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**Exploring themes in the narratives of couples in which one partner has dementia to
identify what short couple interventions should focus on**

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Abstract

Objective: Despite strong evidence showing the association between relationship quality and outcomes for both partners in couples with dementia, studies show little or no statistical evidence of the effectiveness of short-term couple interventions in dementia. The aim of this study was to address the question of what topics a short couple intervention should focus on, and what content and components such an intervention should include.

Method: In this cross-sectional, qualitative investigation we used thematic analysis of transcribed interviews from couples (N=4), after they participated in the short-term couple intervention for dementia. Using thematic analysis, we extracted codes and identified the themes appearing in the narratives of couples obtained in in-depth interviews.

Results: The main four themes which emerged were *Loss, Change, Relationships,* and *Coping with difficulties*, which included several sub-themes.

Conclusion: This study indicates that high relationship quality and effective dyadic coping should be seen as a “relationship reserve” (a concept alike to cognitive reserve), that may act as a resilience factor in dementia. Well-designed, structured, multi-component couple interventions can enhance couples’ relationship reserve and, what follows, help to prevent carer burden, depression and burn-out, slower cognitive decline in the partner with dementia and improve the psychological well-being of both partners. To be more effective, such interventions should include both an educational and a therapeutic modules (with the latter consisting of a relational component, a component focused on self-care of caregiving partner, and a component addressing depression in both partners), and should be tailored for the needs of individual couples and adjusted depending on stages of dementia.

Keywords: qualitative study, thematic analysis, short couple intervention, dementia

Introduction

Around 850,000 in the UK (Alzheimer's Research UK, 2018) and around 50 million people worldwide have dementia; it is estimated that 5-8% of the general population aged 60 and over have dementia (World Health Organization, 2019). With the rising prevalence of the condition, there is also an increase in the number of partners providing care to people with dementia (Richardson, Lee, Berg-Weger, & Grossberg, 2013).

Couplehood and dementia: findings from qualitative studies

The majority of existing literature has focused either on the experience of the person with dementia, or on the experience of their caregiving spouse (Egilstrod, Ravn, & Petersen, 2019), even though there is robust evidence that in couples, where one partner has dementia, the condition impacts both partners individually, as well as their relationship itself (Daniels, Lamson, & Hodgson, 2007). In particular, the existing literature from qualitative studies only reveals the perspective of one member of the couple, leading to limited understanding of the relational aspect of the disease (Daniels et al., 2007; Evans & Lee, 2014; Wadham, Simpson, Rust, & Murray, 2016). This is despite the fact that qualitative research would allow an in-depth exploration of relational aspects and encourage a more holistic representation of the shared couple experience of dementia (Wadham et al., 2016).

Evans and Lee (2014) review of 19 qualitative studies identified two main interrelated themes: transition (where one spouse took over the roles their partner could no longer manage) and loss. Wadham and colleagues (Wadham et al., 2016) in their review of 10 qualitative studies found four overarching themes: efforts to maintain a sense of togetherness, shifts of balance and power within the relationship impacting on both partners' sense of identity, empathy and sensitive attunement between partners as they work to protect each other's sense of roles and identity, and the resilience couples demonstrate in the face of fear,

uncertainty, and hopelessness. Resilience frequently took the form of couples attempting to manage the distress of the diagnosis through acceptance of the situation and using humour to normalise their experience (Wadham et al., 2016). Moreover, cultivating a positive attitude to life and adopting a greater appreciation of life's pleasures were strategies couples used to protect themselves from emotional distress (Wadham et al., 2016).

Cross, Garip, and Sheffield (2018) in their meta-synthesis of the qualitative studies on the psychosocial impact of caregiving in dementia on quality of life reviewed 14 studies and identified themes related to understanding and making sense of the dementia diagnosis, changing symptoms and the caregiver role, coping strategies, challenges of caring for a person with dementia, caregiver's relationship with care-recipient and other caregivers, and the caregiver's experiences of formal support services and material resources. Within the theme of the relationship between the caring partner and care-recipient, content emerged related to the challenges of the changes in the balance of a previously equal relationship to the one of caregiver-care recipient (Cross et al., 2018).

Holdsworth and McCabe (2018) conducted an integrative qualitative analysis on the impact of younger-onset dementia on relationships, intimacy, and sexuality in midlife couples. This systematic review identified several themes, including shifts in roles and responsibilities, the decline in relationship quality, changes in identity and self-esteem, increasing social isolation and loneliness, and shifts in intimacy and sexual activity. Some evidence from quantitative studies suggests that in addition to feelings of the loss of a partner, some spouses reported feelings of loss of their marriage, and a loss of shared meaning and connection to their spouse (Massimo, Evans, & Benner, 2013). Such a loss of connection to one's spouse was reported to be associated with a greater sense of burden, lower well-being and fewer rewards from the caregiving role (Riley, 2019; Riley, Evans, & Oyebode, 2018). Studies have also reported a loss of intimacy (Massimo et al., 2013), as meaningful communication between partners

becomes increasingly difficult due to the progression of dementia. In the face of considerable changes within the marital relationship, some spouses attempt to sustain couplehood and reconstruct marital closeness (Hellström, Nolan, & Lundh, 2005) by focusing on former rituals and routines and maintaining shared activities (Hellström et al., 2005).

Couplehood and dementia: findings from quantitative studies

One review of quantitative studies found that the quality of the couple relationship prior to the diagnosis affects the maintenance of the bond in the context of dementia, and, in turn, the decrease in relationship quality as the dementia advances, negatively affects both partners (Ablitt, Jones, & Muers, 2009). Norton *et al.* (2009) found that higher relationship quality predicts slower progression of dementia and better functional ability of the person with dementia (Burgener & Twigg, 2002). Self-rated relationship quality was also found to be associated with own life satisfaction and well-being for both caregiving and care-receiving partners (Rippon et al., 2019) and was predictive of lower depression and strain in a caregiving partner (Ablitt et al., 2009; Riley, 2019; Riley et al., 2018).

Studies also show that dementia puts a lot of strain on a spousal relationship and has a negative impact on its quality (Baikie, 2002; Holdsworth & McCabe, 2018; Wadham et al., 2016), and while many couples strive to maintain their bond (Clark, Prescott, & Murphy, 2019; Davies, 2011), many caregiving partners report burden (Etters, Goodall, & Harrison, 2008), stress (Pinquart & Sörensen, 2003) and tension between meeting their own and their spouse's needs (O'Shaughnessy, Lee, & Lintern, 2010). Caregiving partners also report reduced shared activities, loss of emotional support from their spouse and a diminished quality of verbal communication, leading to low marital satisfaction (Baikie, 2002). The results also suggest that many caregiving partners experience grief (Meuser & Marwit, 2001), as well as anger and resentment towards the care recipient (Croog, Burleson, Sudilovsky, &

Baume, 2006; Kristin Martin-Cook, Remakel-Davis, Svetlik, Hynan, & Weiner, 2003; Shim, Barroso, & Davis, 2012) and may experience a heightened psychiatric and physical morbidity (Garand, Dew, Eazor, DeKosky, & Reynolds, 2005; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Schulz & Martire, 2004). The association between being a caregiver in dementia and an accelerated cognitive decline in caring spouses has been also reported (Dassel, Carr, Vitaliano, & Pruchno, 2017).

Couple-focused interventions

The strong link between relationship quality and outcomes for both partners in couples with dementia is increasingly recognised in clinical practice (Edwards et al., 2018; Nordheim et al., 2019). A number of interventions designed for couples with dementia have been recently developed and tested (Lamotte, Shah, Lazarov, & Corcos, 2017; Laver, Milte, Dyer, & Crotty, 2017; Moon & Adams, 2013; Nordheim et al., 2019; Prick, de Lange, Scherder, Twisk, & Pot, 2016; Van't Leven et al., 2013). For example, Ingersoll-Dayton et al. (2013) proposed a short-term dyadic intervention that addresses the need for meaningful engagement, shared communication, and pleasurable activities for both partners. Baker, Grocke, and Pachana (2012) proposed an intervention model that focused on music therapy to facilitate the sharing of meaningful experiences within couples, reduce apathy and agitation in those with dementia, and improve mood of both partners, their communication and quality of life. Two randomized clinical trials (RCTs) by Särkämö et al. (2014) and Davidson and Almeida (2014), as well as one qualitative investigation by Unadkat and co-workers (2017) indeed reported that singing couple therapy had beneficial effects for both partners.

Aim of the present study

Despite evidence suggesting the association between relationship quality and outcomes for both partners in couples in dementia, and evidence that some interventions for couples might be beneficial, there are also indications that many couple interventions in dementia show little or no evidence of effectiveness (Collins, Gilligan, & Poz, 2018; Eloniemi-Sulkava et al., 2009; Elvish, Lever, Johnstone, Cawley, & Keady, 2013; Nordheim et al., 2019), e.g. Rausch, Caljouw, and Van Der Ploeg (2017) in their review of seven couple interventions concluded: “None of the included studies showed clear, indisputable positive effects of any intervention” (p.8). Clearly, the exploration of the perspectives of both partners (i.e., focusing on the dyadic perspective rather than only an individual perspective of the carer or the person with dementia) is needed to bring better understanding of couples’ relationship functioning, the challenges as well as the resources for couples’ resilience in coping with the condition and to improve the effectiveness of couple interventions.

This qualitative investigation explored the themes appearing in the narratives of couples after they participated in an experimental, eight-session *Living Together with Dementia* (LTWD) intervention focusing on improving couple relationships (Balfour, 2014). We aimed to address the question of what topics a short couple intervention should focus on, and what content (and components) such interventions should include in order to best address the emotional needs of both partners and improve their relationship quality and everyday interactions. Our ultimate goal was to propose ways of improving the effectiveness of couple interventions.

Method

Procedures

After the LTWD intervention, couples who expressed interest, participated in an in-depth interview on topics related to their relationship, coping with dementia, their experience of formal care (e.g., health care staff and nursing homes) and of the LTWD intervention itself (see interview questions in the online Appendix). The interviews lasting between 34 and 49 minutes (on average 38.41 minutes), and were conducted in participants' homes between November 2014 and March 2015 by a senior clinician experienced in services for older people and were audio-recorded and then transcribed verbatim. The quotations in the online Appendix and manuscript were anonymised (real names of people and places were replaced with fictional names).

Sample

Participants were residents of London and Bristol (UK), referred through various contacts in memory services, carers' associations and from professionals in Older Adults' Services. The inclusion criteria were that the couple spoke English and that one of the partners had dementia. N=33 couples meeting these criteria were recruited and five couples were interviewed after the intervention. After initial familiarisation with the content of the transcripts, it was decided that one transcript would be excluded from the analysis due to the low quality of the recording. Thus the study is based on transcripts from N=4 couples.

