

**THE EXPERIENCE OF HAVING A PARENT WITH YOUNG-ONSET DEMENTIA
DURING TRANSITION TO ADULTHOOD**

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ABSTRACT

This thesis focuses on the exploration of young adults' experience of having a parent with Young-Onset Dementia (YOD). In particular, their experience of the developmental tasks typically associated with young adulthood and their understanding of changes within family roles and relationships in view of their parent's illness were investigated.

Previous research examining parental illness has not yet fully examined the young adult cohort as a distinct group, focusing on the experiences of adolescents and younger children instead. There is also an absence of YOD as a specific form of parental illness within the literature. Previous studies have also typically used quantitative methods to gain retrospective or parental accounts of younger people's coping and burden as a result of parental illness and there is little understanding of the current experiences of younger people.

As an exploratory study, this thesis used qualitative methods. Five young adults (aged between 23 and 37) were interviewed about their experiences, and their transcripts were analysed with Interpretative Phenomenological Analysis – IPA (Smith, 1995). Four super-ordinate themes emerged within the analysis of group themes. These were: Experiencing change in relationships, Understanding Change, Managing Change and Experiencing change in self. The analysis also revealed that participants had a range of experiences of the interview process itself.

The findings indicate that completion of the developmental tasks of young adulthood and family roles and relationships are affected by having a parent with YOD, and clinical implications are discussed in view of the distressing nature of changes experienced. Recommendations for future research include investigating the various moderators that seemingly impact on young adults' experiences of parental YOD and an exploration of clinical interventions that would be most efficacious with this cohort.

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ABBREVIATIONS

HIV	Human Immunodeficiency Virus
AIDS	Acquired Immune Deficiency Syndrome
WHO	World Health Organisation
NHS	National Health Service
YOD	Young-Onset Dementia
YPWD	Younger People with Dementia
LYPD	Leeds Younger People with Dementia Team
IPA	Interpretative Phenomenological Analysis
AD	Alzheimer's Disease

CHAPTER I - INTRODUCTION

Within this chapter I will present an overview of the background literature influencing the design of this thesis and development of my research questions. This overview will firstly include details of theories and current thinking about the developmental stage of young adulthood. Secondly, a review of the literature around parental chronic illness will be discussed. Thirdly, Young Onset Dementia (YOD) will be presented as a form of parental chronic illness affecting young adults that has until now been overlooked within the literature. Lastly, the rationale for and details of the current study will be presented and the research questions outlined.

Developmental challenges of young adulthood

There are particular events during the lifecycle such as leaving the family home, having children and retiring which most individuals complete at roughly similar times. These events can be thought of as developmental tasks and each stage of the lifecycle (such as childhood, adolescence, young, middle and older adulthood) involves a number of unique tasks that may be social, physiological or psychological in nature.

The developmental tasks of young adulthood are about ascertaining adult status. They include increasing independence from the family unit and leaving home, making career and education decisions, developing more intimate relationships with peers outside of the family unit and parenthood. The completion of these tasks results in the establishment of an adult identity (Erikson, 1959; Levinson, 1986; Hendry & Kloep, 2002).

Dellmann-Jenkins, Blankemeyer and Pinkard (2001) provide further details about the nature and importance of these tasks. They suggest that differentiation from the family of origin is achieved by moving out of the family home and assuming financial and emotional responsibility for oneself. This in turn enables a more objective relationship with parents to develop however, the young adult may still need to turn to their parents for support and advice during this time. If differentiation from the family occurs, the young adult will be able to form closer, more intimate relationships with peers (whether these are love, friendship or sexual relationships). Dellmann-Jenkins et al (2001) also suggest the importance of career development during young adulthood, citing this as a major source of self-worth, confidence and an important factor in identity development.

The typical age range for this developmental period is 16 to 40 years old (Shaie & Willis, 1996), however Levinson (1986) suggests that the era of young adulthood has distinct developmental periods within this. These begin with the 'early adult transition' (age

17 to 22 years old) which bridges the eras of childhood and early adulthood. This is followed by the 'entry life structure for early adulthood' (age 22 to 28 years old); a key period for developing an initial model for adult living. The next stage is the 'age thirty transition' (age 28 to 33 years old) which is a time for reappraisal of adult living this far. The final stage is the 'culminating life structure for early adulthood' (age 33 to 40 years old) in which goals are reviewed and aspirations for youth completed.

Timing of events

Neugarten (1979) suggests that life cycle events can occur 'on time' or 'off time' and that if they do not occur at expected times, they are 'non-normative' and more problematic for the individual (Hendry & Kloep, 2002). In addition to 'off time' transitions, idiosyncratic transitions (events experienced by very few individuals) are also difficult to cope with. Hendry and Kloep (2002) suggest that this is because non-normative developmental shifts are stigmatising and that the individual facing them is left to cope alone in the absence of role models or understanding others that can support them. They also suggest that individuals will meet developmental challenges differently, regardless of how non-normative they are and that coping and adaptation is dependent on the interaction between an individual's resources (internal and external) and the demands of the task. Therefore, if an individual is faced with a very challenging situation but has few applicable resources, they are likely to become 'stuck' (stagnation) or regress to an earlier developmental stage (decay), both of which prevent further successful development.

More recently, Shanahan, Porfeli, Mortimer and Erickson (2005) suggest that the reliance on the traditional criteria (or markers) of young adulthood would render a significant proportion of those in this age range today unable to qualify as adults. They note that social changes in recent decades (the extension of education well into twenties for many individuals; postponing marriage and parenthood) mean that these traditional markers are no longer considered timely (Neugarten, 1979) and age bound as they were for previous generations, rather the criteria for adulthood have become more subjective and individualised. Fussell and Furstenberg (2005) however suggest that once in their late thirties, the majority of young adults have completed the tasks traditionally associated with this developmental period. They purport that although the pathway to achieving these markers may have altered significantly since Erikson (1959) and Levinson (1986) shared their theories, the end state is usually the same suggesting that these markers may still be useful gauges, even if the experience of 'off-time' events is less marked.

The family lifecycle

Carter and McGoldrick (1989) suggest that the 'launching' of a young adult from the family unit is a "cornerstone" (Carter & McGoldrick, 1989, p13) stage in the family lifecycle whereby the manner in which the developmental tasks of this stage are completed will impact on the successful completion of developmental tasks further in the life cycle. Levinson (1978) suggests that the 'early adult transition' period is a 'centrifugal' period for the family in that it is a time of decreased family cohesion where family members disengage in preparation for the young adult's increasing autonomy and independence. Griffiths and Griffiths (1987) suggest that this transition period is a difficult time for most families but that additional, non-normative family events can exacerbate distress and decrease cohesion during this time.

One such 'off-time' developmental challenge would be the chronic illness of a parent during early adulthood. In a recent study examining the prevalence, characteristics and responsibilities of 18 to 25 year olds with an ill parent, Levine, Gibson, Halper, Hart, Lautz and Gould (2005) reported that the young adult population as a distinct cohort is largely unstudied in terms of their responses to parental chronic illness. Research has mainly focused on child and adolescent experiences of having an ill parent and consequently this is the literature drawn upon as a background to this thesis.

The impact of chronic parental illness

Considering the whole family

In a review of the literature into parental chronic illness, Kahle and Jones (1999) conclude that having an ill parent during childhood interferes with the child and family's ability to achieve developmental goals. Similarly, Lewandowski (1992) suggests that age and developmental level are important factors in children's response to illness and that adolescents and the family as a whole may respond differently at different stages in the life cycle.

Rolland's (1999) 'family systems-illness model' provides a conceptual framework for understanding the challenges that a family faces when a parent becomes ill and essentially this consists of three dimensions. Firstly, Rolland (1999) suggests that characteristics of the particular illness are important in family adaptation and coping (such as acute versus gradual onset and whether the illness is terminal). Different stages of illness (such as pre-diagnosis, chronic stage or terminal stage) also have their own tasks and challenges to meet. Secondly, Rolland (1999) proposes that individual family members and

the family as a whole will respond to parental illness according to their individual developmental tasks (such as transition to adulthood) and stage in the family life cycle (such as children leaving home). Thirdly, the family's belief systems (such as cause of illness) and wider cultural influences (such as stigma about HIV) will impact upon how the family adjust to and manage the illness. With regard to parental illness during an adolescent's transition to adulthood, Rolland (1999) suggests that such an 'off-time' event challenges the social and chronological expectations and parenting needs of the adolescent requiring families to be flexible about normative developmental goals. If families have rigid beliefs and expectations about development and illness, problems may be more likely to result.

More recently, Pederson and Reverson (2005) have offered a 'family ecology framework' for understanding parental chronic illness. Like Rolland (1999) this framework assumes that "individual behaviour can only be understood within its social context" (Pederson & Reverson, 2005, p405). Their model attempts to look at the interrelationships between individual and family level mediators (such as family role redistribution, day to day hassles of the illness and the level of threat to the family in terms of stigma or loss), parental illness characteristics and individual and family wellbeing (seen through family cohesion, levels of conflict and youth wellbeing).

Rolland (1999) and Pederson and Reverson's (2005) frameworks suggest considering the impact on the entire family when exploring parental chronic illness. Family-systems theorists such as Carter and McGoldrick (1989) propose that an individual's coping and adaptation to chronic illness cannot be examined in isolation and that the family's current beliefs and history of illness beliefs must also be considered. Through exploration of individual beliefs about illness within the context of intergenerational illness beliefs, patterns of adaptation and the individual's experience of illness can be understood.

Factors affecting responses to parental illness

Research suggests that chronic parental illness has a range of effects on children and other family members including increased reports of physical illness by the child, low self-esteem, anxiety and other psychological difficulties (Nelson, Sloper, Charlton & While, 1994) as well as increased academic and social problems (Hammen, 1997). Other research suggests that positive outcomes such as feeling closer to the ill parent may also result (Le Gallez, 1993).

There has been an attempt by researchers to ascertain the factors affecting child and adolescent responses to parental chronic illness and the factors addressed thus far include

child factors such as age, gender and coping style, family factors such as family views about the illness and relationships and roles prior to and during illness and illness factors such as severity and type of illness. Each of these areas will therefore be addressed in turn.

Child factors

Age and developmental stage appear to be important factors in a child's response to parental illness. Research suggests that adolescents experience more distress, psychological difficulties and poorer adjustment compared with younger children (Worsham, Compas & Ey, 1997; Issel, Ersek & Lewis, 1990) and various mechanisms have been highlighted in an attempt to explain this change.

Coping strategies are one such mechanism of adaptation. Compas, Worsham and Howell (1996) found that adolescents use more emotion-focused coping strategies, namely avoidance, in response to maternal cancer. This finding is replicated by Issel et al (1990) and Christ, Siegel and Sperber (1994) who found that adolescents and young adults generally used avoidance to cope with parental cancer whereas younger children tended to be more problem focused by doing tasks to help a parent.

Christ et al (1994) found that young adults had a greater cognitive capacity to understand the implications of their parent's impending death and were able to empathise more closely with their parent's physical pain and discomfort. They often felt helpless and as a result, they often distanced their daily lives from the illness and focused on more abstract aspects of their relationship with their parent such as the impact on finances as a coping strategy. The authors add that young adults felt torn between the desire to continue the usual transitional tasks of adulthood (i.e. separation from the family and focusing on academic and social concerns) and the increasing demands of their parent's illness upon them. Adolescents often felt anger, resentment and then guilt about this.

In contrast, when interviewing young adults of parents with Parkinson's Disease about their futures, Grimshaw (1991) found that generally young adults stated that their parent's illness would not affect their decision to leave home and that they had felt able to negotiate their independence from the family unit so far. Grimshaw (1991) also stated that many of the young adults he interviewed thought that they had greater knowledge and understanding of their parent's illness as they had become older and that in concordance with the findings of Christ et al. (1994), this enabled them to identify with their parent's distress. Such findings indicate that factors outside of the age of the child may also be important in experiences of parental chronic illness. It should be noted however that Grimshaw (1991) asked young adults how they envisaged their parent's illness would affect

certain developmental tasks in the future as opposed to collecting a retrospective account of previous experiences like Christ et al. (1994). This may account for the more positive experience of parental illness within Grimshaw's (1991) study.

Whilst it is generally agreed that adolescents experience distress as a result of their parent's illness, gender of the adolescent and parent are also important factors. Wellisch, Gritz, Schain, Wang and Siau (1992) found that where onset of parent's breast cancer was during adolescence, girls made more changes to their long-term life plans and had the greatest adjustment problems. These girls reported that they perceived a change in role in relation to their mother and identified more with their mother's distress following mastectomy. Grant and Compas (1995) and Grimshaw (1991) also suggest that the increase in household responsibilities for girls adds to their distress.

There is a lack of research examining positive outcomes resulting from parental illness, however positive wellbeing also appears to be related in part to individual factors. Milam, Ritt-Olson and Unger (2004) found that older adolescents experienced more personal growth than younger adolescents following a traumatic event. This may be a result of their level of cognitive development which enabled them to view the traumatic event as an opportunity for personal growth.

Family Factors

Pederson and Reverson (2005) suggest that the markers of positive family functioning with parental illness are good communication, a fair redistribution of roles that will not compromise one individual's development over another and a family identity that is defined by something other than the illness.

Christ et al (1994) found that an adolescent's relationship with a parent prior to the onset of cancer was a good indicator of their emotional response to the illness, whereby prior conflict in relationships resulted in poorer adaptation. The adolescent's relationship with their other parent was also important as this parent could be seen as a source of support to the young person.

In relation to this, a qualitative study looking at adolescent experiences of parental HIV/AIDS (Woodring, Cancelli, Ponterotto & Keitel, 2005) found that loss was a major theme. In particular, losing the consistent, reliable care provided by their parent was anxiety-provoking for them. Adolescents also had an increasing worry of being left alone should anything happen to their other parent.

The ill parent's response to their own illness was found to be relevant in a qualitative study by Le Gallez (1993) looking at the impact of rheumatoid arthritis on

family members. Although most adolescents in the study did not find their parent's illness detrimental, those who did experience anger and guilt had a parent who themselves was unable to accept the pain and limitations caused by their illness, corroborating Rolland's (1999) proposal that family beliefs about illness are important. Similarly, in a comparative study of depressed, arthritic and 'healthy' parents, Hirsh, Moos and Reischl (1985) found that higher levels of parental distress resulted in poorer adolescent self-esteem, though there was no difference between illness groups.

Changes in family roles and responsibilities are also thought to relate to young adults' experiences of parental illness. Christ et al (1994) found that female offspring took on a greater proportion of domestic chores. This enabled them to develop a new sense of closeness with the ill parent though it also restricted their levels of independence and individuation from the family unit. In contrast, males were more likely to continue to separate from the family or help the family through external means such as getting a job to provide income for the family. Grimshaw (1991) also reported a 'role reversal' between the parent and young adult in some families whereby the young adult viewed themselves as taking increasing responsibility for the well-being of their parent.

In relation to family responsibilities, Grimshaw (1991) found that when both parents provided their offspring with regular information about Parkinson's Disease, they were less distressed about the illness than young adults who had to find their own information or had one parent who was unwilling to discuss the illness. Similarly, Bolton (1995) found that adolescents with the responsibility of providing informational support to other family members had higher distress, whereas those receiving informational support from others resulted in lower distress.

In addition, Bolton (1995) also reported that female adolescents receiving social companionship from other family members were more distressed than those who were supported by peers or others outside the family. These findings fit with the concept of 'role engulfment' within the adult family carer literature suggesting that one difficulty resulting from caring particular to younger carers is that of 'self-loss' (Skaff & Pearlin, 1992) whereby carers give up their own plans and hopes to give care to a relative. Over time, other external sources of self-evaluation are gradually reduced which results in a greater affiliation to the caregiving role and loss of other roles which provide a sense of self, mastery and esteem. Skaff and Pearlin (1992) found that younger carers experienced the greatest self-loss and role engulfment as they were at a developmental stage where many other emerging priorities and plans in competition with the carer role had to be sacrificed.

Older carers, in contrast, appeared to integrate their caregiver role more easily within their established sense of self.

Illness Factors

There is little research looking at the impact of severity and type of parental illness on children's response. Rolland (1999) suggests that in order to fully understand the impact of a particular chronic illness for individuals and families, certain aspects of the illness must be considered. Specifically, the onset, course, possible outcome and level of incapacitation need to be looked at in relation to the usual lifecycle tasks facing the family. To clarify further, Rolland (1999) suggests that the illness itself has a lifecycle and consequently an interface between the illness, individual and family life cycle results.

Within the research literature into parental chronic illness, Roy (1991) suggests that a key unanswered question is whether different kinds of illness impact on offspring to a different extent. Grimshaw (1991) suggests that the degenerative and terminal nature of Parkinson's Disease was important in understanding young people's views of the future and that particular physical and behavioural symptoms of the illness (such as depression, anger and later confusion) featured in the accounts of their experience. In relation to this Pederson and Reverson (2005) suggest that family adaptation may be easier if the illness progresses slowly and steadily giving family members time to adjust to new roles, responsibilities and future difficulties.

Mukherjee, Sloper and Lewin (2002) found a link between severity of inflammatory bowel disease and impact of the condition on young people. Welsh, Wadworth and Compas (1996) also suggest that a hereditary component to the parent's illness can increase distress for adolescents.

Pederson and Reverson (2005) also consider the stage of illness to be important, purporting that a label such as 'cancer' tells us little about the impact of that illness. They suggest that highlighting the individual day to day tasks or hassles of an illness for the family is important for gauging understanding.

Comparative studies of the impact of parental depression, chronic physical conditions and 'healthy' controls on adolescents consistently reveal that depressed parents resulted in lower self-esteem, increased symptomatology and social impairment in adolescents compared with other groups (Hirsh et al, 1985; Klein, Clark, Dansky & Margolis, 1988) suggesting that features of particular illnesses may be important in determining young adults' experiences and require further exploration. In the following

section, one particular form of parental illness which is not currently cited in the literature is discussed, namely Young Onset Dementia.

Younger People with Dementia

Some definitions and statistics

Dementia can be defined as “a syndrome due to a disease of the brain, usually of a chronic or progressive nature, in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied and occasionally preceded by deterioration in emotional control, social behaviour or motivation” (WHO, 1992).

The occurrence of dementia in individuals under the age of 65 is termed Young Onset Dementia. This age cut-off appears to result from the distinction within the National Health Service (NHS) between working age and older people and possible social conventions around the age of retirement. Within this thesis the terms Young Onset Dementia (YOD) and Younger People with Dementia (YPWD) will be used to refer to the condition and the individuals with this condition respectively.

Dementia can have a number of causes. Williams, Cameron, Dearden, Harris, Pritlove and Richards (1999) cite the most common cause of dementia in younger people as Alzheimer’s Disease (AD). AD is characterised by changes in memory and other higher cortical functions. Multi-Infarct or Vascular Dementia is the second most common cause, resulting from brain damage due to cerebro-vascular disease. The Lobar dementias (such as Pick’s Disease and Frontotemporal Dementia) result in early changes in personality and social functioning before other higher cortical functions decline. Dementia can also result from infections, metabolic disorders, neurological conditions such as Parkinson’s Disease or HIV/AIDS or chronic exposure to toxic substances, typically alcohol. The average survival rates (accounting for type of dementia and speed of diagnosis) usually range from four to eight years (Williams et al., 1999).

Harvey (1998) notes that among younger people, the incidence of some of the rarer forms of dementia is increased compared with older people. This is important as rarer forms of dementia typically take longer to diagnose and can result in less specialised support being available for individuals and their families (Keady and Nolan, 1994).

There has been an increasing recognition within the past ten years that dementia affects a significant proportion of adults under the age of 65 (Alzheimer’s Society, 1996;

Department of Health, 2001). Harvey (1998) suggests that the prevalence of dementia in working age adults is around 67 per 100,000 total population aged between 30 and 64. More recently the National Service Framework for Older People (Department of Health, 2001) has stipulated that arrangements within the NHS should be made specifically for the care of YPWD. There is an increasing awareness that people with dementia under the age of 65 will have different needs from older people and that this is also the case for their family.

Gregory (2000) suggests that living with a younger family member with dementia differs from living with an older person with dementia in that those with YOD show more non-cognitive symptoms. These include mood disturbance (such as depression and anxiety), psychotic symptoms (such as hallucinations) and challenging behaviour (such as verbal and physical aggression and sleeplessness). The presence of these non-cognitive symptoms has been highly correlated with carer burden (Donaldson, Tarrier & Burns, 1997). The small body of research looking at the impact of YOD on family carers will now be discussed.

Carers of younger people with dementia

Currently there is little research exploring the impact of caring for a younger family member with dementia on family carers and much of the work into the impact of this chronic illness has focused on dementia in people over age 65 due to the increased prevalence in this population. There is an extensive literature on the effects of carer stress and burden in dementia family caring for older adults (see Biegel & Schultz, 1999; Burns & Rabins, 2000 and Morris, Morris & Britton, 1988 for full reviews in the area) and problems range from psychological stress and depression, fatigue, social, occupational and relationship changes to financial difficulties.

With regard to the impact of caring for an older family member on young adults, Dellmann-Jenkins et al (2001) found that when adults under the age of forty provided daily care to an elderly relative, this had an impact on the three developmental tasks of differentiating from their family, establishing intimate relationships and their career development. They recruited young adults, who were the primary caregivers to an older relative, administering a questionnaire (consisting of both closed and open-ended questions) designed to explore how the caregiver role impacted on the three developmental tasks. Qualitative analysis (specifically content analysis) was used to reveal five themes about why young adults had assumed the role of primary caregiver. These were a) a sense of filial duty to reciprocate earlier care from their relative, b) the flexibility of their current lifestyle which enabled them to provide care, c) an opportunity to reciprocate nurturance and love

that they had received from their relative, d) having the knowledge and understanding of the aging process and e) being able to mediate between their relative and care agencies.

Dellmann-Jenkins et al (2001) noted that participants reported an unexpected and premature role reversal with their older relative and that this phenomenon was more likely to occur when the relative had dementia and the young adult was involved in personal care tasks. They found that participants also reported several benefits as a result of their carer role. These included feeling closer to their relative, enhanced self-concept, satisfaction from enabling their relative to avoid a residential placement and increased empathy for older people.

