Research Project Portfolio

University of Nottingham

School of Medicine

Division of Psychiatry & Applied Psychology

Doctorate in Clinical Psychology

2019

Exploring the process of adjustment to a diagnosis of dementia at working-age: a qualitative study

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Submitted in part fulfilment of the requirements for the

Doctorate in Clinical Psychology

Acknowledgements

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Thesis Abstract

42,000 people are thought to be living with a diagnosis of working-age dementia (WAD) in the UK (Prince, 2014). For the person with dementia, the unexpectedness of receiving a diagnosis at this age (Roach, Drummond, & Keady, 2016), alongside other factors, may lead to additional difficulties to those diagnosed at an older-age. In addition, informal carers are thought to suffer significantly greater levels of stress than their older-age counterparts (Luscombe, Brodaty, & Freeth, 1998).

There is a lack of qualitative information on adjustment to a diagnosis of dementia, and particularly on adjustment to dementia at working-age. It has been suggested that the process of adjustment in illness is ongoing for as long as the illness continues; it is vital that adjustment is understood in this way (Brennan, 2001), to ensure that services are not complacent or expect an end-point of change. To start to understand this for those affected by dementia, at all ages and stages, is crucial to developing psychological interventions that facilitate this process. This thesis aimed to explore the early adjustment process (including areas of agreement and difference) between people living with dementia and their cohabiting companions. In addition, it aimed to use this information to consider how services may help to facilitate adjustment.

A qualitative, longitudinal, prospective design was employed to meet the aims of this research. Five working-age dementia dyads (person with dementia and cohabiting companion) were interviewed separately within three months of receiving a diagnosis, and again three months later. Thematic analysis was used to explore the adjustment process for individuals in this early stage. The identification of patterns across the data is important to start to understand the phenomenon being studied and thematic analysis allows deep and rich accounts of experience to be drawn out (Braun & Clarke, 2013); this was considered key for giving both members of the dyad a voice.

From the analysis of the 20 semi-structured interviews completed, three overarching themes were constructed based on their frequency and salience: 1) 'connectedness', a relational theme describing a process of disconnecting and

reconnecting with others, 2) 'negotiating roles', a theme describing the evolution of becoming a carer or caree, and the steps taken in an attempt to adapt to these new roles, and 3) 'forming narrative', a latent theme describing how participants oscillate between contemplating the past and the future, while intermittently surviving the present. Additional themes were found to frame the main process themes: 1) 'tolerating (or not) uncertainty', whereby participants discussed the varying levels of uncertainty that characterise a diagnosis of dementia, and how responses to this impact adjustment and 2) 'being of working-age', where participants described the nuances of a diagnosis of dementia at a younger age, and how this permeated the overall process.

These findings support the idea of adjustment as a process, highlighting movement within and between themes. Similarities and differences between members of the dyad bring to light how interventions may support the adjustment process in the early stages.

Statement of contribution

For this research, the majority of responsibility for project design, application for ethical approval, reviewing the relevant literature, participant recruitment, data collection, scoring, transcription, data analysis, and write up was held by the trainee clinical psychologist.

Advice regarding project design, application for ethical approval, data analysis and write-up was provided by Dr Danielle De Boos and Dr Nima Moghaddam (Research Supervisors).

Dr Sarah Wilde (Research Supervisor) provided further advice on data analysis and presentation of results.

Dr Jennifer Ditchfield (Field Supervisor) put me in contact with Nottinghamshire Working Age Dementia service (through which the majority of participants were recruited) and provided advice regarding adaptation of participant information sheets, consent forms, and interview schedules for people with dementia.

Journal Paper

'Exploring the adjustment process in working-age dementia: a qualitative study'

The following article is prepared for submission to the journal 'Dementia'. Author guidelines can be found at https://uk.sagepub.com/en-gb/eur/journal/dementia#submission-guidelines

Abstract

It has been suggested that the process of adjustment in illness is ongoing for as long as the illness continues. To start to understand this for those affected by dementia, at all ages and stages, is crucial to developing psychological interventions that facilitate this process. There is a lack of qualitative information for the adjustment to a diagnosis of dementia, and particularly to the adjustment of dementia at working age. Five working-age dementia participant dyads (person with dementia and cohabiting companion) were interviewed separately within three months of receiving a diagnosis, and again three months later. Thematic analysis was used to explore the adjustment process for individuals in this early stage. Three overarching themes were constructed from a thematic analysis: 'connectedness', 'negotiating roles', and 'forming narrative'. These findings support the idea of adjustment as a process, highlighting temporal, yet non-linear, movement within and between themes. Similarities and differences between members of the dyad highlight how interventions may support the adjustment process in the early stages.

Introduction

Prince's (2014) overview estimated that there are over 850,000 people living with dementia in the United Kingdom (UK), with 42,000 of these being people of working-age[1] (under the age of 65).

Individual responses to a dementia diagnosis vary; for some, diagnosis confirms suspicions, improves understanding and provides access to specialised support (Bamford et al., 2004; Wilkinson & Milne, 2003). However, for many, the changes and losses associated with such a disorder lead to understandable negative responses, including depression, anger, denial, and lowered self-esteem and confidence (Aminzadeh, Byszewski, Molnar, & Eisner, 2007). Limited research into experiences of people receiving a diagnosis at working-age suggests that this population experience additional difficulties relative to those diagnosed at an older age. Factors such as the unexpectedness of receiving a diagnosis at this age (Roach, Drummond, & Keady, 2016) and the

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[1] Please see extended paper 1.1 for further information on working-age dementia (WAD)

possibility that at the point of diagnosis people may still be working and supporting their families financially, may result in heightened stress.

Whilst the impact of receiving a diagnosis can be devastating for people with dementia, Flicker (1999) maintains that the weight of ongoing day-to-day difficulties is also held by carers, both informal and professional. For informal spousal carers, Merrick, Camic, and O'Shaughnessy (2016) argue that the difficulties associated with dementia symptoms warrant a shift in perception of roles, meaning that couples may experience a change in levels of intimacy. Brodaty and Donkin (2009) highlight that the burden experienced by informal carers puts them at higher risk for depression, anxiety, and fatigue. It has been argued that working-age spousal carers suffer significantly greater levels of stress than their older-age counterparts, leading to interference with their occupational roles, including choosing to leave paid employment or reducing working hours (Luscombe, Brodaty & Freeth, 1998)[2].

Whilst much published literature focuses on the negative impact of receiving a diagnosis, and the burden on the caregiver, research has also highlighted the ability to live well with dementia (e.g., Downs, 2013), and positive aspects of caregiving (e.g., Cohen, Colantonio, & Vernich, 2002). The Department of Health's National Dementia strategy (2009) aims to ensure that people with dementia and their companions are able to maintain wellbeing and quality of life[3]. It is therefore necessary to consider differing adjustment and adaptation journeys of individuals and what factors may mediate the diverse experiences of this.

Adjustment has been conceptualised variously as the process of change for individuals (Brennan, 2001) and responses that allow individuals to become habituated to changes in the environment (Sharpe & Curran, 2006). Within coping literature, Lazarus and Folkman (1984) stress the need for problem and emotion-focussed coping for humans to maintain equilibrium. Coping (the strategies employed to manage instances that are appraised as stressful,

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[2] Please see extended paper 1.2 for further information on informal carers of people with dementia
[3] Please see extended paper 1.3 for further information on living well with dementia

Folkman & Moskowitz, 2004) is often considered analogous to adjustment (Clemerson, Walsh, & Issac 2014; Spendelow, Joubert, Lee, & Fairhurst, 2018).

Lazarus and Folkman's (1984) model has been used to think about adjustment to a diagnosis of chronic illness (Bombardier, D'Amico, & Jordan, 1990) and when considering the adaptation of carers to their new role (Hinrichsen & Niederehe, 1994); while the model has not been subject to qualitative examination, or been applied to a working-age context, it has been applied to dementia caregivers (Haley, Levine, Brown, & Bartolucci, 1987), and describes a dynamic process amenable to change over time (Hawken, Turner-Cobb, and Barnett, 2018). Thus, the model may allow a consideration of how people attempt to restore equilibrium after a diagnosis of dementia[4].

Rationale

Research has focused on responses to diagnosis[5] (e.g. Pratt & Wilkinson, 2003; Aminzadeh et al., 2007) but rarely on early ongoing adjustment. It is important to explore this critical phase of adjustment that is inclusive of responses to diagnosis, but may also encompass noticing and adapting to changes that dementia brings post-diagnosis (and that may precede diagnosis). Research that *has* looked into early adjustment has been done retrospectively (e.g. Clemerson et al., 2014) and with older adults (e.g. Robinson, Clare, & Evans, 2005; Roach et al., 2015). Robinson et al.'s (2005) paper provided a valuable insight into the process of adjustment (proposing a model similar to that of the dual process model of grief [Stroebe & Schut, 1999]) but asked people two years after diagnosis what their experiences were. A prospective design[6] was considered apt to capture the dynamics of adjustment unfolding over time.

There is a lack of qualitative information for the adjustment to a diagnosis of dementia, and particularly to the adjustment of dementia at working age. What literature there is has been informed by advocates of younger people, i.e. paid

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[4] Please see extended paper 1.4 for further information on adjustment and coping
[5] Please see extended paper 1.5 for further information on reactions to diagnosis and associated debates
[6] Please see extended paper 2.1.2 for further information on prospective vs. retrospective research

carers and professionals, rather than the person living with dementia their carers themselves (Beattie, Daker-White, Gilliard, & Means, 2002). Aminzadeh et al. (2007) stress the necessity for research that will help to comprehend the experiences of people living with dementia at various points throughout the disease, while Bamford et al. (2004) suggest qualitative methodology to better understand meaning and process.

Sharpe and Curran (2006) put forward that the process of adjustment in illness is ongoing for as long as the illness continues; to start to understand this for those affected by dementia at all ages, at all stages, is crucial in developing psychological interventions that facilitate this process, to better respond to the specific needs that people with dementia and their carers have (Aminzadeh et al., 2007). For the present study, adjustment was operationalised as a continuous process, characterised as attempts by individuals to maintain equilibrium in response to recurrent challenges. As 'coping' in adjustment is well-theorised, Lazarus and Folkman's (1984) model will be held in mind.

Research Aims
The present study aimed to 1) explore the process of adjustment for people with dementia of working-age and their cohabiting carer (companion), in the first 6 months after receiving a diagnosis, 2) to explore areas of agreement and difference between people living with dementia and companions, and 3) to use this information to consider how services may help to facilitate adjustment.

Methods

Design

A qualitative study[7] using semi-structured interviews was used to explore the views of the person with dementia and their cohabiting companion (a dyad). Service users' feedback informed the design of the present study[8].

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[7] Please see extended paper 2.1 for further information on qualitative research
[8] Please see extended paper 2.2 for further information on service user involvement

Epistemological position

The present research adopted a position of critical realism[9]. Though each participant brought with them a different way of understanding and responding to the world around them, it was acknowledged that there is something to find that 'exists' independent of the way it is interpreted. This allowed a consideration of how the present findings could have transferable implications for others within the same population, necessary to achieve research aim 3.

Participants

Five dyads (comprising of a person diagnosed with dementia in the last three months and their cohabiting companion) were recruited from National Health Service (NHS) settings in the midlands of England, UK. Purposive sampling was used with participants invited to take part, if both members of a dyad were willing to talk about the process of adjustment. Participants were living in the community and the person with dementia was under the age of 65 when they received the diagnosis, thereby meeting criteria for inclusion. Participants were excluded if the person with dementia had a diagnosis of fronto-temporal dementia (FtD); FtD presents significantly differently to Alzheimer's and Vascular Dementias, including speech and personality changes (Chapman, Marshall-Williams, Strine, Anda, & Moore, 2015). Dyads were excluded if both members had had a current diagnosis of dementia[10].

Demographic and clinical information was collected at first interview. Table 1 displays this information with pseudonyms used to maintain anonymity.

Ethical considerations

Research governance approval was granted from three NHS sites and the Health Research Authority (HRA). Ethical approval was received by the NHS Research Ethics Committee in the North West[11]

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[9] Please see extended paper 2.3 for further information on epistemology
[10] Please see extended paper 2.4 for further information on participants (including recruitment)
[11] Please see appendix F for ethical approval

Table 1. Participants' demographic data

Dyad no.	Participants	Age	Length of cohabiting relationship	Time since diagnosis	Occupational status
1	Finlay (Person with Dementia [PwD])	61	41 years	9 weeks	Retired from part-time work due to diagnosis
	Anne (companion)	59			Working full-time
	Alistair (PwD)	61	25 years	8 weeks	Retired from full-time work due to diagnosis
	Isobelle (companion)	66			Retired
3	Albert (PwD)	64	24 years	11 weeks	Retired due to poor physical health prior to diagnosis
	Rhonda (companion)	71			Retired
4	Nicholas (PwD)	61	30 years	11 weeks	Retired from full-time work due to symptoms of dementia prior to diagnosis
	Florence (companion)	57			Working full-time
5	Nella (PwD)	57	33 years	6 weeks	Retired from full-time work due to diagnosis
	Rufus (companion)	57			Working full-time

In thinking about working with people with dementia, it is necessary to consider capacity to consent to research, due to potential communication and decision making difficulties (Beuscher & Grando, 2009). There were no indicators to suggest that capacity was lacking throughout participants' involvement. Informed consent was taken at an initial visit in line with Good Clinical Practice (GCP) guidelines. Participants were offered breaks, the opportunity to resume interviews at a later date, or to be referred to their local dementia service should needs arise that may have benefited from ongoing support[12].

Data collection

Longitudinal qualitative research aims to answer questions of lived experience over time (Calman, Brunton, & Molassiotis, 2013)[13]. To prospectively research the months following a diagnosis, it was decided that interviews would be conducted at two time-points. To explore adjustment over time, and allow sufficient time for new experience, a pragmatic decision was made to interview within three months of diagnosis and again three months later[14].

Participants were interviewed separately in their homes[15]. The first author conducted all interviews.

Semi-structured interviews

Interview guides included inductive questions related to the participant's understanding of adjustment and the individual process of adjustment for them. Deductive questions related to the stress and coping model (Lazarus and Folkman, 1984) were included to make use of broad areas understood to be implicated in the construct of adjustment; these included questions on initial thoughts following diagnosis, and practical and emotional issues faced (including management of these). The same interview topic guides were used for both the PwD and companion. At second interview, questions as detailed

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[12] Please see extended paper 2.5 for further information on ethical considerations
[13] Please see extended paper 2.1.1 for further information on qualitative longitudinal research
[14] Please see extended paper 2.6 for further information on data collection
[15] Please see extended paper 2.6.4 for further information on paired vs. individual interviewing

above were asked again, alongside questions that followed up on topics discussed by participants at first interview[16].

Interviews lasted between 45-60 minutes. They were audio recorded and later transcribed by the first author.

Data analysis

Data (audio recordings and transcriptions) from semi-structured interviews were analysed using Thematic Analysis (TA)[17]. Data collection was completed prior to beginning analysis; this diachronic approach takes into account data at both time points, intended to help to capture process over time (Grossoehme & Lipstein, 2016; Nevedal, Ayalon, & Briller, 2018).

Braun and Clarke (2006) outline six phases to code and interpret the data. These are familiarisation with the data, generating codes, looking for, reviewing and defining themes, and using these to form a report. Analysis was completed, following these steps, on an inductive basis. Inductive analysis stipulates that researchers should generate themes from the raw data rather than generate an analysis informed by existing theory[18]. Themes were generated across the time-points for all participants - data from people with dementia were compared and contrasted with data from companions.

Data was analysed at a mixed semantic-latent level. A semantic level of analysis includes taking what is said by participants explicitly, to mirror participants' language and understanding. A latent level of analysis allows the researcher to identify meanings from the data that are less explicit. Typically, thematic analysis involves analysis at both levels. (Braun & Clarke, 2013).

To ensure the analysis was credible, throughout each stage the second and third authors checked the themes generated by the primary researcher. Any queries were discussed and resolved in supervision with final themes agreed upon by all parties.

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[16] Please see appendix G for interview topic guide
[17] Please see extended paper 2.7 for further information on Thematic Analysis
[18] Please see extended paper 2.7.4 for further information on inductive vs. deductive analysis

Reflexivity and positioning

Prior to getting on clinical training, much of the first authors' experience was gained through working in dementia services; this led to a particular interest in this population. In this role, it was observed that people diagnosed with dementia would not be routinely contacted until six months post-diagnosis, which influenced the time period focused on in the present study.

It was considered important that the first author examined their role in, and influence on, the process of data collection and analysis, to increase trustworthiness of the research. In line with Critical Appraisal Skills Programme (CASP) guidelines[19], reflexivity is one such way to evaluate this, thus, a reflexive diary was kept throughout all stages of the study[20].

Results

Three main themes, with subthemes, were constructed from the inductive analysis. These themes are displayed in figure 1[21]. The arrows between overall and sub-themes reflect that participants were considered to flexibly move within and between these themes during the process of adjustment, and that the process was not linear.

Connectedness

This overarching theme is relational in nature and describes the process by which people with dementia and their companions notice a negative change in emotional connection with others (disconnecting) and then make efforts to reconnect, or remind themselves how connection is still possible (seeking connection).

Disconnecting

All participants described relational disconnection[22]. In these examples, Finlay (PwD[23]) and Rufus (companion) identify this in relationships outside the dyad.

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[19] Please see extended paper 2.8 for further information on the quality of qualitative research and how CASP was considered.

[20] Please see extended paper 2.8.3 for further information on reflexivity

[21] Please see extended paper 3.11 for findings from extended themes

[22] Please see extended paper 3.1 for extended comments on the subtheme 'disconnecting'

[23] PwD will be used to denote 'person with dementia' for results sections

> *"The hardest part, is people looking at you, thinking, 'what's up with that idiot?' you know what I mean?" (Finlay, PwD)*

> *"People are sympathetic and they say 'can we do anything to help?'… but this is my problem, this is what I'm going to have to deal with… I want to remain friends but it's never going to be the same so our lifestyle is going to change." (Rufus, Companion)*

Finlay had felt pushed away from friends as a result of forgetting mid-conversation. In contrast Rufus describes overt offers of support from friends but his sense is that disconnection is, nonetheless, an inevitable outcome. Both men find discomfort in the disconnection and their accounts are characterised by shame and regret.

More frequently the disconnection was described within the dyad. For Albert this manifested through reduced verbal interaction with Rhonda.

> *"I don't seem to converse with her much…I'm ashamed of it really…it's not something that I do on purpose, it's just…how I am now…I don't talk much." (Albert PwD)*

Albert identifies changes within himself as the cause of disconnection.

Anne describes disconnection, in her relationship with Finlay, in the context of no longer doing things together. This seems to relate to Finlay making different choices to what he may have done before the dementia.

> *"It's hard… when you've always been together and I've said 'I want to do things with you' but he doesn't want to do the things that I want to do…and he's not sure what he wants to do… sometimes we lead separate lives." (Anne, companion)*

Anne and Finlay's relationship has changed in an important way and her account suggests that she has to recharacterise their relationship.
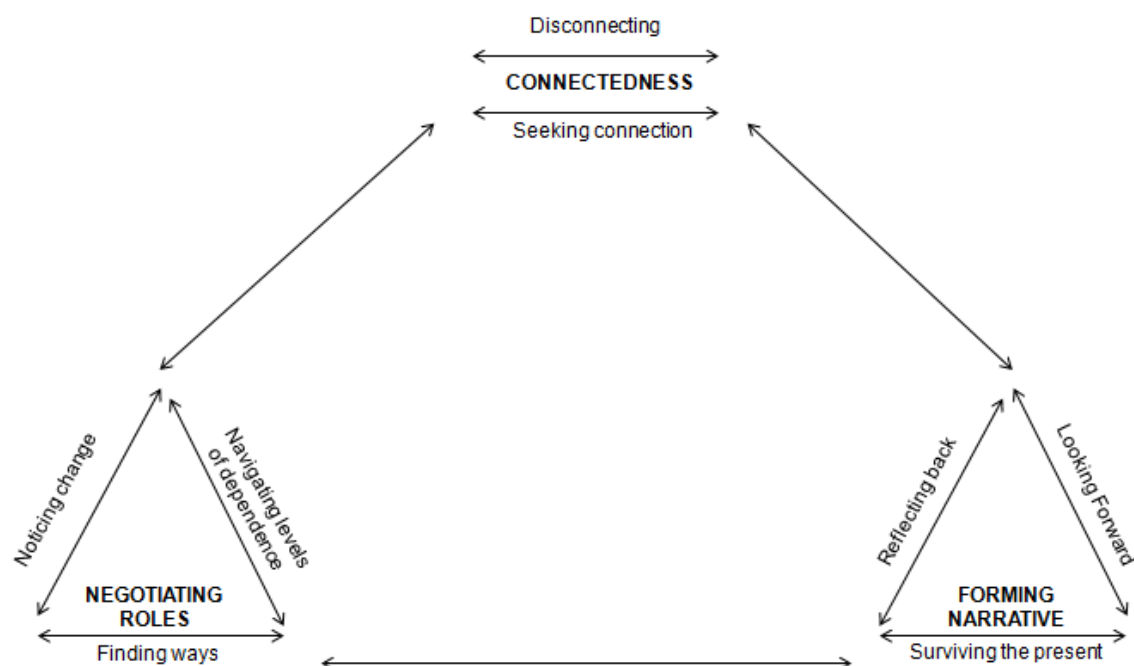
Figure 1. Thematic map of the adjustment process.

Disconnection also appeared in the context of emotional intimacy. Isobelle and Rhonda speak frankly about concealing emotions and losing a confidante.