All four couples were within the post-retirement age range of 65-75 with very small age differences between the partners (male partners being up to three years older). In two couples the male spouse was a caregiving partner and in two couples the female spouse was a caregiving partner. All four couples had middle-class occupations prior to retirement and three couples had adult children. In the case of three couples, both partners were living at their homes; two couples had a professional carer visiting them at their homes; in one couple, the partner with dementia was living in a care home.

Ethical approval

Ethical approval for the intervention and data collection were obtained from the Integrated Research Approval System, the National Health Service (IRAS NHS project numbers: #137317/930923/14/876 and #137317/1031558/13/505/60357).

Data analysis

In this cross-sectional qualitative study, we used thematic analysis (Downe-Wamboldt, 1992). The method involved three stages: 1) coding the content of transcripts of the interviews; 2) identifying homogenous groups of codes (sub-themes) based on the shared content; 3) categorisation of the sub-themes into more general, overarching themes based on the meaning and the interpretation of the content. The detailed step-by-step thematic analysis is described in the supplementary online Appendix, along with the list of the codes and extended verbatim citations from all transcripts. Below (due to the limited space) we provided shortened citations of the narratives of partners with dementia (PWD) and the caregiving partners (CP) to exemplify the themes.

Results of thematic analysis: extracted main themes and sub-themes

Main theme 1: LOSS

Seven sub-themes were related to the topic of loss: Cognitive decline, Physical decline, Death, Loss of the relationship (or a partner) and separation, Loss of intimacy, and Abandonment and fear of abandonment. In one interview, the caregiving partner recollected

his childhood (which we then named as the sub-theme “Childhood”), however, the dominant topic of this recollection was the loss of his mother.

Cognitive decline: “(...) unfortunately my memory is missing” [PWD, male]. **Physical decline:** “(...) because the brain is not controlling the epiglottis properly, you're ingesting food into the lungs too often and too much, and it's causing nutrition for the bacteria” [CP, male]. **Death:** “(...) there is a path to being dead there, which maybe involves some suffering I mean when you're ill, really ill...” [CP, male]. **Loss of the relationship (or a partner) and separation:** “(...) sometimes it's hard to separate it's hard to um... leave each other when we are having a nice time.” [CP, female]. And another quote from a PWD (male): “Mm yep... the physically separate from me hit me the most hardest part.” **Abandonment and fear of abandonment:** “(...) so I started investigating care homes and eh and that investigation, in order partly to have a bolt-hole ready for if Megan [the carer] really did get fed up and leave.” [the CP, male]. **Loss of intimacy:** “And um...[pause] Well, sex in dementia, I'm not going to talk about because I haven't experienced it. We don't have any sexual relations at all, my husband and I.” [PWD, female]. **Childhood:** “(...) we went to the Caribbean, and I don't remember my mother much there” [CP, male].

Main theme 2: CHANGE

This theme, related to the change in life circumstances, was formed of the following six sub-themes: Change, Change in the relationship, Change in roles and responsibilities, Looking ahead (this also appeared in the main theme *Coping with difficulties*), Cognitive decline, and Physical decline (the latter two also appeared in the main theme *Loss*). **Change:** “(...) what I realised, it wasn't the end of conversations (...) it was just, it was just a change, it was a change in how we... could cohabit?” [CP, female]. **Roles and responsibility change:** “(...) I

felt like I had to protect him [the spouse with dementia] and I wouldn't thought of that before dementia." [CP, female]. **Looking ahead:** *"(...) there is dignity to look back at how it all started, but more importantly, you better be looking forward to where it is all going to go."* [CP, male].

Main theme 3: RELATIONSHIPS

A major theme that emerged from the transcripts was that of relationships – predominantly the relationship with one's partner, but also with other people (doctors, carers, therapists). There were 12 sub-themes that formed this theme: Positive aspects of the relationship, Connection/bonding, Affection, Support (and the lack of it), Caring, Conflict, Caregiving partner as the rescuer, Permission – asking and giving, Carer burden (which also was classified as a part of the theme *Coping with difficulties*), Intimacy, Abandonment and fear of abandonment, and Loss of the relationship (or a partner) and separation; the latter three sub-themes were also found in the main theme *Loss*.

Positive aspects of the relationship: *"(...) but the times that we do have together umm we talk a lot and we have a lot of fun together."* [CP, female]. **Connection/bonding:** *"You remember who I was and that I was your girlfriend. Yeah, these things are everything (...)."* [CP, female, talking to her PWD]. **Affection:** *"(...) Yeah and I think you Ed show people very much that we are a couple when I arrive if you see across the room you shout 'hello this is my lovely woman'."* [CP, female]. **Support (and the lack of it):** *"(...) when I was diagnosed with dementia the thing that shocked was that when the doctor who came (...) was very unsympathetic and she... she said to me 'you've got dementia'. And so then she explained a little bit what dementia was but she didn't know very much and then she left and then she left me with this information. I went completely crazy."* [PWD, female]. **Caring:**

“(...) I always repeat what I said from the beginning you having dementia, Ed, that I will stay with you on the journey through thick and thin – I’m going to be here and help you (...).”

[CP, female]. **Conflict:** *“(...) but that stayed strongly with me as a view about the disastrous nature of conflict, if you allow conflict to get out of hand and you just go off fighting about them without having any way out (...).”* [CP, female]. **Caregiving spouse as the rescuer:**

“... And then Martin [CP] used to come and rescue me and would take me down to the, we’d both go down, to the front door, and cross over the road and back into our house (...).”

[PWD, female]. **Permission asking and giving:** *“(...) and it was a really hot day (...) and I did have a shower and then I came to him and said ‘I just had a shower in your bathroom, I hope you don’t mind’ and then Ed said ‘No, I don’t mind’.”* [CP, female].

Main theme 4: COPING WITH DIFFICULTIES

This main theme was formed of 14 sub-themes: Carer burden (also identified as a part of the *Relationships* theme), Physical health of caregiving spouse, Therapy, Looking ahead (also part of the theme *Change*), Emotions, Vulnerability, Care home, Adjustment, Maladaptive coping, Low mood, Acceptance, Assertiveness, Positive outlook. **Carer burden:** *“(...) there are some people who better not be left in in the care of their umm inevitably weaker partner, because they are going to an Alzheimer’s... into Alzheimer’s disease and the strain then for the healthy one, comparatively healthy one eh, could easily erupt in the sort of madness that leads to them killing their wives (...).”* [CP, male]. **Physical health of caregiving spouse:** *“I see that as being really significant that um that we had the intervention at a time where my blood pressure em shot up really high and I said I could wing it off emmm I was really stressed (...).”* [CP, female]. **Therapy:** *“(...) I needed desperately to have a very professional listener (...). It’s helped a lot... hm... because every day sometimes I’d be in a*

harsh mood towards him. I hated myself, but sometimes I couldn't stop it, but still I am now (laughter). But uh, if we have a very high-standard professional listener, therapist with us... is to understand what's going on in his mind, and if possible, in my mind (laughter), as well, from the third person's eyes. Especially to understand him, but also to understand myself."

[CP, female]. **Emotions:** "*(...) I forget sometimes I don't need to be afraid of things, how they are right now, saying how I feel.*" [CP, female]. **Vulnerability:** "*Well still here is*

vulnerable and uh... how do I put it? Help... uh hopelessness and uh... and I was psychologically and emotionally very weak (...)." [CP, female]. **Care home:** "*(...) she [the*

professional carer] was getting tired and overworked and I thought oh yes and depressed by the course of the illness a bit and umm eh she wanted to leave and give me a bit of time while we sorted something out. And so I started investigating care homes (...)." [CP, male].

Adjustment: "*(...) actually thinking about it some of my some of my expectations were I think, I think at the sort of the beginning trying to readjust...*" [CP, female]. **Maladaptive coping:** "*(...) there were questions about umm drugs and food and alcohol and ehh well I*

don't take drugs but em I certainly was eating too much umm em you know comforting myself and then emm the other thing was around alcohol and I said 'I do drink more' and I get home from work and I can't wait to have a glass of wine." [CP, female]. **Low mood:** "*(...) it was completely mugging me down. So what was all that about? That was all about the difficulty of remembering and going gently gaga. It's not a big... It's not a big eh it's not a collapse.*"

[CP, male]. **Acceptance:** "*And thoughts like that kind of... [pauses] kind of, sort of being able to look at dying without getting upset by the thoughts I think is essential. Is essential for anybody.*" [CP, male]. **Assertiveness:** "*Martin, I might remind you I'm talking now. First I*

don't want to be interrupted constantly A. And B, my idea of hallucinations might be different to yours, if you don't mind..." [PWD, female]. **Positive outlook:** "*(...) I found eh, yes I found*

new ways of looking at things and new ways of understanding Ed [PWD] and communicate better (...).” [CP, female].

Discussion

The main four themes which emerged were *Loss, Change, Relationships, and Coping with difficulties*. The themes related to changes in partners’ roles were intertwined with the theme related to loss – in particular the loss of cognitive ability of the person with dementia, which impacted upon their ability to perform daily tasks – subsequently caregiving partners took on more responsibility to compensate. We did not identify themes reported in other qualitative studies (Hellström, Nolan, & Lundh, 2007) related to extreme role changes where decisions had to be made on behalf of the person with dementia or themes related to feelings of powerlessness experienced by the person with dementia. On the contrary, the interviewed couples were keen to continue having reciprocal relationships as much as possible, maintaining a high level of individuality. Where diminished verbal capabilities ceased to support communication between partners, the couples relayed through their emotional bond and communicated through a shared sense of humour, shared activities or through small gestures of affection (“... *we have a lot of fun together*” [CP, female]). Humour, acceptance, as well as positive outlook, were notable elements of psychological resilience. These findings are in line with two studies, conducted on cohorts including more than 1,000 participants, showing negative associations between depressive symptoms and capability to live well in people with mild to moderate dementia and their carers (Martyr et al., 2019; Wu, Clare, & Matthews, 2019).

In agreement with other studies (Wadham et al., 2016), one of the major themes found in our analysis was related to the topic of loss. We identified this theme in several narratives,

including sub-themes about cognitive and physical decline, the terminal nature of dementia, the sense of loss of the partner (expressed by the caregiving partner) or loss of intimacy (expressed by a partner with dementia), and physical separation due to a partner with dementia living in a care home (expressed by both partners).

Contrary to earlier studies (Martin-Cook, Remakel-Davis, Svetlik, Hynan, & Weiner, 2003), our study did not find themes related to resentment among dementia caregivers. However, we did identify themes related to diminished coping – these were the themes of carer burden, maladaptive coping (over-eating and excessive drinking), as well as positive coping – the themes related to adjustment and acceptance. It has been well-documented that dementia caregivers suffer considerable carer burden, significantly greater than in comparable groups of caregivers or peers, and are likely to experience depression and physical health problems. Schoenmakers, Buntinx, and Delepeleire (2010) reported that depression occurs in one in three caregivers and it occurs more frequently in those who care for patients with dementia than in caregivers of patients with other chronic illnesses. It is not surprising, therefore, that participants' narratives in our study included sub-themes of emotional and physical vulnerability, low mood, overwhelming emotions or hopelessness. This finding adds to the broad existing literature on this topic; below we propose some important implications of our findings for improving the effectiveness of couple interventions.

