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Psychology

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Doctoral Thesis

**Understanding Shared Experiences of Couples and Families in Which One Person  
has Dementia**

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## Word Count

Section	Main text	Appendices (including title page, abstract, tables, figures, and references)	Total
Thesis Abstract	265	N/A	265
Literature Review	7,985	5,607	13,592
Research Paper	8,000	14,238	22,238
Critical Appraisal	3,989	829	4818
Ethics Section	4,135	4,475	8,610
Total	24,374	25,149	49,523

## **Thesis Abstract**

This thesis explored the co-constructed experiences of couples and families in which one person had a diagnosis of dementia. It includes a literature review, a research paper, a critical appraisal and an ethics section.

The literature review is a meta-synthesis of 10 qualitative studies which explored the impact living with dementia can have on the couple relationship, or the impact the couple relationship has on dementia. The synthesis resulted in four interrelated themes: (1) togetherness – continuing as ‘we’ are; (2) upsetting and re-defining the balance – a new ‘normal’ is evolving; (3) sensitive attunement – shielding one’s partner from the effects of dementia; and (4) resilience – distancing distress and cherishing the present moment. These themes highlighted couples’ shared efforts to maintain aspects of their relationship in the context of dementia. Findings have important implications for services to support couples’ efforts to enhance their sense of couplehood.

The research paper extended these findings to explore shared experiences of family units in which one person has dementia. Semi-structured interviews with seven families were analysed using interpretative phenomenological analysis. This resulted in five themes (1) conflicting identities: person or ‘dementia patient’; (2) loneliness and isolation: finding ways to maintain belonging and connection; (3) family support: protecting and enabling; (4) feeling trapped: shifting power and control; and (5) fear and uncertainty: making sense and reigniting hope. Findings have implications for services to consider the whole family system, encouraging connection and belonging to enhance the natural therapeutic capacity of families.

Finally, the critical appraisal includes reflections of a number of ethical, methodological and conceptual issues that became pertinent when conducting this research.

### **Declaration**

This thesis presents research undertaken for the Doctorate in Clinical Psychology at the Division of Health Research, Lancaster University from August 2013 to May 2014. The work presented within this thesis is the author's own, except where due reference is made. The work has not been submitted for any other academic award.

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Date:



## **Acknowledgements**

Firstly I would like to thank the families I interviewed for openly sharing their stories and experiences with me. Witnessing their great strength and resilience has inspired me to see this project through and ensure their experiences are heard. I greatly appreciate the help and assistance I received from staff teams who connected me with the families I interviewed.

I would like to express special thanks to my supervisors, Craig Murray (Deputy Research Director), Jane Simpson (Research Director) and Jonny Rust (Senior Clinical Psychologist) for their ongoing feedback and advice which has proved constructive and reassuring throughout the process. I am also grateful to Julia (LUPIN) for her generous offer of consultation and helpful suggestions. I owe immense gratitude to the amazing group of people who have shared this journey through training with me, their continued containing presence has been invaluable, and I know I have made friends for life.

Finally I would like to thank my family and my partner Andy for their continued love, support and encouragement - through the stress and tears you have always been there, never failing to elicit a smile and I cannot articulate how much that has meant to me!

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**Section One: Literature Review**

**Couples' Shared Experiences of Dementia: A Meta-Synthesis of the Impact Upon  
Relationships and Couplehood**

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**Abstract**

There is a growing recognition of dementia as a condition that effects relationships rather than individuals. Accordingly this review synthesises qualitative studies that explore couples' shared experiences of dementia. A comprehensive literature search identified 10 papers that met criteria for inclusion and the method of meta-ethnography was used to draw novel insights from the studies in combination. Key findings highlight couples' efforts to maintain their sense of togetherness; shifts in balance and power within their relationship which can impact upon both partners' sense of identity; the empathy and sensitive attunement between couples as they work to protect each other's sense of role and identity; and the resilience couples demonstrate in the face of great fear, uncertainty and hopelessness. Findings have important implications for both research and practice, particularly the need for services to support couples' efforts to enhance couplehood in spite of dementia.

**Keywords**

Couple; dementia; meta-synthesis; relationships; review.

**Couples' shared experiences of dementia: A meta-synthesis of the impact upon  
relationships and couplehood**

The dominant, yet controversial, understanding of dementia remains that of organic origin characterised by neurodegeneration - widely termed a progressive 'disease of the brain' (Alzheimer's Society, 2013; World Health Organisation (WHO), 1992). Many types of dementia exist; the most common being Alzheimer's disease and vascular dementia (Alzheimer's Society, 2013). All diagnoses describe progressive deterioration in cognitive abilities (e.g. memory, comprehension, language) and sometimes changes to emotional control and behaviour (WHO, 1992). The medicalised understanding emphasises pharmacological treatments and explains the international pressure on curative research (WHO & Alzheimer's Disease International, 2012), overshadowing the importance of supporting people with dementia to maintain a good quality of life (Department of Health, 2009). This focus together with ongoing pressures for early assessment and diagnosis, prompt services to 'forget that there's a real, living individual behind the disease' (Gubrium, 1986, p. 91).

The organic model of dementia has been heavily criticised for its reductionist approach, which neglects other factors (Cheston & Bender, 1999; Kitwood, 1997). Kitwood (1997) proposed a more holistic understanding of dementia, acknowledging the important influence of personal, social and contextual factors in addition to neurological changes. His seminal work precipitated a movement towards 'person-centred care' that appreciates the individual behind the diagnosis. This engendered increased research on the subjective experience of the individual with dementia (Caddell & Clare, 2010; de Boer et al., 2007). The active involvement of people with dementia in research can inform

development of effective interventions (Kitwood, 1997), thereby improving the care they receive (Woods, 2001).

While important to develop greater understanding of the experience for people with dementia, changes are not experienced in isolation; they reverberate through close relationships, with significant impact upon the individual's partner or spouse (Baikie, 2002). Most research involving partners of people with dementia focuses on their role as the main caregiver (Etters, Goodall, & Harrison, 2008; Schulz & Martire, 2004). However, the couple relationship is greater than a caregiver/recipient exchange, and such focus on caregiving neglects exploration of the complexity of the relationship experienced (Graham & Bassett, 2006). Furthermore, partner studies often utilise models of caregiver 'burden' to interpret findings (e.g. Etters et al., 2008; Montgomery & Williams, 2001; Schulz & Williamson, 1997). Although such research can yield valuable insights, it risks adopting a universally negative view (Molyneaux, Butchard, Simpson, & Murray, 2011), and neglects positive aspects of caregiving, such as the attendant sense of meaning and purpose (Farran, Miller, Kaufman, Donner, & Fogg, 1999), or the pleasure experienced in maintaining the identity of their loved one (Phinney, 2006).

Studies exploring the subjective experience of only one member of the dyad (i.e. people with dementia or their partners) can provide valuable insights into their individual experience; however, it is also important to acknowledge the interactional and relational aspects of experience. Partners do not live in 'parallel life spaces' (Davies & Gregory, 2007) but within a 'multi-dimensional and dynamic inter-relationship' (Whitlatch, 2001). Dementia impacts both members of the couple individually while also influencing the intimate relational bond between them (Daniels, Lamson, & Hodgson, 2007). Both the person with dementia and their partner must adapt to the changes together and compensate

in relation to one another. For example people with dementia may rely increasingly on their partner for prompts or reminders, which can create resentment within the relationship (Clare, 2002). Furthermore both individuals' identities are constructed within mutual conversation and interaction (Forbat, 2005; Graham & Bassett, 2006). The relationship is therefore key in their individual and shared identity formation. Ultimately, their experience as individuals impacts upon their shared experience and sense of couplehood.

The importance of the influence of dementia on an individual's close relationships is acknowledged within theory and research as a 'relationship-focussed' approach (e.g. Henderson & Forbat, 2002; McGovern, 2011). The couple relationship can influence both partners' wellbeing and quality of life in the context of dementia (Quinn, Clare, & Woods, 2009). Furthermore, the quality and mutuality within their relationship can determine whether they can manage at home or require residential care (Hirschfeld, 2003). Greater understanding of these relational experiences is therefore vital to ensure the best quality care for both members of the dyad.

An increasing number of studies have sought to explore these relational aspects of living with dementia. A review of primarily quantitative studies in this area (Ablitt, Jones, & Muers, 2009) demonstrated valuable insights. They found that dementia onset can lead to a decrease in reciprocity, communication, shared activities, and overall quality of the couple relationship. Couples also reported positive outcomes such as increased closeness, affection and emotional warmth. Dementia was found to influence couples' relationships, while in turn influencing their experience of dementia. Accordingly, lower relationship quality correlated with increased strain and depression for carers and decreased functional ability of people with dementia (Burgener & Twigg, 2002). Conversely higher relationship quality acted as a protective factor for couples (Ablitt et al., 2009).



Prompted by these results Ablitt and colleagues (2009) developed a theoretical framework to understand the interaction between the couple relationship and dementia. They proposed that the couple's prior relationship influences the maintenance of their bond in the context of dementia. Any decrease in relationship quality then directly impacts both partners' emotional wellbeing, resulting in an increasingly negative dementia experience. Ultimately negative experience then exacerbates the presentation of dementia. This creates a vicious circle whereby dementia is exacerbated, worsening the relationship as the cycle continues (Cheston & Bender, 1999; Kitwood, 1997; Norton et al., 2009). A greater understanding of these complex relational patterns is therefore warranted.

While a growing body of qualitative literature explores the nuanced nature of such relationships, much still relies on the perspective of only one member of the dyad. This leads to only a partial understanding of the relationship, particularly as people with dementia and their partners can have conflicting perceptions of the relationship (Quinn et al., 2009). Studies involving both members of the dyad as active research participants encourage greater exploration of relational aspects and provide a more holistic picture of shared couple experience (Daniels et al., 2007; Molyneaux, Butchard, Simpson, & Murray, 2012). With no current review of this literature these types of studies could benefit from synthesis.

Reviewing the literature on couples' shared experiences of dementia enables the synthesis of a broad range of findings to reach novel insights and interpretations, thereby enhancing understanding (Evans, 2002). Meta-ethnography, a method of systematically analysing and synthesising qualitative research (Noblit & Hare, 1988), encourages the critical examination and integration of numerous papers to develop more robust and

substantive findings. The resulting ‘whole’ offers more than ‘the sum of its parts’, reflecting couples’ experiences of dementia more widely.

In respect to previous reviews, Evans and Lee (2013) examined the qualitative literature relating to the impact of dementia on marriage, however this excluded studies focussing on caregiving, burden, couplehood or non-married couples. The current review also differs from that of Evans and Lee by only including studies involving both members of the dyad; this avoided privileging one perspective over another, instead encouraging holistic understanding of shared experience as a couple unit. This review therefore seeks to synthesise qualitative studies that either aim to understand the impact dementia has on relationships or conversely the impact relationships have on dementia.

## **Method**

### *Search and selection*

In order to address the research question (What are couples’ shared experiences with dementia?) a search was conducted of various databases in November 2013: PsycINFO (searchable years 1887-2013), PsycARTICLES (searchable years 1988-2013), CINAHL (searchable years 1982-2013), MEDLINE (searchable years 1814-2013), and Academic Search Complete (searchable years 1887-2013). The Boolean operator ‘AND’ was used to combine searches relating to the condition (dementia OR Alzheimer), the sample (spouse\* OR husband\* OR wife OR wives OR couple\* OR "significant other\*" OR partner\* OR marriage OR married OR marital), and the method (questionnaire\* OR interview\* OR "focus group\*" OR "case stud\*" OR "grounded theory" OR narrative OR thematic OR ethnolog\* OR qualitative OR phenomenolog\*). Results were then filtered to show articles available in English. No date limiters were applied, as there is no published review known of this specific kind. These searches resulted in 2,303 articles (PsycINFO =

380, PsycARTICLES = 10, CINAHL = 692, MEDLINE = 707, and Academic Search Complete = 514), which reduced to 1,555 once duplicates were removed.

Titles and abstracts of resulting articles were reviewed to determine their relevance. Subsequently the full text of articles was examined to apply inclusion and exclusion criteria. Studies were included in the review if they met the following criteria: (a) available in English; (b) published in a peer-reviewed journal; (c) employed qualitative methods which were content based rather than discursively oriented; (d) involved people with dementia and their partners as active research participants and synthesised both perspectives through analysis and results; (e) dementia, of any type, the primary diagnosis or the main focus of the article; (f) findings presented thematically or narratively and evidenced through quotes; (g) results addressed to some degree the impact dementia has on relationships and couple dynamics or vice versa.

In addition, papers were excluded if: (a) studies employed mixed methods, but the primary focus was quantitative; (b) data collection involved observational methods only; (c) one partner was used to corroborate the other partner's perspective, rather than both being active participants; (d) participants included other dyads (e.g. parent and adult-child) and couples' experiences could not be distinguished separately in results; (e) participants with other diagnoses (e.g. mild cognitive impairment) were included and not separated in analysis; (f) the research evaluated a specific approach, service or intervention. Where two or more papers utilising the same sample met the criteria for inclusion (Hellström, Nolan, & Lundh, 2005a, 2005b, 2007), the most recent paper with the most extensive data (Hellström et al., 2007) was included in the review.

To ensure an extensive search, reference sections of included articles along with any relevant reviews were checked, however no further articles met inclusion criteria. The search process resulted in 10 articles being included in the present review (see Figure 1).

[INSERT FIGURE 1 HERE]

### *Study characteristics*

Characteristics of the 10 studies are summarised in Table 1. Studies included samples drawn from Europe (two from the UK, three from Sweden), and North America (four from Canada, and one from the USA); all articles were published between 2004 and 2013.

Most studies involved people in the early- to mid-stages of dementia, however two longitudinal studies captured more advanced stages of the condition (e.g. Atta-Konadu, Keller, & Daly, 2011; Hellström et al., 2007). Alzheimer's was the most common diagnosis, however some samples included people with vascular dementia (Robinson, Clare, & Evans, 2005; Vikström, Josephsson, Stigsdotter-Neely, & Nygård, 2008), or mixed dementia (Hellström et al., 2007). Several studies did not state the specific types of dementia (Atta-Konadu et al., 2011; Phinney, Dahlke, & Purves, 2013; Svanström & Dahlberg, 2004).

All articles involved couple dyads (90 couples in total), although two articles (Phinney, 2006; Phinney et al., 2013) included other family members. Therefore, only sections of resultant themes relating to couple experience were included. While it is acknowledged that both members of the dyad are 'partners', the terms 'partner' and 'person with dementia' are used to identify each member for clarity and to avoid the controversies around the term 'carer' (Molyneaux et al., 2011).

Approaches to analysis varied: four adopted a grounded theory approach, three utilised interpretative phenomenological analysis (IPA), one employed holistic content narrative analysis, one adopted a phenomenological approach using ‘life-world theory’, and the final study used a combination of narrative analysis, thematic and content analysis. One of these studies (Davies, 2011) employed a mixed methods design, however qualitative methods occupied a substantial focus within the research, justifying their inclusion in the review.

All studies collected data via interviews, conducted individually with each partner, jointly, or a combination of both. Three studies (Phinney, 2006; Phinney et al., 2013; Svanström & Dahlberg, 2004) employed additional data collection methods (e.g. observation or diaries). One article (Daniels et al., 2007) involved a single case-study design.

The focus on dementia varied, with some studies explicitly focusing on the impact on couples. Others focussed on the impact of the couple relationship on the experience of dementia (e.g. Davies, 2011), or a combination of both (e.g. Molyneaux et al., 2012). Some articles focused on specific aspects of the dementia experience as a couple - e.g. food related role shifts (Atta-Konadu et al., 2011), and engagement in activities (Phinney, 2006; Phinney et al., 2013; Vikström et al., 2008). Synthesis of these articles therefore facilitated a reasonably holistic view of the impact of dementia on couples’ relationships and vice versa.

[INSERT TABLE 1 HERE]

### *Quality appraisal*

Currently no consensus on criteria for the appraisal of qualitative research exists (Dixon-Woods, Booth, & Sutton, 2007). However, to provide a framework for considering

quality, papers in this review were appraised using the Critical Appraisal Skills Programme (CASP; Public Health Resource Unit, 2006), which assesses qualitative research against 10 questions. The first two questions are screening measures and all studies met these criteria; the remaining questions were evaluated against a three-point rating system (Duggleby et al., 2010) to facilitate comparison. Scores reflected a weak (1), moderate (2), or strong (3) explanation and justification of that area, which resulted in a maximum score of 24 for each paper (Table 2). Total scores ranged from 15-22 and reflect the quality of reporting published, not necessarily the quality of the study itself.

As a further credibility check a group of peers with experience of the CASP tool reviewed ratings for a selection of the papers; this improved consistency and reduced subjectivity. No papers were excluded based on quality; instead scores provided a framework to ensure that themes were evidenced by studies reflecting a range of quality scores.

[INSERT TABLE 2 HERE]

### *Analysis and synthesis*

A meta-ethnographic approach was employed for synthesis according to guidance from Noblit and Hare (1988). This involved a rigorous procedure of comparison and analysis, with the aim of reaching novel insights and interpretations. A systematic search was conducted to identify all relevant studies. Papers were then read repeatedly to become familiar with their content while extracting key concepts, metaphors, phrases or quotes. The relationship between studies was then considered by listing key concepts from each paper in juxtaposition with those from other papers. These were then compared and translated across papers by grouping according to emerging themes. This process was iterative, with papers revisited repeatedly to ensure resulting themes captured original

findings accurately, while also offering novel insights through the combination of findings (Appendix 1-A).

## Results

Synthesis produced four interrelated themes: (1) togetherness – continuing as ‘we’ are; (2) upsetting and re-defining the balance – a new ‘normal’ is evolving; (3) sensitive attunement – shielding one’s partner from the effects of dementia; and (4) resilience – distancing distress and cherishing the present moment. Each theme is evidenced by quotes from the original studies.

### *Togetherness: Continuing as ‘we’ are*

Couples’ strong sense of commitment to each other and their struggles to hold on to their shared identity as a couple was highlighted in all reviewed papers. Couples felt that dementia affected their lives as individuals and as a couple, thereby viewing dementia as a shared experience. They often spoke in terms of ‘us’ and ‘we’, demonstrating the strength of their shared identity and indicating a sense of being ‘one’: ‘We don’t segregate. We don’t separate. We’re together’ (Davies, 2011, p. 222).

A strategy that enabled couples to sustain togetherness was externalising the dementia. Rather than seeing dementia as part of one of them, they labelled it as ‘the dementia’ or ‘the Alzheimer’s’, effectively locating it outside of them both and holding it accountable (Daniels et al., 2007; Molyneaux et al., 2012). This allowed couples to ally against the dementia, empowering them to collaborate and face the difficulties together as a united front.

A key aspect of this teamwork and togetherness was a sense of mutual support and interdependence. This reciprocity sometimes appeared in partners’ reasoning for the additional support they now provided to the person with dementia – viewing it as returning

the favour for the support they had received previously (Atta-Konadu et al., 2011). This give and take inherent in the reciprocal nature of their relationship, meant they greatly valued and appreciated one another. One person with dementia described her husband: ‘he’s just the best thing I’ve ever had’ (Daniels et al., 2007, p. 167). Couples’ affection for one another was also demonstrated within joint interviews:

Person with dementia: ...you’ve got to stick together.

Partner: Yeah, there’s lots of love in this house.

Person with dementia: That’s the main thing to me anyway.

Partner: (...) And I think it’s so important. (Molyneaux et al., 2012, p. 490)

Couples expressed immense gratitude to one another for the connection they experienced during time spent together:

Partner: We have a nice time together at home, and that is what we are saying every day. “Oh God, such a nice time we have, you and I”; “Yes” says my husband “that is thanks to you”; “No”, I say, “it is thanks to you”. That’s how it is (Hellström et al., 2007, p. 394).

Couples acknowledged that doing things together required some adjustment and negotiation, although the sense of connection this prompted was often the most important thing in their lives (Daniels et al., 2007; Molyneaux et al., 2012; Phinney, 2006; Phinney et al., 2013; Vikström et al., 2008).

This love and mutual commitment was often so profound that the idea of life without one another was unbearable: ‘I don’t even want to think about leaving her’ (partner; Daniels et al., 2007, p. 168). Fears of losing one another strengthened their commitment, enhancing their efforts to retain their relationship as it was before the dementia (Molyneaux et al., 2012; Svanström & Dahlberg, 2004). Their enduring



commitment to a future as ‘us’ meant they hoped to maintain their partnership for life: ‘[I] say, “I’ll help you, I’ll protect you, I will be here.” He knows that I’ll always be here and that I will take care of him...He knows that he’s safe’ (Phinney, 2006, p. 93).

While almost all partners wished to support the person with dementia as long as they possibly could, there were conflicting attitudes towards this. Some couples saw it as their pleasure to stand by their partner and felt anxiety regarding separation (Molyneaux et al., 2012). Others perceived this as their duty and being together became a necessity (Davies, 2011; Vikström et al., 2008). This sense of enforced togetherness could become suffocating for partners, as they became less able to continue their own activities and social engagements. This could result in a sense of feeling trapped, wanting their own privacy and solitude and seeing the person with dementia as a burden (Svanström & Dahlberg, 2004; Vikström et al., 2008). These perspectives seemed fluid, with partners fluctuating between different experiences dependent upon context, pressure and stress.

Some couples felt that despite their attempts to encourage togetherness, emotionally they grew apart, losing their feelings of closeness, which created a growing sense of distance between them (Davies, 2011; Hellström et al., 2007). Being together then became physical accompanying for safety reasons, devoid of emotional connection; partners subsequently described more often inhabiting separate ‘worlds’, suggesting a gradual loss of their shared identity. This provoked feelings of loneliness and isolation with a sense of becoming strangers (Svanström & Dahlberg, 2004). Sometimes this loss of shared identity signified a loss of the relationship and the person they once knew:

Partner: I miss the support I got from him. He used to be my counterpart, to give me advice on what to do and how to act. Now there is nothing there, no compassion or anything (Vikström et al., 2008, p. 260).

As dementia progressed some partners no longer defined themselves as part of a couple and began working towards a new life without the person with dementia, although others managed to retain the love, affection and strong sense of couplehood even after the death of the person with dementia (Hellström et al., 2007). Couples' sense of togetherness or detachment was often influenced by shifting roles and power for the couple - explored within the next theme.

*Upsetting and re-defining the balance: A new 'normal' is evolving*

Shifting roles and responsibilities, which created power imbalances and threatened identities, was highlighted in all reviewed papers. Changes in cognitive ability of the person with dementia impacted upon their ability to perform daily tasks, subsequently partners took on more responsibility to compensate. Both partners were often keen to continue reciprocating as equally as possible, as this wife with dementia states: 'So I just want to make sure I'm pulling my share or more than my share' (Atta-Konadu et al., 2011, p. 311). However this reciprocity changed over time - a steady transition involving negotiating and re-establishing roles and expectations. Wide variations were evident in how couples described role change – from active choice to passive decisions, or most extremely powerlessness where decisions were made on behalf of the person with dementia (Hellström et al., 2007). These different approaches may be underpinned by the levels of openness, communication and trust between the couple.

Active choice involved couples proactively planning the process of transferring responsibility. Sometimes people with dementia coached their partner, highlighting an underlying desire to protect and prepare them for days when they would need to manage alone:

Person with dementia: ...my wife is helping me when we work with our expenses, so she is becoming familiar with it if something happens. I am happy that my wife gets familiar with all our joint business, sooner or later there is only one of us left, probably my wife will live longer than I (Hellström et al., 2007, p. 401).

Some people with dementia relinquished responsibility in a more passive manner as they struggled to cope. Correspondingly some partners allowed the person with dementia to gradually and implicitly transfer responsibility - sometimes described as 'sliding' into new roles without explicit discussion: 'it's just one of those things. I don't think I made any conscious decision' (partner; Atta-Konadu et al., 2011, p. 308). Some partners exerted control and assumed the other's responsibilities, leaving the person with dementia seemingly powerless (Hellström et al., 2007). This powerlessness was sometimes shared by the couple as they felt controlled by the effects of dementia (Svanström & Dahlberg, 2004).

Gradually the balance between partners adjusted. Their positions moving from coach (person with dementia) and assistant (partner), to working together, before gradually becoming assistant (person with dementia) and coach (partner). Partners therefore began to assume a 'carer' role, although the term was avoided as partners perceived their care as essential to their relationship (Molyneaux et al., 2012) - reciprocating love and nurturance. The decreasing abilities of the person with dementia sometimes resulted in complete disengagement, requiring the partner to manage alone (Hellström et al., 2007). This reduced togetherness with a sense of becoming an 'I' rather than a 'we' (first theme). The shifting balance provoked differing emotional responses. Some partners relished the opportunity to learn new skills and adopt new routines (Phinney et al., 2013), while others experienced the weight of responsibility:

It's not so very nice because...here...as I said before, there has been stress and nervousness then...worries, lots of worries, yes...about her, I don't think I've thought about everything...Clean clothes when she is going out and which clothes...(Svanström & Dahlberg, 2004, p. 678).

This extra responsibility occasionally created resentment due to feeling trapped (Robinson et al., 2005; Svanström & Dahlberg, 2004).

Along with shifting responsibility came changing power and status, creating imbalances in relationships:

Partner:...where he'd sort of like be the leader in a way, it's come round to me you know. I make the decisions and erm, you know he'd sort of earn the, alright I mean neither of us earn the money now, our pensions and what not come in but I mean he always erm he was like always the man of the house but er now I've er...

Person with dementia: Now I'm the woman of the house [Laughs].

Partner: Well you're not. I've sort of taken over, well everything really.

(Molyneaux et al., 2012, p. 489)

Such power shifts had a significant impact on the identity and masculinity or femininity of individuals. Some partners resented their new power, not wanting to be the 'boss' in their relationship (Phinney et al., 2013). Changes therefore provoked mixed and conflicting emotions for both partners:

Person with dementia: You've [wife] kind of taken the bull by the horns and said "Oh no honey I'll drive" and I think well what's wrong with me? Why can't I drive? And so I thought, well no harm done, go ahead drive yourself to death; I've been driving for forty years I don't care. (Phinney et al., 2013, p. 363).

Driving was central to his identity as a man and a husband. Changes therefore had significant consequences for both partners' sense of identity.

Changes characterised an iterative process as couples strived for comfortable ways to redefine roles and re-establish balance - allowing a new 'normal' to evolve: 'You adjust to it, I mean the abnormal has become normal' (person with dementia; Robinson et al., 2005, p. 342). Some couples faced changes with openness and willingness, continually renegotiating roles and expectations, whilst appreciating each other's new responsibilities (Phinney et al., 2013). Couples recognised the impact of these changes on their partner and strived to preserve their identity – explored in the next theme.

*Sensitive attunement: Shielding one's partner from the effects of dementia*

Couples' natural empathy for their partners and their subsequent efforts to protect them and preserve identity featured in seven reviewed papers (Atta-Konadu et al., 2011; Hellström et al., 2007; Molyneaux et al., 2012; Phinney, 2006; Phinney et al., 2013; Svanström & Dahlberg, 2004; Vikström et al., 2008). Individuals strived to maintain their partner's best interests despite changes (Phinney et al., 2013). People with dementia were often aware of the added stress placed upon their partner, and understood their frustration:

My wife gets irritated if she asks a question that I cannot answer until I know what it is all about, and she needs a quick answer. It might be a phone call and she needs more information and I can't be prepared to give my opinion about different things, this leads to irritation, and I fully understand, it does not offend me in any way.

(Hellström et al., 2007, p. 398).

Empathy therefore allowed forgiveness, reducing feelings of resentment and blame.

People with dementia wanted to protect their partner and avoid being a burden to them (Hellström et al., 2007; Phinney, 2006; Svanström & Dahlberg, 2004). Here a

husband with dementia describes his desire to remain together in the family home, while acknowledging the consequences for his wife: 'It hinges on her. I mean, I think I'm pliable. I think I can bend. But I don't want to see her suffer you know. We've been together too long.' (Phinney et al., 2013, p. 363). People with dementia often emphasised their abilities and concealed difficulties, which served to preserve identity, but could also represent attempts to avoid becoming a burden to their partners.

Partners were aware of how changes impacted upon the identity and independence of the person with dementia, making considerable efforts to promote their autonomy and sense of self in other ways (Hellström et al., 2007; Molyneaux et al., 2012; Phinney, 2006; Phinney et al., 2013). Partners provided necessary support to allow people with dementia to remain involved in their typical activities, thereby maintaining their role and preserving their masculinity or femininity. This promoted agency and valued contribution, reducing feelings of uselessness. People with dementia often recognised their partner's efforts: 'I have somebody to watch me, you know...he's good to help me out, or if I forget to turn off the stove, he'll be right there to turn it off, you know. Like he's very good' (Atta-Konadu et al., 2011, p. 311). Partners were mindful of the need to keep them safe, while preserving freedom and autonomy, but sometimes struggled to offer guidance and support without interfering (Vikström et al., 2008).

Partners adjusted tasks according to the ability of the person with dementia, thereby structuring activities to reduce demands, guarantee success and avoid embarrassment (Phinney, 2006; Vikström et al., 2008). Partners modified their expectations to allow the person with dementia to achieve, recognising that their involvement, rather than actual input, promoted agency - their involvement was therefore prioritised over the efficient completion of a task (Atta-Konadu et al., 2011). Partners repeatedly praised the person

with dementia to emphasise their abilities rather than dwell on failures (Hellström et al., 2007; Molyneaux et al., 2012). This enhanced their self-esteem and protected them from self-reproach and guilt:

Partner: We perhaps do them [crosswords] together now, I mean you have a go and then leave the easy ones for me.

Interviewer: [Laughs]

Person with dementia: That's what I tell him anyway.

Partner: No, it's surprising actually that erm, I mean I was never terribly good at crosswords but now I mean sometimes we'll, or I've had a look at the one you've done or part completed and you've come up with words that I couldn't think of, you know. I mean it's remarkable really that. (Molyneaux et al., 2012, p. 490).

These efforts reflect the importance of fostering the identity of the person with dementia, preserving meaning and wholeness for the individual and the couple (Phinney, 2006).

Sometimes partners concealed these efforts to avoid undermining their partner's sense of independence and to preserve balance and reciprocity (Hellström et al., 2007). This echoes the efforts of people with dementia to conceal their difficulties and avoid being perceived as a burden. Partners described offering support in more subtle ways: 'He is incredibly thankful for whatever I do. I don't want him to feel like a burden for me. Instead I always try to cover up [some of my caring]'. (Hellström et al., 2007, p. 394). Sometimes people with dementia still noticed this concealment, appreciating their partners ability to 'steer me with invisible wheels' (Phinney, 2006, p. 92). Partners also concealed the truth to preserve enjoyment of an activity for the person with dementia: 'He reads a comical history book now and he laughs and has the most joyful time I've seen in a long

time. Consequently, I don't bother telling him that he has recently read it.' (Vikström et al., 2008, p. 262).

As the dementia advanced, the need for scaffolding and support increased (Hellström et al., 2007). Sometimes it became difficult for partners to keep the best interests of the person with dementia at heart, particularly when sacrificing their own needs. This created ambivalence around balancing their needs as individuals and as a couple (Phinney, 2006; Vikström et al., 2008). Couples demonstrated remarkable resilience in coping with these difficulties and dilemmas - explored further in the next theme.

*Resilience: Distancing distress while cherishing life and the present moment*

Couples demonstrated great resilience through their strategies to manage distress and make the most of their time; this notion was highlighted in all of the reviewed papers. For some couples the future was of uncertain but inevitable deterioration, which provoked deeply distressing emotions, including hopelessness, powerlessness and futility: 'Well, actually I have no aims anymore. Life is over' (person with dementia; Svanström & Dahlberg, 2004, p. 680).

Couples often attempted to distance these distressing feelings and continue with activities regardless:

Partner: I am mentally so filled with sorrow. In practical situations I go on like a machine. And emotionally, I also go on like a machine. You just go on, and on, and on. My frustration increases, and my husband is victimized by it. (Vikström et al., 2008, p. 259).

This vividly illustrates the 'machine' state whereby partners believed they must cope, and therefore would not allow themselves to pause or confront their emotions. Such efforts to



cope could lead to a build-up of frustration or emotion that could negatively impact upon the relationship.

Some couples coped by accepting the situation, while using humour and selective comparisons to normalise their experience: 'There is a problem, and I have what plenty of other people have' (person with dementia; Robinson et al., 2005, p. 341). People drew comfort and reassurance from others experiencing the same plight, while humour and normalising distanced emotional distress. Some couples preferred not to talk about dementia at all:

Partner: I suppose I close my eyes to those things. (...) I ignore that time [when help will be needed], that situation.

Interviewer: You manage now, you mean?

Partner: I don't want to look forward, but to live today. It is much nicer.

(Hellström et al., 2007, p. 397).

Such strategies to distance dementia both protected couples from distress and served to 'save face' and avoid potential shame (Svanström & Dahlberg, 2004). The quote above highlights couples' focus on making the most of the current situation. The diagnosis of dementia provided couples with a new perspective on life, which encouraged greater appreciation of life's little pleasures (Daniels et al., 2007; Hellström et al., 2007).

Some couples cherished the present moment by maintaining a positive attitude and focussing on the good things in life:

Person with dementia: I try to think about the things that are a little brighter, on the bright side, than to think about all the bad stuff, you know. You just can't dwell on it or it will run your life (Daniels et al., 2007, p. 168).

