, Alves da Silva, Papolio, Mateos & Zarit (2010)	To investigate the relationship between knowledge of dementia and other aspects of caregiver's experiences, particularly its association with caregiver's burden and positive feelings, in a Portuguese sample.	116 relative caregivers <i>(Gender; 67% female. Mean age; 56.1 years. Rel. to patient: 34% spouse, 55% child, 1% sibling, 10% other family member.</i> Recruited from 3 health practices where the person with dementia was seen as an outpatient. Convenience sample for the FAMIDEN cross-sectional study.	Cross-sectional design. Questionnaires; the majority were self completed. Some questionnaires were translated into Portuguese – method of translation and reliability and validity data provided for these.	Positive Aspects of Caregiving Scale ($\alpha = .87$).	Dementia Knowledge Questionnaire. Zarit Burden Interview ($\alpha = .88$). Caregiver Activity Survey. General Health Questionnaire. Camberwell Assessment of Need for the Elderly. Carer's assessment of Management Index (Information seeking questions only).	Descriptive statistics. X^2 tests. Fisher's Exact. Mann-Whitney U. Kruskall-Wallis. (the above tests were used as required) Spearman's coefficients. Hierarchical multiple regression.	<ul style="list-style-type: none"> • More positive aspects were recognised by older caregivers ($P=0.016$) and those living with the patient ($P=0.041$). • Caregivers from low social class ($P=0.029$) and lower education ($P<0.001$) evidenced higher PAC scores • In regard to psychological stress needs, those deemed in-need presented with lower PAC levels ($P=0/015$). • Strong negative association between burden scores and PAC scores ($P=0.008$). • Dementia knowledge was not significantly associated with PAC.

Author	Purpose of study	Participants	Design	Gain measures	Other measures	Analysis	Key results
Liew, Luo, Ng, Chionh, Goh & Yap (2010)	To explore factors, which may be related to the caregiver, the person with dementia or the caregiving situation, that are associated with the experience of gains in dementia caregiving.	334 caregivers (<i>Gender</i> ; 71% female and 29% males. <i>Ethnicity</i> ; 94.6% Chinese, 3% Indian and 2.4% other. <i>Rel. to care receiver</i> ; 13.5% spouses, 74.2% child, 8.1% in-laws, 1.2% grandchildren and 3% other). Recruited from a tertiary hospital dementia clinic and the local Alzheimer's Association (Singapore).	Cross-sectional survey design. Self administered surveys (these were explained to participants before they were left to answer them on their own).	Gain in Alzheimer's care Instrument ($\alpha = .89$)	General Health Questionnaire-28 (GHQ-28) Dementia Management Strategies Scale (DMSS) Revised Memory and Behavioural Problems checklist (RMBPC) Zarit Burden Interview (ZBI) Short Sense of Competence Questionnaire (SSCQ).	Descriptive statistics Univariate analysis (independent t-test, ANOVA or Pearson's correlation). Correlation analysis Multiple Linear Regression (using variables found to be significant in the univariate analysis).	<ul style="list-style-type: none"> • The regression model accounted for 32.3% of variance of the GAIN score ($F=7.56$, $P<0.0001$). • Higher gain was positively correlated with sense of caregiver competence, positive management strategies, and inversely associated with caregiver burden, mental health problems, negative care strategies and behavioural problems. • Frequent or close contact with care receiver, caregiver wellbeing, positive caregiver strategies and participation in caregiver educational/ support groups were significantly associated with gain.

APPENDIX E:
QUALITY FRAMEWORK FOR QUALITATIVE STUDIES

Quality criteria	Specific questions to consider when rating
1. Rationale clearly described?	<ul style="list-style-type: none"> • Does the author(s) describe the current evidence base? • Does the author(s) identify the gaps in the evidence base? • Does the author(s) justify the need for the area of research?
2. Research aims clearly stated?	<ul style="list-style-type: none"> • Does the author(s) clearly state what they plan to research?
3. Ethical issues addressed?	<ul style="list-style-type: none"> • Does the author(s) state that ethical approval was sought? • Does the author(s) demonstrate an awareness of the ethical issues raised? (E.g. informed consent, confidentiality, responding to upset or distress, withdrawal etc.).
4. Methodology appropriate to the research question?	<ul style="list-style-type: none"> • Is the use of qualitative methodology appropriate to the research aims? (E.g. to interpret or illuminate the actions and/or subjective experiences of the participants).
5. Philosophical background identified?	<ul style="list-style-type: none"> • Does the author(s) state their philosophical background?
6. Study design/ approach identified and the rationale for choice evident?	<ul style="list-style-type: none"> • Does the author(s) clearly state the design of the study? • Does the author(s) discuss the reasons for employing qualitative methodology? • Does the author(s) justify the research design used? (E.g. grounded theory, content analysis etc.).
7. Major concepts identified?	<ul style="list-style-type: none"> • Does the author(s) define the key concepts (E.g. caregivers, positive effects etc.) in the study?
8. Sample population situated?	<ul style="list-style-type: none"> • Does the author(s) adequately describe the sample (E.g. Gender, age, relationship to care receiver etc.) so that the reader can determine transferability of findings?
9. Selection of participants adequately described?	<ul style="list-style-type: none"> • Does the author(s) describe the context of where the samples were recruited from? • Does the author(s) describe the method of recruitment used? (E.g. the sampling method, recruitment procedure etc.) • Does the author(s) identify the inclusion criteria?

10. Method of data collection auditable?	<ul style="list-style-type: none"> • Does the author(s) describe how the data was collected? (E.g. semi-structured interviews, where data collection took place, who collected the data etc.) • Does the author(s) describe the areas covered in the interview and/or provide a copy of the questions asked?
11. Method of data analysis credible and confirmable?	<ul style="list-style-type: none"> • Does the author(s) clearly describe the analysis process? • Does the author(s) describe how they addressed the issue of validity during the analysis and/or interpretation stages? (E.g. external reviewers, dual coders etc.). • Does the author(s) provide sufficient data/quotes to support their findings? • Does the author(s) provide quotes that appear to be relevant to the themes identified?
12. Reflectivity considered and described?	<ul style="list-style-type: none"> • Does the author(s) acknowledge the influence of the research process and the presence of the researcher (including the role of potential biases in analysis and selection of data, assumptions and experiences etc.) on the data collected?
13. Findings clearly stated?	<ul style="list-style-type: none"> • Does the author(s) explicitly state their findings? (E.g. Themes/subthemes identified). • Does the author(s) clearly distinguish themes/subthemes within the results section?
14. Comprehensive discussion?	<ul style="list-style-type: none"> • Does the author(s) summarise the main findings? • Does the author(s) link their findings back to the research aims? • Does the author(s) link their findings current literature and/or psychological theory?
15. Strengths and limitations identified?	<ul style="list-style-type: none"> • Does the author(s) identify the limitations of the research? (E.g. Sample size, recruitment strategies, method of data collection, analysis etc.) • Does the author(s) identify the strengths of the research? (E.g. Its usefulness etc.)
16. Justifiable conclusions made?	<ul style="list-style-type: none"> • Does the author(s) make conclusions that are supported by their discussions of their findings?