> *I just try and not let Alistair see…that I'm upset" (Isobelle, companion)*

> *"I think that the hardest thing in my life is that I don't have anybody to turn to now." (Rhonda, companion)*

Of those participants who identified losing connection in this way, most described it as a gradual shift in their desire to share emotional topics and difficult feelings as their partners displayed more symptoms of dementia. The accounts were characterised by loss.

Seeking connection

All participants reported ways in which they seek connection with others[24], particularly in the second interview[25]. One way that members of dyads attempt

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[24] Please see extended paper 3.2 for extended comments on the subtheme 'seeking connection'

[25] Please see extended paper 3.10 for results on differences between time-points

to reconnect is through groups, which can provide a sense of 'togetherness' that is shared from either side of the dyad.

> "...there's always been somebody else who's in the same boat…completely different job, completely different background…but we're all together...not so frightening I think, when there's more of you." (Alistair, PwD)

> "The thing I think I did really benefit from, was...the realisation that Nella's exactly the same, she has exactly the same traits, and the frustrations that other carers have are exactly the same as mine" (Rufus, companion)

Both Alistair and Rufus demonstrate the reassurance and comfort that can arise from meeting others who are in the same situation. Rufus's experience demonstrates a change over time; at first interview he had a stereotyped view of groups and was not convinced of their utility.

> "I'm not a great one for group therapy and group situations…I'm not going to go to groups and sit round and crochet and things…" (Rufus, companion)

For some dyads, reconnecting with others was a joint venture.

> "On a Monday we go to the cardio club, myself and Rhonda go and it's all people with similar things to myself…I do like that." (Albert, PwD)

This shared weekly event provided enjoyment and positive feelings for Albert, countering those described in the subtheme 'disconnection'.

The earlier example of disconnecting, borne out of wanting to protect Alistair from her own feelings of sadness, led to Isobelle sharing difficulties with other family members.

> "We can talk to one another, and say 'just take each day as it comes' and we'll get by." (Isobelle, companion)

Regularly speaking with her sister on the phone provides Isobelle with reassurance and a coping strategy to get through moments appraised as stressful.

A definitive way that all companions reported connection with their loved one was by reminding themselves of the person beneath the symptoms. This brings comfort and describes a way for companions to retain the narrative of their relationship.

> *"He's still Nicholas…he's no different after diagnosis than he was before it" (Florence, companion)*

> *"…things have changed, she's a bit different this way, a bit different that way…but she's still my Nella". (Rufus, companion).*

Negotiating Roles

This theme describes the evolution of becoming a carer/caree and the steps taken in an attempt to adapt to these new roles that are unfamiliar, yet thrust upon participants. This theme is tightly linked to ability and competence. Participants describe a process by which they start noticing a transition to new roles, or losing old identities (noticing change). A level of dependence on others is experienced by both members of the dyad (navigating levels of dependence) and participants describe finding ways to gain autonomy and become more skilled within the constraints of their new role (finding ways).

Noticing change

Participants diagnosed with dementia noticed a change in their abilities[26], resulting in a loss of confidence and autonomy.

> *"Things that I've just gone ahead and done, I know what I'm doing and just do it. But sometimes now I think, well hang on a minute, should I ask?" (Alistair, PwD)*

> *"I got clobbered with a ridiculous bill, which I paid ...I was conned I suppose. After that I was not allowed to make any payments for things. I*

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[26] Please see extended paper 3.3 for extended comments on the subtheme 'noticing change'

> *don't   look after my own finances or anything like that…I'll occasionally be allowed" (Nicholas, PwD)*

Alistair demonstrates an appraisal that others are more competent or able, and that he may need help where he would not have before, while Nicholas describes an experience which highlights the transition to being a caree. The use of being 'allowed' to do something suggests a loss of self-sufficiency.

As participants with dementia noticed a change in role, companions noticed a steady transition to becoming a carer.

> *"…it's evolved gradually…and you realise your relationship's changed… I suppose I am becoming a carer! ... he would have taken the lead on that sort of thing…" (Florence, companion)*

> *"It's silly little things…before you could sit and talk and you'd go through it and we'd discuss what was in the bank…he just doesn't have a clue about it all now… it's more responsibility on me, all of the time" (Anne, companion)*

Florence and Anne highlight the increasing demands felt by them alone. The use of the words 'gradually' and 'little things' suggest the subtle way the change has presented itself.

Navigating levels of dependence

There was a general discourse that both the PwD and companions go through a process of depending on others for help and advice, to enable the transition into new roles[27]. For the PwD there is a main reliance on the companion, which can be helpful:

> *"Some things I can't understand…I talk to Anne, talk to daughters or whatever…and…it comes a picture in my mind" (Finlay, PwD)*

But for some the reliance on others leads to irritation and negative feelings towards the self:

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[27] Please see extended paper 3.4 for extended comments on the subtheme 'navigating levels of dependence'

"I do rely on Rhonda… not all the time, but I do rely on her sometimes to help trigger my mind. Yea, and she says…and I'm like 'Oh crikey, why didn't I think of that?' And I'm irritated with myself then because I couldn't think of that" (Albert, PwD).

Companions too go through a period where they describe depending on others, but outside of the dyad relationship, seeking advice from professionals and resources to learn the way to care.

"I spoke to the dementia team …and they were saying to me 'do this, and do that' so all the little bits that I took from everybody…made my mind clearer if you like…I suppose they're there to lean on…" (Anne, companion)

"I've read a lot on the internet…so I've made sure that he has nuts all the time, cos…that's something that's gonna help.' (Isobelle, companion)

Finding ways

This subtheme demonstrates that members of dyads utilise different strategies to feel competent and confident in themselves within their new roles[28]. Participants with dementia described accommodating the difficulties they are facing by learning alternative ways of accomplishing daily tasks.

"I've perhaps done it in a different way, it's taken time but I've still got what I've wanted! I've gone a different way around it." (Alistair, PwD)

Throughout both interviews, a common discourse from the PwD was an attempt to take control of their own health and well-being.

"I try and keep my brain active…I wanted to do the logical challenge… 'crikey, I've cracked it, I've done that one!' So it was an achievement." (Albert, PwD)

"...when I actually saw the doctor …I did say all this to her, so it's not something that I haven't said to her…I told her it straight" (Nella, PwD)

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[28] Please see extended paper 3.5 for extended comments on the subtheme 'finding ways'

Albert described the way he was decidedly stimulating his brain to manage symptoms of dementia, while Nella describes asserting herself in a situation she felt was detrimental to her health. Both participants with dementia demonstrate autonomy and quotes are characterised by accomplishment.

Companions employed individualised strategies to achieve success within their role, described at second interview.

> *"A simple thing…a list for him each day with the day on the top. We've tried lists for ages…but he'd take them round the house and then not know where he'd put them. So I just got a notepad and tied it to the kitchen table…so you know, we are finding ways." (Florence, companion).*

Florence's account suggests that learning ways takes time, requiring a trial and error process that is dependent on both members of the dyad.

Ultimately, companions at second interview described feeling more comfortable within their new role.

> *"I think I feel a bit more confident in myself with it all, if you like, understanding it more if that makes any sense" (Anne, companion)*

Forming narrative

Forming narrative exemplifies an overarching theme that was derived at a more latent level. Throughout both interviews, participants spoke of their dementia story, contemplating the stages that have been and those that are still to come. Participants looked back on previous chapters to make sense of experiences (reflecting back), considered the future - what it might bring and what they might do to influence their path (looking forward), but also described efforts to 'be' in the moment (survive the present).

Reflecting back

This subtheme arose from the many accounts of the lead up to diagnosis[29].

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[29] Please see extended paper 3.6 for extended comments on the subtheme 'reflecting back'

> *"It seems inevitable after how I'd been…some things took longer to work out…I knew things wasn't probably going along as it should do…but I didn't understand it" (Finlay, PwD)*

> *"I was right! It's been really… to me, a long getting up to that stage. Cos I think probably 4, 4 and a half years…noticed things weren't as they used to be…" (Anne, companion)*

For Finlay, an eventual diagnosis brought clarity to a situation he had been struggling to understand, while for his wife, Anne, the diagnosis was a long-time coming; being able to look back while holding a formal diagnosis in mind, provided confirmation and validation to the changes she had noticed.

The unexpectedness of receiving a diagnosis at such a young age was reflected on through discussion of previous misconstruing of symptoms and misdiagnosis from professionals.

> *"I sometimes thought 'I think some of the symptoms are very much like depression aren't they?' Is he just depressed? Is there something we can, or maybe he can do, is he trying hard enough?" (Florence, companion)*

> *"3 years ago, my doctor wasn't concerned about my memory, well he said, 'I don't really know'… I suppose looking at it, that not really knowing was good in a way, because I just got on with my life." (Nella, PwD)*

Both participants describe benefiting from not knowing it was dementia for a time. For Florence, understanding symptoms as those of depression enabled an internal locus of control at how to address the difficulties. For Nella, an unconfirmed diagnosis provided a sense of comfort and space away from worry.

Looking forward

All companions commented on varying levels of insecurity that characterise a diagnosis of dementia, with an uncertain timeline featuring heavily in the data.

"…we have absolutely no idea of the timescale of this you know" (Rufus, companion)

One interpretation of the data is that a diagnosis of dementia is akin to receiving an unexpected but largely determined ending to a story, rendering individuals powerless. Looking forward and putting plans in place is a way in which companions described gaining some control over this future and reducing potential hardship[30].

"I suppose if you can prepare for the future that's as much as you can do really at the moment isn't it? We just hope that if they're in place it's going to lessen the…chaos that potentially there could be…" (Florence, companion)

Companions demonstrate a pragmatic response:

"I've spoken to the boss who's very good about it…I've told them it's going to shorten my career with them" (Rufus, companion)

Rufus's account suggests a possible nuance of the experience of caring at working age, with planning to retire from work earlier than planned.

While companions look to the future, to plan and prepare, participants with dementia adopted more passive responses to manage the fear of a predetermined future.

"but there is hope isn't there? There's drug help… hope from Switzerland I think" (Nicholas, PwD)

"You can't look to the future because you know that you'll get worse…" (Nella, PwD)

Nicholas remains hopeful for a cure, while Nella assumes a strategy of avoidance.

Surviving the present

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[30] Please see extended paper 3.7 for extended comments on the subtheme 'looking forward'

All participants oscillated between past and future contemplations but intermittently settled on ways to reside in the moment[31].

> *"I suppose at times I think about the future, the unknown, and then think 'no, live for today'…make the most of what we've got now." (Florence, companion)*

> *" what I tend to do is just carry on as I would do normally…and at the moment, I don't think I've come across anything that's you know made me think, you know, I can't do that." (Alistair, PwD)*

> *"Whatever cards you're dealt, you've got…simple as that!" (Finlay, PwD)*

Florence describes an active resolution to move away from the past and the future, to be able to appreciate the present. Alistair describes an approach of maintaining normality for as long as possible, while Finlay surrenders to the situation as it is. To survive in the present, the above accounts are distinguished by gratitude, resilience and acceptance.

Discussion

This study has explored the adjustment process for the PwD and their cohabiting carer in the first six months after receiving a diagnosis. While other papers have interviewed older-adult dyads together, and retrospectively, the present research has explored the adjustment process for working-age adults prospectively over two time-points, through separate interviews.

Three main themes were identified from the data. These were 'connectedness', 'negotiating roles' and 'forming narrative'[32]. All participants demonstrated fluid movement through and within the themes, and subthemes, which was ongoing at second interview. This provides support for Brennan (2001) and Sharpe and Curran (2006) who defined adjustment as a continuing process. Within each theme there is an awareness of change or difficulty, alongside moments of positivity - ways that participants attempted to make things better, improve

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[31] Please see extended paper 3.8 for extended comments on the subtheme 'surviving the present'
[32] Please see extended paper 4.5 for discussion of extended subthemes

wellbeing and maintain equilibrium. This is similar to Robinson et al.'s (2005) model, where people oscillated between loss-orientated or restoration-oriented phases.

The ongoing movement, or process, described in the present study is non-linear. In line with Keady's (1999) model, devised to demonstrate the experience of living with dementia for caring dyads, the present study supports that while both members of the dyad appeared to travel through the process themes flexibly, it was not simultaneous and their adjustment experience often diverged. This demonstrates the importance of research into the person with dementia's perspective independent to the caregiver, the latter of which has received much dedicated research (e.g. O'shaughnessy, Lee, & Lintern, 2010; Orr & Teo, 2015). To understand a dyads' dementia adjustment journey as the same, or responding to the needs solely reported by the companion, would be to neglect the different needs of the PwD (Lepore, Shuman, Wiener, & Gould, 2017).

Connectedness

This theme showed an oscillating process of connection, akin to O'shaughnessey et al. (2010) who identified a theme of 'connection and separateness', when interviewing spousal carers at least two years after their partner had received a diagnosis of dementia. The present study demonstrates that this process starts happening early in the dementia journey, and is felt not just by companions, but by the PwD too.

A salient pattern in the data was how companions commented on the way they remind themselves that the PwD is still the same person, underneath the symptoms of dementia. Perry and O'Connor (2002) highlight the importance of preserving the personhood of loved ones. They suggest that in doing so, spouse carers are able to hold on to the narrative of a marriage.

Negotiating roles

The theme 'negotiating roles' demonstrated the way in which a dyads' experience may diverge.

Participants with dementia cited an awareness of change in their ability. Kitwood (1997) suggested that such changes can lead people with dementia to be undermined by those around them. In the present data participants living with dementia described ways in which they attempt to gain autonomy amongst the degenerative nature of their illness, which may be understood as attempts to be seen as competent in the eyes of others. Kitwood (1997) maintained that a person's well-being and personhood can be enhanced by others' respect and trust and so people with dementia should be encouraged and supported to demonstrate competence, and their attempts to make changes for themselves be recognised.

The present research demonstrates that alongside adapting to the changes noticed in their loved ones, the companion is required to learn a new skill and adapt to increasing responsibility early on in the adjustment process (and often prior to diagnosis). With many companions still working in the present population, it is understandable how this pressure can lead to feelings of burden (e.g. Burns & Rabins, 2000). Henderson and Forbat (2002) criticise services which place informal carers akin to professional carers, though this is often done. While a person with dementia's dependence on informal carers has been well documented, a companion's dependence on others to learn their new role, particularly in the early stages, is less commonly discussed. It should not be assumed that as the PwD becomes less able, that companions will automatically become competent and confident.

Forming narrative
The movement between different points up and down the timeline is akin to forming an individual's story. Kitwood (1997) suggested that being able to narrativise a journey allows a stronger sense of identity for storytellers.

The idea of making sense of experience is not uncommon in the literature. An overarching theme in Robinson et al.'s (2005) study was that of making sense of early stage dementia. The focus on pragmatic plans for the future that companions reported, may highlight the practical-focussed coping described by Lazarus and Folkman (1984), while the active avoidance of thinking about the

future in favour of attempts to maintain normality in the present, as most often identified in the accounts of those diagnosed with dementia, may be reappraised as the emotion-focussed coping Lazarus and Folkman (1984) detail[33]. The two approaches to coping may reveal the positioning of members of the dyad - the person with dementia spending time looking back may reflect the nature of symptoms, whereas the future focused stance of the companion may reveal the necessity of such for the person holding more responsibility.

Critique

When considering recruitment, those who declined cited that the diagnosis was 'too raw' to discuss. This leaves open the possibility that the sample may have included only those who felt they were better able to adjust or perceived they were already doing so successfully.

Participants interviewed for the current research were at the upper end of the working-age remit. Given that the WAD population starts in 30s and 40s, present results may be a limited articulation of the voice of the population[34].

Clinical Implications

Within the theme of connectedness, both members of the dyad speak about the benefit of emotional support groups to feel understood, validated and less alone, suggesting that such groups may be helpful in the early stages of adjustment. Lawrence, Fossey, Ballard, Moniz-Cook, and Murray (2012) support that the most beneficial interventions allow people with dementia to 'connect with others'; present findings would suggest that this benefit extends to companions.

Findings from 'negotiating roles' suggests that people with dementia at working-age may seek out opportunities to stimulate their brain as part of their adjustment trajectory; cognitive stimulation therapy groups (Spector et al., 2003) could allow an opportunity for the PwD to do this in collaboration with services. Skill-based groups may be beneficial for companions who are in the early stages of adjustment and learning ways to care. Evening groups, with a focus

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[33] Please see extended paper 4.4 for further discussion on the applicability of Lazarus and Folkman's (1984) model to the present results
[34] Please see extended paper 4.7 for further critique of methodology

on local venues, are likely to be important for companions who are still working full-time.

Boje (1991) suggests that a 'temporal openness' of storytelling can be transformative for organisations. Given that participants seemed to naturally tell their story in this way across interviews, the transformative power Boje (1991) cites may be extended to individuals. Narrative therapy provided by psychologists may be a helpful therapy to consider, but further research into the utility of this should be done.

Further research
The present findings suggest that people with dementia become increasingly reliant on their cohabiting companions as they move through their dementia journey. Further qualitative research could explore how those who live alone at working-age adjust to a diagnosis. Furthermore, in response to a limitation of the present study, future research could explore the experience of those living with dementia at younger ages.

Conclusion
As per O'shaughnessy et al (2010), and as is evident in the present paper, the nature of a person's dementia will continue to change; for this reason it is unlikely there will be a point at which a participant would consider themselves fully adjusted. However, if we can incorporate research findings into the ongoing adjustment for those affected by WAD, to help individuals to achieve moments of equilibrium, we can create more opportunities for people to not only survive in the present, but to live well in the present.

Journal paper word count (excluding footnotes, tables and references): 5970

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Extended paper

1. Extended Introduction

1.1 Working-Age Dementia

Dementia is a progressive disorder describing a set of symptoms that severely affect daily living; this includes memory impairment and difficulties with thinking (Age UK, 2016). The term 'working-age dementia' (WAD) is used interchangeably with 'early-onset dementia' and 'younger-onset dementia' in the literature. It refers to people with dementia who are under the age of 65. For the purpose of this research the term 'WAD' will be used. The rates of WAD in the UK have increased over the years; Prince's (2014) figure is four times that of a review by Sampson, Warren, and Rossor (2004), which approximated that there were 10,000 people with WAD in the UK 15 years ago. However, the propensity for misdiagnosis in this age group means that recorded numbers may underestimate the true prevalence of this condition (Harvey, Skelton-Robinson & Rossor, 2003). Misdiagnosis is attributed to atypical presentations in a younger population. Behavioural changes are often thought to be responses to stress or depression in this age-group and people with WAD experience delays in diagnosis twice the length of their older-age counterparts (NHS England, 2017).

The range of dementias experienced by those of working age is vast; fronto-temporal dementia (often characterised by changes in behaviour and language), dementias secondary to other health conditions (such as Multiple Sclerosis and Huntington's disease) and dementias with a more preventable cause (such as HIV and substance misuse) are more common (Withall, 2013). Despite many occurrences of WAD being due to unusual presentations (compared to those typically found in older adult populations) Alzheimer's disease (AD) is still the most common cause (Sampson et al., 2004; Vieira et al., 2013).

Kitwood (1997) advocated for person-centred care for those with dementia at all ages. NHS England (2017) stress the need for this in younger adults,

highlighting that 'age-appropriate' support is essential. They cited diverse needs including the possibility of dependent children, the impact on working life, and financial concerns (such as potential difficulties with accessing pensions), for this population.

1.1.2 Current care

Current NICE guidelines (2018) detail the assessment, diagnosis and management of dementia. The guidelines recommend that people have access to a memory service, have an initial assessment with a named care-coordinator and are offered activities such as cognitive stimulation and group reminiscence therapy to promote cognition and well-being. Despite these guidelines, a report from the Alzheimer's Society (2017) highlighted that only 17% of the people surveyed felt that there was adequate support from services. For those of working-age, there are no specific NICE guidelines related to management of the disorder; currently, two thirds of dementia services in the UK do not provide distinct support for those with WAD (NHS England, 2017). Withall (2013) describes that people of working age do not fit in well with services aimed at older-adults, while Rabanal, Chatwin, Walker, O'Sullivan and Williamson (2018) state that those with WAD are also excluded from adult mental health services, as dementia is thought to be a disease of the elderly. This can leave those with WAD unsupported by services.

The Young Dementia Network (YDN) maintains that services should be tailored to meet the unique needs of those diagnosed with WAD (YDN, 2018). McMurtray, Clark, Christine, and Mendez (2006) suggest that clinicians need to have a greater understanding of WAD, but a lack of research into this age-group impedes on this. The YDN have produced a pathway with recommendations informed by a steering group (YDN, 2018), however recommendations rely on research to inform best practice, providing further support for the necessity of further research to be carried out in this population.

1.1.3 Responses and struggles for those with WAD

Little research has been done into the subjective experiences of those living with dementia at working-age, despite a number of studies demonstrating that individuals diagnosed with dementia are able to put their views forward (Beattie,

Daker-White, Gilliard, & Means, 2004). Reamy, Kim, Zarit, and Whitlatch (2012) found that family members and carers are often consulted about the values and perspectives of those with dementia, but that this does not reflect the views of the PwD themselves.

Clare (2002) did look at the experience of dementia from the perspective of the PwD. She proposed a model of adjustment and coping for the PwD and found that participants' responses reflected intermittent attempts to protect the self from the threat of diagnosis, alongside attempts to 'fight' the threat head on. Clare (2002) described the similarity to Lazarus and Folkman's (1984) stress and coping model, described in greater detail later in this extended paper[35].

Beattie et al. (2004) interviewed 14 people with WAD and found that the majority reported being treated differently to 'normal' people and were increasingly neglected in matters requiring decisions. Those interviewed commented on the process of receiving a diagnosis, the length of time it took and the poor overall experience they had of services. Beattie et al. (2004), cite further issues around employability and financial strain as leading to challenge.