One way couples stayed positive was by preventing arguments to keep the peace between them (Hellström et al., 2007) - forgiveness considered essential to keep the peace:

Partner: 'It's a balance and we've, at least I look at it, well if I want to be okay between us, then I just have to make sure that nothing goes between us and he does the same thing, you know. We don't go to bed with a bad attitude' (Davies, 2011, p. 229).

For some couples, the diagnosis of dementia prompted a re-evaluation of their life together, which helped them appreciate what they had previously taken for granted, and ensure they made the most of their time together, which had become very precious (Davies, 2011). This often prompted fond recollections of their life together, which fostered new meaning within the present (Daniels et al., 2007; Molyneaux et al., 2012; Robinson et al., 2005). Such reminiscence enhanced couples' positive attitude and helped them understand and cherish the present moment. Couples reflected on their relationship as a whole:

Person with dementia: We were always happy weren't we?

Partner: Yes, we were happy and we didn't have a lot of money to spend, but nobody did in those days but er, we used to, we used to make our own fun didn't we?

Person with dementia: Yeah, we were happy and gay when things were bad weren't we? (Molyneaux et al., 2012, p. 494)

Reflecting on difficulties they survived together created a strong sense of resilience for couples.

Overall this theme encapsulated how couples cherished and reminisced about the past, accepted and made the most of the present, while distancing thoughts and feelings

about the future. This facilitated togetherness (first theme), preserved identities (third theme), and avoided shame and stigma.

## **Discussion**

This review has highlighted key aspects of couples' lived experience with dementia, including what became most important to them and how they managed the challenges that arose. The meta-synthesis method enabled the identification of key aspects and an in-depth exploration of couples' experiences in relation to them. The diversity within the samples (e.g. varying age, gender, country of residence, and type of dementia), and methods (e.g. cross-sectional and longitudinal data collection utilising varying analytical approaches) of the studies reviewed indicates the robustness of these findings. Of particular importance to couples was the connection and attunement between them, which supported their coping and resilience in the face of identity issues, power struggles, fear and distress.

A key issue identified by the review is that while dementia most certainly affects the life of the couple as a unit, it was not the actual ability of the person with dementia that couples were striving to maintain but rather their shared sense of couplehood. This encompassed togetherness, reciprocity, their interdependent identities and ultimately their happiness. Couples' efforts to sustain their sense of togetherness despite difficulties were remarkable and clearly demonstrated the importance and strength of their couplehood. This adds weight to the concept of the couple relationship fundamentally determining their experience of dementia, as noted previously (e.g. Ablitt et al., 2009; Davies & Gregory, 2007). Efforts to externalise the dementia seemed important in enhancing couples togetherness, as this allowed unity rather than blame or resentment (Rolland, 1994; White, 2006)

For some couples dementia only seemed to enhance their sense of couplehood, whereas for others their relationship became more strained. Keady and Nolan (2003) suggested that the effects of dementia lead partners to gradually start to work apart more than together. However this review suggests that while this is true for some couples, some manage to maintain a sense of couplehood into the more advanced stages of the condition. Hellstrom and colleagues (2005a) described this as the 'nurturative relational context' in which couples' relationships have the potential to thrive despite dementia. Similarly to chronic illness, dementia therefore reflects opportunity for growth within the relationship as well as deterioration (Rolland, 1994). Couples prior relationship is likely to be a large factor in these individual differences (Ablitt et al., 2009), along with their openness and willingness to adjust (Rolland, 1994).

Doing things together was one way that couples maintained connection, and the actual activity was less important than the sense of being together. Research suggests that even just 'being in the atmosphere of the doing' can be highly valuable (Van't Leven & Jonsson, 2002). This suggests the detail of who is actually involved and to what extent is less important than the experience of involvement for them both. Such involvement promotes their identities, roles and togetherness. Furthermore, research has shown that undertaking activities together as a couple can reduce distress and feelings of low mood in carers (Searson, Hendry, Ramachandran, Burns, & Purandare, 2008).

A crucial part of couplehood seemed to be the element of reciprocity. Literature emphasises the work of the partner to sustain the balance within the relationship (Keady & Nolan, 2003). However this review suggests that while the balance of power and responsibility shifted over time, some couples were still able to reciprocate love and nurturance to sustain their sense of connection. It was clear that people with dementia

made an important contribution to sustaining a nurturing relationship and maintaining balance, even if this was not to the same degree or in the same way as their partner. Furthermore, couples' efforts to retain balance meant partners were often reluctant to step into a role they formally identified as a 'carer' – this would fundamentally upset the balance of power.

This review has demonstrated the attunement that can exist between couples, with both being sensitive to the other's needs and feelings. It seems that changes in roles and power had the potential to threaten both partners' identities, particularly when their positions contradicted their ideas of traditional masculinity or femininity. However their mutual awareness of the impact this had on each other enabled them to work to compensate where possible. This attunement appeared crucial in managing and re-establishing the balance in their relationship, which corresponds with previous findings that mis-attunement within couples is associated with power imbalances (Jonathan & Knudson-Martin, 2012). However this review highlights that at times attunement led to both partners concealing information to protect their loved one, thus creating secrets in relationships, which could also be destructive (Rolland, 1994).

When considering the theme of resilience, couples used a number of coping strategies to distance the future, while cherishing the past and present. Some couples reminisced about happy times together and challenges they had overcome. The accuracy of such memories appeared less important than the function they served for the couple. Couples reminisced as a form of evaluating their life to make sense of their current situation, and promote their shared identity as a couple. This also emphasised that their relationship was not defined by dementia alone. In addition, remembering challenges they faced together may have given them strength and hope that they can also face dementia

together. Manier (2004) suggests memories are reconstructed as they are recalled and described in conversation, which links with narrative ideas around the therapeutic purposes of selectively remembering, interpreting and adjusting memories as they are shared and discussed (Hunt & McHale, 2007).

Findings from this review reinforce the discrepancies between societal narratives and the actual lived experience of the couples. In reality while responsibilities may be lost, and roles may be difficult to hold on to, many couples manage to maintain a sense of togetherness and commitment despite the less active role of the person with dementia. Societal narratives, however, present a bleak future for couples facing dementia. Such discrepancies have been noted previously as people with dementia can report a more subtle sense of suffering compared to the picture portrayed within the general public (de Boer et al., 2007). One study within this review (Svanström & Dahlberg, 2004) depicted dementia as a uniformly negative experience. No other study included in this review portrayed couples' experiences so negatively. It is likely that different couples manage and cope in different ways, giving rise to a huge variety of experiences.

Researchers have directly challenged the emphasis on the deficits caused by dementia, and have highlighted the positives that can accompany these, particularly the personal and relational growth that can result from living with dementia (McGovern, 2011). While this review acknowledges some of the great challenges couples face when living with dementia (uncertainty, despair, loss etc.), which should not be understated, it also holds a strong message of resilience, highlighting the potential for couples to maintain a good quality of life and find benefits by cherishing the past and present, while maintaining a strong sense of interconnection.

*Clinical implications*

Services must recognise couples as the interdependent and dyadic unit they represent. Current practice often prioritises the monitoring and management of the individual's physical and cognitive decline, however greater emphasis should be placed upon encouraging togetherness and couplehood given that this is crucial to the couple's experience of dementia. This supports arguments for interventions that enable togetherness, rather than 'separateness' (McGovern, 2011).

Although services acknowledge the impact of dementia on a spouse or partner, the emphasis tends to be on supporting them as a 'carer'. The use of the term 'carer' implies a shift in power and responsibility, positioning people with dementia as care-recipients, thereby dichotomising and dividing the couple (McGovern, 2011; Molyneaux et al., 2011; Searson et al., 2008), which could undermine their efforts to sustain balance and promote each other's identities. Critiques of the term carer have been noted within the literature previously (Forbat, 2003; Molyneaux et al., 2011). Instead services should focus on couples as a partnership, particularly as this is what they are fighting to maintain.

Exploration of couplehood could form part of assessments and interventions, with both involving the dyad (Charlesworth, 2001). Efforts could be focussed on supporting the couple to collaborate within the home to enhance togetherness. This echoes the 'relationship-focussed approach' mentioned in the literature, and consistent arguments to reconceptualise dementia as a condition that effects relationships rather than individuals (Henderson & Forbat, 2002; McGovern, 2011). Such a focus on sustaining couplehood and maintaining a nurturing relationship offers more hope than focusing directly on the inevitable cognitive decline. Hope is important given the intense distress, despair, and hopelessness that couples can face.

Couples efforts to distance thoughts about the future with dementia has potential implications for information giving within services. Future uncertainty may be preferred over the harsh reality. Information could therefore focus on coping, resilience and maintaining the couple relationship. While important not to be dishonest, sharing the potential positive outcomes and benefits to relationships could foster hope for couples.

Where maintaining togetherness proves difficult for couples, joint interventions could be helpful. Such work could encourage the sharing of perspectives to foster greater attunement and collaboration. Some preliminary explorative research suggests couples' counselling when one member has a diagnosis of Alzheimer's disease could support the maintenance of the relationship and the preservation of both partners sense of self (Auclair, Epstein, & Mittelman, 2009; Epstein, Auclair, & Mittelman, 2006). However, interventions would need to be tailored to each couple due to the nuanced impact of the prior relationship on what will be desired and achievable (Ablitt et al., 2009). Couples' interventions could therefore increase the potential for positive outcomes, including increased closeness and affection, self-efficacy and coping (Ablitt et al., 2009).

This review suggests that couples could also benefit from approaches that encourage them to share their stories and reflect on their life together – enabling them to gain strength and make sense of their current situation. Services could for example, adopt a couples' life story approach, which supports partners to narrate the story of their life together (Scherrer, Ingersoll-Dayton, & Spencer, 2013). Such work could foster meaning for the couple, while enhancing their sense of connection.

#### *Future research*

Further exploration of the influence of prior relationship factors in the experience of dementia could help to establish what enables some couples to retain their couplehood



throughout the experience, whereas others struggle much more. This could highlight potential risk factors to enable services to identify couples who may need additional support. Additionally, research needs to understand what this means for individuals who live alone, or perhaps where other relationships are more significant (i.e. family relationships). Research may therefore benefit from exploring other close relationships.

The variety of methods used within the reviewed studies provide some important insights. The use of joint interviews allowed couples to support one another in telling their co-constructed and shared story (e.g. Daniels et al., 2007; Molyneaux et al., 2012), while researchers witnessed interactions and observed dynamics. Joint interviews therefore allowed togetherness to appear not only in the content of the discussion, but also demonstrated and witnessed within the couple's interaction. Joint methods therefore seem an important method for future couplehood research. However researchers also acknowledged that the nature of joint interviews meant that contextual aspects of the relationship may have influenced what each individual felt able to share (Clare & Shakespeare, 2004). Accordingly, a combination of both joint and individual interviews could offer a more holistic view to enhance understanding (Taylor & de Vocht, 2011).

### *Limitations*

The nature of meta-ethnography requires interpretation and while the researcher has endeavoured to ground interpretations in the content of the papers included and reduce the impact of their own bias, interpretations are ultimately subjective. The reasonably small number of studies included in this review may also be considered a limitation, however this has allowed exploration of these papers in greater detail to enrich understanding.

The quality of studies included within the review varied, however it is noted that the reflexivity of studies was rated consistently low. This was because the majority of studies

did not state how they checked credibility of interpretations to reduce individual subjectivity of researchers (Denzin & Lincoln, 2003). Evidence of reflexivity was therefore generally poor across the studies, and needs to be improved in future research.

### *Conclusion*

This review has synthesised findings from 10 studies that explored couples' experiences of dementia. Results have highlighted couples shared efforts to maintain their relationship in the context of great fear, uncertainty and hopelessness. Shifts in roles and power can present a threat to both members sense of identity, with the potential to erode their sense of couplehood. Couples therefore work to sustain and enhance couplehood, promote each other's identities, and ultimately find meaning in their lives together despite the difficulties dementia brings. These findings offer important insights, which can inform policy and practice to ensure services are meeting the needs of couples. Ultimately, this review adds further weight to arguments to refocus dementia care on relationships rather than individuals.

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Table 1

*Study characteristics of the 10 papers reviewed*

Article	Research question	Participants	Data collection	Type of analysis
Atta-Konadu, Keller, & Daly (2011)	To provide insight into the food-related role shift experiences of husbands and their wives with dementia - as a window into the lives and coping of couples with dementia	9 couples; Age: 58-88 years; Sex: 9 females with dementia, and 9 husbands. Diagnosis: dementia stages 2-5 (type not specified). Recruited from: dementia clinics in Canada.	Joint and individual interviews (60-90 minutes) once a year for 3 years	Grounded theory
Daniels, Lamson, & Hodgson (2007)	To focus on the couple's experience of Alzheimer's and the dynamics of their couple relationship	One couple who had been married 63 years; Age: mid 80's; Sex: female with dementia and her husband. Diagnosis of Alzheimer's 5 years prior. Recruited from: local centre for the aged in USA.	Single case study - 3 semi-structured interviews over 6 months	Holistic content narrative analysis
Davies (2011)	To gain a better understanding of couples' commitment to their marriage relationship, and how that commitment influenced the experience of dementia	6 married couples; Age: 65-83 years; Sex: 4 females and 2 males with dementia and their partners. Diagnosis of early stage Alzheimer's. Recruited from: Memory Assessment Clinics in Canada.	One semi-structured joint interview and quantitative measures	Mixed methods: Narrative, thematic, and content analysis and quantitative scales

Hellström, Nolan, & Lundh (2007)	To explore the ways in which people with dementia and their spouses experience dementia over time, especially the impact it has on their interpersonal relationships and everyday life	20 couples; Age: 65-85 years; Sex: 12 males and 8 females with dementia and their spouses. Diagnosis: most commonly mixed dementia. Recruited from: Assessment unit in Sweden.	Separate interviews with each spouse repeatedly over 5 years (1-6 interviews per spouse lasting 30-45 minutes). Some joint interviews towards end of research.	Grounded theory
Molyneaux, Butchard, Simpson, & Murray (2012)	(a) What impact dementia has on a couple's relationship, and a couple's relationship has on dementia; (b) How do couples co-create their account of couplehood in dementia?	5 cohabiting couples; Age: 72-84 years; Sex: 3 men and 2 women with dementia and their partners. Diagnosis of Alzheimer's received 1-4 years ago. Recruited from: CMHT in UK.	One semi-structured joint interview per couple (70-110 minutes)	Grounded theory
Phinney (2006)	(a) How do family members support the involvement of the person with dementia in activity; (b) What does this supported involvement mean to families?	7 couples and 1 adult-child care dyad; Age: 64-88 years; Sex: 4 men and 4 women with dementia and their carers. Diagnosis: Mild to moderate Alzheimer's disease diagnosed within 4 years prior. Recruited from: A geriatric research centre and support group in Canada.	3 individual interviews with each person (6 per dyad) over 6 months, supplemented with observations	IPA

Phinney, Dahlke, & Purves (2013)	To understand how people with dementia and their families perceive and interpret changing patterns of involvement and the meaning of these experiences	2 families (1 couple, and 1 couple with their 3 daughters); Age: people with dementia aged 74 and 80 years; Sex: both males with dementia, and their female partners. Diagnosis: Dementia diagnosis received within 6 months prior to study (type not specified). Recruited from: Speciality memory clinic in Canada.	Various individual and dyadic interviews over a 4 month period (9 hours of interview data in total), supplemented with observations and video recordings	IPA
Robinson, Clare, & Evans (2005)	To explore psychological reactions to a diagnosis of dementia in couples and its impact on their relationship	9 married couples; Age: 65-85 years; Sex: 5 women and 4 men with dementia and their partners. Diagnosis of Alzheimer's ( $n = 7$ ) or vascular dementia ( $n = 2$ ), in the early stages and received within 2 years prior to participation. Recruited from: Memory Clinics in UK.	One semi-structured joint interview per couple (20 - 90 minutes)	IPA
Svanström & Dahlberg (2004)	To investigate the lived experience of dementia for spouses where one of them is diagnosed with dementia	5 married couples; Age: 72-80 years; Sex: 2 females and 3 males with dementia and their spouses. Diagnosis of dementia (specific types and stages not stated). Recruited from: Primary care within the community in Sweden.	Separate unstructured interview with each spouse (40-80 minutes) based on diary entries	Phenomenological approach using life-world theory

Vikström, Josephsson, Stigsdotter-Neely, & Nygård (2008)	To identify and describe how people with dementia and their spouses perceive their own, their spouses' and their mutual engagement in everyday activities	26 cohabiting couples; Age: 59-86 years; Sex: 14 males and 12 females with dementia, and their opposite sex partners. Diagnosis: Mild to moderate Alzheimer's or Vascular dementia (received within 8 months prior to study). Recruited from: Memory assessment units in Sweden.	Individual semi-structured interviews with each partner (10-50 minutes)	Grounded theory
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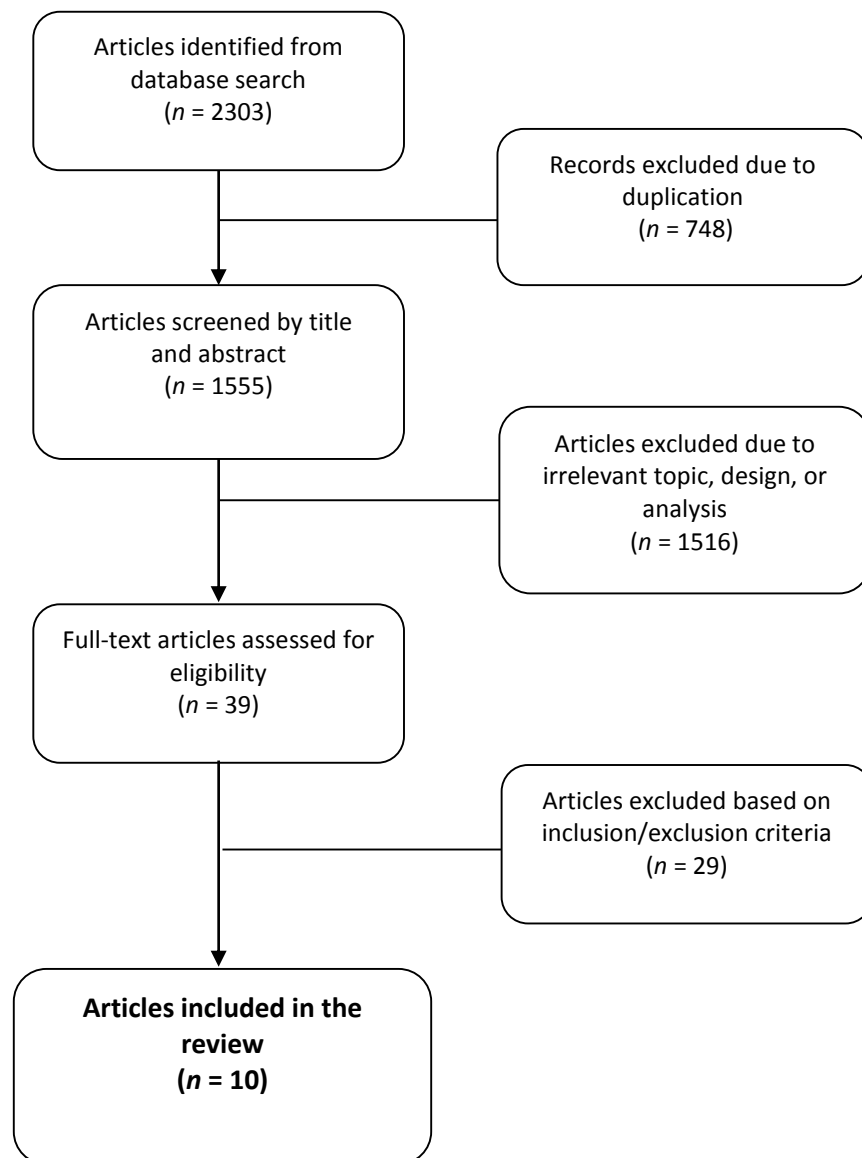
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Table 2.

*Quality assessment of the papers reviewed, based on the CASP tool.*

Article	Design	Sampling	Data collection	Reflexivity	Ethical issues	Analysis	Findings	Value	Total score
Atta-Konadu, Keller, & Daly (2011)	3	2	2	1	2	3	3	3	19
Daniels, Lamson, & Hodgson (2007)	2	3	3	3	2	3	3	2	21
Davies (2011)	2	2	2	1	2	1	2	3	15
Hellström, Nolan, & Lundh (2007)	3	3	3	1	3	3	3	3	22
Molyneaux, Butchard, Simpson, & Murray (2012)	3	2	3	2	3	3	3	3	22
Phinney (2006)	3	2	3	2	2	2	3	3	20
Phinney, Dahlke, & Purves (2013)	2	2	2	2	2	3	3	2	18
Robinson, Clare, & Evans (2005)	3	2	2	2	2	3	3	3	20
Svanström & Dahlberg (2004)	2	3	3	1	2	2	3	2	18
Vikström, Josephsson, Stigsdotter-Neely, & Nygård (2008)	3	3	2	1	2	3	2	2	18





*Figure 1.* Flowchart of the literature search process.

**Appendix 1-A: Table Illustrating Merging of Original Themes into Review Themes**

Article	Themes from the original article	Final themes from this review <sup>a</sup>
Atta-Konadu, Keller, & Daly (2011)	The sliding into food role process <i>Reciprocating nurturance</i> <i>Navigating through food roles</i>	Upsetting and redefining the balance Togetherness / Sensitive attunement Sensitive attunement / Resilience
Daniels, Lamson, & Hodgson (2007)	Global Impression <i>Positive reflections</i> <i>Lifelong commitment</i> Theme 1: Perspectives and preparation for future changes Theme 2: Family influences and social support <sup>b</sup> Theme 3: Life evaluation Theme 4: Experiences with AD	Resilience Togetherness Togetherness / Resilience  Resilience Upsetting and redefining the balance
Davies (2011)	Relationship impact - pre-diagnosis: 'Something's going on' Relational impact – diagnosis: 'Looking for answers' Relationship impact – post-diagnosis: 'Us with a future' Theme 1: Partnership for life Theme 2: Reciprocity Theme 3: Resilience Theme 4: Forgiveness	Togetherness / Resilience Resilience Togetherness Togetherness Upsetting and redefining the balance / Togetherness Resilience Resilience
Hellström, Nolan, & Lundh (2007)	Sustaining couplehood <i>Talking things through</i> <i>Being affectionate and appreciative</i> <i>Making the best of things</i> <i>Keeping the peace</i>  Maintaining Involvement <i>Playing an active part</i> <i>Taking risks</i>	Togetherness / Sensitive attunement   Resilience  Upsetting and redefining the balance / Sensitive attunement

	<i>Handing over</i> <i>Letting go</i> <i>Taking over</i>	
	Moving on <i>Remaining a 'we'</i> <i>Becoming an 'I'</i> <i>New beginning</i>	Upsetting and redefining the balance / Togetherness
Molyneaux, Butchard, Simpson, & Murray (2012)	Shifting identities within couplehood Maintaining the relationship despite dementia The good old days Technically being a 'carer' Sharing the experience of dementia	Sensitive attunement Togetherness / Sensitive attunement Resilience Upsetting and redefining the balance Togetherness
Phinney (2006)	Reducing demands Guiding Accompanying	Upsetting and redefining the balance Togetherness / Sensitive attunement Togetherness / Resilience
Phinney, Dahlke, & Purves (2013)	The best kind of man <sup>b</sup> It's a little different now You have to do something	Togetherness / Upsetting and redefining the balance Sensitive attunement / Resilience
Robinson, Clare, & Evans (2005)	Not quite the same person, tell me what actually is wrong <i>Theme 1: You don't notice straight away</i> <i>Theme 2: Coming to the conclusion</i> <i>Theme 3: I quite accepted it</i> <i>Theme 4: It did nothing for me</i> <i>Theme 5: Coming here helped</i>	
	Everything's changed, we have to go from there <i>Theme 6: I would say I have changed</i>	Togetherness / Resilience

	<i>Theme 7: Taking over the reins</i> <i>Theme 8: Take it as it comes</i> <i>Theme 9: Coping very well</i> <i>Theme 10: I wouldn't mind doing it all again</i>	Upsetting and redefining the balance / Resilience
Svanström & Dahlberg (2004)	The essence of living with dementia Imbalance in responsibility  Futility Hopelessness Homelessness	Togetherness / Resilience Upsetting and redefining the balance / Togetherness  Resilience / Togetherness Resilience Sensitive attunement / Togetherness
Vikström, Josephsson, Stigsdotter-Neely, & Nygård (2008)	Perceived changes in activity engagements Consequences of experienced changes <i>Loss of social engagements</i> <i>Changes in relationship</i>  Dilemmas experienced by the caregivers <i>Interfering with the spouses engagement or not</i> <i>Placing the spouse's or one's own needs first</i>  Caregivers' management approaches to handle changes <i>Encouraging initiatives from the partner or taking over chores</i> <i>Lowering demands or avoiding potentially problematic engagements</i> <i>Collaboration</i>	Togetherness Resilience / Togetherness/ Upsetting and redefining the balance  Sensitive attunement  Resilience / Togetherness / Sensitive attunement

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*Note.* Subthemes denoted by italics.

<sup>a</sup> Final themes from this review are referred to by shortened titles.

<sup>b</sup> These themes were excluded from analysis as they did not focus on the couple experience.

## Appendix 1-B: Author Guidelines for Target Journal

### Manuscript Submission Guidelines

#### ***Dementia: The International Journal of Social Research and Practice***

1. [Peer review policy](#)
2. [Article types](#)
3. [How to submit your manuscript](#)
4. [Journal contributor's publishing agreement](#)
  - 4.1 [SAGE Choice and Open Access](#)
5. [Declaration of conflicting interests policy](#)
6. [Other conventions](#)
7. [Acknowledgments](#)
  - 7.1 [Funding acknowledgement](#)
8. [Permissions](#)
9. [Manuscript style](#)
  - 9.1 [File types](#)
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    - 9.4.1 [Keywords and abstracts: Helping readers find your article online](#)
    - 9.4.2 [Corresponding author contact details](#)
    - 9.4.3 [Guidelines for submitting artwork, figures and other graphics](#)
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*Dementia* publishes original research or original contributions to the existing literature on social research and dementia. The journal acts as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families.

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*Dementia* operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

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*Dementia* welcomes original research or original contributions to the existing literature on social research and dementia.

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**Section Two: Research Paper**

**Families' Experiences of Changing Roles and Relationships When One Family  
Member has Dementia**

Word Count: 8,000

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Prepared for submission to *Ageing and Society*

**Abstract**

Growing recognition of the relational elements of the dementia experience, has led to an increase in the number of dyadic studies. However, there is still minimal understanding of how dementia impacts upon the family as a system. This qualitative study aimed to address this gap and shed further light on the changing roles and relationships between family members in the context of dementia. The experiences of seven family units, in which one person had a diagnosis of dementia, were analysed using interpretative phenomenological analysis. Key findings related to conflicting identities, striving for connection and belonging, a chain of support, shifting power and control, and finding hope within fear and uncertainty. Collectively results reflected a core struggle between maintaining relationships and identities as they were, and adjusting or redefining to accommodate change. Ultimately, findings suggest the experience of each individual is a result of complex interactions between family members, which adds further weight to arguments for relationship focussed care. There is also a clear need for interventions to involve the whole family system, to encourage connection and belonging and enhance the natural therapeutic capacity of families.

**Keywords**

Dementia; experience; families; relationships

**Families' experiences of changing roles and relationships when one family member has dementia**

An estimated 44 million people are living with dementia worldwide - a figure predicted to more than treble within 40 years. The annual global cost of dementia, currently some \$604 billion, is also increasing exponentially (Alzheimer's Disease International [ADI] 2013). Unsurprisingly dementia was declared an international public health priority (World Health Organisation [WHO] and ADI 2012), prompting considerable investment in services to ensure best possible care for people with dementia.

Dementia is considered a 'chronic illness' requiring long-term care focussed on prolonging and improving quality of life for the person and their family (Department of Health 2009, WHO and ADI 2012). Historically dementia research has focussed on deficits and factors affecting deterioration, giving the impression that dementia is universally devastating; researchers have, therefore, argued for a greater focus on strengths and adjustment to the diagnosis, informing development of effective interventions to enhance quality of life (McGovern 2011). A multitude of factors (e.g. personal background, living environment, relationships, and societal factors) can influence and be influenced by an individual's self-esteem, quality of life and overall experience of dementia (Cheston and Bender 1999, Kitwood 1997, O'Connor *et al.* 2007).

Healthy adjustment to chronic illness involves maintaining a positive view of oneself and the world despite illness (de Ridder *et al.* 2008, Sharpe and Curran 2006). The progressive nature of dementia means individuals are continually adjusting to new losses (Charmaz 1995). Understanding adjustment is vital to ensure interventions

support and enhance this process, reducing necessity for long-term care (Sharpe and Curran 2006).

An integrative model of adjustment to chronic illness has been proposed (Sharpe and Curran 2006), which synthesises aspects from a number of theorists. This suggests that adaptation to illness depends upon the congruity between an individual's beliefs about the illness, themselves and the world. Where there is considerable mismatch, individuals firstly attempt to adjust the meaning of the illness (e.g. looking for benefits). Where incongruence remains they attempt to adjust their beliefs about how to manage the illness (i.e. coping rules). If still unsuccessful they may ultimately attempt to adjust their beliefs about self and the world (e.g. redefining values). This process can result in positive outcomes, whereby an individual separates the illness from the self and copes effectively, rather than feeling defined by the negative aspects of the illness, resulting in poor psychological functioning (Sharpe and Curran 2006).

This struggle to avoid becoming defined by the illness signifies the fundamental assault on identity that chronic illness can present (Bury 1991, Charmaz 1983). To accept that one's body, and in the case of dementia one's mind, is changing and deteriorating can undermine self-image, self-worth, values and integrity (Charmaz 1995). Evidence suggests that in response to the existential threat dementia can present, individuals tend to oscillate between 'self-maintaining strategies', which minimise impact and preserve continued identity, and 'self-adjusting strategies', which confront the difficulties and adjust identity accordingly (Clare 2003).

However others' constructions of our identity also influence our sense of self (Sabat and Harré 1992). Stereotypes of people with dementia as 'old', 'useless' (Bender 2014, Cheston and Bender 1999), 'mad' and 'mentally ill' (Langdon, Eagle and Warner 2007) create significant and enduring stigma (Crisp *et al.* 2000). This only

serves to disempower, intimidate and infantilise people with dementia (Cheston and Bender 1999, Kitwood 1997) as others begin to view them as 'dysfunctional patients' (Sabat, Napolitano and Fath 2004). Maintaining one's sense of self therefore becomes even more difficult (Langdon, Eagle and Warner 2007).

Much of the literature around identity and adjustment focusses on understanding experience from an individual perspective. However, dementia does not impact upon the individual in isolation; changes also affect the experience and wellbeing of those around them (Quinn, Clare and Woods 2009). Studies suggest relatives often adopt a caregiving role, the impact of which can be stressful and burdensome, resulting in increased risk of both physical and mental health problems for relatives (Schulz and Martire 2004). However, research focussing on one relative alone is unable to address more interactional elements of relationships. Systemic theorists argue that people are best considered as 'persons-communicating-with-other-persons' (Watzlawick, Beavin and Jackson 1967) thereby acknowledging relationships between people that influence experience. Viewing the family as a system enables exploration of relational elements of dementia experience and adjustment, with the ultimate aim of developing interventions to target the whole family rather than each member individually (Garwick, Detzner and Boss 1994).

Family systems theory describes how family members must be seen as a group of interconnected, interdependent individuals with complex relationships which create the family unit (Jones 1993, Nichols and Schwartz 1998). Families establish unique patterns of interrelating, involving rules, roles, and routines which become familiar, thereby providing safety, stability and equilibrium (Carr 2000). A healthy and reliable network of relationships can create a secure family base (Byng-Hall 1995). The actions and feelings of each individual both respond to and elicit those of others (Fredman



2010, Jones 1993). Problems are thereby considered circular rather than a simple linear model of cause and effect (Carr 2000). Therefore when changes affect one member of the system reverberate through all members (Bateson 1972, 1979), and families must work together to re-establish security and equilibrium (Nichols and Schwartz 1998), continuously adjusting to evolving demands across the life course (Carr 2000). The progressive nature of dementia therefore presents additional challenges in this process of adjustment.

These wider systemic influences are acknowledged in UK dementia strategies (e.g. Department of Health 2009), and internationally (WHO and ADI 2012). However people with dementia are often separated from their family in both research and practice (Keady and Harris 2009). With family members' experiences so inextricably linked, research must explore these systemic elements further, with the ultimate goal of ensuring dementia care services meet the needs of the whole family. Adopting a family systems approach within dementia research allows insight into the complex circular patterns of difficulties and shared experiences of adjustment (Purves and Phinney 2012); thereby acknowledging dementia as an illness affecting relationships rather than individuals alone (McGovern 2011).

Recognition of the above issues has led to studies adopting joint interview methods with family dyads where one person has dementia, generally focussing on couples (Molyneaux *et al.* 2012, Robinson, Clare and Evans 2005). Joint interviews allow exploration of co-constructed meaning and experience: each member's account supporting, prompting or supplementing another to provide a more holistic view (Kosny 2003). Such research has highlighted notions of shared identity and couplehood, with both partners working to maintain their relationship despite dementia. To further

understand systemic elements, research must explore shared experiences of the family as a unit (O'Connor and Purves 2009).