In line with other studies suggesting the importance of social relationships between the person with dementia, their caregiving partner and health and social care professionals, especially when receiving the diagnosis (Jones, Mioshi, & Killeth, 2019; Pointon, 2011), we found themes describing the negative impact of the lack of adequate support at the point of diagnosis. There was evidence for caregivers' need for support, and fear of being left "on their own" with caregiving duties, as well as themes related to care homes and beneficial effects of therapy.

Implications for improving the effectiveness of couple interventions

Some extracted sub-themes (Positive aspects of the relationship, Connection/bonding, Caring) strongly suggest that couple interventions which are focused on dyadic coping and relationship quality may be the key to supporting the resilience of both partners. Current results suggest that the timing of such an intervention would be best around the point of diagnosis. This is in line with studies suggesting that the quality of the couple relationship prior to the diagnosis affects the maintenance of the bond in the context of dementia (Ablitt et al., 2009).

Couple-focused interventions could be an alternative to interventions focusing on changing carers' attribution and resentment, which showed no significant effect in one RCT (Martin-Cook et al., 2003). We recommend that an effective intervention for couples with dementia should include components focusing on relational aspects, caregiving partners' self-care, as well educational elements (drawing on evidence which indicates that mastery and caregiving competence are negatively associated with caregiver burden, anxiety and depression (Belmin, Hée, & Ollivet, 1999; Chan, Glass, Chua, Ali, & Lim, 2018; Gough et al., 2019)).

The relational component of such interventions should, in addition to facilitating non-verbal communication and supporting the emotional bond between the partners, also encourage and support couples' health-promoting behaviours and encourage, or even provide opportunities of engagement in shared activities, e.g., participation in music, singing or dance therapy (in line with RCTs showing effectiveness of these forms of interventions in couples with dementia (Davidson & Almeida, 2014; Särkämö et al., 2014)). Couples could also engage in mindfulness, yoga or Tai Chi practices (in line with the RCT studies showing beneficial effects of mind-body interventions (Farhang, Miranda-Castillo, Rubio, & Furtado, 2019)) or engage in moderate exercise (in line with several RCTs studies showing beneficial effects of

moderate-intensity aerobic exercise on cognitive function and quality of life of people with dementia (Särkämö et al., 2014; Song, Yu, Li, & Lei, 2018) and their caregivers (Rha, Park, Su, Lee, & Lee, 2015)).

An intervention component focused on caregiving spouses' self-care would allow them to express their caregiving burden and difficult feelings related to their caregiving role (in particular if the partner with dementia displays challenging behaviours), and to develop the skills related to self-care and to nurture their self-compassion (in line with research showing that self-compassion is an important element of resilience (Jones et al., 2019)), as well as improving their self-care behaviour, including adherence to health-promoting activities, such as relaxation, healthy diet, and physical and social activities allowing them to preserve their own mental and physical health (following the literature on carers of partners with cancer (Rha et al., 2015)). Our results, along with earlier research (Kajiwara, Noto, & Yamanaka, 2018), suggest that a component for caregiving spouses could also focus on improving their subjective appraisals of their roles as caregivers, and on enhancing positive aspects of caregiving (which were found in another study to be associated with lower burden (Cohen, Colantonio, & Vernich, 2002)).

Our study also suggests the need for effective interventions to address caregiving and care-receiving partners' depression. It is well-evidenced that depression in caregivers remains the main cause of early, or premature admission to institutional care (Schoenmakers et al., 2010). The study of Schoenmakers, Buntinx, and Delepeleire (2009) showed that depression occurred independently of objective care characteristics and the mental and physical state of the partner with dementia. Rather, it was related to coping mechanisms and to the perceived burden reported by the caregiver; the authors suggested that offering support and counselling to caregivers is an important factor in supporting and maintaining home-care situations. Moreover, depression was found to predict cognitive deterioration in various forms of

dementia (Chung et al., 2016). As follows, psychological interventions for couples with dementia could draw on models of work in couple therapy for depression, e.g., cognitive-behavioural approach (Barbato, D'Avanzo, & Parabiaghi, 2018; Cohen, Daniel O'Leary, Foran, & Kliem, 2014; Scott et al., 2016), psychodynamic approach (Hewison, 2017; Hewison, Casey, & Mwamba, 2016; Leff et al., 2000) and approaches addressing depression symptoms in dementia (Baruch, Burgess, Pillai, & Allan, 2019).

Limitations

We had no data about the type, duration or pharmacological or other treatments of partners with dementia and /or their caregiving partners. Also, we had no information about the functioning of the four couples prior to the diagnosis of dementia. More importantly, the study design did not include pre-intervention interviews, so we had no data to conclude about the effectiveness of the intervention (this, however, was not the aim of this study). The content of the interviews suggests that the participants had fairly harmonious relationships, which may have biased our sample towards including couples with higher relationship quality (couples self-selected for the interviews), and what follows, bias our findings. On the other hand, as the couples showed relatively resilient functioning, it allows us to infer that their relationship satisfaction might have been an important element contributing to their resilience. Finally, as the intervention had an experimental character, the sample of analysed interviews is relatively small.

Conclusions and future directions

This study indicates that high relationship quality and effective dyadic coping should be seen as a “relationship reserve” – a concept alike to cognitive reserve (Cabeza et al., 2018; Stern, 2014), that may act as a resilience factor in dementia. Well-designed, well-structured, multi-component couple interventions could enhance couples’ relationship reserve and, what follows, help to prevent carers burden, depression and burn-out (in more extreme cases also mistreatment or neglect (Coyne, Potenza, & Berbig, 1996), slower cognitive decline in the partner with dementia (Norton et al., 2009) and improve psychological and physical well-being of both partners (Riley, 2019; Riley et al., 2018). To be more effective, such interventions should include both an educational and a therapeutic component (Clarkson et al., 2017; Dickinson et al., 2017; Van’t Leven et al., 2013) and should be tailored for the needs of individual couples and adjusted depending on stages of dementia (Roland & Chappell, 2015) or carer’s characteristics (e.g., the gender of the carer, as being a female caregiver was found to heighten the risks of burden, depression and physical health complaints (Joling et al., 2016)). Future studies could investigate the feasibility and effectiveness of improved multi-component couple interventions, first in pilot studies applying pre- and post-intervention assessment, and then, if data showed promising results, using RCT methodology.

Authors contribution:

EP has written the manuscript. EM and AW carried out the initial literature review and thematic analysis. AB developed the LTWD intervention and carried out interviews with the participants. DH provided feedback and senior supervision of the thematic analysis. All authors critically appraised the manuscript and provided their edits and comments.

Data statement:

Data in the Appendix and quotations in the manuscript were anonymised, thus real names of people and places were replaced with fictional names. The original transcripts are available upon a reasonable request from the authors, subject to data protection limitations.

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APPENDIX

Thematic analysis: step-by-step description

1. Initial stage

Two researchers (EM and AW) with some experience in clinical psychology (both have been working for ca. 6 years in posts involving direct clinical contact) independently read the same transcript in order to familiarise themselves with the data and to generate initial codes. Next, these two researchers met to gain consensus on how the codes were being generated: they read the transcript page-by-page, compared their codes and discussed how they generated them. Following this, the two researchers met with an experienced clinician (ca. 25 years of clinical experience) and a qualitative researcher, DH, who discussed with them their initial coding and provided feedback and instructions on how to use a semantic approach to content analysis based on Braun and Clarke's method (Braun & Clarke, 2006). The coding of themes applied the approach described in Braun and Clarke (2006, page 84): "the themes are identified within the explicit or surface meanings of the data and the analyst is not looking for anything beyond what a participant has said or what has been written". The aim was to ensure that the researchers coded all data extracts inclusively, so as not to exclude any text at this stage. Following this feedback-and-instructions session, both researchers, EM and AW, coded two transcripts independently and split one transcript in half and then repeated the coding done by the other researcher. The list of all generated codes with the extracts of the text from transcripts has been done for each interview/transcript. The researchers met again with two supervisors (EP and DH) to review whether the generated codes closely matched the data extracts and that codes were not overly interpretative. The agreed outcomes were to re-read and re-code the transcripts with a new perspective: this was to ensure that text coding was more data-driven and descriptive rather than interpretive. Researchers (EM and AW) carried out this task and then met with a supervisor (EP) and cross-checked the codes generated by the two researchers for

one whole and one-half of the transcripts in order to check convergence and cross-coder agreement for the codes. It was found that approximately 80-90% of the codes generated independently by the two coders were the same or very similar, which indicated high fidelity of the two coders to the original transcripts and high cross-coder consistency.

2. Identifying sub-themes and grouping the codes

Next, three researchers (EM, AW, EP) collectively read the codes and discussed potential grouping of the codes based on the content and researchers' knowledge of the literature on dementia. Researchers then printed the lists of all the generated codes, cut them all out (so each code was on a separate stripe of paper) and then collectively decided about the assignment of each code to a sub-theme. Tentative sub-themes have been written on a large sheet of paper, and the stripes of papers with the codes were affixed underneath.

The sub-themes and the codes assigned to them were reviewed by the same researchers collectively a week later for their homogeneity and cross-checked with the related citations in the original transcripts to examine whether the context they were extracted from appropriately reflected the meaning of the sub-theme. Subsequently, 3 codes that did not fit any sub-themes were classified as "*miscellaneous*" and a further 3 codes were re-worded to better reflect the content of the original data from which they were extracted.

3. Identifying main topics (overarching themes)

Researchers (EM, AW, EP) collectively grouped the sub-themes, finally producing four overarching themes. Some sub-themes were categorised into more than one overarching theme, due to the overlapping content. Next, the researchers collectively checked the codes under each sub-theme (now assigned to the four more general themes) and cross-referenced them to the

original text extracts to check whether the codes formed a coherent pattern and reflected the meaning of the main theme.

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Living Together with Dementia: Interview Schedule

1) Can you tell me about your relationship with each other?

Prompts:

- How long have you been together?
- How did you meet?
- Do you like to do things together or are you quite independent of each other?
- Can you describe what you are like as a couple? Are you close? Are you similar?
- How much do you feel you can discuss things with each other?
- Do you think you are able to understand how each other feels?
- How happy are you with communication between you two?
- What strategies do you use to cope, together or not together?
- Do you feel you are a romantic couple?