There are a number of limitations with the study. The kinship ties to the older adults in this study were varied (including children, grandchildren, nieces and nephews amongst others) and there was no attempt to explore the impact of particular family relationships on response to caregiving. The context of relationships within the family of origin was also absent from the analysis. The state of family relationships prior to and after commencing caregiving was not investigated as a factor impacting on their experience of both caregiving and the developmental tasks facing them.

Although a qualitative methodology was utilised within the analysis, the use of a questionnaire to collect data may also have limited participants' ability to share their experiences in detail and may also have stifled the emergence of unanticipated or novel responses.

Whilst Dellmann-Jenkins et al's (2001) study provides some useful insights into the current experiences of young adult caregivers, caring for an older relative is generally seen as a more accepted and possibly expected role for many people, which in turn will impact on their experience. In relation to Neugarten's (1979) thoughts about 'off-time' life events, dementia in younger people represents a double jeopardy for their offspring which is not fully comparable with caring for older family members with dementia.

Firstly, young adults have to adjust to their parent's diagnosis of dementia, a degenerative, eventually fatal disease typically presenting in older people. The idiosyncratic nature of this life event leaves them with few others in similar circumstances outside of the family to turn to, thereby creating greater potential for distress. Secondly, offspring are usually younger in age as a natural consequence of the timing of the disease in the family life cycle and so they must take into consideration the parent's chronic illness in a developmental stage usually reserved for development of self.

In a recent study by Williams, Dearden & Cameron (2001) two thirds of the family carers of younger people with dementia described their emotional wellbeing as poor. There

is also evidence that carer burden is significantly higher in carers of younger people with dementia compared with carers of older people with dementia and the younger age range of carers in this group has been considered as a factor affecting coping and adaptation. (Freyne, Kidd, Coen & Lawlor, 1999; Luscombe, Brodaty & Freeth, 1998). One main limitation of these studies is that they have included a range of family members (typically spouses and partners) rather than solely children. Freyne et al. (1999) suggest that further exploration of the reasons for increased burden in younger carers of people with dementia under age 65 is needed.

Rationale and plan for the current research

Why the research needs to be done

There are a number of gaps within the current literature on parental chronic illness which suggest a need for the current study:

- *The absence of the young adult cohort within the parental illness literature* - There is still little known about how informal family caregiving affects young adults as a distinct cohort or the different factors impacting on adaptation and coping within this role (Levine et al, 2005). Unfortunately much of the research has not distinguished between younger and older children (Christ et al, 1994).
- *The absence of YOD within the parental illness literature* - One form of parental illness which has received little attention until recently is dementia in people under age 65 or YOD. Offspring of YPWD will often be young adults as a natural consequence of the age of onset of the disease though it has not yet been researched as a form of parental chronic illness affecting young adults. Comparative studies of parental physical and psychological illness suggest that the type of illness may also be an important factor in determining a young person's response to their parent's illness. Roy (1991) and Hirsh et al (1985) propose that further research looking at the impact of different physical and psychological disorders is important.
- *The absence of an exploratory approach to understanding the experience of parental illness* - An exploratory methodology which allows breadth in an individual's account is currently lacking in the research. Most of the research is also focused on indicators of burden, distress and mental health difficulties in

children (Crist, 1993) rather than subjective descriptions of experience. This makes it difficult for a global picture to emerge, highlighting potentially positive experiences as well as negative ones.

- *The absence of an understanding of current experience* – The literature is often based on retrospective accounts of adult offspring or parent’s reports of their children’s coping (Feeney & Ryan, 1994). There is relatively little understanding of the processes through which parental illness impacts upon young adults as much of the research is quantitative in its approach (Worsham et al., 1997). Levine et al (1999) advocate that qualitative studies are needed to understand the current experience of caregiving for the young adult, in particular finding out about the impact of their experiences on education, employment and social life. There appears to be an increasing need for a more in-depth exploratory account of the experience of parental chronic illness for young adults.

Clinical Relevance

The research is clinically relevant as it will increase understanding of how YOD affects the sons and daughters of those with this diagnosis. It will also increase knowledge about whether young adults require support or intervention as a result of having a parent with YOD and the nature of such support. The current literature suggests that young adults experience higher levels of burden compared with younger children (Worsham et al., 1997) though little is known about the support needs of this cohort.

The dissemination of the research findings will enable the YPWD service to adapt their service protocols in order to meet the needs of family members or carers of individuals with YOD.

The study will also form the basis of future research on how young adults are affected by parental chronic illness, in particular YOD, enabling services offering care to individuals with chronic or degenerative illnesses to understand and respond to the needs of their families in a more evidence-based way.

The study is timely and increasingly necessary considering the social changes in recent generations which may result in greater responsibility for parental care being placed on young adults. Levine et al (2005) suggest that young adult caregivers as a cohort will increase significantly in future generations as a result of social changes (such as delaying parenthood and having fewer children). Parents will increasingly look to their children to help them as they become older at a time when they will still be relatively young.

Consequently, services which offer support to informal family carers will be increasingly faced with the specific issues pertaining to young adult caregivers within their services in the foreseeable future.

Outline of the current study

In view of these considerations, the current study will focus on the experience of having a parent with YOD during young adulthood. Specifically, the study will aim to explore and understand how young adults describe the developmental tasks facing them and how they are meeting them in view of their parent's illness. The research will also explore their accounts of how they understand their parent's illness has affected the family in terms of roles and relationships. A qualitative methodology will be utilised which allows participants accounts to emerge fully. This is described in detail in the methodology section.

Research Questions

The two questions I planned to explore within this study were:

1) How does the young adult describe their experience of their parent's YOD as impacting on the developmental tasks they currently face? In particular their experience of:

- becoming more independent
- developing their own sense of identity
- relating to people outside of their family

2) How does the young adult describe the impact on them of family changes as a result of their parent's YOD? In particular their description of the family's:

- experience of family roles
- experience of relationships with other family members

CHAPTER II - METHODOLOGY

Within this chapter I will describe how the study was designed and carried out. Firstly I provide some reflections about myself, my background and possible assumptions which I consider relevant to the research and which may impinge on the analysis of the data. Secondly, I will consider the methods used to collect and analyse the data and the rationale for this selection. Finally I will describe the study design and procedure and how this developed throughout the course of the research in terms of recruitment and sampling, data collection and the process for analysis.

Reflections about the author

I feel it is necessary to consider any ways in which I may have influenced the research process and in turn how it has influenced me. This is in keeping with Elliott, Fischer and Rennie's (1999) avocation of 'Owning one's perspective'. This is intended to provide the reader with a sense of the dynamic between my own experiences and those of the participant in relation to the data that eventually emerged. I feel the main features from my own background that may have influenced my expectations and assumptions about conducting research into this area are:

- I am a woman in her late twenties currently studying for a Doctorate in Clinical Psychology of which this study comprises a substantial portion of the assessed academic component. I have no personal experience of having a family member or friend with dementia.
- My initial interest in researching the area came from my own clinical work as an Assistant Psychologist co-facilitating a support group for younger people with dementia with Leeds Younger People with Dementia (LYPD) Team three years ago. During this period, I became aware through clients in the group and through informal conversations with staff in the service that there was little contact with or support for the children and adult offspring of younger people with dementia in the service but that there was a sense that these people were struggling to cope with having a younger parent with dementia and did need support.
- Later clinical work with young adults with physical impairments also developed my interest in understanding the factors which affect an individual's ability to respond

to typical developmental tasks at this stage in the life cycle. I also became aware of how illness and disability has implications for the whole family as a result of my clinical work.

- Working in a system in which people with dementia are referred to Clinical Psychology with more severe difficulties or are seen as a 'problem' by services, may have negatively impacted upon my view of what dementia is and could be like for family members.
- I am a similar age to the participants that I intended to interview and so acknowledge that at times I have considered how I would have experienced my own parents having dementia and the impact that this would have had on my own life choices, identity and family relationships.

As a consequence of the above points I have been aware that I initially assumed that the young adults would report that having a parent with dementia had an impact on their relationships with other family members. I also assumed they would be finding their situation extremely difficult and expected that they would experience their situation in a purely negative way. Consequently, it was necessary to reanalyse some of the data after acknowledging this assumption to ensure that experiences construed as positive were not overlooked, particularly as this is an area missing within the literature into parental chronic illness (Crist, 1993).

An additional consideration when analysing data has been my theoretical orientation in my own clinical practice. I have an interest in psychodynamic approaches to understanding people's experiences and difficulties. Again it has been important to use particular credibility checks such as 'peer audit' (Stiles, 1993) to counteract this possible bias and also to make a conscious effort to consider the transcripts in light of various areas of theory and literature after developing themes.

Choice of data collection and analytic method

Interpretative Phenomenological Analysis

I decided to use Interpretative Phenomenological Analysis (IPA) (Smith, 1995, 2004) as my method for this study. IPA is a qualitative research technique which has emerged relatively recently and has its philosophical roots in the traditions of Phenomenological

Psychology and Symbolic Interactionism. IPA is phenomenological in its approach in that it is interested in understanding an individual's experience and perception of events. Smith, Jarman & Osborn (1999) also suggest that it is concerned with cognitions; understanding an individual's thoughts and beliefs about a topic. IPA uses the analyst to make sense of an individual's experience and so it is also interpretive and hermeneutical in its approach. Willig (2001) suggests that a double hermeneutic occurs with IPA whereby the researcher tries to make sense of the individual trying to make sense of particular events.

Symbolic Interactionism is concerned with understanding the meaning that individuals attach to their experiences and stresses that the meanings of an event for the individual can only be obtained through interpretation (Smith, 1995). As a phenomenological approach, IPA is concerned with exploring personal perceptions of experience rather than seeking to ascertain statements of objective reality (Smith & Osborn, 2003) which suggests that this method fits with the aims of this study. IPA draws upon some constructionism, to take up something of a critical realist position. It has been called 'post-constructionist' or 'contextualist' (Madill, Jordan & Shirley, 2000).

Smith (2004) has also suggested three essential tenets to consider when selecting IPA from other qualitative approaches. Firstly, IPA is ideographic as each case is analysed separately before a cross-case analysis is attempted. Secondly, IPA is inductive in that themes are allowed to emerge during the data analysis even if they were not previously anticipated. I felt that these two considerations were important considering the exploratory nature of the current study as I wanted each participant's account to be given equal consideration in developing resultant themes. I also wanted to use a method that would allow me to incorporate the participant's experience of the interview itself within the analysis and enable me to comment upon the dynamic process between myself and those I interviewed. Thirdly, Smith (2004) suggests that IPA is interrogative as the results are discussed in relation to the current psychological literature in the hope of corroborating or 'interrogating' current theory and evidence.

When selecting IPA over other prominent qualitative approaches adopting a contextualist constructionist approach such as discourse analysis, I considered the following points by Larkin (2003) and Willig (2001):

IPA is distinct from discourse analysis because:

- IPA may utilise more directive or empathic interview questions
- IPA will go beyond the text, adopting a critical realist or contextualist ontology as it illustrates not only how something *can* be understood but also how something *has* been understood by an individual
- The focus of Discourse Analysis is on what is said, not the underlying mental state or cognitions (as with IPA). It examines the way in which language is used to construct the world and manage social interactions.
- IPA has a relatively transparent methodological procedure
- IPA requires a roughly homogenous sample.

The aim of the current study was to look at the lived experience of having a parent with young-onset dementia during young adulthood. Looking at the lived experience of any phenomenon requires the researcher to move beyond the role of language in the construction of the social world and so Discourse analysis does not seem an appropriate method. IPA seemed a well-suited methodology for the current study as it allowed the researcher to explore the individual's perception of an event

Semi-structured interviews

Smith (2004) suggests that semi-structured interviews are the most appropriate method of obtaining suitable data for IPA as one advantage is that they allow the researcher to follow up on unanticipated areas raised by the participant. Semi-structured interviews would therefore allow me to modify questions in response to the individual participant which I felt was particularly important considering the exploratory nature of the study. A semi-structured interview also would enable me to spend time engaging and building rapport with participants and pace the interview so that participants would respond openly to difficult questions as they arose.

Design of the interview schedule

I constructed an interview schedule to ensure that similar material was covered with each participant. Questions were designed to be non-directive and to elicit an in-depth

narrative of the various areas. Prompt questions were also included to access feelings and cognitions (for example, “can you tell me how you understood this change?” or “how did you feel at that time?”). More general prompts were also used to encourage the participant to continue or expand on particular elements as suggested by Smith and Osborn (2003). These prompts included “can you tell me more about that” and non-verbal signs of encouragement.

The schedule was constructed to address areas which were raised as possible areas of concern for young adults experiencing parental chronic illness within the previous literature and therefore needed to explore the participants life before their parent began to develop signs of dementia and then continue to facilitate an account of their experience as their parent’s dementia progressed and their subsequent experience to date. At each stage in their journey as described by them, it was important for me to understand their own experience but also their account of their family’s experience of dementia and their understanding of any change in family relationships. The questions I attempted to cover within each interview are given within the interview schedule shown in Figure 1 below.

Towards the end of the interview I included questions about the participant’s experience of the interview itself. Smith, Jarman and Osborn (1999) suggest that an important question to consider with participants is whether the process of thinking and talking about their experiences during the interview has had any impact on their thinking. Using a semi-structured interview allowed for this meta-cognitive question to be explored more fully.

Figure 1 Interview schedule used with participants

- To begin with can you tell me a bit about yourself, your life at the moment?
 - *Follow up on work, education, social activity*
- Can you tell me about your family at the moment?
 - *Follow up on relationships with each family member, details of day to day experience of parent's dementia*
- Can you tell me about your life before your parent became ill?
- Can you tell me about your family at that time?
 - *Follow up on role in family, relationships between family members*
- How did you see your future at that time?
 - *Follow up on plans, hopes, dreams, how saw themselves at the time*
- Can you recall a time when you first started to notice any change in your parent?
 - *Follow up on thoughts, feelings*
- How did you and your family explain these changes at that time? And now?
- Can you tell me about any changes within your family since that time?
 - *Follow up on change in parents condition, change in roles following diagnosis*
- Can you tell me about any times where you have had to make changes in your life due to your parent's dementia?
 - *Follow up on thoughts and feeling associated with such times*
- How do you think having a parent with dementia has made any difference to the original plans you talked about earlier?
 - *Follow up on relationships with friends/own family, academic/career plans*
- How do you think having a parent with dementia has changed or affected how you are as a person?
 - *Follow up on how see themselves now, how they see themselves in relation to family.*
- How has your parent's dementia affected how your family are with each other?
 - *Follow up on their thoughts about themselves, parent and other main family members perspectives.*
- As we've been talking, has anything else come to you that you haven't thought about before?
- How have you found talking today? Does the fact that I'm a researcher make any difference?
- Is there anything else you want to talk about as part of your experience that we have not touched upon?
- Do you have any questions or comments?

Piloting the interview schedule

I used the first two interviews to pilot the interview questions and to reflect on my questioning style, with the intention of using these interviews within the final analysis unless they were considered unsuitable. Consequently, after the first interview I discussed the transcript with my supervisors and colleagues identified for peer audit or 'debriefing' (Stiles, 1993). The quality of the experiences elicited and the style of questioning I had used were examined and the consensus was that the interview was suitable for inclusion in the final analysis. No significant changes were made to the interview schedule at that stage except to add an area of questioning which the first participant raised spontaneously. This was the participant's experience of services for themselves and their parent.

Post-interview questionnaire

In addition to the semi-structured interviews I also designed a brief structured post-interview questionnaire (refer to Appendix 1). This consisted of general demographic and factual information such as their age, their parent's official diagnosis and duration of onset of dementia. This was administered in order to ensure that similar levels of factual information were available for each participant in case this was not elicited during the semi-structured interview. It also allowed for comparison between participants which was intended to assist with purposive sampling. Purposive sampling can be defined as "sampling in which you select the units to be observed on the basis of your own judgement about which ones will be the most useful or representative" (Babbie, 2004, p183).

Ethical clearance

Ethical approval for the design of the study was given in September 2005 by Leeds East Research Ethics Committee (refer to Appendix 2 for details of correspondence with ethics committees). A Notice of Substantial Amendment was submitted and approved in January 2006 by the same committee after difficulties in recruiting participants to the study. I have discussed the amendments to the recruitment procedure within the section on recruitment below.

Conducting the study

Context

All participants had a parent who was receiving care from LYPD Team. This is an NHS multi-disciplinary service which provides assessment, diagnosis and community-based post-diagnosis interventions (such as information, psychosocial interventions and care review) to individuals with a diagnosis of dementia who are under the age of 65.

Sample criteria

A number of inclusion and exclusion criteria were established in order to ensure the welfare of any individuals taking part and also to respond to the research aims of the study.

Individuals could be included in the study if:

- a) they had a parent who was currently receiving care from LYPD Team
- b) they were in regular contact with their parent, either in person or by telephone. I decided that participants did not need to undertake any caring tasks for their parent as the aim of the study was to explore participants' experience of having a parent with dementia during this period in their lives and so was not dependent on them providing any form of physical or emotional support to their parent.

Individuals would be excluded from the study if:

- a) they were under the age of 16 or over the age of 40. The original age limit for participants was 30 though this was increased due to recruitment difficulties. This is discussed further in the section on recruiting participants below.
- b) they did not speak fluent English as IPA relies on the richness of an individual's verbal account of their experiences. Smith (2004) also suggests that an interviewer would "need to become more interventionist" in their interviewing style with such individuals (Smith, 2004, p49) which I felt may create a very disparate form of interview data to that from individuals speaking fluent English
- c) their parent was currently being assessed by LYPD Team with a view to diagnosis as this would be a particularly distressing period of contact with the team. Consequently, individuals were only included in the study after their parent had attended their first post-diagnosis review appointment which was approximately one month after diagnosis.

Recruiting participants

During the planning stage of the study I met with LYPD Team to present my proposal for the study and to discuss how they thought I would best access potential participants. A recent piece of service research (Jones, 2004) had identified that most offspring aged 18 to 35 with parents accessing the service did not have any contact with members of the team, particularly if they did not reside with their parent. Consequently, we agreed that I would need to recruit participants via their parent. The most reliable and convenient way of accessing parents would be at their out-patient review appointment. These review clinics were held fortnightly and all service users were reviewed by the team within a six month period.

I generated some recruitment materials for the study. Firstly a flyer for parents (see Appendix 4) was devised. This gave parents a brief outline of the study and contact details should they have any further questions before choosing to notify their son or daughter about the study. Secondly I devised a participant information leaflet (see Appendix 4) which parents could pass on to their son or daughter if they wished. This provided potential participants with more in-depth information and details of how to opt-in to the study.

At this stage I also completed a brief, informal audit of all service user notes for this study which allowed me to identify individuals with a son or daughter aged 16 to 30. I identified 63 parents within the service who either had a son or daughter suitable for inclusion or of whom the team were unsure of their family status.

Once recruitment began I attended the team's fortnightly review meetings in which service users attending the review clinic later that day were discussed. I was able to identify suitable individuals to approach with the team. I also felt that my presence at these meetings was important for keeping the study in the minds of busy professionals.

At the review clinics, I approached parents about the study either before or after their appointment. I discussed the study with and presented the flyer to both the parent (i.e. the identified service user) and their attending spouse, partner or family member, ensuring that both were informed and agreeable to passing on the information leaflet to their son or daughter. It was important that both parents were agreeable in order to minimise the potential for family stress or conflict as a result of their son or daughter taking part.

After three months of attending these review clinics I had only managed to recruit two participants to the study. Informal feedback from LYPD Team was that some younger people did not want to take part due to the potentially upsetting nature of such conversations. Consequently, I submitted a Notice of Substantial Amendment to the Ethics

Committee in order to widen my sources of recruitment. There were three main changes to the recruitment protocol at this point:

- I introduced a poster about the study with contact details for parents to take away. This was displayed in the waiting room at the review clinic and also at a day centre attended by some parents
- Several identified staff from LYPD Team approached parents in their own homes with the study information if they were no longer able to attend the out-patient review clinic
- I increased the upper age limit for participants from 30 to 40. This change was made as informal feedback from LYPD Team was that they were aware of a larger number of offspring within this age banding. Forty was also the upper age range for the period of young adulthood within the developmental psychology literature (Schaie & Willis, 1996). At this stage, I also reviewed my interview schedule with supervisors and colleagues to ensure that the areas of questioning were broad enough to cover the experiences of participants in their thirties as well as those in their teens and twenties. It was felt that the schedule would be applicable to all participants

Procedure

Once in receipt of an information leaflet, potential participants opted into the study by contacting me by telephone or email. During this initial conversation I continued the informed consent process by discussing the study in more detail, answering any questions and arranging a time and place to conduct the interview if they so wished. I met two participants within university or NHS facilities and three within their own homes.

When meeting with participants, I repeated the consent issues and answered further questions before participants signed a consent form to take part in the study. I then conducted the semi-structured interview using the schedule outlined above. This interview was audio-taped. Afterwards I completed the structured post-interview questionnaire with participants.

At this point I asked participants whether they wished to receive a summary of the research findings once completed and also ascertained whether they needed signposting to any of the identified avenues for support or further information.

I also asked participants to select their own pseudonym which I informed them would be used when writing this document. I decided to do this to give the participants a greater sense of collaboration in the research process. I also felt that ethically it was important that participants could identify themselves if they chose to receive a summary of the research findings or read any related documents.

Transcription

I transcribed all of the interview tapes myself in order to immerse myself within the participants' accounts. Charmaz (1995) advocates that the qualitative researcher should transcribe the interview themselves in order to become closer to the data and to develop a greater understanding of underlying meaning as well as what is explicitly stated by participant. I often made notes when transcribing which I later used to aid my analysis. Transcribing the tapes myself also ensured participants' confidentiality.

During transcription, the participants' accounts were anonymised by changing all names of people and places and any other identifiable details. I also adopted some conventions (presented in Table 1 below) when transcribing the tapes to enhance readability and for consistency within and between transcripts. All data has been retained in a secure place until completion of this study.