APPENDIX F:
QUALITY FRAMEWORK FOR QUANTITATIVE STUDIES

Quality criteria	Specific questions to consider when rating
1. Rationale clearly described?	<ul style="list-style-type: none"> • Does the author(s) describe the current evidence base? • Does the author(s) identify the gaps in the evidence base? • Does the author(s) justify the need for the area of research?
2. Research aims clearly stated?	<ul style="list-style-type: none"> • Does the author(s) clearly state what they plan to research?
3. Ethical issues addressed?	<ul style="list-style-type: none"> • Does the author(s) state that ethical approval was sought? • Does the author(s) demonstrate an awareness of the ethical issues raised by the study? (E.g. informed consent, confidentiality, responding to upset or distress, withdrawal etc.).
4. Methodology appropriate to the research question?	<ul style="list-style-type: none"> • Is the use of quantitative methodology appropriate to the research aims? (E.g. to determine relationships between a number of variables).
5. Study design identified and the rationale for choice evident?	<ul style="list-style-type: none"> • Does the author(s) clearly state the design of the study? • Does the author(s) justify the research design used? (E.g. longitudinal, cross sectional etc.).
6. Experimental hypotheses stated?	<ul style="list-style-type: none"> • Does the author(s) clearly state what they expect to find?
7. Key variables identified?	<ul style="list-style-type: none"> • Does the author(s) identify the main variables investigated in the study?
8. Sample population situated?	<ul style="list-style-type: none"> • Does the author(s) adequately describe the sample (E.g. Gender, age, relationship to care receiver etc.) so that the reader can determine transferability of findings?
9. Selection of participants adequately described?	<ul style="list-style-type: none"> • Does the author(s) describe the context of where the samples were recruited from? • Does the author(s) describe the method of recruitment used? (E.g. the sampling method, recruitment procedure etc.) • Does the author(s) identify the inclusion criteria?

10. Method of data collection reliable and valid?	<ul style="list-style-type: none"> • Does the author(s) justify that the measure is suitable for this population? • Does the author(s) use measures that measure the desired constructs? • Does the author(s) indicate whether the measures used have good psychometric properties? (E.g. test-retest reliability, inter-rater reliability, internal reliability and internal consistency (Cronbach's alpha)). • Does the author(s) indicate that the measures used have demonstrated validity?
11. Method of data analysis reliable and valid?	<ul style="list-style-type: none"> • Does the author(s) state which statistic tests were used? • Does the author(s) use statistical tests that appear to be appropriate to the nature of the data collected? (E.g. Does the data meet the assumptions of the test). • Were the statistical tests used appropriate to the research question? • Does the author(s) consider the impact of extraneous variables and control for these within the analysis process? • Does the author(s) provide evidence of statistical findings? (E.g. Data within the text, tables etc.). • Does the author(s) state the levels of significance?
12. Findings clearly stated?	<ul style="list-style-type: none"> • Does the author(s) explicitly state their findings? • Does the author(s) present the statistical data in a clear manner? • Does the author(s) clearly differentiate between significant and non-significant findings?
13. Comprehensive discussion?	<ul style="list-style-type: none"> • Does the author(s) summarise the main findings? • Does the author(s) link their findings back to the research aims? • Does the author(s) link their findings current literature and/or psychological theory? • Does the author(s) consider the clinical usefulness of their findings?
14. Strengths and limitations identified?	<ul style="list-style-type: none"> • Does the author(s) indentify the limitations of the research? (E.g. Sample size, recruitment strategies, method of data collection, analysis etc.) • Does the author(s) identify the strengths of the research? (E.g. Its usefulness etc.)
15. Justifiable conclusions made?	<ul style="list-style-type: none"> • Does the author(s) make conclusions that are supported by their discussions of their findings?

APPENDIX G:

EXAMPLE OF THE DECISION MAKING PROCESS: QUALITATIVE STUDIES

Beach (1997) Family caregiving: the positive impact on adolescent relationships (Quality checks were reviewed by the research supervisor).

Quality criteria	Specific questions to consider when rating	Comments about article	Rating
1. Rationale clearly described?	<ul style="list-style-type: none"> • Does the author(s) describe the current evidence base? • Does the author(s) identify the gaps in the evidence base? • Does the author(s) justify the need for the area of research? 	<ul style="list-style-type: none"> • Describes current focus of research – spouses and adult-children, the trauma and burden on primary caregivers. • Identifies gap in literature around young children and adolescents in the caregiving environment and positive experiences associated with caregiving. • Indicates why research into this population group is needed. 	++
2. Research aims clearly stated?	<ul style="list-style-type: none"> • Does the author(s) clearly state what they plan to research? 	<ul style="list-style-type: none"> • The author clearly indicates the aim of the study and the specific questions addressed within it. 	++
3. Ethical issues addressed?	<ul style="list-style-type: none"> • Does the author(s) state that ethical approval was sought? • Does the author(s) demonstrate an awareness of the ethical issues raised? (E.g. informed consent, confidentiality, responding to upset or distress, withdrawal etc.). 	<ul style="list-style-type: none"> • Confidentiality of potential participants discussed and methods to address this were stated. • State informed consent was gained prior to interviews – however does not describe how this was done. 	+/-
4. Methodology appropriate to the research question?	<ul style="list-style-type: none"> • Is the use of qualitative methodology appropriate to the research aims? (E.g. to interpret or illuminate the actions and/or subjective experiences of the participants). 	<ul style="list-style-type: none"> • Yes – to examine the potential positive caregiving experiences of adolescents and their perceptions of relational enhancement as a result of caregiving. 	

5. Philosophical background identified?	<ul style="list-style-type: none"> Does the author(s) state their philosophical background? 	<ul style="list-style-type: none"> The philosophical background of the author is not described. 	--
6. Study design/ approach identified and the rationale for choice evident?	<ul style="list-style-type: none"> Does the author(s) clearly state the design of the study? Does the author(s) discuss the reasons for employing qualitative methodology? Does the author(s) justify the research design used? (E.g. grounded theory, content analysis etc.). 	<ul style="list-style-type: none"> Non-experimental study; features of content analysis methodology (Glass, 1978) stated. Rational for chosen method given – due to usefulness in ascertaining perceptions of experiences while limiting opportunities for the introduction of perceived consequences. 	++
7. Major concepts identified?	<ul style="list-style-type: none"> Does the author(s) define the key concepts (E.g. caregivers, positive effects etc.) in the study? 	<ul style="list-style-type: none"> The idea of ego-development is described and referred back to within the discussion of findings. No other major concepts are defined. 	+/-
8. Sample population situated?	<ul style="list-style-type: none"> Does the author(s) adequately describe the sample (E.g. Gender, age, relationship to care receiver etc.) so that the reader can determine transferability of findings? 	<ul style="list-style-type: none"> Number of participants stated. Demographic information provided in the text and in a table – information collected on gender, age, ethnicity, average. age of person with the dementia, relationship to the person with dementia and additional characterises -enough information to determine transferability of findings. 	++

<p>9. Selection of participants adequately described?</p>	<ul style="list-style-type: none"> • Does the author(s) describe the context of where the samples were recruited from? • Does the author(s) describe the method of recruitment used? (E.g. sampling method, recruitment procedure etc.) • Does the author(s) identify the inclusion criteria? 	<ul style="list-style-type: none"> • Recruitment site stated. • Participant inclusion criteria given. • Described how participants were initially approached about the research and how they opted in. 	<p>++</p>
<p>10. Method of data collection auditable?</p>	<ul style="list-style-type: none"> • Does the author(s) describe how the data was collected? (E.g. semi-structured interviews, where data collection took place, who collected the data etc.) • Does the author(s) describe the areas covered in the interview and/or provide a copy of the questions asked? 	<ul style="list-style-type: none"> • Data was collected through the use of semi-structured interviews which focused around three main areas. These areas are listed. • The author provides a copy of the open ended questions used. • The author does not describe where the interviews took place or who conducted them. 	<p>++</p>
<p>11. Method of data analysis credible and confirmable?</p>	<ul style="list-style-type: none"> • Does the author(s) clearly describe the analysis process? • Does the author(s) describe how they addressed the issue of validity during the analysis and/or interpretation stages? (E.g. external reviewers, dual coders etc.). • Does the author(s) provide sufficient data/quotes to support their findings? • Does the author(s) provide quotes that appear to be relevant to the themes identified? 	<ul style="list-style-type: none"> • State that the interviews were audio taped and transcribed verbatim. • Analysed using 2-tiered system of sorting and analysis (Glass, 1978) – provided evidence of how this was done and how categories were determined. • Verification of data described – some participants were asked to comment on accuracy of a section of their transcript, caregiving adolescents not involved in the study and colleagues were asked to comment on findings. • Sufficient quotes are provided to support findings and they appear to be relevant to the themes identified. 	<p>++</p>