2) Can you tell me about your experience of *dementia*? (*ascertain and use their term for dementia here*)

Prompts:

- Can you describe what it was like to receive the diagnosis?
- What changes have occurred in your life because of *dementia*? Can you recall more details of a specific incident?
- Did you talk about it together?
- Do you have the same views about what caused these changes?
- How has life been since the diagnosis? Have you adjusted to these changes?
- How would you describe your relationship after the diagnosis but before Living Together with Dementia intervention?
- Can you describe the impact *dementia* had on your relationship? Did it change things between you? Can you give examples of any changes in your relationship?
- Has there been a change in identity (in how you see yourselves or how you view your personality)?
- Have the roles or responsibilities held by you changed at all?
- Are there things you do more or do less together?
- Has dementia affected your plans for the future?

3) Can you tell me about your experience of *Living Together with Dementia* intervention?

(firstly remind them who was involved, how often they met, where it was carried out and have an idea about what happened in the sessions)

Prompts:

- Why did you decide to do Living Together with Dementia intervention?
- What were your initial thoughts or expectations about it?
- How did you get on with your practitioner?
- Can you describe what it was like at the start, during the middle and at the end?
- What was good about it?
- What was challenging about it?
- Could it have been better? How?
- Can you describe what it was like as a couple during sessions and in-between the sessions?
What were you like with each other?
- Can you tell me what it was like to talk about your feelings and relationship in the sessions?
What was it like to hear your partner talk about how they felt in the sessions?
- How, if at all, has your relationship changed after Living Together with Dementia intervention? (why do you think that has changed?)
- Have your coping strategies as a couple changed as a result of having undergone Living Together with Dementia intervention? How so?
- Can you describe any changes in the way you communicate with each other?
- What are your experiences of living with dementia after having had the intervention? How do you feel about?
- What are your thoughts and feelings for the future?
- Is there anything else you would like to add?

Codes in transcript 1

The couple lives apart: Partner with dementia (advanced stage) lives in a care home.

A= Therapist P=Caregiving spouse (female) E= Spouse with dementia (SWD) (male)

Data Extracted from the transcript:	Coded for:
<p><i>Page 1:</i> P: Yeh, well it was eh it was such a lovely experience because it at the time I made contact with you and I first of all had gone through... trying to find a permanent person with the help of um a contact that I had at the Tavistock</p>	Tavistock sessions were good
P:and I think at that time em for me em I was just feeling really burdened um full of (inaudible)	Feeling burdened
P: ...and um Barbara [<i>the therapist</i>] really helped um supporting us to talk together more and um what I realised was that it wasn't the end of conversations.	Not the end of conversations Supported to talk together
P: ... but you know we have conversations about all sorts of things and how the things would have been without the conversation I don't know but umm eh can I give you an example?	Having conversations about a variety of topics
P: ...so there's an example there, I was saying that um so I've made this journey going around in a bit of a campervan, ... (inaudible) so everything was replaced in the campervan and we were going to Stratford which is where she lives over the bridge, the Stratford eh bridge	Making a journey in a van Belongings were replaced in van
P: and in the van its really, it feels dangerous its windy and on top of this big bridge it was really scary and I was just describing this, I forget the context, I was saying I was trying really hard to keep hold of the wheel and keep hold of umm my my stress so I wouldn't upset Ed [<i>partner with dementia</i>] and Barbara said um why do you worry about upsetting Ed and I said well I don't know really um but it I felt like I had to protect him and I wouldn't of thought that before dementia	Dangerous and scary in the van Trying to control the van to not upset SWD Need to protect SWD SWD needs protection following dementia diagnosis
<p><i>Page 2:</i> P: and um that for me was a huge turning point where I realised you know its ok Ed is my partner I can share my stress with him and he can still complain to me about and help me (inaudible) if you know if I'm struggling</p>	Feeling able/ Realisation that spouse can share stress with SWD and vice versa

<p>A: and actually having a sense that you could turn to Ed still more P: and without doing so when I wasn't doing that I could feel myself being frightened underneath but also irritated you know "just a minute Ed I've got to concentrate, I've got move on" and actually I didn't need to do that I could just say I'm really scared of this wind it's moving the van around and um you know it's worrying for me.</p>	<p>Not sharing with SWD led to fear and irritation Spouse feels able to share fears with SWD</p>
<p><i>Page 3:</i> P: shall I.... umm how's it for you Ed, how's your relationship with me E: (inaudible) it's good yeah P: yeah</p>	<p>Asking for SWD's views of relationship</p>
<p>E: and eh things happen and eh but (inaudible)stops (?) P: one of things has stopped since then is when I come and see you and I come and see you about three times a week and um and we have a lovely time and you tell me how much you love me and I tell you how much I love you and I think umm and when its time for me to go home or do some shopping or get supper prepared and um its really sad and I go. Sometimes you get really upset about that</p>	<p>Visiting spouse in care home regularly Declaration of love between each other Feeling sad when spouse leaves</p>
<p>P: no I don't think it's bad for me but sometimes it's hard to separate its hard to um leave each other when we are having a nice time</p>	<p>Hard to separate from each other</p>
<p>P: but the times that we do have together umm we talk a lot and we have a lot of fun together</p>	<p>Communicating and having fun in whatever time we have together</p>
<p>A: These are the continuing conversations that you were talking about? P: yeah yeah they are and going with it wherever it goes out and a lot of time I follow and something (inaudible) and it's early days. I think it's been really confusing so we tried to um you know we found a local park that we go to and we found like a cafe bar and eh there ...it's very often we drink water and we have these places we can go outside of the home</p>	<p>Identifying different places to visit outside of care home</p>
<p>P: ... I go to psychotherapy once a week and I was telling the therapist about how I came here one day and it was a really hot day and everyone was having supper and um so I went into his room and there was, um a bit of everything thrown together and he's got a shower that's got a (inaudible) and I did had a shower and then I came to him and said "I just had a shower in your bathroom I hope you don't mind" and then Ed said no I don't mind</p>	<p>Permission asking, permission giving</p>
<p><i>Page 4:</i> P: ...and you know my therapist said that also says that you are a couple</p>	<p>Nice to be recognised as a</p>

<p>A: yeah P: that's a nice way of putting it A: I think it's a wonderful way of putting it. Yes absolutely. Yeah and establishing being a couple here in a new place</p>	<p>couple in this place</p>
<p>P: yeah and I think you Ed show people very much that we are a couple when I arrive if you see across the room you shout "hello this is my lovely woman" E: <i>laughs</i></p>	<p>Showing people that we are a couple</p>
<p>P: and then you come running over and and and you know you hug me so tight you hold me so tight that you shake and its such...it's so full of love. And umm that's another communication</p>	<p>Run over and hug me tight - another communication</p>
<p>P: that we have umm and that I feel...I feel very loved.</p>	<p>Feeling loved</p>
<p>P: they have a lot of, there's activities on everyday there's always something happening isn't there E: (inaudible) come and go as well P: and there's lots of volunteers and they bring they move the chairs in so everyone always has a seat and um the first day that you came here Ed there was umm I think it's a music club that's on and you came and you came and sat down and listened to music and um at one point I closed my eyes and it was it was a piece from 'Chaviaka' and I was just away with this music and you gave me (inaudible) "Pauline are you alright?" and I said "yes I'm really alright" because it was so relaxing and calm and just beautiful</p>	<p>Activities happen everyday in the home Everyone has a seat Listening to music Getting lost in the relaxing music</p>
<p><i>Page 5</i> P: I was here one day when we in the middle part of the hallway and um I mean it was a folk band and eh we got up and had a dance E: that's right P: and people clapping and one woman kept (inaudible)</p>	<p>Having a dance together</p>
<p>A: Gosh, so it sounds in which there are lots of ways you are making this a sort of new home in a way as a couple, putting your mark on it P: yeah actually (inaudible)...yes well from my point of view and we did dancing very well before umm there was a lot of times where it was very difficult there and um we we we're respected as a couple</p>	<p>Feeling respected as a couple</p>
<p>A: really? P: and emmm and it just didn't always feel very welcoming</p>	<p>Didn't always feel welcomed</p>

<p>A: and that's very heartening to hear that here you do feel respected as a couple</p> <p>A: yes</p>	<p>Now feel respected as a couple</p>
<p>A: they recognise...</p> <p>P: absolutely it's such a contrast and you know really important for both of us because we always had a really close relationship haven't we</p> <p>E: yeah</p> <p>P: and umm for me umm it's very important that continues</p> <p>A: yes</p>	<p>Important for both of us to feel respected as a couple</p> <p>Important to continue close relationship</p>
<p>P: and umm one of the things... you know I've said a few times that especially in times where we are struggling with some problem or another um I always repeat what i said from the beginning you having dementia Ed that I will stay with you on the journey through thick and thin, I'm going to be here and help you when feel the need for help or when you need to be held</p>	<p>There are times of struggle in relationship</p> <p>Spouse committed to Dementia journey</p> <p>Through thick and thin</p> <p>'I'm going to be here and help you' (caregiving spouse to SWD)</p>
<p>E:... sounds like are we ok?</p> <p>P: we are very ok. The thing about saying that, even now we have different home, we got different homes and we've got our relationship together and um but even when I am not here with you um in mind I am always with you cause I think about you you know every day and lots of times during the day</p>	<p>We are ok</p> <p>Different homes but relationship still remains</p> <p>Even when I am not here with you, in mind I am always with you (caregiving spouse to SWD)</p>
<p><i>Page 6:</i></p> <p>P: yeah, cause we are strong together</p> <p>E: we are very good together</p>	<p>Stronger together</p> <p>Good together</p>
<p>P: hmm that's really good. And (inaudible) ...you know (inaudible) we are very close as a family (inaudible) you know we just have a lovely party together um I think (inaudible) you know everyone is thrilled Ed is here in such a lovely place and you that we can stand to have a really good time together</p>	<p>Close knit family</p> <p>Other family members are thrilled SWD is in lovely place</p>

	Experience good times together
P: but half-past three. The other thing about Barbara umm was um there are two things that really stick in my mind. One of them was um reminding me about being curious about things um because when I was in the midst of all sorts of feelings and emotions sometimes umm I wasn't able or I forgot to stand back and be curious to ask myself the question "I wonder why, I wonder why I'm feeling upset about something I'll wonder why this feels so difficult	Reminded to be curious Can forget to be curious whilst in midst of feelings and emotions Ask myself, why am I upset, why is this difficult?
P: and umm and I still, I don't know whether this is... but a lot of the time and um for particularly if I get tired or you overwhelmed overruled em then, then I stop being able to think clearly	Being tired or overwhelmed impairs ability to think
P: and um it really helps me to be able to, be able to just stop and just ask myself the question and there's something about curiosity that umm that's umm vital in this kind of journey	Curiosity is vital in the journey
<i>Page 7</i> P: yeah and when I think, and I suppose it's true of everyone but for me anyway, when I can think then it can become unhealthy and underneath I'm doing umm, I'm thinking you know, I keep saying I'm thinking no, but I'm umm I can explore myself and the ways that I'm feeling umm	Exploring self and the ways I'm feeling
P: yeah and umm the other, I mean that's, that's a big area umm for me that I have continued um just reflecting on and umm that- the other area was um it was, I don't know whether it was right at the beginning where we filled in all the forms or whether it was the end when we filled in all the forms again (inaudible) or the same question would of come up but em it was question of what sort of, what sort of ..what kind of ways of I can't remember the the....the phrase but it was what do you use to get yourself through you know difficult times and then there questions about umm drugs and food and alcohol and ehh well I don't take drugs but em I certainly was eating too much umm em you know comforting myself and then emm the other thing was around alcohol and I said "I do drink more" and I get home from work and I can't wait to have a glass of wine	Continued to reflect Getting self through difficult times by eating too much and comforting myself Drinking more alcohol Get home from work and can't wait to have a glass of wine
P: and eh Barbara's response....I don't know the exact words but she just eh she just put it in such a way that I felt anything but judged or but eh she didn't say go ahead drink the whole bottle of wine but she gave me permission that it was ok P: And that...that's was just so valuable to me	Not feeling judged by therapist Therapist didn't encourage excess drinking

