## Section 1: Literature Review

# Experiences of having a partner with dementia in long term care: a review

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## Abstract

The current literature review aims to explore the experiences of people whose partner is living with dementia in a long term care setting. Specifically, thirteen qualitative papers were identified by searching four databases (PsycINFO, Academic Search Complete, CINAHL and Scopus) and applying inclusion and exclusion criteria. Moreover, the findings from the thirteen were synthesised and interpreted utilising a meta-ethnographic approach as described by Noblit and Hare (1988). As a result of the synthesis the four themes that emerged were; i) a continuation of social isolation; ii) challenges to planning for the future; iii) embracing the changing boundaries of marriage and iv) negotiating a new sense of self. Moreover, across each of the themes participants identified how important social relationships were in supporting their adjustment to their partner living in long term care. Consequently, recommendations are made about how partners can be best supported during and following this significant life transition in addition to suggestions for future research.

## Keywords

Dementia, interpretative phenomenological analysis, long term care, partner

Recent reports suggest that the number of people with dementia is increasing each year, with the projected number around 75.6 million in 2030 and 135.5 million by 2050 (World Health Organization, 2016). In 2010 it was estimated that in high income countries, 34% of individuals with dementia reside in care homes, compared to only 6% in low and middle income countries (Prince, Prina & Guerchet, 2013). Consequently, a large proportion of individuals with dementia across the world are being cared for at home, primarily by family members (Prince, Prina, & Guerchet, 2013). However, it is also likely that the trend towards long term care away from the family home will increase so decisions around what future care would be best are likely to be considered by many (Macdonald & Cooper, 2007).

Indeed, for many people, particularly those whose dementia presents additional challenges, continuing to be cared for at home is not a long term option. In particular, a review by Gaugler, Yu, Krichbaum and Wyman (2009) identified a number of factors which can prevent an individual being cared for at home, including severity of cognitive impairment, depression in the individual with dementia and caregiver stress. Furthermore, it has been suggested that the trend to provide care within the home is changing due to factors such as fewer children being born, fewer two generational families living together and increasing divorce rates (Shaji, Smitha, Lal & Prince, 2003). Therefore, long term care placements provide essential care when carers are unable or unavailable to continue providing care at home.

Indeed, a number of factors can effect whether a partner has a positive experience of providing care. For example, a review of quantitative studies by Quinn, Clare and Woods (2009) suggested that having a strong sense of couplehood prior to the onset of dementia can have a positive impact on the psychological wellbeing of both partners and contribute to more positive experiences of the current relationship. Moreover, a review of both qualitative and quantitative studies explored the experiences of individuals who provide care to stroke survivors, in which a number of positive consequences of providing care were identified. Specifically, the development of new skills, strengthened relationships and feeling appreciated by the care recipient and the community were all positive aspects of providing care. Therefore, positive experiences of caregiving can contribute to improved psychological wellbeing and as a result may facilitate home care for a longer period. All these factors are also likely to affect the decision to change care provision and the subjective experience of that change for both the person with dementia and their care provider.

However, if the decision to discontinue home care is made, the placement of an individual in residential care can elicit both positive and negative experiences for the community dwelling partner. For example partners may experience relief from direct caregiving responsibilities and improvements within their own social life (Matsuda, Hasebe, Ikehara, Futatsuya & Akahane, 1997). Moreover, quantitative studies have suggested that individuals who are in a relationship with someone with dementia (i.e. partner) may experience improvements in stress related to the caregiving role (Zarit & Whitlatch, 1993) and social relationships (Matsuda et al., 1997) following the residential care placement. Specifically, an increase in social activities and social inclusion was noted to have a positive impact on psychological wellbeing following a partner's long term care admission (Bond, Clark & Davies, 2003. Conversely, partners may experience feelings of guilt, a loss of companionship and loneliness (Rosenthal & Dawson, 1991). Specifically, this can contribute to partners feeling that their lives are 'on hold', as they cannot progress with plans or decisions they had once made as a couple (Collins, Liken, King and Kokinakis, 1993). Therefore, understanding the decision to discontinue home care may help to understand individual's experiences following their partner's admission to long term care.