Table 1 Conventions for transcribing

Convention	Description
,	A pause of one second or less
...	A pause of more than one second
[tearful]	Details of non-verbal communication
[inaudible]	A single word, clause or sentence of inaudible speech

Analytic procedure

My initial intention was to analyse the transcripts after I had completed all of the interviews to minimise the influence that my analysis of early transcripts could have on conducting later interviews. Sporadic recruitment meant that this was not possible and so I carried out an initial analysis of the first two interviews before conducting the latter ones. I decided to analyse each interview individually before attempting a cross-case analysis rather than using the first analysis to guide the others as is sometimes used in IPA (Smith

and Osborn, 2003). This was because I was unsure whether each account would be very different and also I wanted to ensure that each account was given a similar weighting within the analysis. However, I acknowledge that the experience of conducting earlier interviews would impact on my approach to subsequent interviews to some extent.

A detailed description of the conventional process of IPA is given by Smith and Osborn (2003). I used this description as well as guidelines by Larkin (2003) in order to draw up a protocol for analysing individual transcripts. This is given in Figure 2 below.

Figure 2 IPA protocol used to analyse individual transcripts

- 1. Read through the transcript whilst listening to the audio-taped interview in order to re-orient the researcher into the individuals account. Underline and note any use of prosody, vocal tone or language which is not clear from the written transcript. Check accuracy of written transcript.**
- 2. Read through the transcript again noting on a separate page any general areas of content or language that seemed important in the previous reading and informed by the researchers own experience of the actual interview.**
- 3. Read through the transcript again making notes in the left hand column of general patterns, phrases, links, language use and comments on areas of interest.**
- 4. Re-read the transcript to consolidate and add to anything previously noted. Check that the notes made are grounded in the individual's original account.**
- 5. Read the transcript and notes made again and note in the right hand column any recurrent patterns and initial inferences about the meaning and context of these patterns, any inconsistencies and possible links to theory and any questions.**
- 6. Re-read the transcript to consolidate and add to anything previously noted. Check that all notes made are based on the individual's original account.**

I began my analysis with NS's transcript, utilising the steps in Figure 2 as a guide. During my analysis I considered the following questions proposed by Larkin (2003) to facilitate my move from a descriptive to a phenomenological understanding of NS's experiences:

- What experiences are being described and claimed by the participant?
- What are the key features of those experiences for the participant?
- What do those experiences appear to mean to the participant?

After an initial analysis of the transcript I then focused on the notes themselves, making a list of all potential themes and their corresponding quotes and attempted to group similar themes together. An example of this process is given in Table 2 below:

Table 2 Initial clustering of NS's themes

Text	Theme
“now I wouldn’t think twice about saying ‘I love you mum’, when I wouldn’t three or four years ago, I would have cringed at the thought of saying that”	Change in relationship with parent
“I’ve got to look after her now instead of... it’s like as though roles have reversed, as though I’ve got to look after her”	
“I do home and make tea and I do the shopping, it’s habitual now, just part of my life really”	Change in self
“ I suppose I’ve had to grow up a little bit quicker than what I would have done”	
“you just think ‘oh I wish I could be like that with my mum’ and you just see the relationship what they’ve got”	Feeling different to peers
“it’s harder with new friends because if they come round you’re in two minds whether to tell them”	

I analysed the remaining transcripts in a similar way (refer to Appendix 5 for an example of annotated transcript) and found that my understanding of earlier accounts would often shift in response to analysing later transcripts so that when my individual analysis of all transcripts was complete, the initial themes generated from earlier transcripts such as NS’s often looked very different in terms of the language used to label themes and the clustering of quotes under various themes headings.

An example of this occurred during a discussion with my supervisors about how participants were exemplifying coping strategies (such as using humour and looking for positives) during the interview itself. I had initially clustered these instances under a more general theme of ‘coping’, however Claire and KA’s account featured many more of these instances prompting me to reconsider this as a theme in its own right. I eventually viewed

this as the participants' attempts to reduce feelings of distress during the interview and so placed it under the overarching theme of 'experience of the interview'.

I attempted to create a table of joint themes at this stage. This also resulted in some changes in hierarchy and labelling of themes. For example, I had originally considered the theme of 'relating to parent differently' as a possible super-ordinate theme as this seemed particularly prominent within each account. After creating a joint theme table I felt that a change in participants' relationship with their parent with dementia was one of many relational changes that they experienced with family and peers. I finally categorized this as a conceptual theme under the super-ordinate theme of 'experiencing change in relationships'. The change in this super-ordinate theme also exemplifies my later shift towards thinking more interpretatively as opposed to remaining purely phenomenological.

I was also aware at this stage that some of the theme labels appeared too broad and in my attempt to label themes in a way which encompassed the experiences of all participants, I had lost some sense of individual experience. For example, I originally labelled participants' attempt to understand the changes they experienced in their parent by relating it to their previous experiences of dementia with grandparents as 'using past experience'. This label did not fully reflect Chantelle's experience of this theme. Whereas other participants had used their past experience of a grandparent with dementia to make sense of their current situation, Chantelle seemed to *relive* her past experiences, describing a resurfacing of unresolved grief for the loss of her grandfather in response to her mother's diagnosis. After a final audit of themes, I relabelled the theme 'linking past and present experience' to capture Chantelle's experience more fully. An example of my attempt to jointly present themes is shown in Table 3 below:

Table 3 The process of jointly conceptualising the themes

Text	Element	Sub-theme	Conceptual Theme	Super-ordinate Theme
NS "I've got to look after her now instead of... it's like as though roles have reversed, as though I've got to look after her"	Reversal of mother-daughter roles	Reversing roles	Experiencing parent differently	Experiencing change in relationships
CHANTELLE "sometimes it's like having another child in the house and I think I'm sort of...I mean when I were a kid if I were poorly she used to look after us so I think well"	Reversal of roles with parent	Reversing roles	Experiencing parent differently	Experiencing change in relationships
BILL "I couldn't necessarily rely upon that because clearly he was struggling himself with certain things"	Unable to rely on parent emotionally	Unable to rely on parent	Experiencing parent differently	Experiencing change in relationships
NS "it's harder with new friends because if they come round you're in two minds whether to tell them"	Difficulty with new peer relationships	Uncertainty within relationships	Experiencing peers differently	Experiencing change in relationships
KA "I don't know anybody else who's in the same situation as me apart from my brother"	Feeling different to peers	Feeling different	Experiencing peers differently	Experiencing change in relationships
BILL "if anything happened to my mother then that really would be a big, big, big problem, so as long as my mother's health and well being is ok then things will be manageable at least"	Feeling concerned for mother's health	Fearing for other parent's wellbeing	Experiencing other parent differently	Experiencing change in relationships

Checking the quality of analysis

I used a number of strategies to provide quality checks for the analytic process:

- I attempted to look at the reliability of the data. Firstly I submitted a transcript and themes for peer auditing (Stiles, 1993). This involved one of my supervisors reading through an annotated transcript and the themes I had generated and then meeting to discuss their reflections on my themes as well as their own interpretation of the data. Secondly, I attended a local qualitative research support group where I was able to present sections of annotated transcript to colleagues familiar with IPA. I used these groups for peer debriefing (Stiles, 1993) whereby I was “trying out interpretations” (Stiles, 1993, p612) with my colleagues, attempting to reach a consensus and ensuring that my initial interpretations of the data were grounded within the individual’s original account. Thirdly, I submitted my list of joint themes and supporting quotations for audit by one of my supervisors. This enabled me to reach a final consensus on the positioning and hierarchy of themes and the language used to name them.
- I looked for deviant themes which differed from and challenged my current understanding and interpretation of the data. For example in Bill’s account there were unique themes about him trying to make sense of his own reactions to his parent’s dementia. Whilst two of these themes (looking at others’ reactions, feeling unable to react) remained unique to Bill in the final analysis, examining these further highlighted how other participants also attempted to make sense of their own reactions to their situation (within the theme of considering developmental stage) which broadened my understanding of the super-ordinate theme of ‘understanding change’.
- I made notes immediately after each interview and whilst transcribing. These included details of my initial personal feelings and reactions, possible themes and links to theory and any important aspects of conversation which were not audio-taped. These were particularly useful for my analysis of the ‘experience of the interview’ for participants (this is presented in depth within the results section). For example within KA’s account the sub-theme of re-affirming shared narratives emerged because she used similar phraseology after the interview was over to convey her experience of sharing her story with another individual.

- I also attended the Annual IPA Conference 2005 and used the IPA website in order to ask questions and learn from other researchers' approach to this methodology.

Conventions for presenting the results

When selecting supporting quotations I attempted to choose extracts which best exemplified a theme however, I was aware that some quotes were applicable to more than one theme. I discuss any links between quotations as necessary within the results and discussion chapters.

I also adopted some conventions when editing the supporting quotations for presentation within the results. Firstly I removed or added short pauses to enhance the flow of the text for the reader. I also removed all long pauses except where they add to the reader's understanding of the participant's experience, for example in this quote by Bill I decided to leave the long pause in the quotation in order for the reader to gain a sense of the frustration that he had with his father repeating himself:

“you can literally get a recollection of something three to four times over a dinner or whatever, which is a bit of a...”

Secondly I removed some colloquial terms such as “like”, “erm” and “you know” which hindered the sense of the text for the reader. For example the following transcribed quotation

“I suppose it's just kind of, erm...I suppose making me aware that that sort of thing, can happen, like I said my grandmother had Alzheimer's my dad got...this problem and, you know you supposedly think 'well you know perhaps I might get it in years to come'”

is presented within the results chapter as

“I suppose it's making me aware that that sort of thing can happen, my grandmother had Alzheimer's, my dad got this problem and you supposedly think 'well perhaps I might get it in years to come'”

In order to avoid confusion when presenting and discussing the results, I refer to the participant's parent with dementia as 'parent' or 'parent with dementia' and their parent without dementia as 'other parent'.

CHAPTER III - RESULTS

Within this chapter I will discuss the results of the semi-structured interviews I carried out and analysed using IPA. This discussion is provided within three distinct sections. Firstly I will outline my sample and proceed to give a series of vignettes describing each participant in detail. Secondly I will present an overview of the themes emerging from the analysis and then proceed to give a detailed account of each of these themes in turn. Finally I intend to present an analysis of the experience of the interview process for participants, again detailing emergent themes in this area.

Description of the sample

The five participants I interviewed had a range of experiences and backgrounds. Included in the group were both males and females of various ages and socio-economic backgrounds. With regard to ethnicity all participants were white.

There was also some diversity in the nature of their parents' dementia in terms of duration of onset, specific diagnosis and day to day difficulties experienced by themselves and their families. Each participant was able to give a rich account of their experience which would be amenable to analysis using IPA. An overview of the participants is outlined in Table 4 below:

Table 4 Outline of the sample

Pseudonym	Sex	Age	Parent with dementia	Duration of impairment observed by participant	Official diagnosis	Duration of diagnosis
NS	Female	23	Mother	5years	AD	3 years
Chantelle	Female	37	Mother	4years	AD	3 years
Bill	Male	31	Father	7years	Pick's Disease	2 years
KA	Female	35	Mother	2years	Atypical AD	1 year
Claire	Female	35	Father	5 years	AD	4 months

I developed vignettes for each participant which are intended to 'situate the sample' (Elliott et al, 1999) for the reader, giving a more in-depth account of each participant's experiences. This allows the reader to make a more critical evaluation of my analysis. I will present the pen portraits for each participant in turn giving details of their current lifestyle,

relationships, employment and family structure and details about the nature of their parent's dementia. I will then provide some details about the interview process.

NS

NS is a 23 year old woman who recently qualified as a teacher and is now working full time in a comprehensive school. She lives with her parents and has an older brother and sister who are both in their thirties. Her brother and sister live within a mile of NS with their respective partners and children and are in weekly contact with their parents. NS has taken on the majority of her mother's household responsibilities in recent years. She feels this has reduced the amount of free time she has to socialise with her close circle of friends outside of the family home. NS will cook and clean for her parents as well as manage shopping and bills. She also assists her mother in self-care tasks and administers her medication. She thought that on balance she now shares the running of the household with her father who also works full time. They also have a carer who sits with her mother two mornings each week. NS said she had always been close to her family and although she felt similarly now towards her parents, the imbalance in the amount of care she provided for her mother compared with her siblings was creating tension within the family.

NS's mother is 56 years old and was diagnosed with AD three years ago however, NS first began to notice some deterioration in her mother's presentation five years ago. NS reported that her mother is forgetful and repetitive and needs assistance with self-care tasks such as washing, dressing and prompting to eat. Her mood and impairments are variable as there are times where she can present as NS remembers her prior to the onset of dementia. At other times she can become distressed when she is left alone, asking NS to stay with her.

My first interview with NS lasted approximately one and a half hours. As this was my first interview I felt that we were both apprehensive to begin with and I spent a relatively long time (compared with later interviews) building rapport prior to beginning the taped interview. Initially NS appeared guarded and I felt that this was not solely a consequence of the interview situation. NS appeared to need to protect and defend her mother and seemed initially reluctant to share negative or unhappy feelings which could be construed as finding fault with her mother. Consequently, I too was reluctant to probe these areas and fortunately NS shared more of this spontaneously as the interview progressed.

Chantelle

Chantelle is 37 years old and has lived with her parents for several years. She has a brother in his thirties who also lives at home at the weekend, working away during the week. Her sister is also in her thirties and lives a mile away with her partner and children and visits at least weekly. Chantelle described a turbulent relationship with her father and siblings during her twenties but thought that since the onset of her mother's dementia there had been less conflict within the family. She had always had a good relationship with her mother who she described as a close friend and companion until recently. Chantelle has taken over her mother's household responsibilities; cooking, cleaning and shopping. Her father works full time and has numerous physical health difficulties so Chantelle tries to carry out any physically demanding care tasks herself. Chantelle also works part time in a supermarket and uses work and socialising with friends in order to take time out from her responsibilities at home.

Chantelle's mother is 57 years old and was diagnosed with AD three years ago though Chantelle began to see some deterioration a year earlier. Chantelle's mother can be low in mood and often wants to stay in bed in the morning requiring a lot of encouragement from Chantelle and her father to get up. Her mother has memory difficulties and can be repetitive. She needs help with all self-care tasks and supervision at all times especially when cooking or using stairs. She uses a wheelchair when going out.

I interviewed Chantelle for two hours. She appeared nervous and began to talk about her experiences without me asking her any questions. She began by talking about her grandfather having AD in the 1980's and how this had an impact on her response to her mother's diagnosis. Chantelle had not spoken about these events before with her family or friends. She was very tearful at times and appeared to find some sort of release from sharing her experiences. I was reluctant to probe her with any questions initially and she spoke continuously for about thirty minutes before I felt it appropriate to question her further about particular aspects of her account.

Bill

Bill is 31 years old and lives with his fiancée approximately one mile from his parents. He has worked as an accountant since graduating from university ten years ago. He currently sees his parents at least once a week and whilst his mother is the main carer for his father, Bill has taken over his father's previous role of managing financial matters and

household maintenance for his parents. He has one sister (two years younger) who lives 180 miles away and has regular telephone contact with their parents. Bill spends his spare time socialising with his fiancée and friends but rarely talks to them about his father.

Bill's father is 61 years old and began to exhibit difficulties seven years ago. These impairments remained undiagnosed until two years ago when he was given the diagnosis of Pick's Disease. The main changes Bill has noted in his father have been around his personality and emotional availability. He is often jovial and will become persistent and repetitive when talking about certain topics or overly excited when meeting friends and family. He is also increasingly forgetful during conversations and has difficulty maintaining his attention in group conversations which has limited his ability to maintain his established social network. He also struggles with planning and executing everyday tasks such as cooking and using money and can no longer drive.

My interview with Bill was rather succinct compared with others and I interviewed him for approximately 45 minutes. Bill had not shared his experiences of his father having dementia before and initially had difficulty talking about his thoughts and feelings. My experience of the previous interviews allowed me to anticipate this to some extent and I was able to prompt him about these areas. As the interview progressed, it seemed that what I initially viewed as an understandable reluctance to share difficult experiences with a stranger was rather Bill's inability to make sense of his situation and his feelings about it. He appeared to be processing some of this within the latter part of the interview itself and as he did so I was able to explore his understanding of his situation, creating a more complete account of his experiences.

KA

KA is a 35 year old woman who has worked within the media industry since completing a degree in her twenties. She has also volunteered weekly for a national helpline for six years. She lives 170 miles away from her parents with her partner who works within the same industry. KA works long hours and weekends and her friends and leisure time generally revolve around this industry. KA has one brother four years younger than herself who lives near to her, though their contact is limited to the times when they see their parents together. KA sees her parents about once every month or two for weekends and speaks to them at least weekly by telephone. KA thought her relationship with her parents had always been supportive but described herself as very independent and self-reliant. Since her

mother's diagnosis she has increased her telephone contact with her parents but finds the physical distance and her time-consuming work increasingly problematic as she is unable to see her parents as often as she would like.

KA's mother received a diagnosis of Atypical AD one year ago though KA first began to notice a change in her mother two years ago. Her mother is 61 years old and lives with KA's father who is the main carer for her. KA described her mother as becoming increasingly forgetful and repetitive. She also struggles with everyday tasks such as dressing, cooking and writing and can no longer drive. In recent months she has also started to misidentify KA's father for a stranger on occasion and will become confused and at times distressed when entering an unfamiliar environment.

I interviewed KA for three hours. She had thought about her experiences in detail over the last two years and was able to articulate her feelings with clarity. KA would talk at length, needing little prompting to share her thoughts and feelings as well as anecdotes and analogies to exemplify these. I needed to ask relatively few questions on my interview schedule compared with all other participants. She emphasised the process of adaptation and adjustment to her mother's diagnosis that she had been through and still faces today as she is confronted by novel areas of her mother's impairment.

Claire

Claire is 35 years old and lives with her husband and two young children about three miles away from her parents. She works full time in the public sector. She currently sees her parents three or four times a week as they care for her children after school. She has an older sister living nearby with her own family who also has regular contact with their parents. Claire described her family as having always been close and supportive although her mother's difficulty with adjusting to her father's diagnosis has created some tension within the family. Claire's mother is the main carer for her father and she also works part time.

Claire's father is 62 years old and was diagnosed with AD four months ago however he had been increasingly impaired according to Claire for over four years prior to diagnosis. Claire and her sister had instigated the assessment of her father's impairment despite her parent's reluctance to investigate this. Claire's father repeats himself and struggles to find

the right word in conversations. He also struggles with some day to day tasks such as dressing.

Claire talked openly about her experiences for an hour. Unlike all other participants, Claire reported that she did not experience her father's dementia as greatly impacting on her life currently, which in part I attributed to the more recent onset and diagnosis of impairment compared with other participants. Consequently Claire's account often centred around her anticipation of future impairment and potential distress. There was also a strong emphasis on her need to remain positive for her family and I was left feeling that her reluctance to share difficulties in the present was partly an attempt to maintain her protective and supportive role within her family.

Discussion of emerging themes

Within this section I will present an in-depth discussion of the themes emerging from the analysis. The four super-ordinate themes which emerged were:

1. Experiencing change in relationships
2. Understanding change
3. Managing change
4. Experiencing change in self

A table of the four super-ordinate themes and their associated conceptual themes and sub-themes is presented in Table 5. I will discuss each of these themes in turn, grounding examples with supporting quotations which give the reader a sense of the individual's experience of particular themes.

Table 5 List of the four super-ordinate themes, conceptual and sub-themes

1: Experiencing change in relationships	2: Understanding change	3: Managing change	4: Experiencing change in self
1:1 Experiencing parent differently	2:1 Making sense of dementia	3:1 Resisting family changes	4:1 Changing self-perception
1:1:1 Feeling frustrated	2:1:1 Updating understanding	3:1:1 Maintaining parental role	4:1:1 Maturing prematurely
1:1:2 Missing out	2:1:2 Linking past and present experience	3:1:2 Maintaining level of contact	4:1:2 Increasing empathy
1:1:3 Losing parent gradually	2:1:3 Looking for explanations	3:1:3 Seeking out relational experiences	4:1:3 Increasing emotionality
1:1:4 Unable to rely on parent	2:1:4 Hypothesising parent's feelings	3:1:4 Limiting family discussion	4:1:4 Considering own vulnerability
1:1:5 Reversing roles	2:1:5 Reappraising past events	3:1:5 Avoiding information	4:1:5 Re-evaluating life choices
1:1:6 Considering parent's mortality	2:1:6 Feeling unable to make sense	3:1:6 Avoiding future planning	4:1:6 Observing change in self
1:1:7 Protecting parent from distress			4:2 Changing plans
1:1:8 Growing closer		3:2 Confronting family changes	
1:2 Experiencing other parent differently	2:2 Making sense of one's reactions to dementia	3:2:1 Anticipating loss of relationship	
1:2:1 Compensating for lost parent	2:2:1 Considering developmental stage	3:2:2 Envisaging increased deterioration	
1:2:2 Fearing for other parent's wellbeing	2:2:2 Looking at others' reactions	3:2:3 Expecting increased involvement	
1:2:3 Pursuing a closer relationship	2:2:3 Feeling unable to react	3:2:4 Talking as a family	
		3:2:5 Seeking information	
1:3 Experiencing siblings differently		3:3 Managing change in self	
1:3:1 Feeling jealous		3:3:1 Using social support	
1:3:2 Feeling unsupported		3:3:2 Taking time out	
		3:3:3 Using medication	
1:4 Experiencing peers differently			
4:1:1 Feeling different			
4:1:2 Feeling jealous			
4:1:3 Uncertainty within relationships			

1: Experiencing change in relationships

All participants experienced changes within their relationships with others. Whilst most of these centred around their relationship with their parent with dementia, they also saw various changes in their relationship with their other parent, siblings and peers. These various relationships are now discussed in turn.

1:1 Experiencing parent differently

Each participant reported a change in their relationship with their parent as a result of the onset of YOD. These changes were largely negative for most participants with only NS suggesting positive growth within the relationship.

1:1:1 Feeling frustrated

Four participants reported feeling frustrated with their parent at times. In all cases, frustration was felt in response to their parent's repetitive behaviour and forgetting. NS seemed particularly frustrated in the early stages when she could not understand why her mother repeated herself.