	Therapist gave permission that its ok
P: because I was often critical of myself....	Self-criticism
<p><i>Page 8</i></p> <p>P: especially now I look back to em how tough it was</p> <p>A: yes</p> <p>P: I think, I mean no wonder I eh I mean no wonder I needed a glass of wine</p> <p>A: yeah</p>	<p>Reflecting on how tough it was</p> <p>No wonder glass of wine was needed</p>
P: (laughs). But no I took a decision not to drink (inaudible) but now I don't feel the need to and both were ok at that time eh you know I needed to and I lost weight em	<p>Decided not to drink</p> <p>Don't feel need to drink now</p> <p>Loss in weight as a consequence</p>
but now what's really good about now is that emm I have got my life back you within my relationship (inaudible) but my eh you know I say yes to everything em	It's really good that 'got my life back'
<p>P: you know outside of work emmm whereas for a long long time I was emm I was in a bubble [...] and when I said yes to that over a year ago I always said not it's then I got ...(inaudible) I've got too much to do, I don't know how things are going to be I can't commit to things</p> <p>A: yes</p> <p>P: and um there was a reality in that that was also ummm a bit I think my head was just too pulled to be able to to commit.</p>	<p>Felt in a bubble for a long time</p> <p>Felt like too much to do</p> <p>Feeling unable to commit</p> <p>Felt head was too pulled to commit</p>
<p>E: (inaudible).....</p> <p>P: Sorry to interrupt you, I just thinking you have got a lot in the reserve services and I'm often struck, like I mean you are telling me that story and then you tell me that you sorted it out and eh you know problem solving</p> <p>A: yeah</p> <p>P: yeah and I suppose that is something that you have always done. You have helped me sort out a lot of my problems.</p> <p>E: that's right</p>	<p>Problem solving</p> <p>Spouse recognises SWD problem solving ability</p>

<p><i>Page 9</i></p> <p>P: and your own problems and eh you know ... you were sorting out the cutlery earlier when I came in to the kitchen</p> <p>E: yeah?</p> <p>P: yeah. putting spoons and forks away gutting everything in it's path</p> <p>A: (laughs)</p> <p>P: which is really good</p> <p>E: (inaudible)</p>	<p>SWD sorts the cutlery in the kitchen</p> <p>Its good that SWD puts cutlery away</p>
<p><i>Page 10</i></p> <p>A: and how emm managing these changes has been so important for you and this latest one has made you feel more available I think you are saying in a sense</p> <p>P: yeah. It has. Even umm thinking about together that there is a lovely room that we can come through to and have a quiet talk with you. We wouldn't have been able to do that (inaudible) Ed would has been gone to his room, children sitting on the bed emm or going into the dining room with constant interruptions and emm it just feels so free and the staff are lovely....</p> <p>A: so its a tremendous relief after Abbey field yeah?</p> <p>P: yes yes it has been just continuously been</p>	<p>New care home provides opportunity to feel free when together</p> <p>Feeling relieved in a new care home</p>
<p><i>Page 11</i></p> <p>P: Well I'm talking about here (inaudible), it's both really where the umm you know the place itself you know is just really comfortable and homely</p>	<p>Care home is comfortable and homely</p>
<p>P: yeah we often go into the garden which goes...its lovely here but it goes right round the back and it's got emm you know wild parts to it and lovely wooden animals</p> <p>A: gosh</p> <p>P: there's a squirrel and a cat and beautiful trees and flowers and birds umm it's lovely hmmm. For me coming here, to be with you Ed I feel umm I just always feel so happy. I feel really happy coming to see you but I also feel really comfortable when I am here.</p>	<p>Feeling happy with care home environment</p> <p>Feeling happy and comfortable when visiting SWD</p>
<p>P: and eh its a place where we can carry on our relationship and feel feel free and respectful.</p>	<p>Relationship can continue in care home</p> <p>Feeling free and respected</p>
<p>P: emm just this really wonderful relationship that we have had since the time I met Ed and I thought dementia was ending that eem but it hasn't ended it, it's changed it.</p>	<p>Wonderful relationship</p>

	Dementia has changed the relationship but hasn't ended it
<p>P: But there is a lot of good things happened that I haven't haven't really thought would</p> <p>A: really?</p> <p>P: yeah and continued things like, your amazing sense of humour eh I can't remember some of the quips that you made when we had the meeting emm earlier but eh referred to, what you did today and you said emm that emm that i got up this morning and she laughed that actually it was a joke but it was also true that You did get up this morning and there were things in-between that you couldn't remember what you had for lunch but that's not really important. You remember who I was and that I was your girlfriend an umm yeah. Yeah these things are everything ...</p>	<p>Good things have happened unexpectedly</p> <p>Continues sense of humour</p> <p>Making jokes</p> <p>SWD does have memory decline but this isn't important</p> <p>Remembering who spouse is</p> <p>Remembering what spouse represents 'girlfriend' is everything</p>
<p><i>Page 12</i></p> <p>P: I dropped a lot of the unimportant clutter that used to emm upset me and emm that I would focus on and emm I don't know how I would be of course without dementia emm (inaudible)</p> <p>A: yeah yea</p> <p>P: emmm but emmm the journey has improved me</p>	<p>Dropped unimportant clutter that was upsetting</p> <p>Dementia journey has improved me</p>
<p>P: In what sorts of ways do you think? It's made me ... I'm mental health nurse by background</p> <p>A: yeah I remember</p> <p>P: emm and you know I've looked after people with dementia and people in hospital with dementia emmm but I've learnt more about Ed emm how can I explain it.. in a way that I thought I knew everything but emm but I think I've learnt more about your vulnerabilities and emm you know some of the way that previously I would see you in one way and as a very strong person but I think with umm some of the things that memory loss strip away then it leaves more of the real person and so I think I haven't thought about this before Ed. This is the first time I've said it but I think it's more about, it's almost like meeting for the first time. I see some really lovely things eem about you know and some of the</p>	<p>Learnt more about SWD's vulnerabilities</p> <p>Seeing SWD as strong person</p> <p>Memory loss strips away and leaves real person</p> <p>Feels like meeting SWD for the first time</p>

<p>things that would make me warm to you even more than I normally are, how much you need me on this journey emm and I'm just so willing to be on it with you that's emm it makes me feel. It me feel good and fulfilled in a very different way than before but good. Really good.</p>	<p>Spouse feels needed on this journey</p> <p>Willing to be on the journey</p> <p>Feeling good and fulfilled in a different way than before.</p>
<p>P: (inaudible)...there's a beauty you know there's a there's an inner beauty that shines out of you E: yeah.inaudible.... inaudible</p>	<p>Inner beauty</p>
<p>P: hmm, and that's what we do best. Sometimes I find it hard when you are trying to tell me something Ed, I feel like it's something really important you are trying to tell me but I don't always understand it. I try to understand it.</p> <p>E: hmm</p> <p>P: I love you</p>	<p>Hard to understand SWD</p> <p>Caring spouse trying to understand SWD</p> <p>Caring spouse loves SWD</p>
<p><i>Page 14</i> P: see you in a minute. (pause) I feel very lucky that we, when I contacted em Tavistock it was just about it was just about really what we wanted it to do</p>	<p>Feeling lucky</p>
<p><i>Page 15</i> P: umm I think that it could of been...more longer um and I think that came out when we had the follow-up at Warren Street [<i>caring partner refers to therapy sessions at Tavistock Relationships</i>]</p>	<p>Intervention could have been longer</p>
<p>P: umm i just found it eh it was like finding a port in a storm for me um at that time and what I have gained from it has saned me and even though I wanted more and I think a lot of people have the same view have said that. I found eh, yes I found new ways of looking at things and new ways of understanding Ed and communicate better ehh and I still (inaudible)... I thought Barbara [<i>the therapist</i>] was excellent eh she just got us and eh I felt free to just to say whatever... I wanted to cry eh (inaudible)...all of the emotions of life that were very much there and just needed to come out</p>	<p>Finding a port in a storm</p> <p>I have gained from therapy</p> <p>Wanted more in sessions</p> <p>New ways of looking at things</p> <p>New ways of understanding and</p>

	<p>communicating with SWD</p> <p>Therapist was excellent</p> <p>Felt free to express emotions that needed to come out</p>
<p>P: and eh and I think my health has improved as well. I see that as being really significant that um that we had the intervention at a time where my blood pressure em shot up really high and I said I could wing it off emmm I was really stressed so overbearing and umm I couldn't think of a way to help myself you know apart from what I was doing having already been in therapy emm having the supports umm but it was trying to hold down a full time job and you know be a carer as well</p>	<p>Physical health of a caregiving spouse</p> <p>Couldn't think of ways to help myself</p> <p>Holding down a full-time job and being a carer</p>
<p>P: So it's given me loads yeah and I think it's given a lot as well cause we we ... I remember one day when she [the therapist] came and eh I think we were talking about difficult things and Ed went upstairs for a rest on the bed and she... I think I spoke to her and she encouraged him to come back down again and I said it was ok. Its fine Ed was asleep so but you know explored...sometimes we explored things together and sometimes it was on my own</p>	<p>Therapy has given a lot to us</p> <p>Explored things together in therapy</p> <p>Explored things alone in therapy</p>
<p><i>Page 16</i></p> <p>P:...actually thinking about it some of my some of my expectations were I think, I think at the sort of the beginning, trying to readjust to this awful like.... emm and I was clinging on to certain things as in the thoughts and I was so frustrated and so angry at times emm but so (inaudible) down it was just such a whole mixture of things and emm I think being... being able to be honest about emm about how I felt and eh you having (inaudible)...lost I felt some of the time em it was just emm it was an amazing thing to be able to do that. And to be able to do that together as well</p>	<p>Making readjustments</p> <p>Clinging on to thoughts</p> <p>Feeling frustrated and angry</p> <p>It is amazing to be honest about feelings alone and together</p>
<p>P: and you know the things that you know like.....(inaudible) talks about then I know now... I forget sometimes I don't need to be afraid of things how they are right now saying how I feel</p>	<p>No need to fear how things are right now</p>
<p><i>Page 17</i></p> <p>P: ...but that stayed strongly with me as a view about the disastrous nature of conflict if you allow conflict to get out of</p>	<p>Conflict</p>

hand and you just go off fighting about them without having any way out...	
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Transcript 2

The couple lives in their home, a professional carer, Megan, visits every day. The female spouse has an advanced Alzheimer's disease – present in the house but not participating in the interview.