<p>12. Reflectivity considered and described?</p>	<ul style="list-style-type: none"> • Does the author(s) acknowledge the influence of the research process and the presence of the researcher (including the role of potential biases in analysis and selection of data, assumptions and experiences etc.) on the data collected? 	<ul style="list-style-type: none"> • The author does not acknowledge or discuss the issue reflexivity. 	<p>--</p>
<p>13. Findings clearly stated?</p>	<ul style="list-style-type: none"> • Does the author(s) explicitly state their findings? (E.g. Themes/subthemes identified). • Does the author(s) clearly distinguish themes/subthemes within the results section? 	<ul style="list-style-type: none"> • Italicised and larger text is used to identify themes within the text. • There is no summary/overview of the themes or the number of themes identified. 	<p>+/-</p>
<p>14. Comprehensive discussion?</p>	<ul style="list-style-type: none"> • Does the author(s) summarise the main findings? • Does the author(s) link their findings back to the research aims? • Does the author(s) link their findings current literature and/or psychological theory? 	<ul style="list-style-type: none"> • Summarises main findings within discussion. • Each main finding is discussed in relation to previous research findings and literature. • Findings linked back to the ego-development theory discussed in the introduction. 	<p>++</p>

<p>15. Strengths and limitations identified?</p>	<ul style="list-style-type: none"> • Does the author(s) indentify the limitations of the research? (E.g. Sample size, recruitment strategies, method of data collection, analysis etc.) • Does the author(s) identify the strengths of the research? (E.g. Its usefulness etc.) 	<ul style="list-style-type: none"> • Limitations are identified – small N, retrospective nature of the study, limited ethnicity mix, limited mix of relationship to caregivers. • Suggests directions for future research – longitudinal studies addressing the adolescents and primary caregiver’s experiences, adolescent’ caregivers from other ethnic backgrounds, adolescent caregivers with different relationships to the person with dementia and adolescents of various age groups. • Strengths (not explicitly stated) – raises questions about ego-development and identifies that there are a number of positive outcomes for adolescent caregivers 	<p>++</p>
<p>16. Justifiable conclusions made?</p>	<ul style="list-style-type: none"> • Does the author(s) make conclusions that are supported by their discussions of their findings? 	<ul style="list-style-type: none"> • The conclusions made appear to be supported by the discussion of findings. 	<p>++</p>

APPENDIX H:

EXAMPLE OF THE DECISION MAKING PROCESS: QUANTITATIVE STUDIES

Ott, Sanders and Kelber (2007). Grief and personal growth experiences of spouses and adult-children of individuals with Alzheimer's disease and related dementias (Quality checks were reviewed by the research supervisor).

Quality criteria	Specific questions to consider when rating	Comments about article	Rating
1. Rationale clearly described?	<ul style="list-style-type: none"> • Does the author(s) describe the current evidence base? • Does the author(s) identify the gaps in the evidence base? • Does the author(s) justify the need for the area of research? 	<ul style="list-style-type: none"> • Identifies lack of research around grief and personal growth in dementia caregiving. • Describes background research in the area of grief and personal growth. • Research will help theory development. 	++
2. Research aims clearly stated?	<ul style="list-style-type: none"> • Does the author(s) clearly state what they plan to research? 	<ul style="list-style-type: none"> • Experiences and factors contributing to grief and personal growth. 	++
3. Ethical issues addressed?	<ul style="list-style-type: none"> • Does the author(s) state that ethical approval was sought? • Does the author(s) demonstrate an awareness of the ethical issues raised by the study? (E.g. informed consent, confidentiality, responding to upset or distress, withdrawal etc.). 	<ul style="list-style-type: none"> • State ethical approval sought • Process of ensuring informed consent described – providing information on the study and time for questions. • Issues of consent, confidentiality, voluntary, withdrawal, responding to upset or distress etc not discussed. 	+/-
4. Methodology appropriate to the research question?	<ul style="list-style-type: none"> • Is the use of quantitative methodology appropriate to the research aims? (E.g. to determine relationships between a number of variables). 	<ul style="list-style-type: none"> • Yes –aim of research to identify factors contributing to experiences of grief and personal growth. • Note – state looking at experiences and state participants were interviewed for hour and a half but not mentioned in article. 	Yes

5. Study design identified and the rationale for choice evident?	<ul style="list-style-type: none"> • Does the author(s) clearly state the design of the study? • Does the author(s) justify the research design used? (E.g. longitudinal, cross sectional etc.). 	<ul style="list-style-type: none"> • State cross sectional descriptive study. • No rationale for choice of design given. 	+/-
6. Experimental hypotheses stated?	<ul style="list-style-type: none"> • Does the author(s) clearly state what they expect to find? 	<ul style="list-style-type: none"> • No hypotheses stated – discussion implies they had hypotheses. 	--
7. Key variables identified?	<ul style="list-style-type: none"> • Does the author(s) identify the main variables investigated in the study? 	<ul style="list-style-type: none"> • Variables outlined in the descriptive/conceptual titles in the measures section. 	++
8. Sample population situated?	<ul style="list-style-type: none"> • Does the author(s) adequately describe the sample (E.g. Gender, age, relationship to care receiver etc.) so that the reader can determine transferability of findings? 	<ul style="list-style-type: none"> • Number of participants stated and separated into groups. • Reasons for non-participation given. • Demographic data given descriptively and numerically in tables and within text. • Enough information provided to determine transferability. 	++
9. Selection of participants adequately described?	<ul style="list-style-type: none"> • Does the author(s) describe the context of where the samples were recruited from? • Does the author(s) describe the method of recruitment used? (E.g. the sampling method, recruitment etc.) • Does the author(s) identify the inclusion criteria? 	<ul style="list-style-type: none"> • Recruitment sites stated. • The term caregivers defined. • Participant inclusion criteria given. • Recruitment procedure clearly described – sent pamphlet, returned post card, contacted to give further info and ask questions. • Actual sampling method not stated. 	++

<p>10. Method of data collection reliable and valid?</p>	<ul style="list-style-type: none"> • Does the author(s) justify that the measure is suitable for this population? • Does the author(s) use measures that measure the desired constructs? • Does the author(s) indicate whether the measures used have good psychometric properties? (E.g. test-retest reliability, inter-rater-reliability, internal reliability and internal consistency (Cronbach's alpha)). • Does the author(s) indicate that the measures used have demonstrated validity? 	<ul style="list-style-type: none"> • Completion time for questionnaires stated. • Described how collected demographic/contextual data – e.g. support. • Cronbach's alphas stated for 6 of the 8 measures. Those stated are all above .7. • Limited statements of reliability and validity of scales – One measure states scale has high internal consistency reliability and is psychometrically supported. • No justification of measures being suitable for population group – grief measure developed with population group, personal growth and social support scales derived from bereaved adults, positive states of mind tested on college students. • Subjectively the majority of scales appear to be appropriate to the constructs measuring. • ? Use of positive states of mind scale to assess the construct Emotional health/wellbeing. 	<p>+/-</p>
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<p>11. Method of data analysis reliable and valid?</p>	<ul style="list-style-type: none"> • Does the author(s) state which statistic tests were used? • Does the author(s) use statistical tests that appear to be appropriate to the nature of the data collected? (E.g. Does the data meet the assumptions of the test). • Were the statistical tests used appropriate to the research question? • Does the author(s) consider the impact of extraneous variables and control for these within the analysis process? • Does the author(s) provide evidence of statistical findings? (E.g. Data within the text, tables etc.). • Does the author(s) state the levels of significance? 	<ul style="list-style-type: none"> • Test used appropriate to aim of exploring differences between spouses and adult-child caregivers - Dependent chi square tests, group t-tests, analysis of variance and two-way multivariate analysis of variance. • Appropriate tests used to determine relationships between variables - correlations and hierarchical regression analyses. • Mean scores and regression analysis data given in tables. Other statistical data quoted in text. • Don't provide tables of data from all statistical tests in tables, just statistically significant results in text. • P values stated. • Interaction effects between variables noted and analysis amendments stated. • Confidence intervals and test assumptions not stated - means & SD's are similar and all measures are ordinal scales – authors assume parametric assumptions are met. 	<p>++</p>
<p>12. Findings clearly stated?</p>	<ul style="list-style-type: none"> • Does the author(s) explicitly state their findings? • Does the author(s) present the statistical data in a clear manner? • Does the author(s) clearly differentiate between significant and non-significant findings? 	<ul style="list-style-type: none"> • Headings used to separate analyses and factors looking at. • Statistical findings stated and data provided to back up findings. • Regression analysis results displayed in table. • Significant and non significant findings clearly stated and indicated in tables. 	<p>++</p>