Rabanal et al. (2018) suggest that receiving a diagnosis at working-age leads to increased anxiety; they maintain that the PwD may still be physically well, but that the inevitability of degenerative symptoms creates stress for the person diagnosed and the people around them. Rabanal et al. (2018) conducted interviews with 14 people with WAD and found similar themes to Beattie et al. (2004) regarding the challenge of being diagnosed correctly; many participants first noticed behavioural changes rather than the stereotypical memory changes associated with dementia, serving to lead people to the wrong conclusion. In addition, Rabanal et al. (2018) found that of those interviewed, just over half were working at the point of diagnosis; the sadness felt at having to give up work as a result of symptoms was felt by the PwD. Participants reported a fear of the future and what it may bring for them, but found that engaging in meaningful activities served to improve well-being.

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[35] Please see extended paper 1.4.5 for information on Lazarus and Folkman's (1984) model

The literature that has explored the experience of people with WAD comments on the abnormal and unexpected timing of receiving a diagnosis at this age (Svanberg, Spector, & Stott, 2011; Clemerson, Walsh, & Isaac, 2014). Erikson (1982, 1993) proposed a model of lifespan development in which those aged 24-65 (coined 'adulthood' by Erikson) were likely to be engaging in caring for others (dependent children and aging parents) at this stage. Chaston (2011) supports that working-age people are likely to be caring for dependent children and relied upon. To instead become the 'caree' at that age is likely to have a profound impact, especially on identity. Harris and Keady (2003) interviewed 23 people with dementia and found that the impact on identity and 'self-hood' was commonly discussed. In addition, the PwD was found to experience difficulties with relationships (both romantic and platonic); often these changes would lead to feelings of isolation.

A review by Sansoni et al. (2016) reports on the most common difficulties faced by people diagnosed with dementia at working-age. They reference feelings of stigma, being missed by services, having a lack of appropriate services offered to them, and financial difficulties, as paramount. In addition, feelings of loss permeated much of the discourse, along with the challenge of reframing the narrative of one's life.

1.2 Carers of people with dementia

Martin-Carrasco et al. (2009) highlight that as the rates of dementia are increasing, so is the reliance on care being provided by family members. Much research has been conducted into the experiences of such carers (e.g. Luscombe, Brodaty, & Freeth, 1998; O'shaughnessy, Lee, & Lintern, 2010; Orr, 2015), and the difficulties associated with caregiving and adapting to a new role, with a particular focus on burden and interventions to reduce this (Williams, Moghaddam, De Boos, & Ramsden, 2018)[36]. Schneider, Murray, Banerjee, and Mann (1999) maintain that over time, spousal carers have a reduced quality of life due to a lack of rapport with their partner, leading to feeling 'alone' in the relationship.

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[36] Please see extended paper 1.4.2 for further information on carers adjustment

1.2.1 Positive aspects of caregiving

While there is much research into the negative aspects of caregiving, it can also be linked to positive outcomes (Brodaty & Donkin, 2009; Lloyd, Patterson, & Muers, 2016). Positive experiences of caregiving are linked to positive attitudes, which are aided by practising gratitude (Butcher & Buckwalter, 2001), the quality of a relationship (Donovan & Corcoran, 2010), and humour (Hickman, Clarke & Wolverson, 2016).

1.2.2 Comments on caregiver gender

Baker and Robertson (2008) suggested that where in the past the majority of caregiving was performed by the woman in a relationship, changing times mean that more and more men are taking on a caregiving role, particularly in dementia care. In a comparison of level of burden, Pöysti et al. (2012) found that females are more likely to experience higher levels of distress and burden than their male counterparts, and go so far as to suggest that male gender acts as a protective factor for caregiving. They attribute this to a difference in coping strategies – experiencing higher levels of distress has been associated with more emotion-focussed coping strategies, whereas lower levels of distress are associated with practical-focussed strategies, something Pöysti et al. (2012) found to be employed most in male caregivers. However, this study was conducted with older adults who may be of a generation with different gender expectations; the results cannot be applied reliably to caregivers who are of working-age.

1.3 Living well with dementia

The Department of Health (DoH) dementia strategy and challenge (2009) called for services to be transformed, for members of the public and professionals to be better informed about dementia, and for an end to the stigma associated with the diagnosis. The report places particular emphasis on the aspiration for people to 'live well' with dementia. Living well alongside a chronic illness can be defined as 'the best achievable state of health that encompasses all dimensions of physical, mental and social well-being' (Institute of Medicine, 2012). Actions to work towards this goal, outlined in the strategy, include keeping the person diagnosed with dementia and their family well-informed, to ensure that they can

be involved in decision-making related to care, and providing the right support at the right time. In relation to this timely support, retrospective accounts of experience may only be providing part of the picture, and so it is vital that more research is done prospectively, to better understand temporal needs. While the DoH report is no doubt important, 'younger people with dementia' is only referred to in vague terms (e.g. 'younger people with dementia's needs should be taken into account' is given as a recommendation). It is difficult for government initiatives to be clearer when there is a lack of research into this population.

Hickman et al. (2016) operationalised 'living well with dementia' as maintaining wellbeing and accumulating positive experiences; within this definition they demonstrated the strength of humour and dyads' shared experience of such. They proposed that in addition to simply being a positive experience, humour can in fact be used as a positive shared coping strategy.

Measures of Quality of Life (QoL) and well-being are frequently used to capture whether people are 'living well'. In ongoing longitudinal research, Lamont et al. (2019) have thus far demonstrated that a multitude of factors impact the ability to live well; alongside the symptoms that characterise dementia these included physical health of the PwD and caregiver, social location, assets, resources, and the dyadic relationship. They suggest that by actively intervening in these areas, dyads' capacity to live well may be increased.

Lamont et al. (2019) have found that 'living well' is dependent on an individual's self-esteem, self-efficacy and optimism. Typically, as dementia progresses so does the capacity for these concepts; Bartlett, Windemuth-Wolfson, Oliver, and Dening (2017) highlighted that a perpetual positive view of living with dementia, while possible at times, denies the reality of the dementia experience and a recognition of suffering. They suggest that correcting this imbalance means that we can start to understand the suffering experienced by individuals living with dementia and find ways to alleviate this.

Living well is achieved when there is "a self-perceived level of comfort, function and contentment with life" (Institute of medicine, 2012). Adjustment, as defined

by the present study is a 'continuous process, characterised as attempts by individuals to maintain equilibrium in response to recurrent challenges'. By these two working definitions, if individuals can successfully maintain equilibrium, they can go on to achieve a self-perception of comfort and contentment. This means that if we can start to understand how individuals adjust, we can, as a result, understand how individuals can live well for as long as possible.

1.4 Adjustment

Watson et al. (1988) highlights the role of both cognitive and behavioural processes in adjustment; a number of models of adjustment to various physical health threats have been formulated that integrate such processes (e.g. Rosenstock, 1974; Aizen, 1991). However, Sharpe and Curran (2006) recognise the limitations of models that neglect to incorporate the influence of affect in adjustment or those which focus too heavily on what people *do*. Whilst how people act on the process of adjustment is essential, models that fail to include emotional responses to external threats can be criticised for being over-simplistic and unable to account for the likely complexity. Sharpe and Curran (2006) integrated findings from the models cited above, alongside models that recognise the role of emotional response, benefit-finding and meaning-making (e.g. Brownlee, Leventhal, & Leventhal, 2000) to produce an adapted model. While this integration may serve to reconceptualise our understanding of adjustment to physical health diagnoses more broadly, there is limited evidence on the adjustment processes specifically involved in dementia and the relational applicability of models for people with dementia as well as those that support them.

Within the oncology literature, Brennan (2001) stresses the need for an understanding of adjustment processes, to mitigate the impact of stressors and reduce the psychological disorders associated with a diagnosis of cancer. The rationale for exploring adjustment in the present study is towards the same goal. Furthermore, it is vital that adjustment is understood as ongoing, creating both positive and negative outcomes for people (Brennan, 2001). This is to ensure that services are not complacent or expect an end-point of 'living well', rather

than a continuous process of change for individuals whereby dementia is a part of their story.

1.4.1 Adjustment for the person with dementia

There is some sparse research about the responses of people with WAD, and even less into the adjustment process of such individuals, independent from their partner, relative, or companion. However, Clemerson et al. (2014) started to bridge this gap, with their study investigating the coping of those with WAD. They found a theme of disruption of the life-cycle along with broad themes of changes in identity, agency and social connection. Within their findings they discuss the ways that people noticed negative changes across themes, and detailed the ways they coped with each. This is a useful contribution to the literature, but interviews were conducted retrospectively, with the most recent diagnosis of dementia occurring a year before.

1.4.2 Carer adjustment

When considering the ways that spouses may adapt to a caring role, Hooker, Frazier and Monahan (1994) found a link between a carer's personality and coping style, finding that this could influence adjustment. Graham, Ballard, and Sham (1997) found that family members who felt more knowledgeable about the course of dementia felt more competent and confident as carers, creating higher reported levels of wellbeing. More recently, O'Shaughnessy et al. (2010) highlighted the wealth of literature implicating the strength of a couple's relationship on subsequent adjustment to a diagnosis of dementia.

To understand the stressors affecting a caring dyad's interpersonal relationship, O'Shaughnessy et al. (2010) interviewed 7 spouses after they had been caring for their partner for at least 2 years. They found that in the early to mid-stages of dementia, carers described an oscillating process, continually changing depending on the person with dementia's abilities. They argue that carers of dementia must continually re-evaluate their own position with their relationship and in response to their partner with dementia; the nature of dementia means that this is likely to be ongoing for the duration of the illness, leaving carers in a state of flux. Ways of responding to this included seeking emotional

containment from friends and adopting practical approaches to problems in an attempt to gain control.

Carers of those with WAD may have a more intense experience of transitioning to the responsibility of caring (Vliet, de Vugt, Bakker, Koopmans, & Verhey, 2010); Freyne, Kidd, Coen, and Lawlor (1999) highlight that a lack of WAD services may leave younger carers feeling alone in their role, and Luscombe et al (1998) identified feelings of grief and guilt amongst relatives caring for people with WAD, along with higher emotional impact for such carers; Svanberg et al. (2011) posit that this may be attributed to bitterness about being 'robbed of the future' and secondary guilt about this resentment.

We cannot reliably apply the findings from older-adult research to the WAD population. Like the person with dementia at working-age, companions too may have distinct needs.

1.4.3 Shared adjustment

While it is important to research the individual perspectives of a dyad, research into the shared experiences of dementia dyads has also provided vital insight into possible adaptation journeys.

When attempting to explore the experiences of people with dementia and their informal carer (in particular by looking at where trajectories may cross), Keady and Nolan (2003) build on a temporal model by Wilson (1989) in which carers described the experience and coping involved with living with a person who has dementia. In Keady and Nolan's extension (2003), they highlight the active process of 'working through' situations and difficulties, particularly in the early stages of the disease. They identify that 'working through' can be experienced together (where symptoms and management of such is recognised by both members of a caring dyad), alone (for example if a PwD has had to keep their symptoms hidden or masked in some way, or if professionals do not provide help in management of symptoms), separately (where both members of a dyad are working hard at managing symptoms - the relationship is healthy but approaches do not coincide) and apart (where the relationship is strained and working separately leads to relational and management difficulties). Keady and

Nolan (2003) hypothesise that the longer that a couple can work through difficulties together, allowing the PwD to maintain an active role in management of symptoms, the more likely quality of life and wellbeing can be maintained. In keeping with the importance of the dyad relationship for quality of life, Hellstrom, Nolan and Lundh (2007) found that a couple's primary shared goal was to be able to maintain the narrative of their relationship, particularly in the early stages of dementia.

Robinson, Clare, and Evans (2005) looked at an older-adult population and proposed a model of adjustment to a dementia diagnosis for patient-carer dyads, similar to that of the dual process model of grief that comes from Stroebe and Schut (1999). In this model, people alternate between loss-oriented experiences (where the individual will focus on the loss they feel, for example feeling helpless) and restoration-oriented experiences (coping with issues secondary to the loss, for example managing financial matters) throughout the course of adjustment and within the changing context of dementia.

The research findings detailed above on the shared adjustment processes (Keady and Nolan, 2003; Robinson et al., 2005; Hellstrom et al., 2007) along with findings from Clare (2002), O'shaughnessey et al. (2010) and Clemerson et al. (2014) on the adjustment processes involved for individual members of a dyad, all described iterative processes occurring for both members of a dyad, throughout the course of dementia. The literature in this area has shown movement within qualitative themes identified, meaning dyads move through varying positions throughout the stages of dementia. This provides support for adjustment referring to a process, rather than an end-point of change, especially within the progressive decline of a dementia diagnosis. However, the majority of studies were done retrospectively or with older-adults and so the applicability of processes is unclear when thinking about those in the early stages of WAD.

1.4.4 Coping

The ways in which people 'cope' is widely considered to impact an individual's adjustment journey (e.g. Felton & Revenson, 1984; Stanton, Tennen, Affleck, & Mendola, 1992; McCaul, Sandgren, King, O'donnell, Branstetter, & Foreman, 1999). In Clemerson et al.'s (2014) study into the experiences of those with WAD, coping strategies were defined as the ways that individuals attempted to maintain wellbeing and normalise experiences - this is in line with the definition of adjustment being used in this study. Positive coping strategies have been suggested to enhance well-being and aim towards 'living well with dementia' (e.g. Clemerson et al., 2014; Hickman et al., 2016)

1.4.5 Lazarus and Folkman (1984) model
In Lazarus and Folkman's (1984) transactional theory, it is proposed that the environment can provide external stressors - in the case of terminal illness, being given a diagnosis may be appraised as an existential threat. People have an initial appraisal of the situation (i.e. whether it is significant, threatening or benign) and then go on to have secondary appraisals about whether they have the ability to cope or not. Coping can be understood as problem-focussed (looking to define the problem, learning new skills, finding new solutions and a practical approach) and emotion-focussed (including avoiding and distancing, seeking emotional support and acceptance).

Problem focussed coping is often thought to increase the likelihood of well-being, whereas emotion focussed coping is thought to predict negative affect (Folkman, 1984). Sahler and Carr (2009) suggest that poor well-being derives from the body's unsatisfactory attempt to deal and 'adjust' to stress - by understanding the different coping strategies people employ, it may be possible to affect wellbeing through targeted interventions.

The coping processes outlined in Lazarus and Folkman's transactional model are alluded to in much of the literature on coping in dementia (e.g. Haley, Levine, Brown, & Bartolucci, 1987; Mok, Lai, Wong, & Wan, 2007) and in caregiving literature (e.g. Hawken, Turner-Cobb, & Barnett, 2018). Whilst there have been updates to this model (e.g. Pearlin, Mullan, Semple, & Saff, 1990; Sharpe & Curran, 2006) the original model was considered both broad and

focussed enough to allow new and differing responses to get through if used as a basis to explore the processes that may be occurring in an individual's adjustment journey. For this reason, this model was used to inform interview schedules.

1.5 Diagnosis

Diagnosis is a pivotal point in the person diagnosed with dementia and their family member's journey (Gibbons, Ross, & Bevans, 2014). Watts, Cheston, Moniz-Cook, Burley and Guss (2013) put forward that the NHS are under pressure to diagnose dementia as early as possible, with a rationale given that people with dementia and their families are then able to better adjust to the illness.

Pratt and Wilkinson (2003) proposed a non-linear model to encapsulate the reactions of people with dementia to receiving a diagnosis. They found that an individual moves through a number of responses following diagnosis, including learning to adopt coping strategies (more likely to be successful if an individual had a social support system). This provides support for diagnosis as helpful, to learn to adopt coping strategies that would help with adjustment. However, the study also acknowledges that expected responses to diagnosis include denial and distress.

Robinson, Tang, and Taylor (2015) highlight the benefits of early diagnosis as allowing access to efficacious drug treatments as well as providing practical and emotional support and information, allowing the PwD and their families to plan for the future. However, there is a debate about the usefulness of early diagnosis and concern that early diagnosis, particularly without capacity to offer evidence-based intervention, is potentially harmful to the person diagnosed and their loved ones (Le Couteur, Doust, Creasey, & Brayne, 2013); they posit that receiving a diagnosis is equivalent to receiving threats to identity, roles and relationships which leads to understandable reactions of grief, anger, and frustration. Despite providing a way to make sense of symptoms (Robinson et al., 2015), diagnosis actually leads to further uncertainty (Le Couteur et al., 2013), which raises the utility of early diagnosis to an individual's adjustment.

1.5.1 Uncertainty

Van Wijngarden, van der Wedden, Henning, Komen, and The (2018) found that receiving a diagnosis is a paradoxical relief. The participants interviewed in their 2018 study found that diagnosis provided closure to not knowing but also were reported to feel ambivalent, echoing findings from Le Couteur et al. (2013) which posited that diagnosis leads to more uncertainty and instability. A degenerative disease such as dementia has an unclear trajectory, requiring people who are touched by the disease to continually adjust in response to changing goal posts.

O'shaughnessey et al. (2010) put forward that the uncontained uncertainty and continuous movement involved in responding to the trajectory of dementia left caregivers overwhelmed. They suggest that not knowing the future provides a way to feel more content in the present, as it acts as an effective defence mechanism against the pain of reality.

1.5.2 Stages of dementia

Amidst the uncertainty of the trajectory of dementia, there is an agreement that people move through stages. Efforts to capture this and provide some certainty for individuals and clinicians comes from Reisberg, Ferris, de Leon, and Crook (1982) who suggested seven stages of dementia ranging from 'no cognitive decline' to 'severe dementia'.

When considering research into the varying stages of dementia, those at the point of diagnosis are likely to be at stage four. If accounts of this stage are normally informed by retrospective research (one-two years after diagnosis), it is possible that findings are being influenced by a different stage entirely.

2. Extended methods

2.1 Qualitative research (QR)

QR lends itself to the exploration of new avenues (Marshall & Rossman, 1999), with qualitative researchers being interested in the rich meaning of phenomena.

QR allows us to make sense of patterns and processes (Braun & Clarke, 2013) which fits into the first two research aims of the present study and the epistemological position of 'critical realism'. QR and quantitative research differ in assumptions on what 'the truth' is and whether it is something which can be measured (Newman & Ridenour, 1998). Quantitative research may be looking for the cause of trends, while QR aims for understanding. Beuscher and Grando (2009) stress the importance of qualitative research to explore the viewpoints of people with dementia, who are underrepresented in the literature. QR provides an avenue to allow their voices to be heard.

It is acknowledged that methodology is dependent on epistemology[37]. The different assumptions and aims of qualitative research mean that it cannot be judged by the same quality criteria as quantitative methodology[38].QR does not aim for replication, instead recognising that different researchers may generate different results (Braun & Clarke, 2013). QR does not attempt to view participants as constant stable figures in the way that quantitative methodology needs to, but allows complex aspects of reality to be actively constructed by the researcher (Silverman, 2016).

2.1.1 Longitudinal qualitative research (LQR)

To better understand change and processes over time, LQR can be used. It requires data to be collected at two time-points or more, allowing researchers to study change in relation to context in a non-linear fashion if required (Nevedal, Ayalon, & Briller, 2018).

Whilst LQR can be an incredibly useful way to capture an area of research that cannot easily be met through other methods, it can be challenging. It can be labour-intensive, requiring the dedication from a team of researchers over potentially long periods of time (Thomson & Holland, 2003). Nevedal et al. (2018) highlight that large data sets and complex decisions on when analysis

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[37] For further comments on epistemology, please see extended paper 2.3
[38] For further information on quality criteria for QR please see extended paper 2.8

should occur[39] mean that LQR may be underused; furthermore, they posit that decision-making by researchers is underreported.

Nevedal et al. (2018) reviewed 71 articles and found that the approaches to LQR varied significantly across studies. They suggest that this opens up opportunities for creativity amongst researchers, whilst making recommendations for LQR going forward. To improve the quality of LQR, it is recommended that researchers should include a rationale for decisions made on time-points and duration, the consistency of data collection (to facilitate comparisons), and synchronic vs. diachronic analysis (Nevedal et al. 2018).

2.1.2 Prospective vs. retrospective research

Prospective research aims to better understand a phenomenon by conducting research in real time (Euser, Zoccali, Jager, & Dekker 2009); this is done by collecting present reports on a current situation. This can then be repeated to build up an understanding of what is unfolding in an individual's life. Retrospective research on the other hand involves gaining participants' recollections about a past event (Scott & Alwin, 1998).

In longitudinal research, collecting retrospective accounts may allow researchers to cover a wider time frame and this method of data collection tends to be less expensive and time-consuming. However, difficulties in recalling memories, along with bias in retrospection can impact on the validity of self-report (Scott & Alwin, 1998; Schwarz, 2004). Scott and Alwin (1998) suggest that when possible prospective research should be employed: the ability to collect accurate data as well as reducing the likelihood of bias induced by human memory, means that prospective data collection is considered more reliable and valid. This was employed in the present research - participants were interviewed about contemporaneous experiences at repeated intervals soon after the point of diagnosis and through the early stages after diagnosis.

The salient responses immediately following a dementia diagnosis as outlined by Pratt and Wilkinson (2001), coupled with Vernooij-Dassen, Derksen,

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[39] For further information on qualitative longitudinal analysis please see extended paper 2.7.5

Scheltens, & Moniz-Cook's (2006) suggestion that adjustment occurs in the three months following diagnosis, means that this is an area needing research. Prospective research into those early crucial months was considered apt to capture the 'live' experience of adjustment at this stage.

2.2 Service user involvement

Since 1999, the Department of health and NHS have encouraged researchers to consult with service users on research, to ensure the needs of clients are met and increase the likelihood that findings can be applied to clinical practice (Trivedi & Wykes, 2002).