This study aimed to explore collective experience of the family unit when one member has dementia. More specifically, it endeavoured to identify how families co-construct meaning, manage roles and relationships and adapt to change. Qualitative research methods can provide an in-depth understanding (Elliott, Fischer and Rennie 1999), which can facilitate exploration of the intricate, nuanced and interactional relationships within families (Åstedt-Kurki, Paavilainen and Lehti 2001). Furthermore, the method of interpretative phenomenological analysis (IPA; Smith and Osborn 2008) enables detailed focus on unique meaning-making and lived experience of dementia for each family unit. It was envisaged this would enhance understanding of families' experiences of dementia, and highlight how dementia services can recognise and best meet the needs of the whole family system.

## **Method**

### *Design*

A qualitative research design was adopted to gain detailed information via semi-structured interviews. Members of Lancaster University Public Involvement Network (LUPIN), a group of experts by experience, provided guidance on design. One member of LUPIN with relevant personal experience offered consultation throughout the project, along with professionals from local memory assessment services, dementia support services and stroke teams. Their input informed design and ensured materials were adjusted appropriately for people with dementia.

Interpretative phenomenological analysis (IPA; Smith and Osborn 2008) was used to explore families' lived experiences of dementia and their shared meaning-making. IPA acknowledges the subjectivity of the analyst who applies their own

interpretations to participants' accounts of experience – known as the double hermeneutic (Smith and Osborn 2008). IPA was originally developed for use with individuals, enabling an idiographic focus on understanding subjective experience (Smith 2004). While this study did not focus on individuals, it retained an idiographic commitment by focussing on experience of each family unit in detail and elaborating the experiences of individuals within. The small sample is ideal for IPA to elucidate in-depth the phenomenological experience of a small homogenous group (Smith, Flowers and Larkin 2009). While individually participants represented a diverse group (gender, age, role, etc.), as collective family units they comprised a more homogenous group as they were all living with early-stage dementia.

#### *Ethical approval*

The project was approved by the National Research Ethics Service, and the local Research and Development department. Additional approval was gained from the Alzheimer's Society for Dementia Advisors to help identify suitable families. A key ethical issue considered was gaining consent from adults with cognitive difficulties. The ability to provide informed consent was a criterion for recruitment, although participants' understanding was checked prior to interview. Capacity to consent was assumed unless evidence suggested otherwise (UK Mental Capacity Act 2005).

#### *Sampling and participants*

Families were recruited via staff from memory assessment services across the north of England, while staff employed by the Alzheimer's Society supported identification of families. Seven 'family units' participated in the research; each unit included a person with dementia and two relatives ( $N = 21$ ). No definition of 'family' was imposed; participants therefore decided which relatives took part. For practical reasons one criterion was applied to 'family': two or more relatives had to be willing to

participate along with the person with dementia. This prevented the research becoming a study of couples' experiences, and encouraged representation from more than one generation.

Inclusion criteria regarding other aspects included: (a) one family member had a diagnosis of dementia (any type); (b) all persons were able to engage in conversation about experience; (c) all persons were able to give informed consent to take part. To maintain homogeneity of the sample, families were excluded if the person with dementia was in residential care. No criteria determined time since diagnosis, as this does not necessarily reflect conversation ability or duration of memory difficulties.

Of the fourteen families initially contacted, five did not meet inclusion criteria (e.g. not enough participating relatives), one person with dementia changed their mind, and one family could not participate due to illness. Furthermore, one participating family arranged a second interview, which they later cancelled as the person with dementia did not wish to continue. However, all family members consented for the initial data to be included in the research.

Of the seven people with dementia, four were women and three were men, and all were aged between 61 and 82 ( $M = 73$ ). Their diagnoses included Alzheimer's disease ( $n = 3$ ), vascular dementia ( $n = 3$ ), and mixed dementia ( $n = 1$ ), received between nine months and four years prior. Relatives included partners (aged 64-82;  $M = 74$ ) and adult-children (aged 38-50;  $M = 45$ ). Detailed participant characteristics are illustrated in Table 1. Within results, people with dementia are referenced by a pseudonym (e.g. Ron), while relatives are referenced by their relationship to the person with dementia (e.g. Ron's wife).

[INSERT TABLE 1 HERE]

#### *Data collection*

Staff members (memory nurses and dementia advisors) identified families who met criteria and requested their consent to be contacted. After telephone contact by the researcher, families were sent the information sheet. A second call was made to seek consent and arrange the interview. Interviews took place within people's homes and while capacity was assumed (UK Mental Capacity Act 2005), understanding was checked at the outset. Family members signed consent forms; the person with dementia was supported if necessary. The interviewer remained alert to changes throughout and where appropriate reiterated information and re-checked understanding.

An interview schedule was constructed in light of previous research and consultation with staff. This guided discussions through questions such as 'What has family life been like since you received the diagnosis?'. The schedule was repeatedly reviewed and adjusted to ensure meaningful data was collected. For example revision after the first interview resulted in including more generic questions to allow more spontaneous and open discussion.

Interviews lasted between 40 and 85 minutes ( $M = 69$  minutes) and were digitally recorded. After each interview the debrief sheet was presented, which reminded families of key information and sources of support. Interviews were later transcribed.

### *Data analysis*

Data were analysed inductively, using IPA to interpret accounts (Smith and Osborn 2008). Analysis involved repeated reading of a transcript while noting descriptive, linguistic and conceptual comments in the margin (Appendix 2-A). These were then clustered by moving iteratively between individual quotes, the family account, and the whole transcript to formulate meanings and develop themes. Colour codes denoted data derived from each participant, which allowed the researcher to

check themes reflected family experience as a whole. Narrative summaries of themes were then written (Appendix 2-B). Re-reading transcripts with the summaries in mind facilitated evaluation of theme coherence and accuracy in reflecting the family's experience.

This process was conducted separately for each transcript; previous findings were bracketed to allow fresh and detailed analysis for each family in turn (Smith, Flowers and Larkin 2009). Analysis then continued across transcripts, synthesising meanings by moving back and forth between each family unit and the data as a whole; this resulted in higher-order interpretations which became final themes (Appendix 2-C). Results are presented with supporting quotations to evidence interpretations and enhance transparency of analysis (Elliott, Fischer and Rennie 1999).

#### *Quality and rigour*

Conversations with supervisors about emerging themes reduced subjectivity and improved analytic rigour, ensuring themes were coherent and appropriately evidenced. For example, feedback regarding final themes encouraged the researcher to maintain a focus on families as a whole rather than privileging individuals. Further credibility checks, essential to qualitative research (Elliott, Fischer and Rennie 1999), were completed with a group of colleagues with experience using IPA. Excerpts of transcripts were coded by group members and discussed in relation to emerging themes, providing additional assurance of the consistency and coherence of analysis.

#### *Reflexive stance*

When conducting qualitative research it is important to make transparent my own views and experiences (Elliott, Fischer and Rennie 1999) to support my own reflections, while allowing readers to draw their own conclusions as to the extent these influenced the research. I am a trainee clinical psychologist, with previous professional

experience working within a memory assessment service. In this role I noticed the influence dementia had on the whole system around an individual, which motivated me to explore systemic influences further through research. I have also witnessed the impact dementia can have on relatives through personal experience. The common dementia discourse, to which I too am exposed, often portrays a bleak picture with emphasis on medical explanations. However through my professional training I have developed a more critical stance, and naturally apply psychological concepts to understand the impact of dementia.

I made concerted efforts to minimise my own influence by maintaining a reflexive stance (Ahern 1999) - 'bracketing' my own experiences, beliefs and assumptions to communicate families' experiences as accurately as possible. The research process particularly challenged my beliefs around diagnosis and medication, for which my reflective journal proved useful to support the process of bracketing (Appendix 2-D). Conversations with supervisors also supported maintenance of a reflexive stance.

## **Results**

Analysis resulted in five themes: (1) Conflicting identities: person or 'dementia patient'; (2) Loneliness and isolation: finding ways to maintain belonging and connection; (3) Family support: protecting and enabling; (4) Feeling trapped: shifting power and control; and (5) Fear and uncertainty: making sense and reigniting hope.

### *Conflicting identities: person or 'dementia patient'*

The meaning of dementia presented conflicting identity issues as family members struggled to reconcile the diagnosis with the person's identity. The deteriorating abilities of the person with dementia were frequently highlighted by relatives, which undermined the identity of the person with dementia and signified their

developing dementia status. Meaning of dementia was influenced by family members' previous understandings and assumptions:

Mary's step-daughter: It's not portrayed on the TV as somebody who goes about everyday...life normally like you do.

Mary: Yeah.

Mary's step-daughter: You see an old lady sitting in a corner dribbling or not knowing where she is, whereas you...you're not like that.

This spotlights common conceptions and stigma that underpinned family members' understandings and conflicted with their perceptions of the person with dementia.

For some families dementia signified being different and almost less human, which seemed far removed from the person's previous identity, therefore dichotomising the idea of the person, and the emerging 'patient' identity. Accepting a diagnosis of dementia was effectively accepting a fundamental change in self-image whereby the person becomes a 'dementia patient'. The description of being hit by a "bomb" (Sue), conveyed the distress and devastation – violently destroying the person beneath. This sense of existential threat also influenced relatives' internal representations of their loved one. These understandings generated a sense of shame, particularly for the person with dementia, about how others may perceive them – reflected in statements such as "I'm not that daft" (Ron), demonstrating efforts to distance these conceptions. Occasionally relatives reinforced conceptions referring to the person with dementia as "the patient" (June's son).

Family members became acutely aware of others' reactions to the diagnosis. Ted described his neighbour's reaction when he became disorientated outside his own home:



Ted: I was sat on the wall like a little boy wondering where I am, and I thought well there's only one way, I'll have to ask [...] and the first thing she did was bring all her kids in, I always remember that, because it seems funny.

Ted's wife: ...but that was medicine from the doctor [...] that was very scary because I wasn't here you see...

Ted: It was very scary for me really [...] You wouldn't think you could lose yourself would you?...How can you lose yourself?

Ted's wife: Well you can! You've never done that again, but I think...I'm convinced that was the tablets.

The lost little boy image emphasised Ted's feelings of vulnerability and fear as he experienced a loss of himself, further evidencing existential threat. Ted's description of his neighbour's reaction implied concern that others perceive him as strange, echoing the 'dementia patient' identity.

In an effort to resist the unwelcome dementia status families attributed difficulties to other causes, just as Ted's wife above, blamed medication rather than seeing the behaviour as part of him. Ron, Ted and Sue attributed all changes to other causes, not acknowledging any impact of the dementia. These families had received the diagnosis most recently, so resistance may have characterised initial reactions to diagnosis. Ron and Sue's relatives perceived their resistance as 'denial'; their subsequent efforts to encourage acceptance led to exposing flaws. As 'denial' effectively preserved identity, relatives' challenges inadvertently undermined this protective mechanism, only serving to strengthen resistance of the person with dementia and polarise positions within the family.

Some relatives showed implicit awareness of the impact of the dementia status on the individual, and strived to nurture their family member's threatened self. They

offered praise and emphasised their abilities, thereby preserving identity. Relatives often concealed mistakes, or reframed loss positively:

Jim's daughter: You driving everywhere, it's not a good thing when you're getting older, it's better that she [Jim's wife] gets behind the wheel...because that's what happened to [aunty] isn't it, aunty never drove, [uncle] drove everywhere, and when he died she was stuck then wasn't she?

Jim: That's right.

Jim's daughter: Remember you had to take her out...teaching her how to drive again. So we didn't want that for mum did we?

Jim: No.

The notion that giving up driving was to support and teach his wife enabled Jim to assume an empowered rather than enfeebled role. While relatives' efforts promoted the identity of the person with dementia, they also preserved their personal representations of their loved one.

Mary's family expressed immense pride in her achievements and described her transition from "being like...not a vegetable exactly but 'I've got vascular dementia I'm going to be useless'", to finding meaning and purpose: "She then suddenly had a new aim, a new...venture in life". The restoration of her role appeared to quieten, although not entirely silence, the conflicting 'patient' identity.

*Loneliness and isolation: finding ways to maintain belonging and connection*

Reducing ability sometimes precluded active participation of the person with dementia, leading to feelings of isolation and exclusion from the family, but to avoid this, families promoted belonging through shared time. An individual's dementia status naturally separated them from the family as they were alone in their experience: "you're [relatives] not in the position that I'm in! [...] and I wouldn't like you to get in my

position [Becomes tearful]" (Sue). Some people with dementia felt abandoned by certain relatives, resulting in blame and resentment. Whereas other families shared a sense of abandonment from services, effectively externalising blame and enabling greater cohesion.

Some relatives found the exclusion of the person with dementia distressing and unsettling:

Ted's wife: ...you're just a little bit slower to answer and people haven't the patience. So...they don't listen to what he has to say. I found that.

Ted's daughter: Have you?

Ted's wife: Yeah, I do find that. I've probably done it myself, you know. [...] If sometimes I ask you something Ted and you don't...you have to think about how to reply?

Ted: Yeah I must admit sometimes it does take me as though you've not taken any notice.

Ted's wife: That's right yeah. As though you're ignored, and that's upsetting.

Ted conveyed a sense of invisibility that echoed the content of his visual hallucinations, which he described as "seeing people who are there but not really there", and although he recognised them, nobody spoke to him. Some families experienced this sense of exclusion as separate lives. For example June's family lived in the same house and her son commented: There's a lot to be said for...a flat pack house in the garden, [...] so therefore 'that's my [June's] world' and this is our world. Reference to 'worlds' highlighted a sense of great separation even though they lived together.

However, togetherness was important and therefore promoted within most families. They found ways to involve everyone in conversations, fostering an important

sense of belonging, which reduced feelings of loneliness. Relatives also encouraged greater connection between others:

Sue's daughter-in-law: at the end of the day, when we all go home, you two have got each other.

Sue's husband: Yeah.

Sue's daughter-in-law: That's not to say I'm not here, but I go home to my family, [your daughters] go home to theirs [...] you've got each other... and you've got to make the best of each other.

Sue: Yeah I know.

Sue's daughter-in-law: I know you could kill him at times, I could kill your son at times [all laugh]... They might say the same [laughs], but you know, at the end of the day we all go home and it's you two left.

This family interaction seemed therapeutic and reflected the importance Sue's daughter-in-law attached to maintaining her parents' relationship. Family members enjoyed witnessing the contentment of others – this contagious happiness reverberated through families.

The humour in the quote above was an important element of all interviews, representing an important coping strategy. Humour prompted shared laughter, enhancing togetherness. Families maximised time spent together which became more precious in the context of dementia. They communicated belonging by referring to themselves in terms of 'we' and 'us':

Liz's 1<sup>st</sup> son: I think we're...equally close...

Liz: Oh yeah.

Liz's 1<sup>st</sup> son: we're...it's just us three as such. [...] there's always been us three.

Liz's 2<sup>nd</sup> son: [...] So it's us three really.

This repetition highlighted shared identity and emphasised the importance of the family as a unit. Moreover, talk of relatives who were not present created a sense of belonging to the wider family.

*Family support: protecting and enabling*

Empathy underpinned family support networks, which protected and enabled individuals. A relative's presence for practical and emotional support provided reassurance, enabling the provision of care to another. This represented a chain of support whereby each relative primarily supported the next - the supported becoming the supporter to another family member:

Jim's daughter: ...It's a knock on effect. It's not just looking after dad, it's caring for mum, so she can care for him. To me, mum's the bigger worry, I've got to make sure she's ok, so she can see to dad.

Jim's wife: It's the carer looking after the carer looking after the patient [laughs].

Jim's daughter: It really is yeah!

This chain of support included those not present; for example Jim's daughter appreciated the "back-up" received from her husband and children.

Providing support included protecting the individual's best interest and advocating on their behalf, particularly regarding services. Accordingly, Jim's wife fought for him to receive extra care services, and Jim's daughter fought for her mother to receive respite care. However, the person with dementia was effectively depicted at the end of the chain - supported by others but not obviously supporting anyone else. Awareness of this could reinforce existential threat as their supporting role was undefined. Support provided by the person with dementia seemed less practical and therefore less obvious, but their concern for their family and efforts to protect them

continued: "You know what your mam is. [...] She's not so good herself. Anyway I do know she's meant to be going to the doctors...I'll be glad, you know, when she's been and gets treatment" (Ron). Although perceived as unidirectional, much of the support seemed reciprocal, albeit not returned to the same degree as provided.

Furthermore the type of support provided by relatives seemed to have changed since the diagnosis. Relatives described supervising or guiding the person with dementia:

Liz: You look after my interests.

Liz's 1<sup>st</sup> son: Just like supervising really...I'm not...someone who's going to say, don't do that...I let you do most things...I just say, I wouldn't do it like that, why don't you try it like this, and try to help you out that way.

Liz: Yeah, sometimes I go out without my purse...

Liz's 1<sup>st</sup> son:...yeah so I always make sure if she's going to the shops, I just say, have you got your phone? Have you got your purse?

Such prompts enabled people with dementia to maintain independence, despite extra support. Sue's daughter-in-law described "steering" Sue, sharing the responsibility rather than leaving her to manage alone, which emphasised the notion of providing 'back-up' support.

Underpinning these support mechanisms was the ability to empathise. Receiving the diagnosis enabled relatives to understand that the individual's mistakes were not deliberate: "you've to stop yourself getting annoyed, whereas if you didn't know, you'd be really... you'd be furious wouldn't you? If you'd to keep answering the same questions over and over again" (Ron's wife). Frustration at their forgetfulness was therefore replaced by acceptance. Mary's family developed the motto 'you've got a condition', allowing them to forgive mistakes and laugh instead.

Reduced empathy disabled these support mechanisms, provoking frustration for families. Relatives were angered by wider family who dismissed the impact of dementia. Sue's daughter-in-law explained the lack of support from wider family: "they seem to be ostrich-ing everything [...] they just don't get it". She referenced the myth that ostriches bury their head in the sand when threatened, reflecting family members' refusal to accept the diagnosis.

Even very understanding relatives occasionally struggled to appreciate each other's position, provoking frictions:

Mary's husband:...it's like oh for god's sake, how many times do I need to remind you?...That's my frustration.

Mary: So when he snaps at me...

Mary's step-daughter: Sets you off doesn't it?

Mary:...then I get upset...and then I go 'I can't help it'. It's horrible, and I do understand that it must be frustrating...for other people.

This mirrored frustration provoked mutual blame. Families with a more recent diagnosis particularly struggled to empathise, bringing tension and conflict.

*Feeling trapped: shifting power and control*

Families experienced changes in power and control within their relationships sometimes resulting in feeling trapped. The supervisory support relatives provided implied subtle power imbalances, more pronounced within certain families. Relatives sometimes sanctioned or prohibited activities undertaken by the person with dementia, suggesting permission was required from another exerting control. For example being prevented from driving provoked feelings of restriction and dependency.

Several adult-children described increasing responsibility, implying a growing sense of power and authority: "I'm trying to teach you" (Liz's son). Adult-children often experienced role reversal, as they assumed a parental position:

Ron's son: ...when I was a child, they were me parents and that was that.

Obviously you grow older [...] when...one of your parents gets to that age and has health issues, you become in a caring role. I feel as though there are things I'd have to say to him, that you're not doing it. Whereas obviously...40 years ago he would have said to me...you're not doing such a thing.

While not completely comfortable with this role-reversal, he described it as "the natural progression of things", as he returned the care he received as a child.

Increased supervisory control could lead people with dementia to feel restricted - particularly for June as she was prevented from accessing certain rooms in her home:

June: I knock on the door, and I can't...they don't let me in [laughs].

June's son: So therefore she could get a little bit annoyed about that, and it's how we talk to her about her room, keeping it clean and so on. Perhaps she'll get annoyed about that.

June: I don't get annoyed about it but it does...it does you know...I do try!

This sense of being trapped mirrored general feelings as people with dementia became more dependent and resented restrictions.

Restriction was also experienced by relatives who perceived a lack of choice, taking responsibility by 'default'. They believed they must adapt and support, experiencing guilt when unable to do so:

Ted's wife: You felt very, very guilty that you're not here, but if you don't do something. If I don't do something for myself, I'd just feel like a bit of a prisoner.



Ted's daughter: Yeah and it also makes me erm...and I suppose my sister feel like we should be doing more...We are restricted working nine 'till five Monday to Friday...

This mirrored the sense of imprisonment expressed by people with dementia. Relatives described gradually accepting a "curtailed" life (Jim's wife). Recognising this, provoked those with dementia to worry they were a burden:

Jim: Oh I'm a nuisance you know [said to Interviewer]

Jim's daughter: No you're not, not at all.

Jim's wife: No, no!

People with dementia seemed to oscillate between feeling burdensome to relatives and resisting restriction, which may reflect conflicting identities.

The mutual sense of restriction often provoked conflict within interviews and aroused resentment and blame between family members:

Ron's wife: It's that long since you've driven, it's not worth bothering about.

Wherever you go, we can go and it's no hassle.

Ron: It's alright you saying these things 'we can take you, we can take you', what about me wanting to take myself?

Ron's wife: [...] It's not wise when you've not driven for such a long time.

Ron:...Well I don't think it would be a problem, it's just you [wife]. You just stop me from doing everything!

Some people with dementia resisted others' control, rebelling against commands to reassert power. Such rebellion increased tensions and conflict. June's family referenced war metaphors repeatedly, such as 'battles', 'fights', and "World War four". June's son remarked that he and his wife previously acted like "little Hitlers" by dictating rules, epitomising this sense of power imbalance. Families who received a

more recent diagnosis exhibited greater conflict, potentially reflecting initial struggles to adjust.

This theme was not apparent for Mary's family; with four years to adjust to the diagnosis they had established a role and purpose for Mary, restoring independence and reducing the power imbalance

*Fear and uncertainty: making sense and reigniting hope*

The diagnosis of dementia was frightening for families, who struggled to make sense and remain hopeful amid such uncertainty. Family members often experienced significant fear and trauma at the initial diagnosis:

Mary: ...and then to get diagnosed...on top of everything I just thought...

Mary's step-daughter: Enough's enough.

Mary: I didn't want to be here. I'll be honest...I just thought what's the point, you know. It was awful...I thought my life was over...

The hopelessness and resignation was sometimes reinforced by services: "well you've got vascular dementia. Yeah ok well what do we do about it, Oh nothing tarrar!"

(Mary's husband). The futility was particularly frightening for families.

Families worked together to understand dementia and its implications, but struggled to accept its progressive nature:

Ted: Well the first thing I thought was that I...that I could work me way out of this, I'm sure I can, [...] I was asking different people and I don't think you can. You can't override it, you've got to go with it and if you're poorly, you're poorly.

Ted's daughter: Yeah, because you did say dad that you thought you might get better didn't you?

Ted: Well I was wondering because I wasn't...I didn't seem to be that bad. But some of the people we've seen at these schools and the memories have gone haven't they?

Ted's wife:...Well yes...

Such comparisons were made by families to benchmark progression and make sense of an uncertain future. While comparisons provided reassurance that others were worse off, there was an attendant sense of fear and distress in witnessing their potential future: "I'm going to be like that one day!" (Mary).

Relatives expressed concern about being unable to offer continued support in the future: "my worst nightmare that, if I get ill" (Ted's wife), which provoked fears of abandonment and helplessness for people with dementia: "I'd be stuck in the middle of the island" (Ted). This future uncertainty provoked significant distress:

Sue: Could you manage if you have to...I know it sounds silly and stupid but if anything ever had to happen to me and I couldn't bath myself or anything like that...could you do it? [Very tearful]

Sue's husband: I'd have to do it, yeah.

Sue's daughter-in-law: but there are people...don't be worrying about things like that, because there are people that can help with that, you don't need that.

Sue expressed fear of future incapacity, while her daughter-in-law discouraged such speculation with reassurance. Relatives often reassured with promises of future support although some acknowledged potential difficulties:

Ron's son: If it drags her [Ron's wife] under then I just cannot cope with everything myself. It's not like I'm at home and...that part of it is very scary [...]

Ron's wife: It is frightening though...you know. Because I've got to keep going...

Ron's wife dismissed her own needs, increasing pressure on herself to continue coping, which could inadvertently make illness more likely.

Future speculation provoked pain, sadness and fear for families, who learnt to distance these feelings by focussing on the present. It often proved easier to maintain some degree of future uncertainty, rather than accept the seemingly inevitable. There was a delicate balance between striving to understand while preserving some uncertainty to maintain hope.

Families' efforts to distance the future while making sense of their current situation involved several strategies. Shared reminiscence about challenges previously overcome promoted strength and hope. While superficially irrelevant, stories often echoed themes and emotions relating to life with dementia, assisting families' shared processing, and allowing expression of feelings without referencing dementia and the future directly. Families used metaphors and imagery to communicate difficulties: "if our tractor wouldn't work it's... I couldn't carry on with what I were doing, [...] But I have a way of mending it, whereas Sue doesn't have does she?" (Sue's husband). While highlighting the resignation brought about by the diagnosis, his phrasing as a question implied uncertainty, signifying a glimmer of hope.

Families' evolving understanding of dementia influenced hope, with the medical explanation received at diagnosis being augmented by ongoing experience. Families recognised deterioration triggers in others with dementia, which enhanced their understandings of the factors affecting decline:

Mary's husband: The fact that she's got so involved in it I think is good, and as I say it's given her a purpose [...] well you sort of think that as long as her mind's

active...maybe it'll slow down the progression of dementia, that's the way I look at it

Mary: That's what they think [laughs]...we hope.

Prior experience informed them that loneliness, bereavement, and capitulation precipitated deterioration. The family therefore believed that togetherness, stimulation, and maintaining a shared positive attitude could minimise the impact of dementia. This shift in understanding was crucial to ignite hope for this family and others.

## **Discussion**

Findings highlight a number of conflicting experiences, which perhaps reflect the needs of families to: maintain a positive identity for the person with dementia (being a person rather than a patient); promote belonging and connection between them (rather than loneliness); and remain hopeful about the future (rather than hopeless and despairing).

The conflict between identities has been documented previously, with researchers reporting dementia represents a threat to the person's sense of self (Caddell and Clare 2010). These results extend this notion, suggesting that individual conflict results from complex interactions within and between family members. All family members experienced a dilemma between acknowledging the diagnosis, which signified a transition from person to 'patient', and retaining the person's identity by nurturing the threatened self. While people with dementia experienced identity threats, their relatives' internal representations of their loved one were also threatened. Family dynamics further complicated this process. For example relatives inadvertently undermined the self-protective mechanism of 'denial' (de Ridder *et al.* 2008) by exposing the flaws of the person with dementia, thereby creating divisions in families.

Oscillation between two extremes is mirrored throughout results (e.g. isolation or belonging, hopeless or hopeful), reflecting 'self-maintaining' and 'self-adjusting' approaches (Clare 2002, 2003). These polarisations suggest some families believe the two cannot co-exist, reflecting the incongruity of the families' illness beliefs and their beliefs about the identity of the person with dementia. Where healthy adjustments prove unsuccessful, theory suggests the person with dementia may feel defined by their illness (Sharpe and Curran 2006), which echoes families fears that to have dementia is to become a patient and lose, to some extent, the person underneath. However individuals with dementia can retain a sense of being valued for who they are rather than what they do (Steeman *et al.* 2013). Recognising that task performance does not equate to change in the person may therefore enable a more helpful integrated position.

For families in this study accepting an integrated position seemed particularly difficult due to the social discourses that underpinned their illness beliefs. With such stigma around dementia (Cheston and Bender 1999, Crisp *et al.* 2000) it is unsurprising that individuals, and families, resist the diagnosis in order to protect identity and reduce threat (Clare 2003). While stigma disempowers, infantilises and marginalises the individual (Beresford 2013, Cheston and Bender 1999, Kitwood 1997), the present findings suggest this could be subtly mirrored within the family as polarised views and conflicting identity issues create divisions leaving people feeling excluded and alone. Moreover, shifting power and role-reversals risk further disempowering the person with dementia.

A further key theme was the chain of support whereby each family member supports the next. In reality this is most likely an intricate network with everyone supporting one another to some extent; however, this chain concept provides a useful framework. The links of the chain effectively act as a secure-base (Bowlby 1953,

1969), with each relative providing the essential protection, support and scaffolding for the next, enabling them to do the same for another. This acts as a 'holding environment' (Winnicott 1965), with each chain link metaphorically holding the next, thereby containing distress, echoing the principle of 'containing the container' (Bion 1962).

These chains, like attachments, seem important throughout our lives, becoming tighter at critical times (Bowlby 1969). For families in this study the support chain seemed to have tightened in the context of dementia; however this brought the weight of responsibility and feelings of being trapped. The supporting and holding function of the chain thereby became restrictive, provoking conflict within families. These dynamics seemed to disrupt supportive attachments, leaving individuals feeling abandoned, frightened and unsafe.

The people with dementia were not clearly identified as supporting others - sometimes seen as a redundant link in the chain. This left them feeling a nuisance to their family, which further undermined their sense of purpose. However, one family within this research (Mary's family) demonstrated that this sense of purpose can be restored. The person with dementia was able to find a valued role in supporting others with dementia, promoting agency, and meaning for the family. The potential to find benefit in chronic illness, achieve positive outcomes and post-traumatic growth has been documented (de Ridder *et al.* 2008, Sharpe and Curran 2006). Findings from this study support these notions, however such improvement is not possible within a purely medical, degenerative-focused model (Cheston and Bender 1999).

Furthermore, the medical explanation of dementia shared at diagnosis provoked great hopelessness for families. Over time families developed new meanings and understandings from their situation, as is fundamental to being human (Bruner 1990).

Developing a more holistic understanding engendered hope in the belief that stimulation, togetherness, and positivity could reduce the impact of dementia. This provided an enhanced sense of control over chronic illness, which can be helpful as long as beliefs are realistic (Park, Folkman and Bostrom 2001). Hope is crucial to restoring these feelings of agency and purpose (Snyder 2002), and seemed to rest upon how families' understandings developed.

Families in this study continuously strived to make sense of their situation together, often through comparisons, recollection and reminiscence, as previous research with couples has demonstrated (e.g. Molyneaux *et al.* 2012). Although content of stories appeared superficially unrelated, memories echoed themes relating to families' experiences of dementia, allowing expression of powerful feelings without directly referencing dementia. These mechanisms therefore helped families to process distress while developing shared meaning from their current situation.

#### *Clinical implications*

It is important for professionals to recognise the serious threat a diagnosis of dementia poses to families, and to avoid reinforcing discourses (Ekdawi and Hansen 2010). Dementia assessments emphasise deficits, often experienced as humiliating and threatening (Hellström *et al.* 2007); instead resources could focus on optimising abilities and promoting personal continuity (Cheston and Bender 1999). Professionals could instigate open discussion with families about the influence of discourses and discrimination, which could 're-humanise', restore compassion (Weingarten 2005), and enable relatives to appreciate the self-protective function of denial. This could prompt families to continue discussions between them as part of their natural meaning-making.

To counter individuals' sense of powerlessness and loss of hope, services should focus on promoting their continued role and identity. Opportunities could be identified



to enable the useful and valued role of the person with dementia (e.g. meet and greet roles, mentoring programmes and oral history projects) - effectively extending the support chain as the person with dementia becomes a link within another chain. Such roles could foster a sense of agency and ignite hope for individuals and their families as a sense of meaning and purpose is restored. Where further deterioration results in greater limitations, problem-solving approaches could enable adaption of the environment to empower people to continue meaningful roles. Compensate for difficulties in this way, helpfully portrays dementia as a disability rather than a 'disease' (Cheston and Bender 1999).

Diagnosis alone can limit space for exploring and understanding difficulties (Fredman, Johnson and Petronic 2010). Instead of the primary aim of assessment being to establish the type of dementia, assessments could explore what having dementia is truly like for this person, and within this family, with the aim of guiding psychosocial interventions. At the stage of diagnosis, a more holistic understanding of dementia could be shared with families, acknowledging personal, psychological, social and organic factors, allowing positivity and hope for the future (McGovern 2011).

Interventions that encourage reminiscence and story-telling could support families' unique sense-making process (Cheston 1996, Cheston and Bender 1999). Reminiscence therapy has shown some positive results for people with dementia and their family caregivers (Woods *et al.* 2005). Identity is constructed through our narratives, so story-telling, irrespective of accuracy, can promote continuing identity (McAdams, Josselson and Lieblich 2006). Group interventions based on reminiscence empower the story-teller, while promoting belonging and acceptance through group membership (Terrion and Ashforth 2002). Individual interventions, such as life-story work also allow construction of a narrative to make sense of experience (Fredman 2010)

and enhance preferred identity (Ekdawi and Hansen 2010). Indeed, narrative approaches could enable people with dementia to connect with their preferred stories (White 2007); involving family in such work could enhance empathy, belonging and shared identity (White and Epston 1990).

When experience is so connected with relatives it makes sense to involve them in interventions (Jones 1993). Indeed findings relating to the chain of support, imply that the tendency within services to identify a single or primary 'carer' within families may not be entirely helpful, instead the family should be viewed as a caring unit. Systemic approaches view those connected to the problem as able to 'dis-solve' the problem (Anderson and Goolishian 1988). Family therapy could therefore be useful to empower collaborative working within families, enhancing empathy and connection by introducing different perspectives and opening space for change (Cecchin 1987). It would also build hope by focussing on strengths, resources and exceptions (Carr 2000).

Focussing on what is happening between people rather than within separates the person from the problem (Carr 2000, Fredman 2010, Watzlawick, Beavin and Jackson 1967), thereby reducing blame and division within families. Such an approach may help staff to emphasise the distinction between skills, which may be lost, and the person underneath who remains, with the aim of supporting an integrated identity. Family interventions could therefore strengthen the inherent supportive chain within families, creating an additional holding environment or secure base (Byng-Hall 1995), with the aim of making families more resilient in the face of difficulties.