NS: "she'd ask me three or four times within a space of twenty minutes 'are you in for your tea', and I'd go 'mum you've already asked me, no I'm not', I just thought my mum were being stupid"

Bill also found his father's stories a frustrating aspect of spending time with his family.

Bill: "he repeats himself a lot and tells you lots of stories, it does get a bit repetitive, you can go round and he keeps repeating himself, you can literally get a recollection of something three to four times over a dinner or whatever, which is a bit of a..."

KA seemed to find her mother's repeated need to be close to her invasive and annoying.

KA: "if I'm in the kitchen, she wants to help out but she also wants to be close to me and I could say 'can you go and sit down' and that would be fine, but five minutes later she would be back in the kitchen standing right behind me so every time I'd turn round, bang, there would be this person"

Chantelle highlighted the contrast between her sense of freedom and fun at work with the mundane, repetitive conversation she then returns to at home.

Chantelle: “tomorrow I’m going to work and I’ll be thinking ‘oh good back to work, have a laugh’ and then when I get home my mum will go ‘have you been busy?’, and that’s her question, every night she still asks that question ‘have you been busy?’, and then I’ll go in the kitchen and I’ll come back and she’ll go to me again ‘have you been busy?’ and I’ll go ‘mum, you’ve just asked my that question’, if she could remember the days of the week I worked it would be good you know, she’d be good if she could remember that”

Claire also noticed that her father repeated himself though this was not associated with feeling frustrated.

1:1:2 Missing out

Participants commented on the loss of the relationship they had expected to have with their parent at this stage in their lives. NS highlighted the unique losses associated with having a parent with YOD in view of both her and her mother experiencing these changes at a younger age compared with other people.

NS: “I feel as though I’ve missed out in a sense with her getting poorly when I were young and when she was young, it’s like missing out compared to other people”

Bill also reported missing out on the development of a close relationship with his father during adulthood which he sees in his friend’s relationships with their fathers.

Bill: “it’s difficult to forge a close relationship with my dad because of how he is, I suppose one thing that’s difficult is that when you’re in your teens and early twenties, you always get on with your parents but there’s always a degree of rebelliousness and it’s only when you get to mid twenties, late twenties, early thirties where you can actually forge a closer bond, and I see certain people I know, they do a lot with their fathers because their relationship gets to a different level”

Claire seemed to feel cheated out of time with her father developing dementia at such a young age.

Claire: “if he was seventy-two and this was diagnosed, it wouldn’t be a massive issue, if dad was seventy-two and was diagnosed, we’d think not a bad innings seventy-two, it’s because it’s sixty-two it’s an issue so we see the next ten years really as being key, and I think if we could get through the next ten years of him being ok, all be it he will get worse and we accept that, then I think if somebody was in their seventies we’d be far more accepting of it”

1:1:3 Losing parent gradually

Whilst some participants had been comforted by the slow progression of dementia which enabled them to maintain some form of relationship, others reported that losing their parent slowly was particularly distressing and confusing. Chantelle’s emphatic repetition of how her mother is “getting worse” suggested a sense of desperation about the constant deterioration.

Chantelle: “it’s difficult to accept, she’s getting worse now every day, she’s getting worse, she’s started getting worse she can’t remember things and the tablets have been upped”

For KA the gradual series of losses and readjustments to her mother’s increasing impairment seemed important, with the loss of her mother’s personhood particularly distressing.

KA: “of course my mother’s going to die I think the difference with dementia is that the person dies while they’re alive, and then they die later, it’s like you’ve got a series of different people going away into the distance, it’s the reverse of having a child you watch as a child can do something and you watch as this person can’t do something”

1:1:4 Unable to rely on parent

A loss of dependability of their parent to fulfil emotional and practical needs was apparent for some individuals. NS was upset by her mother’s inability to acknowledge her educational achievements.

NS: “it got to me at uni a little bit because you ask my mum what degree I did and she wouldn’t have a clue, obviously she’s got Alzheimer’s, and that were a little...don’t know

how to describe it, not annoying because it isn't her fault but upsetting, she probably wouldn't be able to tell you what A levels I did"

Bill seemed to feel abandoned as he realised he would no longer be able to discuss plans and decisions with his father.

Bill: "I couldn't necessarily rely upon that because clearly he was struggling himself with certain things so now I know that, but you still like to have a sounding board of people, so you realise that I'm sort of by myself now really"

Claire noticed her inability to rely on her parents for practical support was atypical compared with friends.

Claire: "some of my friends really put a lot on their parents in relation to child care and babysitting and I try not to do that cos I'm mindful that they're not hundred percent"

1:1:5 Reversing roles

All three women who also had a mother with dementia reported a reversal of parent-child roles at times. Bill also had taken on aspects of his father's role in the family, however this appeared more when relating to his mother rather than within his relationship with his father. Claire did not report any reversal of roles with her father. NS appeared to miss the day to day care from her mother.

"I: So what kind of things do you think you might have missed out on?"

NS: just having normal conversation really, doing things with her, and looking after her, I've got to look after her now instead of... it's as though roles have reversed, as though I've got to look after her"

Chantelle compared her relationship with her mother to that with her nieces and nephews. She also seemed to feel a duty to repay past care from her mother.

Chantelle: "you've got to put your mind into another gear like I would if I were going to do something for the twins, sometimes it's like having another child in the house and I think I'm sort of, I mean when I were a kid if I were poorly she used to look after us"

KA appeared uncomfortable with the reversal of roles, wanting to avoid infantilising her mother. I also felt her appreciation of her mother's perspective was partly a result of her anticipated development of dementia herself in the future.

KA: "you don't want to start treating the person like they're not an adult who's your mother, who was responsible for you and looked after you and you are now treating her as a non-independent entity"

1:1:6 Considering parent's mortality

Bill and NS viewed confronting their parent's mortality as off-time developmentally.

Bill: "I suppose I've probably got a sort of awareness of my parent's mortality slightly earlier than I would have liked"

NS also related this to premature maturation and felt that facing the loss of her mother had made her appreciate the present.

NS: "I realize that she isn't going to be here forever, made me appreciate what I've got, that's what I mean about having to grow up I wouldn't have thought about that when I were nineteen or even twenty, but now I do, it's hit home a bit"

Claire considered the loss of her father not only for herself but also for her children.

Claire: "probably made me realise that my mum and dad are not going to be around for ever looking after me or my children"

KA viewed the loss of a parent to YOD as equally distressing compared with any other illness.

KA: "I think it would be the same whatever your parents had, I don't think it's got anything to do with it being dementia, if my father had a stroke if my mother had a heart attack, facing your parent's mortality"

1:1:7 Protecting parent from distress

Claire provided reassurance to her father when he became despondent about taking medication for the foreseeable future.

Claire: “I have said to him ‘what do you think about your tablets’ and I’ve been to hospital with him when my mum couldn’t go, say ‘I think you should take them, I think you’re doing really well, I think you’ve improved’”

KA tried to find a balance between her own needs and those of her mother. She seemed to be questioning the best way to manage situations in order to avoid her mother’s distress.

KA: “it’s a very tough decision when you don’t see your parents that often between is it right to sit around crying because it’s part of the process that you should go through, or should you try to make the times you see somebody as happy as possible so that you don’t get too stuck into them being very upset about things”

She also avoided situations in which her mother would struggle to manage.

KA: “I kind of didn’t want to give her that confrontational situation where you are confronted with the fact that you cannot do something”

Developing family strategies to avoid her mother’s distress was KA’s more recent approach to protecting her mother.

KA: “my father and I have started to talk about things separately now because it’s not useful having that conversation in front of my mother because it will worry her and upset her or she’ll get very defensive or angry about it and to no good end”

1:1:8 Growing closer

Despite her sense of missing out on the relationship she desired with her mother, NS felt that she had developed a closer bond with her mother in recent years, valuing the increased expression of positive feelings within their relationship.

NS: “I’ve realized how much I love her now because we’re not a family who tell each other ‘oh I love you’, we’re just not that kind of family, and now I wouldn’t think twice about

saying ‘I love you mum’, when I wouldn’t three or four years ago, I would have cringed at the thought of saying that”

1:2 Experiencing other parent differently

All participants also experienced some change in their relationship with their other parent.

1:2:1 Compensating for lost parent

Some participants perceived their other parent as beginning to fulfil certain roles originally belonging to their parent with dementia. The other parent appeared as a substitute for some of the care and support previously provided by their ill parent. NS noted the change in her father’s approach to housework as her mother became unable to take on this role for the family.

NS: “My dad has had a personality transplant since it’s happened because my dad was a lad’s lad, he didn’t know what an iron was, and now it’s my dad does everything with me, he isn’t scared to iron his own trousers or his shirt, where before, he would not have dreamt of ironing his own shirt, he’s become domesticated”

KA seemed surprised at how well her father had maintained the family’s social network as her mother’s ability to do this deteriorated.

KA: “it’s interesting that he has become a carer because my mother was the carer, she did the social side of the relationship much more than my dad so it’s strange that he’s ended up in the situation and that he’s coped with it as well as he has, he definitely has taken the bull by the horns and they are seeing people more, my dad’s made this little network which is good, he’s actually kind of fitted into the role quite well”

1:2:2 Fearing for other parent’s wellbeing

Participants raised some concerns about the health and wellbeing of their other parent. There was a sense of duty to support them whilst also fearing further loss should they become unwell. NS felt a sense of duty and responsibility towards her father, also fearing that leaving him would disrupt the equilibrium they had established together.

NS: I couldn't leave my dad on his own with my mum, just for the fact that I feel as though I'd be shifting everything onto him"

Chantelle feared the additional burden that caring for her father would bring.

Chantelle: "my dad's poorly himself, so this is another reason that they get scared if...for my mum but worried for my dad, I've got my dad with that and my mum with this, so it's sort of given me a little bit of both"

Bill also feared the additional responsibility and burden of caring for both parents.

Bill: "my key objective is to make sure that things are as easy as possible for my mum because the worst thing that could happen would be for my mum's health to suffer, if anything happened to my mother then that really would be a big, big, big problem, so as long as my mother's health and well being is ok then things will be manageable at least"

KA found it difficult to even consider such a catastrophic event.

KA: "the worst possible thing that could happen is that something would happen to my father, if my father became ill, incapacitated or died that is the situation that I, well there's no point thinking about it till it actually happened but I do not know what I would do"

1:2:3 Pursuing a closer relationship

There was an attempt to pursue a close relationship with the other parent in order to support them and ease their burden of care and seemingly as a response to the gradual loss of their parent with dementia. Chantelle compared the turbulent relationship with her father during her twenties with their more recent positive relational experiences. They seemed to have a new collaboration where both were working to maintain the peace in order to avoid further distress and upset within the family.

Chantelle: "me and my dad are too alike and we always have been, we've always had a clash of personality, but at the minute we're alright, we haven't argued we haven't shouted we've just gone out, and done stuff more with my dad than I do with my mum"

Bill also described feeling closer to his mother as a result of taking on aspects of his father's role within the family.

Bill: "I've always been slightly standoffish just because that's the person I am, but I'm certainly closer to my mother than I was because she's had to rely upon me more"

In contrast with all other participants, Claire reported a negative impact on her relationship with her other parent as a result of her father's dementia. She was concerned about her mother's response to and ability to cope with her husband's diagnosis.

Claire: "I don't know if she deals with him right, her way of dealing will be to give him tasks to do, she thinks he's better when he's busy, but I just don't know if she really thinks 'well I'll get him out of the way' and busy him up with things, I think she thinks he's better because he's active and that he's not just sat about, whereas it depends how you look at it doesn't it, is she thinking 'get a bit of free time'"

Claire seemed frustrated about her inability to forge a closer bond with her mother and to support her with her depressed mood, offering help and advice which (unlike her father) her mother was reluctant to accept.

Claire: "I feel more frustrated towards my mum than I do towards my dad because my dad's poorly and my dad's gone to the doctors even though he didn't want to go and he's been diagnosed, my mum I think I should go should go back to the doctors and seek some medication"

1:3 Experiencing siblings differently

Whilst all participants had at least one sibling, it was only those participants living with their parents who experienced a change in sibling relationships. According to these individuals the changes in their relationships were largely negative.

1:3:1 Feeling jealous

As a much younger sibling within her family, NS was jealous of the relationship her sister was able to have with her mother during her twenties.

NS: “my sister will have had that relationship with my mum cos she’s thirty-seven, so when she was my age she will have had all that with my mum but I feel as though I’ve missed out”

1:3:2 Feeling unsupported

NS seemed to feel some resentment towards her siblings in view of the greater portion of care that she provided for her mother. In particular, the discrepancy between NS and her sister’s involvement seemed unfair to her.

NS: “I just feel as though because I live at home it’s expected that I do all these things but I don’t think they appreciate how hard it is, cos there’ll be days that we don’t see my sister and then she’ll call in and spend a few hours which is good, but I just don’t think she appreciates how hard it actually is, and I’m the baby of the family, I just think sometimes they’ve got to understand that it’s as though they’ve gotten off scott free because they don’t need to do anything”

Chantelle also perceived the support offered by her siblings as disproportionate to her own involvement.

Chantelle: “my sister she’s got a family to look after so she’ll worry about my mum and my dad, but then she’ll say well ‘I’ve got our David and Charlotte to think of’, and my brother’s only there on a Friday and then he goes back to work Sunday and he’s got a girlfriend and he’s never in, so it’s difficult”

1:4 Experiencing peers differently

Some participants also experienced a change in peer relationships with a friend or partner.

1:4:1 Feeling different

KA seemed to feel different to her peers as a result of having a younger parent with dementia. She was also concerned about others responding to her differently when aware of her situation.

KA: “I don’t know anybody else who’s in the same situation as me apart from my brother, I don’t know anybody else who’s parent who isn’t eighty plus had dementia, I think it makes it harder for other people cos they don’t know what to say or do or what the drill is”

1:4:2 Feeling jealous

NS compared her friends’ relationships with their mothers, feeling jealous and sad about missing out on a similar experience with her own mother.

NS: “you look at my friends relationships with their mum and it’s, well it’s jealousy I suppose, you just think ‘oh I wish I could be like that with my mum’ and you just see the relationship what they’ve got”

1:4:3 Uncertainty within relationships

Having a parent with dementia also created some uncertainty within peer relationships in terms of how they could progress and also whether the changes individuals had experienced within themselves would in turn have an effect. NS seemed to have some anxieties about her peer and family relationships coming together. This appeared to make the formation of new peer relationships difficult.

NS: “it’s harder with new friends because if they come round you’re in two minds whether to tell them before they get there, say ‘if you meet my mum she’s got Alzheimer’s so she might act a bit funny’ or tell them after, you don’t know what the best thing is to do”

KA considered the implications of her own possible susceptibility to dementia for her partner, giving him the opportunity to leave the relationship.

KA: “it must be a strange experience for James because he’s seeing me going through all of this, and I’ve said to him ‘I’m not being dramatic but do you think you actually want to invest the rest of your life in a relationship with someone who might end up in that situation, you’re going to go from having that person to not having that person gradually and do you want to have kids with that person”

2: Understanding change

Participants attempted to make sense of and understand the changes they experienced within their relationships with others. This involved using past and present knowledge and experience to create explanations about their parents' dementia and their own reactions to it.

2:1 Making sense of dementia

All participants tried to understand their parent's day to day difficulties, their behaviour and also reasons for YOD occurring within their family.

2:1:1 Updating understanding

There was an attempt by participants to update and readjust their understanding of dementia as this progressed over time. In all cases there was an updating of early explanations as the dementia became more pronounced. Bill updated his understanding of his father's changing personality.

Bill: "there was probably times where in the very first stage I thought perhaps he was getting older or something was changing a bit, but I think that was partly just what I now understand was a sort of personality change"

NS began to realise her mother's behaviour was not merely absentmindedness over time.

NS: "I just thought my mum were being stupid, then as it you know, you start thinking there is something wrong here"

KA described how she and her father were no longer able to rationalise her mother's impairment as it progressed.

KA: "the first time my dad and I ever discussed that there was probably something wrong with my mum I was standing at a bus stop and my phone rang and it was my dad, and said to me that he thought that it wasn't just a question of my mum being very tired at work, which she had been, or any kind of hangovers from the menopause cos she had quite a difficult menopause, he did actually think that there was something else wrong with her"

2:1:2 Linking past and present experience

All participants with a grandparent with dementia used this earlier understanding to assist them in making sense of their current experiences. Bill found it difficult to contemplate his father's impairment progressing in a similar way to his grandmother.

Bill: "my grandmother had Alzheimer's and she was into her eighties when she died and you hear stories about other people who have Alzheimer's, it sounds a horrible way to go and so just hope that it doesn't go like that but we're open minded and realise that there's a chance that it could"

KA noticed similarities between her grandmother and her mother's behaviour.

KA: "my grandmother had something very similar to this, my grandmother and my mum are doing similar things, my mum reads the names of things out or reads something off the television, I remember my grandmother used to have these place mats with pictures of birds on and the Latin name of the bird, and my grandmother would point to that and read the name of the bird out and my mum does the same thing"

Chantelle not only recognised the similarities across the generations but also found that the onset of her mother's dementia had brought past grief for her grandfather to the fore again. She was anticipating distress and loss in the future to be similar to that she had already experienced with her grandfather.

Chantelle: "when my granddad died I hadn't spoken about him for a very long time, and these feelings have been put to one side and have only surfaced again when my mum had been diagnosed as having Alzheimer's, it took me a long while to accept that my mum has got Alzheimer's because it's like a nightmare come back again"

2:1:3 Looking for explanations

Some participants tried to find reasons why their parent had developed dementia. Chantelle found it difficult to understand how one family could be unfortunate enough to experience dementia in more than one instance. She seemed to be questioning why to little avail.

Chantelle: “once were bad enough with my granddad, and then with my mum sometimes I think, ‘why is happening again’, it does not happen twice in one family, these things don’t happen, I can’t find an answer, I puzzle over it and I wonder over it and I just can’t make an answer, I keep coming out with five”

In an attempt to make sense, she later wondered if the distress and worrying over the safety of her brother in the army had contributed to the onset. This seemed to be an explanation for dementia across the generations as the family suspected that grandfather’s dementia was a result of his traumatic experiences during World War Two.

Chantelle: “my brother were in army, whether that’s in back of my mums mind and this is maybe something to do with some of her Alzheimer’s, I don’t know, she used to worry about him, whether my mums frightened as well, all this you see in my mum’s mind”

NS and KA related the onset of dementia to punishment for past callousness about and disregard for dementia. There seemed to be a sense of guilt associated with this explanation for them both. NS considered how she may be punished by God for her disregard for other’s distress.

NS: “our neighbours’ mum has got Alzheimer’s and I used to baby-sit for her when I were thirteen fourteen and she used to talk about it, and I used to be like ‘oh, what’s she on about, Alzheimer’s, I don’t want to know about that’ and now I could cringe because I thought ‘is that bloody God getting me back for saying that or something in a funny sort of a way’, and if you see people who have got obviously problems walking about, I probably used to laugh at them”

KA reviewed how innocent joking with her mother about her developing dementia in the future had become a reality.

KA: “I’d always joke about, she’d say ‘oh god what if I get old and I lose my mind and blah blah blah’ and I’d always joke and say ‘oh I’d just lock you in the cellar and tell people that you’ve gone away on holiday’ or I’d say ‘oh yes, if you’re mad don’t come crying to me, I’ll be locking you in the garden shed and feeding you coal through a letterbox’, you know just joking about it, and of course it has happened”

2:1:4 Hypothesising parent's feelings

KA and Claire considered their parent's perspective by trying to understand how their parent may be feeling about their dementia. KA tried to formulate why her mother became distressed about her inability to drive. She seemed to empathise with her mother's experience of powerlessness and lack of control.

**KA: "she always drove, and my dad didn't know how to drive till he was forty so she was the driver, and then close to the time that she was officially diagnosed she couldn't really drive, but the problem was that she didn't make that decision for herself, and to always be the passenger and not be the person driving when you probably would have driven before
I think psychologically is quite a big step for someone"**

Claire wondered if the label of dementia at a younger age had altered her father's perception of himself and his capabilities.

Claire: "I don't know if now he feels that because it's all out in open and that somebody's recognised that there is something wrong with him, then that it's ok, I think he probably feels frustrated some of the time as well, that he's only 62 and all of a sudden he's been diagnosed and labelled with this illness, being struck off so to speak"

2:1:5 Reappraising past events

KA and Claire looked back at their parent's behaviour many years ago, reappraising this in light of their more recent diagnoses.

KA: "you start to look back sometimes and think 'was that thing that didn't seem out of place at the time actually something to do with the progression of the illness, and how long has she really been displaying symptoms without you necessarily realising'"

Claire seemed to take comfort in the longstanding nature of her father's repetitiveness, equating this with the dementia remaining stable rather than deteriorating.

Claire: "my husband said when he met my dad twelve years ago he always used to repeat and tell the same stories, which I've never realised but on reflection he did, so you don't even know if it's been bubbling around in there from a long time ago, whereas I'd never see that cos that's just my dad"

2:1:6 Feeling unable to make sense

Some participants felt that living with the constant ambiguity and uncertainty that dementia brings made it difficult for them to make sense of their experiences. Both seemed to be looking to health professionals for answers, feeling despondent about the lack of clarity. Chantelle felt she had to live day by day as a result of uncertainty for the future.

Chantelle: “you find out that you’ve got something but nobody can give you a definite yes or no and that’s how I look at it, there’s no definite yes’s, there’s no definite no’s, it’s just a case of taking each day as it comes and if she’s alright it’s a bonus, and if she’s having a bad day you just get on with it”

Bill compared dementia with cancer and seemed to find the chronic nature of dementia too ambiguous, wanting clearer knowledge of his father’s prognosis.

Bill: “if a parent had cancer, then you could say ‘well yes my mothers got breast cancer, she’s having chemotherapy and the doctors have told us she’ll be alright’ or whatever, and you can actually say that is the diagnosis, whereas you can’t, it’s difficult to explain, it’s difficult to know what the outcome is really”

2:2 Making sense of one’s reactions to dementia

In addition to struggling to make sense of the nature of their parent’s dementia, some participants were also trying to understand why they were reacting in particular ways and trying to understand the nature of these reactions.