It is important to consult service users for the right reasons, rather than as a tokenistic gesture to obtain funding (Lemonsky, 2015). Goodare and Lockwood (1999) suggested that service users views are best utilised when researchers value the many benefits of user involvement.

For the present research, feedback was received on initial ideas by service users from the Service User and Carer Advisory Panel (SUCAP). These individuals offer consultative input to the Trent Doctoral training course at two time points during the writing of the research proposal. The study plan was informed by this feedback. In addition, service users that were present on the ethics committee provided feedback on study aims and design. Whilst the majority of this feedback was positive, there were limitations of the study protocol that service users recommended be changed - one particular suggestion was to change the term 'carer' to 'companion' for information sheets as it was considered that the term 'carer' is problematic. This suggestion was invaluable; the change was made and may well have encouraged participation.

2.3 Ontology, epistemology and position

Ontology is concerned with the idea of reality; whether we assume that reality is dependent on human understanding and interpretation, or whether there is something 'real' that exists independent of the human mind (Braun & Clarke, 2013). Epistemology is concerned with all aspects of knowledge; it addresses questions of what there is to 'know', what knowledge is meaningful and what knowledge we can trust (Goldman, 2004; Braun & Clarke, 2013). When

conducting a study, researchers adopt a position through which to answer these questions.

Critical realism, as adopted in the present study, acknowledges the 'two sides of knowledge'; the knowledge that can be seen as a social product, that humans construct (e.g. language, individual perspectives and rules we live by) and the knowledge that would exist regardless of whether humans were able to understand it or not (e.g. the phenomenon of gravity [Bhaskar, 2013]). This position is commonly adopted in qualitative research and can be used alongside a number of approaches, including thematic analysis, used in the current research. Braun and Clarke (2013) put forward that coherence across ontology, epistemology and adopted approach is crucial for good quality research; it would be inaccurate to conclude that there is a right or wrong methodological approach, but different frameworks provide us with different knowledge.

2.4 Participants and recruitment

2.4.1 Identification
An *a priori* decision was made to recruit five-six dyads which would result in at least 10 participants and 20 interviews to be analysed. This decision was based on similar research into qualitative accounts of 'coping' within this population (Clare, 2002; Robinson et al., 2005) in which around 12 participant interviews were conducted; this was considered adequate to develop a sound thematic map. Qualitative researchers concur that for interview data that is to be analysed with thematic analysis, 10-20 interviews allows a researcher to identify any patterns that may be found within the data (Braun & Clarke, 2013).

Time was given to considering the use of saturation, when data is thought to no longer generate new knowledge (Sandelowski, 1995). This method for knowing when the number of participants recruited is 'enough' is often used in Grounded Theory (GT), but lends itself to a more positivist model, as it assumes that there is a 'truthful' account of what exists, if enough people are interviewed (Braun & Clarke, 2013). As this was not fully in keeping with the present position, saturation was not employed.

Purposive sampling, by its nature is a non-random sampling technique that is often used in qualitative research. It allows the researcher to define what qualities a participant must have, and involves the deliberate selection of participants that are best placed within the area of interest to answer the research question (Etikan, Musa, & Alkassim, 2016). Limitations of this recruitment method involve potential bias - Etikan et al. (2016) highlight that those recruited will have been available and willing to take part.

Eligible participants were identified from two NHS Trusts. Originally, it was considered reasonable to recruit all dyads from one service that offers specialised input to those with WAD. This was thought to be feasible after consultation with the service and field supervisor. Recruitment from this service was opened in May 2018, but by July, only one dyad had been recruited. A supervision meeting highlighted that a choice had to be made – to continue with the proposed study or to change tack. It was considered appropriate to continue with the present research question and the decision was made to open additional sites from nearby counties. Only one of these additional sites recruited before the target number of dyads was met.

Inclusion criteria
Referrers were given an information sheet (appendix E) to refer to, for eligibility criteria to assist with identification of participants. People with dementia were deemed eligible for inclusion if they:

1. Were under the age of 65.
2. Had received a diagnosis of Dementia within the last three months.
3. Were living with a companion.

Whilst it was understood that a carer could be children, spouses, other family members and friends, in order to explore the homogeneity of experience, it was deemed that a companion living with the PwD was a useful way to narrow down the congruence of data collected for the carer perspective.

4. Had a cohabiting partner willing to take part in the study.

5. Were sufficiently fluent in English to take part in a semi-structured interview.

6. Had capacity to give informed consent

5 and 6 were assessed by the referrer, who used clinical opinion to decide whether potential participants fit this criterion. Capacity was reconsidered at all contact points by the researcher.

Companions were deemed eligible for inclusion if they:

1. Cared for a person with dementia.
2. Lived with person with dementia also taking part in the study.
3. Were sufficiently fluent in English to take part in semi-structured interview.
4. Had capacity to give informed consent.

Exclusion criteria

A person with dementia would be excluded if they:

1. Had a diagnosis of Fronto-Temporal Dementia.

Of the dementia presentations, Alzheimer's Disease (AD) and Vascular Dementia (VD) are the most common amongst people of working-age, making up 50% of the diagnoses of dementia in this population (Young Dementia UK, 2017). Fronto-temporal Dementia (FtD) is less common and presents differently. In addition to the memory problems commonly associated with AD and VD, this less common presentation includes significant changes in speech and personality (Chapman, Marshall-Williams, Strine, Anda, & Moore, 2015). Whilst this could be an interesting topic of research going forward, for the purpose of this study it was considered apt to focus on more analogous presentations, in an attempt to make it easier to identify common processes across participants.

A companion was excluded if they:

1. Had a current diagnosis of Dementia

It was thought that this would add a different element to the perception of process of adjustment, and was not consistent with the aims of the research.

2.4.2. Initial contact

At the point that a service user and their companion were identified as being eligible (including an initial judgment on capacity), a clinician in the service asked whether they would be happy to speak to a researcher and if they consented to having their details passed on. A number of dyads were deemed eligible to take part but declined. A main reason cited was the earliness with which the first interview was to take place. Those who declined reported that the diagnosis was 'too raw' to discuss. All participants recruited completed both first and second interviews.

If a dyad was interested, the clinician provided the relevant Participant Information Sheet (PIS - see appendices A and C - please note that due to changes in General Data Protection Regulation [GDPR], the PIS included in appendices complies with the new regulation). Participants were informed of changes if they had been recruited prior to the change being implemented). The clinician informed the researcher that a dyad may wish to participate. The researcher contacted the dyad and arranged to do an initial visit to provide further information.

If it had been needed, the usual hospital interpreter and translator services were available to assist with discussion of the research, the participant information sheets, and consent forms.

2.4.3 Recruitment

At initial visit, the researcher discussed the information on the PIS. Prior to giving informed consent, the opportunity was given for participants to ask the researcher any questions they may have had and the researcher answered these. Participants were told that their participation was voluntary, and gave consent on the understanding that they were free to withdraw from the study at any time. Although dyads were offered a minimum of 24 hours in which to

consider the information provided before consenting, all dyads provided informed consent during the initial visit.

Early in the progression of the disease, it was expected (after consultation with dementia services) that the person with dementia would have capacity to consent, but this was assessed by the referring clinician during the initial approach, and there were no contra-indicators to suggest that participants lacked capacity throughout the remainder of the research; ongoing consent was confirmed at each interview.

It was decided that if capacity had diminished, then a companion could provide consent by proxy; however, this was not expected and ultimately not necessary.

2.5 Ethical considerations

Favourable ethical approval for this research was obtained from the Health Research Authority (HRA) and National Research Ethics Service (NRES) in Preston, North West.

Research requires that ethical standards be followed to support the aims of knowledge and truth, essential to credible research, and to uphold moral values for human rights (Resnik, 2015). Braun and Clarke (2013) maintain that rather than ethics being a stage to work through in a research project, it should pervade every element of the research process. A way in which it is possible to do this is to follow British Psychological Society (BPS, 2009) ethical guidelines as per below.

2.5.1 Confidentiality

Thinking about the respect of participants, confidentiality means that personal information is protected. The limits of confidentiality were explained to potential participants in the initial appointment (and before each subsequent interview).

The importance of confidentiality is not disputed, though Braun and Clarke (2013) highlight that in qualitative research, promising anonymity can mean that people's individual voices can get lost. In this study, participants agreed to have a pseudonym allocated to them, to protect privacy, but consented to individual quotes to be included in the final write-up.

2.5.2 Ethical considerations in dementia research

Alzheimer Europe (2012) outlines the importance of the involvement of people with dementia in research (in large part to the significant contribution they can make to the literature). However, they detail ethical factors to consider, including considerations for communication. In the early stages of dementia it is accepted that people may have word finding difficulties, take more time to assimilate a question and be susceptible to distraction (Proctor, 2001; Bourgeois, 2002). The researcher endeavoured to be clear and open with people, checking the understanding of questions throughout interviews and at the same time making sure to give people space and time to answer. In addition, the researcher avoided the use of jargon and interviews were conducted in participant's homes to help people feel more comfortable and less susceptible to distraction.

2.5.3 Ethical considerations in qualitative research.

Sanjari, Bahramnezhad, Fomani, Shoghi, and Cheraghi (2014) caution that the nature of qualitative research means that a researcher is personally involved throughout each stage of the study, which can lead to bias. They also highlight that clinician-patient interactions in interviews are at risk of providing some therapeutic intervention for participants. The recognition in qualitative research that different researchers could, and are likely to, construct interpretations of the data differently, also means that findings can be controversial (Braun & Clarke, 2013); it is important that we recognise the inherent power difference in researcher-participant relationships, and that the story a researcher constructs about data may not be the same story a participant would tell. Sanjari et al (2014) stress the importance of reflexivity in qualitative research, to decrease the likelihood of harmful effects from such practice[40].

2.5.4 Data protection and retention

Participants' right to privacy was protected in line with the Data Protection Act 1998 (Legislation.gov.uk, 2019). In the present qualitative research, participants' interviews were recorded. Braun and Clarke (2013) highlight that voices are easier to identify than words written in text, and so it is vital that

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[40] For further consideration of reflexivity and its importance, please see extended paper 2.8.3

these recordings are kept safely and securely. Data from the present study was kept in a password protected file. Records and documents from the study will be retained at the University for at least seven years.

2.6 Data collection

Once dyads were recruited to the study, a first interview with the first author was scheduled. Vernooij-Dassen et al. (2006), suggest that within three months of a diagnosis, the adjustment process has begun. For this reason, the first interview was conducted within three months of receiving a formal diagnosis. Please see appendix J for a participant schedule of events.

2.6.1 Demographic information

Braun and Clarke (2013) stress the importance of collecting demographic information to adequately consider the findings against the sample.

Demographic information included a participant's age and length of relationship with the other member of the dyad - though it was not a requisite of the research that couples should be in a romantic relationship, all were in a heterosexual relationship and had been for a number of years. All participants identified as White British.

2.6.2 Semi-structured interviews

Semi-structured interviews represent a flexible way of interviewing that involves asking open-ended questions prepared ahead of time (Cohen & Crabtree, 2006). Rubin and Rubin (2011) put forward that interviews allow participants to express their individual experiences and conceptual thoughts on a topic that is presented by the researcher. Typically an interview guide is used, but 'guide' is the operative word as participants can choose to talk about the subjects that are important to them, in and around the questions that are presented by the researcher. Interviews were conducted face to face, the 'gold-standard' of collecting interview data (Novick, 2008).

Using semi-structured interviews allowed participants to take as much time as needed to answer; they were free to say as much or as little as they wanted to

each question and could interpret the question asked in whatever way they saw fit. In addition, the interviewer was free to explore other topics that came up.

While it was decided that semi-structured interviews were most appropriate for the current research aims and methodology (particularly the utility of this method of data collection to exploring process, and gaining rich, detailed data for such), there are some limitations. Braun and Clarke (2013) emphasise that semi-structured interviews are time-consuming for researchers and participants, can hamper the discussion of sensitive topics, and the lack of full anonymity can be disconcerting for some. However, the limitations of semi-structured interviews can be why they are so valuable - a skilled researcher can allow people to feel comfortable talking about sensitive issues and can allow access to more vulnerable groups (Braun & Clarke, 2013). In addition, the interactive nature of interviews (aided by an audio recorder) allows more spontaneous responses to be captured (Opdenakker, 2006).

2.6.3 Interviews over time

When considering the interview process at different time-points, Calman, Brunton, and Molassiotis (2013) suggest that questions can be tailored to explicitly reflect on time. In the present research, questions were asked that required participants to reflect on the previous interview including topics that came up, and on the past three months. This meant that process was considered throughout data collection. Calman et al. (2013) maintain that being able to reflect on the past, while also being encouraged to look forwards in an interview means that researchers can move away from strictly linear ideas of time.

2.6.4 Paired vs. individual interviewing

As has been mentioned earlier in this extended paper, with a minority of exceptions (e.g. Hellstrom et al., 2007; Clemerson et al., 2014) the person with dementia's voice is often missing from qualitative dementia research. Merrick, Camic, and O'Shaughnessy (2016) suggest that without understanding the views of those directly living with dementia, it becomes difficult to develop necessary services and interventions.

In Robinson et al.'s (2005) study, which contributed a useful way in which to understand a dyad's adjustment, the person with dementia and their carer were interviewed together. Paired interviewing, which involves interviewing two people together at the same time, has been criticised for use with dyads in which there may be a power difference (Wilson, Onwuegbuzie, & Manning, 2016), if one person within a dyad may dominate (Houssart & Evens, 2011), or if a dyad may have incongruent perspectives (Shelton, Orsulic-Jeras, Whitlatch, & Szabo, 2017). Similarly, responses may not be authentic if a dyad is conscious of presenting a united narrative, and the joint interview can serve to create conflict if something is revealed that was not previously known to the other participant (Wilson et al., 2016). The shared discourse should not be ignored, but at the same time, it is to be expected that the process of adjustment will differ at times between members of the dyad. For this reason, it was decided that participants would be interviewed separately, with ethical factors (discussed previously) considered prior to interviewing participants.

2.6.5 Triangulation

The QoL-AD (Quality of Life in Alzheimer's Disease, [Logsdon, Gibbons, McCurry, & Teri, 1996]) and WEMWBS (Warwick-Edinburgh Mental Well-Being Scale, [Tennant et al., 2007]) were administered prior to each interview to triangulate qualitative data. How people adjust is linked to quality of life and well-being (Sharpe & Curran, 2006) therefore the decision was made to assess these two domains with the assessments below.

QoL-AD – Quality of Life in Alzheimer's Disease scale

This scale measures quality of life against a set of 13 questions including questions on mood, relationships and living situation. The QoL-AD was originally created for use in AD but has been repeatedly used for non-Alzheimer's' dementia populations, with research showing good reliability and validity across these different presentations (Torisson, Stavenow, Minthon, & Londos, 2016).

WEMWBS – Warwick-Edinburgh Mental Well-Being Scale

The WEMWBS measures mental well-being and is appropriate to use in a general population; it has 14 items that are positively worded in order to capture this phenomenon. It is a robust self-report measure that is easy to complete or administer (Clarke et al., 2011). Permission was granted from Warwick University to use this measure in the current research.

Diaries

In between sessions, participants were asked to complete a diary to record reflections. Participants were asked to use these diaries to enhance recall of topics for discussion in second interviews. Johnson and Bytheway (2001) state that diaries provide a dated record of important events in the eye of the participant.

The use of diaries in qualitative research has been criticised as time-consuming (Johnson & Bytheway, 2001). In the proposed study diaries were used to enhance recall rather than as a primary data source; therefore when participants were unable to complete diaries, this was not an exclusion criterion[41].

2.7 Thematic Analysis

Thematic Analysis (TA) defines a way, by which patterns (themes) in data can be recognised, analysed and reported upon (Braun & Clarke, 2006). Joffe (2012) posits that the outcome of TA (namely, the themes arrived at) should describe the most meaningful aspects of the data, in relation to the phenomenon being explored (denoting saliency). TA requires the researcher to be active in identifying and constructing themes, rather than analysis being a passive process by which themes 'emerge' (Braun & Clarke, 2006).

2.7.1 Rationale for TA

There are a number of reasons why TA was chosen as the analytic method for the present research aims. Firstly, TA outlines an extremely flexible method of analysis, not tied to just one method of data collection, epistemological position

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[41] Please see extended paper 3.13 for results from diaries

or approach (Braun & Clarke, 2013). This meant that TA was considered an apt choice for the various choices and positions taken in the present study.

The identification of patterns across the data is important to start to understand the phenomenon being studied; using TA for analysis allows deep and rich accounts of experience to be drawn out (Braun & Clarke, 2013), vital for giving both members of the dyad a voice. This helped to address research aims 1 and 2.

TA is a useful method of analysis for applied research (Braun & Clarke, 2013). As one of the research aims was to identify how the findings from this study could be applied to the improvement of services, TA was deemed a fitting way to examine this and arrive at conclusions that may be helpful clinically.

TA (done correctly and adhering to good quality standards) offers an accessible and transparent way of conducting analysis (Joffe, 2012). A minor point, but one which influenced the choice of TA, is that Braun and Clarke (2006) suggest that TA provides a solid grounding in QR, and should be learned first by researchers wanting to become more proficient in QR and its techniques. As the first author had not previously conducted qualitative research, this, in combination with other aspects of rationale, made it a sensible choice.

Criticisms of TA include suggestions that TA lacks the depth of the more theory driven approaches and guidance for more interpretative analysis, and that a focus on themes means that voices of individuals can be lost (Braun & Clarke, 2013). However, it can be argued that TA, done well and alongside the flexibility it provides, can defy these criticisms.

2.7.2 Consideration of other qualitative analytic approaches

Two other qualitative analysis methods (Interpretative Phenomenological Analysis [IPA] and Grounded Theory [GT]) were reflected on as possible analytic approaches for the present research question.

IPA is interested in understanding the experience of participants, recognising that they are the expert in their own lives (Reid, Flowers & Larkin, 2005). IPA is a complete methodology, outlining research questions, design, and data collection methods as well as providing in-depth guidance on analysis (Braun & Clarke, 2013). A strength of IPA is its clearly defined guidance on how to interpret and its transparency about the effect of the researcher; Reid et al. (2005) reports that an IPA researcher should explicitly enter into a 'subjective and reflective' process, during interpretation.

While the current research was interested in participants' experiences following diagnosis, to understand the processes in which they adjust, IPA was not considered suitable. IPA is inductive in its nature, meaning that the researcher aims to evade prior assumptions and theory (Reid et al., 2005). Given the wealth of literature on adjustment as a process, it was important that an analytic approach allowed recognition of previous theory; a hybrid approach of inductive and deductive methodology was regarded as key[42].

GT involves generating theory from data collected (Heath & Cowley, 2004), making it more applicable than 'grand' theories to local settings (Pidgeon & Henwood, 1997; Braun & Clarke, 2013). Like IPA, GT is a whole methodological approach and can be used across different epistemological positions. While there are many similarities across TA and GT, including the identification of patterns and a similar approach to coding (Braun & Clarke, 2013) GT is bound by a particular theoretical framework and aims to inductively arrive at a theory (Strauss & Corbin, 1998); as previously mentioned it was important to be able to conduct a mixed inductive-deductive analysis in the present study.

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[42] Please see extended paper 2.7.4 for comments on inductive and deductive analysis

GT is deemed complex, demanding and time consuming (Heist, 2012). GT was developed within sociology and so is more appropriate to address questions regarding social context and structure, rather than psychological processes (Braun & Clarke, 2013). In addition, it is noted that rarely do researchers embarking on GT research fully develop a theory, but instead develop a 'lite' version resulting in a process of coding data that is process rather than very similar to TA (Braun & Clarke, 2006). For this reason, it made sense to use TA above GT; it was not a prerequisite of the question that a theory be produced from the data obtained, and TA was considered apt to allow an exploration of a process (which may have resulted in 'lite' theory), without deciding a priori that this was essential.

Tuckman and Harper (2012) suggest that different approaches are better at answering different questions in qualitative research, and while there is no doubt that other analytic approaches may be more nuanced or specific, TA's greatest asset is precisely the flexibility to adapt. TA was considered the best choice to achieve the present research aims.

2.7.3 Description of stages of analysis

Whilst not the only way to conduct a TA (e.g. Boyatzis, 1998; Nowell, Norris, White, & Moules, 2017), an a priori decision was made to follow the six steps as outlined by Braun and Clarke (2006, 2013). Attride-Stirling (2001) stresses the importance of researchers making the steps of analysis clear.

Planning for analysis

Prior to beginning the six stages of TA, the audio recordings had to be transcribed. The first author completed all orthographic transcription using DSS software to playback recordings; headphones and a foot pedal helped to complete the transcription efficiently. Braun and Clarke's (2013) recommendations on how to complete transcription (including anonymising data when transcribing) assisted with this process. In line with Arksey and Knight's (1999) suggestion that transcribers should allow an hour for each 10 minutes of interview data, the first author allowed plenty of time for this.

Familiarisation with the data

Braun and Clarke (2013) stress the importance of a researcher becoming fully immersed in their data to start to notice data that is relevant to research aims. The process of familiarisation with the data began during transcription. As a product of the longitudinal design, first interviews were scanned for seemingly salient points (this included broad topics that came up for individuals, which were spoken about extensively or seemed to elicit emotions in the participant, though it is acknowledged that this was dependent on what was considered salient by the first author), prior to conducting the second interview.

When all data had been collected, re-listening to audio recordings, coupled with reading through the transcripts a number of times, provided a chance to notice further points of interest.

It was reflected on that even though these initial thoughts may well inform what codes may be noted later, the thoughts are not based in 'systematic engagement'. Braun and Clarke (2013) highlight that initial thoughts may simply be the most obvious points, or the areas which mean something to the researcher personally.