### *Limitations*

Findings are based on one interview per family and do not reflect longitudinal experience. As duration since diagnosis appeared to affect experiences, this warrants further investigation. Often the most involved and supportive relatives took part, so

further research could explore other relatives' perspectives, making comparisons with those who face dementia alone (Graham and Bassett 2006), to understand further the impact of family support. Additionally the small sample does not capture the diversity within society; future studies could explore how differing cultural values around family impact upon dementia experience.

Potential biases in the recruitment method should be acknowledged; while staff were encouraged to invite participation from all families who met criteria, elements of bias may have been apparent within these choices (e.g. perhaps selecting families who are coping or working together well). Additionally it is possible that families who felt more connected with one another were more likely to take part. The method of joint interviews may also have encouraged socially desirable comments and influenced honesty and openness; participants may tell a different story individually (Clare 2002). However, understanding both shared and individual accounts is important to build a holistic picture of dementia experience.

### *Conclusion*

The findings of this study suggest that dementia experience should be viewed as part of a wider interlocking web of family experience with greater focus on family needs adopted within services and policy documents. Interventions should aim to promote holistic understandings and enhance empathy, utilising the natural family support network. While some individual therapy may still be appropriate, these findings suggest that family work could be beneficial to actively promote belonging and connection.

Findings extend previous research by acknowledging the impact on the whole family, and the complex, intricate and interacting relationships within, which warrant further investigation. Together these findings provide new insights into the dynamics

and interactions between family members when faced with a diagnosis of dementia and highlight the inherent therapeutic capacity of the family process.

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Table 1.

*Family characteristics.*

	Family 1	Family 2	Family 3	Family 4	Family 5	Family 6	Family 7
<b>Person with dementia</b>							
Pseudonym	Liz	Ted	Mary	Jim	June	Ron	Sue
Gender	Female	Male	Female	Male	Female	Male	Female
Age	65	74	61	82	78	81	67
Diagnosis	Alzheimer's	Vascular dementia	Vascular dementia	Vascular dementia	Mixed dementia <sup>a</sup>	Alzheimer's	Alzheimer's
Received	1.5 years ago	10 months ago	3 years ago	4 years ago	1 year ago	1 year ago	9 months ago
<b>Family member 1</b>							
Relation	Son	Wife	Husband	Wife	Son	Wife	Husband
Gender	Male	Female	Male	Female	Male	Female	Male
Age	41	72	64	82	48	76	75
<b>Family member 2</b>							
Relation	Son	Daughter	Step-daughter	Daughter	Daughter-in-law	Son	Daughter-in-law
Gender	Male	Female	Female	Female	Female	Male	Female
Age	39	47	38	50	45	50	43
<b>Living arrangements</b>							
	All live separately	Ted and his wife live together. Their daughter lives separately.	Mary and her husband live together. Mary's step-daughter lives separately.	Jim and his wife live together. Their daughter lives separately.	All live together	All live together	Sue and her husband live together. Sue's daughter-in-law lives separately.

*Note.* <sup>a</sup> A combination of Alzheimer's and vascular dementia

## Appendix 2-A: Excerpt of Interview Transcript With Exploratory Comments

Transcript	Exploratory comments/notes
<p><b>Jim's daughter:</b> Yeah. Yeah we decided it's not a good idea if you drive these days isn't it? We're letting mum do the driving.</p> <p><b>Jim:</b> Oh, that was a private one, yeah.</p> <p><b>Jim's daughter:</b> Yeah, we just decided it was better didn't we?</p> <p><b>Jim:</b> get mum to do the driving.</p> <p><b>Jim's daughter:</b> Well she'd been sat around for too long hadn't she not driving.</p> <p><b>Jim:</b> She had...</p> <p><b>Jim's daughter:</b> You driving everywhere, and it's not a good thing when you're getting older, it's better that she gets behind the wheel... because that's what happened to aunty [name] isn't it, aunty never drove, uncle [name] drove everywhere, and when he died she was stuck then wasn't she?</p> <p><b>Jim:</b> That's right.</p> <p><b>Jim's daughter:</b> Remember you had to take her out driving again, teaching her how to drive again.</p> <p><b>Jim:</b> That's right</p> <p><b>Jim's daughter:</b> So we didn't want that for mum did we?</p> <p><b>Jim:</b> No.</p> <p>Int: and what's it like having [wife] do the driving instead of you Jim?</p> <p><b>Jim:</b> Oh... Alright...</p> <p>Int: It's alright yeah?</p> <p><b>Jim:</b> Oh ay, yes, yes. Well it's no bother.... Erm she's... confident enough with her driving and what have you, so... I'm happy about it, you know.</p> <p><b>Jim's daughter:</b> I tell you something that has come of it though, recently, isn't it?</p> <p><b>Jim:</b> It's what love?</p> <p><b>Jim's daughter:</b> Erm.. you've been feeling car sick again.</p> <p><b>Jim:</b> Car sick?</p> <p><b>Jim's daughter:</b> Yeah, when we go in the car now, if we go any distance. Yeah. You're alright coming up to our house and that but when we went to [another town] to uncle [name], by the time we got off the motorway, I had to pull over...</p>	<p>Explains to dad about not driving – reframes as 'letting mum do driving'</p> <p>Making decision out to be due to mum's inactivity/lack of driving, rather than dad's memory/reactions – suggests letting mum is kind as need to help her manage alone</p> <p>Points out how Jim saved the day – teaching aunty how to drive again (<i>puts Jim in expert position – teaching mum</i>)</p> <p>Compliments wife in driving – (<i>taking expert position daughter created</i>)</p> <p>Impact of Jim not driving now = car sick</p>

Jim: Yeah

Jim's daughter: ... and that's something that's changed recently.

Jim's wife: When he was a lot younger he was car sick, but while he was behind the wheel, he never was. But, mind you, it's almost six months since he started this car sickness again.

Jim's daughter: It's more than that.

Jim's wife: Is it?

Jim's daughter: Well we went to [city] last summer, didn't we? He did it the year before when we went to....

Jim's wife: Sorry it's 12 months [laughs]

Jim's daughter: It is, it's at least that. Because we don't make many long journeys. I don't like mum driving a long way. So if we're going to [another town] or anything, we went down to some friends at [city] didn't we.

Jim's wife: We did yeah.

Jim's daughter: That were a nightmare of a trip!

Jim's wife: Well it was, yeah.

Jim's daughter: We didn't go on the motorway, we went on the back roads, but we had to stop 3 times on the way there.... I was exhausted by the time we got there [all laugh].

Jim's wife: That was a real mistake wasn't it [daughter]?

Jim's daughter: Yeah. But yeah that's a difference, something that's shown up since he's not been driving.

Jim: Why what did you do wrong?

Jim's daughter: Ay? I went round too many bends and made you feel sick... It were my fault.

Jim: It were your fault was it?

Jim's daughter: Oh yeah, I guarantee that [laughs]

Trying to make sense of difficulties (e.g car sickness) - understand – doesn't always add up

Correcting mum

Wife and daughter co-constructing stories

Jim joins laughter even though not immediately part of conversation

Reframes problem as her going round too many bends – 'my fault' (*not wanting to blame dad*)

## Appendix 2-B: Example of Narrative Summaries of Themes for One Family

Theme 1: How others do and don't see 'it': the shame of dementia		
Notations	Narrative summary	Quotes
<p>'it's not an obvious thing' (the dementia)  Mary doesn't fit stereotypical media portrayal of dementia (old lady in corner, dribbling, disorientated) – 'you're not like that'  'they are plugging it everywhere' – raising awareness of dementia  'you can't see it. So it's not there' – invisible nature of dementia – Don't notice until 'really bad'  Family don't believe anything wrong due to invisibility of dementia  Compares experience to operation - Can seem alright outwardly, but months before 'fully healed inside' (inner impact on self – can't be seen – people can't understand?)  On good day – never notice dementia (invisible?) – all agree  Doesn't use word dementia  Bad days = notice dementia more. Good days = 'just a normal person' (dementia = not normal person?)  Recalling incident – themes of being on my own/feeling a fool/questioning myself/calling on husband for support (links to experience with dementia)  'it sounds daft'  Don't overplay difficult times – ignore it/pretend not there  Café incident: Recognises Mary felt frustrated and silly (humiliation – links to dem?)  'I do daft things' – forgetting  'It's silly little things' (feels silly?)  'I do daft things like that' – embarrassment  Mary's friends making contact via husband – frustrates him – contact Mary (reflects how society speak to the partner/carer rather than PWD)  feelings excluded/forgotten by friends, friends giving up on you – reflects society's response to dementia?  'the dementia' (not her dementia as with 'her medical conditions')  Dementia as 'it' (depersonalising? But also externalising?)  To get diagnoses with 'that' = 'awful'  Good ones/bad ones – lucky mary's still a good one (spoken about as objects? good or bad)</p>	<p>This covers the concept that Mary's dementia is not visible to others and therefore some family and friends find it hard to believe that Mary is struggling, or even has dementia at all. Mary felt excluded by her family and friends which may reflect how she felt others responded to her and the dementia.</p> <p>The family talked about Mary in comparison to media portrayals of someone with dementia, who they believe is characterised by being old, inactive, useless and 'dribbling'. This taps into the stigma that they acknowledge exists around dementia. They describe Mary's dementia as less visible, and understand why this makes it hard for others to understand or acknowledge. Indeed Mary and her family allude to their own ambivalence around whether she has dementia or not at points, particularly as Mary is a younger person and is relatively highly functioning at present. In fact they suggest that on a good day others may think she is 'normal'. This belief is interesting as it implies that dementia is somehow 'abnormal' and potentially hints at their own underlying stigma towards dementia, which is also apparent in other comments they make about people with dementia.</p> <p>Mary and her family talk about specific members of her family who refuse to believe that Mary has dementia, which they attribute to the invisible nature of it and perhaps to the difficulties others may have in accepting this due to its meaning for Mary and her future. They describe that other family members refuse to discuss this and as such they</p>	<p>Mary's step-daughter: There's what people perceive dementia is and what the characteristics are. It's not portrayed on the TV as somebody who goes about everyday... everyday life normally like you do.</p> <p>Mary: Yeah.</p> <p>Mary's step-daughter: You see an old lady sitting in a corner dribbling or not knowing where she is, whereas you... you're not like that. So it's.... it's how people perceive what dementia is and the levels and the stages it goes from.</p> <p>Mary: I think a lot of it is fear of....not actually understanding it. Not knowing too much about the condition. But it's like they don't want to know anyway, because I got all this information for them, didn't I, when me mum was diagnosed. But it's like... 'no it's because she's lonely', I said No! and I just think you're banging your head against a brick wall, and erm... Actually it's funny because they don't discuss, well we just don't discuss it me brothers and sister,</p> <p>Mary: Yeah... but... it was a shock, it was. Even now sometimes I still think, have I got it? [laughs]. I know I have, but...</p> <p>Mary's husband: Yeah, but on a good day, you don't know any different do you?</p> <p>Mary: No</p> <p>Mary's step-daughter: No</p> <p>Mary's husband: It's on bad days when you know that you have... On good days you're just a normal person aren't you?</p> <p>Mary: Yeah...</p> <p>Mary: Yeah, I think with... I mean it's my own personal opinion, I think with dementia it.... I mean they are</p>

<p><u>'You'd have vegetated eventually' (suggesting state of inactivity/insensitivity/meaningless)</u>  Referring to people with dementia as 'them' – 'got enough of them' (<i>depersonalising?</i>)  <b>Family not understanding/denial</b>  Brothers and sisters 'in denial', tried to explain  Bro's and sis's may find it difficult as echoes your mum's experience  family members 'wouldn't accept'... but family should accept perceived or felt to be the 'bad one' as sought diagnosis for mother – they wouldn't accept  Different explanations in family – lonely vs dementia  Mary's efforts to provide info/explain = 'may as well bash your head against the wall' – they didn't want to know – frustration  Different when it's 'your own' rather than looking after someone  Family in denial about Mary's condition  Family don't want to know so it's not talked about  Take it on board = understanding = being there and supporting  Feeling pleased when others acknowledge 'my condition'.  Recognises sister knows on some level that 'I've got the problem'  Wishing other family could laugh about it too (<i>were part of 'we' too?</i>) – upsets me  They're ignoring 'it'  Feeling hurt/taking things to heart (when family exclude)  <u>Upset/hate to think nobody liked me</u>  <b>Impact on self-esteem – questioning yourself/ambivalence</b>  Frustration/frustration at her mistakes  Get cross at myself – direct anger towards self  <u>Loss of ability to be calm – not Mary at all. Taking little things more personally/not able to cope as well with them</u>  <u>Notices Mary looks for approval from family</u>  <u>Upset/hate to think nobody liked me</u>  <u>'I like to think' they're friends, 'I think I'm right'? – doubts self</u>  Checking – am I miserable? – <i>unsure of self – self esteem</i></p>	<p>experience significant frustration around this. Their efforts to help her family understand and accept her condition therefore feel futile and they describe 'banging their head against a brick wall'. Mary describes how these other family members in particular have excluded her and not offered any help or support. Whilst she does not attribute all of this to the stigma around dementia, it does seem to echo themes around her experience of how others and perhaps society can respond to her dementia and how she can be left feeling ignored, excluded, forgotten, hurt and upset.</p> <p>These feelings of being ignored and forgotten by others seemed to have a profound impact on Mary's self-esteem, and how she talked about herself within her family. She often described things she said or did as seeming 'silly' or 'daft' to others, so there was a general sense of her feeling embarrassed or humiliated in front of others which may relate to some of the underlying shame around having dementia. Furthermore Mary seemed to question herself at times, particularly in relation to whether people really liked her, and she often looked to her family members to check this out. In turn she also directed a lot of anger and frustration towards herself when she noticed she got things wrong, or when she couldn't remember.</p> <p>Although feelings of shame and difficulties with self-esteem may well have been around in the past, it seems that the diagnosis of dementia along with the reactions from others and perhaps society, have only compounded the sense of shame and her fragile sense of self.</p>	<p>plugging it everywhere aren't they [...] it's one of those things isn't it, you can't see it.. it's (not there).</p> <p>Mary's step-daughter: (Well not until it's really bad)  Mary's husband: (Well it's like [Mary's step daughter] said before about you), you can't see it so you family thought that there's nought wrong with you.</p> <p>Mary: 'Oh she's alright, you know, there's nought wrong with her' [imitating family]. It's like people say 'oh have you had your operation are you alright?', 'yeah, course I'm alright', but... yeah outwardly, but it's going to take months before I've fully healed inside,</p> <p>Mary: I know a lot of people probably think I'm silly, you know, but [laughs].</p> <p>Mary: I think what you've just said is spot on really. And it hurts... I take things to heart don't I?</p> <p>Mary's step-daughter: You do.</p> <p>Mary: I take... I can get upset very easily if I think... I would hate to think... that nobody liked me... (you know what I mean?)</p> <p>Mary's husband: (Yes and she called in) with her brother's card, erm Christmas card, [...] and the girl said 'Oh he's gone out delivering Christmas cards', you know. And then when we got home, or when Mary got home, we didn't get a Christmas card...</p> <p>Mary: So I thought oh, well he hasn't bought me one!</p> <p>Mary: Erm... so it's silly things... and it... for me personally... a lot of it's frustration. I get...</p> <p>Mary's step-daughter: She does get wound up.</p> <p>Mary: I get wound up quick don't I?</p> <p>Mary's step daughter: (I know).</p> <p>Mary: (I get really cross), but I get cross at myself. I don't always get cross at other people.</p>
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Theme 2: From hopelessness to holding on to hope		
Example Notations	Narrative Summary	Example Quotes
<p>Traumatic circumstances of heart attack which prompted dementia.  'just little things you were doing' – noticing memory problems  Scary/horrible feeling knowing been there before but no recollection  Process of diagnosis = long  To get diagnoses with 'that' = 'awful'  Recognises it as a shock for her – and 'us'  'It's scary you know, it is..'  Diagnosis as a shock  It's hard.  I could have given up  'You'd have vegetated eventually' (<i>suggesting state of inactivity/insensitivity/meaningless</i>)  Days when I just go off and cry – for no real reason  Shock of diagnosis  <b>Futility/hopelessness</b>  Diagnosis = didn't want to be here/life is over/awful/what's the point?  I could have given up  'You'd have vegetated eventually'  First got diagnosis = life is over, may as well kill myself – 'awful' 'I didn't want to live'  Frustration at lack of treatment/medication - feels advert is 'silly' and misleading/gives false hope.  <u>You get your diagnosis and then you're discharged (echoing societal beliefs around dementia – no point in trying/hopeless) –</u>  Feeling like there's no support from services  Got diagnosis – what do we do about it? 'Oh nothing, tarrar!' – <u>No medication (feeling hopeless)</u>  Understanding of brain damage caused memory problems  <b>Fear</b>  Frightening if anything happens to me – Mary would be alone – needs family around her for support  Will my family be there for me?  Worry about Mary if anything happened to me – shock of losing me could cause deterioration  Frightening to know there's nothing  Scares me when I do something never done before/strange/ashamed/foolish  Very upset by mistakes - <i>that make her feel stupid?</i> 'It's horrible'  Try not to think about the future but can't help it – future = frightening  Worry about what is anything happens to me – frightening  Worries about more serious things – fire, cooker, etc  Frightening to think where will her family be? Will they be there for her when she needs them?</p>	<p>This captures the initial sense of hopelessness that the whole family felt when Mary received her diagnosis, and how their past experience with people with the condition only compounded their fear for the future. However as their shared understanding of the factors affecting dementia shifted, this began to make space for hope.</p> <p>The family described how the circumstances surrounding the lead up to Mary's diagnosis were traumatic and frightening (several heart attacks requiring prolonged resuscitation, and multiple TIAs). Mary underwent several tests and scans before being told her diagnosis, at which point the family felt they were abandoned by services who offered no treatment and left them feeling hopeless about the future. The family felt a shared sense of shock at the diagnosis and felt that no support was initially offered from services. Mary described feeling that life was over, there was no point in living anymore and she wanted to die. Her family felt this time was difficult for everyone, although they recognised it was most difficult for Mary.</p> <p>There were shared fears and concerns around family support in the future as well. In particular relating to the potential that something could happen to Mary's husband, and this could leave Mary struggling to cope. Her husband also recognised that the stress and upset of losing her husband could prompt</p>	<p><b>Mary:</b> It's horrible because... and I have an uncle that's, at the moment he's 91 and he's got vascular dementia... He's still a very, very physically ... very smart upright man. But he's a fruitcake [laughs]. I mean that in the nicest possible way but [laughs] I go to see him and he'll say 'who are you?'. I go 'hello [uncle]', 'well who are you?', and I tell him who I am and... five minutes later it's 'who are you?', you know, and 'where's Pat?', which was my mum, and I've told him that they've all passed on. I have to go through it again, but five minutes later, 'who are you?'. You know I think....</p> <p><b>Mary's husband:</b> 'Where's your Pat, where's our Pat?' [imitating uncle].</p> <p><b>Mary:</b> ... and I don't... I haven't been for a while, because it upsets me, because I... I..... and then I come away thinking.... I'm going to be like that one day! I try not... to think too much of the future... but I can't help it. It does frighten me,</p> <p><b>Mary:</b> (It's been a long)... yeah. It has! And to get diagnosed with that it was erm... well it was awful.</p> <p><b>Mary's husband:</b> Well it was awful for... more for Mary really than for the rest of us, or for anybody because... Mary had worked in a care home and seen the results of Alzheimer's and dementia. Erm... so she's, she was like now suffering it first hand and dealing with it. So it was obviously a bit of a shock for her.... And for us really because we obviously knew about it. I mean I worked on the ambulance service so... obviously I've seen patients with it, good ones and bad ones and luckily our Mary's still a good one. [Mary laughs].</p> <p><b>Mary:</b> erm... well as you know there's not a lot of medication for vascular dementia so you basically get your diagnosis and then you're discharged.</p>

<p>You won't let risks hold you back          Scary to think may lose control over self          Unsure/uncertain about planning for future – e.g. POA          Thinking about the future = frightening          Try not to think about future as it scares me          'We' – shared fear of future  <b>Memories/past experience creates fear?/comparisons</b>          Dementia = dying for mum (and for me?)          'really really difficult' caring for mum – clashed, frustration – 'it was awful'          Caring for mum held her back as she was 'exactly the same' – <i>being with other people with dementia holds you back? All people with dementia the same?</i>  <u>Horrible – fear of becoming a 'fruitcake' like my uncle and people used to work with. Seeing others causes upset because 'I'm going to be like that one day' - frightening</u>  <u>Upset by stories about people with dementia – empathise with PWD</u>  <u>Try not to think about – due to experience with own nan.</u>          Longer –term thoughts= upsetting to see someone deteriorate/become someone you don't recognise at all          Try not to associate Mary with my nana – but deal with it when that time comes          Going into nursing home can cause people to either give up or thrive on it/get on with it – Mary agrees from her experience          Recalling mum's struggles with dementia and eating          Prior experience of dementia makes it scarier/<i>know what's coming?</i>          Most frightening for Mary – seen 'person-to-person' 'the end result'.  <b>Hope</b>          Wanting to prevent Mary's deterioration          'we' hope          If she keeps active = makes brain work and prevents deterioration – gives hope          Volunteering providing involvement and purpose – hold on to hope          Acknowledges loneliness had impact on <b>Mary's mother with dementia</b>          Understand having family around as protective and preventative against dementia – loss of family/role as causing dementia?  <u>Doing things/puzzles to 'keep my brain kicking over'</u></p>	<p>further deterioration – this was a shared concern for the family.</p> <p>The family's prior experience of witnessing the deterioration of dementia in other people or family members served to heighten and emphasise their shared sense of fear and hopelessness around the future of the dementia. They had each witnessed family members eventual death due to Alzheimer's or dementia and all felt that this was a picture of the end result which Mary would one day reach.</p> <p>However overtime the family's understanding of the dementia seemed to have shifted from the medical understanding they were given at diagnosis (i.e. vascular dementia is due to the repeated TIAs and heart attacks Mary had experienced which had caused irreversible brain damage which would continue to progress), to an understanding where they began to appreciate other factors. The family described how their prior experience told them that loneliness, bereavement, and giving up were all factors in the deterioration of other family members with dementia or other illnesses. As such the family found hope in the belief that by sticking together as a family around Mary, by keeping Mary's brain active, and maintaining a positive attitude together they could hold off the progression of dementia. This shift in their understanding of dementia seemed crucial to the ignition of hope for this family.</p>	<p><b>Mary's husband:</b> and that's when you got annoyed because, we haven't said... [Step-daughter]'s mum was diagnosed with MS and they said oh they'll be loads of support and we got her home and there was nothing. And the same happened with Mary... initially.</p> <p><b>Mary:</b> Yeah it did.</p> <p><b>Mary's husband:</b> er... she was diagnosed and then it was like... well you've got vascular dementia. Yeah ok well what do we do about it, Oh nothing tarrar! There's no medication for it.</p> <p><b>Mary:</b> So that was frightening. But I suppose I was fortunate erm...</p> <p><b>Mary's husband:</b> and that's the frustrating thing, because Mary is obviously going to get worse, and the frightening things is if anything happens to me.... (because I've.... never been....)</p> <p><b>Mary:</b> (I don't ....)</p> <p><b>Mary's husband:</b> ... then Mary's going to be on her own, when she should have her family around her, including her brothers and sisters.</p> <p><b>Mary:</b> (Are they going to be there you know?)</p> <p><b>Mary's husband:</b> .... (And they won't be there to support her).</p> <p><b>Mary's husband:</b> I mean....the fact that she's got so involved in it I think is good, and as I say it's given her a purpose and I dread to think what she'd be like if she didn't have that. Erm... so to me I think... well you sort of think that as long as her mind's active erm... maybe it'll slow down the progression of dementia, (that's the way I look at it)</p> <p><b>Mary:</b> (That's what they think) [laughs]... we hope.</p> <p><b>Mary:</b> Puzzles yeah, I do a lot of ... the like wordsearch... things like that, erm... and I just think to keep my brain ticking over you know.</p>
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Theme 3: Coping as a family: Overcoming it and not letting it overcome 'us'		
Example Notations	Narrative summary	Example Quotes
<p>Granddaughter teases nana – 'you've got a condition' – allowing/forgiving  <u>'It's a condition' used by all family – helps laugh at it, 'good way of dealing with it'</u>          'live each day as we go...family round us and just get on with it' (<i>carry on, making the most, not looking forward</i>)  <u>Pull together as a family to manage difficult times – just work through it</u>          Live day for day – don't overplan. Make the most of each day  <u>Don't overplay difficult times – ignore it/pretend it's not there/ignore</u>  <u>Try not to think of future</u>          The future is always in the background          Don't plan for getting any worse          Don't dwell on it – enjoy what life we have/make the best of it  <u>Try not to think about – due to experience with own nan.</u>          Easier to cope when don't live with Mary – 'funny things she does' – laugh it off          Cope by 'shrugging it off'          Granddaughter got memory board          Granddaughter supporting/prompting – uses strategies to aid memory          Support and strategies from granddaughter – 'little things like that it's brilliant'          All laugh – jokes about mistakes – buying too many bananas          Wanting to manage bad times on her own – always has done this          Trying to forget about future – but uncertainty whether should think about it/prepare          Try to get on with things rather than whinge and moan          All about how you overcome it and not let it overcome you          Attitude towards the illness is important          But have now got a purpose and 'learnt to deal with it', and recognise can still do things = no longer as big an issue  <u>Knows Mary doesn't share when she has a bad day – empathises that she probably doesn't want to upset or worry him (attunement)</u>          When angry/upset – copes alone by talking to memory of dad and screaming (releasing frustration) – 'then I feel wonderful'  <u>Even family who have died still hold huge importance in life – part of coping</u>          Assuming people would think her coping by talking to dad's memory is strange (<i>links with stigma around dementia?</i>) 'I know a lot of people probably think I'm silly'          'this dementia thing, it's just horrible, and I wish I hadn't got it, but I've got it and I've just gotta deal with it' (<i>acceptance</i>)          Can't stop 'it' (recognises progression) – family accept it will get worse  <u>Recognising her mum 'went down hill' from day given diagnosis – believes should not have been shared (supports her understanding that attitude helps - not adopting an illness narrative/position)</u></p>	<p>This encapsulates how the family worked together in an attempt to overcome the impact of dementia. They acknowledged and accepted that they could not cure or eliminate the dementia, it would always be there, yet they had develop some shared ways of coping together. This included in particular living for the moment and taking each day as it comes rather than thinking into the future or making any long-term plans, and laughing and joking together to cope with distress.</p> <p>The family described making the most of every day, and not looking to the future due to the fear and hopelessness that this could evoke. They actively tried not to think about the dementia or what might happen in the future, choosing instead to effectively ignore it. The family also described naturally using humour to cope with things. They would often introduce jokes to lighten moments of potential upset within the interview. They also described laughing and joking together when Mary forgets or makes a mistake, and this helped them to accept it and reduce any frustration or blame.</p> <p>The family as a whole (including other members who were not in the interview) seemed very important to their efforts to cope. In particular Mary's grandchildren were mentioned repeatedly and they seemed to occupy a very important role</p>	<p><b>Mary's step-daughter:</b> I really don't think we... I don't think we overplay it, do we? We don't...</p> <p><b>Mary:</b> No I just...</p> <p><b>Mary's husband:</b> We just try to... I was going to say for want of a better word we try to ignore (it as best we can).</p> <p><b>Mary:</b> (Ignore it). Yeah.</p> <p><b>Mary's husband:</b> Erm... and just... just... I suppose, pretend it's not there.</p> <p><b>Mary's husband:</b> ...well we just live basically each day as we go. Because as I say she's got lots of other medical problems besides the dementia so we just have to sort of... live each day and we have our family round us and we just get on with it. We've got my little tiny blondie [referring to granddaughter] who's a wonderful help and teases her nana rotten.</p> <p><b>Mary:</b> No, she's very good.</p> <p><b>Mary's husband:</b> Because every time nana misses something or forgets something its 'oh nana well you have got a condition' so....</p> <p><b>Mary:</b> That started as a joke didn't it at first.</p> <p><b>Mary's husband:</b> She's [granddaughter] probably more forgiving than I am, I mean I get quite frustrated at times,</p> <p><b>Mary:</b> Well I know... that's part of it, and some days.. erm... and I think he knows what I'm going to say. I go down to the river erm... well mum's there now, her ashes...</p> <p><b>Mary's husband:</b> Her mum and dad's ashes are on the river bank</p> <p><b>Mary:</b> and there's the plaque down there for them. So I go, if I want to talk, because I get very angry 'where are you dad when I need you?' and... and I've done that some days, if I'm that way out. I'll go down there and I'll just scream across the river. Nobody</p>

<p><u>Attributing mum's behaviour and aggression to her 'condition' (echoing what her family does – forgiving/allowing)</u></p> <p><b>Humour</b></p> <p>Laughing</p> <p>Mary laughs at the tragic description of her multiple heart attacks 'we laugh it off'</p> <p>Laugh rather than frustration – but recognises not around as much as dad</p> <p>Used to tease nana – Laughing</p> <p>Joke made turns convo from suicidal to getting life back</p> <p>Mistakes provide laughs and enjoyment for family all year round (presents)</p> <p>Always used humour as a family – 'we've' always been like that</p> <p>Humour is natural for this family rather than conscious or forced</p> <p>Granddaughter part of 'we' too – laugh together</p> <p>Step-daughter copes by laughing anyway (in other areas of life)</p> <p>Son and daughter haven't hidden it – just laugh it off with me</p> <p><u>laughing as 'our way of dealing with it'.</u></p> <p>Makes joke when talking about down days/pain</p> <p>Jokes</p> <p>Making repeated jokes</p> <p><b>'we' – shared experience (coping together)</b></p> <p>We've been 'as happy as most people want to be'</p> <p>'we' got through that, 'we' got the bypass over</p> <p>Granddaughter as wonderful help</p> <p>Step daugh can't remember and laughs – normalises forgetting</p> <p>Being 'family oriented' – very important – closeness/connection</p> <p><u>laughing as 'our way of dealing with it'.</u></p> <p><u>Wishing and hoping for something that won't happen (family together again)</u></p> <p><u>Relationships haven't changed between 'us'</u></p> <p><u>Not a big impact on 'us'</u></p> <p><u>No change, 'we just carry on as normal basically'</u></p> <p>Step-daughter sees less</p>	<p>in the family by offering a fresh perspective that was perhaps more allowing and forgiving than other family members at times. One of Mary's grandchildren had introduced the phrase 'it's ok because you've got a condition', which seemed to have become the family's mantra to coping with many of the difficulties experienced. This created an accepting and forgiving atmosphere, which reduced blame and frustration and over time had developed into a family joke, and prompted much shared laughter.</p> <p>Furthermore, even family members who were no longer alive were still important to the family's coping at times. For example Mary talked about visiting the place where her parents' ashes were when she was upset or distressed. By talking out loud to the memory of her father she was able to express and relieve her distress and frustration which became an effective coping strategy for her. This emphasises the importance of the whole family when coping together with the impact of dementia.</p>	<p>can hear me and I just get it out... and then I feel wonderful. When I come away from there I think thanks dad, you know. Or I'll just go and sit on the bank and talk to him.</p> <p><b>Mary:</b> It is! I think its... it's like any illness, isn't it, it's how you...</p> <p><b>Mary's step-daughter:</b> overcome it...</p> <p><b>Mary:</b> What?</p> <p><b>Mary's step-daughter:</b> overcome it and not let it overcome you.</p> <p><b>Mary:</b> Yeah it's definitely your attitude towards things isn't it, you know. Erm...</p> <p><b>Mary's step-daughter:</b> Well we've always been like that haven't we, anyway?</p> <p><b>Mary:</b> Yeah I mean we don't... we haven't thought about it, it's just naturally happened that way, hasn't it?</p> <p><b>Mary's step-daughter:</b> a bit like most things...</p> <p><b>Mary:</b> I mean we just laugh don't we? And [my granddaughter] will say 'Oh nana' [laughs], you know.</p> <p><b>Mary's step-daughter:</b> I know that's how I cope with things naturally anyway.</p> <p><b>Mary:</b> No I ... It's like silly things. Like at Christmas I buy little things for the kids and then I can't find them can I?</p> <p><b>Mary's husband:</b> (Stocking fillers and things. She buys or she's seen something in July...)</p> <p><b>Mary:</b> (and I'll find them in erm... [my granddaughter] got lots of little presents last year, all year.</p> <p><b>Mary's step-daughter:</b> Yeah because she found them in summer and they should've been for Christmas [all laughs].</p>
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Theme 4: Supporting each other: attuned and advocating		
Example Notations	Narrative summary	Example Quotes
<p>Husband provides support when needed – <i>call him when encounter difficulty</i></p> <p>Protection/assertiveness/advocating for wife - Angry at services for not supporting her better</p> <p>Angry at colleagues for not telling her – advocates</p> <p>She's got herself all worked up and I'm not happy about this</p> <p>I went down as soon as I could – make sure she was ok</p> <p><i>Recognises Mary felt silly (humiliation – links to dem?)</i></p> <p>My concern is Mary</p> <p>Got upset because will make her worse – upset and stress could cause TIA – <i>fear of deterioration – desperate to prevent</i></p> <p>Recognises Mary had calmed down</p> <p><i>Appalled at the way Mary was treated (badge given). 'I went mental'</i></p> <p>Not a nice label though – don't like being defined by dementia</p> <p>Label wasn't professional, or appropriate</p> <p>Wanting to fight her cause/advocate – Mary wouldn't let him (<i>her choice – she still has control</i>)</p> <p>Shouldn't label a person</p> <p>Like labelling attributes of black/gay</p> <p>Prompting Mary</p> <p><i>Recognises Mary get's 'wound-up'</i></p> <p><i>Offers support – when frustrated need to let it go and calm down and it will come back to her</i></p> <p>Recalling past incidents/examples</p> <p>Provide context to prompt Mary's memory</p> <p>Upset at not finding things</p> <p>Normalises her not remembering – 'I can't remember myself'</p> <p><i>'She laughed that away but I know what was going through her head' – attuned to her feelings even when not shared</i></p> <p>Don't care for her family because of the way 'they treat you' – I won't help them if they won't help you (give and take) - <i>protective</i></p> <p><i>Frustrating family not there for her = concerns if anything happens to me</i></p> <p><i>Recognises husbands 'cross' when she drives off alone – understands her worries due to her being ill</i></p> <p>Offers praise/validates – she has got better</p> <p>Frustration when can't check she's ok</p> <p>Supports Mary in her argument</p> <p>Sees Mary upset and frustrated but not 'down'/miserable</p> <p>Empathising with Mary – bad days hold her back and don't give her the 'escape' she needs</p> <p><i>Husband also hurt by friends not showing care or concern?</i></p> <p>Checking on her is concerned about wife</p>	<p>This highlights the efforts of family members to empathise and recognise how they are each feeling and offer care and support. Mary's husband in particular was very protective over Mary, and often advocated on her behalf. When empathising was more difficult within the family there were times when they expressed frustration towards one another. However they felt that understanding the other person's perspective was key to supporting one another. Mary herself was also offering support to other people with dementia.</p> <p>All family members supported and empathised with one another. Not only did they describe times when they supported one another, but they also demonstrated this within their conversations as they helped prompt each other's memory, affirmed others comments and recognised how others felt at times.</p> <p>The nature of support that Mary's step-daughter, and particularly Mary's husband offered to Mary had a more protective feel to it. He was keen to advocate and stand up for her when needed, and made efforts to prevent situations where she may experience stress or upset. As a result he often expressed significant anger and frustration towards others when he felt Mary was treated unfairly.</p> <p>There were times when family members found it more difficult to empathise or understand each</p>	<p><i>Mary's husband:</i> So... it was like he'll of probably been to [other family members], but he hasn't been here. It's like, she says, she laughed that away but I know what was going through her head</p> <p><i>Mary:</i> No. I mean, as I said before I still have bad days but [husband] doesn't always know, because... (I don't tell him).</p> <p><i>Mary's husband:</i> (Well you don't talk to me about them do you?) Because you probably don't want me to get upset or worried.</p> <p><i>Mary:</i> Well I know... that's part of it, and some days.. erm... and I think he knows what I'm going to say.</p> <p><i>Mary's husband:</i> (and she got) a badge, and I was appalled (at this badge).</p> <p><i>Mary:</i> (It wasn't good).</p> <p><i>Mary's husband:</i> ... because everybody was there, Mr Smith, psychologist, Mr Smith, Alzheimer's society, Mr Johnson whatever.... Mary Jones, dementia sufferer.</p> <p><i>Mary:</i> No... Mrs M Jones, person with dementia.</p> <p><i>Mary's husband:</i> I went mental!</p> <p><i>Mary:</i> They were all screaming and shouting at me, and I thought Oh my god.</p> <p><i>Mary's husband:</i> (So she rung me and I said right I'll come and take you home)</p> <p><i>Mary:</i> (I rang him at half 11 at night), take me out of here, it's going to drive me insane, and the nurse was quite horrible and said you know, you should have some empathy for these people... I said 'Ay, I've got all the empathy in the world but.... Please I can't stop in here all night' you know. (It was awful).</p> <p><i>Mary's husband:</i> She weren't right happy? She said 'you better sign this'. I said 'I'm signing nothing' I said 'you've driven her to discharge herself!'. So it's down to your bad nursing... or the nursing care that she's getting that she's going home...</p>