2:2:1 Considering developmental stage

KA and Claire reflected on their age as a factor in how they had responded to their parent’s dementia. Whilst KA felt that her experiences were difficult to cope with, she acknowledged that the situations and experiences she was facing during her twenties would have left her feeling less prepared.

KA : “I’m thirty-five, I own my own home, I have a good job, I have friends, my life is basically very stable and yet this has still been a big situation for me to deal with, if I was younger and maybe just coming out of university, just doing whatever I was doing in my early twenties and I had to deal with this stuff, then of course you’d deal with it but at the

same time would it change your life more, would it be more difficult to cope with if you were younger”

Similarly, Claire also seemed to be appreciative that this had occurred in her thirties rather than when she was younger.

Claire: “timing’s important and if I’d been at school or in my twenties it’d be different, whereas when I started to get concerned about my dad I was already married, looking forward to having a second baby so I’m quite settled myself, it’s not like I’m nineteen twenty or at school, I’m sure it would be completely different if you were at school and had a parent diagnosed with Alzheimer’s but I’m not at school I’m in a work place so I’m probably older for it to have a massive effect because I’ve got my own life”

Unlike KA however, she did not seem to find her situation difficult to cope with at present which may be a result of her additional role as a wife and mother, rather than solely a daughter.

2:2:2 Looking at others’ reactions

Bill seemed to be struggling with why he was experiencing distressing feelings. His father’s dementia was not openly discussed within his immediate family and he seemed to be looking at other family members’ reactions in order to validate his own distress. He seemed to take some comfort from his great uncle’s similar distress over the loss of a relationship with his father.

Bill: “we had a great uncle who died recently, he lived on his own and my dad was closest to him so he would always rely on my dad to go over and help out, and he realised quite late in the day what was going on and I think found it quite strange and difficult that his nephew who he used to take out on days trips as a little toddler, and he used to rely on, how he’s changed”

2:2:3 Feeling unable to react

The invisibility of his father’s difficulties also made it difficult for Bill to validate his feelings of distress.

Bill: “you always feel a bit phoney, you almost feel like you don’t really have the right to change your life too much and be too upset about it, because people can look at my dad, particularly if they don’t know him that well and say ‘well, there’s nothing wrong with him, he’s just a cheerful bloke cracking a few jokes”

I wondered if this was in part a result of his father having Pick’s Disease whereby the predominant personality changes could be rationalised as non-organic for much longer, making the boundary between health and illness blurred and less obvious to those outside of the family.

3: Managing change

Participants attempted to manage or cope with the changes they experienced in their families in various ways. They tended to either avoid and resist change or confront change head on.

3:1 Resisting family changes

All participants wanted to keep their circumstances as they had been prior to the onset of dementia at times. They attempted this by avoiding or resisting some of the changes that they faced as their parents’ impairments progressed.

3:1:1 Maintaining parental role

Some individuals tried to maintain the role that their parent had within the family. There seemed to be a need to keep the parent included in family events. Claire made an effort to maintain her father’s role as grandparent to her children.

Claire: “he’ll come to the pool, he can pick his two grandchildren out of forty children in a swimming pool which isn’t easy but my dad can work it out, he’ll come back here, have his tea, have a glass of beer, he’ll play with the children”

Chantelle seemed desperate to prevent her mother from deteriorating as she had seen with her grandfather previously. She tried to encourage her to stay positive and motivated.

Chantelle: “the kids keep her going so it’s not as if she’s going to dwindle away like my granddad did, and my dad and I keep telling her ‘yes, you’ve got a family who care about you, we aren’t going to let you sit in the chair and degenerate like my granddad did [tearful], we’re going to shout at you to get a move on, telling you you’ve got to get out of bed, get yourself motivated”

KA tried to increase her mother’s quality of life by ensuring that she felt included in family activities. Maintaining her ability to have a meaningful role was important to her.

KA: “we’re playing a game, she can’t really play the game anymore so we cheat massively and we arrange stuff so that we’re helping her, we were playing that Jenga game where you pull wood out and she was going to knock everything and James’s holding onto the whole base of the thing, and I’m holding onto the side while she pulls it out, cos she’s still having fun she’s still joining in and we’re still all doing something together, but we’re all massively cheating to make it not completely frustrating and a waste of time for her”

3:1:2 Maintaining level of contact

KA and Claire felt a pressure to increase their level of support and contact with their parents. Resisting this pressure by maintaining their usual level of contact was a way of resisting change within the family. KA seemed to feel some guilt about not increasing her contact with her mother. She viewed her mother as critical of her level of involvement. She attempted to resist these guilty feelings by asserting that she was not being neglectful of her mother.

KA: “I said to her that I might be coming up next weekend, she was like ‘oh that would be nice cos I haven’t seen you for ages’, at which point I did say ‘you saw me at the beginning of February’ which for us is not ages to see each other, once every month would be a lot”

Claire appeared to feel pressure to be more involved from her other parent. Like KA she also experienced this as a criticism, comparing her level of parental contact favourably to that of her friends.

Claire: “I think my mum is worried as to how he will turn out in that obviously she’s the main carer, and me and my sister we’ve got our own lives even though we’re only a couple of miles down the road, we’re a lot closer than a lot of other families, I have friends that

don't see their parents from one month to the next so she probably doesn't realise how close we are compared to other families"

3:1:3 Seeking out relational experiences

Many participants described how they purposely tried to involve their parent in various activities or day to day interactions in order to maintain a sense of a relationship with them. NS and Bill seemed to be going through the motions of relational experiences with their parent. NS seemed to think it was important to give her mother a sense of a parental role in her relationship with her daughter.

NS: "I still ask her 'oh does this look nice mum?', and totally disregard what she says but still ask her just so she feels as though...I could have the most horrendous outfit on and she'd still say 'oh it looks lovely'"

Bill's attempts to create father-son experiences seemed dissatisfying for him, though he appeared to have a sense of duty to continue these sorts of interactions.

Bill: "I've done things like go to the rugby with him and he enjoys that, but it's not really the sort of thing that you really, I wouldn't be able to do that with him being like he is, that said I should continue to make the effort cos I'm sure that it helps and it's good"

Chantelle appeared to feel pressured to create situations in which her mother could take part.

Chantelle: "other week I said to her 'oh we'll go swimming', I said to my dad 'hang on a minute, can I take my mum?', she can't swim, and I've got to think to myself 'well come on, you've got to think of something here', like going out in the car or walking on the canal, you've got to think of things"

KA seemed to feel guilty about the inability to be the daughter she felt her mother wanted. She was attempting to rectify this by altering her home and lifestyle in order to facilitate this sort of relational experience for her mother.

KA: "I think in her idea the perfect sort of family situation is where you all live near each other, have a big family, loads of grandchildren, big lunches where you sit round this big

table and somehow she's managed to have two kids that have completely failed to do that, I've got a dining room now, we can all sit down comfortably and it's better for me in terms of being able to spend more time with them"

I noted that Claire did not appear to be seeking out relational experiences with her father. I suspected this was a consequence of her father's ability to maintain his old way of relating to Claire, considering the early stage of his impairment.

3:1:4 Limiting family discussion

Talking about dementia seemed too painful for some families and these participants commented on how there was limited family discussion around dementia. Bill seemed to want to protect his mother from shame and embarrassment and so did not talk with his family about his father's impairments.

Bill: "my mum initially was ashamed of it I think she said so she wouldn't admit to people, I suppose there's not really open debate about it"

Chantelle described how she used her families coping style of avoidance. She seemed dissatisfied with this strategy for managing distress though felt unable to make changes.

Chantelle: "my brother's like me, he'll bottle things up and then like me, I'll just explode and everything will all come out at once and it's not good to be like that, but it's how I am, it's how I've always been, can't change how I am, can't change"

3:1:5 Avoiding information

Learning more about what the future may bring seemed too difficult for some participants. They avoided contact with health professionals and finding out more about their parent's prognosis. NS initially suggested that a support group may be helpful for her though later thought that she would not attend. She seemed to find the prospect of confronting others in a similar situation anxiety-provoking, possibly providing her with a view of her own future that she was not ready to face.

NS: "maybe if you talk to somebody who's in a similar position and if their parent is worse than what yours is, they might tell you something what you don't want to know, I might

think ‘oh that could happen, what if my mum did that?’, putting ideas into your head, and because my mum isn’t that bad at the minute knowing what she could be like off other people I think it would scare me a little bit more”

Bill was reluctant to expose his need for support and information. He seemed to realise that accessing this was within his control but was reluctant to do so.

Bill: “I’m sure that if I really wanted to accompany my parents to the appointments then no one would object to that so I suppose in a way it’s in my own hands, if I really wanted to find that out then I don’t think anyone would object, if I really wanted to seek it out I probably could get that support, if I looked really really hard out there, there might be some sort of resources that talk about what life is like if you have a parent with this problem”

3:1:6 Avoiding future planning

Confronting the future was anxiety-provoking for some participants and they avoided preparing for this. Chantelle used uncertainty about the future as a reason for avoiding planning.

Chantelle: “I’ve resigned myself to the fact that my mum’s not getting better, she is going to get worse, when that’s going to happen I don’t know, could be tomorrow could be next year, cross that bridge when we come to it”

Bill displaced the responsibility for initiating planning onto health professionals.

Bill: “what we’re going to do in ten years time, I suppose why dwell on that when you should just make every opportunity, cos at the end of the day we’re not being told at the moment there’s lots of forward planning to do”

Claire seemed to be trying to distance herself from anxiety about the future by avoiding planning.

Claire: “we’ll just have to cross that bridge when we come to it, touch wood we’ll be a long way off that but, obviously you don’t know what’s round the corner do you”

3:2 Confronting family changes

Most participants also attempted to confront changes within their family, however this was mainly limited to anticipating change in the future. Only KA and Claire appeared to be taking active steps to confront and manage change in the present. My sense was that this would have been too distressing for other participants, particularly Bill and Chantelle, who did not have the opportunity to discuss their experiences with anyone.

3:2:1 Anticipating loss of relationship

Chantelle and KA struggled with their expectation of the loss of a relationship with their parents. In particular, both identified the point when their mother would no longer recognise them as a key event.

Chantelle: “I know that day is going to come, and it’s a bit scary when you look at my mum and you think to yourself, ‘well is today going to be the day and I’m going to go out and come back and my mum maybe not know who I am’”

Like Chantelle, KA seemed to need her mother’s recognition in order to have some semblance of a relationship with her. KA also considered how her happiness over moving to a new house was tainted by the recognition that there would be an inevitable series of losses and distress within her new home in the future.

KA: “when we moved into this house I was completely not sad to leave and really happy to move here but the one thing before we left the flat, I thought ‘this house is the house that my mum is going to forget who I am in it’, and this is the one thing that I cannot say out loud”

3:2:2 Envisaging increased deterioration

Some participants were able to talk about their expectations of their parent deteriorating in the future. KA highlighted the time when her mother would no longer recognise her as a key event. She was able to think about this in some depth and it seemed that she needed to process the difficult feelings associated with her mother’s deteriorating. I felt that this was not only to cope with the loss of her mother but also as preparation for her own possible vulnerability to YOD in the future.

KA: “I imagine that by the time I’m forty, if it continues to progress at the rate it is now, that she will be at a point where she doesn’t know who I am, and that she doesn’t know who she is and that she will be functioning in a much more stimulus-based way”

Claire was clear about what she expected for the future.

Claire: “dad’s got Alzheimer’s and he’s going to get worse and we accept that and we can’t do anything else, we accept that he’s going to get worse”

Bill however was still reluctant to fully accept that his father would deteriorate.

Bill: “it sounds like there’s no real conclusive picture of what can happen, but it sounds as if there’s potential for things to have quite a rapid deterioration”

3:2:3 Expecting increased involvement

KA and Claire had begun to anticipate the increasing time and involvement that they would need to give their parent as they deteriorated.

Claire: “I might have to drop a day and I might have to do care on a particular day, so I may have to do say Monday to Wednesday and maybe do Thursday caring for dad”

Like Claire, KA also anticipated this would have an impact on her career.

KA: “we are going to get to the point, and by ‘we’ I mean me and the people I work with, as my mum’s illness gets worse they are going to need to know because I am going to have to take more time off”

3:2:4 Talking as a family

KA described how her family discussed the management of her mother’s distress and took a problem-solving approach to any dilemmas around her mother’s care.

KA: “it was my brothers birthday and she had bought him a birthday card, she wrote the first letter of ‘mum’ she wrote ‘m’ and then she got completely distracted and now because she was focusing on the fact that she couldn’t do it she started to get upset that she

couldn't do it and that's the moment when as a family we have to decide whether we discuss the fact that she couldn't do it or whether we should divert attention away from the fact that she can't do it"

3:2:5 Seeking information

Claire was the only participant who had actively sought information on dementia when her father began to present with some impairment. Knowing more about what she could expect from her father's condition seemed to enable Claire to prepare for the future.

Claire: "November it was diagnosed, but in the mean time me and my sister had been on the internet, cos neither of us are from a medical background, and done some research really around Alzheimer's, and we saw that there was the early onset of dementia which was classed in people in their sixties or below"

3:3 Managing change in self

In addition to managing change within the family in various ways, most participants reported using a range of strategies in order to manage the changes they experienced within themselves.

3:3:1 Using social support

The support of friends seemed especially important to some individuals. NS seemed comforted by her friend's admiration of her coping and valued their practical support in times of crisis.

NS: "I know they think 'god if that were happening to my mum, I wouldn't be able to do it', so it's opened their eyes and they do things, like my dad got taken into hospital a few weeks ago and my friends were like 'we'll go and sit with your mum while you do this', they're good"

Chantelle also valued having access to friends at difficult times.

Chantelle: "I've got people who I can talk to, they're really nice, I know if owt bad, there's somebody at the end of the phone if I need it which helps me a lot some days"

KA felt that her experiences had enabled her to develop a deeper relationship with friends coping with loss. She seemed to need to feel understood by her friends in order to share with them.

KA: “my best friend, her husband died, she didn’t want to articulate that kind of thing to people, but now my mum’s ill and I can talk to her about something from the same perspective, we’ve talked in much more detail”

3:3:2 Taking time out

Both participants who lived with their parents acknowledged the importance of having time outside of the family home. NS valued her father’s support in allowing her to take time out.

NS: “I can go to my friend’s house knowing that my mum’s at home with my dad, on an evening I can have a couple of hours out and then go back”

Chantelle also valued time for herself outside of the home.

Chantelle: “how I get away from it, go walking with my friend and that’s my way of getting away from it for a few hours, my way of chilling out for a few hours and then you go back home

I: And what does that give you?

Chantelle: Everything, I know it sounds awful but I feel as if a great big weight’s been lifted off my shoulders”

Claire also used a number of established ways of coping with day to day stresses. She did not see her father having dementia as unique in the stresses it created for her.

Claire: “life stresses include my dad, probably glass of wine, talking to my sister and my friends, going to the gym cos I can just switch off and my holidays, but I don’t see the coping strategy in relation to my dad and my mum any different from just life stresses really, cos it is hard”

3:3:3 Using medication

Chantelle noted that she finds antidepressant medication helpful for managing her distress and coping with care tasks. She seemed reluctant to disrupt the delicate equilibrium she had found by altering this way of coping.

Chantelle: “I’m on Amytriptyline, cos of my nerves and to help me sleep, if I weren’t on Amytriptyline I’d be terrible, I’d be shouting all the time, I’d be at my mum with her being like she is, if my mum hadn’t got Alzheimer’s fair enough I wouldn’t need them as much, I mean tablets aren’t the excuse, I’d like to think I wouldn’t go back on them but I’ve got health problems of my own and with my mum being like she is they do help, cos I’m not snapping at her all the time like I would be if I wasn’t taking them”

4: Experiencing change in self

Each participant’s account suggested that they had seen a change within themselves as a result of their parent having dementia. These changes either occurred internally (for example a change in self-perception) or externally (for example changing plans).

4:1 Changing self-perception

All participants reported a change in how they viewed themselves. Their parent’s dementia had resulted in new thoughts and feelings and re-evaluations of old ways of thinking and being.

4:1:1 Maturing prematurely

Four participants reported a sense of responsibility and premature maturation which felt uncomfortable for their age and stage of development. Bill reflected on how in his early twenties the support he expected from his father was unavailable resulting in him feeling alone with the decisions and responsibilities he encountered.

Bill: “I guess it was a bit sort of overwhelming cos he was always someone you could look to, when I first left university I was making decisions about what to do with my life, buying a new car, I could be fairly assured that he’d be a good sounding board and I’d sort of the realisation then that actually I’m to fend for myself”

NS reflects on how she has been forced to take life more seriously.

NS: “before, worst thought I could have is whether I’ve got enough money to go out with, whether I’ll be able to go out on Thursday as well as Saturday, where obviously my priorities have had to change, it’s probably opened my eyes to more things and make me grow up, I suppose I’ve had to grow up a little bit quicker than what I would have done”

Chantelle also found herself taking responsibility for her parents in a way she had never done previously.

Chantelle: “I know I don’t have to do it, nobody makes me do it but I think ‘well, thirty-seven, I’m old enough to go out and do stuff for my mum and dad now’, that I would never think...but now I’ve got to think well it’s quicker for me to go shopping sometimes than my dad”

Whilst KA acknowledges that she has maintained a lifestyle with relatively little responsibility compared with others of a similar age, she still seems to view her maturation as forced upon her.

KA: “it’s just been a very odd emotional turning point, I’ve had all the clichéd reactions of having to lose the Peter Pan complex that I’ve always had, behaving and feeling like a teenager that in some way this disease has now...I’m thirty-six this year I work in a creative job I don’t have any children of my own I don’t have any responsibilities really, it’s not the life that a lot of people lead”

I noted that Claire did not raise premature maturation as part of her experience. Claire was the only participant who was married with children and I felt that her completion of these developmental tasks (as raised by Claire under the theme ‘considering developmental stage’) may have accounted for this discrepancy in her experience.

4:1:2 Increasing empathy

Two participants reported that they had become more empathic with others in similar circumstances as a result of their experiences. NS seemed to feel particularly empathic towards others living with mental health difficulties.

NS: “I’ve become more sympathetic with people, I’ve always been quite soft but I think mental health problems, because they’re not physically ill, because you can’t see it, you just dismiss it a little bit, where I’m not like that any more, if I know there’s something wrong I can sympathise with them a little bit more because I’ve got to live with it”

Claire had been prompted to think about the range of people caring for parents in her workplace.

Claire: “it’s probably made me think in my work ‘my god there could be blokes as well as women that have got elder care issues or dependants on them who are older”

4:1:3 Increasing emotionality

KA reported feeling more emotionally labile and experiencing a range of emotions of which she was previously unaware. These uncharacteristic feelings seemed to surprise and interest her.

KA: “I have become much more emotional about things, stupid things make me cry, my friend says it’s like I’m pregnant the whole time, I’ve come out of the other end of that now but I was like that for a long time and it was a very strange experience, but it was also quite interesting, I almost felt like I should write a diary of what reactions I was having because it was really unusual to see myself behaving in this way”

KA also spoke repeatedly about how her emotional responses to her situation had varied greatly over time. There was an emphasis on the process she had worked through in order to adjust to the threat of losing her mother.

KA: “if you’d caught me a year ago I would have been in a different emotional place to where I am now, but because I’ve had such a long time I’ve already gone through a lot of different emotions to reach this point and I am in a position where I can talk about things, I think it’s just a question of time”

4:1:4 Considering own vulnerability

Some participants had considered whether they may develop dementia themselves at a younger age. Bill and KA also had a grandparent with dementia and the repetition of

illness through previous generations seemed to stimulate concerns which were not shared by participants whose grandparents did not have dementia. Bill was beginning to question whether he would develop dementia in the future.

Bill: “I suppose it’s making me aware that that sort of thing can happen, my grandmother had Alzheimer’s, my dad got this problem, and you supposedly think ‘well perhaps I might get it in years to come’”

KA had considered heritability in more detail and seemed to have begun preparing herself for this outcome. As a result she was beginning to feel some pressure to live life to the full.

KA: “faced with my own mortality you do go through all these horrible clichéd feelings of ‘oh no I’m going to die’, I cannot think about my own mortality it really scares me, it’s been a thing ever since I was a kid that the idea of being dead is ridiculous, all women go on forever in our family on my dad’s side and so I’ve always assumed that I would just go on forever, but of course my mum’s side of the family that’s not true, her mother didn’t, she isn’t so maybe actually I’m already more than halfway through my life and oh my God, what am I doing I should get on with it”

4:1:5 Re-evaluating life choices

KA was reviewing her earlier lifestyle decision to not have children. The threat of losing her mother seemed to stimulate feelings that she may be missing out on motherhood for herself and not be living life to the full.

KA: “I’ve never had any wish to have any children, once every couple of years I’ve thought ‘do I really want to have children’ and I always think ‘no I definitely don’t want them’, and then when my mother was diagnosed you start thinking ‘am I doing the right thing am I making the right decisions’, I’ve come out of the other side of this now as well but I did have probably about six months where I thought maybe I should be having kids”

As she talked further, it was clear that the heritability of young-onset dementia for herself and her future children were key features in her reflections.

KA: “should I have children because you think well A, do I want children and for them to see this happen to me and B, should I have children because if this is inherited should I pass it on”

4:1:6 Observing change in self

Some participants felt that they had seen clear changes within themselves. Claire noted her need to stay strong and how the onset of her father’s dementia had resulted in her taking on a coping role for the family.

Claire: “I think I’ve got to stay positive for my mum who is obviously a little bit wobbly at the minute, and my sister’s got the new baby and she’s had postnatal depression before, she needs to look after herself and get better herself in order to help with dad”

NS experienced herself as different outside the family home; returning to her ‘old self’ with peers. Initially I thought that her increased sense of responsibility and maturity was context-specific to some extent.

NS: “I can act how I want when I’m not at home, just as long as everything’s done and everything’s in place, once I go out I seem to forget about it all, I act as though I did when I was younger, cos I don’t have to worry about anything”

As she talked further however, I was also aware of the integration of her carer role into her self-concept.