A= Therapist P=Caregiving spouse (male) T= Spouse with dementia (SWD) (female)

Data extracted from the transcript:	Coded for:
<p><i>Page 1:</i> P: and also emmmm I mean the whole idea of continuing with your life together as a married couple is good a good idea in theory but kind of makes the hackles rise a bit and I think Megan and I have a problem which is a bit of jealousy between us.</p>	<p>Continuing life together</p> <p>Jealousy</p>
<p>P: because of course she i mean shes...we've talked about this she is, she is committed to being a carer and partly I think its the cultural thing the feeling (inaudible).. and partly she had a really big family and emm she is committed to looking after people who give no repent really</p>	<p>Commitment in caring role</p>
<p>P: and you compare looking after somebody who is dying with somebody who is at the beginning of life, a baby, and the thing is the baby looking after and caring which people make a big woo-hah about...</p>	<p>Caring for the dying vs Caring for new life</p>
<p>P: After three or four years you're going to see real progress and get fulfillment out of that.</p>	<p>Progress and fulfillment in caring</p>
<p>P: What you have done will help create this being whereas when it is somebody who is going into decline it's more difficult and (pause) and and more upsetting and you have to have a kind of commitment to it</p>	<p>Caring for someone going into decline is more difficult</p> <p>Commitment to caring</p>
<p>P: which I think probably is more difficult for me than for Megan. and she eh and I'm getting bit thick and my brain is definitely not working properly in the way that it used to and eh it was always a difficult a really bit</p>	<p>More difficulties for spouse than carer</p> <p>Brain isn't working the way it used to</p>
<p><i>Page 2:</i> P: and eh (laughs) it (pauses) umm for that you see that there I introduced a lema into my talking and my ideas and it's actually thrown out my memory, how you say it derails me. That's right and that derailment is is I think umm eh a year ago I tried to give a talk to a research group in Cambridge about the stability and I got into the most</p>	<p>Losing memories</p> <p>Feeling derailed</p> <p>Difficulties with writing</p>

<p>terrible difficult with it because as I was writing which I enjoy doing very much when there was a stream of writing, a stream of con a stream of consciousness coming out</p>	<p>Stream of consciousness</p>
<p>P: but when i came back later and wanted to put it into shape and kind of tailor it a bit.....I couldn't remember what I had said or thought and I got into a terrible depression about that</p>	<p>Feeling low due to memory loss</p>
<p>P: and Sean came down here and said why was I looking so gloomy and I explained why I was looking very gloomy and he sorted me out and he kind of pulled what I had written into shape and said can't we do it like this and like that and that was a big help but that talk wasn't very good as in I had my view and (pauses) and I've never been asked to do another (laughs)</p>	<p>Looking gloomy Feeling supported</p>
<p>P: eh not at that kind of level and (pauses) that's and another thing indeed the London review books published an article on oh there's a name for it ... a name for the modern geological era which is a name given to this era which is dominated by homosapians and its got some funny greek title. Em anyway and I looked at this and thought hmmm actually I could take this article which is about social evolution and and build round it a picture of the evolution of planet Earth in so far as I think there are cultural and sustainability lessons to be learned...</p>	<p>Social evolution Evolution of planet Earth Cultural and sustainability lessons to be learned</p>
<p>P: from all that and I wrote I wrote quite a bit of this article but then I got very bored of it and have given up. Hmm and I'm at the moment in the process of having to give up any creative umm (long pause) ahh any creative edition will do but you see I can't remember the words, to our society which I think ...our political system is not, is not helping the sustainability argument at all.</p>	<p>Feeling bored and giving up Giving up creativity Memory loss</p>
<p>P: ..and it completely mugging me down. So what was all that about? That was all about the difficulty of remembering and going gently gaga. It's not a big... It's not a big eh it's not a collapse</p>	<p>Feeling down Difficulty remembering</p>
<p><i>Page 3:</i> P: But I think and my ability to handle computers got very very slow and (inaudible) I keep crashing it and crashing all the work I've done</p>	<p>Slower abilities</p>
<p>P: not too bad but yes and actually you see I've got this book and I try vaguely to classify what notes I'm thinking about but actually it's just a terrific muddle and really no use to man or beast</p>	<p>A terrific muddle and no use</p>
<p>A: You were telling me about real losses that feel in yourself as well as changes P: yes, yes that's right and in a way that's I mean of the things that I've been thinking more about is the practice, the engineering practice which I started and eh there has been more emphasis on the social context of the practice because it was, we set it up, wait now, as cooperate where everybody was the agent of every other person and had to act in the other member's best interests and and that, we had a fifty-year anniversary and I was asked to give a little talk about that</p>	

<p>P: to about 300 people (inaudible) and umm the eh and of course what one has to say at an anniversary like a 50 year anniversary is that there is dignity to look back at how it all started but more importantly you better be looking forward to where it is all going to go</p>	<p>Looking back on how it started</p> <p>Looking ahead</p>
<p><i>Page 4:</i></p> <p>P: so and so actually where it was all going to go is in the interests of the people who have joined the practice in the last decade or so and eh actually the banking crisis has deflected a lot of clever scientist mathematicians away from being bankers and coming to joining the engineering which I, I mean there are some amazingly smartly bright people now in the practice which is lovely and umm but then at the same time the economics are getting all, I mean they are being misguided I think is probably the safe thing to say and all the bad news in these talks concentrates on salaries</p>	<p>Where are things going now</p> <p>Change in roles</p> <p>Becoming misguided about it all</p>
<p>A: Can I you a bit about how things are with you and Tessa? Things have changed a lot since I was...</p> <p>P: They have changed havn't they</p> <p>A: yes yes I was just about to say that actually at night we have, there is quite a lot of, well I grasp Tessa because she has got a bit of a tremor and also if she is going into kind of upset whinging mod (makes groaning noise) noises actually to hold her wrist and squeeze it gently. Very often quietens her down and so there is you can feel, well I feel that a communication taking place</p> <p>A: yes</p> <p>P: just you know with a bit of hugging but that's less less demonstrative than a kind of warm flesh to flesh sort of grasping of her wrist and her hands and when she gets, she, her right hand tends to grasp but it does like that very hard she's squeezing very hard. Even to the extent that she sometimes breaks the skin....</p>	<p>Changes in relationship</p> <p>Hugging</p> <p>a communication by hold her wrist</p> <p>Squeezing very hard</p>
<p>P: so that there is there is a lot of emotion in what she is doing with her hands and those movements</p>	<p>Lots of emotions</p>
<p>P: ... (inaudible) and a little bit of that because there's I mean she keeps me awake at night with the screaming</p>	<p>Kept awake at night</p>
<p>A: Do you find that difficult</p> <p>P: hmm not too difficult, it has, I have shouted at her once or twice in a loud voices but it's eh counterproductive (laughs) and eh it's interesting because I do, I certainly have a reputation for losing my temperature, certainly Megan [<i>the carer</i>] who is very straight lace and whose father was a was a police officer in the Philippines, a high ranking police officer so she thinks I was controlled much too easily (laughs) I mean losing control is just letting your emotions out so so where do we go from there</p>	<p>Shouting at spouse is counterproductive</p> <p>Losing my temperature</p> <p>Losing control</p> <p>Letting emotions out</p>
<p><i>Page 5</i></p>	<p>Father was depressed</p>

<p>What sorts of things or are there particular things that you think are more likely to make you feel full of emotion like that and...</p> <p>P: its emm it's very different that's where my memory for my reaction with people is very poor and I attribute to my upbringing for I was about seven silly psychological fantasies I call them (laughs) but thinking that em my father graduated in chemistry in medicine and then came to St Matthew's hospital and eh was the houseman there and he did some neurologically-based research and I think got very depressed by it because it didn't really work and he didn't, he wasn't able to do anything for old old mad people so he was one of the first Alzheimer's researchers</p>	
<p>P: Possibly, I don't know so I don't think he wrote any papers on that but he did then go to the Addendrooks Hospital just about when he got married and I think started off on an analysis with was it (inaudible), I don't know, I can't remember and it doesn't really matter except that I think he got quite depressed</p>	Feeling depressed
<p>P: This is hearsay really from people who have told me he was and then so his marriage began to break up so by the time I was 2 my mother and my father were having shouting rows and emm and I hmm not long after that they separated...</p>	<p>Marriage breakdown</p> <p>Marital separation</p>
<p>P: I went to live with my mother in Hill road and she put me in a bedroom which was in a kind of an annex to the flat she had and would she was a gay socialite journalist working for <i>[name of the magazine]</i> and founding a project called <i>[name of the project]</i> which is, was part of the <i>[name of the magazine]</i> tradition and then she became a journalist in the <i>[name of the magazine]</i> a sort of political journalism which for all women in 1938 was probably quite umm quite a surprise</p>	Living with mother
<p>P: I remember being bored walking about in our garden, there was a little garden to the flat and wondering what I was going to do and then then when the war broke out she decided to have a change into her... and her brother lived in the Caribbean and was the commissioner for forests in the Caribbean and he said why don't you come out, evacuate to Caribbean and so in June the middle of June we went to the Caribbean and I don't remember my mother much there but she then left in about 1942 or something like that in about I think to get married to somebody else, the divorce having gone through by then and her ship was torpedoed by the Germans and the when my uncle told me that she hadn't arrived in England it left me completely cold because the trauma when my mother left was when she went to get into the boat</p>	<p>War broke out</p> <p>Evacuated to another country</p> <p>Traumatized when mother left</p>
<p>P: and I can remember that kind of being left screaming in the house while she drove off</p>	Left screaming in house
<p>P: and that kind of I don't I don't know whether that that sort of tailoring of of your childhood emm I mean when people talk about truama I, my hackles rise cause I think don't be so bloody silly cause there are plenty of survivors</p>	<p>Trauma in childhood</p> <p>Plenty of survivors</p>
<p>Page 6 P: eh on the other hand, the survival perhaps leave some traces difficulty</p>	Trauma survival is difficult
<p>P: and umm and whether and whether that has got a bearing on, I mean the outcome of your sort of work might be there are some people who better not be left in in the care of their umm inevitably weaker partner because they are going to an Alzheimer into Alzheimer's disease and the</p>	Left in care of weaker partner