<p><u>Frustration if can't get hold of his wife – worries?</u>      Recognises his wife has blips and takes herself off in the car      Appreciates his wife needs this time alone  <u>Knows Mary doesn't share when she has a bad day – empathises that she probably doesn't want to upset or worry him (attunement)</u>      He knows what I'm going to say (even though not said before) – attunement  <u>Upset by stories about people with dementia – empathise with PWD – they don't know what they're doing.</u>      If anything happens to dad - 'You'll have us' – shows support      Reassured to know step-daughter and granddaughter will 'look after me'      Mary affirms husband      'the fact that I've got dementia as well has helped so many people' – giving something back – helping others      'If I can just help one person' – personal meaning from helping others      Supported wife to give speech at her daughter's wedding  <b>Frustration</b>      Frustration – repetition – <u>why</u> forgotten? Try not to but it's not easy      Understands the frustration of her family      Mary's efforts to provide info/explain = 'may as well bash your head against the wall'  <u>Bad day = Mary doesn't meet expectations = frustration</u>  <u>Recognises dad's frustration/anger 'sets Mary off'</u>  <u>Mary gets upset when husband is frustrated- 'I can't help it' (blame/fault). But does understand</u>      Notices Mary is less patient/snaps quicker – frustration  <u>Appalled at the way Mary was treated (badge given). 'I went mental'</u>  <u>Recognises Mary get's 'wound-up'</u>  <u>Offers support – when frustrated need to let it go and calm down and it will come back to her</u>      More frustrated at forgetting and more try to think of it – worse it gets      Frustrates and annoys me that they exclude her      Frustrating family not there for her = concerns if anything happens to me  <u>Recognises husbands 'cross' when she drives off alone – understands he worries due to her being ill</u>  <u>Frustration directed towards her friends when they don't make an effort</u>  <u>Frustration if can't get hold of his wife – worries?</u></p>	<p>other, and as such this could result in frustration between them. Mary's husband described getting annoyed at times when Mary kept forgetting, or had not done something she agreed to do. He felt he shouldn't get frustrated as he knew she couldn't help it, but he explained that it was sometimes hard to hold on to this understanding. In turn the family recognised that his frustration would often foster upset and frustration in Mary as she became cross that he didn't understand that it wasn't her fault. Together the family described how understanding each other and the difficulties was key to offering support.</p> <p>Mary felt she now empathised more with other people with dementia, as she appreciated what they were going through. Subsequently she had started to offer support and guidance to other people with dementia and was advocating on their behalf. She gained a great deal of pleasure from this and the notion that she was able to help. The care and support that her family members offered her may well have been the foundation and secure footing that she needed to enable her to provide this for others.</p>	<p><b>Mary:</b> Yeah, (you [husband] used to get cross about that).  <b>Mary's step-daughter:</b> (But now you're actually doing stuff).  <b>Mary:</b> 'Where's your phone?', and I'd just go off and drive and that were it.  <b>Mary's husband:</b> Well as we said she's got many medical conditions. I wasn't mad because of the dementia...  <b>Mary:</b> No (I know it was because he was worried, because I was ill)  <b>Mary's husband:</b> ...(it was because of her other medical conditions). And I'd ring her and I'd make sure she's alright  <b>Mary:</b> ...And I think the fact that I've got dementia as well has helped so many people.  <b>Mary's husband:</b> ...and you just think... if you just take it on board then at least you could understand and maybe be there and be supportive.  <b>Mary's husband:</b> .... And as I said before it's only when Mary has a bit of a blip or a bad day erm... and I come home and... she was going to do this and she was going to do that or she was going to do the other, why's that not been... (why haven't you done that?)  <b>Mary:</b> (Why haven't you done that?)... That's because I've forgotten you know.  <b>Mary's husband:</b> ...and it's like oh for god's sake, how many times do I need to remind you. So I get, you know as I say, that's my frustration.  <b>Mary:</b> So when he snaps at me...  <b>Mary's step-daughter:</b> Sets you off doesn't it?  <b>Mary:</b> ... then I get upset... and then I go 'I can't help it' [in whimpering voice]. You know, and then I.... It's horrible, and I do understand that it must be frustrating... for other people erm</p>
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Theme 5: Finding a reason to live and building a better life		
Example Notations	Narrative summary	Example Quotes
<p>Being invited to volunteer has 'given me a purpose to my life again' (<i>dementia stripped me of purpose?</i>). Best thing ever done</p> <p>Recognises volunteering as 'best things to happen' – 'opened up real big new life' (<i>dementia closed life?</i>)</p> <p>'I'm a different person' after volunteering</p> <p>Volunteering 'It took her away and gave her something else' – 'a purpose' - rather than being a 'vegetable', 'useless', 'I can't do anything'.</p> <p>a new aim/venture in life – strength to strength – growth – No stopping me (determination)</p> <p>being headhunted – being valued</p> <p>Passing courses</p> <p>New college qualifications</p> <p>Getting involved</p> <p>Other's recognising her talents/ability/value</p> <p>Allowed to do the course with monitoring/support to check ok</p> <p>Working again</p> <p>Having input into svcs/professionals</p> <p>Some things quite nerve wracking – building confidence</p> <p>Prompting Mary on all the things she's done/achieved – proud?</p> <p>(Mary's family = part of building/sustaining this new life for Mary)</p> <p>'Using me as a case study really' – <i>object to demonstrate rather than input??</i></p> <p>Received lots of positive feedback</p> <p>'that's basically my story now' – <i>rewriting story (new narrative)</i></p> <p>Volunteering given me life back – previously lost confidence, self-esteem, lost everything - slowly getting back/ <i>Rebuilt yourself</i></p> <p>Recognise still have bad days – cope alone</p> <p>6 death in 12 months = recent blip/awful (<i>life continues- still managing life events</i>)</p> <p>Stress of life creates 'blips' – but recognise and understand</p> <p><u>Loss of ability to be calm – not Mary at all. Taking little things more personally/not able to cope as well with them (impact of confidence/self esteem rather than dem?)</u></p> <p><u>Relationships haven't changed between 'us'</u></p> <p><u>Not a big impact on 'us'</u></p> <p><u>No change, 'we just carry on as normal basically'</u></p> <p>Since diagnosis Mary has 'a better life' – out there doing more.</p> <p>More involved – 'her life has changed'</p> <p>No-one else's role has changed</p> <p>New role and meaning in Mary's life.</p> <p>We carry on around her and enable her to continue</p> <p>My life has changed for the better – never at home</p>	<p>This captures how the family helped Mary to find a purpose, which gave her life new meaning. The family enabled Mary to be able to become more involved in volunteering and other activities, where she was able to feel valued and appreciated, both by her family and others. Mary describes having a much better life now than before her diagnosis, and although her family members feel their lives and roles have continued as they were, they experience more happiness and pride in witnessing Mary rebuilding her new life.</p> <p>The family described how Mary's life had changed drastically and they all felt that this was for the better. Mary had become more involved in volunteering, and particularly supporting other people with dementia. These new roles had given her a sense of purpose in her life, and she described now having a reason to live. Since becoming more involved in volunteering etc, her input had gone from strength to strength as she was valued and appreciated by others who wanted further input from her and often gave her very positive feedback.</p> <p>There was still an air of the existing stigma and hopelessness around as Mary believed that others would wonder why she was doing course, as she would not be able to use it in the future. However, what was important to Mary was that she enjoyed these course and her new role, and this was crucial to her making the most out of her life.</p>	<p><b>Mary's husband:</b> So... the fact that she's got herself involved in this... I mean it's like when she goes on... well her daughter got married, and she wanted her to give a speech but she didn't really know what to say, so I wrote the speech but she gave it, but she gave it and made it funny. Erm... just because of the way she is... and she turned it... I mean it wasn't a serious story or anything... She made it her own by the way she did it. And I'm sort of sat there, chuffed to hell, and like crying, because she's able, albeit that she did it and read it, but because she was doing it, it made me proud of her....</p> <p><b>Mary:</b> and the fact again, because I'm able to tell my story...erm... we've had such a lot of positive feedback. It's been brilliant, and if I can just help one person...</p> <p><b>Mary's husband:</b> Even the prime minister's seen your videos.</p> <p><b>Mary:</b> Yeah I believe so [laughs].</p> <p>Int: Wow.</p> <p><b>Mary:</b> So I was told.... But it... so that's basically my story now. But it... when I was diagnosed, well you heard the other....</p> <p><b>Mary's step-daughter:</b> Well she's got a bit of a better life in a sense, she's out there doing more things, but otherwise no.</p> <p><b>Mary's husband:</b> I was going to say it's changed more for Mary than anybody, because as I say she's... because she's got involved in .... Erm... with the [service] and that, her life has changed...</p> <p><b>Mary:</b> for the better</p> <p><b>Mary's husband:</b> Because she's got a life as it were... and a new role in life, and a new meaning to life. Whereas we just carry on around her, and like she'll say 'Get me up in the morning, I'm going</p>

<p>Like my mum I can't sit at home  Always been busy – <i>preserving this part of herself?</i>  <u>'the dementia' (not her dementia as with 'her medical conditions')</u>  Thinking has changed following dementia/illnesses = I died that day – every day is now a bonus.  Voluntary work has given me new friends  <u>'I like to think' they're friends, 'I think I'm right'? – doubts self – self-esteem/confidence</u>  It's important to me to have friends and be liked  Volunteering gives me a purpose to get up in the morning – reason to live, an incentive, 'I love it' – <i>spurs you on</i>  Missing volunteering when not doing it  Has witnessed Mary 'come alive', 'a little sparkle in her eye'  Keeping in touch – friendships are important – contact/connection  Like seeing Mary happy  Reassuring to know she's found a purpose in life  Dread to think what life would have been like without volunteering  Recognised she needed her own space – couldn't continue caring for her mum  Glad that volunteering gave her a break from caring  Made wedding speech funny, her own – I'm 'chuffed to hell, and crying because she's able...' – Proud of her  Spend time crocheting bed blankets  Questions why doing courses – when 'can't work' but 'thoroughly enjoy them'  Excited about helping others – but also nervous and frightened when trying new things  Aims to be professional – <i>boosts sense of self?</i></p> <p><b>Life continues – other stress</b>  So many other medical problems – struggle and pain. Diagnosis on top of everything = overwhelming  Recognises couldn't deal with anymore  Other losses (life outside of dementia has huge impact)  Friends not showing care or concern hurts  <u>Mary's friends making contact via husband – (reflects how society speak to the partner/carer rather than PWD)</u>  Life's struggles separate to dementia</p>	<p>Mary and her family acknowledged that life was not all wonderful, she still experienced 'bad days' where she would feel more pain and distress and would tend not to share this with people, but cope alone. The family also still coped with life's continued stressors and struggles, which existed separate to the dementia. For example she had recently experienced a series of family bereavements which she recognised had prompted a 'blip' in the way she felt.</p> <p>Overall Mary and her family repeatedly noted how much better Mary's life was now compared to the past, and certainly compared to when she initially received the diagnosis of dementia. There was a strong sense of the trauma and struggle she went through having made her a stronger person, and able to face more and appreciate life more – similar to notions of post-traumatic growth.</p> <p>Mary's husband and her step-daughter repeatedly showed their happiness and pride in relation to what Mary had achieved. They described how Mary had 'come alive' and now had a 'sparkle in her eye'. Such comments would always be met with smiles, and laughter from Mary which implies how important this was to her self-esteem and sense of self. What was also interesting is how strongly this new image and narrative around Mary contrasts so strongly to the image from Theme 1 of someone questioning themselves, feeling stupid and being ignored by others. Mary's new life and what she's now involved in has enabled her to feel included rather than excluded – she no longer felt invisible to others!</p>	<p>such and I've got to do this, or I've got to do that'. So erm... it's changed for Mary rather than changed for us.</p> <p><b>Mary:</b> Changed for the better for me. Well I'd of just, I think... I could have give up.</p> <p><b>Mary's step-daughter:</b> Oh she's definitely come alive. You can see a little sparkle in her eye now [Mary's step daughter smiles and Mary laughs] when she thinks about it.</p> <p><b>Mary's husband:</b> ...and they keep you keeping on...</p> <p><b>Mary:</b> Well they do! I mean at my age now, I mean I'm 62 next year, but... and I think why am I doing these courses – I'm not... I can't work [laughs]. They're never going to sort of.... (really)</p> <p><b>Mary's husband:</b> (they're not going to be of any use to you)..</p> <p><b>Mary:</b> ... but I've just thoroughly enjoyed doing them...erm... and I'm hoping, well in a few weeks I will have a mentee. Hopefully... I can't wait!</p> <p><b>Mary:</b> But.... As I say this volunteering it's just given me my life back hasn't it?</p> <p><b>Mary's step-daughter:</b> mmmm.</p> <p><b>Mary:</b> I'm.... Because I'd lost.... Because of all my illnesses, I'd lost my... confidence, my self-esteem, I'd lost everything really... But I've slowly... getting it back.</p> <p><b>Mary's husband:</b> Rebuilt... rebuilt yourself haven't you?</p> <p><b>Mary:</b> Yeah. Erm... don't get me wrong I do have bad days... I'm not you know. I do have bad days but I don't always tell them...[laughs], do I? I have mood swings erm... and I know I've had a blip because this last 12 months has been awful, [...] And I thought... god, when's it all... gonna end. And I know because of the stress of all that... I know I've had a blip. Erm...</p>
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**Appendix 2-C: Table Illustrating Merging of Themes into Final Themes**

	<b>Final Themes</b> (and contributing themes from each family)				
	<b>Conflicting identities: person or 'dementia patient'</b>	<b>Loneliness and isolation: finding ways to maintain belonging and connection</b>	<b>Family support: protecting and enabling</b>	<b>Feeling trapped: shifting power and control</b>	<b>Fear and uncertainty: making sense and reigniting hope</b>
<b>Liz's family</b>	Changing capabilities: being on the other side	Being together: 'just us three'	Having someone there: providing comfort From secrets to shock	Having someone there: providing comfort	Confusion and uncertainty: trying to make sense From secrets to shock
<b>Ted's family</b>	Being the joker to being 'funny' 'There but not there': not being acknowledged	'There but not there': not being acknowledged Empathy and connection: making sense	Safety and support through the struggle Empathy and connection: making sense	Safety and support through the struggle Restricted or enabled: nurturing to combat loss	Safety and support through the struggle Empathy and connection: making sense
<b>Mary's family</b>	How others do and don't see 'it': shame of dementia Finding a reason to live and building a better life	Overcoming it and not letting it overcome 'us' How others do and don't see 'it': shame of dementia	Supporting each other: attuned and advocating		From hopelessness to holding on to hope Finding a reason to live and building a better life
<b>Jim's family</b>	Being open or covering up: preserving roles	Shared pleasure and reciprocal happiness Accepting a 'curtailed' life: 'this is life now'	Having a 'back-up': the knock on effect of support Being open or covering up: preserving roles	Accepting a 'curtailed' life: 'this is life now'	Accepting a 'curtailed' life: 'this is life now'
<b>June's family</b>	Understanding the patient	Private but excluded: Two separate worlds	Understanding the patient Taking control: parenting your parent	Battles and conflict: A family at war Taking control: parenting your parent	Overcoming the 'war': now it's easy Understanding the patient
<b>Ron's family</b>	Being different: Bionic Man Polarized views around Ron's capability	Me vs 'the enemy' Being different: Bionic Man	Parental control: managing resistance Being different: Bionic Man	Me vs 'the enemy' Parental control: managing resistance	Fear of the future
<b>Sue's family</b>	I'm still me but 'a bomb's hit me' Unfairness and resentment	Feeling abandoned and alone	Empathising and comforting one another	Unfairness and resentment Becoming 'cared for' as others take more control	Empathising and comforting one another

**Appendix 2-D: Excerpt From Reflective Diary****Reflective Diary****Post Interview Reflections –Interview 7**

FAMILY IDENTIFIER:	Family 7 (Pseudonym: Sue)
<b>Initial environment/setting notes</b>	Sat at kitchen table Sue and Sue's husband at either end, me and Sue's daughter-in-law in middle. Perhaps reflects Sue's daughter-in-law acting as mediator at some points?
<b>What seemed particularly significant?</b> Themes / things that stood out etc.	Sue's distress – not wanting to be seen as stupid/loopy etc. Significant anger/resentment around losing her licence had an impact on whole family – loss of freedom/independence
<b>Notes on dynamics/relationships between family members</b>	Some hostility between family members to begin with (I felt this too), which seemed to dissipate when Sue's daughter-in-law took a role as mediator (almost therapist) and the conversations at times felt very therapeutic for the family, who seemed to be early in the process of adjustment.
<b>What went well?</b> Any difficulties overcome?	Management of Sue's distress – giving her time, but continuing when she was happy to.
<b>What didn't go as well?</b> Did you encounter any problems?	Difficult finding the balance between being mindful of where Sue was at/her vulnerability and offering support/normalising etc whilst also maintaining research role. Support was offered at points, but this was necessary, and as far as possible I left this to the end so that it did not influence the interview.
<b>What might I do differently next time?</b>	No further interviews – but I would have emphasised the options for everyone if they feel upset (i.e. can take a minute/take a break/leave the room etc). Emphasise this more before-hand.
<b>How did I feel through the interview?</b> Towards the person? About the content? Did my feelings change throughout the interview?	Initially felt a little uncomfortable and could sense some tension/hostility. Felt some concern when Sue became very upset and left the room, although remained calm, and took things tentatively when she returned. I felt reassured by Sue's daughter-in-law's role in the family and her honesty and openness when encouraging togetherness. I then felt quite positive about the family towards the end of the interview, as it seemed the family were in a different place to when I arrived – shows power of discussing openly as a family and sharing perspectives.

<p><b>What did others feel about the interview?</b> Your perception of this? Their comments during debrief? Did this change?</p>	<p>Initially Sue may have felt attacked? Which led to her becoming very upset – although her understanding shifted. Sue's daughter-in-law seemed to appreciate the opportunity to talk openly to Sue's husband and Sue. They seemed to like sharing their story – by the end I believe Sue felt listened to and validated reflected in her asking me to visit again (managing finality of ending was more difficult for this reason) Sue's husband seemed to be seeking reassurance due to all the questions he asked.</p>
<p><b>What actions do I need to take now?</b></p>	<p>Transcribe – begin to analyse transcripts</p>
<p><b>Has this affected my thoughts on this topic / assumptions etc</b></p>	<p>My view on professionals removing driving licences has changed- I think it's important for professionals to do this/communicate this as can create blame in family if they are left to do this. 'Insight' seems less to do with their awareness, but instead the attack on their identity (i.e. knowing but not wanting to accept/agree?) Families need more info on what it's like/might be like for them all (to allow comparisons/normalise/reassure) It seems like it would be helpful for professionals to openly discuss the stereotype/portrayal of Alz/Dem and that to allow people to express 'that's not me' – also emphasise everybody is different</p>
<p><b>What have I learned?</b> What will I take forward to my next interview / to analysis?</p>	<p>Has made me reflect on the overlap between research and clinic role more. Is it possible to completely separate the two? Especially when a participant becomes so upset – the principle to do no harm in research must surely take precedence?</p>
<p><b>What are my initial ideas on the key themes from this interview?</b></p>	<p><b>Reassurance seeking</b> – how do we compare to other families <b>I'm not mad/stupid</b> – I can do things <b>Losing my freedom and relying on others</b> <b>It's like a bombs gone off.</b> <b>Everyone must adjust/adapt.</b> <b>Support from family</b> – 'ostriching'/not understanding</p>

**Appendix 2-E: Author Guidelines for Target Journal****CAMBRIDGE** | Instructions for Contributors

## **Ageing & Society**

### **Submission**

Ageing and Society is an interdisciplinary and international journal devoted to the understanding of human ageing and the circumstances of older people in their social and cultural contexts. We invite original contributions that fall within this broad remit and which have empirical, theoretical, methodological or policy relevance. All submissions, regardless of category, are subject to blind peer-review. Authors are reminded of the requirement to avoid ageist and other inappropriate language and to avoid the stereotypical representation of individuals or groups.

All papers must be submitted using Manuscript Central through the Journal's website at:  
<http://journals.cambridge.org/aso>.

All books for review should be sent to: Stella Allinson, Review Editor's Assistant, Ageing and Society, Faculty of Health and Social Care, The Open University, Walton Hall, Milton Keynes, MK7 6AA, UK.

All submissions must conform to the submission guidelines outlined below. Failure to do so may result in the submission being rejected.

### **Article categories**

**(a) Research articles**

Research articles must contain between 3,000 and 9,000 words, excluding the abstract and references. Most papers usually have the following sections in sequence: Title page, Abstract (200-300 words), Keywords (three to eight), Main text, Statement of ethical approval as appropriate, Statement of funding, Declaration of contribution of authors, Statement of conflict of interest, Acknowledgements, Notes, References, Correspondence address for corresponding author. However authors have the flexibility to organise the main text of article into the format that best suits the topic under consideration.

**(b) Forum articles**

In addition to research papers, the Journal welcomes critical/reflective commentaries on contemporary research, policy, theory or methods relevant to the Journal's readers. These articles reflect a viewpoint of the author and they may form part of an ongoing debate. These articles should contain 2,000-5,000 words. There is no preset organisational structure.

**(c) Special issues**

Proposals are invited for special issues that fall within the remit of the journal. Ageing & Society especially looks for proposals that show originality and which address topical themes. Proposals which involve authors from a range of disciplines and/or countries are particularly encouraged and the special issue must demonstrate clear added value in advancing an understanding of ageing and later life that is more than the sum of the individual papers.

Proposals should be submitted by the co-ordinating Guest Editors by email to the Editor, Christina Victor: [christina.victor@brunel.ac.uk](mailto:christina.victor@brunel.ac.uk)

Proposals should be submitted by 28 February each year. For further information see the guidelines for special issue proposals available at: [http://journals.cambridge.org/images/fileUpload/images/A&S\\_Special\\_Issue\\_Proposals.pdf](http://journals.cambridge.org/images/fileUpload/images/A&S_Special_Issue_Proposals.pdf)

It is Ageing & Society practice that all papers in special issues are subject to blind peer review, undergoing the same refereeing process as all other submissions, led by the Ageing & Society Editor and co-ordinated by the journal's Editorial Assistant. The final decision whether to publish individual papers submitted as part of a special issues remains with the Editor.

## **Submission requirements**

### **(d) Exclusive submission to Ageing & Society**

- Submission of the article to Ageing & Society is taken to imply that it has not been published elsewhere nor is it being considered for publication elsewhere. Authors will be required to confirm on submission of their article that the manuscript has been submitted solely to this journal and is not published, in press, or submitted elsewhere. Where the submitted manuscript is based on a working paper (or similar draft document published online), the working paper should be acknowledged and the author should include a statement with the submitted manuscript explaining how it differs from the working paper. Articles which are identical to a working paper or similar draft document published online will not be accepted for publication in Ageing & Society.

### **(e) Appropriateness for Ageing Society**

- All submissions must fall within the remit of the journal, as described at the beginning of this document.
- All manuscripts must meet the submission requirements set out in this document, closely following the instructions in the 'Preparation of manuscripts', 'Citation of references' and 'Table and Figures' sections below.
- Authors are requested to bear in mind the multi-disciplinary and international nature of the readership when writing their contribution. Care must be taken to draw out the implications of the analysis for readers in other fields, other countries, and other disciplines. Papers that report empirical findings must detail the research methodology.
- The stereotypical presentation of individuals or social groupings, including the use of ageist language, must be avoided.

### **(f) Submission documents**

All submissions should include:

- A copy of the complete text of the manuscript, with a title page including the title of the article and the author(s)' names, affiliations and postal and email addresses.
- A copy of the complete text minus the title page, acknowledgements, and any running headers of author names, to allow blinded review.

### **(g) Named authors**

- Papers with more than one author must designate a corresponding author. The corresponding author should be the person with full responsibility for the work and/or the conduct of the study, had access to the data, and controlled the decision to publish. The corresponding author must confirm that co-authors have read the paper and are aware of its submission. Full contact details for all co-authors should be submitted via Manuscript Central.
- All named authors for an article must have made a substantial contribution to: (a) the conception and design, or analysis and interpretation of data; (b) the drafting of the article or revising it

critically for important intellectual content and (c) approval of the version to be published. All these conditions must all be met. Participation solely in the acquisition of funding or the collection of data does not, of itself, justify authorship.

**(h) Peer-review process**

- The corresponding author should prepare (a) a complete text and (b) complete text minus the title page, acknowledgements, and any running headers of author names, to allow blinded review. References to previous papers of the authors must not be blinded, neither in the text nor in the list of references.
- Papers are peer-reviewed. Authors may be asked to submit a revised version of the original paper. In any revised submission, we prefer you to indicate these revisions using track changes where appropriate. An accompanying letter from the corresponding author should outline your changes, and comments on advice that you have chosen not to accept. The corresponding author should confirm that co-authors have agreed to any changes made.

**(i) Ethical considerations**

- Where the paper reports original research, confirmation must be given that ethical guidelines have been met, including adherence to the legal requirements of the study country. For empirical work conducted with human subjects authors must provide evidence that the study was subject to the appropriate level of ethical review (e.g. university, hospital etc.) or provide a statement indicating that it was not required. Authors must state the full name of the body providing the favourable ethical review and reference number as appropriate.

**(j) Declaration of funding**

- A declaration of sources of funding must be provided if appropriate. Authors must state the full official name of the funding body and grant numbers specified. Authors must specify what role, if any, their financial sponsors played in the design, execution, analysis and interpretation of data, or writing of the study. If they played no role this should be stated.

**(k) Copyright**

- Contributors of articles or reviews accepted for publication will be asked to assign copyright, on certain conditions, to Cambridge University Press.

## **Preparation of manuscripts**

All contributions (articles, reviews and all types of review articles) should be typed double-spaced with at least one-inch or two-centimetre margins throughout (including notes and the list of references).

Most research articles usually have the following sections in sequence: Title page, Abstract (200-300 words), Keywords (three to eight), Main text, Statement of ethical approval as appropriate, Statement of funding, Declaration of contribution of authors, Statement of conflict of interest, Acknowledgements, Notes, References, Correspondence address for corresponding author.

The title page should give the title of the article and the author(s)' names, affiliations and postal and email addresses. When composing the title of your article, please give consideration to how the title would be shortened to appear as a running head in final version of the Journal.

The tables and figures should be presented one to a page in sequence at the end of the paper. Black and white photographs may be submitted where they are integral to the content of the paper. Charges apply for all colour figures that appear in the print version of the Journal (see below for further details).

Authors are asked to follow the current style conventions as closely as possible. Please consult a very recent issue of the journal. In particular, please note the following:

- Use the British variants of English-language spelling, so 'ageing', not 'aging'.
- **First level headers are in bold, sentence case and left justified**
- *Second level headers are in italic (not bold), sentence case and left justified*
- Do not number paragraphs or sections. Avoid very short (particularly one sentence) paragraphs.
- Do not use **bold text** in the text at all. For emphasis, use italic.
- In the main text, the numbers one to ten should be written as words, but for higher numbers the numerals (e.g. 11, 23, 364) should be used.
- All acronyms must be expanded on first use, even EU, USA, UK or UN, for those which are commonplace in one country are not in others.
- Do not use footnotes. Endnotes are permitted for technical and information details (including arrays of test statistics) that distract from the main argument. Endnote superscripts should be placed outside, not inside a punctuation mark (so.<sup>3</sup> not<sup>4</sup>.).
- Write per cent (not %) except in illustrative brackets.

## Citation of references

Contributors may follow either the standard conventions: (a) in-text citation of sources (author/date system); or (b) citations in notes.

- (l) *In-text citation.* Give author's surname, date of publication and page references (if any) in parentheses in the body of the text, e.g. (Cole 1992: 251). For references with one to three authors, all authors should be named (Black, Green and Brown 2003). For references with four or more authors, the following form is required: (Brown *et al.* 2003). Note that all authors must be named in the list of references, and *et al.* is not permitted in the list. A complete list of references cited, arranged alphabetically by authors' surname, should be typed double-spaced at the end of the article in the form:

Cole, T. 1992. *The Journey of Life: A Cultural History of Aging in America*. Cambridge University Press, Cambridge.

Elder, G.H. and Clipp, E.C. 1988. Wartime losses and social bonding: influences across 40 years in men's lives. *Psychiatry*, **51**, 1, 177-98.

Ruth, J.-E. and Oberg, P. 1996. Ways of life: old age in life history perspective. In Birren, J.E., Kenyon, G., Ruth, J.-E., Schroots, J.F.F. and Svensson, T.(eds), *Aging and Biography: Explorations in Adult Development..* Springer, New York, 167-86.

- (m) *Citation in notes.* References should be given in notes, numbered consecutively through the typescript with raised numbers, and typed double-spaced at the end of the article. Full publication details in the same format as (a) should be given in the notes when a work is first cited; for second and subsequent citations a short form may be used.

For both styles of reference lists, please particularly note the following:

- Authors are requested to minimise the citation of unpublished working and conference papers (because they are difficult for readers to acquire). Where they are cited, complete details of the title of the conference, the convening organisation, the location and the date of the presentation must be given. Papers that have been submitted to journals but on which no decision has been heard must not be cited.
- *Titles of Books and Journals are in Title Case and Italic.*
- Titles of papers, articles and book chapters are in sentence case and not italicised.
- Please note carefully that part or issue numbers should be given for journal paper citations, that page ranges for book chapters should always be given and should be condensed, so 335-64 not 335-364, and S221-9 not S221-229.
- Please use (eds) and (ed.) where required (no capitals, full stop after truncated ed. but not compressed eds).