To date the majority of qualitative research regarding individuals who provide care for their partners has largely focused on their experiences of providing care within a community dwelling. Primarily this has been due to the fact that the majority of people with dementia are cared for at home (Wimo, Jönsson, Bond, Prince & Winblad, 2013). Furthermore, the majority of studies exploring partners' experiences following their partner's admission to long term care have utilised quantitative methods. Additionally, providing care within the home can result in better health outcomes for the individual with dementia (Schulz & Martire, 2004). However, as there is no qualitative review that specifically explores the experiences of caring for a partner with dementia at home there is a limited understanding of these experiences and therefore it is difficult to develop interventions which can promote positive experiences.

Consequently, this meta-synthesis intended to answer the research question, what are the experiences of individuals whose partner with dementia resides in long term care? Specifically, a meta-ethnography approach, as described by Noblit and Hare (1988), enabled a deeper exploration and integration of the current empirical qualitative studies literature, while preserving the integrity of the original data. Moreover, the development of third order interpretations in relation to a specific research question takes this methodology beyond a traditional literature review (Britten et al., 2002). Specifically, the analysis of secondary data to form higher order constructs enables the development of a clear line of argument in relation to the research question. As a result, it is anticipated that the findings of the meta-synthesis can provide a useful contribution to furthering our understanding of the experiences of individuals whose partner is in long term care.

# Method

This meta-synthesis was conducted following the seven stage meta-ethnographic approach described by Noblit and Hare (1988). This method utilises an interpretative approach which involves both the induction and interpretation of findings. Specifically, the themes and findings of multiple primary papers are subsumed to form higher order concepts and a more developed understanding of the research question (Atkins et al., 2008).

According to Noblit and Hare's (1988) model the first stage, 'getting started', involves establishing the research question. Specifically, this was done by reviewing current dementia research. The review highlighted an increase in studies exploring the process of admission to a long term care facility and the consequences for intimate relationships. However, there were no specific reviews or collation of findings from the studies that had been conducted to date. As a result, this led to the development of the research question: what are the experiences of individuals whose partner with dementia resides in a long term care facility?

## Inclusion/Exclusion Criteria

The second stage is to 'decide what is relevant to the initial interest', which includes defining the focus of the review by developing inclusion criteria. This involved only including studies with a clear and transparent description of a qualitative method and findings which were supported by participant quotes (Dixon-Woods, et al., 2006). Additionally, the concept of partner was defined as individuals who were in a long term relationship and cohabited with the individual with dementia, prior to the diagnosis. Therefore, this review did not distinguish between individuals who were legally married and those who were not. Moreover, due to limited information about the relationship (e.g. length of relationship) in many studies it would have been difficult to include only those of a particular duration. As this review was concerned with experiences of having a partner live in residential care it was decided not to include studies which focused on respite care as the implications of a temporary admission would differ from those of a long term placement (Gaugler, Kane, Kane, & Newcomer, 2005). Finally, it was important to establish that all individuals in residential care settings had a diagnosis of dementia but it was often unclear if this was the primary reason for admission. Therefore, if it was clear that individuals within the study were living with a type of dementia, papers were not excluded based upon the reason for admission.

Furthermore, exclusion criteria were developed to filter out studies which did not adhere to the focus of the review. In particular, studies which analysed the experiences of a range of family members (e.g. children, siblings) together were excluded from the final review (e.g. Fleming, 1998). It was anticipated that the experiences of different family members would vary significantly due to their varying relationships and living arrangements with the individual with dementia (Pinquart and Sorensen, 2011). Furthermore, studies which did not describe a clear analytical method were excluded to ensure the quality of the review was maintained. Finally, studies which were not published in English or peer reviewed were excluded from the final review.

## Search Strategy

Potential papers were obtained through four databases; PsycINFO, Academic Search Complete, CINAHL and Scopus. These databases were selected to provide a broad scope of papers from a variety of perspectives including psychological, medical and sociological. Following an initial scoping study the broad search terms [partner] and [dementia] were exploded by using either the thesaurus in PsycINFO, MESH terms in CINAHL, subject terms in Academic Search Complete or the OR function in Scopus. Moreover, filters were not applied to the searches as during the scoping study relevant papers were excluded largely due to qualitative methodology not being explicitly stated. However, the reference sections of the selected papers were hand searched for any additional papers.