13. Comprehensive discussion?	<ul style="list-style-type: none"> • Does the author(s) summarise the main findings? • Does the author(s) link their findings back to the research aims? • Does the author(s) link their findings current literature and/or psychological theory? • Does the author(s) consider the clinical usefulness of their findings? 	<ul style="list-style-type: none"> • Clinical significance of findings considered and additional literature identified. • Findings linked to other studies and relevant literature. • Findings linked back to aims of study (first discussion paragraph). • Main findings not summarised. 	++
14. Strengths and limitations identified?	<ul style="list-style-type: none"> • Does the author(s) indentify the limitations of the research? (E.g. Sample size, recruitment strategies, method of data collection, analysis etc.) • Does the author(s) identify the strengths of the research? (E.g. Its usefulness etc.) 	<ul style="list-style-type: none"> • Limitations identified – cautiousness of causal inferences, use of self reported measures, sample selection and generalisability. • Strengths – first study to investigate grief and personal reactions, clinical usefulness of findings, identifies new avenues of research and alternative measures used. 	++
15. Justifiable conclusions made?	<ul style="list-style-type: none"> • Does the author(s) make conclusions that are supported by their discussions of their findings? 	<ul style="list-style-type: none"> • Conclusions appear to match well with findings 	++

APPENDIX I:
INSTRUCTIONS TO AUTHORS: LITERATURE REVIEW

Dementia: The International Journal of Social Research and Practice:
Manuscript Submission Guidelines

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APPENDICES
EMPIRICAL PAPER

APPENDIX A:

Original ethical approval 2009

APPENDIX B:

Ethical approval 2011 (Change of chief investigator)

APPENDIX C:
R & D approvals

APPENDIX D:

Ethical approval 2011 (National Voluntary agencies)

APPENDIX E:

Online recruitment advertisement

Young people's views and thoughts of having a parent who has Young onset dementia

What is it like having a parent with Young onset dementia? How has it affected your family? What has changed? How do you cope?

Very little is known about young people's experiences of having a parent with Young onset dementia. We hope to learn more about these experiences so that we may find better ways to help you and other young people in a similar situation. We are really interested in hearing about your experiences!

Who can take part?

We would like to talk with young people who;

- Are aged between 13 and 24 years of age
- Have a Mother or Father diagnosed with Young onset dementia
- Live with or are in regular contact with this parent.

What would this involve?

If you decided to take part in the study Susan Tolley (a Trainee Clinical Psychologist from the University of Birmingham) will arrange to meet with you. This can be at a time and place that's convenient for you. She will talk with you about your experiences of having a parent with Young onset dementia.

Very little is known about the ongoing experiences of young people and we would like to know more about these. We would like to meet up with you every 1-2 years, if you agree, to see how things are going. It will be up to you how many times you agree to meet and you can stop meeting us at anytime.

What happens after I take part?

We will send you a summary of the study's findings. We also hope to publish the findings in professional journals. You do not need to worry about people knowing anything about what you say during our conversation. We will treat your responses as confidential. Some of the

comments that you make may be used in the final report, however we will not use your name or identify anyone that you may mention.

What do I do if I want to take part?

If you are interested in taking part, please give me a call or ask your mum/dad to contact me for you. Please contact me at **XXXXXX** or leave a message for me on (**XXXXXX**) and I will get back to you. I will then send you some information about the study for you to read before deciding if it is something you would like to do. If you are under the age of 16 your parents would also need to agree for you to take part. After reading the information please return the consent form to me if you wish to take part. If I have not heard from you after two weeks I will call you to see if you have any questions about the study and to see if you would like to take part.

So still interested? ...please speak to (insert name) or call or email Susan to find out more. We will be pleased to hear from you.

APPENDIX F:

Young person's invitation letter



UNIVERSITY OF
BIRMINGHAM

Dear

Study title: Young People's Views and Thoughts of Living with Their Parent who has Younger Onset Dementia

We would like to invite you to take part in a research study. Before deciding that this is something that you would like to do, it is important to understand why we are doing this study. Please read the information book and talk about it with your family if you want to.

We know very little about what young people may be worried about or how things might have changed since their parent got Younger Onset Dementia. We wonder how it has affected their family, and how they cope. We hope that this research will help us to learn more about how to help young people who find themselves in a situation like yours.

If you would like to take part in the research, please tell your parent's keyworker who will then pass your details onto Susan Tolley. Susan will then call you to arrange a time to meet. If you have any questions before then, you can always contact Susan on XXXX. You do not have to give Susan any information and this does not mean that you have said yes to be in the study.

Yours sincerely,

Susan Tolley

Trainee Clinical Psychologist

Dr Jan Oyebode, Consultant Clinical Psychologist

Dr Natasha Lord, Clinical Psychologist

Dr Joanne Allen, Consultant Clinical Psychologist

APPENDIX G:

Parent/guardian's invitation letter



UNIVERSITY OF
BIRMINGHAM

Dear,

Study Title: Exploring Children's Perceptions of Having a Parent with Younger Onset Dementia and the Effect on Their Transition into Adulthood

Researcher: Susan Tolley, Trainee Clinical Psychologist

We would like to invite your child to take part in a research study. Before you decide whether you would like your child to take part, it is important for you to know and understand why the research is being done and what it will involve. Please read the enclosed information booklet and if you have any questions, you are always able to contact Susan at any time.

Little is known about children's ongoing experiences of living with a parent who has Younger Onset Dementia (dementia occurring before the age of 65 years), the impact on relationships within the family, the progression into adulthood and what coping mechanisms children may use. This study will attempt to fill some of these gaps by exploring the lives of children who live with a parent who has Younger Onset Dementia. This research will hopefully help us to understand the healthcare, psychological and emotional needs of children, and help us to build services in the future based on the needs of families.

If you would be willing for your child to partake in the study, please let your keyworker know. Your keyworker will pass the details to Susan Tolley, who will contact you by telephone to arrange an interview. If you have any questions before this time, please contact Susan on **XXXX**. You do not need to give Susan any information and this does not mean that you have consented for your child to take part.