**(n) Citation of Internet pages or publications that are available online**

Give authors, date, title, publisher (or name of host website) as for a printed publication. Then follow with ... Available online at ... full Internet address [Accessed date].

**Tables and figures**

There should never be more than ten tables and figures in aggregate, and only in exceptional circumstances more than eight. Please do not use Boxes or Appendices. Present all illustrative material as tables or figures. Please indicate in the text where approximately the Table and Figures should appear using the device < Insert Table 1 about here > on its own line. For figures generated by Excel, please send the original file (rather than a 'picture' version) so that the figures can be copy-edited.

Tables and figures should be clearly laid out on separate pages, numbered consecutively, and designed to fit a printed page of 228 x 152 mm (actual text area 184 x 114 mm). Titles should be typed above the body of the table, with an initial capital only for the first word and proper names and italicised or underlined (for italics). Vertical lines should not be used and horizontal lines should be used only at the top and bottom of the table and below column headings. Authors are asked to give particular attention to the title and to column and row labels (they are often poorly selected, incomprehensible or inadequate). All multiple word labels should be in sentence case. Short titles that concentrate on the subject of the table are recommended. Technical or methodological details (such as sample size or type of statistic) should be described in the labels or in table notes. Spurious accuracy should be avoided: most statistics justify or require only one decimal place.

Figures should also be provided on separate pages and numbered consecutively. For each figure, the caption should be below and in sentence case. Separate lists of captions are not required.

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Figures should be provided in the following formats:

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Proofs will be sent to the corresponding author as a PDF via email for final proof reading. The proofs should be checked and any corrections returned within 2 days of receipt. The publisher reserves the right to charge authors for excessive correction of non-typographical errors.

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### **Section Three: Critical Appraisal**

Word Count: 3,989

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The purpose of this paper is to critically appraise the research undertaken as part of the empirical paper within this thesis. A reflective and critical stance was adopted throughout the course of the research, which is a core competency of practicing psychologists (British Psychological Society, 2009). This stance was facilitated by my reflective journal, which also supported the application of interpretative phenomenological analysis (Smith & Osborn, 2008). Some salient themes from my reflective journal form the key issues discussed within this paper. These include ethical, conceptual and methodological issues around including people with dementia in research, conducting family interviews, managing dynamics, and separating the research and clinical role.

### **Involving people with dementia in research**

Research focussing on the perspectives of carers or partners alone to understand the wider experience of dementia, has been criticised for not directly including the person with dementia - effectively seeing them as an 'object' to be observed or described by others (Clarke & Keady, 2002; Cotrell & Schulz, 1993). Such critiques argue that people with dementia must be actively involved in research to ensure their voices are heard within literature, policy and services.

My experience within memory assessment services supports this, with communication often being via the partner of the individual with dementia, and interventions based on evidence from research that did not actively involve the individual. This practice promoted my interest in research, and I felt passionate about ensuring that people with dementia were included within my study. I did however question the strength of my resolve when faced with the practical and ethical challenges of conducting such research (Beuscher & Grando, 2009; Heggstad, Nortvedt, & Slettebø, 2013; Moore & Hollett, 2003). On occasion, advice from others suggested I

should 'make life easier' for myself by not including people with dementia due to the added ethical issues which could prolong the ethical approval process, thereby delaying the project. Efforts to protect this vulnerable group therefore became a potential barrier to conducting this research, and could discourage other researchers (Heggestad et al., 2013).

However, excluding people with dementia from research about them, only serves to reinforce their marginalisation within society, services and policy (Hellström, Nolan, Nordenfelt, & Lundh, 2007), which echoes findings from my research around their feelings of isolation and loneliness. Indeed, their exclusion may reinforce their vulnerability (Heggestad et al., 2013). Instead, researchers must balance the need to protect people with dementia with the responsibility to listen to their voices and include them in research in an ethical but meaningful way. This is core to my belief, despite the challenges it may represent.

The issue of consent is perhaps the most documented ethical issue within research on people with dementia (e.g. Dewing, 2002; McKeown, Clarke, Ingleton, & Repper, 2010; Slaughter, Cole, Jennings, & Reimer, 2007). It is important not to assume that a diagnosis of dementia means an individual is not capable of providing consent (Heggestad et al., 2013). I therefore felt it was unnecessary and inappropriate to formally screen the ability or capacity of people with dementia within the research (Heggestad et al., 2013) as their capacity should be assumed (Mental Capacity Act, 2005). Staff members therefore used their own judgement and procedures to select individuals who they considered to have capacity to make a decision about research. I then reviewed their understanding upon commencement of the interview and at points during, if necessary.

The way understanding was checked became vital. After the first interview, I recognised the need to modify my approach. I noted within my reflective journal that there were some difficulties around the initial questions designed to check the understanding of the person with dementia; while she demonstrated her understanding well through conversation, her difficulties with immediate recall meant she struggled to repeat specific sections of the information back to me. Unfortunately this resulted in the questions becoming an unhelpful test of her memory rather than understanding. I noted within my journal that this seemed to create some anxiety, which impacted upon engagement in the rest of the interview. The experience of memory testing has been found to be humiliating and threatening to individuals (Hellström et al., 2007), and it was important to prevent this negative effect. Subsequently, I adjusted my approach, checking understanding in a more conversational way - this facilitated rapport and was not experienced as a test.

On a practical level, flexibility was essential when conducting this research (Hubbard, Downs, & Tester, 2003). From aspects of the interview environment (e.g. location and timing of their choice, reducing noise and distractions etc.) through to methods of communication (e.g. support in reading the information and completing the consent form, monitoring pace of the conversation, drawing people into discussions, using brief and accessible language, taking breaks etc.) it has been vital to ensure the person with dementia is comfortable and able to understand the materials and the course of the conversation (Hellström et al., 2007). It is important that this is not a standard or prescriptive approach, as each person with dementia will experience this very differently and have differing needs in relation to this.

Since completion of the research I have reflected upon another consideration: the potential ethical issue around encouraging people with dementia to talk about their

experience. Although all the families in my research wished to share their experience, the findings suggest that families often coped by ignoring the dementia, and choosing not to talk about it. By definition the research works against this coping strategy. Furthermore it is interesting that in discussion with the family who dropped out of the research, the person with dementia stated that they did not wish to discuss the dementia any further as they preferred to live in “blissful ignorance”. If talking about dementia is indeed something individuals wish to avoid, research that requires them to discuss this must be managed sensitively. The interview may have highlighted this lady’s difficulties, which could have been quite uncomfortable to confront. This emphasises the need for sensitivity within research (Heggestad et al., 2013), recognising that qualitative research requiring discussions about experience could work against individuals efforts to distance distress.

In addition to these practical and ethical challenges in including people with dementia in research, it seems there can also be personal challenges which can further discourage people from conducting research in this area. Researchers may choose to protect and shield themselves from emotionally challenging situations where they may be faced with the great difficulty and distress that people with dementia and their families experience, which could illicit fears about their own future (Ablitt, Jones, & Muers, 2009; Kitwood, 1997). Distancing themselves from such research may relieve these anxieties and enable them to avoid facing the possibility of them experiencing life with dementia in the future (Kitwood, 1997). I prepared for these more personal challenges by ensuring appropriate support and supervision was available (Pratt, 2002), and found it useful to reflect upon my own emotional reactions using my reflective journal. For example, at times I noted feeling quite hopeless when thinking about life with dementia and how services could support families - an unusual outlook for me. On

reflection, and through discussions with others, I wondered whether this mirrored feelings of some of the families interviewed, and perhaps even wider societal narratives in relation to dementia. Recognition of this helped me to separate and attempt to bracket these feelings.

I thereby acknowledged the moral, ethical and personal challenges of including people with dementia in research, but prepared for and managed these by using flexibility, reflection, supervision and perseverance. Alongside the challenges of including individuals with dementia I also considered issues relating to the involvement of families within research.

### **Focussing on families**

My decision to interview ‘family units’ collectively resulted from careful consideration of the advantages and disadvantages of several options in relation to my research question and approach to analysis. In order to decide on the most appropriate method I first needed to define what was meant by a ‘family’.

Great diversity exists within and between families - much the same as all individuals are unique, the family systems to which they belong are equally unique. As such I felt an exact definition was unnecessary and was not my decision to make, but that of the participating individual and families. The sense of ‘family’ will mean something different to each unit and any attempts to impose my own views of what ‘family’ is would therefore be inappropriate. The definition of family was left to participants, although for practical reasons an inclusion criterion of three or more participating family members (including the person with dementia) was applied to prevent the research becoming a study of couples’ experiences. It also encouraged representation from more than one generation within the family, facilitating a broader view of the family. The interviews conducted therefore often represented a sub-group

of the family, but most importantly the sub-group defined and chosen by the person with dementia and their relatives.

I then faced a decision as to whether to interview family members together or separately. Comparisons between individual interviews or group and dyadic interviews reveal various advantages and disadvantages of both (Taylor & de Vocht, 2011). Individual interviews can allow people to speak more freely, being less restricted by the context of the relationships with others present. However, individual interviews for members of a dyad or unit may create greater anxiety or tension within relationships due to the element of secrecy in their separate accounts (Forbat & Henderson, 2003). The interviewer may also struggle to bracket the information from one member of a relationship when interviewing the next (Forbat & Henderson, 2003; Taylor & de Vocht, 2011).

Group interviews carry the risk that one member may dominate conversations leaving others silenced or excluded, and the context of members' relationships may influence what people feel able to share. However, the group context places greater control and power with participants, who can narrate and co-construct their own story, with less guidance and direction from the interviewer (Kosny, 2003). This facilitates a more natural evolution of conversation, sharing stories and developing meaning in context rather than a formal question and response created within individual interviews (Eggenberger & Nelms, 2007). Group contexts allow individuals to comment and elaborate on one another's contributions, enriching understanding and creating a co-constructed, multi-faceted, holistic picture of their collective experience and its meaning (Kosny, 2003). I used my reflective diary to record aspects of this decision process. I noted that interviewing relatives separately would likely yield different results, as individuals would be less influenced by the presence of others. However this does not

imply that one method is superior to another. I recognised that my aim was to understand families shared reality, witnessing how relationships shape collective understanding and allowing interactions and dynamics to enrich analysis.

Furthermore, families are naturally occurring groups and could therefore be considered as one participating family unit, rather than several participants. Indeed, researchers have argued that the family cannot be fully represented through a series of individual interviews because 'family' is more than simply the sum of its individual members (Åstedt-Kurki & Hopia, 1996); this implies the need for a systemic approach whereby the family becomes the unit of analysis (Åstedt-Kurki, Paavilainen, & Lehti, 2001).

Research has not often focussed upon families collectively, although this method has been used and evaluated within the nursing profession (Åstedt-Kurki et al., 2001). The nature of the interactive dialogue within collective family interviews provides opportunity for the phenomenon under investigation to be enacted, which can enrich analysis (Halling, Kunz, & Rowe, 1994). Group formats also incite 'collective remembering', adding a new dimension and additional synergy (Kitzinger, 1994). The format of collective interviews could therefore provide data which cannot be obtained from individuals. I used my reflective journal to note any interesting dynamics and interactions within interviews, which enriched the analysis process. For example, after an interview with Jim and his family I noted that Jim looked to his wife for reassurance on certain topics, and in turn Jim's wife looked to her daughter. It was important this interaction alone did not inform theme development, however it did enhance and strengthen the families' theme of 'having a back-up: the knock on effect of support', which later formed part of the final theme which reflected chains of support within families.



A further advantage of family interviews, particularly when this includes people with dementia, is that relatives can provide a source of support and comfort which can enable greater honesty and openness (Kosny, 2003). Relatives can also support the person with dementia to communicate through prompts, reminders and reassurance which may result in a more detailed account of their experience. I considered the element of co-construction afforded within collective interviews to be crucial to my understanding of families' shared experiences and meaning-making. However it was also important to recognise that individual interviews also hold advantages, and future research could combine these methodologies which may provide a richer understanding of phenomena (Taylor & de Vocht, 2011).

### **Managing dynamics within family interviews**

This was the first time I had conducted research that involved interviewing families together, and the prospect appeared quite daunting at first. Informed by the disadvantages of group interviews described above I anticipated a number of challenges, and made considerable efforts to manage these and minimise their impact on the research.

I strived to facilitate an honest and open atmosphere to encourage free expression of views from all family members. I therefore welcomed contradictions and differing perspectives or accounts of experience and normalised such occurrences within families. I endeavoured to include and involve all family members as equally as possible, inviting quieter members into conversations and redirecting back to members who were interrupted. However after the first interview, I noted within my reflective journal that family members sometimes seemed surprised or caught off guard when I addressed questions to them specifically. While I did this to include them in the conversations and encourage equal representation of voices, they were perhaps less

aware of these motives. Being transparent about this at the beginning of all subsequent interviews reduced this problem as families' awareness meant they supported this as well.

I was aware that interviewers often make natural and unavoidable connections on an emotional level with certain members of a group to a greater extent than others, which could produce an imbalance in the analysis as they privilege one account over another (Forbat & Henderson, 2003). I remained aware of this within interviews to prevent aligning myself with any one person (Eggenberger & Nelms, 2007). I then used my reflective log to document specific feelings towards individuals to support the process of bracketing during analysis. After one interview I noted my feelings of upset in relation to the division between family members, which resulted in the apparent exclusion of the person with dementia. I felt I strongly empathised with this person, and therefore found it difficult to appreciate others' points of view. Through discussions with my supervisor I was able to empathise with the other family members more, which was essential to ensure my feelings did not bias the analysis or lead to the privileging of one perspective. For all families I ensured that themes were represented by quotes from all family members to further prevent one account being privileged.

I was also aware of the risk of being drawn in to family dynamics and I resisted taking sides within interactions; this has been documented previously as a potential pitfall of interviewing people within an existing relationship (Forbat & Henderson, 2003). This was most evident to me when interviewing one family, where a divide between the person with dementia and relatives was apparent. At one point within the interview the two relatives joked about using the audio recording of the interview as evidence of their discussions as they anticipated the person with dementia would later deny this. The person with dementia then checked if I was still recording, and when I

answered yes, he jokingly remarked “you’ve joined the enemy”. By confirming that I was recording he seemed to conclude that I was using this to give his relatives evidence. Noticing the dynamic at this point I offered reassurance and reiterated what the recording would be used for. Whilst this was a series of light-hearted comments it demonstrates quite powerfully the potential for interviewers to be drawn into divisions and dynamics within the interview. It would be important in any future family research to be aware of such dynamics and develop strategies for noticing and managing these.

My strategy for managing family interviews involved the key principles of being open and transparent, avoiding taking sides or being drawn into dynamics, and encouraging equal representation of voices. Additionally it was important that dynamics and my emotional responses to them were bracketed and did not impact upon analysis. Despite my reservations, I found family interviews greatly rewarding, and was left feeling inspired by the great strength, resilience and connection within families, highlighting the tremendous therapeutic potential of the family system.

### **Separating research and therapy**

The potential overlaps between a research interview and a therapeutic interview have been documented previously (Thompson & Russo, 2011), with one of the key differences of the two being their aim – the former seeks to gather data, whereas the latter is an attempt to intervene or facilitate change (Seidman, 2012). However, researchers report that participants commonly find qualitative interviews therapeutic and can therefore struggle to separate research from therapy (Dickson-Swift, James, Kippen, & Liamputtong, 2006), particularly as therapeutic environments can form naturally through the process of qualitative enquiry (Dickson-Swift et al., 2006; Glesne & Peshkin, 1992).

I believe that various aspects of the interviews I conducted were inherently, yet unintentionally therapeutic. Providing a space for people to talk about their experiences with someone who listens empathically and values the sharing of their story can be therapeutic in itself (Cheston & Bender, 1999; Dickson-Swift et al., 2006) and to lose this in research interviews would be unethical. Indeed this therapeutic aspect may be emphasised further when conducting interviews with people with dementia, as a formal or detached style of questioning is unlikely to be possible or even appropriate for such individuals (Clarke & Keady, 2002; Pratt, 2002), which creates greater need for a genuinely responsive, respectful and validating stance (Clarke & Keady, 2002). Within my reflective journal I noted possible reasons why one family dropped out of my research; one suggestion being that the experience of the initial questions as a memory test perhaps interfered with the key elements of rapport building, empathy and validation, preventing the establishment of a safe space to talk.

The discussion of sensitive and emotional content, such as the experience of dementia, is likely to increase the level of intimacy that develops between individuals and the interviewer (Seidman, 2012). In addition, the process of a qualitative interview often allows participants to construct a narrative of their story, and through doing so to understand their experience and their own story in different ways (Birch & Miller, 2000). The nature of family interviews therefore enabled shared story-telling as individuals co-constructed a narrative, potentially providing a sense of shared identity and belonging. Indeed, the importance of this sense of connection and belonging has been demonstrated through the results of the research. Families generally reported thoroughly enjoying the interview and the opportunity it gave them to discuss some difficult issues. The experience of being guided through a family discussion regarding their experience, seemed to allow family members to express their feelings safely,

which often facilitated the appreciation of one another's perspectives, and development of a shared understanding (Eggenberger & Nelms, 2007). While these aspects are not intended outcomes of the research interview, to some extent they are self-fulfilling.

There are attendant risks to participants feeling that the interview provides a therapeutic atmosphere, as they may raise more profound issues or difficulties requiring greater support, which the interviewer may not have the training or the time to address (Kvale & Brinkmann, 2009). Indeed my training in clinical psychology complicated this further, representing a personal challenge for me to separate my clinical role and my role as a researcher, particularly where similar skills were required – e.g. empathic listening and discussing emotive topics (Dickson-Swift et al., 2006).

I found it difficult to resist the pull to offer help and support, which has been described as the need to tame the 'rescuer' within (Drury, Francis, & Chapman, 2007). This was most difficult when participants asked me questions and sought reassurance and advice. It was important that I tried not to influence the content of the interview so I tried to balance this by using the debrief time after the interview to answer any questions, and signpost them to appropriate sources of further information and support. Where appropriate I offered some reassurance and normalisation at the end of interviews to minimise any distress that arose.

While it was important not to adopt a clinical role it was also vital to minimise harm to participants and ensure they were not left in a position of greater emotional vulnerability than before (British Psychological Society, 2010); this can create a core ethical issue when conducting qualitative interviews and can further blur the boundaries between the research and clinical role (Drury et al., 2007). I therefore used my clinical skills and experience to manage any highly emotional situations. For example one person with dementia became very upset and quite angry, at this point I used my clinical

skills to de-escalate, while assessing risk. The participant took a break at this point. When they requested to continue with the interview, this was managed sensitively. They were later signposted to appropriate sources of support. It was interesting that this family seemed to find the process most therapeutic, which supports the notion that sensitive and emotional content of interviews can enhance the participant-researcher relationship (Seidman, 2012).

This family requested to see me again as they had found the interview process very helpful. It was a challenge to reinforce boundaries at this point, without giving a sense of rejection or abandonment, especially as I had learnt that families were perhaps more sensitive to feeling abandoned and isolated. I therefore endeavoured to do this as sensitively as possible, while communicating my gratitude for their participation. Learning from this experience, in subsequent interviews I reiterated at the outset of each interview that I would only see the family as part of the research.

I recognise that my training and skills in psychological and therapeutic approaches have formed part of who I am and my attitude to people, including those outside of my working environment. As such the warmth, empathy, validation, and rapport building that I have developed over time cannot be 'switched off' for research interviews - and arguably should not be - as building rapport encourages openness and honesty in interviews. I would therefore argue that the research and clinical role are not entirely separable. Rather than aiming to completely separate the two, it may be more helpful to recognise the inherent overlaps that can blur the boundaries for participants and have strategies to manage these. For me it was important to notice any pulls to rescue or step into a clinical role, balancing the need to ensure no harm while maintaining the integrity of the research.

**Conclusion**

This paper has discussed the issues and challenges in undertaking research involving people with dementia, conducting joint interviews, managing dynamics between family members in interviews and negotiating the boundaries between the research and therapeutic roles. The challenges I have faced in conducting this research have led to key learning around managing ethical and methodological issues in research with a flexible and sensitive approach. Adopting a reflective stance enabled learning, which has enhanced my research practice. It is vital that research involving people with dementia and their families continues, despite the perceived difficulties, as this is a most fertile field in which to grow our understanding and knowledge of the dementia experience.

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**Section Four: Ethics Section**

Word Count: 4,135

Olivia Wadham

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

NHS REC Form

Reference:

IRAS Version 3.5

**Welcome to the Integrated Research Application System****IRAS Project Filter**

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

**Please enter a short title for this project** (maximum 70 characters)

Families' experiences of dementia

**1. Is your project research?**

☒ Yes ☐ No

**2. Select one category from the list below:**

- ☐ Clinical trial of an investigational medicinal product
- ☐ Clinical investigation or other study of a medical device
- ☐ Combined trial of an investigational medicinal product and an investigational medical device
- ☐ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- ☐ Basic science study involving procedures with human participants
- ☐ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- ☒ Study involving qualitative methods only
- ☐ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- ☐ Study limited to working with data (specific project only)
- ☐ Research tissue bank
- ☐ Research database

**If your work does not fit any of these categories, select the option below:**

☐ Other study

**2a. Please answer the following question(s):**

- a) Does the study involve the use of any ionising radiation? ☐ Yes ☒ No
- b) Will you be taking new human tissue samples (or other human biological samples)? ☐ Yes ☒ No
- c) Will you be using existing human tissue samples (or other human biological samples)? ☐ Yes ☒ No

**3. In which countries of the UK will the research sites be located?** *(Tick all that apply)*

- ☒ England
- ☐ Scotland
- ☐ Wales
- ☐ Northern Ireland

**3a. In which country of the UK will the lead NHS R&D office be located:**

NHS REC Form

Reference:

IRAS Version 3.5

- ☒ England  
☐ Scotland  
☐ Wales  
☐ Northern Ireland  
☐ This study does not involve the NHS

**4. Which review bodies are you applying to?**

- ☒ NHS/HSC Research and Development offices  
☐ Social Care Research Ethics Committee  
☒ Research Ethics Committee  
☐ National Information Governance Board for Health and Social Care (NIGB)  
☐ National Offender Management Service (NOMS) (Prisons & Probation)

*For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.*

**5. Will any research sites in this study be NHS organisations?**

- ☒ Yes ☐ No

**5a. Are all the research costs and infrastructure costs for this study provided by an NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC) or NIHR Research Centre for Patient Safety & Service Quality in all study sites?**

- ☐ Yes ☒ No

*If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).*

**5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) support and inclusion in the NIHR Clinical Research Network (CRN) Portfolio? Please see information button for further details.**

- ☐ Yes ☒ No

*If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP) and you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form immediately after completing this project filter and before completing and submitting other applications.*

**6. Do you plan to include any participants who are children?**

- ☐ Yes ☒ No

**7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?**

- ☐ Yes ☒ No

*Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.*

**8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?**

NHS REC Form

Reference:

IRAS Version 3.5

☐ Yes ☒ No**9. Is the study or any part of it being undertaken as an educational project?**☒ Yes ☐ No

Please describe briefly the involvement of the student(s):

The student is a Trainee Clinical Psychologist at Lancaster University who will act as the Chief Investigator for this research which will become part of their thesis.

**9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?**☒ Yes ☐ No**10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?**☐ Yes ☒ No**11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?**☐ Yes ☒ No

**Integrated Research Application System**  
**Application Form for Research involving qualitative methods only****Application to NHS/HSC Research Ethics Committee**

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

**Short title and version number:** (maximum 70 characters - this will be inserted as header on all forms)  
Families' experiences of dementia

*Please complete these details after you have booked the REC application for review.*

**REC Name:**

**REC Reference Number:**

**Submission date:**

15/08/2013

**PART A: Core study information****1. ADMINISTRATIVE DETAILS****A1. Full title of the research:**

Families' experiences of changing roles and relationships when one family member has dementia

**A2-1. Educational projects**

Name and contact details of student(s):

**Student 1**

	Title	Forename/Initials	Surname
	Miss	Olivia	Wadham
Address	Division of Health Research, Furness College		
	Lancaster University		
	Lancaster		
Post Code	LA1 4YG		
E-mail	o.wadham@lancaster.ac.uk		
Telephone	[REDACTED]		
Fax			

Give details of the educational course or degree for which this research is being undertaken:



Name and level of course/ degree:  
Doctorate in Clinical Psychology

Name of educational establishment:  
Lancaster University

Name and contact details of academic supervisor(s):

**Academic supervisor 1**

	Title	Forename/Initials	Surname
	[REDACTED]	[REDACTED]	[REDACTED]
Address	[REDACTED] [REDACTED] [REDACTED]		
Post Code	[REDACTED]		
E-mail	[REDACTED]		
Telephone	[REDACTED]		
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):  
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Miss Olivia Wadham	<input checked="" type="checkbox"/> [REDACTED]

*A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.*

A2-2. Who will act as Chief Investigator for this study?

☒ Student

☐ Academic supervisor

☐ Other

<b>A3-1. Chief Investigator:</b>	
	Title Forename/Initials Surname
	Miss Olivia Wadham
Post	Trainee Clinical Psychologist
Qualifications	BSc Psychology (Hons)
Employer	Lancashire Care NHS Foundation Trust
Work Address	Clinical Psychology, Division of Health Research, Furness College Lancaster University, Lancaster
Post Code	LA1 4YG
Work E-mail	<a href="mailto:o.wadham@lancaster.ac.uk">o.wadham@lancaster.ac.uk</a>
* Personal E-mail	

NHS REC Form

Reference:

IRAS Version 3.5

Work Telephone

\* Personal Telephone/Mobile

Fax

*\* This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*

*A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.*

**A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?**

*This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.*

Title Forename/Initials Surname

Address

Post Code

E-mail

Telephone

Fax

**A5-1. Research reference numbers. Please give any relevant references for your study:**

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number:

Protocol Version:

2

Protocol Date:

30/06/2013

Funder's reference number:

Project website:

**Additional reference number(s):**

Ref. Number	Description	Reference Number
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*Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.*

**A5-2. Is this application linked to a previous study or another current application?**

☐ Yes ☒ No

*Please give brief details and reference numbers.*

**2. OVERVIEW OF THE RESEARCH**

*To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.*

**A6-1. Summary of the study. Please provide a brief summary of the research (maximum 300 words) using language**

NHS REC Form

Reference:

IRAS Version 3.5

*easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.*

This research aims to explore the collective experience of the family unit where one family member has dementia. Families will be recruited from various older adult services across [REDACTED] (these may include Memory Assessment Services, Dementia Cafes and Community Mental Health Teams). Semi-structured interviews will be conducted with families, who will be interviewed together to capture the co-construction of meaning that happens within and between family members. Families will consist of the person with dementia and at least two other family members. The interviews will explore how the family make sense of the current situation, what they have noticed about roles and relationships within the family, and how they have faced challenges and adapted to any changes as a family. This research will encourage a greater understanding of the experience of the family unit and how they adapt to the changes dementia may bring to their lives. This understanding will highlight key priorities when supporting families after diagnosis, to ensure services can meet the needs of the family as a whole. Results should contribute to the evidence-base by providing a more systemic perspective on experience that encompasses the family unit as a whole.

**A6-2. Summary of main issues.** *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

*Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.*

- **Informed consent:** It is important that all members of the family are fully informed about the research prior to providing consent. Staff will only have identified families where the person with dementia is able to understand and provide informed consent as this is detailed in the inclusion criteria. Consent will also be considered at the time of interview. Capacity to consent will be assumed until proven otherwise as per guidance. The information sheet will be talked through with families prior to commencing the interview, taking particular care to ensure information is accessible to the person with dementia. The person with dementia will be asked prompt questions to check their understanding of the information shared. All families will be informed of this process prior to arranging an interview time.
- **Confidentiality and anonymity:** To protect the identity of participants no-one else but the chief investigator will know who has taken part. Although staff will be aware of families who they identified as meeting the inclusion criteria, they will not be told which families took part. Pseudonyms will be used for all participants to preserve anonymity, and any identifying information will be removed.
- **Possible identification of risk:** Participants will be made aware of the limits to confidentiality. If any risk to themselves or others was identified, the chief investigator's duty to share this information would be reiterated to the family and would then be discussed with supervisors. Any necessary actions would be taken.
- **Participant distress:** As with any research it is possible that something may unintentionally cause some distress. The chief investigator will use their clinical skills and their experience in this area to manage any distress that arises. The presence of the family is hoped to increase the element of support during the interview, and participants will be supported to access any help that was necessary. The information sheet details a variety of sources of support. The interview can be terminated at the request of any member of the family.
- **Risks to chief investigator:** As interviews will be conducted in person and may be at participants' homes the [REDACTED] Lone Worker Policy will be followed.

**A6-3. Proportionate review of REC application** *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.*

☒ Yes - proportionate review   ☐ No - review by full REC meeting

*Further comments (optional):*

This was discussed with the [REDACTED] REC Centre who felt this was suitable for proportionate review. Additionally an email from nres.queries@nhs.net (PRS enquires email address) has confirmed the applications suitability for proportionate review.

*Note: This question only applies to the REC application.*

**3. PURPOSE AND DESIGN OF THE RESEARCH**

**A7. Select the appropriate methodology description for this research. Please tick all that apply.**

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☒ Qualitative research
- ☒ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

**A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.**

Aim:

To understand the experience of families when one family member has dementia, with particular focus on changes dementia brings to family life, relationships and roles.

**A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.**

Aims:

1. To contribute to the evidence base regarding dementia and families
2. To develop recommendations for how dementia services can meet the needs of the family as whole

**A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.**

The National Dementia Care Strategy emphasises improving quality of care for people with dementia and their families (Department of Health, 2009), yet the current focus within services is primarily increasing diagnosis rates (Department of Health, 2013), which may somewhat neglect the importance of supportive and meaningful treatment or intervention. There is a need for 'togetherness', by working with the family as a whole in interventions (McGovern, 2011).

When dementia enters the life of one person it really enters the lives of the whole family unit, and changes permeate throughout relationships (Daniels et al, 2007). Research must, therefore, explore the family as a system to ensure we understand how challenges are approached collectively as a family unit (Purves & Phinney, 2012).

Whilst some research has been done with particular family caregivers or family dyads, little research has explored the collective experience of the family unit when one person has dementia. This research intends to do this by interviewing the family together, including the person with dementia, to explore their collective experience. Whilst encouraging a greater understanding of how families adapt to the changes dementia may bring to their lives, results will also highlight key priorities when supporting families after diagnosis, to ensure services can meet the needs of the family as a whole.

**A13. Please summarise your design and methodology. It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.**

Design

NHS REC Form

Reference:

IRAS Version 3.5

This project is a qualitative study which aims to explore the experience of family units where one family member has dementia. Various people have been consulted in the design of the research including professionals with specialist knowledge in the area of dementia, and experts by experience (Lancaster University Public Involvement Network).

#### Participants

Participants will include 6-10 families who meet the following criteria:

- One family member has received a diagnosis of any type of dementia
- The person with dementia is able to provide informed consent and engage in conversation about experience
- Two or more family members must be willing to take part along with the person with dementia, and these people must be involved in the person's life to ensure a sense of the family as a whole
- The person with dementia should be living at home rather than residential care.

#### Procedure

##### Recruitment

Participants could be recruited from various services across [REDACTED]: Memory Assessment Services, Dementia Cafes, and Community Mental Health Teams. Staff will identify people suitable for the research using the inclusion criteria. They will then seek consent from service users to be contacted for research purposes. This consent will be sought by staff working with the service users in accordance with their usual procedures (e.g. some teams routinely seek consent to be contacted regarding research opportunities at initial assessment, whereas other teams approach service users who meet criteria post diagnosis to seek consent to be contacted).

Contact details of service users who meet criteria and consent to be contacted will be passed to the Chief Investigator, who will contact potential participants (most likely by telephone) to introduce themselves and the research. Family Information Sheets can be shared with potential participants via post or via the staff they work with. If families would like some time to consider whether they wish to take part a second telephone call can be arranged, at which point if they are willing to take part a convenient meeting time and place will be arranged.

##### Interviews

When the Chief Investigator meets with the family they will re-introduce themselves and the research, go through the information sheet, and ask family members to sign the consent forms. The Chief Investigator will ask the person with dementia some prompt questions to check they have understood the information. Interviews are estimated to last between 60 - 90 minutes. Families will be given the opportunity to take breaks and meet more than once if they wish. An interview schedule will be used to guide discussions, which will be recorded on a digital video or audio recorder according to the families preference. Families will be given a debrief sheet once the interview ends.

#### Analysis

Recordings will be transcribed anonymously and analysed using a suitable method of qualitative analysis to elucidate in depth the experience of the families interviewed. The process of analysis will involve regular discussion with the Academic Supervisor to ensure themes are an accurate reflection of the data and to increase scientific credibility.

**A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?**

- ☒ Design of the research
- ☐ Management of the research
- ☐ Undertaking the research
- ☐ Analysis of results
- ☐ Dissemination of findings
- ☐ None of the above

*Give details of involvement, or if none please justify the absence of involvement.*

The project proposal was shared with members of the Lancaster University Public Involvement Network (LUPIN), which included many experts by experience (i.e. they have previously used services and now provide advice and guidance). LUPIN members provided feedback and comments on the research, which were taken on board. Ongoing consultation is also being offered by one expert by experience from LUPIN, who has offered advice on various elements of the project design, and in particular consultation around the materials (e.g. Information Sheets and Consent Form).