The searches were conducted in July 2016 and yielded a total of 1,445 papers (figure 1). The abstract and titles of each of the papers were reviewed against the inclusion and exclusion criteria. As a result, 1,368 papers were excluded and the full text copies of the remaining 77 papers were sought. Subsequently, the remaining papers were reviewed, of which 13 were considered suitable for the final meta-synthesis.

**INSERT FIGURE 1**

## Characteristics of Studies

Thirteen papers were selected for inclusion in the final meta-synthesis (table 1). The included studies originated in a variety of countries including USA (seven), Sweden (one), UK (one), Norway (one), Canada (one), Republic and Northern Ireland (one) and Netherlands (one). While all of the studies utilised one to one interview procedures as part of the methodology, eleven studies interviewed each participant on one occasion (two studies utilising the same participants) and two studies with different samples interviewed each participant on three separate occasions. Moreover, the studies utilised a number of different approaches to analyse the data, including variations of content analysis (six), thematic analysis (three), grounded theory (two), narrative (one) and interpretative phenomenological analysis (one).

Furthermore, the majority of studies involved interviewing predominately female partners with husbands who resided in long term care facilities; three studies interviewed only female participants and of the remaining ten studies, an average of 53% of participants were female. Additionally, the average amount of time that participants were married was 49.6 years (six studies). Moreover, the average length of time spent living in the long term care facility was 26.4 months (five studies) and the average time since diagnosis was eight years (three studies). However, only eight studies specified the type of dementia participant's partners were living with; five studies included Alzheimer's disease and three studies included a combination of Alzheimer's disease, fronto-temporal and vascular dementia. Furthermore, some of the participants' spouses died during the research process and therefore they withdrew from the studies or provided retrospective accounts of their experiences (Baxter et al., 2011; Braithwaite, 2009; Hemingway et al., 2016).

**INSERT TABLE 1**

## Quality Appraisal

The use of quality appraisal tools to exclude papers in literature reviews continues to be an area of active debate. In particular, there remains uncertainty about how quality should be assessed and utilised within research (O'Connell & Downe, 2009). Furthermore, some researchers argue that all qualitative findings can add to the understanding of the human experience regardless of the methodological flaws of the study (Downe, 2008). Therefore, it can be beneficial to assess the quality of the studies included in a meta-synthesis but not necessarily exclude them based upon the appraisal.

Consequently, the quality of the included papers were considered, but not excluded, using the Critical Appraisal Skills Programme (CASP; Public Health Resource Unit, 2006). The CASP comprises of two screening question, followed by eight questions which focus on varying aspects of methodological rigour and study design. As the CASP was not intended as an exclusion tool in this review, the studies were rated using the letters A-D (with A indicating the highest level of quality) as opposed to the more commonly used numerical rating scale (Downe, 2008; table 2). As a result, the quality of each paper was explored and considered in the context of the findings without the creation of a subjective hierarchy of the included studies. It was anticipated that creating a hierarchy of studies would not reflect the philosophy that all qualitative studies are able to contribute to the understanding of a particular experience (Downe, 2008).

**INSERT TABLE 2**

### Analysis

Noblit and Hare’s (1988) next stage involves the researcher becoming familiar with the content and identified themes within each of the included studies. Specifically, each paper was read repeatedly and the identified themes or findings were recorded (table 3). This enabled the themes to be compared and contrasted, in a process termed reciprocal translation (Noblit & Hare, 1988), highlighting any differences or relational links between the studies. However, as no specific guidance is included, it is unclear about the specific process of comparing the themes or concepts from each paper. Therefore, the themes were grouped according to the approach described by Atkins et al. (2008) in which the papers were arranged chronologically, followed by the sequential comparison of themes. For example, emerging themes from the original data in paper one were compared with the themes in paper two to develop a more comprehensive list of themes. Furthermore, initial themes aimed to reflect participants' understandings, as reported in the included studies. As a result, the process was repeated for all selected papers by continually merging and developing new themes, whilst ensuring that they related back to the original text.