Generating codes

Complete coding involves identifying anything in the data that may be relevant to answering the research question (Braun & Clarke, 2013). In the present study this involved creating a template table (please see appendix K) by which anonymised transcripts could be transferred to. The first author went through the data manually and wrote a short phrase (code) that 'summed up' that particular point of interest. Discussion in supervision allowed a checking of these codes and the second author commented on how codes could be made more succinct, or clear; in particular, it was suggested that codes should be able to be read and understood, independent of the data from which codes were derived. Examples of initial coding for the person with dementia and companion are presented in appendix L and M. This was done carefully, with regular supervisions booked to subjectively check the validity of these codes. Coding was the most time-consuming part of analysis, to ensure that subsequent analysis was as well-founded as possible.

<u>Semantic and latent level analysis</u>
Coding was completed at a semantic, or participant-generated, level so that the individual voices of the participants interviewed could be reflected. It was also deemed imperative to code data at a latent level to allow interpretations of the researcher to be captured, in attempt to tackle the complexity of adjustment.

Looking for themes
When looking for themes, Braun and Clarke (2013) suggest that alongside looking for those ideas that reappear in much of the data, researchers should look for salient aspects of the data - those which reflect meaningful elements.

In the present research, codes were collated and organised into broader features that reflected the codes. For example the codes 'life carries on as normal' and 'importance in doing things the same way I always have' were grouped under the title 'maintaining normality'. See appendix N for a photograph of codes being grouped conceptually. Once codes had been grouped, the raw data from codes was collated and areas of overlap identified. At this point, in line with recommendations from Braun and Clarke (2013), it was helpful to see if there were themes or concepts that a number of codes/features related to (termed a 'central concept' by Braun & Clarke [2006]). This led to candidate themes (please see appendix O for an extract of candidate themes showing selected codes).

The process written above was a useful way to collate frequent patterns that were recurring in the data.

Reviewing themes
To arrive at the themes settled on for the present study, a number of visual thematic maps were put together during the process to check how themes related to each other and the research question.

To check that themes are telling a story that is faithful to the data, collated data and codes were reviewed, and the whole dataset was re-read, to check that the themes 'worked' (Braun & Clarke, 2013).

At this stage, research supervisors were consulted, which allowed a chance for themes to be scrutinised. While there are not necessarily 'true' themes to be found within data, and it is recognised that different researchers could arrive at very different themes (in line with the active process of the researcher), others should be able to see how themes could feasibly have been arrived at. Research supervisors agreed with the themes that had been constructed.

Defining themes
As per recommendations from Braun and Clarke (2013), definitions were put together to ensure that themes were clear, and to characterise the boundaries of each. When naming themes, titles were used that should allow readers to get a sense of the focus of a theme, prior to reading the extracted data. Semantic level themes were much easier to name. The more latent theme of 'forming narrative' took some time to arrive at, to allow a title that would sum up the complexity of the theme and the phenomenon observed in the data.

Writing the report
At this point, analysis could be written up. The analysis continues during the production of the report, in how themes were presented and in what data was chosen to demonstrate and do justice to themes. To effectively address the aims of the present research, within the write up of themes, instances of how data 'fit' the themes was presented for people with dementia and companions within the same section. This allowed processes that were agreed upon to be presented as well as comments on areas of difference. Exceptions were also included in the write up to demonstrate individual experience - how patterns do not reflect all aspects of reality.

2.7.4 Inductive vs. deductive analysis
Inductive research sets out to generate a new way to view the data collected, whereas deductive research aims to see how applicable current theory is to explain the phenomena that are being observed (Thomas, 2006). At the same time as gathering new perspectives on what the process of adjustment may be for people after a diagnosis of dementia, it is important to recognise that research has been done into different models of adjustment that may be relevant (e.g. Lazarus & Folkman, 1984, used to inform the interview guide). TA

allows data to be analysed using a mixed inductive-deductive method (Fereday & Muir-Cochrane, 2006), and this hybrid approach was deemed to best 'fit' the epistemological position of critical realism. For this reason, this approach was employed to analyse data.

An *a priori* decision was made to follow the inductive analysis with a deductive sweep of the data. Deductive analysis involves being led by existing theory to see how it may apply to the raw data (Hyde, 2000).

Rather than carrying out 'complete coding', where anything relevant to the research question is identified and coded (as accomplished during the inductive analysis mentioned above and within the journal paper), selective coding (as outlined by Braun & Clarke [2013]) was completed for the deductive sweep, systematically searching for occurrences of the different phenomena outlined in Lazarus and Folkman's (1984) model.

This deductive sweep was included to consider the applicability of the Lazarus and Folkman (1984) model on the data collected[43]. As this was not a specific aim of the research, it was decided that the first author would qualitatively comment on the appearance of aspects of Lazarus and Folkman's (1984) model, rather than requiring themes to be developed from this analysis.

2.7.5 Qualitative longitudinal analysis

Nevedal et al. (2018) outlined considerations for researchers when tackling qualitative longitudinal analysis (QLA). They maintain that diachronic (or trajectory) analysis (as used in the present study) is useful for exploring individual or small group processes, as opposed to synchronic analysis which analyses data after each wave of data collection. Synchronic analysis assumes a change after each wave; as there was not sufficient evidence to suggest that major changes would be found between time-points, this approach was not deemed appropriate. In addition, Calman et al. (2013) suggest that synchronic

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[43] Please see extended paper 3.9 for deductive findings

analysis often results in a descriptive account of a particular time-point, rather than examining processes of change[44].

2.7.6 Analysis of outcome measures

In order to analyse data collected from outcome measures (QoL-AD and WEBWMS), questionnaires were scored according to individual standardised measure guidelines. This gave a score on which to compare results from outcome measures against individual interviews. The first author interpreted whether the results obtained from measures reflected the qualitative perspectives gathered. This was subjective and results are detailed in extended paper results[45].

2.8 Quality of qualitative research

Mays and Pope (2000) suggest that the terms used to assess the quality of quantitative research (e.g. validity and reliability) can apply to qualitative research, but that the terms needs to be defined differently.

2.8.1 Trustworthiness of qualitative research

In order to check the trustworthiness of qualitative research, Guba (1981) suggested that credibility (how reflective of 'reality' something is) and dependability (how the researcher demonstrates the changing nature of the research) map on to the constructs of validity (how sound your research is) and reliability (how repeatable a study is), but are more appropriate for qualitative research.

Credibility

Shenton (2004) suggests that triangulation (using more than one method of data collection or using different informants), peer scrutiny and reflective commentary are ways to ensure the credibility of data.

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[44] Please see extended paper 3.10 for findings on differences between time-points
[45] Please see extended paper 3.12 for outcome measure findings

Triangulation was employed by using different methods of data collection (semi-structured interview, diaries, outcome measures and different informants [PwD and carers]).

There were a variety of opportunities for peer scrutiny – proposal panels and supervisor meetings being forums utilised. Different perspectives helped to refine and change elements of the study to further ensure credibility.

A final way the first author attempted to ensure credibility was through a reflective diary. It was important to reflect on the subjective bias that was potentially being brought to the research throughout data collection.

Dependability
Whilst it may not be possible to replicate the findings of qualitative research (due to the changing nature of data), it should still be possible for a researcher to repeat the work done. Shenton (2004) posits that a way to do this includes the researcher providing a detailed explanation of methods. A detailed explanation of what was done has been included in this extended paper.

In addition, the reflective diary and research supervision logs were used to track any changes that were made, as well as detailing any decisions that lead to changes in the aims, method and data analysis.

2.8.2 CASP checklist
The CASP qualitative checklist provides a way to assess the quality of a research paper - how trustworthy it is, and how relevant the results are (CASP, 2018). Each question on the checklist was considered to assess the present research in the way an outside researcher might. The majority of considerations have already been included in the extended paper, with the exception of reflexivity, detailed below.

2.8.3 Reflexivity

Braun and Clarke (2013) define reflexivity as a 'critical reflection on the research', in which one's own influence, as researcher, on the process of the research is made apparent. Mills, Durepos, and Wiebe (2010) suggest that by

reflecting on a researchers own assumptions makes this more explicit; this transparency allows researchers and readers of the qualitative study to determine how valid results might be. However, Finlay (2002) points out that reflexivity is difficult for a researcher to engage in and can be presented in an ambiguous manner. Braun and Clarke (2013) concur that reflexivity has to be handled carefully, suggesting that some researchers can make their own reflection the research focus, creating difficulty in reporting results. However, Finlay (2002) suggests that despite criticism, reflexivity can be a valuable tool for the qualitative researcher.

Mills et al. (2010) suggest that researchers should declare their stance, so that the reader may take this into consideration. This is given in the journal paper, but in addition, the first author worked with a number of people with WAD in jobs held prior to doctoral training; anecdotal reports suggested different experiences to older adults, which meant that prior to starting the research the first author had assumed that adjustment would look different in this population. This reflection was used to inform interview schedules and an explicit decision was made to not to ask about the WAD experience specifically, until the end of data collection, so that interviews were not unduly influenced with these assumptions.

Lincoln and Guba (1985) put forward the idea of a reflexive diary as a way to track decisions made as well as personal thoughts, values and preconceptions that may alter the path of the research. A reflexive journal was kept by the first researcher for the full course of the study. Entries that seemed worthy of further discussion, were taken to supervision to check possible impact on the research[46].

3. Extended Results

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[46] Please see extended paper 4.9 for examples from the reflexive diary

The extended results will begin with extended comments on previously discussed themes. This will be followed by a presentation of findings from deductive analysis and a consideration of process across the two time-points.

In addition, supplementary themes not previously reported on (that were found to frame and moderate the themes established in the journal paper) and results from quantitative outcome measures will be presented.

3.1 Extended comments on 'disconnecting'

Throughout both interviews participants considered reasons for disconnecting and offered ways of understanding the severance that was taking place. For the person with dementia, reasons for disconnecting centred on other people's ability to understand the dementia experience.

> *"I don't want to be nasty about it, but she's, she's not fully understood I think, what it's like…". (Nicholas, PwD)*

> *"people kinda look at you different and can't understand if you know what I mean… some people won't talk about it cos they don't know what to say, they feel uncomfortable themselves". (Finlay, PwD)*

Nicholas feeling it necessary to say that he did not want to be 'nasty' suggests that his wife's lack of understanding is causing him difficulty, while Finlay highlights the unwillingness of others to talk about the diagnosis: Both extracts demonstrate great insight and empathy about how others' ability to understand could lead the PwD to feel alone in their experience.

For companions, reflections centred on the effect of the dementia symptoms.

> *"I don't know what makes a relationship but it's not just about the physical presence of somebody, it's about the memories, it's about talking about things…there's a lot of things that go into a relationship like that" (Rufus, companion)*

> *"when it was my birthday I had to go and buy my own birthday present, and I've never ever done that…I've even wrote it on a piece of paper and*

given it him to put in his pad, but he still didn't…It's silly little things like
that...it really winds me up!" (Anne, companion)

Rufus's account demonstrates that even though his wife is still physically
present, dementia has removed something from the core of their relationship;
this quote is characterised by loss. Anne's quote shows a significant change in
her and Finlay's relationship. Although Anne minimises the impact that Finlay
forgetting to buy her a birthday present has, this change in the narrative of the
relationship is emotionally impactful and leads to feelings of frustration.

The disconnection is felt by families.

"we sometimes go out with the kids for a meal or whatever…and we're all
enjoying ourselves but Nella might be a bit detached from it and she's not
really keeping up with the conversation…it's not the same as it was…"
(Rufus, companion)

"conversations that he actually takes part in… even when as a family
we're round the table, whether it's his concentration, whether he's finding
it difficult to process what he's heard, he's not keeping up." (Florence,
companion)

These extracts demonstrate how amidst typical family situations there is a
change in the previously expected behaviour of the person with dementia and
awareness that they are somehow not part of the shared experience.

3.2 Extended comments on 'seeking connection'
Across all interviews, the majority of participants reported that they are open
with others about the diagnosis they have received (for themselves or on behalf
of their partner).

"I think it's better that people know and can understand" (Nicholas, PwD)

"I tend to be up front with people…I say in front of Alistair, 'Alistair's got
Alzheimer's Disease' and he knows that I say that, or he'll even say it
himself, you know…and that he can't do this or that, so we're very up

front about it…and Alistair's more comfortable then…well he seems more
comfortable" (Isobelle, companion)

The accounts above suggest that being open with others leads to feeling more comfortable around others. For Nicholas this leads to increased understanding for those around him, while Isobelle's quote suggests that she is open with others to allow Alistair to feel more comfortable. However, she followed this comment with 'you know I don't think 'oh my god he's telling them over and over again!' This suggests that being open with others serves to avoid feelings of awkwardness and embarrassment for Alistair *and* Isobelle, possibly in anticipation of, and to protect against, other people rejecting both members of the dyad.

Participants referred to the ways that sharing a diagnosis meant that their local community assembled.

"It's been really good with people who live round us as well, how they've
all said to us, if you need anything or need to go anywhere or…you
know." (Anne, companion)

"I know that people kind of rally round and pray for me and everything
so…I think I will, I'll be fine" (Nella, PwD)

In this case it seems that while receiving a diagnosis may serve to create emotional distance, sharing a diagnosis can serve to create or strengthen other relationships, which is described as positive by participants.

For one companion, the anticipation about how others might react led to a decision *not* to share the diagnosis with others.

"We didn't discuss it any further with anybody else…it's not easy to
accept is it?" (Florence, companion)

Florence may be a describing a way in which she manages her own difficulty with accepting the diagnosis. However, in particular, she wanted to protect her husband's mother from the news. Despite understanding that it may lead to a

rupture in her relationship with her mother-in-law, her empathy meant that she chose the rupture over the alternative:

> *"the boys both said 'well you must, because it's going to affect your relationship with her', but I don't think they could see it from the point of view of a mother." (Florence, companion)*

Florence was unique amongst companions in not sharing the diagnosis with others, however, this finding was still considered fitting for the theme of 'connectedness' and was considered salient to the process that families of people with WAD may experience. In older adults it is not expected that companions would be put into a position in which they had to share a diagnosis of dementia with a parent-in-law.

3.3. Extended comments on 'noticing change'

While an awareness of change is discussed within the journal paper, participants with dementia spoke further about the experiences that led them to realising that change. Common amongst participants with dementia was an awareness of the constraints their symptoms were placing on ability and becoming conscious of change after making mistakes.

> *"I knew that something was wrong with me... I was going to get the sack because I couldn't do my job properly, so that was horrible" (Nella, PwD)*

> *"I might say something and she'll just look at me as if to say 'I don't believe ya'…I don't like the feeling, I don't like the feeling at all...if anybody ever makes a judgement by sight, she does it" (Finlay, PwD)*

Nella's experience at work suggests that process of noticing change begins before a diagnosis of dementia. Finlay described picking up on non-verbal cues and perceived judgement from others. Both of these accounts embody shame.

Data suggests that these negative feelings are often turned onto the self, for not being able to do the things one always could.

"I know I should be able to do these things, like water off a duck's back…I mean I went to university to…and did physics and I'm struggling thinking which wires are going to go into this system with only two or three wires in it...so I'm acutely aware that, unless it's really straight forward I can't do that anymore." (Nicholas, PwD)

The journal paper pointed out that companions had gone through a process of noticing their transition to carer and having to hold increasing responsibility. In response to noticing this change, all companions shared a discourse about this new role being unwanted, and yet their responsibility to bear.

"sometimes I think 'oh, what if I have to start doing this for him, and that for him?' I really don't want to be the person who has to …and eventually I will…but I really don't want to be the person who has to do that...but…when you sign up for relationships with people, you sign up for better or for worse" (Rhonda, companion)

Rhonda suggests that the role of carer should be assumed, due to values of what a relationship should be and what is expected. Also included in this quote is a sense of certainty that although a companion may not want to become a carer that they will be able to adjust to this, a sentiment all companion participants shared.

3.4 Extended comments on 'navigating levels of dependence'
Throughout the data, the participant with dementia reports depending mainly on their companion, rather than on others outside of this relationship. Companions on the other hand not only spoke of dependence on services and tools such as the internet, they also spoke about dependence on members of their family for assistance.

"if I don't talk to the girls I'm texting them ...to keep them in the loop you know...cos if anything happens to me, they're going to want to know what they're dealing with, so at least this way they know what's going on." (Anne, companion)

> *"she's (nurse) managed to come at lunchtimes when he (son) can be home, and he's sat here and he's written notes bless him, for me, so I know what's been said" (Florence, companion)*

Both quotes demonstrate an increasing dependence on children to support with the caring role. Due to the age of participants, these children were in their 20's either having just left, or still living at home. This represented a change in dynamic between parent and child.

Not all companions choose, or are able, to lean on others.

> *"…the best way for me to cope with it is to…sort problems out in my own head, without having to chat to anyone about it…"(Rufus, companion)*

Rufus's knowledge of his own strategies reflects an approach to adjustment that may depend on an individual's coping style.

When asked specifically if she had any assistance with her caring role, Rhonda responded:

> *"No! That's my role in life I'm afraid...my son would be supportive but he's not well at all...and my stepfather has also got dementia..."*

She reports on the different difficulties and physical health needs that others have, which means that she navigates the new role without help.

3.5 Extended comments on 'finding ways'

In the journal paper, it was reported that participants with dementia spoke about attempts to keep their brain active, in an attempt to help with symptoms of dementia and take some control of their health. However, participants with dementia also spoke about keeping physically and mentally active to maintain a sense of identity and relax.

> *"I want to go back to swimming and perhaps doing a keep fit class and that…" (Nella, PwD)*

"I like to sit back and…have a look at…the television or read my books on horses you know, cos I like horse racing." (Albert, PwD)

Albert spoke about his love of horse racing when describing the ways he relaxed while Nella spoke about hobbies that had been important to her prior to receiving a diagnosis.

In the journal paper, the actions that companions took to learn their new role were discussed, but there was a general discourse that seemed to precede the ways they eventually 'cared'. Companions acknowledged that they did not know how to approach the role:

"Is there steps…that would be a practical thing that if you do this, this and this, it's going to calm the situation down…or just walk away from? I don't know what the answer is..." (Rufus, companion)

These comments reflect a period in which the companion feels overwhelmed by the enormity of caring. At that time, they are unsure how to proceed, but eventually ways are learned. Florence demonstrates the active process by which she struggled with this:

"I find myself saying 'we've always done this! Why aren't you doing it like this?' well I suppose if he could, he would! Wouldn't he? So I shouldn't keep saying that to him, but it's hard not to…" (Florence, companion)

 This quote captures an underlying feature of this theme, that caring is hard.

A common pattern within companion interviews was one of pragmatism. They described the necessity of maintaining their own health and practising self-care, to be able to be a carer to the best of their ability.

"If I'm tired and in pain and I'm irritable, that doesn't help Albert...there's always an outlet…I disappear into the kitchen… and chop vegetables and just cook! I know he's safe and I'm with him, but it's just…I can go into there and it's my own little capsule" (Rhonda, companion)

Companions recognised that while they want to keep themselves as well as possible, to fulfil their role and responsibility, the gravity of the situation is still there. And that again, it is hard.

> *"I do feel… just a little bit angry about the way things have worked out…I just think that…I'm not really doing anything I could do to stay well…"*
> *(Rufus, companion)*

3.6 Extended comments on 'reflecting back'

Participants with dementia spent a large portion of interviews talking about, with hindsight, what they perceived was the start of their dementia journey. This happened with all participants with dementia, despite not being asked specifically about this moment.

> *"when it first happened with me…I'd…I finished late the night before, started early ...coming back I thought I was just tired, that I'd nodded off or something, because sometimes you do feel tired… can't do anything, boredom sets in so you just nod off…but...that's when I had the blackout…and that's where I really couldn't understand where I was, what I was doing and that's when it all started" (Alistair, PwD)*

For a length of time prior to diagnosis, Alistair described not being able to understand the blackouts he was having. He had become convinced that they were the result of the inactivity that was part and parcel of the work he was doing. Receiving a diagnosis helped him to understand this, but he (along with others) spent a large amount of time wanting to discuss the story he could now make some sense of.

For both members of a dyad, diagnosis meant that the start of the dementia journey could be reflected on. Companions shared a discourse about suspecting dementia, long before doctors formally diagnosed their loved one.

> *"before we got that result we'd gone to Alistair's doctor a few times, and we hadn't got the lumbar puncture result back at the time... the results had come back and our doctor, he was saying 'it looks like you've got*

Alzheimer's' and he was more upset than we were, because we'd expected it. (Isobelle, companion)

Isobelle highlights a common narrative amongst all companions - that the dyad was reliant on doctors for a diagnosis they had already anticipated.

Another way, in which participants with dementia reflected back, was with regard to previous experiences of aging parents. Receiving a diagnosis prompted searching for a point of recognition and comparison, to make sense of the experience that was happening for them.

"I suppose, thinking back now, not how it was at the time and everything else…I think my mum went a bit like how I went..." (Finlay, PwD)

Rufus's experience of his mum having had AD meant that he was drawing comparisons between his mum and his wife. He commented:

"I keep going back to mum and dad, cos it's just…it's the perfect reflection, it's life reliving itself". (Rufus, companion)

3.7 Extended comments on 'looking forward'

When looking forward, people with dementia tended to express hopes, rather than making concrete plans in response to a possible future 'issue'; often reflecting back informed what that meant for them moving forward. An example of this comes from Finlay (PwD). He uses a reflection on his experience of caring for his mother and father, to inform what he would like to be different for him and his wife.

"I keep saying to Anne, it's me and Anne's time now, and I always think of her mum and dad, and my mum and dad, they didn't have that at the end of their lives, you know what I mean? And I want that to happen" Finlay (PwD).