#### 4. RISKS AND ETHICAL ISSUES

## RESEARCH PARTICIPANTS

**A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).**

1. One family member must have received a diagnosis of dementia (any type).
2. The person will be in the relatively early stages of dementia, and will be able to engage in conversation about experience.
3. The person with dementia must be able to give valid consent to take part in the research.
4. Two or more family members must be willing to take part along with the person with dementia. These family members need to be involved/present in the person with dementia's life to ensure there is a sense of the family as a whole (i.e. these family members must be present in their life, and in contact with them).

**A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).**

1. Families where the person with dementia lives in residential care
2. Any families who are unable to conduct interviews in English (this is due to difficulties this creates methodologically, and insufficient funds for interpreters)

## RESEARCH PROCEDURES, RISKS AND BENEFITS

**A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.**

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Seeking consent to be contacted	1	1	5 minutes	Staff will seek consent from service users to be contacted in relation to future research opportunities. To be conducted at their place of work.
Reading the Information Sheet	1	n/a	15 minutes	Families will be given the information to read in their own time and at a place of their choice.
Telephone call to potential participants if they consent to be contacted	2	n/a	10 minutes	Maximum of 2 telephone calls from the Chief Investigator to the potential participants to introduce themselves/the research and later arrange an interview time.
Seeking consent to take part in the research	1	n/a	15 minutes	Chief Investigator to obtain consent prior to interview at participants choice of location (e.g. home or local Trust site).
Semi-structured family interview	1	n/a	60-90 minutes	Chief Investigator to conduct at a time and place to suit the family (e.g. home or local Trust site).

**A21. How long do you expect each participant to be in the study in total?**

This is likely to vary from family to family but it is anticipated that families will be part of the study for up to a maximum of 6 months (i.e. from initial contact from practitioner, to receiving a report).

**A22. What are the potential risks and burdens for research participants and how will you minimise them?**

*For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.*

NHS REC Form

Reference:

IRAS Version 3.5

As many service users embrace the opportunity to discuss their experiences, it is anticipated that interviews will be enjoyable and perhaps even therapeutic for families. However, as with any research it is possible that something may unintentionally cause some distress. During the interview the Chief Investigator will use their clinical and therapeutic skills. Their experience working with families with dementia, and with families in distress will help them to manage any distress that arises. They will discuss any concerns or distress if they are made aware of them and give families an opportunity to talk through their distress. If necessary advice will be sought from project supervisors who hold experience in this area of research and clinical practice. The presence of the family is hoped to increase the element of support during the interview, and the Chief Investigator would also support anyone to access any help that was necessary, which would be guided by the participant's wishes. The Information Sheet for the project states that distress may be aroused with any research and gives a variety of sources of support. The interview can be terminated at the request of any member of the family. The debrief sheet acts as a reminder for families of potential sources of support.

Some family members may also find the length of the interview burdensome. The Chief Investigator will endeavour to minimise the burden by offering breaks, and further meeting times if necessary.

**A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?**

☒ Yes ☐ No

*If Yes, please give details of procedures in place to deal with these issues:*

Potential upset: Although questions are not anticipated to be upsetting, it is possible that some of the topics may be difficult for families to talk about. The Chief Investigator will remain aware of family members mood and distress levels throughout the interview, and will discuss any concerns or distress if they arise. Families will also be made aware of further sources of support which are detailed on the Information Sheet and Debrief Sheet.

Families will be made aware that they can take a break at any time, and have the right to withdraw during or after the interview. Families will also be informed that they do not have to answer questions if they wish not to.

Potential disclosures: Although unlikely, it is possible that a family member may identify risk in some way (i.e. risk of harm to themselves or others). During the interview participants will be made aware of the limits to confidentiality. If any risk was identified, my duty to share this information would be reiterated to the family and I would discuss this with my supervisors and would take any necessary actions (e.g. contacting relevant services).

**A24. What is the potential for benefit to research participants?**

Although there are no direct benefits to families for taking part, it is hoped that families will enjoy being a part of these conversations and reflecting upon their experience together. Indirectly, other families may benefit from this research as a better understanding of the experience of the family unit may help to shape theory and practice.

**A26. What are the potential risks for the researchers themselves? (if any)**

Interviews will be conducted face to face and may be at participants' homes or local Trust sites. If conducted at families' homes, the Chief Investigator will follow the [REDACTED] Lone Worker Policy to minimise risk to them as the researcher. In addition, when staff identify potential participants who meet the criteria for inclusion, any necessary risk information about home visits will also be shared at this stage

#### RECRUITMENT AND INFORMED CONSENT

*In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.*

**A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used?** For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).

Potential participants will be identified by staff working within the relevant services. They will identify service users on their case-load who meet the inclusion criteria. The researcher will meet with staff in teams to explain the research in detail and to talk through the inclusion criteria, staff will therefore be well aware of who will be suitable participants.

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Service users' consent to contact regarding research opportunities will then be sought according to each team's usual procedure (e.g. some teams obtain consent at initial assessment, others post-diagnosis). This will involve reviewing a client's language comprehension and checking they understand the concept of research and the implications of their consent, and consideration of their language expression to ensure they have the language ability to discuss their experience. Consent procedures will be guided by relevant policies (e.g. [REDACTED], 2013) and legislation ("Mental Capacity Act," 2005). Once consent to contact is received, staff will share contact details of potential participants with the Chief Investigator. The Chief Investigator will not be aware of anyone's names or contact details until this point.

**A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?**

☐ Yes ☒ No

*Please give details below:*

Staff members will be responsible for identifying participants and seeking initial consent to contact. Researchers will not be aware of any personal or identifiable details until after consent to contact is obtained.

**A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?**

☐ Yes ☒ No

**A29. How and by whom will potential participants first be approached?**

Staff members will initially discuss the opportunity for involvement in future research with service users on their case-load. This initial discussion will therefore be with someone the service user knows already. If they express an interest in future research, staff members may also share the Information Sheet with them to inform them of this current research. If potential participants consent to be contacted about future research, the Chief Investigator will later contact them.

**A30-1. Will you obtain informed consent from or on behalf of research participants?**

☒ Yes ☐ No

*If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.*

*If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.*

When the Chief Investigator meets with the family, they will re-introduce themselves and the research. They will provide further copies of the Information Sheet and Consent Form if necessary and will talk the family through the Information Sheet. During this process, they will regularly ask the person with dementia to reiterate the information back to the researcher, this is to ensure that they understand the information. These initial prompt questions are included at the beginning of the interview schedule. If the participant cannot answer these questions, even with extra effort to explain in more detail, this is likely to raise concerns about the individual's ability to understand the information and to therefore make an informed decision to take part. The researcher will not continue with the interview if such concerns are apparent, and instead will explain this sensitively to the family and the person with dementia. Families will already be aware of this potential outcome due to the information sheet, and reiteration of this when the meeting is arranged.

If no concerns are apparent with the person's understanding, then capacity to consent will be assumed as per guidance, particularly as staff selected service users who they deemed to be able to provide consent. Family members will have the opportunity to ask any questions, and then they will all be asked to read and sign a consent form.

The interviewer will endeavour to remain aware of any changes at any point during the interview, which, although unlikely, may require reiteration of the information sheet and re-evaluation of an individual's understanding and decision to continue or withdraw.

*If you are not obtaining consent, please explain why not.*



Please enclose a copy of the information sheet(s) and consent form(s).

**A30-2. Will you record informed consent (or advice from consultees) in writing?**

☒ Yes ☐ No

**A31. How long will you allow potential participants to decide whether or not to take part?**

The researcher will endeavour to give potential participants as long as they need to make a decision, as long as this is prior to data collection ending. All participants will have time in between their initial conversation about research participation with their practitioner, then the telephone conversation(s) with the Chief Investigator, and the the interview itself. This will give families plenty of time to consider the information and make a decision.

**A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?(e.g. translation, use of interpreters)**

As people with a diagnosis of dementia may struggle to understand certain information due to cognitive difficulties, information has been adapted in several ways to compensate for this. The information sheet was developed in accordance with guidelines on making information accessible for people with cognitive difficulties and consultation was also sought from professionals experienced in this area (e.g. Psychologist, and Speech and Language Therapist). Text on the information sheet is printed in large, easy-to-read font, with key words within sentences highlighted in bold. Sentences are short and use simple language, and pictures are provided to support content. Off-white paper will also be used as this is thought to support easier reading. In addition to the written information sheet, content will also be explained in detail to families by the Chief Investigator.

Due to insufficient funds, translation of materials into another language and the use of interpreters will not be possible.

**A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.**

- ☒ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ☐ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ☐ The participant would continue to be included in the study.
- ☐ Not applicable – informed consent will not be sought from any participants in this research.
- ☐ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

*Further details:*

Although unlikely to occur, the Chief Investigator will endeavour to remain aware of consent issues and if any concerns are apparent during the interview (after consent has already been sought), then the Chief Investigator would first reiterate the details from the information sheet, and check the person's understanding of this information. In the unlikely event that concerns were apparent regarding the person's ability to understand the information at this point, the interview would be terminated and the family would not be included within the study. This would be explained sensitively to the family and any data already gathered would be destroyed. This is because the inclusion criteria state that the person with dementia must be able to give informed consent.

Additionally, if the Chief Investigator was made aware of a change in a participant's capacity to consent at a later stage in the study, they would endeavour to withdraw their data prior to analysis.

**CONFIDENTIALITY**

In this section, personal data means any data relating to a participant who could potentially be identified. It includes

pseudonymised data capable of being linked to a participant through a unique code number.

#### Storage and use of personal data during the study

**A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? (Tick as appropriate)**

- ☐ Access to medical records by those outside the direct healthcare team
- ☐ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☒ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☒ Publication of direct quotations from respondents
- ☐ Publication of data that might allow identification of individuals
- ☒ Use of audio/visual recording devices
- ☒ Storage of personal data on any of the following:
  - ☒ Manual files including X-rays
  - ☐ NHS computers
  - ☒ Home or other personal computers
  - ☒ University computers
  - ☐ Private company computers
  - ☒ Laptop computers

#### Further details:

##### Personal Information:

When potential participants consent to be contacted, staff members will pass the relevant contact details (likely to be a telephone number) onto the Chief Investigator. An electronic record will be kept of contact details, which will be encrypted and stored on a password protected computer, to which only the Chief Investigator has access. These contact details will be permanently deleted if the family either declines to take part, or once their participation has ended. If families wish to be sent a copy of the report, contact details will be kept until this has been sent out. Where laptops are used, files will be encrypted and the laptop will be password protected so that only the Chief Investigator can access the files.

##### Publication of direct quotes:

Family members' quotes from interviews will be used to illustrate themes within the data. Quotes will be anonymised, and all identifying data will be deleted. Pseudonyms will be assigned to participants.

##### Audio/visual Recording:

Portable audio or video recorders will be used during the interview. The family will have the opportunity to choose which method they feel happy with. Video recordings are used as an option as it will facilitate transcription for the researcher as they will be able to see who is talking from the family. Recordings will be transferred onto a password protected computer and encrypted straight after each interview to ensure the information is secure; the files will then be deleted from the recorder. All recordings will be transcribed anonymously, removing any identifiable data. Recordings will be transcribed within 3 months of the interview, at which point recordings will be permanently deleted.

##### Custodian of data:

The custodian of data will be the Chief Investigator during the study, however, once complete the custodian of data will then be the programme research director at Lancaster University.

**A38. How will you ensure the confidentiality of personal data? Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.**

When interviews are transcribed any identifiable information will be removed and all information will be anonymised. Pseudonyms will be used to identify different family members when reporting results. Data will always be securely stored (as above) and complies with Lancaster University's procedures around data storage for research purposes.

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**A40. Who will have access to participants' personal data during the study?** *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

No-one but the Chief Investigator will have access to participants' personal details (e.g. names, addresses, contact details). Excerpts from anonymised transcripts may be shared with the two project supervisors to support the analysis process, although there will be no identifiable information included at this point.

#### Storage and use of data after the end of the study

**A43. How long will personal data be stored or accessed after the study has ended?**

- ☐ Less than 3 months  
☐ 3 – 6 months  
☒ 6 – 12 months  
☐ 12 months – 3 years  
☐ Over 3 years

#### INCENTIVES AND PAYMENTS

**A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?**

- ☒ Yes ☐ No

*If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.*  
If participants meet at a venue other than their own home, travel expenses will be reimbursed up to the value of £10.  
This will require completion of mileage forms or production of receipts.

**A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?**

- ☐ Yes ☒ No

**A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?**

- ☐ Yes ☒ No

#### NOTIFICATION OF OTHER PROFESSIONALS

**A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?**

- ☐ Yes ☒ No

*If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.*

#### PUBLICATION AND DISSEMINATION

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**A50. Will the research be registered on a public database?**

☐ Yes ☒ No

*Please give details, or justify if not registering the research.*

In the event that the research project is accepted for publication, the abstract will appear on the journal website and therefore be publicly available to access.

*Registration of research studies is encouraged wherever possible.*

*You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.*

**A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:**

- ☒ Peer reviewed scientific journals
- ☒ Internal report
- ☐ Conference presentation
- ☐ Publication on website
- ☐ Other publication
- ☐ Submission to regulatory authorities
- ☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- ☐ No plans to report or disseminate the results
- ☒ Other (please specify)

The research will be written up as part fulfilment of a Doctorate in Clinical Psychology at Lancaster University. The Chief Investigator hopes to publish the paper in a peer-reviewed journal, and will also present the research at a Lancaster University Doctorate in Clinical Psychology presentation day.

**A53. Will you inform participants of the results?**

☒ Yes ☐ No

*Please give details of how you will inform participants or justify if not doing so.*

At interview stage participating families will be asked if they wish to receive a copy of a report summarising the results when the project has ended. Those participants that request a copy will be sent a copy via post. All staff and services that take part in recruitment will also be informed of results, through summary reports and presentations at team meetings where appropriate.

**5. Scientific and Statistical Review****A54. How has the scientific quality of the research been assessed? Tick as appropriate:**

- ☐ Independent external review
- ☐ Review within a company
- ☐ Review within a multi-centre research group
- ☒ Review within the Chief Investigator's institution or host organisation
- ☒ Review within the research team
- ☒ Review by educational supervisor
- ☐ Other

*Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:*

The project proposal was reviewed by a panel of Trainee Clinical Psychologists, service users, and two members of

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the research staff at Lancaster University. Potential problems and solutions were discussed in this forum. The Chief Investigator then amended plans and submitted revised information to be reviewed once again by the two members of the research staff.

A more detailed research protocol was then developed by the Chief Investigator, which has then been reviewed by a service user with person experience in the area of dementia, and the two project supervisors. The research protocol has been amended in accordance with their comments and advice.

*For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.*

*For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.*

**A59. What is the sample size for the research?** *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 8

Total international sample size (including UK):

Total in European Economic Area:

*Further details:*

NOTE: Sample size hoped to be between 6 and 10 families which should result in 18 or more participants in total (depending upon how many family members wish to take part from each family).

**A60. How was the sample size decided upon?** *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

Literature suggests that a sample size of 6-10 is sufficient for qualitative methodologies - this allows qualitative data to be analysed in depth.

**A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.**

A suitable qualitative methodology will be used to analyse data. Transcripts will be coded and then themes will be derived from the codes. Themes will rise directly from the data rather than from a pre-existing framework.

Throughout the analysis, the Chief Investigator will discuss the process and potential themes with their supervisors to improve rigour and credibility of analysis. The Academic Supervisor for the project will also read excerpts of anonymised transcripts to comment on coding and development of themes.

## 6. MANAGEMENT OF THE RESEARCH

**A63. Other key investigators/collaborators.** *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title	Forename/Initials	Surname
Post			
Qualifications			
Employer			
Work Address			
Post Code			
Telephone			

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Fax	
Mobil	
e	
Work Email	
	Title Forename/Initials Surname
Post	
Qualifications	n/a
Employer	n/a
Work Address	
Post Code	
Telephone	
Fax	
Mobil	
e	
Work Email	

**A64. Details of research sponsor(s)****A64-1. Sponsor****Lead Sponsor**Status: ☐ NHS or HSC care organisation

Commercial status:

☒ Academic☐ Pharmaceutical industry☐ Medical device industry☐ Local Authority☐ Other social care provider (including voluntary sector or private organisation)☐ Other*If Other, please specify:***Contact person**

Name of organisation Lancaster University

Given name

Family name

Address

Town/city

Post code

Country

UNITED KINGDOM

Telephone

Fax

E-mail

**Is the sponsor based outside the UK?**☐ Yes ☒ No

Date: 15/08/2013

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131799/489814/1/52

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*Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.*

**A65. Has external funding for the research been secured?**

- ☐ Funding secured from one or more funders  
☐ External funding application to one or more funders in progress  
☒ No application for external funding will be made

What type of research project is this?

- ☒ Standalone project  
☐ Project that is part of a programme grant  
☐ Project that is part of a Centre grant  
☐ Project that is part of a fellowship/ personal award/ research training award  
☐ Other

Other – please state:

**A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?**

- ☐ Yes ☒ No

*Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.*

**A68-1. Give details of the lead NHS R&D contact for this research:**

	Title	Forename/Initials	Surname
Organisation			
Address			
Post Code			
Work Email			
Telephone			
Fax			
Mobile			

*Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>*

**A69-1. How long do you expect the study to last in the UK?**

Planned start date: 02/09/2013

Planned end date: 30/05/2014

Total duration:

Years: 0 Months: 8 Days: 29

**A71-2. Where will the research take place?** *(Tick as appropriate)*

- ☒ England  
☐ Scotland  
☐ Wales  
☐ Northern Ireland  
☐ Other countries in European Economic Area

Total UK sites in study 3

**Does this trial involve countries outside the EU?**

☐ Yes    ☒ No

**A72. What host organisations (NHS or other) in the UK will be responsible for the research sites?** *Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:*

- ☒ NHS organisations in England 1
- ☐ NHS organisations in Wales
- ☐ NHS organisations in Scotland
- ☐ HSC organisations in Northern Ireland
- ☐ GP practices in England
- ☐ GP practices in Wales
- ☐ GP practices in Scotland
- ☐ GP practices in Northern Ireland
- ☐ Social care organisations
- ☐ Phase 1 trial units
- ☐ Prison establishments
- ☐ Probation areas
- ☒ Independent hospitals 1
- ☐ Educational establishments
- ☐ Independent research units
- ☐ Other (give details)

Total UK sites in study: 2

## A76. Insurance/ indemnity to meet potential legal liabilities

*Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland*

**A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.**

***Note:** Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.*

- ☐ NHS indemnity scheme will apply (NHS sponsors only)
- ☒ Other insurance or indemnity arrangements will apply (give details below)



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Lancaster University legal liability cover will apply

*Please enclose a copy of relevant documents.*

**A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.**

***Note:** Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.*

- ☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)  
☒ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply

*Please enclose a copy of relevant documents.*

**A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?**

***Note:** Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.*

- ☒ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)  
☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

*Please enclose a copy of relevant documents.*

**PART C: Overview of research sites**

**Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites.** For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.

Research site	Investigator/ Collaborator/ Contact
Institution name	Title
Department name	First name/
Street address	Initials
Town/city	Surname
Post Code	
Institution name	Title
Department name	First name/
Street address	Initials
Town/city	Surname
Post Code	
Institution name	Title
Department name	First name/
Street address	Initials
Town/city	Surname
Post Code	

<b>PART D: Declarations</b>
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**D1. Declaration by Chief Investigator**

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
  - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D Offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
  - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
  - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
  - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
  - May be sent by email to REC members.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

**Contact point for publication** *(Not applicable for R&D Forms)*

*NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.*

- ☒ Chief Investigator
- ☐ Sponsor

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- ☐ Study co-ordinator  
☐ Student  
☐ Other – please give details  
☐ None

**Access to application for training purposes** *(Not applicable for R&D Forms)**Optional – please tick as appropriate:*

☐ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

Signature: .....

Print Name: Olivia Wadham

Date: 15/08/2013 (dd/mm/yyyy)

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Reference:

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**D2. Declaration by the sponsor's representative**

*If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.*

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.
7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Signature: .....

Print Name:

Post:

Organisation:

Date: 15/08/2013 (dd/mm/yyyy)

**D3. Declaration for student projects by academic supervisor(s)**

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.
2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.
3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.
4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

**Academic supervisor 1**

Signature: .....

Print Name: [REDACTED]

Post: [REDACTED]

Organisation: Lancaster University

Date: 15/08/2013 (dd/mm/yyyy)

**Appendix 4-A: Research Protocol**Version 2 – June 2013**Research Protocol****General Information**

**Study title:** **Families' experiences of changing roles and relationships when one family member has dementia.**

**Applicant:** Olivia Wadham, Trainee Clinical Psychologist, Lancaster University & Lancashire Care NHS Foundation Trust.

**Supervisors:** Academic Supervisor - [REDACTED], Lancaster University.  
Field Supervisor – [REDACTED], [REDACTED].

**Introduction**

The term 'dementia' describes a group of symptoms including impairments in memory, reasoning, communication and functioning (Alzheimer's Society, 2013). These changes are thought to be caused by changes within the brain due to disease or a series of strokes, which continue to cause a decline over time (Alzheimer's Society, 2013). Recent reports suggest there are around 800,000 people living with dementia in the UK (Department of Health, 2013), with the cost to the economy of caring for people with dementia estimated to be £24 billion. The prevalence of dementia is predicted to double in the next 20 years, with cost to the economy predicted to treble. There is therefore, considerable Government investment in the diagnosis and treatment of dementia.

Whilst much past research has focussed on investigating the neurobiological basis for dementia in search of a cure (e.g. Shinosaki, Nishikawa, & Takeda, 2000), more recently there is growing evidence that wellbeing and quality of life for people with dementia is not simply a product of brain changes, but rather is influenced by personal background, social interactions, environment and context (Kitwood, 1997; O'Connor et al., 2007). The work of Kitwood (1997) first highlighted the need to become more aware of the social and interactional environment around the person with dementia, with interpersonal relationships having a profound effect upon the person's experience of living with dementia (O'Connor et al., 2007).

Whilst relationships can influence the experience of dementia, it appears that the changes that dementia brings can also influence relationships (Steeman, de Casterlé, Godderis, & Grypdonck, 2006), particularly as dementia can significantly affect communication (Small, Geldart, & Gutman, 2000), which is essential when building and maintaining relationships. This suggests that these influences are reciprocal.

**Systemic Context**

Changes for the person with dementia also impact upon the experience and overall wellbeing of those around them (Quinn, Clare, & Woods, 2009). This could include

partners, children, siblings, grandchildren and many more. The circumstances of one family member can create shifts for the entire family, which will at times disrupt equilibrium. Families then face the difficult task of changing and adapting to re-establish balance (O'Connor & Purves, 2009). A diagnosis of dementia for one family member and the changes this brings to family life will be a significant life event for the family, prompting such changes and adaptations. These wider systemic influences have been acknowledged in the National Dementia Strategy, which notes the profound impact that dementia has on family members as well as the person with dementia (Department of Health, 2009). It is important that experience is considered in this systemic context, both in practice and in research. Many researchers have now called for a shift from person-centred care to relationship-focussed care (O'Connor, 2007), which begins to acknowledge the inherent systemic elements of the dementia experience.

### Dementia and the Family

There is a large body of literature exploring dementia and family relationships, however, much of this research has tended to focus on family carers, often exploring caregiving aspects of these relationships (O'Connor et al., 2007). Whilst such research is important to understand the experience of caring for someone with dementia, it neglects other aspects of the relationships and may inadvertently encourage a biased account of experience which focusses primarily on the stress and strain of caring. It also seems to dichotomise experience by separating the 'carer' and the 'cared for', rather than exploring shared and collective experience (Purves & Phinney, 2012). Such research loses the focus on the relationship which is integral to the experience of care.

Additionally, some researchers argue that the use of the term 'family caregivers' is flawed: many family members although they may provide support do not identify with or consider themselves as 'caregivers', and instead see their care as a feature of their relationships within the family (O'Connor, 2007; Purves & Phinney, 2012). Research has shown that although there may be one member of the family who provides the majority of the care, the responsibility is often shared throughout the family network (Purves & Phinney, 2012). Research focussing on family carers or exploring caregiving aspects alone may therefore result in a limited and narrow understanding, which does not reflect the lived experience of the family.

### Collective Experience

Some studies have begun to explore shared experience of family members, focussing on the co-construction of meaning between two family members; most commonly this has included the person with dementia and their partner or spouse, (Daniels, 2009; Daniels, Lamson, & Hodgson, 2007; Hellström, Nolan, & Lundh, 2005; Molyneaux, Butchard, Simpson, & Murray, 2012). Other family relationships have been tentatively explored, such as the mother-daughter relationship (e.g. Perry, 2004). This body of evidence starts to address the relational context in which living with dementia occurs,



although more research is needed on relationships within the family as a whole unit (O'Connor & Purves, 2009)

When dementia enters the life of one person it really enters the lives of the whole family unit, and changes permeate throughout relationships (Daniels et al., 2007). Research must, therefore, explore the family as a system to ensure we understand how challenges are approached collectively as a family unit (Purves & Phinney, 2012). Keady and Harris note that "people with dementia have become separated from their family systems within research, practice and policy attention with the weight of these resources being targeted at individual or dyad based methods of support/understanding" (2009, p. 6). Research must now adopt a family-systems approach to dementia, reconceptualising dementia as an illness affecting relationships rather than individuals, and therefore impacting upon the entire system (McGovern, 2011).

The family unit includes the person with dementia, however, too often in dementia family research, the person with dementia is not included (McColgan, Valentine, & Downs, 2000), and thereby results do not reflect the experience of the whole family system. Historically, people with dementia have not been included in research due to an assumption that their memory problems render them unable to report and reflect upon their experiences. Therefore, 'People with dementia have been a silent presence. If we hear their voice it is predominantly through others' (McColgan et al., 2000, p. 99). However, there is a growing evidence-base to suggest that people with dementia are often well aware of their current situation and therefore are able to contribute important reflections and insight into their experiences, and highlight their key needs (Clare, 2003), often having a valued role in research (Alzheimer Europe, 2011). Whilst this has prompted more research with people with dementia individually, research with families still often excludes or segregates their voice. This reliance on those around the person with dementia without including the person themselves has been heavily criticised (Clarke & Keady, 2002), as the family is a collective unit of which the person with dementia is an integral part.

People with dementia may also be excluded to avoid potential ethical issues surrounding the inclusion of vulnerable groups in research (Heggestad, Nortvedt, & Slettebø, 2013). However, it seems entirely unethical to exclude them from research which is about them, and may actually serve to reinforce their vulnerability. Instead, family research must include the appropriate ethical safeguards to ensure people with dementia can be included and their voices can be heard.

### **This Research**

As yet there has been little research which has explored the collective experience of the family system as a whole, including the person with dementia. This research hopes to address that gap, with particular focus on changes to roles and relationships that might be experienced. The research will explore families' experience after a family

member has been diagnosed. This is thought to be a key point in the dementia journey, which has been split into stages, including noticing memory problems, deciding to seek a diagnosis, receiving the diagnosis, and integrating the diagnosis (Steeman et al., 2006). The decision to seek a diagnosis is considered a key decision point in the families journey and becomes a key point of transition (O'Connor & Purves, 2009). By exploring family experience soon after diagnosis this allows exploration of these key stages and points of transition, and will capture families during a time when integration of the diagnosis is beginning to happen. Families will be able to share their experience of this change and how they approach and adapt to the challenges as a family unit.

The National dementia care strategy emphasises improving quality of care for people with dementia and their families (Department of Health, 2009), yet the current focus within services is primarily increasing diagnosis rates (Department of Health, 2013), which may neglect the importance of supportive and meaningful treatment or intervention. There is a need for 'togetherness', by working with the system or family as a whole in interventions (McGovern, 2011). This research will encourage a greater understanding of the experience of the family unit and how they adapt to the changes dementia may bring to their lives. This understanding will highlight key priorities when supporting families after diagnosis, to ensure services can meet the needs of the family as a whole.

### Aims

This research aims to explore the collective experience of the family unit where one family member has dementia. The family will be interviewed together to capture the co-construction of meaning that happens within and between family members. The interviews will explore how the family make sense of the current situation, what they have noticed about roles and relationships within the family, and how they have faced challenges and adapted to any changes as a family. It is envisaged that this will not only contribute to the understanding of how families experience dementia, but will also highlight how dementia services can best meet the needs of the family as a whole. Results should contribute to the evidence-base by providing a more systemic perspective on experience that encompasses the family unit as a whole.

## Method

### Participants

Participants will include 6-10 families who meet the specific criteria below:

#### Inclusion/exclusion criteria

1. One family member must have received a diagnosis of dementia (any type).
2. The person will be in the relatively early stages of dementia, and will be able to engage in conversation about experience.

3. The person with dementia must be able to give valid consent to take part in the research.
4. Two or more family members must be willing to take part along with the person with dementia. These family members need to be involved in the person with dementia's life to ensure there is a sense of the family as a whole (i.e. family members must be present in their life, and in contact with them).
5. The person with dementia should not be living in residential care.

There is no criteria around how long ago the person with dementia was diagnosed, this is because people can receive a diagnosis at different stages of dementia, so this may not reflect their ability to engage in conversation, and may not even reflect how long memory has been a problem for someone.

The small sample has a good fit with qualitative analysis methods which seeks to elucidate in-depth the experiences of a small group of people rather than aggregating responses. Participants will be recruited from various services across [REDACTED], which could include:

- Memory Assessment Services. This includes three teams: [REDACTED].
- Dementia Cafés across [REDACTED]
- Community Mental Health Teams across [REDACTED]

These services will only begin recruiting participants after the appropriate Research and Development approval is received.

### Design

A qualitative research design will be adopted for this study to gain detailed information in the form of semi-structured interviews. A single group will be used, which will include family units where one person has dementia. An appropriate method of qualitative analysis will be adopted to explore the experience of the family unit. My position as a researcher will be acknowledged in order to make transparent the subjectivity that will be apparent in my account of the research. The process of analysis will be documented in detail so that evidence will be available to show how themes were reached. Analysis will be reviewed by my Academic Supervisor.

### Materials

An interview schedule, based on the research aims of the project, will be used to guide discussions with families. The researcher will use the schedule flexibly, adapting questions where necessary and learning from previous interviews to ensure meaningful data is collected. Interviews will be recorded using either a digital video camera, or a digital voice recorder.

### Procedure

The research has been agreed with all three MAS teams and with the Older Adult Professional Lead for Psychology in [REDACTED], and approval will be sought from the relevant Research and Development Departments prior to the research commencing.

### Recruitment

Individual staff members within the teams will identify families who they believe meet the criteria for inclusion in the research. Consent to contact these families about the research will be gained through each team's usual procedures. For example, some teams routinely ask all clients at assessment whether they consent to be contacted regarding future research opportunities, whereas other teams approach any clients on their caseload who meet the criteria to ask whether they consent to be contacted regarding a research opportunity. Staff members may share the Family Information Sheet at this point. Once families have been identified and they have consented to be contacted, staff members will pass their contact details to the researcher. The researcher will then contact families, ideally by telephone, to introduce herself and the research and to invite participation. Families can then be sent copies of the information sheet and consent form, if they have not seen this already, to help inform their decision whether to take part. This can be sent via families' preferred method (e.g. via email or post). If families would like time to decide or to liaise with other family members who may take part, a second call can then be made to families to discuss whether they wish to take part and arrange a time to meet. The researcher will arrange a convenient and comfortable location and time to meet with the family to undertake the interview. The preferred location is likely to be one of the family members' home addresses, however they will also be given the option to attend a local trust site where a room can be booked.

### Interviews

When the researcher meets with the family, they will re-introduce themselves and the research. They will provide further copies of the Information Sheet and Consent Form if necessary and will talk the family through the Information Sheet. During this process, they will regularly ask the person with dementia to reiterate the information back to the researcher, this is to ensure that they understand the information. These initial prompt questions are included at the beginning of the interview schedule. If the participant cannot answer these questions, even with extra effort to explain in more detail, this is likely to raise concerns about the individual's ability to understand the information and to therefore make an informed decision to take part. The researcher will not continue with the interview if such concerns are apparent. In such instances this would be explained to the family sensitively. The interviewer will endeavour to remain aware of changes at any point during the interview, which, although unlikely, may require reiteration of the information sheet and re-evaluation of an individual's understanding and decision to continue or withdraw.

If no concerns are apparent with the person's understanding, then capacity to consent will be assumed as per guidance (Mental Capacity Act, 2005), particularly as staff selected service users who they deemed to be able to provide consent. Family members will have the opportunity to ask any questions, and then they will all be asked to read and sign a consent form. Families will then be reminded about consent, confidentiality, and the right to withdraw, prior to beginning the interview. Interviews are anticipated to last approximately 60-90 minutes, although timings will be very flexible to suit the family. If the family wishes to take a break at any time, or arrange a further meeting to continue the interview this will be accommodated as far as possible. The interview schedule will be used as a guide for the discussions. All interviews will be recorded using either a digital voice recorder or a digital video recorder. Video recordings would facilitate transcription for the researcher when multiple people are involved in conversations. However, families will be able to choose which method of recording they prefer.

When the interview comes to an end families will be thanked for their participation, and the researcher will talk them through the debrief sheet. This is designed to remind families of the key information, and contains details regarding further information or sources of support. They will have the opportunity to ask any further questions, and will also be reminded that they can still withdraw from the study up until completion of the assignment or publication. The interview schedule will be reviewed after the first interview, and may be adjusted accordingly.

#### Transcription and Analysis

Each participant will be assigned a pseudonym, and their interview will be transcribed. [REDACTED] (Academic Supervisor) may review excerpts of transcripts to assist in the analysis process. Recordings and anonymised electronic transcriptions will be encrypted and stored on a password protected computer to ensure that only the researcher can access these. Recordings will be deleted within three months.