Furthermore, from the identification of initial themes, second order constructs were cross referenced and developed within a large grid. Specifically, initial themes were written on individual cards and displayed in separate groups to allow the process to be fluid and themes could be re-grouped as the analysis progressed. Moreover, these constructs went beyond the original descriptions to understand the relationship between each of the original themes. In particular, this was done by understanding the interpretations of participants' understandings made by authors of the selected papers. Additionally, throughout the analysis process the researcher would return to the original data to ensure that the developing themes remained as close to the original quotes as possible.

Finally, third order constructs were identified by synthesis of both first and second order constructs into a new understanding of the research question. Specifically, as the process of synthesising research in meta-ethnography is not clearly defined, the chosen method of synthesis was based on the reading of a number of existing reviews. In order to develop third order interpretations, the translated themes were listed in a table alongside the secondary themes which were derived from author interpretations. Moreover, the researcher was able to utilise supervision sessions to discuss the generated interpretations and explore emerging hypotheses, which produced a 'line-of-argument' synthesis. Additionally, the themes were considered in the context of the researcher’s interpretations and own experiences on the development of the themes. As a result of a thorough and reflective analysis process a ‘line of argument’ and higher order interpretations to be developed in relation to the original aims of the review.

**INSERT TABLE 3**

## Results

Data from thirteen papers were synthesised and interpreted to develop four third order constructs. Specifically, the four identified constructs which highlighted the continuation of social and emotional difficulties beyond their partner's admission to long term care. Moreover, while the quality appraisal of selected studies was not utilised to exclude studies, the impact of this was considered during the analysis process. For example, the researcher considered the implications of analysing the results of a single case study (Bonnel, 1996) alongside studies which included a much larger data pool and rigorous analysis method (Hennings et al., 2013). While some qualitative researchers would argue that this would detract from the overall quality of the synthesis, the researcher felt that all studies could contribute to the development of understanding of a relatively under researched phenomena (Downe, 2008). However, it is acknowledged that some studies may have contributed more to the results than others. As a result of this process, each of the constructs are discussed in more detail below.

### A continuation of social isolation

The first theme 'a continuation of social isolation' reflected participant's experience of social relationships since their partner's admission to long term care. Specifically, many participants experienced feelings of sadness and regret regarding a deterioration in social relationships. For many participants this was unexpected as they had observed widowed friends having a more active social life without being part of a couple. However, since their partner had moved into long term care one participant reflected on the difference between themselves and their widowed friends, ‘This might sound awful now, like I have friends who are widowed, well they seem to do a lot more, but I’ve already got three days a week sorted (visiting partner), if you know what I mean…’ (Hennings et al., 2013, p. 688). However, individuals whose partner was living in long term care experienced increased feelings of guilt if they engaged in social activities and relationships which did not involve their partner. Moreover, some participants described how feelings of guilt motivated them to visit their partner more often, even at the cost of their own hobbies and social activities. For example, one participant described how feelings of guilt initiated additional visits to their partner despite knowing that the visits were not always beneficial for themselves or their partner, ‘I want to go ‘cos I think sometimes when I’m sitting here or you know I think, “I wonder what he’s doing? Oh I wish I was there, perhaps I should have gone today”…Then when I get there and he’s you know, no response I think, “Oh why have you come?”’ (Hennings, et al., 2013, p. 687). Consequently, participants were unable to maintain their social relationships while they were visiting their partner on a frequent basis.

Furthermore, most participants felt that social interactions were strained due to other people feeling uncomfortable and not understanding their partner’s dementia. As a result, participants noticed that most social interactions were kept brief and other people avoided asking personal questions about their partner. One participant described how limited interactions could result in feelings of isolation and exclusion, ‘They (friends) say “hi there, how are you?” and “how’s (name)?” “oh he’s the same”, whatever it is. And they’ll say “oh nice seeing you”. They’ve got their little clan, and you aren’t (part of it). You’re alone’ (Kaplan, 2001, p. 93). Moreover, participants described a fear of disclosing too much information and overwhelming the friends they had. As a result, participants would not rely on their friends for emotional support in order to maintain their friendships, as seen in this example, ‘I don’t offload it onto friends. Because friends are fantastic…they’re precious and few and far between.’ (Hennings et al., 2013, p. 689). Therefore, while some participants had maintained their friendships the quality of the support they could expect had reduced since their partner’s admission.