<p>strain then for the healthy one, comparatively healthy one eh could easily erupt in the sort of madness that leads to them killing their wives or</p>	<p>Strain on healthy one</p> <p>Leads them to kill spouse</p>
<p>P: and eh those those kind of outcomes have to be thought about really, I mean outcome of interference in people's lives</p>	<p>Interference in people's lives</p>
<p><i>Page 6</i></p> <p>P: and it also and that's right, do you see that's when my bloody memory, what prompted all of that was the fact that when Sean got that illness it was, my father had a name for it, um we got closer together</p> <p>P: kind of there was an emotional bond in there around Sean being... lying in a coma in Ely hospital</p>	<p>Feeling closer following illness</p> <p>Emotional bond with ill person</p>
<p>P: Yes. Yeah , yeah. Hmm and actually to a certain extent now I feel, I feel, I feel feelings here eh when Tessa is needing support</p> <p>P: Which are fulfilling actually they they.. I mean they are anxious depressing feelings but they are supportive as well for me, I mean I have</p> <p>P: I take comfort from, (laughs) from feeling those feeling</p>	<p>Feel feelings when providing support</p> <p>Anxious and depressed feelings</p> <p>Take comfort from feelings</p>
<p><i>Page 9</i></p> <p>P: and in a way when it comes to that house you see I think rather than just abandon it it's eh supposed to have some ideas of mine about sustainability in it and umm but a statistical sample of one is not enough to show anything so it's not its merely a statement of intent and umm and actually just living in this house, making it as comfortable as we can and the fact that it's to big is a pity um and eh then wait until one of us dies and the other one gets the residue of the estate and there's probably enough to live off as long as we don't live too long (laughing).</p>	<p>Making house comfortable as possible</p>
<p>And thoughts like that kind of ... (pauses) kind of, sort of being able to look at dying without getting upset by the thoughts I think is an essential. Is essential for anybody. On the other hand you don't. It's difficult to talk about it</p>	<p>Look at dying without getting upset</p> <p>Difficult to talk about death</p>
<p>P: and certainly I got, I mean, friends I've got who are on the verge of dying seem not to want to talk about it.</p>	<p>Talking about death is difficult</p>
<p>P: umm and because other people are all sitting around just being a bit gloomy (laughs) not helping, who knows. So that's....what else goes on here. I mean there's, there's the arrangement with Megan</p> <p>A: hmm</p>	<p>Sitting around being gloomy</p> <p>Pushing the carer too hard</p>

<p>P: who is slightly I mean she, she did come down and said she thought I was pushing her too hard</p> <p>A: pushing her or pushing...</p> <p>P: pushing Megan, the carer, too hard</p>	
<p>P: and she was getting tired and overworked and I thought oh yes and depressed by the course of the illness a bit and umm eh she wanted to leave and give me a bit of time while we sorted something out. And so I started investigating care homes and eh and that investation, in order partly to have a bolt-hole ready for if Megan really did get fed up and leave</p>	<p>Carer depressed by the course of the illness</p> <p>Carer wanted to leave</p> <p>Investigate care homes</p>
<p><i>Page 10</i></p> <p>P:.... and then there was another one and then you know we we had also been looking at palliative care and thinking the kinds of treatment that we as an attorney of health and welfare should be thinking thinking about and one of them was don't have repeat antibiotics because it's an indication that you have got an immunity building up in the lungs of bacteria, of immune bacteria and and then because the brain is not controlling the epiglottis properly, you're ingesting food into the lungs too often and too much and its causing nutrition for the bacteria</p>	<p>Looking into palliative care</p> <p>Bacteria building up</p> <p>Brain not functioning well</p>
<p><i>Page 11</i></p> <p>P: and in a way ah who cares, there you are there's a way there is a path to being dead there which maybe involves some suffering I mean when you're ill, really ill I don't know and certainly you don't ...when thinking about Tessa and thinking about her kind of (makes grunt noise) and being upset the capacity to have intense thoughts is presumably decaying as well as everything else so that the suffering you're having in as you approach dying is quieter than, I mean when you to sleep its..the pain has the quite intense to wake you up, I think. Well it certainly has for me and um so that really all this concentration on the degree of suffering of Alzheimer patient I comfort myself with by saying "it must be slightly less intense"</p>	<p>Pathway to death</p> <p>Everything is decaying</p> <p>Degree of suffering in Alzheimer's is less intense</p>
<p>P: yes and in a way I think I mean like whether to build this house here I've just be vacillating about it for the last six months and in a way i think I'm not , I'm just going to let events take their course and the architech has applied for some planning permission because he's altered the house during the development of it and actually planning permission is refused I shall just say well we stop then</p>	<p>Let events take their course</p> <p>Shall we stop</p>

<p>P: ...and eh and its not its not really the issue. In fact the three boys are all in favour of the process of the building going on but actually I think that we live here quietly getting doddery and letting the garden do what it does umm is alright, would be perfectly alright to do that but its not, its its not my character to make a decision about that. I can't do that. I never have been able to do that</p>	<p>Let things continue as they are</p> <p>Not within character to make decision like that</p>
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Transcript 3

The female spouse with early-stage dementia is quite active during the interview. The professional carer is present in the house, but not participating in the interview.

A= Therapist M=Caregiving spouse (male) F= Spouse with dementia (SWD) (female)

Data Extract	Coded for
<p><i>Page 1</i></p> <p>M: Normally, the first group, the first series of sessions you found helpful didn't you?</p> <p>F: Yes</p>	Sessions were helpful
<p>F: Well I just wanted to mention that my daughter...who's um...who's disabled with their mess</p>	Child with disability
<p>F: But she went to a conference, she was invited to a conference in Bulgaria because she and her husband had written about 'sex for the disabled'</p>	Sex for the disabled
<p><i>Page 2</i></p> <p>F: So they, and they told her that practically most GP's didn't know very much about sex</p> <p>F: Well, I've never tried them out on this one but they were....barely concerned that they ought to know more about sex, worldwide</p>	GP's lack knowledge about sex
<p>F: And they had lectures from morning to night and they were absolutely exhausted when they came home</p> <p>A:Wow sounds like a marathon</p> <p>F: Rarely, they've been very, they've been very um.....enterprising in this....uh for disabled sex</p>	Promoting disabled sex
<p>F: I wont bored you with the details because they haven't given me the permission to speak about them but.....</p> <p>M: Well Alice, when she was young used to work in the [name] school</p>	No permission given
<p><i>Page 3</i></p>	No desire to talk about sex

<p>F: And um....(pause) well sex in dementia I'm not going to talk about because I haven't experienced it. We don't have any sexual relations at all my husband and I....and um...so the next step is up to me really...</p>	<p>Lack of sex in relationship</p>
<p>F: I feel.....He's got a mistress and that's his business we wont talk about that....and um he keeps his end I presumed I'd say....but I haven't had sex for many years and I can hardly remember what it was like....but its given me three children for which I'm very grateful</p>	<p>Extra-marital relations</p> <p>Lack of sex for many years</p> <p>Little memory of sexual experience</p> <p>Grateful that sex produced children</p>
<p>F: Alice and Laura have had a tough time, finding an outlet and they've been very inventive but when I was diagnosed with dementia the thing that shocked was that when the doctor who came and that was, I don't know whether she was from the Tavistock or where she came from, do you remember Martin?</p> <p><i>Page 4</i></p> <p>F: And she was very unsympathetic and she..she said to me 'you've got dementia'. And so then she explained a little bit what dementia was but she didn't know very much and then she left and then she left me with this information. I went completely crazy.</p>	<p>Doctor lacked knowledge about diagnosis</p> <p>Doctor was unsympathetic</p> <p>Feeling left with diagnosis information</p> <p>Feeling crazy</p>
<p>F: And started shouting and yelling and...I was very ...very disturbed by it</p>	<p>Shouting and yelling</p> <p>Feeling disturbed</p>
<p>F: And I didn't know what to expect. Alice provided me with a chap called, do you remember who he was called?</p>	<p>Uncertainty about what to expect</p>
<p>M: Who?</p> <p>F: He came over here and he knew something about dementia and he was very sympathetic and very nice because I was being transported in my mind, across the road to the building opposite and I would wake up and I was afraid I was being left in this building and I was left every night in this building</p> <p>A: Being abandoned and your own?</p> <p>F:Yes</p>	<p>Afraid</p> <p>Being left in the building</p> <p>Recurrent fear of being left alone</p>
<p><i>Page 5</i></p>	

<p>F: And then Martin used to come and rescue me and would take me down to the, we'd both go down to the front door and cross over the road and back into our house</p>	<p>A path to getting back home</p>
<p>F: Yes (laughter) he rescued me. I could hear him coming up the stairs and I wasn't afraid that it was a burglar or anything. I knew I could tell it was him.</p>	<p>Certainty about recognition of husband</p>
<p>F: And so....I was having hallucinations all the time, and he told that it was not true and that there were no people sitting in those chairs and there were nobody coming faced to the window or anything</p>	<p>Hallucinating frequently Husband brings reality</p>
<p><i>Page 6</i> M: Yeah that's what I said. So you said hallucinations about uh....what I was trying to explain to her about was hallucinations are really a waking dream you had uh amazing and disjointed things</p>	<p>Hallucinations are a waking dream</p>
<p>F: Martin, I might remind you I'm talking now. First I don't want to be interrupted constantly A. and B my idea of hallucinations might be different to yours. If you don't mind....</p>	<p>Stands up for oneself Ideas might differ</p>
<p><i>Page 7</i> F: Well if it hadn't been for Martin, telling me that I was seeing things, I would have been terrified</p>	<p>Spouse helps reduce terror</p>
<p>F: So I owe him a debt of gratitude really. Was it debt? Do I pronounce it debt or dept'?</p>	<p>Gratitude to spouse</p>
<p>A: Debt. Yes. F:...so... A: yes F: And they gradually subsided A: And touch wood I don't have them anymore</p>	<p>Hallucination symptoms subsided Hope that hallucinations are no longer an issue</p>
<p><i>Page 8</i> F: Well they could have been much worse you know.... A: Yes F: They could have been I'm grateful they weren't</p>	<p>Hallucinations could be worse Gratitude that hallucinations were not worse</p>