The transcripts will be analysed on an inductive level using a suitable qualitative methodology, with themes emerging directly from the data rather than a pre-existing framework. Careful reading and re-reading will take place, along with regular discussions with the Academic Supervisor to ensure that this process is rigorous.

#### Practical Issues

Some practical issues which have been considered include:

- Costs: Cost of all paper copies of materials (family information sheets, consent forms etc) will be covered by Lancaster University. Regarding travel expenses, Lancaster University will reimburse the researcher's travel costs. Participants will not be expected to travel for the interview. However, if they are required to travel at any point the cost will be reimbursed by Lancaster University (up to £10).

- Interview location: it is anticipated that most families will prefer to be interviewed at their home address. The [REDACTED] Lone Worker Procedure will therefore be followed during these visits, and any known issues regarding home visits will have been communicated by staff during the recruitment process. If families would prefer to meet at a Trust location, the researcher will book a suitable room at their chosen location to ensure that the interview will be confidential and that their participation will remain anonymous.
- Interview times: Interviews will be very flexible to suit families. This may include times outside of the usual 9am-5pm working day.
- Data storage: audio and video files and anonymised electronic transcripts will be stored as encrypted files on a password protected computer so that only the researcher can access these. Audio and video files will be deleted following analysis; however anonymised transcripts may be kept by the university for a maximum of 10 years after project completion or following publication if relevant.

## Ethical Considerations

Various ethical concerns have been considered:

- **Informed consent:** It is important that all members of the family are fully informed about the purpose and format of the interview prior to providing consent. Ability to provide informed consent to take part in research is part of the inclusion criteria, therefore staff will identify families where the person with dementia is able to understand and provide informed consent. This will involve reviewing a client's language comprehension and checking they understand the concept of research and the implications of their consent, and consideration of their language expression to ensure they have the language ability to discuss their experience. Consent procedures will be guided by relevant policies (e.g. [REDACTED], 2013) and legislation (Mental Capacity Act, 2005). The nature of dementia requires consent to also be considered at the time of interview. According to guidance (Mental Capacity Act, 2005) capacity to consent must be assumed until proven otherwise. The information sheet will be talked through with families prior to commencing interview, taking particular care to ensure information is accessible to the person with dementia. Once information has been communicated to the person with dementia, they will be asked what they understand about the interview (see the interview schedule for prompt questions). These questions will be used to check the participant's understanding of the information shared. All families will be informed of this process and the potential outcomes prior to arranging an interview time.
- **Confidentiality and anonymity:** To protect the identity of participants no-one but the researcher will know who has taken part. Although staff will be aware

of families who they identified as meeting the inclusion criteria, they will not be told which families took part. Pseudonyms will be used for all participants to preserve anonymity, and any identifying information will be removed. When findings are reported or presented to the team, particular care will be taken to ensure anonymity.

- **Possible identification of risk:** During the interview participants will be made aware of the limits to confidentiality (i.e. if they identify any risk of harm to themselves or others). If any risk was identified, my duty to share this information would be reiterated to the family and I would discuss this with my supervisors and would take any necessary actions.
- **Participant distress:** As with any research it is possible that something may unintentionally cause some distress. During the interview the primary researcher will use their clinical skills and their experience in this area of work to manage any distress that arises. The presence of the family is hoped to increase the element of support during the interview, and the interviewer would also support anyone to access any help that was necessary, which would be guided by the participant's wishes. The information sheet for the project states that distress may be aroused with any research and gives a variety of sources of support. The interview can be terminated at the request of any member of the family. The debrief sheet also reminds families of potential sources of support.
- **Risks to researcher:** As interviews will be conducted in person and may be at participants' homes the [REDACTED] Lone Worker Policy will be followed. In addition, when staff identify potential participants who meet the criteria for inclusion, any necessary risk information about home visits will also be shared at this stage.

## Service User/Public Involvement

The project proposal was shared with members of the Lancaster University Public Involvement Network (LUPIN), which included many experts by experience (i.e. people who have previously used services and now provide advice and guidance on making research accessible and appropriate for everyone). LUPIN members provided feedback and comments on the research, which were taken on board. Ongoing consultation is also being offered by one expert by experience from LUPIN, who has offered advice on various elements of the project design, and in particular consultation around the materials (e.g. Information Sheets and Consent Form). MAS teams have also been consulted regarding the design of the project, and will be further involved in refining wording of interview questions. Professionals within stroke and dementia services were consulted regarding appropriate adjustment of materials to ensure they are dementia friendly and accessible for people with a variety of cognitive difficulties.

## Project Management

A research contract has been drawn up between the primary researcher, their Field Supervisor and their Academic Supervisor. The contract explicitly details each person's role and what is expected. Regular meetings will occur between the researcher and each of their supervisors to ensure good communication and that the project stays on track.

## Dissemination

Once the project is complete, a full copy of the report will be submitted, as part of a thesis, to the DClinPsy course at Lancaster University. Results will be compiled into a separate summary report, which all participating families will receive a copy of if they wish to. Families will be given the opportunity to request this at interview stage. Summary reports will also be shared, along with relevant recommendations, with the various teams who supported recruitment and any other interested services. Findings could also be presented back to staff at team meetings if this was appropriate. The finished project may be submitted for publication in an appropriate journal.

## Timescale

The project will begin once ethical approval and R & D approval have been granted. The proposed start date will be September 2013. Data collection may then continue until December 2013. Analysis and report writing will continue until May 2014 when a final copy will be submitted to Lancaster University as part of the requirements of the DClinPsy course.



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## Appendix 4-B: Family Information Sheet

Version 2 – June 2013

## Research: How do families experience dementia?



My name is Olivia.

I am a **Trainee Clinical Psychologist** at **Lancaster University**.

I would like to invite you to **help** with my **research**.

---



You can **read** this **information** about the research before you **decide**.

You can **ask any questions** and can talk to someone else to help you decide.

You **do not** have to take part.

If you choose not to take part your **care will not be affected**.

It is ok if you **change your mind** at any time.

---



### What is the research about?

I would like to know more about what it's like for **you and your family** living with **dementia**.

I want to **research** this so that I can **help services** to support families better.

### What will you be asked to do?



I would like to **meet you and your family** together. The person with dementia can **choose** which family members they would like to be with them.

It is best if there are **at least 2 people** from their family with them.



I will first check that you **understand the information** about the research. If you really **struggle to understand** you might **not** be able to **take part**.

I will ask you some **questions** about what it is like to live with dementia within your family.

We can **meet** once or several times to talk about these questions. You can choose **where** we meet.

---

### Will our conversation be private?



What you tell me will be **private**.

I will **record** our conversation so I can remember what you say. You can **stop** the recording at any time. I will **delete the recording** when I have typed what you told me.

I will **not use your real name** so no-one will know you took part, except for me and the family members present.

If I am **worried** about your **safety** or the safety of someone else I may need to **tell someone** so I can make sure everyone is safe.



### What will happen afterwards?

I will write a **report** about what people tell me.

If you like I can **send you a copy** of a report.

I can **meet** with you to **explain** the report.

You **do not have to meet** with me or read the report if you do not want to.

I will **share** the report with **other people** so that they can learn from your experiences.

I might **use quotes** from what you say but I will **not use your name**.

---

### Are there any risks?



I hope the conversation **will not make anyone upset**, but it is possible some things might be **difficult to talk about**.

You can **stop** the conversation **at any time**.

If you become **upset** and want **someone to talk to** I can help you find someone.

There are some **contact details** for people who can **help** at the end of this sheet.

---

### Are there any benefits?

I hope you will **enjoy** taking part.

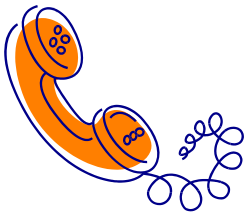
This research will **help other people understand** what it's like to live with dementia as a family. This research might also **help services to support families** better.

### Further information



If you would like some **more information** about this research you can **contact me**:

Olivia Wadham  
Clinical Psychology  
Furness College  
Bailrigg  
LANCASTER  
LA1 4YG



**Tel:** 07908 613788

**Email:** [o.wadham@lancaster.ac.uk](mailto:o.wadham@lancaster.ac.uk)

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### Complaints



If you want to **complain** or raise **concerns** about this research and **do not want to speak to me**, you can contact:

Professor Susan Cartwright  
Head of the Division of Health Research  
Lancaster University  
Lancaster  
LA1 4YT

**Tel:** 01524 592430

**Email:** [s.cartwright@lancaster.ac.uk](mailto:s.cartwright@lancaster.ac.uk)

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

### **Helpful contact details**

**National Dementia Helpline (0300 222 1122)** is run by the Alzheimer's Society and offers information, support, guidance and signposting to other sources of help.

**Admiral Nursing DIRECT (0845 257 9406)** is a helpline supported by the charity Dementia UK. It offers advice and support to people with dementia.

**Age UK advice line (0800 169 6565)** provides information and support for older adults.

**Carers Trust ([www.carers.org](http://www.carers.org))** works to improve support for anyone caring for a family member or friend.



**Carers Direct (0808 802 0202)** is run by the NHS, and provides free information and advice for carers.

You could also contact your GP or anyone else involved in your care.

## Appendix 4-C: Consent Form

Version 2 – June 2013

**Do you want to take part in the research?**

		(Please tick one)
	Yes - I <u>do</u> want to take part	<input type="checkbox"/>
	No - I <u>do not</u> want to take part	<input type="checkbox"/>

- (Please tick)
1. I have **read** the **information sheet** or had it read to me. ☐
  2. I **understand** what the research is about and have had the opportunity to ask any **questions**. ☐
  3. I know I can **choose** if I want to take part and can **withdraw** at any time. ☐
  4. I understand the conversation will be **recorded** and direct **quotes will be used**. ☐
  5. I understand recordings will be **deleted** after **3 months**, and **typed** versions of our conversation will be kept for up to **ten years** after the study has finished. ☐
  6. I understand the results will be made in to a **report** and **shared** with other people (my **name will never be used**). ☐

Your name: \_\_\_\_\_

Signed: \_\_\_\_\_ Date: \_\_\_\_\_

My name: Olivia Wadham

Signed: \_\_\_\_\_ Date: \_\_\_\_\_



## Appendix 4-D: Family Debrief Sheet

Version 2 – June 2013

**Research: How do families experience dementia?**

My name is **Olivia**. I am a **Trainee Clinical Psychologist** at **Lancaster University**.

I would like to say **thank you very much** for taking part in my **research**.

What you have told me will **help services** understand how to **support** people with dementia and their **families better**.

---

**What will happen now?**

I will write a **report** about what you and other **people have said**.

If you like I can **send you a copy** of a report.

I can **meet** with you to **explain** the report.

You **do not have to meet** with me or read the report if you do not want to.

---

**Can I still change my mind?**

If you decide you **do not want** to be a part of the **research** anymore you can **let me know** by calling me on **07908 613788**.

I would **delete** any information I have from our **conversation**.

When I have **written** and shared **the report** it will be **too late** to delete the information.

### What if I feel upset?



I hope the conversation **will not make anyone upset**, but some things might have been **difficult to talk about**.

If you feel **upset** after our conversation and want **someone to talk to** these **contact details** might be helpful:

**National Dementia Helpline (0300 222 1122)** is run by the Alzheimer's Society and offers information, support, guidance and signposting to other sources of help.

**Admiral Nursing DIRECT (0845 257 9406)** is a helpline supported by the charity Dementia UK. It offers advice and support to people with dementia.

**Age UK advice line (0800 169 6565)** provides information and support for older adults.

**Carers Trust ([www.carers.org](http://www.carers.org))** works to improve support for anyone caring for a family member or friend.

**Carers Direct (0808 802 0202)** is run by the NHS, and provides free information and advice for carers.

You could also contact your **GP** or anyone else involved in your care.

### Further information



If you would like some **more information** about this research you can **contact me**:

**Olivia Wadham**

Clinical Psychology

Furness College

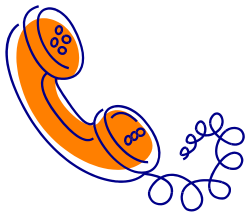
Bailrigg

LANCASTER

LA1 4YG

**Tel:** 07908 613788

**Email:** [o.wadham@lancaster.ac.uk](mailto:o.wadham@lancaster.ac.uk)



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### Complaints



If you want to **complain** or raise **concerns** about this research and **do not want to speak to me**, you can contact:

**Professor Susan Cartwright**

Head of the Division of Health

Research

Lancaster University

Lancaster

LA1 4YT

**Tel:** 01524 592430

**Email:** [s.cartwright@lancaster.ac.uk](mailto:s.cartwright@lancaster.ac.uk)

**Thank you for taking the time to read this sheet.**

**Appendix 4-E: Interview Topic Guide**Version 4 – December 2013**Interview Topic Guide****Families' experiences of changing roles and relationships when one family member has dementia**

This document is an indicative guide to the kind of questions and topics to be covered in the interview and will be used flexibly.

**Introduction to the interview**

- Purpose of research
- Talk through Family Information sheet

Prompt questions for the person with dementia to check understanding, which will be asked after each relevant section of the information sheet – expected answers also included:

- Can I check what you understand the research to be about?  
*(answer to indicate research on families experience of dementia)*
- What do you understand about what we are going to do today?  
*(answer to indicate group conversation/interview about experience)*
- What do you understand about how private our conversation will be?  
*(answer to indicate confidential but limits around risk)*
- What will happen after we have met today?  
*(answer to indicate right to withdraw and write-up/report)*
- What are the risks of taking part?  
*(answer to indicate potential upset/difficult to talk about)*
- What are the benefits of taking part?  
*(answer may indicate enjoyment, benefit to others)*
- Talk through consent form and allow participants to complete
- Would they like to receive a copy of the report and how (email/post/meeting)?
- Audio or video recording preferred
- Reminders:
  - Confidentiality and anonymity
  - Right to withdraw
  - Family members can take breaks at any time
  - Don't have to answer questions if don't want to
  - Can meet more than once
  - Ask any questions as we go along
  - Make family aware I will encourage equal representation of voices

**General family experience**

Initial questions to ask about the family more broadly to establish rapport. For example:

- Can you tell me a bit about you as a family?

**Experience with dementia**

Questions can then begin to focus on their experience following the diagnosis of dementia. For example:

- Can you talk me through how you found out that X has dementia?
- What has family life been like since X received a diagnosis of dementia?
- Has anything changed in the family since X has had memory difficulties? If so, what?
- How does your family now compare to your family in the past?
- What's most difficult about the dementia and the changes it might have brought?
- Have you learnt anything as a family from the experience of dementia so far?
- Has anything positive come out of this experience as a family?
- How much do you talk together as a family about the dementia and any changes it brings?
- How has your experience in relation to dementia changed over time?
- When are relationships in the family most difficult?
- How have your roles and responsibilities changed? What has this been like?

**Appendix 4-F: Response to Request for Further Information**

**From:** Wadham, Olivia [<mailto:o.wadham@lancaster.ac.uk>]

**Sent:** 11 September 2013 17:54

**To:** [REDACTED]

**Subject:** confirmation for ethical approval

**Importance:** High

Hi [REDACTED],

Following our telephone conversation earlier today, I can confirm that I would allow participating families at least 24 hours from when they receive information about the study (i.e. information sheet) to when consent is sought.

Let me know if you require any further information.

Many thanks,

Olivia

**Olivia Wadham**  
**Trainee Clinical Psychologist**  
**Lancaster University and Lancashire Care NHS FT**

**Appendix 4-G: National Research Ethics Service Approval**NRES Committee [REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]

Telephone: [REDACTED]

12 September 2013

Miss Olivia Wadham  
Trainee Clinical Psychologist  
Lancashire Care NHS Foundation Trust  
Clinical Psychology, Division of Health Research,  
Furness College  
Lancaster University, Lancaster  
LA1 4YG

Dear Miss Wadham

**Study title:** Families' experiences of changing roles and relationships when one family member has dementia  
**REC reference:** [REDACTED]  
**IRAS project ID:** 131799

Thank you for your email of 11 September 2013, responding to the Proportionate Review Sub-Committee's request for confirmation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager [REDACTED]  
[REDACTED]

**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.

This Research Ethics Committee is an advisory committee to [REDACTED]  
*The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England*

### Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

*Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

### Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Covering Letter		15 August 2013
Evidence of insurance or indemnity		15 July 2013

This Research Ethics Committee is an advisory committee to [REDACTED]  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England



Investigator CV		01 August 2013
Letter from Sponsor		15 August 2013
Other: Family Debrief Sheet	2	28 June 2013
Other: [REDACTED] CV		
Other: Employers Liability and Public and Products Liability		11 July 2013
Participant Consent Form	2	28 June 2013
Participant Information Sheet: Family Information sheet	2	28 June 2013
Protocol	2	28 June 2013
REC application	3.5	15 August 2013
Response to Request for Further Information: Email Confirming 24 hour consent time		11 September 2013

### Statement of compliance

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

### After ethical review

#### Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

**Please quote this number on all correspondence**

This Research Ethics Committee is an advisory committee to [REDACTED]  
*The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England*

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

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

Yours sincerely

pp

[Redacted signature]

[Redacted name]  
Chair

Email: NRESCCommittee.[Redacted]

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: [Redacted] *Lancaster University*  
[Redacted]

**Appendix 4-H: Research and Development Department Approval**

12<sup>th</sup> September 2013

Miss Olivia Wadham  
Trainee Clinical Psychologist  
Clinical Psychology, Division of Health Research,  
Furness College  
Lancaster University  
Lancaster  
LA1 4YG

Dear Miss Wadham,

**Re: NHS Trust Permission to Proceed**

**Project Reference:** 13/10

**Project Title:** *Families' experiences of changing roles and relationships when one family member has dementia*

I am pleased to inform you that the above project has received research governance permission.

Please take the time to read through this letter carefully and contact me if you would like any further information. You will need this letter as proof of your permission.

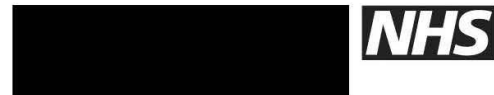
Trust R&D permission covers all locations within the Trust; however you will only be allowed to recruit from the sites/services you have indicated in section 3 of the SSI application form. If you would like to expand recruitment into other services in the Trust that are not on the original SSI then you must contact the R&D department immediately to discuss this before doing so.

You also must ensure you have liaised with and obtained the agreement of individual service/ward managers before commencing recruitment in that service and you must contact the relevant service/ward managers prior to accessing the service to make an appointment to visit before you can commence your study in the trust

**Honorary Research contracts (HRC)**

All researchers with no contractual relationship with any NHS body, who are to interact with individuals in a way that **directly affects the quality of their care**, should hold Honorary





Research NHS contracts. Researchers have a contractual relationship with an NHS body either when they are employees or when they are contracted to provide NHS services, for example as independent practitioners or when they are employed by an independent practitioner (*Research Governance Framework for Health and Social Care*, 2005). If a researcher does not require an HRC, they would require a Letter of Access (LoA). For more information on whether you or any of your research team will require an HRC or LoA please liaise with this office. It is your responsibility to inform us if any of your team do not hold Honorary Research NHS contracts/Letters of Access.

Staff involved in research in NHS organisations may frequently change during the course of a research project. Any changes to the research team or any changes in the circumstances of researchers that may have an impact on their suitability to conduct research **MUST** be notified to the Trust immediately by the Principal Investigator (or nominated person) so that the necessary arrangements can be put in place

#### **Research Governance**

The Research Governance Sponsor for this study is Lancaster University. Whilst conducting this study you must fully comply with the Research Governance Framework. This can be accessed at: [http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\\_ID=4108962&chk=Wde1Tv](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4108962&chk=Wde1Tv)

For further information or guidance concerning your responsibilities, please contact your research governance sponsor or your local R&D office.

#### **Good Clinical Practice (GCP)**

GCP is an international ethical and scientific quality standard for designing, conducting, recording and reporting trials that involve the participation of human subjects. It is the responsibility of all researchers who are carrying out a research project involving NHS patients and carers to complete GCP training and to update this every 2 years. All training certificates must be forwarded to the R&D department to comply with Trust permission. Please note that student projects are exempt from this process.

#### **Risk and Incident Reporting**

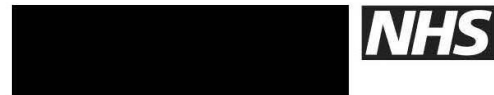
Much effort goes into designing and planning high quality research which reduces risk; however untoward incidents or unexpected events (i.e. not noted in the protocol) may occur in any research project. Where these events take place on trust premises, or involve trust service users, carers or staff, you must report the incident within 48 hours via the Trust incident reporting system. If you are in any doubt whatsoever whether an incident should be reported, please contact us for support and guidance.

Regardless of who your employer is when undertaking the research within [redacted] you must adhere to trust policies and procedures at all times.

#### **Confidentiality and Information Governance**

All personnel working on this project are bound by a duty of confidentiality. All material accessed in the trust must be treated in accordance with the Data Protection Act (1998) For good practice guidance on information governance contact us.



**Protocol / Substantial Amendments**

You must ensure that the approved protocol is followed at all times. Should you need to amend the protocol, please follow the Research Ethics Committee procedures and inform all NHS organisations participating in your research.

**Monitoring / Participant Recruitment Details**

If your study duration is less than one year, you will be required to complete an end of study feedback report on completion. However if your study duration is more than one year, you will be required to complete a short electronic progress report annually and an end of study report on completion. As part of this requirement, please ensure that you are able to supply an accurate breakdown of research participant numbers for this trust (recruitment target, actual numbers recruited). To reduce bureaucracy, progress reporting is kept to a minimum; however, if you fail to supply the information requested, the trust may withdraw permission.

**Recruitment**

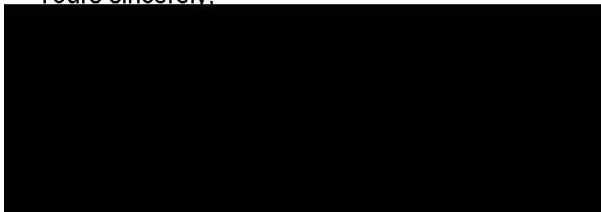
Please provide the trust details of your recruitment numbers when requested. If you have any concerns with recruitment please contact the R&D team immediately for assistance.

**Final Reports**

At the end of your research study, we will request a final summary report so that your findings are made available to local NHS staff. The details from this report may be published on the NHS Trust internet site to ensure findings are disseminated as widely as possible to stakeholders.

On behalf of this Trust, may I wish you every success with your research. Please do not hesitate to contact us for further information or guidance.

Yours sincerely,



*On Behalf of the Research Governance Sub-Committee*

Cc: [Redacted]



## Appendix 4-I: Application to Alzheimer's Society for Research Partnership



### Application for research partnership

#### All applicants please note:


- The principal investigator must be sponsored by a recognised higher education learning institute (e.g. a University)
- The principal investigator must be studying at PhD level OR has already achieved a PhD Or higher Clinical qualification
- The project must have received ethics consent
- The project must be of local interest and show benefit or value to the Society
- The applicant must prove sufficient experience of working with vulnerable adults, knowledge of the intricacies of working with people with dementia and/or their carers and empathy towards the challenges associated with living with dementia.

#### Please attach with your application form:

- Proof of CRB clearance for working with vulnerable adults
- Any additional information which will enhance your application.
- ALL attachments and supporting documentation and the final letter of consent.

**Date submitted: 21/08/2013**

<b>Principal Applicant</b>		
Title and full name	Miss Olivia Suzanne Wadham	
<b>Institution</b>	Lancaster University	
Post held	Trainee Clinical Psychologist	
Department and address	Doctorate in Clinical Psychology, Division of Health Research, Furness College, Lancaster University, Lancaster,	
Contact details	Telephone [REDACTED]	Email o.wadham@lancaster.ac.uk
<b>If you are a student please state the degree you will attain on completion of this research project</b>	D.Clin.Psy (Doctorate in Clinical Psychology)	
Please list other applicants and institutes involved in the application	Applicant	Institute

Research title	Families' experiences of changing roles and relationships when one family member has dementia.					
Does this research have ethics approval from NRES?	<b>Yes / No</b> <u><b>NOTE: It is in the process of application – approval not received yet (final letter can be forwarded on receipt).</b></u>  <b>If yes, please include a full scanned copy of the IRAS application including ALL attachments and supporting documentation and the final letter of consent.</b>					
Research dates	Start date: September 2013			Finish date: May 2014		
Participants (please circle all that apply)	Staff	Volunteers	<u><b>Persons with dementia</b></u>	Carers	<u><b>Family members</b></u>	None
Is funding allocated to supporting any costs incurred by the Society in the application	There should not be any costs to the Society					
Have you contacted anyone within Alzheimer's Society about the proposal?	<b>Yes/ No.</b> If yes, please provide contact details and dates 					
Are there any conflicts of interest? (e.g. do you work or volunteer at the Society)	No					



<p>How specifically do you hope the Alzheimer's Society will be involved and when do you expect involvement to start and finish?</p>	<p>Dementia Advisers within Memory Assessment Services across [REDACTED] would be asked to identify patients who meet the inclusion criteria for the research. When they identify families who meet the criteria they could then obtain verbal consent to be contacted regarding research. If consent is given, their name and contact details will be shared with the researcher (Olivia Wadham). Only 5-10 families are required in total so this would only be a very small amount of work. Recruitment can start as soon as all relevant approval is received and is anticipated to be in September 2013, finishing recruitment by February 2014 at the latest.</p>
<p>Why do you consider the Alzheimer's Society to be an appropriate partner for your research proposal?</p>	<p>I wish to recruit families from Memory Assessment Services, of which Dementia Advisers are a part. The Dementia Advisers undertake some excellent work within the teams and would be in a good place to identify families suitable for the research. Nursing staff are also being used for recruitment in some MAS teams.</p>
<p><b>Please detail your experience working with people with dementia or other vulnerable groups?</b></p>	<p>I have over five years' experience of working with people with mental health problems (including children, adults and older adults and people with a learning disability). I have 2 years' experience of working as a Trainee Clinical Psychologist, offering psychological support to individuals, families, and groups. During my time as a trainee I have also worked for 6 months within The Memory Assessment Service in [REDACTED]. My role involved assessment for Dementia, Dementia Support groups, and individual support after a diagnosis. I am therefore very familiar with the challenges and difficulties experienced when living with dementia, and am confident I can provide support for families in distress. I am also familiar with the relevant research, policies and procedures in this area and within the service.</p>



<p><b>Summary of project</b></p> <p>Please include project aim and objectives, a detailed methodology (including recruitment, anticipated number and location of participants) and details of dissemination plans to a maximum of <b>1000 words</b></p> <p>Please attach all appropriate documents with your submission</p> <p>Including;</p> <ul style="list-style-type: none"> <li>- consent forms</li> <li>- information forms</li> <li>- questionnaires</li> <li>- interview templates</li> </ul>	<p><b>Aims</b></p> <p>This research aims to explore the collective experience of the family unit where one family member has dementia. The interviews will explore how the family make sense of the current situation, what they have noticed about roles and relationships within the family, and how they have faced challenges and adapted to any changes as a family. It is envisaged that this will not only contribute to the understanding of how families experience dementia, but will also highlight how dementia services can best meet the needs of the family as a whole.</p> <p><b>Design</b></p> <p>MAS teams and various experts by experience (i.e. service users) have been involved in the design of the project. Professionals within stroke and dementia services were consulted regarding appropriate adjustment of materials to ensure they are accessible for people with a variety of cognitive difficulties.</p> <p style="text-align: center;"><u>Method</u></p> <p><b>Participants</b></p> <p>Participants will include 5-10 families who meet these criteria:</p> <ol style="list-style-type: none"> <li>6. One family member must have received a diagnosis of dementia (any type).</li> <li>7. The person will be in the relatively early stages of dementia, and will be able to engage in conversation about experience.</li> <li>8. The person with dementia must be able to give valid consent to take part.</li> <li>9. Two or more family members must be willing to take part along with the person with dementia. These family members need to be involved in the person with dementia's life to ensure there is a sense of the family as a whole (i.e. family members must be present in their life, and in contact with them).</li> <li>10. The person with dementia should not be living in residential care.</li> </ol> <p>The small sample has a good fit with qualitative analysis methods. Participants will be recruited from various services across [REDACTED], which could include:</p> <ul style="list-style-type: none"> <li>• Memory Assessment Services. Three teams: [REDACTED]. (this is where Dementia Advisers from Alzheimer's Society will be involved)</li> <li>• Dementia Cafés across [REDACTED]</li> <li>• Community Mental Health Teams across [REDACTED]</li> </ul> <p><b>Procedure</b></p> <p>The research has been agreed with all three MAS teams and with the Older Adult Professional Lead for Psychology, other relevant approval will be sought prior to commencing.</p> <p><b>Recruitment</b></p> <p>Individual staff members within the teams will identify families who they believe meet the criteria for inclusion. They will seek consent for the researcher to contact these families about the research. This is likely to be done by approaching any clients on their caseload who meet the criteria to ask whether they consent to be contacted regarding a research opportunity. Staff members may share the Family Information Sheet at this point. Once families have consented to be contacted, staff members will pass their contact details to the researcher. The researcher will contact families, ideally by telephone, to introduce herself and the research and to invite participation. If families would like time to decide a second call can then be made to</p>
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	<p>families. The researcher will arrange a convenient location and time to meet with the family to undertake the interview. This could be their home address, or a local trust site where a room can be booked.</p> <p><b><i>Interviews</i></b></p> <p>When the researcher meets with the family, they will re-introduce themselves and the research. They will talk the family through the Information Sheet. They will regularly ask the person with dementia to reiterate the information back to the researcher, this is to ensure that they understand the information. These initial prompt questions are included at the beginning of the interview schedule. If the participant cannot answer these questions, even with extra effort to explain in more detail, this is likely to raise concerns about the individual's ability to understand the information and to therefore make an informed decision to take part. The researcher will not continue with the interview if such concerns are apparent. In such instances this would be explained to the family sensitively. The interviewer will endeavour to remain aware of changes at any point during the interview, which, although unlikely, may require reiteration of the information sheet and re-evaluation of an individual's understanding and decision to continue or withdraw. If no concerns are apparent with the person's understanding, then capacity to consent will be assumed as per guidance (Mental Capacity Act, 2005). Family members will all be asked to read and sign a consent form. Interviews are anticipated to last approximately 60-90 minutes, although timings will be flexible to suit the family. Breaks and further meetings will be accommodated as far as possible. The interview schedule will be used as a guide for the discussions. All interviews will be recorded using either a digital voice recorder or a digital video recorder. Video would facilitate transcription for the researcher when multiple people are involved in conversations. However, families will be able to choose which method of recording they prefer.</p> <p>When the interview comes to an end families will be thanked and the researcher will talk them through the debrief sheet. This will remind families of the key information, and contains details regarding sources of support. They will have the opportunity to ask questions, and will be reminded that they can still withdraw.</p> <p><b><i>Transcription and Analysis</i></b></p> <p>Each family will be assigned pseudonyms, and their interview will be transcribed. [REDACTED] (Academic Supervisor) may review excerpts of transcripts to assist in the analysis process. Recordings and anonymised electronic transcriptions will be encrypted and stored on a password protected computer to ensure that only the researcher can access these. Recordings will be deleted within three months.</p> <p>Transcripts will be analysed using a suitable qualitative methodology, to identify themes.</p> <p><b><i>Dissemination</i></b></p> <p>A full copy of the report will be submitted, as part of a thesis, to the DClinPsy course at Lancaster University. A separate summary report will be available to all participating families. Summary reports will also be shared, along with relevant recommendations, with the various teams who supported recruitment and any other interested services. Findings could also be presented back to staff at team meetings if this was appropriate. The finished project may be submitted for publication in an appropriate journal.</p>
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**Appendix 4-J: Alzheimer's Society Approval**

**From:** [REDACTED]  
**Sent:** 08 October 2013 09:22  
**To:** Wadham, Olivia  
**Cc:** [REDACTED]  
**Subject:** RE: research

Hi Olivia

Thank you for providing the additional information and we are now happy for you to proceed with your study. Please contact our Dementia Adviser [REDACTED] to arrange how to proceed with her.

[REDACTED]'s telephone numbers are

Mobile: [REDACTED]  
Tel: [REDACTED]

Regards

[REDACTED]

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**From:** Wadham, Olivia [<mailto:o.wadham@lancaster.ac.uk>]  
**Sent:** 03 October 2013 12:52  
**To:** [REDACTED]  
**Cc:** [REDACTED]  
**Subject:** FW: research  
Hi [REDACTED],

Following your correspondence with [REDACTED] regarding the research being undertaken within Memory Assessment Teams across [REDACTED], I am emailing with confirmation that the project has now been approved by an NHS ethics committee and also by the Trust R & D department. I have attached the approval letters so that you can be reassured of this. You also mentioned wanting to be sure that informed consent procedures are followed by NHS staff so I have also attached a copy of the research protocol, which details the consent procedures, and contains copies of the information sheet and consent form we will be using.

I can confirm that I will agree with dementia advisors that they identify participants and pass names onto another member of the team, who will then liaise with me regarding recruitment. No information shared in confidence will be required at any point from dementia advisors. Could I also check with you that your decision covers all dementia advisors working across [REDACTED]?

If there is any further information you require, please don't hesitate to contact me.

Many thanks,

Olivia

**Olivia Wadham**

**Trainee Clinical Psychologist**

**Lancashire Care NHS FT & Lancaster University**