NS: “you have got to do these things and I just get on with it, it’s become part and parcel that I do home and make tea and I do the shopping, it’s habitual now, just part of my life really”

KA was explicit about viewing herself differently as a result of these experiences.

KA: “that’s not to say that I haven’t really struggled with this and that it hasn’t fundamentally changed my life because it has, I am a different person, or I am a different version of myself because my mother has dementia”

I noted that Chantelle and Bill did not note any observed changes in self and this may be a result of them never having discussed their experiences with anyone in detail prior to the interview (this is discussed further in the section 'experience of the interview'). In contrast, the three participants observing changes in self had begun to process and understand these with other people before the interview.

4:2 Changing plans

All participants were reconsidering or had already made changes within their own lives in response to their parent's needs. NS and Chantelle had both put their plans to move out of their parent's home on hold.

Chantelle: "I'm still looking for somewhere to live, it's put a lot of things on hold, I will move out eventually it's just finding somewhere nearby, getting housing to find me something near so I can still get to my sister and my mum and dad if I need to"

They seemed to have made the decision to place their duty and sense of loyalty to their parents over their own desires for independence and pleasure.

NS: "I would probably have moved out, my intentions would probably have been to be moved in with my friends or have a place of my own, I wanted to go travelling but realistically I don't think I could leave for six months, she could deteriorate"

Bill was also considering how increasing the distance from his parents would impact upon them.

Bill: "we may well move to the other side of Leeds, which is obviously a bit further away from them and conscious that it's probably good for them to know that I am here, only five minutes drive"

Physical distance was also an issue for KA whose recent decision to buy a larger house was in part to accommodate her mother's changing needs.

KA: "we were looking for a house that was big enough so that we could have a separate guest bedroom that people could come and stay in, because I like seeing them and they have stayed at small hotels but my mum gets more nervous if a hotel doesn't quite feel"

**right or she's nervous of her surroundings, she finds that much more difficult to put to one side now than she used to so part of having a house is to make things more convenient cos
I don't live in the same place as them"**

Claire had begun to increase her time and contact with her father, giving up some of her leisure time in favour of parental care.

Claire: "I probably make more of an effort on a weekend when my mum's at work to spend time with him, just because I'm conscious what's he up to, so I'll often speak to my sister and say 'have you seen dad, what was dad like, are you seeing dad tomorrow', I'll give him a ring if mum's at work and I'll go round for a coffee"

She also planned to alter her work pattern in the near future.

Claire: "when my little boy goes to school in September I'm supposed to be going back five days but I'm not going to, I'm just going to do four days"

Experience of the interview

Within this section of the results I will present the various experiences that participants had of the interview process. Specifically, participants attempted to minimise their distress by adopting various strategies. They used the interview to process and reflect upon their experiences in various ways. Some participants also attempted to construct and maintain a positive sense of self in their narratives. An overview of the conceptual and sub-themes under the super-ordinate theme of 'Experience of the interview' are presented in Table 6 below:

Table 6 Levels of themes for Experience of the interview

5: Experience of the interview

5:1 Reducing distress
5:1:1 Looking for positives
5:1:2 Normalising
5:1:3 Minimising
5:1:4 Using humour

5:2 Reflecting and Processing
5:2:1 Talking for the first time
5:2:2 Reflecting on experiences
5:2:3 Using interview to therapeutic effect
5:2:4 Reaffirming shared narratives

5:3 Positive self-affirmation
5:3:1 Refuting negative feelings
5:3:2 Helping others

5:1 Reducing distress

Participants often appeared uncomfortable and at times were openly distressed when discussing difficult experiences. I was aware that throughout each account, various strategies were employed in order to reduce these distressing feelings. I attempted to understand these strategies through the psychodynamic concepts of defence and anxiety; as “devices adopted for avoiding mental pain, conflict or unacceptable feelings” (Malan, 2001, p16).

5:1:1 Looking for positives

All participants attempted to extract a silver lining from problematic or distressing experiences. NS justified her need to stay at home to care for her mother by commenting on the benefits of living there.

NS: “I will move out at some point but it’s convenient for me to live at home, I enjoy living at home, I’ve always got on well with my parents, there isn’t any reason for me to move out so it goes both ways really”

Chantelle compared her situation with that of other families to reassure herself that things could be worse.

Chantelle: “not everybody’s in a position like my mum where she’s got a loving caring family that need her, I know people that have got nobody so when you think about them and think across, I think to myself now ‘well you’re in a better situation, your mum’s in a better situation than a lot of people’”

KA focused on how the family spend more time together.

KA: “you just need to find a way to rearrange things to make the best of the situation you find yourself in, and so the good things that have come out of my mother being ill are we make more effort to see each other, when we see other we do more things”

Bill is comforted by the stability of his father’s impairment.

Bill: “we don’t think he’s really any worse now than what it was probably two years ago, so quite comforting that it doesn’t seem to be running away with itself”

Claire sees her father being alive as a positive.

Claire: “you’ve got to be positive haven’t you, and at the end of the day you could drop down dead tomorrow with a heart attack, well you could, then you’d be gone, so you’ve got to be positive haven’t you”

5:1:2 Normalising

There was an attempt to present unusual or distressing changes as ordinary or usual. Claire spoke of her father slowing down after early retirement as expected.

Claire: “ he probably retired a few years early and financially he could afford to do so that was fine, but then when he retired he seemed to slow down a lot as probably most people do”

Similarly, Bill spoke of how his father’s personality began to change after retirement. He explained this change to himself as his father having less stress to contend with.

Bill: “he retired and clearly if you don’t have the worry of work your outlook on life changes so it’s difficult to distinguish between just a change in outlook in life and things

starting, so he perhaps just reverted more to what he used to be in his youth which was a bit less serious and a bit more sense of humour”

However even when his father begins to struggle with organising himself he maintains that this is usual.

Bill: “my dad, he was just a bit different and sometimes a bit sort of scatty but that said, lots of people are sometimes a bit scatty”

Chantelle attempts to present the family conflict and her own feelings of distress as ordinary by suggesting that the positive appearance of other families must be a façade.

Chantelle: “people are out there and they’re saying ‘I don’t have arguments, I don’t shout, I don’t do this’ and I’m thinking to myself ‘well it’s a load of lies’, cos everybody shouts, everybody gets upset, everybody has things they have to worry about”

5:1:3 Minimising

After sharing details of their parents’ impairments, participants would often follow this with a statement which minimised the extent of their parents’ difficulties. After commenting on the deterioration she has noted in her mother, NS comforted herself by focusing on how things could be much worse.

NS: “she’s got worse since she first got diagnosed with it but, she can be left on her own you know, she’s not really bad, she’s not like the worst stage”

Chantelle minimised her mother’s increasing immobility though seemed unable to convince herself, ending her statement with a questioning “really?”

Chantelle: “she’s waiting for a stair lift to be put in so that will help her getting up and down, but she’s alright, my neighbour across road she knows how we all, what it’s like [laughing] so it’s you know, it’s not so bad...really?”

Claire considered her daughter’s concerns about her grandfather’s driving skills, then quickly maintained that there were no problems.

Claire: “she’ll say little things like ‘every Wednesday when grandpa picks me up, he pulls into the car park, and then he asks me which way to go out of the car park’ cos it is quite confusing the school that she’s at, and she’ll say ‘every week I tell him go back out the same way you came in grandpa’ but he’s absolutely fine to be dispatched to school to get her”

5:1:4 Using humour

Making jokes was another way to dissipate difficult feelings. KA shared the value of reflecting on her experiences, joking about the overwhelming and difficult nature of the process of reflection and readjustment that she has been through.

KA: “the good things to draw from it are that I do take a hard look at what I’m doing and what I think about things, children is another whole area [laughing], you don’t have enough tapes for this”

Claire joked about her own vulnerability to developing dementia.

Claire: “I’m thirty-five now so time’s ticking on for all of us isn’t it, [laughing] sometimes think I’ve got a bit of Alzheimer’s anyway”

NS responded to acknowledging the impact of her mother’s dementia on her friends by joking about memory loss. However the joking seemed to spark some feelings of guilt as she immediately counters her joke by minimising her mother’s impairment.

NS: “my old friends I suppose they have been affected as well, a shame my mum can’t remember any of their names [laughing], she’s got better though, she just gets two of them mixed up who are both blond, she amuses them”

5:2 Reflecting and processing

I asked participants how they had found being interviewed and through this it emerged that there had been a variety of responses, largely dependent upon the extent to which participants had started to process their experiences before the interview through talking with others or reflecting to themselves.

5:2:1 Talking for the first time

Two participants had not shared their experiences before with anyone. These individuals struggled to access thoughts and feelings and Chantelle was extremely distressed at times. Bill suggests that the experience of talking aloud is different to reflecting personally.

Bill: “I suppose they’re things I’ve thought about but never really talked about with people”

Chantelle seemed surprised at how she had survived the outward expression of difficult feelings.

Chantelle: “I’ve never gone to talk to anybody, so you’re the first person I’ve actually sat down with and talked about my granddad and my mum and my family and I’m alright, I admit I got upset but I’m alright”

5:2:2 Reflecting on experiences

Two participants used the interview to develop a new understanding of their experiences and to add to or change old narratives. As she discussed the early signs of her mother’s dementia, NS began to realise that the onset may have started earlier than she had always thought.

NS: “You know it probably even started then when I were doing A’ levels thinking about it, it probably stemmed from back then”

By the end of the interview NS began to acknowledge her lack of awareness of the true impact that her mother’s dementia had on her life.

NS: “it’s such a big part of my life in a sense, with me being the person who does just get on with things, it probably has a bigger impact than what I estimate, just on day to day life, but I probably don’t realize it because I’m used to it now, so I probably don’t realize the impact”

Bill reviews his response to his father’s dementia, using the interview as a catalyst for reflection and change in the future.

Bill: “it’s probably something that I ought to do, I suppose this process will focus my mind on that, I suppose in retrospect I’ve not dealt with things as well as I perhaps could have done in terms of being as open, talking about it to my parents”

5:2:3 Using interview to therapeutic effect

Three participants appeared to find talking about their experiences helpful and even therapeutic. In particular, having their stories witnessed seemed validating for them. Although KA had reflected considerably beforehand on her experiences, she acknowledged the therapeutic benefit of being listened to, likening it to her own work on a helpline.

KA: “I’ve never been in therapy, I’ve never had any kind of professional counselling but I think it is a useful thing for people, I’m the kind of person that this probably isn’t difficult for anyway and I’m used to being in situations where people tell me very personal things about themselves and that doesn’t make me feel uncomfortable, it feels like reverse Samaritans”

Chantelle reported some benefit from talking, appearing relieved and unburdened after sharing her experiences for the first time.

Chantelle: “being here today has helped, my mum said to me ‘when you go today, watch it might upset you’, I think she thinks that it’s going to be too much for me to come and sit here

I: And how has it been?

P: Alright, yes I’ve enjoyed it, I feel alright now I’ve talked to somebody”

5:2:4 Reaffirming shared narratives

Some participants used the interview to affirm their understanding of their situations and there appeared to be very little processing of their experiences in new ways. These participants had shared their feelings and experiences of having a parent with dementia many times before with family or friends and used the interview to tell an established story rather than developing or exploring their thoughts and feelings. Claire felt she had processed difficult feelings through talking with her sister.

Claire: “I’m quite happy to talk about it, I don’t get upset particularly because I think it’s all been said before between me and my sister”

KA also comments on the impact of previous talking and thinking on her emotional response to the interview.

KA: “because this area is something I’ve had to actively look at and work through, I find it easier to talk about because I’ve already gone through a big process that’s taken a long time and a lot of energy”

5:3 Positive self-affirmation

Two participants attempted to preserve a sense of a positive, socially acceptable identity which seemed threatened by having a parent with dementia. Specifically, participants attempted to negate the presence of negative feelings around (and possibly towards) their parent. One participant also presented herself as altruistic in her motivation to take part in the interview.

5:3:1 Refuting negative feelings

There were times when participants attempted to distance themselves from difficult feelings they had raised. Both participants who refuted negative feelings in this way did so after speaking about shame and embarrassment. Refusing to accept or acknowledge the presence of these feelings either within themselves or others around them seemed to be a way of re-affirming and maintaining a sense of self that was morally acceptable in their own and other’s eyes.

Chantelle repeated emphatically that she was not ashamed of her mother, though she seemed uncomfortable with the idea of being seen with her in public.

Chantelle: “I don’t mind at all, I’ve got no secrets, I’m not ashamed you know, I’m not ashamed of my mum, go out with her even, if it’s just a little walk on the canal, if my dad’s not up to it I take her”

NS commented that she is not embarrassed when new people meet her mother for the first time.

NS: “boyfriend wise, maybe I’m a bit more dubious to bring them home to meet my mum, not for the fact that I’m embarrassed or ashamed, I don’t want to confuse my mum”

5:3:2 Helping others

Chantelle felt it was important to take part in the study in order to aid those in a similar situation to herself and her family.

Chantelle: “I said to my mum ‘if it’s going to help somebody, people like my mum I don’t mind’ [laughing]...I don’t mind at all”

At the end of the interview Chantelle offered advice to others struggling with a parent with dementia.

I: “is there anything else that you think is important to say as part of your experience that you feel we’ve not touched on?”

Chantelle: don’t give up on a person if they’ve got dementia, accept them for what they are and what they can do that’s all I can ask, it does change your life, your whole life, and when it does happen it’s difficult, but you’ve got a person you love, and who you have loved, and you’ve got to get them through the bad days and the good days, just don’t give up”

CHAPTER IV – DISCUSSION

Within this chapter I will revisit my research findings in more detail, considering these in light of my initial research questions, the literature I presented within the introduction chapter and novel areas of relevant literature. I will then reflect upon the quality of the research process in terms of my questions, design and data collection and analytic procedure. I will consider the clinical implications of the study and potential areas for further research, concluding with my own reflections on the research process.

Revisiting the research questions

Within the present study five young adults were interviewed about their experiences of having a parent with YOD. These interviews were then analysed using IPA (Smith, 1995) and a collective list of sub-themes, conceptual themes and four super-ordinate themes emerged.

The original research questions I posed were designed to explore participants' individual experiences of having a parent with YOD during the developmental stage of young adulthood. I was firstly interested in their experience of becoming more independent and differentiating from their family of origin; how they were developing their own sense of identity in view of their circumstances; their experience of forming relationships with people outside of the family, whether friendships, working or partner relationships.

The second main question was about exploring participants' individual experience of changes within their family of origin. In particular, I wanted to understand young adults experience of family roles in view of their parent's dementia; their experience of relationships with members of their family of origin. I will take each of these two questions in turn and explore how each of them and their various parts have been answered in light of the research findings.

An overview of the findings

With regard to their experience of the developmental tasks of young adulthood in view of parental YOD, a number of themes emerged suggesting that the developmental tasks outlined in the first research question had been experienced differently from their expectations as a consequence of their parent's dementia.

Becoming more independent

This developmental task refers to differentiating from the family of origin and living autonomously of one's parents. All participants had experienced a change in their plans (whether work, geographical location or moving out of the parental home). These changes were generally experienced as limiting participants' ability to live independently of their parents. For some participants these limitations represented a regression from a previously achieved state of differentiation from the family (for example KA's increasing family contact during work hours and Bill's deliberation around whether to move further away from his parents), whilst for others this developmental task had yet to be achieved (for example NS's inability to move out of the parental home).

Developing a sense of identity

This task is about creating a self-concept and identity based on one's experiences. All participants experienced a change in self-perception as a result of having a parent with YOD. These changes were again largely experienced as negative except for the themes of increasing empathy and re-evaluating life choices. Whilst these themes were not viewed explicitly as positive experiences by participants, they did seem to indicate that these participants had grown and reflected in a helpful way as a result of their experiences. The other changes in self (maturing prematurely, increasing emotionality, considering own vulnerability, observing change in self) were presented by participants as unhelpful and often forced upon them unexpectedly. There was also evidence that NS had begun to incorporate her role as a carer for her mother within her self-concept.

Relationships with people outside of the family

This developmental task is about establishing and maintaining effective peer relationships as opposed to relationships within the family of origin. Some participants did report experiencing their peers differently (feeling different, feeling jealous, uncertainty within relationships) and changes in these relationships were considered unhelpful. All participants seemed to maintain their prior social network in spite of their parent's diagnosis and some participants used peer social support as a way of managing the changes they had experienced.

The second research question is about the young adult's experience of changes within their family of origin. All participants identified changes within their parent and other parent relationships and some within their sibling relationships.

Experience of family roles

There appeared to be some changes within the organisation and redistribution of responsibilities and tasks with the family of origin. Many participants reported taking over aspects of the role that their parent with YOD was no longer able to fulfil for the family. For some this involved taking on physical tasks (such as housework or managing finances) or adopting some of the character traits of their parent (such as peace maker, decision maker, remaining strong for the family). Participants also noted a direct reversal of parent-child roles with their parent with dementia, a change they considered as negative and at times distressing.

In relation to their other parent, some participants reported compensating for their parent with dementia by looking to their other parent to fulfil the missed relational experiences.

Experience of relationships with family members

There were positive and negative changes in the way participants related to their family members. In general the relationship with their parent was perceived to have suffered as a consequence of their diagnosis. Participants reported feeling unable to maintain the relationships they had previously, through their parent becoming unreliable, feeling frustrated with their impairments or having to look after their parent rather than receiving any care. There was a sense of a lost relationship and a view that this could only continue to worsen in the future. Only NS reported growing closer to her mother since the onset of dementia.

Relationships with the other parent were also experienced differently though generally they were seen as changing in a positive way. There seemed to be a need and desire to maintain a good relationship (and working partnership of care provision for NS and Chantelle). This need to relate to the other parent was exacerbated by an apparent fear of losing the other parent to ill health or death. As a result, participants tried to take care of their other parent and pursued a closer relationship with them.

With regard to siblings, only the two participants living within the parental home described a change in sibling relationships. These changes were perceived negatively and

the consensus seemed to be that there was a discrepancy between the amount of contact and care provided by various siblings with the participants feeling both unsupported by their siblings and jealous of their freedom.

Other aspects of the research findings

There also appeared to be various factors which added to the different experiences reported by some participants. Whilst these remain tentative in view of the small sample, the factors I considered as potentially relevant in moderating participants' experience, appraisal and ability to cope with their parent's illness were the following:

Specific diagnosis

The majority of parents had AD whilst Bill's father had Pick's Disease. The focus of early personality change in Pick's Disease seemed to create a different experience of dementia for Bill compared with other participants. In particular the invisibility of symptoms to others outside the family and the ambiguity around whether early symptoms were organic in aetiology or merely fluctuations in mood seemed to make Bill struggle to know how to respond or judge whether or not he should feel worried or distressed.

Duration of onset prior to diagnosis

Whilst some parents (such as KA's mother) received a diagnosis relatively quickly, others (such as Bill's father) had to wait several years before a label for their day to day difficulties was given. This considerable period without guidance or certainty also seemed to be a factor in Bill's ability to make sense of and process some of his experiences and feelings. Bill also noted that his father's diagnosis spurred the family into action and confrontation where as prior to this the family had been increasingly avoidant and ashamed of the changes they were experiencing.

Length of onset

Similarly to the duration of onset prior to diagnosis, the length of onset of change in their parent seemed to relate to the degree to which young adults needed to provide practical support for their parents. All participants noted how the deterioration in their parent over

time created increasing distress, novel challenges and a loss of their relationship with their parent.

Age

Older participants (such as KA and Claire) seemed to be able to reflect upon and understand changes and to cope more effectively with their situation. KA and Claire also reflected themselves that had they been in their twenties when their parent developed dementia, this would have affected their lives and sense of self more radically.

Parent and child gender congruence

When participant and parent genders were congruent, this seemed to impact on the nature of the changes they experienced in their relationships. Claire was the only participant whose gender was not the same as that of her parent with dementia. Like all participants, Claire had taken on aspects of her parent's role for the family (such as remaining strong and making decisions). In contrast to all other participants however, Claire reported that there had been a negative impact on her relationship with her mother as a result of her father's dementia. It seemed that Claire felt frustrated and resentful at having to take over a parental role which could equally have been fulfilled by her mother. It may be that other participants did not feel this sense of resentment as there was no-one else within the family available to fulfil this gender role except themselves or same-sex siblings. In support of this argument, it is noteworthy that when same-sex siblings were present (for example NS and Chantelle had a sister), feelings of jealousy and resentment were noted within these sibling relationships.

Once the analysis was complete, I carried out a new search for literature to bring my understanding of the parental chronic illness literature up to date. The strategies used to search for all literature are shown in Appendix 6. I also explored new areas of seemingly relevant literature in light of emergent themes. The links with the literature are now discussed for each of the super-ordinate themes.

Experiencing a change in relationships

Participants experience a range of both positive and negative effects on their relationship with their parent, other parent, siblings and peers. Most reported some feelings

of frustration with their parent in particular in relation to memory lapses. Memory related problems such as forgetting and repeating questions are reportedly difficult and cause stress within the general dementia carer literature (Teri, Truax, Logsdon, Uomoto, Zarit & Vitaliano, 1992).

There was also a sense of reversing roles with parents for some participants, particularly when living at home. Dellmann-Jenkins et al (2001) also noted a reversal of roles with older family members. Similar to the current study, role reversal was particularly prevalent when participants were involved in care tasks (like Chantelle or NS). However it also seemed to occur in the present study when participants lived far away from the parental home (i.e. KA) and were involved mainly in decision making for their parent rather than physical care. Dellmann-Jenkins et al (2001) also reported young adults having a sense of filial duty to reciprocate care. I found this though a sense of duty also seemed to emerge in relation to the other parent as well as the parent with dementia. Zarit and Edwards (1999) note that feelings of duty and indebtedness can create guilt and frustration in adult child caregivers.

In relation to reversing roles, participants were also unable to rely on their parent which Carter and McGoldrick (1989) assert is still an important need for young adults in the family. Nemiroff and Colarusso (1985) also note that taking on parental roles is a typically middle age task, rather than one associated with young adulthood which in turn suggests the presence of a role reversal is 'off-time' for participants.