Unfortunately, these hopes do not always coincide with that of the companion, who can more easily anticipate the obstacles to overcome. Finlay's partner, Anne, questions the reality of what his expectations are.

> *"his favourite saying was when his mum died…they wanted to do early retirement, spend time together, unfortunately they didn't do it and he always said that's what we're going to do…but that's kind of now…is that going to happen? What kind of retirement are we going to get, because of how he is sort of thing really. He's still young, he's only 61! You know... and I would like to think at least another 10/15 years together doing things but…that's how he is and everything, it's not going to happen so much you know." (Anne, companion)*

The passage above highlights the different expectations that somebody in their 60's may have about their future and how the diagnosis of dementia has put a stop to previous plans. It also brings to light differing narratives for the future from each member of a dyad.

3.8 Extended comments on 'surviving the present'

In addition to companions expressing that they oscillate between looking forward and returning to the present, the following quote from Rufus suggests an awareness of the importance of remaining in the present for both themselves and the person with dementia.

> *"She enjoys the moment...I'll enjoy the moment as well because I'll see her enjoy the moment" (Rufus, companion)*

This sums up how entwined the wellbeing of one member of the dyad is on the other. Wellbeing and feeling that things were 'ok' seemed to be reliant on participants' ability to return to the present and continue with activities that would have been done prior to receiving a diagnosis.

> *"but…I think, kind of my everyday thing is ok…I can remember how to cook and can do things and…everything like that…and I do drive…and…I go to see my sister and my dad and…you know, I get out a bit." (Nella, PwD)*

As highlighted in the journal paper, a way that participants demonstrated surviving the present was by the use of phrases that 'accepted' the situation. While this could be considered as minimising the enormity of a situation, it can also be argued that this is essential for coping and being able to tolerate an experience.

> *"you know we've all got good things and bad things but that's how life is now" (Finlay, PwD)*

> *"I've just, accepted to myself, you know, that…'oh this is how it's going to be" (Albert, PwD)*

> *"I think you just have to accept it. It's frustrating at first...you just have to get on with it, you know" (Isobelle, companion)*

3.9 Deductive findings

The deductive sweep, extracting data which would fit in with Lazarus and Folkman's (1984) model, revealed some support for the constructs within.

The majority of companions described initial thoughts centring on finally being listened to by services, having been through a number of years where they had been left waiting on events to get worse before their suspicions were formally confirmed. This led to relief for some:

> *"what I was thinking all along was real". (Isobelle, companion)*

> *"somebody's actually listening to what I'm saying" (Anne, companion)*

For others, this led to a negative experience of receiving the diagnosis and indignation towards services.

> *'to me the experience wasn't particularly good' (Rufus, companion)*

There was one companion who did not describe initial thoughts as being related to the length of process or confirmation of suspicions. Instead, Florence's initial thought was one of loss, and is characterised by sadness.

> *"I'm going to lose him." (Florence, companion)*

For the participant with dementia, initial thoughts were more varied. For two participants, they experienced diagnosis as expected.

> *"I knew that something was wrong with me". (Nella, PwD)*

However, for others, the diagnosis was experienced as a surprise and unreal.

> *"it didn't really sink in, I've always known it as an older age..." (Alistair, PwD)*

> *"I was a bit shocked…really…you know I haven't come across anything like that before' (Albert, PwD).*

Initial appraisals about diagnosis that could be understood as more 'negative' (for example, shock and loss) seemed to be followed by examples of emotion-focussed coping. Within participants with dementia, there was a pattern of trying to avoid thinking about the diagnosis.

> *"I've sort of had to…try and push it out of my mind" (Nicholas, PwD)*

> *"I try and block it out…and, I suppose, try and suppress it" (Alistair, PwD)*

For Florence, a companion whose initial thoughts were described as being that of loss, she described distraction (another emotion-focussed coping strategy) as a way to manage those thoughts and subsequent feelings.

> *"I suppose busying myself really…being at work…I think it's almost like…it's not that I don't face up to it…it's a distraction isn't it?" (Florence, companion)*

For companions whose initial thoughts tended towards the relief at being listened to, and for whom diagnosis acted as confirmatory, the immediate coping identified was that of 'problem-focussed' strategies.

> *"I'm not bitter about it, it's happened, I've got to deal with it, I will deal with it" (Rufus, PwD)*

> *"It's just kept me on me toes really...and there's been lots of forms to fill in for PIP and the legal power of attorney - we've got the financial one done." (Isobelle, companion)*

Rufus and Isobelle describe a pragmatic and forward focused response to the diagnosis.

For the PwD too, problem-focussed strategies were described when initial thoughts were that of relief or when a diagnosis was more expected. Finlay explained wanting to put steps in place to help him and his family, and how a conversation with his wife was necessary:

> *"we'll talk about how, what we're going to do". (Finlay, PwD)*

Nella described the steps she had already taken since receiving a diagnosis, but highlights that these problem-focussed strategies require a certain amount of vigour.

> *"I've done everything that I can do…to keep my driving license and things like that, but I've still got to ring the people up...you've got to be…I don't know, a bit robust, to do the things that you need to sort out" (Nella, PwD)*

Reappraisals of whether participants believed they could cope or not, were not asked about explicitly. However, iterations of this reappraisal were found within the literature. Differing appraisals are displayed by Rhonda who commented in first interview:

> *"at first I began to feel, oh my god, what am I going to do now?" (Rhonda, companion)*

At a later point in the same interview she stated:

> *"whatever happens…I'll get used to it and I'll do it because that's what I'm here for". (Rhonda, companion)*

Here Rhonda displays a secondary appraisal that this is going to be a challenge she will be able to cope with. Finlay also shows differing appraisals within the second interview. He reflects back on his initial thoughts

> *"it was a bit of a shock, although I know I wasn't right...now I feel a bit more comfortable with it, and I feel because of that I've been better up here (pointed to head)". (Finlay, PwD)*

These quotes suggest differing appraisals at different times. The secondary responses are typified by determination and a sense of better mental well-being.

3.10 Differences between time-points

Due to the nature of diachronic analysis, differences between time point one and two were not specifically looked at. However, in the data that was collated, there were some differences at time points that are worth commenting on.

Throughout second interview the ways people approached 'coping' was comparable to first interview. Albert, who had employed emotion-focussed coping in first interview, reported utilising similar strategies later on.

> *"I just switch off…mm, I just go into my own world…and I can have things going off around me, but it's not registering…I don't know if it's helpful, it's just what I tend to do…my own mechanism." (Albert, PwD)*

Anne's problem-focussed response to her husband's diagnosis was evident in second interview, but she acknowledged that the active nature of problem solving was taking a toll. In response to attempts to help her husband she said:

> *"I kind of suggest things and I'm listening all the time…I must admit, it probably is getting tiring if you like..." (Anne, companion)*

For some however, responses and coping strategies had changed between interviews. Finlay's (PwD) problem focussed plans outlined at first interview, were replaced by repeated comments of acceptance, without detailing problems at second interview.

> "I feel quite content…well not content, that's probably not the right word, but you know…I'm at ease with it now. I always have a laugh and say to Anne 'don't tell me ote, I'll forget!' you know what I mean and things like that, it breaks the ice!"

This could be seen as evidence of a shift to emotion-focussed coping (e.g. use of humour and acceptance) but is successful for Finlay to feel well - it was commented upon earlier that Finlay was feeling mentally more well at second interview.

Florence (companion) who had reported emotion-focussed coping of distraction and avoidance at first interview, demonstrated in the second interview how her responses had become more problem-oriented:

> "I've sorted out all the things he used to do, like the car insurances and so on... and then we've been doing Power of Attorney…we've been sorting that out…" (Florence, companion)

More nuanced examples of change over time were noted in the data. Anne describes a change in how much she wants to share with her daughters, regarding the diagnosis of their father. At second interview she commented:

> "I want the girls to know everything, I don't want them to be left out of it". (Anne, companion)

This differs from what Anne reported in first interview, about wanting to keep difficulties between her and Finlay in the house.

> "they're (daughters) both pretty good really, but more often than not, it's just kept in the house." (Anne, companion)

This could be seen as evidence of a shift to 'leaning on others' as described within the overarching theme 'negotiating roles'.

Rufus's (companion) experience displays a change over time as to the benefit he thought he would get from attending groups. At first interview he had said:

"I'm not a great one for group therapy and group situations, so to me, it was white noise…I'm not going to go to groups and sit round and crochet and things…" (Rufus, companion)

Whereas at second interview, having been to a group he commented:

"I thought it might be a bit 'woe is me' and a bit…everybody could bring each other down…in fact they were very positive...on the balance it's a good thing, it's a service that…I think is worthwhile doing". (Rufus, companion)

This could be seen as evidence of a process of moving through to 'seeking connection' as described in the overarching theme 'connectedness'.

3.11 Extended themes

Extended themes captured features of individuals' experiences that, while considered important as part of participants narratives of adjusting, did not directly address the research aims. These themes are 'Tolerating (or not) Uncertainty', and 'Being of Working-Age'. They were considered to frame and moderate the process of adjustment described throughout this paper[47].

3.11.1 Tolerating (or not) uncertainty

All companions commented on varying levels of security that characterise a diagnosis of dementia. For one companion, a diagnosis of dementia led to some certainty. Rhonda said 'now that we know what's happening, we can plan for the future…now we know that sort of…what we're up against.' This led her to plan positive activities for her and Albert.

> *"there's no way we're going to sort of give in and say 'oh dear, that's it now the future's sorted' - that's not going to happen…we've planned*

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[47] Please see appendix P for extended thematic map

> *holidays, we're going to see the northern lights…we've booked an awful*
> *lot of things" (Rhonda, companion)*

For the majority of companions however, an uncertain timeline and insecurity seemed to characterise a dementia diagnosis.

> *"...we have absolutely no idea of the timescale of this you know'. (Rufus,*
> *companion)*

This lack of clarity over a 'typical' course for dementia meant that while companions were aware of the types of changes that might happen, the pace of this was left unknown.

> *"I understand that there's going to be a lot of changes, down the line...not*
> *sure how fast it's going to happen, or what pace it'll be". (Isobelle,*
> *companion)*

This meant that companions, when wanting to plan for the future, were unable to fully commit to a plan or feel more in control of their developing story (suggesting a link with 'forming narrative). Florence demonstrates this in the following quote and questions whether an element of uncertainty can be beneficial.

"The other thing that concerns me though, is will he suddenly deteriorate, or
how long can we carry on like this...part of me thinks, do I want to know the
timescale or not?" (Florence, companion)

For some participants with dementia, the feature of uncertainty was accompanied by feelings of fear.

> *" we don't know how long it's going to be or anything. We can't…how*
> *long's a piece of string? I don't know, but…it's the fear of the unknown,*
> *isn't it?" (Finlay, PwD)*

Finlay is experiencing ambivalence about the best way to manage these feelings, alternating between wanting to find out more and avoiding finding out more:

"I keep asking myself and I should probably talk to somebody moving forward, is what happens moving forward, in general terms so I can kind of prepare myself or whatever" (Finlay, PwD)

"No, I wouldn't, I wouldn't do that (look on the internet), might frighten my brains out and I'd rather not know" (Finlay, PwD)

For other participants with dementia, it was *knowing* what the course of dementia was that led to feelings of fear.

"I'm not looking forward to what's going to happen…because the problem is that we do know what happens…because both of our mums had it". (Nella, PwD)

Due to her experience with her mother, Nella questions whether there is a benefit to not knowing a diagnosis at all. After years of being misdiagnosed, she commented:

"I suppose as well, looking at it, that not really knowing was good, in a way, because I just got on with my life." (Nella, PwD)

Rufus (companion), having had the same experience as Nella, in caring for their mothers commented:

"my mum had Alzheimer's for 18 years and I saw her go from being my mum to a husk over a period, a long period of time" (Rufus, companion)

Knowing the course of dementia in this case means that the appraisal of the future for Rufus is bleak

> *"I only see Alzheimer's as something that, I know I've got to deal with but it's only bad. I don't see any upside to it; I don't see the future being anything but pain really." (Rufus, companion)*

The theme of uncertainty was also apparent in the *needs* of participants; an uncertain future leads to uncertain needs. Alistair sums this up in the following quote:

> *"I don't really know what I'm likely to need...because I've never really been in this sort of position!" (Alistair, PwD)*

This leads to an ambiguity about when services may be required or desired.

> *'I've never really been in this sort of position... I don't feel that I feel ready at the moment to actually say 'so what's going to happen? Take me through...the deterioration and what we're going to need to do'. Cos everyone's going to be different anyway aren't they? Are we better, as I've said, living for today and not worrying about that and just accessing that when we need it…rather than depressing ourselves at this point?' (Florence, companion).*

3.11.2 Being of Working Age

Being of working age permeated all themes, with nuanced examples of this featured within the journal paper. Further examples of how this appeared throughout the overarching themes are given below.

Within the overarching theme 'connectedness', participants with dementia reported the difficulty with feeling like they are alone in their experience, and how support groups can help to remove these feelings of loneliness. However, some participants reported how services are not equipped for people being of working-age. Alistair reported walking in to a dementia centre early after diagnosis:

> *"...they was in the 80's and 90's that was in there" (Alistair, PwD)*

Anne describes the limitation of groups that require partners to attend along with the PwD, due to the likelihood of partners still working full-time. She stated:

"As we understood it, he'd probably be with people like himself, but when we got there they was in pairs, it was the partner as well as the person that was suffering...if we went down that line, he's going to be there on his own, I'm not going to be there". (Anne, companion)

Anne went on to describe that due to her full-time job, this was not something Finlay could access for the foreseeable future.

Within the overarching theme 'negotiating roles', difficulties with obtaining pensions early, or accessing the funds necessary to attempt to live well impacted on certain participants' adjustment process. Whilst the following point was not raised by the majority of companions, it was raised frequently by one and was considered important to mention. Isobelle reflected that to care effectively, one needs enough money. Due to her husband having to retire early, they had been left in financial difficulty. For Isobelle, this led to her considering getting a part-time job, even though she had retired from working a number of years previously.

"I still have problems with both me shoulders, so I'm limited to what I would be able to do. But I was thinking if I could get a job at night-time, when Alistair would be in bed... but it would need to be somewhere close to home as well in case I needed to get back to him…they say to make memories now and things like that. But how can you make memories? You can't go out anywhere; you daren't spend any money because you haven't got any to pay the rest of the bills…" (Isobelle, companion)

While a diagnosis of dementia is perhaps unexpected for anybody, there is a widely held belief that it is something that happens in older-age. Alistair commented:

"I've always thought of it being a lot older...You don't suddenly think 'you're just 60' and it's happening to you!" (Alistair, PwD)

However, some participants with dementia considered it beneficial that they had been diagnosed at working-age rather than when older, as part of their reflections (located within the theme 'forming narrative').

"it'd be more of a change for them (older adults) in life, the way they live, the way they move, the way they think and everything else...being a bit younger, I think it's helped me - I believe that" (Finlay, PwD)

"probably worse if it's diagnosed later you know. You get the idea that the older you are, the worse symptoms there are." (Albert, PwD)

However, 'looking forward' in this age group is considered to look different for companions, who had previously expected a number of years in which to enjoy retirement with their loved one. Anne sums up this point in the following quote:

"I suppose it's a shock to anybody young to be diagnosed with something like that…to being old when you're at that old age and you think 'I've had my life' don't you? Whereas at our age, you've still got another 15/20 years to go and…that's kind of put it off really hasn't it? I've thought about it because I've thought 'what's it going to be like when we're retired?' because I've always been active…and it's going to be…am I actually going to become a full time carer, so I'm not going to retire, I'm just going to carry on really…"

Rufus describes how this diagnosis has halted any original plans:

"my view was in the next 2 years, so by 2020, both Nella and I would be retired and we'd be financially secure and we'd be enjoying life…the adjustment to that now is that…I'm going to end up in a situation where I'm a carer initially, and so the outcome of that is ... life to me seems it's going to be a lot more difficult" (Rufus, companion)

These quotes are distinguished by feelings of loss and regret.

3.12 Outcome measures findings
Summary data from outcome measures is included in table 2. The QoL-AD provides a total score of 13-52 with higher scores indicating higher QoL. Logsdon et al. (2002) found that higher scores on the QoL-AD correlated with better day-to-day functioning and lower levels of depression.

The WEMWBS provides a total score of 14-70, with higher scores indicating higher wellbeing. Though there is no gold standard for measuring what constitutes 'high mental wellbeing', the top 15% of total scores from population samples in the United Kingdom (UK) range from 60-70, while the bottom 15% range from 14-42 (Warwick Medical School, 2019).

Participants with dementia rated themselves comparably between the two interviews on the quality of life (QoL) measure. Companions (who are asked to rate the person with dementia on the QoL questionnaire) tended to rate their loved one lower in QoL than the person with dementia rated themselves (with the exception of one companion). At second interview, while one companion's responses indicated that the person with dementia's QoL had declined, two companions thought that their loved ones QoL had gone up.

Table 2. Results from outcome measures.

Dyad	PwD/companion	QoL Time-point 1	QoL Time-point 2	WEMWBS Time-point 1	WEMWBS Time-point 2
1	PwD	34	34	55	49
	Companion	27	21	55	45
2	PwD	45	44	56	61
	Companion	34	33	41	34
3	PwD	26	26	32	32
	Companion	30	29	48	35
4	PwD	28	27	32	35
	Companion	26	29	52	50
5	PwD	39	38	57	51
	Companion	27	34	41	50

For measures of well-being (where participants are asked to rate their own well-being), no obvious patterns could be seen to comment on qualitatively. In general, the person with dementia's wellbeing score was always notably different to the companions wellbeing score, though whether wellbeing was better or worse than companions varied between dyads. Companions responses at second interview were generally lower than at first interview (with the exception of one companion - Florence).

3.13 Results from diaries

Three out of five dyads used the diaries to record their thoughts in between interviews (two companions and one person with dementia). The companions that utilised the diaries, used them to comment on changing symptoms in the person with dementia. The one participant with dementia who used the diary wrote down positive events that had happened between the two interviews. As participants were asked to expand on comments made in the diaries during interviews, answers were then incorporated into the overall thematic analysis.

3.14 Comments from participants

Following each interview, participants were asked for their reflections on the interview. No negative reflections were reported, with a number of participants reporting positive assertions related to the process. Finlay commented 'I kind of thank you, for taking something out of my brain if you like! Or putting something in! (laughs) I don't really know.' which suggests that the process of interviewing was helpful to think through thoughts and feelings related to the diagnosis, although the particular mechanism of how it was helpful was unclear.

Extended Discussion

4.1 Extended comments on connectedness

Extended results further highlight the social disconnection that occurs between the PwD and others as result of feeling alone in their experiences as well as the progressive nature of dementia symptoms; this leads to changes in relationships. This is supported by Chaston (2011), who highlighted that people with dementia were likely to experience feelings of isolation due to increasing difficulties with maintaining relationships, and Murray, Schneider, Banerjee, & Mann (1999), who identified the propensity for carers to feel alone in the relationship.

When considering the role of social connectedness more broadly, it makes sense that connectedness, and in particular 'seeking connection', was considered salient for adjustment. Within attachment literature, Bowlby (1979) maintains that sociality provides safety for individuals at times of threat. If we

understand a diagnosis of dementia to be equivalent to an existential threat, then it would make sense that negotiating attachments is important to maintain equilibrium.

In their 2013 research, Clemerson et al. found a theme comparable to the present overarching theme of connectedness, and suggested that this could be linked to other themes regarding identity. Braun and Clarke (2013) put forward that although themes should be able to stand alone, they should also work in combination with other themes. It is possible to see how 'connectedness', while mainly reflected on in the current research as being related to the effect of dementia symptoms, could also be linked to changes in roles and identity (as outlined in 'negotiating roles'). Participants demonstrated a flexible movement through themes and it is likely that different themes are affected by each other.

Extended results on connectedness offer further suggestions on how this could inform interventions. Services and the Psychology team could help to facilitate a conversation around connection - allowing both members of dyad to speak about the losses at the same time as experiencing the ways they are still connected. However, the present research demonstrates that there are some who turn inward to cope effectively, so what may work for the majority may not work for all. Hooker et al. (1994) found that the personality of carers impedes coping style, and so it is unwise to suggest that what is beneficial for one carer may be beneficial for another.

Opportunities for people with dementia to get together without companions, may offer benefit for some. Many participants with dementia said that companions and others do not understand, but others living with a diagnosis of dementia may be able to share an understanding of the experience.

Extended results suggest that attempts to reconnect are also met through the use of community. Services should explore the areas and systems that people affected by dementia already have around in place around them; working within systems that are pre-existing and meaningful for individuals, means that adjustment may be able to be facilitated in an organic way.

Participants with dementia explicitly speak of the shame that is felt when unable to connect. Brown (2013) supports that disconnection creates feelings of shame and a resultant fear of not being worthy of connection; it is therefore important to try and facilitate reconnection for individuals for increased wellness and quality of life.

4.2 Extended comments on negotiating roles

The extended results regarding 'negotiating roles' further highlight the ways in which participants with dementia notice change in their abilities. Participants with dementia reported a decline in skills at work, eventually rendering them unable to continue. This echoes findings from Rabanal et al. (2018), who stressed that people still working at the point of diagnosis were likely to feel sadness at this ending.