Thanking you in anticipation.
Yours sincerely,

Susan Tolley
Trainee Clinical Psychologist

Dr Jan Oyebo, Consultant Clinical Psychologist
Dr Natasha Lord, Clinical Psychologist
Dr Joanne Allen, Consultant Clinical Psychologist

APPENDIX H:

Young person's information sheet

**Young People's Views and Thoughts of Living with Their Parent who has
Young Onset Dementia**

**Information Sheet (Version 2)
Young Person**

Researcher: Susan Tolley, Trainee Clinical Psychologist

Clinical Psychology
School of Psychology
University of Birmingham
Edgbaston
Birmingham
B15 2TT

Tel: XXXXX

Email: XXXXX

Research Supervisors:

Dr Jan Oyebode, Clinical Course Director, University of Birmingham
Dr Natasha Lord, Clinical Psychologist, Older Adult Services, Wolverhampton
Dr Joanne Allen, Consultant Clinical Psychologist, Specialist Young Onset Dementia
Services, Birmingham

Young People's Views and Thoughts of Living with Their Parent who has Young Onset Dementia

We would like to invite you to take part in a research study. Before deciding that this is something that you would like to do, it is important to understand why we are doing this study. Please read the following information carefully and talk it over with your family if you want to. If you have any questions or would like more information, you can ring Susan Tolley on **XXXX**.

Take your time deciding whether or not this is something that you would like to do.

Thank you for reading this

What is the study about?

We know very little about what young people may be worried about or how things might have changed since their parent got Young Onset Dementia. We wonder how it has affected their family, and how they cope over time. We hope that this research will help us to learn more about how to help young people who find themselves in a situation like yours.

Why have I been chosen?

We hope that up to 15 families will take part in the study. Your family has been chosen because your mum/dad has Young Onset Dementia and we are really interested in what you think and feel about things.

Do I have to take part? How often would I be seen?

It's up to you to decide whether or not you want to take part and how many times you want to meet with us. If you do decide to take part, you will be asked to sign a consent form each time we contact you to give your permission. We would like to see you every 1 to 2 years until the age of 25. We will send a letter or an email asking to meet with you to hear how you have been since we last met with you. Sometimes you may talk with a different person. If you do decide to take part, you can pull out at any time without giving a reason and this will not

affect any treatment that your mum/dad may be having. If you want to take a break at any time when we are talking, just say so.

Will the information that I give be kept private?

The form that you sign to say you are willing to take part will be kept separately from other information you give. All other information will have your name and address removed so that you cannot be recognised from it. Should you say that you are going to hurt yourself or others, or that someone is harming you then the researcher will inform your doctor or a social worker so that they can help you.

What will happen after I have been interviewed?

After each interview, we will have a short report summarising the findings of the study which we will send to you. You can show this to your family if you wish to or you can tell us and we will send the report to your family as well. We also hope to publish in leading professional journals.

What do I have to do if I take part?

Ring or talk to your parent's key worker who gave you the information or ask your mum/dad to call them. They will pass your name and telephone number to me and Susan will ring you. Susan will arrange a time to visit you at home or somewhere else if that would be better for you. You will be asked to sign a consent form to say that you have agreed to take part in the study. She will be interested to hear about how your mum/dad's illness has affected you and how you cope. This meeting will last about 60 minutes.

What's in it for me?

The needs of young people like your mum/dad seem to be different to those people who get the illness when they are older. Life changes may affect the way your mum/dad is able to cope with things. Family life may be a bit different now. If we know what young people think and feel when somebody is ill in their family, we may find better ways to help them.

APPENDIX I:

Older child's information sheet

**Young People's Views and Thoughts of Living with Their Parent who has
Younger Onset Dementia**

Information Sheet (Version 2)

Young Person (16+)

Researcher: Susan Tolley, Trainee Clinical Psychologist

Clinical Psychology

School of Psychology

University of Birmingham

Edgbaston

Birmingham

B15 2TT

Tel: XXXXX

Email: XXXXX

Research Supervisors:

Dr Jan Oyeboode, Clinical Course Director, University of Birmingham

Dr Natasha Lord, Clinical Psychologist, Older Adult Services, Wolverhampton

Dr Joanne Allen, Consultant Clinical Psychologist, Specialist Younger Onset Dementia
Services, Birmingham

Susan Tolley is a 2nd year postgraduate student studying for her Doctorate in Clinical Psychology. This research will form part of her overall mark. If you would like further information, please let Susan, Jan, Natasha or Joanne know and they will be happy to provide further information.

Young People's Views and Thoughts of Living with Their Parent who has Younger Onset Dementia

We would like to invite you to take part in a research study. Before deciding that this is something that you would like to do, it is important to understand why we are doing this study. Please read the following information carefully and talk it over with your family if you want to. If you have any questions or would like more information, you can ring Susan Tolley on **XXXXX**.

Take your time deciding whether or not this is something that you would like to do.

Thank you for reading this

Why are we doing this study?

Little is known about young people's experiences of living with a mum or dad who has Younger Onset Dementia. What it is like for a young person, how it has affected their relationships with their mum and dad and siblings, and how they may cope. We would like to find out about the impact that this has had on young people over time. We hope that this research will help us to learn more about young people who are in similar situations to yours.

Why have I been chosen?

We hope that up to 15 families will take part in the study. Your family has been chosen because your mum/dad has Younger Onset Dementia and we are really interested in what you have to say about your experiences over time.

Do I have to take part? How often would I be seen?

It's up to you to decide whether or not you want to take part and how many times you want to meet with us. If you do decide to take part, you will be asked to sign a consent form each time we contact you to give your permission. We would like to see you every 1 to 2 years until the age of 25. We will send a letter or an email asking to meet with you to hear how you have been since we last met with you. You may not always talk to the same person. If you do decide to take part, you can withdraw at any time without giving a reason and this will not

affect any treatment that your mum/dad may be having. If you want to take a break at any time when we meet, just say so.

Will the information that I give be confidential?

The consent form will be kept separately from the interview that you give. We will delete any personal information such as your name and address so that you cannot be recognised from it. Should you say that you are going to hurt yourself or others, or that someone is harming you then the researcher will inform your doctor or a social worker so that they can help you.

What will happen after I have been interviewed?

After each interview, we will have a short report summarising the findings of the study which you will receive a copy. We will not send a report to your family unless you agree to us sending one. We also hope to publish in leading professional journals.

What's in it for me?

The needs of young people who have a mum/dad with Younger Onset Dementia seem to be different to those people who get the illness when they are older. Life changes may affect the way your mum/dad is able to cope with things. Family life may be a bit different now. If we know what young people think and feel when somebody is ill in their family, we may find better ways to help them.

What do I have to do if I take part?

Ring or talk to your parent's key worker who gave you the information or you can ask your mum or dad to ring for you. Your parent's key worker will pass your name and telephone number to Susan and she will ring you directly. Susan will arrange a time to come and interview you. This can be at your home or at a local NHS room if that would be better for you. Before the interview, you will be asked to sign a consent form to say that you have agreed to take part in the study. The meeting will last about 60 minutes and Susan will ask you about your experiences and how you cope.

Complaints

If for any reason, you are not satisfied with how the research was conducted, please contact the name provided below, who will take further action.

Dr Theresa Powell

Associate Director and Admissions Tutor

School of Psychology

The University of Birmingham

Edgbaston

Birmingham

B15 2TT

Phone: XXXXX

E-mail: XXXXX

APPENDIX J:

Parent/guardian's information sheet

Exploring Children's Perceptions of Having a Parent with Younger Onset Dementia and the Effect on Their Transition into Adulthood

Information Sheet (Version 3)

Parent s/Guardian

Researcher: Susan Tolley, Trainee Clinical Psychologist

Clinical Psychology

School of Psychology

University of Birmingham

Edgbaston

Birmingham

B15 2TT

Tel: XXXXX

Email: XXXXX

Research Supervisors:

Dr Jan Oyebode, Clinical Course Director, University of Birmingham

Dr Natasha Lord, Clinical Psychologist, Older Adult Services, Wolverhampton

Dr Joanne Allen, Consultant Clinical Psychologist, Specialist Younger Onset Dementia
Services, Birmingham

Susan Tolley is a 2nd year postgraduate student studying for her Doctorate in Clinical Psychology. This research will form part of her overall mark. If you would like further information, please let Susan, Jan, Natasha or Joanne know and they will be happy to provide further information.