When looking at adolescent experiences of parental HIV/ AIDS, Woodring et al (2005) also found that this group felt unable to rely on their parent suggesting that this is not just a feature of adolescence, occurring when offspring are reliant on parents for survival (i.e. managing the family home and finances) but can also occur long after leaving home and in relation to the other parent too.

With regard to sibling and peer relationships, Zarit and Edwards (1999) suggest that daughters are more at risk of burden than sons due to the role they assume within the family. It is difficult to ascertain whether daughters were at greater risk than sons within the present study due to the limited number of male participants, though daughters did seem to have taken on more active roles in comparison with their male siblings. In relation to this, Pederson and Reverson (2005) note that in more traditional families, maternal illness results in the offspring assuming household roles whereas paternal ill health results in responsibility for economic solvency. My results are consistent with this, particularly if there was gender congruence between parent and participant.

Chantelle and NS reported negative changes in their sibling relationships, particularly with sisters, which concurs with Zarit and Edwards (1999) finding that individuals with siblings will feel more abandoned and have a greater negative reaction to caring compared with only children. Suitor and Pillmer (1993) found that daughters are more likely to experience conflict with their sisters than their brothers.

NS and KA also reported some problems in peer relationships. Dellmann-Jenkins et al (2001) assert that young adults need to differentiate from the family of origin before the focus can be turned to developing and maintaining effective peer relationships in adulthood. NS was still living at home and so had not yet fully differentiated from her family of origin which is in keeping with Dellmann-Jenkins et al's (2001) assertions. However KA had moved out of the parental home, differentiated from her family and established peer relationships many years prior to the onset of her mother's dementia, yet still struggled to maintain relationships with her partner and work colleagues suggesting that parental YOD can disrupt or reverse some previously achieved developmental tasks.

The themes of losing parent gradually and anticipating future deterioration were particularly relevant to KA and Chantelle. The idea of their parent's loss of personhood featured heavily and that when their parent no longer recognised them, this would be a key moment in a series of losses, altering their relationship further. These themes relate to the idea of social death (Sweeting & Gilhooly, 1997). Sweeting and Gilhooly (1997) have looked at the phenomenon of social death (perceived death of a person prior to their actual biological death) and dementia in older people. They suggest that the lengthy, inevitable deterioration and loss of personhood in dementia create a state of 'death in life' for family members.

The progressive series of losses also relates to the work of Boss (2001) and Boss, Caron and Horbal (1988) who suggest that as the dementia sufferer deteriorates, there is increasing ambiguity about family roles and boundaries. Boss (2001) terms this 'boundary ambiguity' and essentially this occurs where a family member is physically present but becomes psychologically absent. Boundary ambiguity is suggested to be a cause of stress and dysfunction within the family rather than the illness itself as the family member gradually becomes less emotionally involved with the carer. Boss et al (1988) found that family stress is at its highest each time a new loss occurs (for example after the family member begins to wander or no longer recognises the carer) as the grieving process is reactivated. KA in particular envisaged increased deterioration and the gradual loss of her mother in the future, pointing out how new losses create a new start to the grieving process.

Boss et al (1988) suggest that adaptation to ambiguous loss in dementia is dependent on a number of factors, namely gender (females use more passive, ineffective coping strategies than males), the family values/ belief system (rigidly perceiving the world with fatalism, passivity, acceptance and fixed rules versus mastery, control, action and flexibility to change results in poorer coping) and current developmental tasks (dementia hinders a family's developmental transitions resulting in increased stress).

Understanding change

The extent to which participants had begun to make sense of their experiences for themselves prior to the interview appeared to relate to their previous opportunities to process, think and talk about their parent's illness. Consequently Bill and Chantelle struggled with understanding the changes they experienced.

Bill in particular was struck by feeling unable to react and make sense and for him this seemed partly related to his father's diagnosis of Pick's Disease which resulted primarily in personality changes. Bill's experience of feeling "phoney" when distressed about his father's dementia relates to Doka's (2005) concept of 'disenfranchised grief'. Doka (2005) says "disenfranchised grief refers to losses that are not appreciated by others. In effect the individual has no perceived 'right' to mourn" (Doka, 2005, p5).

Chantelle seemed unable to begin to make sense of her mother's AD except to compare the changes with those experiences in her past when her grandfather had dementia. The unresolved grief seemed to keep her reliving her past experiences, unable to move forward in processing, understanding and responding to the present changes around her. Chantelle's experiences are supported by a literature suggesting that previous losses, death or otherwise, can complicate current grieving (Rein, 2006).

A less well researched area of the impact of caring is that of carer gain and satisfaction (Kramer, 1997). Many individuals report positive growth following adversity which is related to a range of individual differences (Linley & Joseph, 2004). Nolan, Grant and Keady (1996) propose that the overarching themes of carer satisfaction are reciprocity and establishing meaning. The care receiver needs to be seen as a valued person and able to contribute something worthwhile to the relationship. This links with Equity Theory (Thibaut & Kelley, 1959) and the Congruence model of Caregiver and Receiver Interactions (Kahana & Young, 1990) suggesting that strain in a relationship results from either party contributing too much or too little. Gains in relationships with both parents were reported by some participants. The theme of maintaining parental role can be linked with the notion

of maintaining an equitable relationship and participants (such as Claire and KA) seemed to derive satisfaction from times when they were able to maintain their parent's role in the family.

NS reported new experiences and emotions in her relationship with her mother which had enabled them to grow closer. Nolan et al. (1996) suggest that if caring is seen as a positive experience, then it must have some element of meaning to it and that caring gives the carer opportunities to find meaning in creative ways (such as through learning new skills), experimental ways (discovering new relationships and emotions) and by changing attitudes and beliefs systems. Similarly, Antonovsky's (1987) work suggests that in non normative circumstances, people try to make sense of situations as meaning increases the sense of coherence and manageability of difficult experiences.

Managing change

There is an ample literature on coping styles and strategies within the dementia care literature for older people (Kneebone and Martin, 2003). Lazarus and Folkman (1984) categorise coping strategies into problem-focused ones which attempt to solve difficulties (such as generating solutions, considering the best solution and taking action) and emotion-focused types which are aimed at reducing distress (such as avoidance, minimising difficulties and passivity). Kneebone and Martin (2003) found that emotion-focused coping is more often associated with carer burden and this is particularly relevant to younger carers as problem focused coping is dependent on having the internal and external resources which emerge through relevant life experiences.

This fits with the current research findings in that KA and Claire were the only participants to demonstrate more problem-focused and less avoidant coping styles and seemingly they were less distressed about their experiences. They were also two of the older participants in the sample which may have equipped them with the resources suggested by Kneebone and Martin (2003).

In addition, KA used a problem-solving approach in order to manage the meaning of difficult family situation by re-labelling problems as learning experiences (seen in the theme of talking as a family). Pederson and Reverson (2005) also found that open dialogue decreases the perceived threat to family development and stability.

Pederson and Reverson (2005) also commented that illnesses with a slow deterioration resulted in increased coping as individuals had time to prepare for the future. Whilst some participants did report feeling comforted by the slow deterioration

of their parent, they did not appear to be planning for their futures. Appreciating slow deterioration seemed to be an attempt to hold onto their parent and avoid confronting their deterioration instead.

Experiencing change in self

Participants' experienced a range of changes in self, though the number and extent of these changes appeared to relate to the extent to which they had developed an established sense of identity and their opportunity and ability to actively process their experiences.

Established identity and self-concept

It seemed apparent from my perspective as a researcher that all participants' experienced changes in self however changes tended to be observed and reported by only some of the participants with those who had completed a greater number of developmental tasks generally reporting more changes. Participants' completion of these markers at the onset of their parent's dementia is shown in Table 7 below.

Table 7 Participants' completion of the developmental markers of young adulthood at onset of YOD (developmental marker taken from Shanahan et al., 2005)

MARKER	NS	CHANTELLE	BILL	KA	CLAIRE
Completed schooling	×	✓	✓	✓	✓
Leaving home	×	×	×	✓	✓
Beginning career	×	✓	✓	✓	✓
Marrying	×	×	×	×	✓
Becoming a parent	×	×	×	×	✓

The completion of the developmental tasks of young adulthood is associated with a more established sense of identity and self-concept (Erikson, 1959). Consequently, those participants who had a less established sense of adult identity (such as NS, Chantelle and Bill) may simply have incorporated changes as a result of their parent's dementia within their developing self-concept. In contrast, KA and Claire may have found the changes they

experienced to clash with their established identity and self-concept in a more obvious, notable way.

This line of argument is supported by the finding that participants who had completed fewer developmental tasks at the onset of YOD also appeared more distressed and overwhelmed by the changes that confronted them. These findings concur with the literature on self-loss and role engulfment (Skaff & Pearlin, 1992) stating that younger caregivers will experience the greatest loss of self-concept and change to identity as they will have a larger number of priorities (or developmental opportunities) competing with their caregiving role. NS did describe a larger number of observed changes in self-perception compared with other participants and seemed have integrated her caring role into her self-concept. In relation to this, KA and Claire also commented on the impact of their completion of developmental tasks when making sense of their ability to cope with their parent's dementia.

Processing experiences

Bill and Chantelle noted fewer experiences of change in self compared with other participants and this could also be related to their lack of opportunity to process their experiences. Acknowledging and noticing a change in self appeared to be the last stage in a process which began with experiencing a change in relationships, trying to understand these changes and then managing these changes in various ways. This process of change and adaptation has parallels with the Assimilation Model (Stiles, Elliott, Llewelyn, Firth-Cozens, Margison, Shapiro & Hardy, 1990). This is a model of therapeutic change in psychotherapy, describing a common sequence of stages that clients go through in therapy in order to integrate and assimilate difficult or traumatic experience. Stiles (2001) suggests that individuals "follow a regular developmental sequence of recognising, reformulating, understanding, and eventually resolving problematic experiences" (Stiles, 2001, p462).

Using this model, Bill and Chantelle appear to be in the process of recognising and reformulating their experiences, NS has begun to understand her position, whilst KA and Claire have continued to understand and are now beginning the resolution of problematic experiences by confronting changes in the present. These individual differences in processing and adaptation appear to have some correlation with the completed markers of young adulthood at the time of onset of parental YOD shown in Table 7. Participants who had completed a greater number of markers seemed to adapt and process their experiences

more effectively which also links to Kneebone and Martin's (2003) suggestion that relevant life experiences equip family carers with the resources to cope with carer burden.

Other changes within self can be related to the literature. Dellmann-Jenkins et al. (2001) found that young adult caregivers within their study developed increased empathy for the elderly. NS and Claire also found that their increase in empathy towards others caring was a notable change.

The experience of maturing prematurely is similar to Neugarten's (1979) suggestion of 'off-time' changes in response to difficult, idiosyncratic life events. This theme was largely about feeling a premature sense of responsibility for others and oneself, indicating the 'off-time' aspect of change in this theme related to a change in self rather than perceiving their parent's dementia as 'off-time'.

Experience of the interview

During the interview, some participants appeared to process and reflect upon their experiences enabling them to update their stories and gain a new perspective through talking. At other times participants attempted to maintain a positive view of themselves and there were also occasions where participants minimised feelings of distress and anxiety by using a variety of defences.

There is a precedent for using a psychodynamic understanding of participants' behaviour in qualitative analysis within Holloway and Jefferson's (2000) idea of the defended subject. Boothe, von Wyl and Wepfer's (1999) presentation of 'the psychosocial functions of everyday narratives' also gives a psychodynamic perspective on how individuals use defensive strategies in conversations. Boothe et al. (1999) state that individuals use everyday narratives for a variety of means. These include social integration and coping with anxiety. 'Social integration' is described as "as attempt to integrate oneself into the social community, by both demonstrating personal identity and receiving personal confirmation" (Boothe et al., 1999, p261).

This is relevant to the theme of positive self-affirmation as some participants seemed to be trying to reaffirm to themselves and others that they were doing a good job of caring for their parents. Chantelle used the interview in this way within the sub-theme of helping others. Refuting the difficult feelings of shame and embarrassment was another way which enabled Chantelle and NS to maintain a sense of themselves that was comfortable as opposed to acknowledging any negative reactions towards their parent. Similarly KA and Claire seemed to need to maintain that they were not being neglectful of their parents by

refuting any suggestions that they did not have enough contact with their parents in the sub-theme of maintaining level of contact.

With regard to coping with anxiety, participants used a variety of defences (namely minimising, normalising, focusing on positives and using humour) in order to reduce feelings of distress during the interview. These seemed to be an attempt to lessen their distress about changes in their parent as a result of dementia.

Reviewing the research process

Within this section I will consider the strengths and limitations of the study at various points during the research process.

Methodological issues

With regard to sample size Smith and Osborn (2003) suggest that five or six interviews is adequate for doctoral level research projects using IPA. However, my sense was that even one or two more participants would have helped to corroborate the more subtle nuances and tentative ideas within some accounts which I did not feel could be included in the final list of group themes. Such ideas included participants' use of family stories or scripts as influencing beliefs about health and illness, their experience of the diagnostic process and their experience of the marginalisation of dementia within society.

The transferability of the findings should also be considered. Firstly, my sample was collected from one research site and it may be that other services for YPWD provide a different model of care, creating a significantly different experience of the support available for them. For example, some participants had sporadic, informal contact with Leeds YPWD Team whilst the rest had no contact with the service. There were no support systems or interventions in place specifically for them. The variation in service contact within different services may impact upon participants' ability to adjust to and make sense of the changes within their families. I was also aware that all participants had parents living at home which did not allow me to capture the experience of having a parent residing within specialist inpatient or residential care services. This may also have meant that young people with a parent with more severe dementia were absent from the study. Another possible limitation was that all participants were White British. This may be important considering the cultural variability in approaches to informal family care and family structure (Daker-White, Beattie, Gilliard & Means, 2002).

The heterogeneity of the sample may also have been problematic as the age of individuals participating ranged from 23 to 37. Whilst this is justifiable as a developmental period of young adulthood within the literature (Shaie & Willis, 1996), my reaction was that older participants (such as KA and Claire) differed significantly from younger participants in terms of their coping strategies and the cumulative impact that parental YOD was having upon their sense of identity development. It may be that younger participants were at an earlier sub-stage of young adulthood as described by Levinson (1986). This heterogeneity may have impacted on the development of joint themes during the analysis and resulted in super-ordinate theme labels which could be seen as too general and removed from the sense of lived experience which IPA attempts to capture. This was an exploratory study however, and the large age range of the sample allowed for an array of experiences to emerge which can be further explored in future research and also highlighted common elements within the experience of parental young-onset dementia. I also felt that the exploratory nature of the study made exclusion of certain participants difficult to justify ethically.

My sample was also self-selecting and I was aware from informal feedback through LYPD Team that some offspring had decided not to take part due to the distress they anticipated from such an interview. Consequently, it may be that participants were less distressed than would be expected within this population generally. I also noted that all of the parents of the participants were in contact with one particular health professional that talked with parents and reassured them about the research. My sense was that this professional's support of the research influenced parents' subsequent support and encouragement of their children to participate in the study. As a result, it may be that the parents of participants felt particularly supported by and connected to the service, which may not be the experience of other families using the service.

All participants had also chosen to provide some level of regular support or care for their parent and to adapt their own lives in response to parental need. All participants seemed to have a sense of duty to care and I wondered if duty also influenced their decision to participate in the study, exemplified in the 'helping others' theme as a function of the interview for Chantelle. However, there will also be some sons and daughters who do not choose to be involved in their parent's care and these individuals are absent from the sample. A strength of the sample however is that they did represent some variation in socio-economic backgrounds, levels of contact with parents and care duties undertaken.

With regard to the study design, I chose to complete one interview with each participant. With hindsight, a second interview may have been useful as I did not anticipate that some participants (i.e. Bill and Chantelle) would be talking for the first time. A second

interview would have given them time to reflect upon and process their experiences further. Claire's father had very recently received his diagnosis of AD and I also wondered if a second interview would have highlighted any changes in her experiences over time.

In relation to this latter point, I was aware within the analysis that Claire's anticipation of a negative future accounted for many of the instances within the confronting change theme. It may be that Claire's anticipation of the future was more a reflection of her adjustment to the new diagnosis rather than the longer term experience of living with a parent with YOD. Although her father had exhibited deterioration in his day to day abilities for five years prior to diagnosis, a diagnostic label appeared to be a catalyst for reflection and confronting family changes for other families such as Bill's. Consequently, it may be that the inclusion criteria of three months post-diagnosis was too early to capture a picture of long term experiences. Claire's negative view of the future also refutes Grimshaw's (1991) finding that adolescents of parents with Parkinson's Disease gave relatively positive accounts of the impact of parental illness prospectively compared with other studies focusing on present experiences. This discrepancy with Grimshaw's (1991) findings also supports the possibility of other factors (such as recent diagnosis) contributing towards Claire's negative view of the future.

Quality control issues

Whilst I remain relatively inexperienced at utilising qualitative approaches in research, I feel my interview technique and grasp of the IPA method developed markedly during the research process. In particular, during the interviews I was reluctant to explore or comment on any of the strategies participants used to minimise distress. I was unclear how to follow-up on these within my role as an interviewer even though my clinical experience led me to understand participants' experiences in this way. Consequently, it seemed important to follow-up on these observations within the analysis, acknowledging explicitly that the interview process (my questions for the participant and the dynamic interaction between us) in itself may have added to or shaped a participant's understanding, processing and presentation of the experience (Rapley, 2001).

One quality check that I was aware of omitting was testimonial validity (Stiles, 1993). I primarily decided against this quality check as the nature of IPA is that ultimately the themes produced will always be the researcher's interpretation of participants' experiences. After completing the analysis, I also felt that the inclusion of defensive

strategies may not have been acknowledged by participants and may even have distressed them if I had utilised this form of quality check.

Another important aspect of quality checking is revisiting the initial assumptions outlined within the methodology chapter. These are important in order to consider the impact I personally may have had in shaping the research findings. I expected participants to share largely negative experience though I found that they also shared a small number of positive outcomes too. Most experiences were negative however and it may be that I focused on the themes in this way during the analysis or my framing of questions and possible presentation during the interviews spurred participants into giving me socially desirable, negative experiences.

Similarly, I expected participants to report that having a parent with dementia affected a variety of relationships and my interview schedule focused on this, which possibly limited the opportunity for participants to refute this assumption and present a more positive discourse about relationships.

To assist with quality checking I also referred to the guidelines suggested by Elliott et al (1999). I felt this to be particularly important considering my lack of experience with the qualitative methodology and general research process. I am aware that there is some controversy about Elliott et al's (1999) proposals and they are seen by some within the field to create "methodolatry" (Reicher, 2000, p1) and a narrowing and restriction on creativity within qualitative enquiry (Reicher, 2000). I selected Elliott et al's (1999) guidelines over others as they gave a clear outline of the considerations needed and also encompassed aspects of other prominent guidelines (e.g. Stiles, 1993). I have attempted to check each marker of quality at various points through out the research process:

1. *Owning one's perspective* – I have attempted to acknowledge my biases, assumptions and expectations prior to beginning the study and then have returned to these later, reflecting on their impact on the research findings. I recognise that acknowledging one's perspective may be limited when one considered that the researcher may too be defended against some of their own biases and assumptions
2. *Situating the sample* – I have attempted to give a detailed portrait of each participant, their current life and background in order to assist the reader's understanding of my interpretations and themes
3. *Grounding in examples* – I used direct quotations to support my interpretations and themes to provide the reader with the essence of each participant's account

4. *Providing credibility checks* – I used the peer auditing and debriefing systems available to me as well as extensive notes and memos. I also looked for negative cases to assist me in the iterative analytic process
5. *Coherence* – I have attempted to present an overview of the structure of the themes before describing these in more detail, providing an explanatory account of individual participant's experience within this overarching framework of themes
6. *Accomplishing general versus specific research tasks* – I have acknowledged the limitations on generalisability of the sample to other populations as part of my presentation of the general understanding of the phenomenon. I have tried to balance my discussion of the general conclusions about my findings with a more in-depth presentation and understanding of the individual experience of parental YOD for each participant as well as considering clinical and research implications and recommendations.
7. *Resonating with readers* – although I have attempted to communicate the essence of each participant's experience within this document, the ultimate decision as to whether the account resonates rests with the reader.

Clinical implications

It is clear from the data that individuals were greatly affected in numerous ways by having a parent with YOD and they had thought about their experiences. Some participants were struggling to cope with their situation more than others (in particular Bill, NS and Chantelle) and Chantelle was also using anti-depressant medication to assist with coping. In sum, it seemed that some participants were experiencing psychological distress presumably as a direct result of their experiences and did not have any formal support mechanisms in place. I have discussed and recommended some considerations from the data which may inform services below.

Individual support

One initial recommendation therefore would be the introduction of an assessment of all members of the family's needs by services. This in turn would identify the need for support and intervention for the sons and daughters of younger people with dementia. Individual support or therapy may be one way of addressing some of the issues raised by

participants, to assist with recognising and addressing changes in self and the family and also making sense of these changes.

With regard to the earlier discussion about disenfranchised grief, Doka (2005) suggests that grief and loss can become more enfranchised if services acknowledge and address family members' need to grieve during the life of their relative with dementia as well as after their death. Doka (2005) suggests that in order to do this a service would need to provide information, assist family members in dealing with loss, help them to recognise and then respond to changes resulting from dementia within the family and finally assist with future planning.

Doka's (2005) suggestions highlight the need for a variety of service responses and interventions and some of these will be more appropriate to young adults at distinct times according to the stage of their parent's dementia and the extent to which they have assimilated their experiences (Stiles et al, 1990). Information and support may be more helpful in the initial stages with a need for a more in-depth exploration and discussion of changes and their responses to this as their parent's dementia progresses. More practical support and information about future placement may feature more heavily in the latter stages (Zarit & Edwards, 1999).

Support groups

Within the dementia carer literature, support groups have also often been used with informal family carers of people with dementia (Zarit & Edwards, 1999). Dellmann-Jenkins et al. (2001) noted that young adults caring for older relatives said they wanted emotional support from others of a similar age. This does not corroborate the current findings as participants reported that they did not want to use this type of support for themselves; indeed NS specifically commented that she would find a support group too anxiety-provoking.