Additionally, participants experienced feelings of exclusion and isolation when their partner developed new relationships within the care home. One participant described the feeling of visiting their partner in their new social environment as ‘going into another world’ (Hemingway et al., 2016, p.878). However, while some participants felt excluded by this, they were comforted knowing that their partner was included in social relationships. For example, in Braithwaite’s (2012) study one participant described feeling reassured that her husband had a good relationship with care home staff, ‘My husband thinks of them (nursing home staff) as his very best friends. He loves them and they take awfully kind and loving care of him.’ (p. 168). Despite this, most participants described feelings of isolation, exclusion and lack of belonging deriving from an absence of shared understanding with past friends and the care home community.

Alternatively, some participants described how they would intentionally distance themselves from friends during conversations to avoid exposing their vulnerabilities. For example participants were concerned that by revealing how emotionally challenging it was having their partner in residential care, other people may make assumptions that they were unable to cope or only concerned with their own wellbeing. In particular, one participant described how they did not like talking about their own difficulties as they felt they had no reason to complain,

> She explained she had no time for the Alzheimer's Society, they all sit round and say "oh how are you coping?" (At this stage she imitated their pathetic, sad look). It's not me who has the illness. I am not the one to feel sorry for. (Hennings et al., 2013, p. 688).

Moreover, some participants felt that if they discussed their current situation in too much detail, they may cry which would suggest that they were unable to cope. For some participants if they appeared that they could not cope, they could experience increased feelings of guilt and failure. Additionally, for some participants they reported initial experiences of guilt and failure when they were unable to continue providing home care. Alternatively, some participants felt that by admitting to friends and family that they were struggling to cope, they would feel obliged to provide additional support. One participant described how she would feel a burden if she was to disclose her difficulties to family or friends:

> (crying) I do not do this with my friends. I do not cry. I do not complain. I don't even do it with my brother… I just don't want to burden them… enough burdening, enough terrible things have happened in my life. (Kaplan, 2001, p. 93).

Consequently, participants who experienced burden as a result of caregiving, did not want to pass these experiences on to other family members of friends. In particular, feeling that they had burdened other people could result in feelings of guilt. Therefore, remaining emotionally distant and avoiding personal disclosures prevent partners from experiencing additional feelings of guilt and failure.

Despite the majority of participants feeling isolated and acknowledging a deterioration in social relationships, for some participants there was an opportunity to develop positive relationships with care home staff. Specifically, some participants felt integrated into the care home community and as a result felt that they had support from people who understood their current situation. Moreover, feeling included enabled a trusting relationship to develop between the community dwelling partner and the care home staff. For example, one participant described how being understood by others in a similar situation was an important part of being integrated into the care home community,

> Well I felt part of a family. And somehow or other they treated him like a member of the family you know…I think the dementia unit is like a family you know all the residents are like part of one big family…I think they were feeling what I was feeling, because he was like part of their family. (Cahill, 2012, p. 66).

As a result, participants felt more comfortable and content with their partner's physical needs being met by trained staff. It is anticipated that some partners had been uncomfortable with how their marital role had changed (e.g. providing personal care) prior to their partner's care home admission and the consequences this had on their own physical and mental health. Consequently, seeing their partners needs being met without negative consequences for themselves reduced feelings of guilt regarding their decision to move on with their own lives.

## Challenges to planning for the future

The theme of ‘challenges to planning for the future’ describes how participants found the ambiguity of having a partner with dementia as one of the most distressing aspects of the disease. In particular, many participants struggled with the uncertainty of their partner’s future and the impact that this would have on their relationship. One participant described how the lack of clarity about the status of her marriage prevented her from moving forward with her life,

> I like to think that we have some sort of relationship… out of love and respect for him I go there… that’s a minimal sort of marriage, but I still consider my marriage today…We’re married and yet we aren’t, and we ought to get on with our lives, but that’s very difficult. (Kaplan, 2001, p. 93).