Exploring Children's Perceptions of Having a Parent with Younger Onset Dementia and the Effect on Their Transition into Adulthood

We would like to invite your child to take part in a research study. Before you decide whether you would like them to take part, it is important for you to know and understand why the research is being done and what it will involve.

Thank you for reading this

What is the purpose of this study?

Little is known about children's ongoing experiences of living with a parent who has Younger Onset Dementia (dementia occurring before the age of 65 years), the impact on relationships within the family, the progression into adulthood and what coping mechanisms children may use. This study will attempt to fill some of these gaps by exploring the lives of children who live with a parent who has Younger Onset Dementia over a period of time. This research will hopefully help us to understand the healthcare, psychological and emotional needs of children, and help us to build services in the future based on the needs of families.

Asking Questions:

If you are unsure about anything or would like some more information, you can call Susan Tolley on XXXXXX who will be happy to answer any questions.

Thank you.

Why have my child been chosen?

It is expected that up to 15 families will take part in the study. Your family has been chosen because you have a partner who has Younger Onset Dementia.

What is my role? Does my child have to take part?

It's up to you whether or not to let your child take part. If you would like them to take part, we would ask you to talk about it with your child and you will both be given an information sheet which you can keep. Both you and your child will be asked to sign a consent form, and our researcher, Susan will interview your child about their experiences of living at home with their Mother or Father who has younger onset dementia. Your child can withdraw at any time

without giving a reason. If you decide not to take part or want to withdraw at any time, this will not affect the standard of care your partner will receive.

Because we know very little about children's ongoing experiences of living with a parent who has younger onset dementia, we would like to interview your child over a period of time (up to the age of 25 years). Interviews will be *at least* 12 months apart and you and your child will be asked to consent to the interview each time to ensure that you are happy to continue with the research. If you decide after being interviewed that you do not want to continue with the follow up study, this will not affect the standard of care your partner will receive.

What will happen to my child if they take part?

An appointment will be made at your convenience at your preferred location, for example, your home or an NHS room. You will be asked for your consent for your child/ren to take part in the research. They will be asked about their experiences of family life and the impact of their parent's Younger Onset Dementia may have had on the relationships and roles within the family. The interview will last approximately 60 minutes.

What are the possible benefits of taking part?

The needs of Younger People with Dementia appears to be different to those who experience Dementia when they are older. Life changes such as loss of a driving licence, pension rights, and a job can mean considerable strain for a family. All of these things may impact upon children. Children may react in all sorts of ways. Helping your child to take part in this research would hopefully help us to understand the healthcare, psychological and emotional needs of children and to help build services in the future based on the needs of families.

What are the possible disadvantages and risks of taking part?

Hopefully none! If the young person becomes distressed, they may ask to terminate the interview or may ask to take a break at any time. The researcher will always be mindful of the young person and will terminate the interview in such circumstances should it be necessary for the young person.

What happens after my child has been interviewed?

Each time you and your child agree to be interviewed for the study, a summary of the research will be shared with you and with services for Younger Onset Dementia. We also hope it may be published in leading journals for dementia care.

Will my child's taking part in the study be kept confidential?

Both consent forms will be kept separate from the interview your child gives. The interview will have all names and addresses changed so that you and your child cannot be recognised from it. Only you and the researchers will know that you have taken part in the research. However, if your child disclosed that there was a risk of harm to self or harm to others, I would let you know and I would pass the information on to the relevant authority.

What do I have to do if I am happy for my child to take part?

If you are happy for your child to take part in the study, please let your partner's keyworker know, who will then pass the details onto me. I will then contact you directly by telephone to arrange a time to meet.

Complaints

If for any reason, you are not satisfied with how the research was conducted, please contact the name provided below, who will take further action.

Dr Theresa Powell

Associate Director and Admissions Tutor

School of Psychology

The University of Birmingham

Edgbaston

Birmingham

B15 2TT

Phone: XXXXX

E-mail: XXXXX

APPENDIX K:

Young person's assent form

APPENDIX L:

Older child's consent form

CONSENT FORM

Young Person (16+)

Young People's Views and Thoughts of Living with Their Parent who has Younger Onset Dementia

Name of Researcher: **Susan Tolley, Trainee Clinical Psychologist**

Please place your initials in the box

I confirm that I have read and understand the information sheet (Version 1) for the above study and have had the chance to ask questions.

I understand that I am free to withdraw at any time, without giving any reason.

I agree to have my interview recorded as long as my data is anonymised

I would like to have a copy of the report after each interview

I agree to take part in the above study

I agree to take part in a follow-up study

I understand that I do not have to take part in a follow-up study if I change my mind and I can withdraw at any time

I understand that relevant section of my medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from the NHS trust, where it is relevant to taking part in this research. I give permission for these individuals to have access to my records"

Name of young person

Date

Signature

Researcher

Date

Signature

APPENDIX M:

Parent/guardian's consent form

CONSENT FORM

Parent/ Guardian

Exploring Children's Perceptions of Having a Parent with Younger Onset Dementia and the Effect on Their Transition into Adulthood

Name of Researcher: **Susan Tolley, Trainee Clinical Psychologist**

Please place your initials in the box

I confirm that I have read and understand the information sheet (Version 3) for the above study and have had opportunity to ask questions.

I understand that my child's participation is voluntary, that they are free to withdraw at any time, without giving a reason, and without my medical partner's medical care or legal rights being affected

I would like to receive a summary of the research when it is completed

I consent to my child taking part in the above study.

I consent to my child being involved in a follow-up study

I understand that my child's ongoing participation is voluntary, that they are free to withdraw at any time, without giving a reason and without my partner's medical care or legal rights being affected

Name of parent

Date

Signature

Researcher

Date

Signature

APPENDIX N:

Example of a reflective log

P5 reflective log

Almost immediately after arriving at P5's home I experienced overwhelming feelings of shock, anger and sadness. Whilst I knew that her mother was very unwell, despite the short duration of her diagnosis, I was not prepared for what I saw when I walked into the lounge. Her mother was lying in what I could only describe as an adult sized cot looking there physically but absent inside. P3 stated that the family and carers do everything for her, that she was unable to communicate with them and that they do not think she has that long left. Instantly I found myself wondering how the family coped sitting in the lounge with their Mother/wife there as a constant reminder of the harsh reality of what was happening. Conversely, I also felt a sense of family togetherness; a desire to keep her at the centre and involved in family life. I experienced a sense of anger and sadness about the situation. P3 was so young and her mother had become so unwell so quickly I wondered how she had even begun to cope.

Despite her young age P5 presented as someone who was very mature. During the interview she stated that at the time of finding out about her mother's illness she was "still a child". I wondered how she saw herself now; a child or an adult? She described taking on so many adult type roles and responsibilities and I wondered whether this was how she understood or saw it.

When P5 talked about how her mother had been before the illness she appeared teary eyed. Whilst she seemed to have enjoyed the time they spent together she reflected on how at the time she did not feel that this time together was important. She recalled how wrong she had been about that. There was a real sense of loss of the person that her mother had been and of the family activities that they would engage in. She spoke about her regrets of not spending enough time with her mother before she was unwell and how she couldn't believe that she wasn't going to have a mother growing up. P5 described wishing her mother had been able to see her grow up. To see the person she had become. This was something I found hard to hear and which triggered an overwhelming sense of sadness within me. It felt wrong and unfair that someone of such a young age should have to carry these regrets around.

At times it felt like P5 felt isolated within her family. She was now the only female within a family of four males within the home. This also seemed to bring with it an added responsibility of caring for her mother's personal hygiene as this was something her brothers and Father found uncomfortable. I was amazed at how understanding and respecting she was in terms of how the thought of taking on care that was so personal made her brothers feel. It was such a role reversal and I wondered how she coped with having to do this for her mother. I noticed that she described feeling 'alright' doing this and I wondered whether her not feeling close to her mom had made it easier for her to take on this role.