Comments from participants with dementia related to others' non-verbal judgements, and subsequent feelings of self-doubt, were also found in Clemerson et al.'s (2013) theme around 'identity'. They maintain that AD is a threat to self, impacting on subjective feelings of self-worth, and that others' reactions influenced self-identity. Clemerson et al. (2013) describe that the person living with dementia attempts to manage this by 'holding on' to the self as well as 'redefining' the self. This is akin to participants with dementia in the present study that appear to work through an oscillating process of reminding themselves what they are still able to do, their strengths and their hobbies, as well as learning new skills and adjusting to a new identity. Rabanal et al. (2018) support that people with dementia who are able to engage in meaningful activities had increased well-being. In addition, while skills based groups are generally catered for carers (e.g. Coon, Thompson, Steffen, Sorocco, & Gallagher-Thompson, 2002; Huang et al., 2003), this research shows that the person with dementia is willing to continue to learn and identify strengths within the boundaries of their illness. Thus, skill groups may be beneficial for people living with dementia.

Clemerson et al. (2013) suggest that 'redefining self' is likely to occur later in the process of adjustment, rather than being an early adopted strategy. However,

descriptions that can be understood as 'redefining self' occurred even within the first interview in the present research, suggesting a less linear and more 'messy' approach to adjustment. As dementia progresses, there are likely to be increasing changes. Current findings suggest that the person with dementia will alternate between leaning on others and preserving their own autonomy and identity in response to recurrent change.

For the companion, extended results stress the pressure that is placed on them; this comes from wider systems and themselves. There is an expectation that companions will automatically adopt the role of 'carer' when a loved one has received a diagnosis. Chan, Livingstone, Jones, and Sampson (2012) suggest that companions may experience grief reactions repeatedly from the point of diagnosis as much for the loss of their own role and identity as well as for their loved one. Perry (2004) found that three stages of loss were moved through by the caring companion including 1) noticing change and what that means for their future role, 2) feeling helpless alongside making gradual changes, and 3) employing coping strategies to manage. This echoes findings from O'shaughnessy et al. (2010) who identified that spousal carers utilised strategies to gain some control, and also findings from the current theme of 'negotiating roles'. However, as previously discussed, the process is not linear. Feeling competent on one day does not mean that complete competence is then ongoing throughout the course of dementia. Chan et al. (2012) suggest that a space to grieve losses throughout the changeable course of dementia may help carers. In addition, it may be helpful if services could facilitate open conversations about the concerns companions have soon after diagnosis, and couple this with skills based groups.

Within extended results it is demonstrated that in certain cases the wider family become increasingly involved in assisting the caregiver, meaning that interventions could also be offered to extended family members supporting the primary caregiver. It is important for services to understand who may be involved in care, without assuming that the companion will take on full responsibility, particularly in WAD where the caregiver may be continuing to work.

4.3 Extended comments on forming narrative

Bell (2002) puts forward that individuals put story structures to their experiences, to help make sense of things that are difficult to understand. This is found within the extended results where participants with dementia would look back to when they believed their dementia started. In the present study, the person with dementia was more likely to reflect back and attempt to make sense of past experiences, whilst the companion more explicitly described plans for the future; however, both would intermittently settle on the 'here and now', trying to maintain normality and accept the situation as is. An oscillation between the future and the here and now has been found in the literature for spousal carers previously (O'shaughnessy et al., 2010; Melunsky et al., 2015) which provides support for current findings, at least in relation to the companion's experience.

In Wilson's (1989) research, she presented an '8-stage model' to explain the course of AD when seen through the eyes of family. Stage 5 involved retrospectively reappraising a prior event, with the benefit of hindsight. In the present study, while both members of a dyad demonstrated this, it was observed in responses of the person with dementia more frequently. Stage 7 defines a list of future problems that the caregiver needs to work through – the subtheme 'looking forward' which involves making plans for the future, could be seen to reflect Wilson's seventh stage.

Calman et al. (2013) highlight that the concept of time in the trajectory of serious disease is complicated; they maintain that while quantitative longitudinal research may presume that there is a linearity to experience, longitudinal qualitative research is able to start to explore this complexity. In the current study, participants were found to move through the past, present and future variably and flexibly within the same interview. In this way, individuals considered predictions for the future (or an antenarrative [Boje, 1991]) and assimilated experiences perceived as important from the past. This did not need to be 'truth', yet allowed a sense of structure (and therefore safety). This is analogous to the concept of reauthoring a story, used as an approach in narrative therapy. This therapy assumes not one, but multiple truths (Madigan,

2011) and allows the client to create their own reality, which serves to reduce distress (Merscham, 2000).

4.4 Further comments on Lazarus and Folkman's (1984) model

The deductive sweep showed that Lazarus and Folkman's (1984) model had some applicability for the coping strategies employed by participants. A strength of Lazarus and Folkman's (1984) model is that it is dynamic (amenable to change over time) and that it allows for individual differences. Lazarus and Folkman (1984) suggest that individual's coping strategies are informed by their initial appraisals - in the present study, those whose initial thoughts regarding diagnosis were that of loss and sadness, tended to utilise emotion-focussed strategies and those whose first thoughts were of relief or confirmation, tended to employ problem-focussed strategies. However, the data suggests that this was not fixed; over time participants demonstrated different responses to the situation. This can be explained by new situations, and therefore appraisals, arising over time and participants alternating between believing they could cope with the stress or not.

However, participants' demonstrable changing appraisals highlight a possible limitation of applying the model to dementia adjustment, in that it is difficult to reliably test its utility. The nature of dementia is ever changing and therefore the stressor is ever-changing - participants are not solely responding to one threat, but multiple stressors over time. Whilst Lazarus and Folkman's (1984) model allows for this, it would be hard to measure empirically how this is operating in practice.

4.5 Extended themes

Tolerating (or not) Uncertainty

Extended results demonstrated that an uncertain timeline led to uncertain knowledge of needs. Read, Toye, & Wynaden (2018) support that people living with dementia find it difficult to identify their individual needs due to an unknown disease trajectory.

Receiving a diagnosis can lead to ambivalence amongst those with dementia and their families (Van Wijngarden et al., 2018; Le Couteur et al., 2013). This

was supported by the current findings - while some participants found that diagnosis provided welcome confirmation to what they had already intuitively known, and allowed them to start to make plans for the future, an uncertain dementia trajectory led to increased fear for some. This provides support for O'shaughnessey et al. (2010), who put forward that uncertainty can lead to feelings of being overwhelmed. In the present study, companions described putting plans in for the future (presented in the subtheme 'looking forward') to manage these feelings of uncertainty. Participants with dementia also aimed to learn more about what the future may hold, but this was combined with moments where knowledge of the future felt too overwhelming and frightening and so attempts to remain in the present were employed. This is in line with O'shaughnessy et al. (2010) who suggest that not knowing what the future may bring, protects an individual in the present. O'shaughnessy et al. (2010) suggest that interventions should support caregivers to move in and out of this oscillating process, to enable adjustment to loss to occur at an individual's own pace; this suggestion could be extended to participants with dementia.

For those participants who had previous knowledge of a possible timeline and course (due to experiences of caring for loved ones with dementia), this also led to increased fear and concern. In fact, for these participants, they reported preferring the period when dementia was unconfirmed as it meant that they could continue as normal. The consistent pressure on the NHS to make earlier diagnoses may be beneficial for some, but when there is a lack of suitable interventions, diagnosis can cause more harm (e.g. Le Couteur et al., 2013) and people may have been able to continue feeling more 'well' prior to receiving confirmation of a diagnosis. Both sides of this are reflected in the present study, which suggests that adjustment depends on the viewpoints of individuals - providing a diagnosis may activate already held narratives of what dementia looks like. Appraisals about this look different - adjustment may be moderated by this already held knowledge of dementia and what to expect.

Being of Working Age
The extended results demonstrate the different needs that those living with WAD may face. In particular, concern about finances was reported, with one

companion considering going back into employment, even though she had retired a number of years prior. This result supports Beattie, Daker-White, Gilliard, & Means (2004) and Sansoni et al. (2016) who put forward that financial difficulties are paramount within this population. It may be helpful for services to provide support around the financial administration that companions and people with dementia face, as financial difficulties were reported in the context of increased stress.

It should also be recognised that at working age, companions are likely to be working. A chance to learn new skills and attend support groups is difficult when services operate 9-5, Monday to Friday. Evening groups, with a focus on local venues may be better.

4.6 Extended comments on outcome measures

Results were looked at in comparison to interviews. Interestingly, a companion (Rufus) whose well-being score went up at second interview commented that he had felt quite hopeless at first interview, but that in between interviews things had been better than he had originally predicted. While he did not explicitly mention the following, in response to his well-being score going up, he had attended groups and described the benefit of such within interview 2.

Also notable was that participants who displayed more emotion-focussed coping in one interview when compared to another (e.g. Florence at first interview, Finlay at second interview) scored lower at these time-points. Florence was found to adopt a more 'problem-focussed' approach to coping at second interview and her well-being scores had gone up at this time. However, those who consistently displayed more problem-focussed coping across interviews (e.g. Anne and Isobelle) showed a decrease in wellbeing scores over time, suggesting that consistently using one approach does not necessarily result in better outcomes.

The outcome measures were used to triangulate the interview data. Whilst these results were only commented on qualitatively, further research may aim to assess whether quantitative measures are good substitute indicators for experiences captured in interviews.

4.7 Further critique of methodology

In considering the recruitment process, the research required both a person with dementia and their cohabiting partner to take part in the research, which means that the number of eligible participants was likely to be less. In addition, only people with Alzheimer's disease (AD) were recruited to the study (although it was open to more presentations). This could reflect the nature of WAD (AD is still the most prevalent form of dementia in this age-group), but also might mean that findings are less transferable to other groups.

Whilst the qualitative methodology does not assume generalisability, a larger sample size for future research would achieve a greater degree of transferability. The sample was relatively homogenous, but one couple interviewed included a female PwD and male companion, in contrast to the other dyads. In addition, while the person with dementia in all dyads had been diagnosed at some point in the previous three months, length of time at first interview varied. Whilst the time difference was not huge, it could mean that people were at differing stages of adjustment. Furthermore, the current data supports that adjustment begins prior to diagnosis - differing lengths of time leading up to diagnosis may result in a less homogenous sample. This may have influenced the way adjustment is experienced and reported.

It is important to remember that results are from what was reported in interviews. Diaries were not used in the way that would enable recall and so conclusions are from what was said and divulged at the particular time of an interview. A stricter approach may have got more reliable data from diaries, and may have revealed additional processes. However, diaries were not a compulsory part of the research.

Hubbard, Downs, & Tester (2003) suggest that it is helpful to give participants a copy of the interview schedule prior to conducting qualitative interview. This was not done in the present study to allow a spontaneous account. However, it may have been that different accounts would have been shared had participants been given this opportunity and it could be considered for future research with this population.

Finally, a critique of service user involvement is necessary. While the research design was informed by a service user panel, none of the advisories had diagnoses of dementia. Furthermore, service users were not involved in the analysis or conclusions; Braun and Clarke (2013) suggest that member-checking (or checking analysis with participants) can be useful to add credibility to research. This was reflected on in the latter stages of the research and when writing up, so consent had not been obtained for participants to assist with this, however, for future research it would be appropriate to enlist the views of those living with dementia to gain feedback on design, analysis and findings.

4.8 Further research

This research has demonstrated that not only can people with dementia be recruited to qualitative studies, but actually that this is crucial to understand the potential differing trajectories of those with dementia and those that care for them and so individual interviewing should be considered in future research.

While there has been a call for further research into the adaptation journeys of individuals, there is no widely used scale that assesses this. A further area of research could be developing a scale that assesses adjustment in the early stages of dementia and whether 'adjusting-well' does in fact link with 'living well'. Developing a reliable and valid measure would mean that people can be targeted earlier for involvement in interventions. If interventions can be offered early, for both the person with dementia and their companion, then this may reduce costs further down the line.

4.9 Critical Reflection

In the following account, I will reflect on my experience and what I have learned throughout the completion of this research thesis. This will include comments on central issues, challenges, extracts from my reflexive research diary and reflections on the overall research process.

Central issues

The concept of epistemological position is something that I have spent time considering. Prior to completing the doctorate, the research I had completed utilised quantitative methodology, and though I had not been taught the importance of explicitly commenting on epistemology, on reflection I can see that previous research had been viewed through a 'positivist' lens. This meant that the quality markers of qualitative research looked different to what I had been used to. A way this impacted on the first draft of my discussion, was that I had originally been framing recommendations as 'evidenced' and something that services 'should' be putting in place. Reflecting on current methodology and epistemology reminds me that this was not the aim for the present research. Instead the ways that the discussion can have clinical utility is through offering an informed account of ways in which people *may* adjust which lends itself to more tentative implications.

Another issue reflected on is the vastness of the construct 'adjustment'. To know how to begin initial analysis (coding instances of the ways people 'adjust') meant that I had to arrive at a working definition of adjustment, which is not universally agreed. In addition, the overlap between 'coping' and 'adjustment' meant that it would have been difficult and unwise to neglect the role of coping within adjustment. However, this meant that during interviews I would ask specifically about coping (which steered participants towards giving coping strategies) and during analysis I was coding 'ways to cope' during inductive analysis, and jumping to this understanding prematurely. To manage this, I had to continuously pull away from analysis (utilising the reflexive diary and ongoing discussion in supervision) to check myself. This meant that I could stick close to the data in my eventual interpretations.

Ethically, I had to consider and weigh up the potential harm of research against the benefits. Whilst this was already something that I had considered early on, it was further brought to my attention during the recruitment of dyad 4. I had received confirmation from a clinician that the dyad had consented to me contacting them, but on calling the telephone number provided, the person with dementia's son answered and criticised the research for wanting to enter the family's lives at the most sensitive time. As the person with dementia had

consented to being contacted, I spoke to him and his wife, who wanted to take part, but the son's comments stuck with me. The gravity of the sensitive nature of the research was highlighted and it made me appreciate how honoured I am to be invited into a snapshot of people's experiences, and the importance of fully considering the benefits of research.

After meeting the family, the son apologised, explaining that he himself was struggling to adjust to his dad being diagnosed at the age of 61 which highlights how dementia affects the whole family, and further exemplifies nuances of WAD (i.e. people with dementia having dependent children still living at home).

Regarding analysis, it is recognised that had I completed the deductive sweep first, I may have been influenced by the evidence of problem and emotion-focussed coping, enough to conclude that this was the process that was taking place. However, inductively analysing the data first meant that broader themes, that allowed more reflection on how services could support people with dementia in these stages, were found.

Further thoughts on analysis led me to reflect on the presentation of results. Grossoehme and Lipstein (2016) put forward that it was possible to use matrices alongside coding to get a visual representation of change processes. This was considered for the present study; it is amenable to thematic analysis and seemed a helpful way to present findings. However, during the process of searching for themes, it became apparent that inherent in the nature of subthemes, was the changing processes or temporal movement occurring within each theme. In an attempt to encapsulate this information into a matrix, it was found that nuances and individual voices were lost. As themes already reflected movement over time, and achieved the aims of the research, matrices would have been surplus to requirement.

Challenges and learning
A specific challenge for me was incorporating various people's feedback into the research. Prior to training, feedback that was given on assessments was more obligatory, whereas at doctoral level it has been more appropriate and in fact

necessary to critically appraise and make up my own mind on whether feedback should be incorporated into the final design or not. To do this effectively it is important to have a sound knowledge of prior research and methodology, to decide the best approach and be able to defend this against the inevitable different opinions of other academics. An example is from feedback early on suggesting a different approach to analysis (GT, as critically appraised in extended paper 2.7.2). After taking this to supervision and fully considering the advantages and disadvantages of one method compared to another, I settled on the methodology that best fit (TA), and have learnt that feedback is suggestive but by no means mandatory.

Reflexive diary

Finlay (2002) stresses that reflection and reflexivity are different points on a continuum - while reflection involves looking back on events at a distance, reflexivity is an immediate, subjective self-awareness. The way I used the reflexive journal to think about my impact on the research was from this 'in the moment' subjective way, which influenced future decisions. Entries in the journal were used to change ongoing practice. For example, in interviews I would make a note of what I had done before and endeavoured to not do this in future interviews if I felt it was swaying the participant towards my own preconceptions. Entries in the journal made me think about ethical considerations and my own feelings about the process - this fed into a wider understanding of ethics that I can take forward. Entries in the journal were also read during analysis, to check the ways in which my own values were impacting on the findings. These were taken to supervision and a process of supervisors checking themes helped with this.

An example from my reflexive journal is the way I noticed myself wanting to follow up on answers more during the semi-structured interviews, if I thought they related to a particular construct from Lazarus and Folkman's (1984) model.

Today I realised I was following up on answers given by Alistair as to the emotional impact of a diagnosis if I thought he might be referencing a construct from Lazarus and Folkman's model. He had explained that he tries not to think

about the diagnosis, even though those around him think he should. I found myself mentally agreeing with those around him and wanting to explore further the way the emotional impact of the diagnosis presented itself. This was problematic because these were not responses Alistair was having and I would be asserting my values on him if I were to probe to find evidence of the emotional impact if it was not there.

The above passage was important for me to reflect on. In the moment described above, I recognised that I was making an assumption about how participants should be feeling about receiving a diagnosis. Without reflecting on this, and becoming actively aware that I held this belief, it may have led me to probe more to find evidence of emotional responses, because I believed they should be there, when they may not be present. It meant in subsequent interviews I was able to recognise more quickly if I was about to do this.

In addition, Alistair's response (of trying not to think about the diagnosis), could be seen in itself as a form of emotion-focussed coping as outlined by Lazarus and Folkman (1984), which I only realised at analysis. Jumping to conclusions too early means that important insights may be missed.

Another example of how I used the reflexive diary alongside the research process is considering the different positioning of a researcher compared to a clinician and the propensity to end up talking therapeutically rather than with a researcher hat on.

An extract from my diary is presented below.

It's going to be important to ensure that I'm gathering information that is getting at the adjustment process, rather than following up in a way that is akin to therapeutic techniques during assessment. I noticed in the interview with Anne that I was looking for 'hot thoughts' and following up more closely on these answers.

On writing this in my reflexive diary I realised how important it was for me to actively look out for this, and be careful to pay attention to those answers which required more information on the adjustment process to be gathered, rather than those which were eliciting more 'emotional' responses as I would naturally follow up in therapy. I spent quite a lot of time talking about this with supervisors.

Overall research process

I have used Lazarus and Folkman's (1984) model to reflect on the overall process of research.

It is safe to say that the prospect of completing a doctoral thesis was initially appraised as stressful. In the early stages of the work (project design, protocol writing, and obtaining ethical approval) I believed that I had the ability to cope. Looking back I can see that my response to the stress was through problem-focussed coping; I spent time reading about qualitative methodology (a method I had not previously used), and talking to supervisors about the practical steps necessary. This approach was successful up until recruitment started to be more difficult than originally anticipated. The anxiety of a looming timeline meant that my coping shifted to intermittently feeling competent (and problem solving the issues with recruitment, including getting two new research sites on board) to emotion-focussed (seeking emotional support from peers, trying 'not to think' about whether I had enough time to recruit, complete data collection and subsequently analyse and write-up).

The closer it came to the deadline, emotion-focussed coping became more prevalent, and my appraisal about whether I could successfully cope with the threat of the thesis shifted to thinking it was not possible. At this point, I found myself taking some time away from thesis work. While Lazarus and Folkman (1984) would hypothesise that this approach would lead to negative feelings (which it did), Steinborn and Huestegge (2016) maintain that breaks can lead to restorative effects. This suggests that emotion-focussed coping was necessary

for me to support the problem focussed strategies that can lead to burn-out. Ultimately, I was able to reappraise the thesis as a threat I could cope with.

Extended paper word count (excluding footnotes and references): 22,867.

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Appendices

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

NHS
Nottinghamshire Healthcare
NHS Foundation Trust

Appendix A - Participant Information Sheet - PwD

(Final Version 2.0)

Title of Study: Exploring the process of adjustment to a diagnosis of dementia in working- age cohabiting dyads: a qualitative study

IRAS project ID: 232496

Name of Researcher(s): Francesca Williams

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?
Whilst there has been research done into the adjustment process in older-age dementia, it is recognised that people diagnosed under the age of 65 have different needs and potentially a different process of adjusting to diagnosis. This also impacts upon our loved ones. How people (person diagnosed and their family) adjust to a diagnosis has been linked to improved quality of life and wellbeing. We want to start to understand the process of adjustment so that we can provide interventions to help support this.

Why have I been invited?
You are being invited to take part because you are under 65 and have been diagnosed with dementia in the last 3 months. We are inviting 6 people with dementia and their companions to take part. Each person with dementia and their companion will be referred to as a 'dyad'.

Due to the purpose of the study, we would need both the person diagnosed with dementia and their companion (the dyad) to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your current care or legal rights.

What will happen to me if I take part?

1. Someone from the care team will check that it is ok for you to be contacted by the researcher of this research study.

2. The researcher will contact you and book a time to see you and your family member to give you further information about the study and answer any questions you may have.

3. You will sign a consent form at this meeting if you want to take part in the study. If you want longer to think about the study the researcher will book a different time for you to sign the consent form.

4. You will be booked in for a first interview. You will be invited to this interview separately from your companion. At this interview you will be asked to complete a short memory assessment and asked to fill in 2 short questionnaires on your general mood and well-being (each questionnaire will take approximately 10 minutes to complete).

5. A semi-structured interview will then take place (this should not take more than an hour) where you will be asked various questions about your experiences since being diagnosed. There are no right or wrong answers; we are just interested in your perspective. You will be given a diary for you to record anything you feel is impacting on you since diagnosis. At the end of the interview you will be booked in for a second interview approximately 3 months after the first one.

6. This second interview will be conducted separately from your family member. At the second interview we will check you are still willing to take part in the study. You will be asked to complete the mood and well-being questionnaires that you completed at the last interview. We will then spend another hour (approximately) asking you more questions about your experience in the last few months. You can use the diary you have completed to help you in case you forget important points.