Specifically, many participants felt that they had a responsibility to maintain their relationship with their partner, regardless of their partner’s ability to participate in the relationship. Moreover, some participants maintained their relationship by celebrating moments of intimacy shared between themselves and their partner. For example, in Ford et al.’s (2015) study one participant described how important a brief moment of intimacy with her husband was in building her emotional resilience,

> I’m lucky to still have him; some support group members have lost their spouses. I gave him a kiss goodbye the other day. He looked at me clearly and said “Thank

> you"…that has given me strength for the past couple of weeks…life's simple pleasures. (p. 141).

As a result, some participants expressed their frustrations when other people treated their relationship or their partner differently since their admission to long term care. For example, one participant expressed the importance of her married identity being maintained,

> Respondent: I hate this 'Ms'. It's May (last name). And I get some mail in May (last name) and I don't even open it because it's still Mr and Mrs.
>
> Interviewer: How do you prefer mail to be addressed to you?
>
> Respondent: Yeah! He's not dead. I mean, not only is he not dead, he's not in a coma. He knows fully well what is going on, so why shouldn't he be included? (Kaplan, 2001, p. 91).

Therefore, maintaining the identity of the marriage to both the couple and other people was important in creating stability and certainty within an ambiguous situation.

Despite many participants attempting to create certainty within their marriages, as the disease progressed this was not always possible. Specifically, one participant commented how difficult it was to maintain their marriage over a long period of time,

> Sometimes I have thought it has been going on for so long… ten years of this day by day by day. There were times I felt I couldn't keep my own sanity… There have been

> times when I would get to the nursing home and shut the car door and start praying that I had enough strength to walk in there. (Baxter et al., 2002, p. 11).

Furthermore, many participants experienced feelings of hopelessness and helplessness due to feeling that they had limited control over their own and their partner's futures. Consequently, some participants felt that their partner passing away would be preferable to them both living a life of uncertainty and emotional difficulty. In Hogsnes, Melin-Johansson, Gustaf-Norbergh and Danielson's (2014) study one participant felt that while the death of their partner would be devastating, being able to embark on a grieving process would provide some comfort, 'It's worse than death, god-dam it… no doubt about it. It is, because if someone dies you can start adjusting to the loss from that date.' (p. 156). Therefore, participants were comforted by the more defined expectations of being a widow/er as compared to the ambiguous role of having their partner living in the care facility.

### Embracing the changing boundaries of marriage

'Embracing the changing boundaries of marriage' describes how participants acknowledged that their marriages had changed in some way following their spouse's diagnosis of dementia. Specifically, some participants described how their understanding of their marriage had changed and how this had affected the way in which they interacted with their spouse. However, most participants felt that although the meaning and context of their marriage had changed, their love for their spouse had not. For example, one participant described how his feelings towards his wife remained consistent throughout the progression of dementia,

> There really isn't a marriage, because she doesn't know and doesn't understand, can't speak. But I love her as much as I ever did (…) As long as she still knows who I am, which she does, I'm devoted to her 100%. (Kaplan, 2001, p. 92).

Therefore, while the dynamics of the relationship change as the disease progresses, the strength of the emotional connection remained consistent and motivated the partner to continue providing support and care.

Additionally, many participants described their feelings towards their spouse in terms of commitment and responsibility. In particular, for many people this was related to lifelong promises they had made during their wedding vows. One participant in Hemingway et al.'s study (2016) described how their vows were a motivator to continue to be involved in their husband's care despite their relationship no longer being equally weighted in terms of contribution: 'I feel that I still have that commitment, that I need that form whether he needs me to come or not, I made a vow, in sickness and in health, till death do us part.' (p. 877). However, some spouses felt that the commitments they had made during their marriages were restricting their ability to move on with their own lives. In some cases this lead to the development of resentment towards the person with dementia as one participant described:

> It's kind of like, "Am I going to be chained to him for the rest of my life?"… "What's he still doing here?" Because I want to go on with my life… I've just kind of had it with him… And I just can't do anything more for him. (Kaplan, 2001, p. 95).

As a result, many participants experienced a deterioration in intimacy with their partner but were still unable to move forward with their lives.