<p>F: And um....when you think how ghastly they could be I'm frightened of so many things. Everybody in my family knows that I'm frightened of a lot of things</p> <p>A: Yes</p> <p>F: Particularly spiders, big spiders...</p>	<p>Hallucinations could have been worse</p> <p>Family is aware of fears</p>
<p>F: And um....well I'll remember as I go along. They go out of my mind when I'm not thinking about them but the spiders are all, the tigers and spiders...and so, I've got a lot to be frightened of. If I didn't know that these were hallucinations</p>	<p>Choice not to think about fears</p> <p>Reality that fears were hallucinations</p>
<p>F: A tiger could come into the room and I'd have a heart attack I think.</p>	<p>Fear of tigers</p>
<p><i>Page 9</i></p> <p>A: But what's so striking is how you described Martin's the importance of Martin in a sense, helping you to ground you in what was real</p> <p>F: He usually does that. He isn't always right, sometimes I have.....(takes a deep breath) I have um....feelings or sensations or dreams of....that are genuinely frightening</p>	<p>Supported to feel grounded in reality</p> <p>Hallucinations are scary</p>
<p>F: But on the whole he is the one person who is able to calm me down, if I see or hear anything horrible</p>	<p>Spouse is calming</p>
<p>F: And he doesn't say 'oh well you're a silly idiot for imagining all these things'</p> <p>A: Yes</p> <p>F: Which is a big help</p>	<p>Spouse understands experiences</p>
<p>F: Whereas my carer used to, she just could understand it...she's upstairs</p>	<p>Carer doesn't understand</p>
<p>A: Yes, but Martin could</p> <p>F: Yes Martin could understand that. And I have had years of therapy, but I never thought I'd get dementia. Because I read a lot, think a lot</p>	<p>Surprise at diagnosis despite years in therapy</p>
<p><i>Page 10</i></p> <p>F: So I thought well that would pass me by probably or it would be late in coming</p>	<p>Dementia diagnosis would pass me by or delayed</p>
<p>A: Yes. Well you said earlier that the diagnosis had been an incredible shock and it felt rather abandoned by....it sounds like the doctor came along gave the diagnosis and that was it</p> <p>F: Yes they...</p>	<p>Feeling abandoned</p>

M: Actually it was...	
F: Well because they looked very confused.	
F: Well the doctor didn't have the imagination to see what this diagnosis would do to an ordinary person	Doctor lacked imagination
F: I went away almost immediately on holiday and I went to with a rather stupid girl who used to say silly things and then instead of being nice to her I screamed at her and told her 'shut up' and everything. Everyone had to put up with me screaming my head off at times and...and she never warned me that I might do this otherwise I would have cancelled the holiday	Screaming and shouting Everyone had to put up with me No forewarning of difficult emotions
<i>Page 11</i> M: Which I wouldn't be surprised. I mean you look at the statistics, most of the couples in situations like that, one way or the other, either follow into physical or psychological illness in the relating or caring situation	Spouse-carer gets physical or psychological illness themselves
<i>Page 12</i> M: But then I'm old as well.	Old age
M: Reserves in energy and fortitude are less and less and less	Less energy
M: (pause)...the everyday challenges are working and running, I mean just running a household, running an administration of 2 people or even 5, because we've got children with needs	Every day challenges
M: That is really, a very substantial burden M: Which doesn't seem to stop	Substantial burden
M: So the high...the high damage rate in caring in partners is quite high I thought....understandable	Spouse-carer burden is high
<i>Page 13</i> M: So yes, that is one of the reasons why....in a....uh program like this [<i>referring to Living Together with Dementia intervention</i>], you vanish M: Then there is no other organisation to take over with enough expertise to handle it so you (inaudible) with a little bit of CGT or TLC depending on where you guy and uh...just slowly disintegrate	Feeling abandoned with caring responsibilities No further support Slow disintegration
F: Well the chap who came to see me sent by my daughter, was so busy that he didn't have 5 minutes to spare which I could remember his name...and he stopped me being afraid of, I visualise, I felt that at 10 o'clock at night I was taken across the road and then quite a few cars passed, and I walked across the road, so I hadn't understand why I hadn't been run over	Therapist helped stop fears and hallucinations of being run over by a car
<i>Page 14</i>	Desire to not leave own home anymore (in hallucinations)

F: And when he came round one day, sent by my daughter look I'd like to stop crossing the road going to the house opposite. I want to stay in my bed	
F: and he said....(pause)....'well just say that you don' want to cross the road anymore'	Say you don't want to cross the road
F: And sure enough I did followed his advice and it worked a trick	Following advice gave desired result

Transcript 4

The caring spouse is of Japanese origin. The spouse with dementia recently moved to a care home. The caring spouse visits him daily.

A= Therapist F=Caregiving spouse (female) M= Spouse with dementia (SWD) (male)

Data Extract	Coded for
<p><i>Page 1</i> F: Oh very helpful</p> <p>M: I've always had a good impression of your effort and... unfortunately my memory is missing it</p>	<p>Found helpful</p> <p>Appreciation of effort</p> <p>Memory loss</p>
<p>M: I've seen stuff coming back to my mind I think... positively I hope helpfully of your your... effort.. your attention... I don't know exactly how to put things because my memory is not good enough for that</p>	<p>Appreciation of partner's effort and attention</p> <p>Memory loss</p>
<p>F: I think we are extremely lucky because of the couple, that you are visiting, one of the therapists is you, I found it tremendously lucky (quick laughter) it could have been another couple isn't it? But our case is that you're one of them and we're very vey lucky</p>	<p>Appreciation of therapist</p>
<p><i>Page 2</i> F: Well still here is vulnerable and uh.. how do I put it? Help...uh hopelessness and uh... and I was psychologically and emotionally very weak and uh, I needed desperately to have a very professional listener together the good thing is, it's not only with me, but with 'tuni', that means your approach is trying to understand what's going on in his head (laughter) it's helped a lot...hm.. because every day sometimes I be in a harsh mood towards him, I hated myself but sometimes I couldn't stop it but still I am now (laughter). But uh, if we have a very high standard professional listener, therapist with us is to understand what's going on in his mind, and if possible in my mind (laughter), as well, from the third person's eyes. Especially to understand him but also to understand myself.</p>	<p>Vulnerable and hopeless</p> <p>Psychologically and emotionally weak</p> <p>Appreciate therapist approach to understanding what's going on</p> <p>Appreciation of a professional listener and third person as the therapist</p>
<p>F: Could be continues longer, it happens all the couples said that it was too short</p>	<p>Improve therapy by making longer</p>
<p>F: Yes, yes but also visiting us and not going to the warren street, that also very helpful</p>	<p>Appreciation of therapy in home setting</p>
<p><i>Page 3</i> F: But straight away it was helpful. Before you coming he was really quiet in the back (laughter) but to talk all before, and afterwards no exception, I always feel warm, subtle feeling towards him.</p>	<p>Immediately helpful</p> <p>Warm subtle feeling towards partner</p>

<p>M: And uh..my...basic I don't have I don't have a clearer memory as 'satchi', I think that might be... because I in some way I find this situation a bit invasive... I don't mean that in a hostile way, but it can be that I don't see the need for in some sense for revealing myself to... a new stranger, and uh... it maybe just a male feeling, as opposed to a female one as rudimentary as that... It is a self-protective feeling and men are more likely to have that feeling than women perhaps</p>	<p>Therapy invasive</p> <p>Therapy revealing and this unnecessary</p> <p>Gender differences in revealing</p> <p>Men are more self-protective</p>
<p>M: Well.. the best we've.. we still have a good relationship with each other and we get on well together apart from the occasional bark and bite...</p>	<p>Still having a good relationship with partner</p> <p>Occasional fall out but still get on well</p>
<p><i>Page 4</i> M: Mm yep... the physically separate from me hit me the most hardest part F: It is harder... we have no choice</p>	<p>Physical separation the hardest</p> <p>No choice within separation</p>
<p>F: Yeah normally she seen couples normally dementia, her or himself they are looked after, but it's not fine it's always a carer, exhausted and so you have to also look after yourself. And that time I started to be serious and visiting the care home, and this is the time I felt this...</p>	<p>Recalling feeling exhausted as a carer</p>
<p>F: Physically... It's a house, it has a nice character</p>	<p>Appreciation of dementia care home physically</p>
<p><i>Page 5</i> F: He's got on very well.. those two guys, always talking M: I do have a good personal relationship with them</p>	<p>Agreement between partners of M's relationships at care home</p>
<p>M: Yes.. that's a good phrase, well a friendly distance F: mm... He's (inaudible) because of his sense of humour</p>	<p>Likes to keep friendly distance</p> <p>Fond description of partner</p>
<p>F: I have to look after when I come to, I have to clean it, what am I doing here, that's what I'm thinking. But I have to accept that... he's very well received here, all the staff. And I have a good relationship with him as well, the whole manager, especially Ann</p>	<p>Clean the home representative of house</p> <p>Partner well received at home</p> <p>Good relationship with manager</p>
<p><i>Page 6</i> F: They are always talking but it's always nonsense...hmm yeah. And he's also really very lucky to be here</p>	<p>Partner lucky to be at care home</p>

<p><i>Page 7</i> F: It's not like a typical community (care home). Because there aren't enough people for it to be like that. And I suppose that makes a difference from typical every day life. Which is perhaps a depletion of contact. But uh.. it's bound to happen in our situation and we have to learn to live with it.. but but...</p>	<p>Care home not like typical community</p> <p>Care home different to typical everyday life</p> <p>Depletion of contact at home</p> <p>learnt to live with less contact</p>
<p>F: I think they understand him very well... his character, he's not an annoying person, the sort of things he likes and dislikes. They know...</p>	<p>People understand partner in care home</p>
<p><i>Page 8</i> F: And we have to rely on situations of... minimal or near minimal contact with each other (others in care home)</p>	<p>Rely on minimal contact at home</p>
<p>F: Every time. It's very difficult not to come the following day and also the word is very symbolised 'thank you for coming today' and it symbolises that we're living together and not living separately so yeah he always said that when I say it's time to, well I have to feed the cats for whatever reason</p> <p>F: And uh... every time, he... every time he said that it's good but it's hard</p>	<p>It's difficult not to visit daily</p> <p>Grateful for partner saying thank you</p> <p>Visiting home feels like living together again</p> <p>Past 'routine errand' as reason for leaving</p> <p>It's difficult saying goodbye</p>
<p><i>Page 9</i> F: Well you are a good character thinking about the other person's mind</p>	<p>Appreciation of partner's character/empathy</p>
<p>M: Well that's like that because we like to maintain good relationships with each other</p>	<p>We maintain good relationship</p>
<p>F: And perhaps.. occasionally more intimately, I don't know how well we can get on emotionally, with each other in the situation where we are living,....uh by ourselves and in an institution...mm there's no alternative to that</p>	<p>Uncertainty of emotional relationship if not living in home</p> <p>No alternative to home</p>
<p>F: You know.. there are things we, there are normal things we can do it's very difficult to say anything that to share the likes of a joke with each other, because there's a language difficulty but not saying that it stops us from having a laugh with each other</p>	<p>Despite language difficulty, still share laughter with partner</p>

<p>M: But there are ways in which our relationship is...uh... at times, limited by the difference in language and uh... I don't see what we can do about that. There is... we manage quite well, I think we have managed quite well to have a reasonable or quite good or very good relationship with each other or limited connection with each other... because... we.. we... we do not speak each other's language... I had the idea in my head that I should learn Japanese, extending my ... my... my options too widely</p>	<p>Language difficulty limits relationship</p> <p>Mange difficulties well within limited connection</p> <p>Idea of learning Japanese representing language difficulties</p>
<p>M: When we see each other, well when we separated it was harder</p>	<p>More difficult when separated</p>