7. The interviews will be recorded and later transcribed by the researcher or an appropriate transcription service and any identifiable information will be removed from the content at this point.

8. We will be in touch with the results of the study once it is complete (and if you consent for us to do this).

Expenses and payments
Participants will not be paid to participate in the study. Reasonable travel expenses will be offered for any visits incurred as a result of participation.

What are the possible disadvantages and risks of taking part?
We recognise the sensitive nature of the research, and talking about diagnosis may be difficult at times. It will be possible to take breaks throughout interviews or resume at a later date. With your permission, we may discuss how the care team can provide extra support if necessary. You are also free to withdraw from the research at any time, without your care being affected.

What are the possible benefits of taking part?
There are no direct benefits to taking part in the study. Results from the study may be beneficial to provision of services in the future.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting PALS on 01623 673849.

Will my taking part in the study be kept confidential?
We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, some parts of your medical records and the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the hospital will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Although what you say in the interview is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

Your personal data (address, telephone number) will be kept for 12 months after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

What will happen if I don't want to carry on with the study?
Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?
The results of this study will be written up as part of the requirements for the Doctorate of Clinical Psychology, being undertaken at the University of Nottingham.

It is hoped that the research will be published in a peer-reviewed journal.

A summary of the research findings and a copy of the published results will be sent to you if you consent for us to hold on to your contact details for this purpose.

Who is organising and funding the research?
The University of Nottingham.

Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Research Ethics Committee.

Use of Your Personal Data in Research

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable

information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Our Data Protection Officer may be contacted here:

data-protection@nottingham.ac.uk

Further information and contact details
Francesca Williams
Trainee Clinical Psychologist
University of Nottingham
DClinPsy, School of Medicine
YANG Fujia Building, Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB

0115 8466646

Francesca.williams@nottingham.ac.uk

Appendix B - Consent form - PwD
(Final Version 1.0)

Title of Study: Exploring the process of adjustment to a diagnosis of dementia in working- age cohabiting dyads: a qualitative study

Name of Researcher: Francesca Williams

IRAS project ID: 232496

Name of Participant: **Please initial box**

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

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis.

3. I understand that relevant sections of my medical notes and data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential.

4. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports.

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

6. I agree to the researcher taking my contact details in order to send me

   information about the study once complete (optional).

_____   _____   _____

Name of Participant   Date   Signature

_____   _____   _____

Name of Person taking consent   Date   Signature

3 copies: 1 for participant, 1 for the project notes and 1 for the medical notes

Appendix C - Participant Information Sheet - companion

(Final Version 2.0)

Title of Study: Exploring the process of adjustment to a diagnosis of dementia in working- age cohabiting dyads: a qualitative study

IRAS project ID: 232496

Name of Researcher(s): Francesca Williams

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

Whilst there has been research done into the adjustment process in older-age dementia, it is recognised that people diagnosed under the age of 65 have different needs and potentially a different process of adjusting to diagnosis. This also impacts upon our loved ones. How people (person diagnosed and their family) adjust to a diagnosis has been linked to improved quality of life and wellbeing. We want to start to understand the process of adjustment so that we can provide interventions to help support this.

Why have I been invited?

You are being invited to take part because you are the cohabiting partner of somebody under 65 who has been diagnosed with dementia in the last 3 months. We are inviting 6 people with dementia and their companion to take part. Each person with dementia and their companion will be referred to as a 'dyad'.

Due to the purpose of the study, we would need both the person diagnosed with dementia and their companion (the dyad) to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?
1. Someone from the care team will check that it is ok for you to be contacted by the researcher of this research study.

2. The researcher will contact you and book a time to see you and your family member to give you further information about the study and answer any questions you may have.

3. You will sign a consent form at this meeting if you want to take part in the study. If you want longer to think about the study the researcher will book a different time for you to sign the consent form.

4. You will be booked in for a first interview. You will be invited to this interview separately from your family member. At this interview you will be asked to fill in 2 short questionnaires on your general mood and well-being (each questionnaire will take approximately 10 minutes to complete).

5. A semi-structured interview will then take place (this should not take more than an hour) where you will be asked various questions about your experiences since your family member was diagnosed. There are no right or wrong answers; we are just interested in your perspective. You will be given a diary for you to record anything you feel is impacting on you since diagnosis. At the end of the interview you will be booked in for a second interview approximately 3 months after the first one.

6. This second interview will be conducted separately from your family member. At the second interview we will check you are still willing to take part in the study. You will be asked to complete the mood and well-being questionnaires that you completed at the last interview. We will then spend another hour (approximately) asking you more questions about your experience in the last few months. You can use the diary you have completed to help you in case you forget important points.

7. The interviews will be recorded and later transcribed by the researcher or an appropriate transcription service and any identifiable information will be removed from the content at this point.

8. We will be in touch with the results of the study once it is complete (and if you consent for us to do this).

Expenses and payments
Participants will not be paid to participate in the study. Reasonable travel expenses will be offered for any visits incurred as a result of participation.

What are the possible disadvantages and risks of taking part?
We recognise the sensitive nature of the research, and talking about diagnosis may be difficult at times. It will be possible to take breaks throughout interviews or resume at a later date. With your permission, we may discuss how the care team can provide extra support if necessary. You are also free to withdraw from the research at any time, without your care being affected.

What are the possible benefits of taking part?
There are no direct benefits to taking part in the study. Results from the study may be beneficial to provision of services in the future.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting PALS on 01623 673849.

Will my taking part in the study be kept confidential?
We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, some parts of your medical records and the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the hospital will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Although what you say in the interview is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

Your personal data (address, telephone number) will be kept for 12 months after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

What will happen if I don't want to carry on with the study?
Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?
The results of this study will be written up as part of the requirements for the Doctorate of Clinical Psychology, being undertaken at the University of Nottingham.

It is hoped that the research will be published in a peer-reviewed journal.

A summary of the research findings and a copy of the published results will be sent to you if you consent for us to hold on to your contact details for this purpose.

Who is organising and funding the research?
The University of Nottingham.

Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Research Ethics Committee.

Use of Your Personal Data in Research

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable

information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Our Data Protection Officer may be contacted here:

data-protection@nottingham.ac.uk

Further information and contact details
Francesca Williams
Trainee Clinical Psychologist
University of Nottingham
DClinPsy, School of Medicine
YANG Fujia Building, Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB

0115 8466646

Francesca.williams@nottingham.ac.uk

Appendix D - Consent form - companion
(Final Version 1.0)

Title of Study: Exploring the process of adjustment to a diagnosis of dementia in working- age cohabiting dyads: a qualitative study

Name of Researcher: Francesca Williams

IRAS project ID: 232496

Name of Participant:

<div style="float:right">**Please initial box**</div>

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

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis.

3. I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential.

4. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports.

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

6. I agree to the researcher taking my contact details in order to send me

   information about the study once complete (optional).

_____   _____   _____

Name of Participant   Date   Signature

_____   _____   _____

Name of Person taking consent   Date   Signature

2 copies: 1 for participant, 1 for the project notes

Appendix E - Information Sheet - referrers

Title of study: Exploring the process of adjustment to a diagnosis of dementia in working- age cohabiting dyads: a qualitative study

IRAS Project ID: 232496

Name of researcher: Francesca Williams

What is the purpose of the study?

Whilst there has been research done into the adjustment process in older-age dementia, it is recognised that people diagnosed under the age of 65 have different needs and potentially a different process of adjusting to diagnosis. This also impacts upon their loved ones. How people (person diagnosed and their family) adjust to a diagnosis has been linked to improved quality of life and well-being. We want to start to understand the process of adjustment for this population so that we can provide interventions to help support this.

We are looking to recruit up to 6 couples (Person with Dementia and their cohabiting partner) to take part in 2 semi-structured interviews over a 3 month period.

Inclusion criteria

Person with Dementia:

1. Male or female aged under 65.
2. Received a diagnosis of Dementia within the last 3 months.
3. Lives with partner (companion).
4. Has a cohabiting partner willing to take part in the study.
5. Sufficiently fluent in English to take part in semi-structured interview.
6. Capacity to give informed consent.

Companion:

1. Cares for a person with dementia.
2. Lives with person with dementia also taking part in the study.
3. Sufficiently fluent in English to take part in semi-structured interview.
4. Capacity to give informed consent.

Exclusion criteria - participants who meet the below criteria will not be eligible for the study

Person with Dementia:

1. Have a diagnosis of Fronto-Temporal Dementia.

Companion:

1. Have a diagnosis of Dementia

If you would like to refer a couple to the study, please e-mail Francesca Williams (Trainee Clinical Psychologist) at francesca.williams@nottingham.ac.uk

Appendix F - Ethical Approval letters/documents

NHS
Health Research Authority

North West - Preston Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 020 71048008

18 January 2018

Dr Danielle De Boos
Trent DClinPsy Programme
Yang Fujia building, Jubilee Campus
University of Nottingham
NG8 1BB

Dear Dr De Boos

Study title:	Exploring the process of adjustment to a diagnosis of dementia in working age cohabiting dyads: a qualitative study
REC reference:	17/NW/0672
Protocol number:	17093
IRAS project ID:	232496

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

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, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

<u>Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.</u>

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk 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 management permissions from host organisations

<u>Registration of Clinical Trials</u>

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

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).

Ethical review of research sites

NHS 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).

Approved documents

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

Document	Version	Date
Covering letter on headed paper [Response to the committee 11.12.17]	1.0	11 December 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Liability insurance]	1.0	02 November 2017
Initial Assessment for REC		07 November 2017
Interview schedules or topic guides for participants [INTERVIEW TOPIC GUIDE final version 1.0 date 27.10.17]	1.0	27 October 2017
IRAS Application Form [IRAS_Form_14112017]		14 November 2017
IRAS Application Form [IRAS_Form_15122017]		15 December 2017
IRAS Application Form XML file [IRAS_Form_15122017]		15 December 2017
Letter from sponsor [Sponsor letter]	2.0	30 October 2017
Other [INFO SHEET REFERRER - Adjustment in WAD final version 1.0 date 27.10.17]	1.0	27 October 2017
Other [Transcription Services & Confidentiality Form]	1.0	11 December 2017
Participant consent form [CONSENT FORM - PATIENT Adjustment in WAD final version 1.0 date 27.10.17]	1.0	27 October 2017
Participant consent form [CONSENT FORM - CARER Adjustment in Dementia final version 1.0 date 27.10.17]	1.0	27 October 2017
Participant information sheet (PIS) [INFO SHEET PATIENT Adjustment in WAD final version 1.0 date 27.10.17]	1.0	27 October 2017
Participant information sheet (PIS) [INFO SHEET CARER Adjustment in WAD final version 1.0 date 27.10.17]	1.0	27 October 2017
Participant information sheet (PIS) [INFO SHEET PATIENT Adjustment in WAD final version 2.0 date 11.12.17]	2.0	11 December 2017
Participant information sheet (PIS) [INFO SHEET CARER Adjustment in WAD final version 2.0 date 11.12.17]	2.0	11 December 2017
Research protocol or project proposal [PROTOCOL Adjustment in WAD Final version 1.0 date 27.10.17]	1.0	27 October 2017
Sample diary card/patient card [PARTICIPANT DIARY final version 1.0 date 27.10.17]	1.0	27 October 2017
Summary CV for Chief Investigator (CI) [Staff - CV Danielle De Boos 1512 IRAS (Dec15)]	1.0	27 October 2017
Summary CV for student [Research CV Francesca Williams]	1.0	27 October 2017
Summary CV for supervisor (student research) [Staff - CV Nima Golijani Moghaddam 1708 IRAS 2017]	1.0	27 October 2017
Summary CV for supervisor (student research) [Staff - CV Sarah Ramsden]	1.0	14 November 2017
Validated questionnaire [QOL-AD]	1.0	27 October 2017
Validated questionnaire [WEMWBS]	1.0	27 October 2017

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 HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

17/NW0672	Please quote this number on all correspondence

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

Yours sincerely

Professor Carol Haigh
Chair

Email:nrescommittee.northwest-preston@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Ms Angela Shone
Ms Shirley Mitchell, Nottinghamshire Healthcare NHS Foundation Trust

Dr Danielle De Boos
Trent DClinPsy Programme
Yang Fujia building, Jubilee Campus
University of Nottingham
NG8 1BB

18 January 2018

Dear Dr De Boos

Letter of HRA Approval

Study title:	Exploring the process of adjustment to a diagnosis of dementia in working age cohabiting dyads: a qualitative study
IRAS project ID:	232496
Protocol number:	17093
REC reference:	17/NW/0672
Sponsor	University of Nottingham

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

University of
Nottingham
UK CHINA MALAYSIA

Research and Innovation
University of Nottingham
East Atrium
Jubilee Conference Centre
Triumph Road
Nottingham
NG8 1DH

Assistant Professor
University of Nottingham
workYANG Fujia
Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB

30 October 2017

Dear Sir or Madam,

Sponsorship Statement

Re: Exploring the process of adjustment to a diagnosis of dementia in working age cohabiting dyads: a qualitative study

I can confirm that this research proposal has been discussed with the Chief Investigator and agreement to sponsor the research is in place.

An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.*

Any necessary indemnity or insurance arrangements will be in place before this research starts. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

The duties of sponsors set out in the NHS Research Governance Framework for Health and Social Care will be undertaken in relation to this research.**

* Not applicable to student research (except doctoral research).
** Not applicable to research outside the scope of the Research Governance Framework.

Yours faithfully

Angela Shone
Head of Research Governance
University of Nottingham

world-changing research

Appendix G - Topic guide

<u>Interview 1</u>

Below is an idea of topics/questions that may be asked.

<u>This interview is expected to last 60 minutes.</u>

- Initial thoughts

What were your initial thoughts following the diagnosis of dementia?

What things have you found difficult since diagnosis?

What things have been going well since diagnosis?

- Adjustment

What is your understanding of adjustment?

What do you think 'good' adjustment looks like?

What factors do you think may get in the way of this?

- Practical adjustment

What have you found useful from services?

What do you think would be useful?

What have you been finding difficult in practical terms?

What have you been finding relatively straightforward in practical terms?

- Emotional adjustment

How have you been feeling since diagnosis?

How has your mood been?

What have you found helpful when you have been feeling xxx (use participants' words)?

How do you understand/make sense of feeling x (use participants' words)?

What may be useful to help with this?

- General

Is there anything else you'd like to say today?

Review diary and reflect on what has been recorded – other questions may include:

How have you been coping since the last interview?

You defined good adjustment as x (use participant's words). How do you feel the last few months have been if we compare against this definition?

What has been going well/what have you found difficult?

What have you found useful from services?

What other support do you think would have been useful?

How has your mood been?

Is there anything else you'd like to mention/discuss?

Appendix H - QoL and Wellbeing measures

QoL-AD: http://www.cogsclub.org.uk/professionals/files/QOL-AD.pdf

WEMWBS:
http://www2.warwick.ac.uk/fac/med/research/platform/wemwbs/wemwbs_14_item.pdf

Please note, permission was granted from Warwick University to use WEMWBS (12/03/2017)

Appendix I - Diary for participants

Please use this diary to record anything you feel is impacting upon adapting to diagnosis. There is no 'right' or 'wrong' thing to note down, but this may be a useful way to collect your thoughts and refer back to when it comes to the second interview.

Date	Reflections

Appendix J - Schedule of Events for participants

Participants approached by clinician. Given brief information about the study and if interested, asked if a researcher can contact them. Given a PIS.

↓

Contacted by researcher and booked for an initial visit.

↓

Initial visit: Further information given about the study, opportunity to ask questions. Informed consent may be taken at this session. If the participant would like longer, a minimum of 24 hours can be taken to consider.

1st interview booked for within 6 months of diagnosis

↓

1st interview (including demographic data and measures): Informed consent may be taken if not taken at initial visit.

Second interview booked (approx. 3 months after).

↓

2nd interview (at this point check ongoing consent).

Appendix K - Initial coding template

Line number	Dyad 1, interview 1, (1.1)	Initial Codes
1.		
2.		
3.		
4.		
5.		

Appendix L - Client interview extract with codes (PwD - Finlay)

Line number	Dyad 1, interview 1 (1.1)	Initial Codes
1.	PWD - Finlay (1.1.1)	
2.		
3.	R: First of all, I'm going to ask you about	
4.	some of the initial thoughts that you had	
5.	when you received a diagnosis of	
6.	dementia. So what were your initial	
7.	thoughts following this diagnosis?	
8.	F: It wasn't, wasn't a surprise. Erm, I	Diagnosis - not a surprise 1.1.1.8
9.	suppose in the back of my mind I kind of	Diagnosis - sensed it 1.1.1.9
10.	sensed it was going to happen at some	Diagnosis - inevitable 1.1.1.10
11.	point in time, but I couldn't tell you why.	Unconscious awareness 1.1.1.11
12.	R: Yea.	
13.	F: And I mean, it seems inevitable after	Diagnosis inevitable 1.1.1.12
14.	how I'd been, you know what I mean, so	Noticing symptoms 1.1.1.13
15.	that's how it was...	
16.	R: Ok, so you said that it didn't come as a	
17.	surprise. Had there been things in the lead	
18.	up that you'd suspected might be...	
19.	F: Yea, felt that things weren't operating	Noticing symptoms - sensed decline 1.1.1.18
20.	right up here at times (laughs) it...I say	
21.	they weren't operating right, they weren't	
22.	functioning properly, is probably, might be	Noticing symptoms - decline 1.1.1.21
23.	wrong and right, if you see what I	
24.	mean...and I kinda suspected that. Some	Diagnosis - suspected it 1.1.1.23
25.	things took longer to work out...you know	Noticing symptoms - decline 1.1.1.24
26.	what I mean? I think some things that are	
27.	automatic, that I've done all of my life, all	Noticing symptoms - suddenly things stopped
28.	of a sudden became a bit slower and...you	being automatic, slowed down 1.1.1.27
29.	know...I wasn't as good as I was! So I	Noticing symptoms - decline/change 1.1.1.28
30.	knew things wasn't probably going along	
	as it should do...if that makes sense.	

1019.	probably over the last 2 years he's really,	forgetting 1.1.2.1018
1020.	he seemed to more, decline more, sort of	Noticing symptoms before diagnosis - decline
1021.	thing, so it's, I think, with googling and	1.1.2.1020
1022.	things like that, and talking to people, I've	Action - googling/talking to others led to
1023.	got, I'm quite up there with what's going on	understanding 1.1.2.1022
1024.	more than probably he does so…yeah.	Adjustment begins prior to diagnosis
1025.	R: So your initial thoughts were around,	1.1.2.1023
1026.	kind of being recognised that what you	Wife understands more than PwD 1.1.2.1024
1027.	had thought…was right	
1028.	A: Had said, yeah. Somebody's actually	Diagnosis was validation after long process
1029.	listening to what I'm saying. That there has	1.1.2.1028
1030.	been something wrong…so I mean, we've	
1031.	been going to the doctor's, it's gotta be 4	Action - going to doctors to see what's wrong
1032.	and half years and then we went a couple	for a long time before diagnosis 1.1.2.1030
1033.	of year ago…and he actually had to go on	Wife not listened to for 4.5 years 1.1.2.1031
1034.	his own to see the doctor about	
1035.	something, and I had to write a note,	Wife acts for benefit of PwD - write note for
1036.	explaining to him everything that was	doctor when PwD couldn't 1.1.2.1034
1037.	going off. And say look…we've been down	Wife in charge 1.1.2.1034
1038.	these lines. He'd had a couple of scans	Wife provides a way for PwD to manage prior
1039.	and they said there was nothing there, but	to diagnosis 1.1.2.1035
1040.	there's definitely something wrong…	Adjustment begins prior to diagnosis
1041.	something's not right, sort of thing. And	1.1.2.1039
1042.	then this man, our locum doctor, agreed,	Diagnosis - took a long time 1.1.2.1040
1043.	and that's where the ball started rolling.	Wife - validated by doctor 1.1.2.1041
1044.	R: Ok, so you thought 'I was right'?	
1045.	A: Yea (laughs)	
1046.	R: Ok, and what things would you say	
1047.	you've found difficult since he has received	
	a diagnosis?	

Appendix N - Looking for themes

Print out of all codes
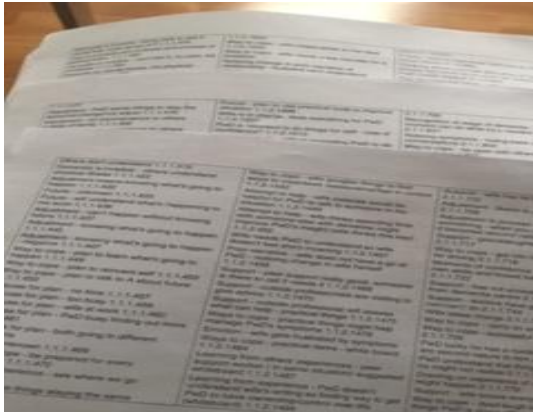
Putting features/groups together conceptually

Appendix O - Reviewing themes - extract of candidate theme 'connectedness' (with selected codes)

Connectedness	
Disconnecting	Seeking connection
Pre diagnosis - others non-verbal reactions were apparent	Hear about/share with others going through the same thing
Dementia is invisible - others don't understand	Remind self that same person underneath
Feeling alone - nobody wants to know	Socialise
	Use of humour
Others can't imagine that anything is wrong	Be open with others
PwD is isolated - doesn't have a friendship group	Would welcome chance to meet others in the same situation
PwD is on his own with this	Community support
PwD frightens some people with his presentation	Everybody involved in this
	Shared experience
Being cut out of the loop	Companion thinks understands PwD's needs
Time away	
Avoid telling people so don't have to face it/protect others	Sharing diagnosis with others

Appendix P - Extended thematic map