I: "Is there anything else that you think is important to talk about in terms of your experiences of having a parent with dementia?"

NS: first intentions would be to say a support group, but then I know I wouldn't use it, that would be just the first answer

I: Why wouldn't you use it, that's important too?

NS: maybe if you talk to somebody in a similar position and if their parent is worse than what yours is, they might tell you something you don't want to know...you're putting ideas into your head, cos you can read in a book and you can look up on the

internet but if you're talking to someone who it's actually happened to, I think it would scare me more"

Within the super-ordinate theme of 'Experience of the interview process' it was clear however that although participants were saying that they would not want support from services, they still found talking within the interview itself helpful. In particular the sub-themes of 'using interview to therapeutic effect' and 'talking for the first time' indicated that these young adults are not always able to gain the informal support they need from friends and family. This in turn highlights a possible need for formal 'talking treatments' with these individuals which is a gap in current service provision.

Anxiety about confronting family changes in the present would suggest that young adults, within this service at least, would not readily seek direct contact with services for themselves, even though some appeared distressed. Bill, Claire and NS all mentioned their use of the internet in order to access information about their parent's diagnosis. Web-based service information and email contact with health professionals is already used in some NHS services designed for young adults (for example The Young Adult Team, Leeds Primary Care NHS Trust, www.leedsyat.nhs.uk). It may be that web and email-based services could be used to enable young adults to access information and advice or join online support groups whilst also allowing them to self-regulate the intensity and frequency of the service input they receive and reduce the need for face to face contact that seemed so difficult for participants to contemplate.

Family interventions

It may be that individual support and service provision are not best adapted to young adults. It is clear that YOD affects the whole family and a more holistic, family-level intervention would be more helpful and used more readily by young adults. Such interventions would help family members to make sense of and talk about change for themselves and as a family unit as the current findings suggest that this did not occur as a matter of course within some families (such as Bill's). Rather it seemed that some families had difficulty naming and sharing thoughts and feelings about dementia, whilst others had long-standing family conflicts which were limiting the family's ability to share distress (i.e. Chantelle's family). Zarit and Edwards (1999) note the need to differentiate between longstanding family problems and acute, reactive difficulties in response to dementia in order to be clinically efficacious. A family therapy approach might enable family members

to identify feelings and distress, family coping patterns, conflicts and alliances which influence the family's experience of having a family member with dementia (Griffiths & Griffiths, 1987; Benbow, Marriott, Morley & Walsh, 1993).

A family approach to assessment and intervention would also identify the distinct needs of different family members. For young adults it appeared that distress was in part related to the impact that parental YOD had on their ability to complete developmental tasks and it may be that if development is compromised in this way, they may be increasingly susceptible to mental health problems in later life (a noteworthy, additional cost to services). A family approach would enable families to ensure that young adults received practical support (from other family members or services) with their care duties which would enable them to achieve young adult tasks as they arise. Considering the developmental needs of young adults in the present may be cost-effective for services in the long term.

A family therapy approach to care and intervention raises the issue of those individuals who do not have a traditional family unit to support them. All participants in the study had two living, married parents and at least one sibling; however this is becoming less usual in recent generations (Fussell and Furstenberg, 2005). The rise in single parent families, divorce and only children will have potentially negative consequences for some young adults with a parent with YOD, leaving them more exposed to the responsibility and possible burden of care. Similarly, the dispersion of family units over a wider geographical area will also have consequences. Thompsell and Lovestone (2002) found that the impact of having a relative with dementia does not lessen according to physical distance and that wider family networks also need support and information. Physical distance was a pertinent issue for KA and currently (at least within this service) there is no specialist support available to offspring living out of the service catchment area.

Future research

In view of the findings of the research, the following is a series of potential areas for expanding upon the current study which would assist in understanding the experiences of young adults with a parent with YOD.

1. A larger sample would help to corroborate or refute some of the tentative suggestions and conclusions made within the current study and increase generalisability. Although the five participants I interviewed provided an ample

amount of data for this study, the various factors influencing their individual experiences of parental illness were often apparent in only one or two participants and consequently it was difficult to establish potential moderators of their experience with any authority. In particular the following moderators would be useful to examine in more detail:

- Age – differentiating between young adults in their teenage years, twenties and thirties
 - Residence – comparing those who live with parents, near to parents and further away
 - Sex – looking at male versus female offspring and also whether the parent and offspring are gender congruent
 - Level of involvement – distinguishing between offspring providing various levels of physical and/or emotional support
 - Stage of dementia – comparing offsprings' experiences according to the stage or duration of their parent's dementia. A prospective longitudinal design would also aid in capturing within participant changes in experience as well as those across participants over time
 - Family structure – examining the differences in responses to dementia according to number and gender of siblings, step-families, single, widowed or divorced parents and married couples
 - Previous mental health difficulties – comparing individuals with previous mental health difficulties with those who do not have a history of these difficulties.
2. A comparative study of the experiences of children, young adults and older offspring of parents with dementia would help to elucidate whether there are distinct features in the experiences of these three groups as a result of their developmental stage. In particular, examining whether individuals in their thirties with a parent with YOD have different experiences to offspring in their forties and fifties would help to clarify whether Claire's ability to cope with her father's dementia was a function of her age and life experience rather than a consequence of the early stage of dementia.
3. A comparative study of young adults with YOD with young adults with other forms of parental chronic illness would assist in corroborating or refuting Rolland (1999)

and Pederson and Reversion's (2005) assertions that the characteristics of the illness impact on the individual's experience. Whilst some attempts to link the current findings to previous literature in this area, the lack of qualitative investigations makes this difficult.

4. As discussed previously with the section on limitations of the research, there were various tentative ideas within participants' accounts which I did not feel could be included within the final analysis. Exploration of these ideas which included family scripts about health and illness beliefs, experiences of the diagnostic process and experiences of society's marginalisation of dementia may be possible with a larger sample.
5. In view of the difficulty in establishing firm clinical recommendations about the best type of support to offer young adults, research which designs and tests out the efficacy of various clinical interventions with this cohort will be useful.

Concluding remarks

This thesis has attempted to explore the experiences of young adults who have a parent with YOD. It would seem that these young adults experienced the developmental tasks of young adulthood differently as a result of their parent's dementia. They also experienced changes within family roles and relationships. It appeared that a number of moderators might affect individual experiences including specific diagnosis, duration of onset and diagnosis, age and gender of parent and child.

The analysis revealed that participants experienced changes within their relationships with family and peers, they attempted to understand and manage these changes and this resulted in changes in self for some participants. The extent of change in self seemed to relate to the extent to which developmental tasks had already been completed and an established sense of identity had developed. Change in self was also related to the extent to which participants had begun to process some of their experiences prior to the interview. In relation to this, it appeared that participants had a range of experiences of the interview such as reflecting on and processing their experiences, minimising feelings of distress and affirming a positive view of self.

In view of the findings, clinical recommendations are assessment of the whole family when in contact with services for YPWD and appropriate interventions for young

adults aimed at a) enabling them to continue with the developmental tasks facing them and b) allowing them to explore, understand and manage the changes they face.

This thesis has expanded on existing knowledge about parental chronic illness in the following ways:

- It has introduced YOD as a form of parental chronic illness affecting younger people to the literature
- It has explored the experiences of young adults facing parental chronic illness as a distinct cohort
- It has broadened the understanding of how YOD affects particular family members
- It has corroborated previous findings purporting that parental illness affects the whole family, though individual, family and illness factors will impact on the individual's perception and experience of this (Rolland, 1999; Pederson & Reverson, 2005).

Some final reflections

In conclusion, this thesis has allowed me to learn about myself as a researcher, in particular recognising how my clinical background has influenced my choice of analytic approach and my results to some extent (for example, my focus on participants' experiences of the interview process).

The thesis has also given me some insight into the experiences of these young adults, which in turn will influence my future clinical work. Returning to my initial reflections within the methodology chapter, I had anticipated that parental YOD would impact upon the lives of young adults however I was not prepared for the extent of the distress and change that this had caused them, nor for the courageous way that they had managed these changes in view of the developmental challenges facing them.

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APPENDIX I - STRUCTURED POST-INTERVIEW QUESTIONNAIRE

Interviewer: Now that we have finished the interview I have a few other short questions that I want to ask you. I'm sure that we will have covered some of them as we have been talking so far so we can run through those ones quickly, but I want to be sure that I have a similar level of factual information about everyone that I interview. Of course, as already discussed you do not have to answer any questions that you do not want to. Do you have anything you want to ask me at this point? [Answer any questions]

- How old are you?

- How old were you when you first noticed any sort of change in your parent?

- How old were you when your parent received their diagnosis of dementia?

- How old is your parent?

- Do you live in the same house as your parent? If not have you ever lived in the same house as them since you first noticed any sort of change in your parent?

- Who is currently the main carer for your parent?

- Do you know your parents diagnosis? What type of dementia does your parent have?

*Ask participant to choose pseudonym

* Signposting for information and support if needed

Interviewer: Thank you for answering these questions. Do you have anything else you want to ask me at this point?

APPENDIX II – CORRESPONDANCE WITH ETHICS COMMITTEES



Leeds (East) Research Ethics Committee

Room 5.2, Clinical Sciences Building
St James's University Hospital
Beckett Street
Leeds
LS9 7TF

Telephone: 0113 2065637
Facsimile: 0113 2066772

13 September 2005

Miss Nathalie Garbutt
Psychologist in Clinical Training
15 Hyde Terrace
Leeds
LS2 9LT

Dear Miss Garbutt

Full title of study: Accounts of Parental Chronic Illness during Transition to Adulthood: The Experience of Young-Onset Dementia
REC reference number: 05/Q1206/109

Thank you for your letter of 15 August 2005, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Committee held on 06 September 2005. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

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

The favourable opinion applies to the research sites listed on the attached form.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

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

Document	Version	Date
Application		22 June 2005
Application		(None Specified)
Investigator CV		(None Specified)
Protocol	5.1	09 August 2005
Covering Letter		21 June 2005
Summary/Synopsis	5.1	09 August 2005
Letter from Sponsor		06 June 2005
Peer Review		28 January 2005

Compensation Arrangements		08 October 2004
Interview Schedules/Topic Guides	4.1	21 June 2005
Letters of Invitation to Participants	4.1	21 June 2005
Participant Information Sheet	5.1	09 August 2005
Participant Consent Form	4.1	21 June 2005
Response to Request for Further Information		15 August 2005
Information flyer for service users and their carer	5.1	09 August 2005
Correspondence with Dr C Chu, Consultant Clinical Geneticist		04 August 2005
Supervisor's CV-Dr Carol Martin		(None Specified)

Management approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final management approval from the R&D Department for the relevant NHS care organisation.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Notification of other bodies

The Committee Administrator will notify the research sponsor and the R&D Department for NHS care organisation(s) that the study has a favourable ethical opinion.

Statement of compliance

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

05/Q1206/109

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project,

Yours sincerely

Ann Prothero

Dr J D Holmes
Chair

Email: ann.prothero@leedsth.nhs.uk

Cc: Clare Skinner, University of Leeds
Susan Porritt, R & D Department, LMHT

Enclosures:

Attendance at Committee meeting on 06 September 2005
Standard approval conditions
Site approval form (SF1)



Leeds (East) Research Ethics Committee

Room 5.2, Clinical Sciences Building
St James's University Hospital
Beckett Street
Leeds
LS9 7TF

Telephone: 0113 2065652

20 December 2005

Ms Nathalie Garbutt
Psychologist in Clinical Training
Academic Unit of Psychiatry and Behavioural
Sciences
15 Hyde Terrace
Leeds
LS2 9LT

Dear Ms Garbutt

Study title: Accounts of parental chronic illness during transition to
adulthood: The experience of young onset dementia.

REC reference: 05/Q1206/109

Amendment number: 6.1

Amendment date: 16/12/2005

The above amendment was reviewed at the meeting of the Sub-Committee of the Research Ethics Committee held on 19/12/2005.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Notice of substantial amendment dated 16/12/2005.

Guidelines for staff distributing study information to participants outside review clinic, version 6.1, dated 16/12/2005.

Study poster, version 6.1 dated 16/12/2005.

Revised protocol, version 6.1 dated 16/12/2005.

Summary of protocol, version 6.1 dated 16/12/2005.

Revised PIS, version 6.1 dated 16/12/2005.

Revised consent form, version 6.1 dated 16/12/2005

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Research governance approval

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

Statement of compliance

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

REC reference number: 05/Q1206/109

Please quote this number on all correspondence

Yours sincerely


Ms C Bedford
Alternate Vice Chair

E-mail: Elaine.hazell@leedsth.nhs.uk

Copy to: R&D Department, LTHT

Enclosures List of names and professions of members who were present at the meeting:

Ms C Bedford, Pharmacist
Dr S Kinsey, Consultant Paediatric Haematologist

Research in the Leeds Early-Onset Dementia Service

Leeds Early-Onset Dementia Service is keen to develop the best possible services for our clients and supports research that may be helpful for planning services in the future. We know from meeting patients in our service that dementia can affect the whole family but there is very little research in this area.

Currently we are collaborating with a researcher from the University of Leeds who wants to find out more about the impact of this illness on family members. She plans to interview young people (aged between 16 and 40 years old) who have a parent or step parent with dementia and find out how this has affected their lives.

The researcher is called Nathalie and over the next six months she will be speaking with many of our clients and their families about this research when they attend their appointments at the Becklin Centre. If you have a son or daughter in this age range and you and your family member would like them to take part in the research, please pass on the information leaflet to them that Nathalie will give you.

If you or your family member do not want your son or daughter to take part for any reason you do not have to tell them about this research. This decision will not affect your care in the Early-Onset Dementia Service in any way.

If you or your family have any further questions about this research please feel free to contact Nathalie Garbutt on 0113 3432732 or Dr Jayne Hawkins, Consultant Clinical Psychologist at Leeds Early-Onset Dementia Service on 0113 3055587.

Thank you for reading this flyer.

APPENDIX IV – PARTICIPANT INFORMATION LEAFLET

Research study – Experiences of the sons and daughters (aged 16 to 40 years) of younger people with dementia

Information sheet for participants

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

Who is doing the research?

Nathalie Garbutt, Psychologist in Clinical Training at the University of Leeds.

What is the purpose of this study?

There is very little information about young people who have a parent with dementia. I am interested in understanding your personal experiences of becoming an adult and how having a parent with dementia may have had an impact on this period in your life or your relationships with family members. I will be interviewing around 10 people and the findings will help to enable families and people working with those with dementia to understand the impact of this condition for the whole family.

Why have I been chosen?

Your parent is receiving care from Leeds Younger People with Dementia Service and I have asked the service to approach any patients who may have a son or daughter aged between 16 and 40. Your parent will also have received a letter about this study as they are in contact with the service. However, I will not have any further contact with your family and I will interview you alone if you decide to take part.

What will happen to me if I take part?

Firstly I would contact you to answer any questions you might have and arrange a convenient time to meet if you agree. We can meet at your home or in a local NHS facility and I will reimburse any travel expenses you incur. The meeting can be during the day or evening. It will usually last between 45 minutes and 1½ hours. It will involve answering some questions about talking about your experiences. Afterwards, you can arrange to meet me again for another interview to follow up on your experiences though this is not a necessity. I will audio-tape the interview to study the information you give me in detail. The audio-tape will be typed up into a transcript to help me do this.

What are the possible benefits of taking part in the study?

The research is not designed to offer any clinical benefit to anyone taking part. However, you may find it interesting and helpful to have an in-depth discussion about your personal experience of your parent's illness.

What are the possible disadvantages or risks of taking part?

It may feel strange to meet with someone you don't know and to tape-record a personal discussion and it may be that you feel uncomfortable about this. It is also possible that talking to someone about your parent's illness may be upsetting. It is also possible that by taking part in the research you become aware of a problem of which you were previously unaware. If this happens, I hope to be able to advise you about where to seek any further information and support you need.

What happens if something goes wrong?

There is no harm expected from participation in this study. If you are harmed by taking part in the study there are no special compensation arrangements. If you wish to complain or are concerned about any aspect of the way you have been approached or treated during your involvement, the usual NHS complaints mechanisms are available.

Do I have to take part?

It is up to you to decide whether or not to take part. You may wish to discuss the study with your parent as they have received a letter about the study through Leeds Younger People with Dementia Service, but the decision to take part is yours to make. If you decide to take part, you will be asked to sign a consent form before being interviewed. If you decide to take part, you are still free to withdraw at any time without giving a reason and any data you provide may be destroyed if you wish.

Will my taking part in the study be confidential?

All information collected about you during the course of the study will be kept strictly confidential. Audio-tapes will be kept in secure cabinets until completion of the study when they will be destroyed (in September 2006). Any written information (such as interview transcripts) will not include personal details, such as name and address. Any reference to you or your family or friends in the final research documents will be anonymised by changing all names and places. Leeds Younger People with Dementia Service and your family will not hear or see any of the information you give during your interview though they will have access to any reports available for public view.

What will happen to the results of the study?

The research will be written up into a doctoral thesis that will be examined by two professional psychologists. Afterwards, the results may also be published in academic journals or presented at conferences. I might use short extracts from the transcript of your interview when writing up or presenting the research but you and your family will not be identifiable from such extracts, and at no point will your identity be divulged. I can send you a brief summary of the results of the research after it is completed if you wish.

Who is organising and funding the research?

Carrying out this research forms part of my training as a Clinical Psychologist. The research is being supervised by Dr Carol Martin, Consultant Clinical Psychologist and Honorary Senior Lecturer at the University of Leeds and Dr Jayne Hawkins, Consultant Clinical Psychologist at Leeds Younger People with Dementia Service. The research is not funded but is supported by the University of Leeds and the service.

What happens next?

If you would like further information or to take part in the study, please contact Nathalie or Jayne by phone, email or in writing using the contact details below.

If you do not wish to find out more about the study or take part then you do not need to do anything further. Your parent's care will not be affected in any way.

Contacts for further information:

Nathalie Garbutt
Academic Unit of Psychiatry
School of Medicine
15 Hyde Terrace
Leeds LS2 9LT
Tel: 0113 3432736 (daytime)
Email: ugmniq@leeds.ac.uk

Dr Jayne Hawkins
Leeds Older People's Psychology &
Therapies Service
The Mount
44 Hyde Terrace
Leeds LS2 9LN
Tel: 0113 3055587 (daytime)

APPENDIX V – EXAMPLE OF ANNOTATED TRANSCRIPT

1701 Yes

1702 [laughing] I've just talked on and on and on but, because of the

1703 kind of family we are and the background we have in our family

1704 and the psychologists and doctors and people in our family who

1705 all know about this and the kind of people me and my dad are

1706 we have, there is no shortage of having we're not a family in

1707 denial we're not we're finding it difficult to cope with like

1708 anyone would but maybe better than other people because... I

1709 have a certain amount of experience with, talking about difficult

1710 subjects but they're not my subjects usually they're somebody

1711 else's but still I can listen to somebody talk about something

1712 very difficult and appreciate where they're how they feel about

1713 it and has actually been very useful to me in this situation, but,

1714 that's not to say that I haven't really struggled with this... and

1715 that it hasn't fundamentally changed my life because it has I am

1716 a different person, or I am a different version of myself because

1717 my mother has dementia, definitely it has changed me and my

1718 friends who know me best say that it has changed me not

1719 necessarily better or worse just different I'm just a different

1720 person now

1721 If we could ask them now what would they say were the main

1722 things that they see differently about you

1723 We've had conversations between us like this kind of

1724 conversation that we would never have had before so, I suppose

1725 you get to a certain age I mean a lot of people I know are in their

1726 mid thirties late thirties and everybody seems to have started

1727 talking about their parents dying recently because some people's

1728 parents have got cancer or have had heart attacks or whatever

1729 because their parents are in their sixties or seventies for some

1730 people I know who are the youngest children erm, so I've had

1731 conversations with them that I haven't had before I've been

1732 more emotional about things than I have before, erm, even

1733 talking about the idea of having children has never been

1734 something that... my friends and I have talked about it often with

1735 not my closest friends it's been them trying to convince me to

1736 have some, cos they've all had them and now I should have

1737 them too but erm, I think, they would possible say that I am

1738 more emotional... than I was before not they wouldn't say I'm

1739 more sensitive or I'm more... oh I don't know if sympathetic or

1740 empathetic's the right word because... I don't think I would have

1741 gone into the Samaritons or stuck with the Samaritons if I hadn't

1742 been the kind of person who understood that, life is not perfect

1743 and that people cannot just have a stiff upper lip and just get on

1744 with it my ex is was before he had this, tragic relationship after

1745 me erm the kind of person who thought that you could just pull

1746 yourself together 'just pull yourself together you'll be fine stop

1747 mucking about' and erm now he knows because him and his

1748 now wife who are very happy now had a horrible time erm

1749 initially together erm, but I think... people who don't know me

1750 very well, no people who don't know me as well as my closest

family coping style + knowledge has been helpful

them still difficult

also as experience at helped

change in self-perception + identity

other perception of her confirms this.

experience of others parents has feeling similar to peers

increasing emotional display

considering/being decisive around children

contenting coping

family coping style has been important/helpful

previous experience been helpful

viewing self differently

change in identity

some of other perceptions changes too

social comparison of other parents illness - similar to peer

experience of more emotion now

considering new life choices.

changing his plans

APPENDIX VI - LITERATURE SEARCH STRATEGIES

Two data bases, MEDLINE (1966 onwards) and PSCH-INFO (1896 ONWARDS) were searched for relevant papers using the following strategies.

\$ indicates a truncation, e.g. parent\$ searched for all words with this root (such as parents, parental)

Younger People with Dementia

dementia

AND

Younger people **OR** early onset **OR** young onset

Limit results to English Language

Parental Chronic Illness

parent\$

AND

chronic illness **OR** dementia **OR** cancer **OR** HIV **OR** AIDS **OR** multiple sclerosis **OR** huntington **OR** diabetes **OR** parkinson

Limit results to English Language

Young Adulthood

young adult\$

AND

Developmental stage **OR** life cycle **OR** developmental task

Limit results to English Language

Abstracts identified by these searches were reviewed for relevance and papers obtained. References of significant papers were also examined to identify additional papers not captured by the search strategies.