Similar to P3 and P4, she described family scripts of not talking to members of the family and as such she also sought advice and support from those outside of the family. I wondered whether this was what kept these young people feeling similar to their peers; sharing what was happening. It felt that the need to keep information within the family, as described in previous interviews, in some way created a distance between the young person and their peers; a feeling that they are in such a different place.

A number of cyclical processes appeared evident in P5's descriptions of hearing her mother's diagnosis. When reflecting upon her description of how she coped with hearing the diagnosis a journey of knowing something is wrong, inquisitive searching, denial and acceptance came to mind. Initially she described noticing things were wrong but wanting to ignore these signs until she described searching for and reading information on the diagnosis to understand what it was about and then not wanting to believe that her mother had this illness; in a sense denying its existence. Finally she described that as she grew up, matured and realised the reality of what was about to happen she had to accept that this was the case. The rapid decline in her mother's independence appeared to have facilitated her need to accept that the illness was real. Another process came to mind when listening to P5. She described a feeling of injustice about this happening to her family which was followed by blame. Blame aimed at herself, her father and her siblings. Finally, accepting that the illness is part of life, that it has happened and that no-one is to blame.

APPENDIX O:
Interview guide

Proposed interview guide

- 1. Thinking back to before your mom/dad became unwell (was diagnosed with YOD) can you tell me a little bit about what life was like?** *How would you have described your family? What things would you do? What roles/jobs did people take on in the house? Had you noticed any changes in your mom/dad?*
- 2. Thinking back to before your mom/dad became unwell (was diagnosed with YOD) I wonder if you could tell me a little bit about your relationship with your mom/dad/ siblings?** *How would you describe your mom/dad/siblings? How would you describe your relationship with your mom/dad/siblings? If you were hurt/upset/ who would you go to? If you were worried about something who would you go to?*
- 3. What was it like for you when you found out that your mom/dad was unwell (had got YOD)?** *How did you respond to/cope with hearing this news? How did other members of your family respond to this news? What did you understand about their illness (diagnosis)? What thoughts have you had about why this might have happened?*
- 4. Can you tell me about any changes that have happened in the family home since your mom/dad became unwell (was diagnosed with YOD)?** *What has changed? How have peoples roles/jobs in the home changed? How have people responded to/coped with these changes?*
- 5. What have been the effects of your mom/dads illness (YOD) on you do you think?** *How do you think things have changed for you? Are there any changes you like/not like? How do you cope with the changes? How do you feel about these changes? What have you had to do in the family home?*
- 6. How has your mom/dads illness (YOD) affected other areas of your life?** *What areas have been affected? E.g. going out/school/work, friendships. How have they been affected? What do you think would be different about your life?*
- 7. I wonder whether you feel your relationships with your mom/dad/siblings has changed in any way since you mom/dad became unwell (was diagnosed with YOD)?** *How have these relationships changed? Who do you talk to about things now? If you're hurt/upset who do you go to now? If you're worried about things who do you talk to now? Why do you think this has changed? What is same or different about your relationships?*
- 8. What impacts do you feel your mom/dads illness (YOD) has had on you as a person?** *How do you see/would you describe yourself as a person? Has this changed? What has it been like growing up with a mom/dad with this illness (YOD)? How do you see your future?*

- 9. How have you coped with your mom/dads illness (having YOD)?** *What is it that you think has helped you to cope? What is it about you that's helped you cope with the changes (strengths)? What have you found difficult to cope with?*
- 10. Has the progression of the illness been as you had expected?** *Did you know what it would be like when your mom/dad became unwell (developed YOD)? What has been different to what you expected?*
- 11. How might things have been different for you if your mom/dad had not become unwell (developed YOD)?** *How do you image life would have been? What would be different?*
- 12. I wonder whether you could tell me a little bit about any support needs you have or have had?** *How have these have been met? How could they have been met?*
- 13. Is there anything that you would like to discuss which you have not been asked about?**

APPENDIX P:

Example of open coding

Open Coding: P5

(I = interviewer, P = participant, XXX = open code)

I: OK so you'd be kind of...you would go out as a family group generally, what kind of...?

P: When we went out for meals it would be me, Mom, Dad, [brother] and [brother] (would go for meals with mom, dad and brothers)...coz the older ones obviously had their friends (older ones had their friends) and...

I: What did you enjoy about those times?

P: Well to be honest I did not really know that it was going to end (didn't know it was going to end), so it was good at the time (was good at the time) and I did not think much of it (didn't think much of it). So it wasn't as important to me then (wasn't as important to me then) but obviously I was wrong (I was wrong). But yeah.

I: You were wrong?

P: Yeah (laughs).

I: In what way?

P: Because we obviously don't do them things now (don't do those things now) and everything revolves around Mom (everything revolves around Mom). So we don't go out for meals much now (don't go out for meals much now)...well we don't go out for meals at all now (don't go out for meals at all now). So everything kind of revolves around here (everything revolves around here) and staying in (staying in) and who's looking after Mom and stuff like that (who's looking after Mom).

APPENDIX Q:

Example of axial coding

<p>Noticing changes Dad needs a shopping list?? We noticed she was getting more forgetful. She'd tell us the same thing a couple of times. She wouldn't pick me up. You knew you'd told her but it wasn't happening. Noticed little things that got me worried. We noticed she was slowing down. Noticed a few things with Mom that weren't quite right. Forgetfulness of where things were. She was losing a lot of things. They were little everyday things: People not living with us wouldn't have known anything was up. Noticed things weren't getting done in the house. Saw Dad smoking: He forgot I didn't know. He was getting frustrated very quickly</p>	<p>Growth I'm more mature. It's made us more mature. It's taught me to grow up a bit. It's forced me to grow up young. The responsibilities have made me grow up faster. We've had to grow up: We didn't really have a choice. We've all matured a lot quicker. I'm more grown up. I feel more adult than child now. I've had to mature earlier than other people my age. We had to grow up so quickly. We've become more mature: We help out more and fight less. I see myself as an adult now; Everything with Mom has been a massive boot to say grow up right now. Brother had to grow up quickly. More mature: Act my age now and focus on what I want.</p>
<p>Stepping up/ role reversal Taking over in the house. I sorted everything out. We decided to start acting our age and step up. I was a girl so I had to look after her hygiene. I've taken on the Mother role. I've become the pivotal point that Mom used to be. Brother has had to take on some of the role of Dad: he looks after us and helps us When Mom's struggling Ill speak to siblings about helping out more. Dad asked me to explain it to my brother. Brothers took on the financial situation. I'm the 'go between' between Dad and siblings. Emotionally I'm the one people turn to: If there's an issue they will turn to me now. I would make sure Dad was safe. I've become my Dad. I would have to feed him. Sometimes I feel like I'm the parent. On a bad day I'm the Mom, she's the child. We are now looking after her.</p>	<p>Relationship with well parent Not as close with Mom now. Our relationship broke down: We just talked about Dad. I don't get on with my Dad as well as I used to. Relationship with Mom was a lot better then. We are always at each other's throats now. Dad vented a lot of his frustrations on us: It wasn't nice to be at home. Relationship with Mom got better when Dad went into care. We aren't as close: We have arguments and I have to put him in his place. Relationship with Dad hasn't changed: Will still go to him first. Dad gets stressed a lot: It's an ongoing battle about who runs the house. I'm very close to Dad now: I will ring him if I need help. Not as close with Mom: We don't spend as much time together.</p>

APPENDIX R:

Example of a memo

Memo: Participant 1

Date: 13th January 2012

- “It was only mom and I” – idea of ‘just us two’ repeated a number of times at the beginning. Missing that life? Now not the two of them as others have to be involved? Anger/annoyance at this? Or relief? Did he like it just being the two of them?
- Close with mom- “I was...then” – changes in their relationship - YOD changed this? CHANGING RELATIONSHIP.
- Insular child – Has this affected the way he copes with this?
- “I was her Mommy’s boy” - Her’s? – did he want to be? Did he see himself that way?
- “Obviously caring because I was her mommy’s boy” - Is she able to care for him now? Is he still her Mommy’s boy?
- Uses ‘we’ and not ‘I, when talking about not realising something was wrong – emphasising that it was not just him that didn’t notice. Guilty? Feels he should have noticed? Blamed by others for not?
- Taking over the house/ sorting everything – ROLE REVERSAL, SWAPPING ROLES, TAKING OVER/ON ADULT ROLE.
- Changing direction or route he is on - Questioning where headed? Stepping up? Need to work to help care for mom? Not wanting to blame mom for this change – Not completely her fault but mostly? Decision based on Mom’s situation?
- Questioning where heading/ changing direction – Not completely mom’s fault – not wanting to blame her? Stepping up?
- “Just took over the administration” – Does he see this as a little thing? STEPPING UP/ ROLE REVERSAL
- Didn’t ask for help - Felt could cope on own? – had been coping with ill mom all his life so felt could cope now? Had coped on own so why need help now? Not wanting to admit needs help? Not wanting to admit mom unwell?
- Only talks about it being upsetting when he talks about seeing the reaction of others – living with it? Blocking upset feelings? Other people’s reactions emphasis the reality of things.
- Hereditary – having to deal with that as well as mom’s illness.

- ‘Hit me that it was irreversible’ – unexpected news? Unprepared for this. Hard hitting language used to portray this – REALISING SHE’S NOT GOING TO GET BETTER
- Seeing it made it hit home – unable to deny that these changes had happened.
- Had hoped it could be reversed – Sense of hope that there would be a cure. What’s it like having this hope taken away?
- It’s almost not my mom anymore / Mental side of relationship gone – LOSING MY MOM
- Choosing to go back to education – needed a break from caring for mom? Need’s a degree? Chose to live away at a uni not far from home – needed a break? Hard seeing the reality everyday?
- Surprise at friends reactions - ? He’s living with it and not upset so why should friends be. Has he processed his grief or is he blocking it? Does his friend’s reaction again remind him of the reality of things?
- Forced him to grow up young – put upon him rather than a choice – GROWING UP
- Existential questioning – what am I doing here? – Questioning life choices.
- Education a means to an end – however chose philosophy rather than vocational course - ? Seeking answers to life.
- Frustration related to her symptoms of depression - ? not understanding them in relation to this illness. Seems to unnerve him.
- Taking job so far away – is this a way of protecting himself? Hard to see the shell of the Mother he once knew? – COPING STRATEGY?
- Sense of absurdity – living with knowing that he could have the illness too. Does this create the distance between him and his friends?
- Talks about mom’s support need first – Where do his come? Mom is the main priority.
- It struck me she doesn’t have that long - Teary and long pauses - has he acknowledged this for a while? How has he coped with knowing this? Looking forward and knowing death is approaching. ‘struck me’ – hard hitting language
- Sense of isolation from his peers – different to them.

APPENDIX S:

Example of minutes from a meeting: Model development

Themes and codes

Susan Tolley

Sent: 04 April 2012 13:19

To: Jan Oyebode

Cc: Natasha.Lord

Attachments: Grouped categories 4.04.12.doc (23 KB)

Hi Jan,

Following our conversation this morning I thought it would be worth noting down the main themes of discussion around the codes and themes from my interview transcripts. I have attached an overview of these showing our initial thoughts on clustering (combined with some after thoughts of mine). Tash I have linked you in for your information.

During our discussion we considered the following;

- Exceptional cases - e.g. P5's description of the process of denial and acceptance she went through when hearing her Mother's diagnosis. To talk about these within the codes.
- Strain and stress of the illness - Discussed making this a main theme with subthemes related to primary (behaviours, burden) and secondary stressors (dealing with parents coping, worry for well parent and own future) associated with the illness.
- We discussed whether the choice to confide in peers has any links to the young person's relationship with the well parent – in that those who can't/don't confide in their parents may confide in peers.
- Discussed the presence of a linear process - noticing changes, realising and hearing the diagnosis. We also discussed including the young people's idealised views of life within this – of life before one parent had dementia.
- Coping - we discussed grouping these into one main theme.
- Theme of loss discussed - past life, parent, future
- We discussed the code 'if this hadn't happened' - it was felt that this was better dispersed among the other themes rather than being a standalone theme because it was a deliberately introduced line of questioning.
- Core theme of stepping up was discussed - felt that this was a standalone theme that then influenced other codes. Felt like a practical response to the illness but felt different to coping.
- Stepping up seems to provoke other codes (Mainly changes in self-concept) - growth, changes in me, out of step with peers and decisions based on illness.
- Also discussed whether influences like young person's position amongst their siblings, gender and age at onset of dementia might be overarching influences on how particular young people cope, how they experience loss, how much they step up etc.

Following on from our discussion I also wondered the following

- Code of 'changes now Dad's in a home' - feel that this can be dispersed within categories. Very specific to the one participant as no others have this experience to date.
- Upon review I wondered whether the 'changes in the well parent' and 'reminders' codes fit within the stress and strain of the illness theme.

If you think I have missed anything, name changes in codes or thoughts on clustering please let me know.

Kind regards,

Sue Tolley
Trainee Clinical Psychologist
University of Birmingham

APPENDIX T:

Minutes from discussion with an older adult psychologist: Model development

Model discussion minutes

Susan Tolley

Sent: 16 April 2012 13:10

To: Jan Oyebode

Cc: Natasha.Lord

Hi Jan,

Please find below the minutes of the discussion that I had with Tash this morning in regard to the emerging model:

- We discussed the category "idealised past". The discussions focused around why it was positioned at the beginning as it appears to suggest that the idealised past links with something wrong happening. It was queried whether this is in fact a category and/or whether it is better incorporated into others. I discussed the idea of drawing on this idealisation in the "loss" category when talking about the "loss of past life". For example mentioning how many of the young people appeared to view their past through this lens.
- The "loss" category was discussed. These discussions focused on the diagram of the model and how the readers view is drawn towards this being an end point or prominent theme as all other themes were linking to it. We discussed other ways of showing the emergence of loss in the model to identify that it was present within the transcripts but that this wasn't as present as others. Ideas such as drawing a dotted circle or having a shaded circle in the background were discussed to show that "stepping up", "reconfiguring relationships", "stress and strain of the illness", "maturity and changes in self concept" and "coping" (?) were all had links with loss. We also discussed reasons for the emergence of this theme (rather than it being prominent) and thought about the stages of the parent's illness and the feeling that the young people were just coping in the moment and that maybe loss could not be fully acknowledged at this moment in time.
- We considered the "stress and strain of the illness" category and felt that it may be more representative of the themes within this to label it as "stress and strain".
- Tash discussed checking out the model and in particular the "stepping up, role reversal" category with a child psychologist.
- We discussed whether links were present between some categories such as "coping" and "reconfiguring relationships", "reconfiguring relationships" and "stress and strain", and "reconfiguring relationships" and "stepping up, role reversal". Links were present in the opposite direction but bidirectional was questioned.

- The theme of “decisions based on illness” was also discussed. It was queried whether this was associated with the sense of responsibility that the young people felt and whether it 'fitted' with the category "maturity and changes in self-concept".

Tash if I have missed anything please let me know. Jan please let me know any thoughts you may have about these points discussed.

Kind regards,

Sue Tolley
Trainee Clinical Psychologist
University of Birmingham

APPENDIX U:

Instructions to authors: Empirical paper

Social Science and Medicine
Manuscript Submission Guidelines

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