Partners' perception of their marital commitments were influenced by their own experiences of marriage and also the expectations of other people. Specifically, some participants felt that friends and neighbours made judgements about their behaviour due to a lack of understanding about their partner's dementia. Furthermore, some participants felt that care home staff were making judgements about their role as a wife or husband. As a result, one participant described how perceiving staff to be making negative judgements would contribute to existing feelings of guilt and a negative self-identity: 'I sometimes wonder if they (staff) think, gee, he's kind of a hard-hearted old guy… now just because she's ill he's kind of turning on her. I just would hate to have anyone think like that.' (Bonnel, 1996, p. 24). Consequently, this would reinforce a spouse's perception of being restricted and yet having an obligation to remain within their marriage.

Conversely, some participants embraced the changing boundaries of their marriage. In particular, the developing nature of their relationship enabled other people to take on roles that previously a partner would have occupied. For example, some participants experienced relief at care home staff providing personal care to their spouse and this no longer being their responsibility. As a result, participants were able to concentrate on more traditional roles of a partner, such as providing companionship and intimacy. However, some participants were protective of their spouse's care and found it difficult to relinquish these more physical roles. For example, one participant described that despite her confidence in the support provided by staff, emotionally she found it difficult to allow others to provide care to her husband,

> I just feel that I've got to be there all the time, to make sure. They do look after them, they're brilliant, they're brilliant. They're kind, they're caring, they do activities- they're really, really good, but I can't let go. (Hennings et al., 2013, p. 686).

Therefore, despite the challenges of providing care, allowing others to take on this role signified the end of one of the few remaining physical elements of the marital relationship. Consequently, partners would find it difficult to relinquish any form of physical contact and allow another person to take on this role.

Furthermore, some participants struggled if their spouse appeared to develop strong emotional connections towards other people. For example, one participant described the emotional pain she experienced when she observed her husband behaving in a jealous manner regarding a member of staff, 'You know, and that really, really bothered me, cause she (care facility staff) was working with other people and he got jealous and I still see that.' (Hemingway et al., 2016, p. 878). Furthermore, some participants felt that the boundary of their relationship now encompassed relationships with other people and as a result their relationship was no longer exclusive. One participant felt this loss of exclusive relationship contributed to their experience of grief,

> I mean you place a person in a care facility, you lose them. They are not really yours anymore. On paper they are, but they are not really yours. The mourning season started the minute I put him in there. (Hemingway et al., 2016, p. 878).

Moreover, it appeared that individuals who perceived their primary role as ensuring their partner's physical needs were met and had a reduced sense of couplehood, were more likely to struggle with their partner's relationship with care home staff. Therefore, the introduction of care home staff into aspects of the relationship could be perceived as providing support through shared responsibility or alternatively as a threat to the relationship. Specifically, it is anticipated that partners who had a strong sense couplehood prior to a diagnosis of dementia would be less likely to perceive the introduction of care home staff as a threat to their relationship.

## Negotiating a new sense of self

The final theme of 'negotiating a new sense of self' describes how partners attempt to adjust to their new situation by developing new roles and identities. Specifically, as a result of living with the ambiguity of having a partner with dementia some participants tried to take control of other aspects of their lives. Moreover, other people (e.g., family, friends and care home staff) would highlight the importance of developing other roles and identities which did not involve the ambiguity of their partner's future and their marriage. However, some participants were resistant to the development of other roles which they thought create further confusion for their partner or marriage. One participant described how she would avoid telling her partner about any changes to her lifestyle to avoid distressing him, 'Well I used to tell him everything personal. Now it's more about other people than about myself. 'Cause I just, I just don't want him to know my lifestyle has changed.' (Braithwaite, 2002, p. 170). As a result, participants reported a lack of intimacy and increased feelings of isolation if they were unable to share details about their other roles from their partner.

Furthermore, participants described the challenge of managing seemingly opposing roles. For example, some participants described their reluctance at developing new intimate relationships while their spouse was still alive, but also acknowledged a desire to move forward in their lives. One participant described that the respect for their partner prevented them from developing new relationships, '…I had one friend who started dating. Well, that's something I don't think I could do. And why not? I mean, your husbands can't take you dancing or places, but I feel like it wouldn't be fair to Jim.' (Braithwaite, 2002, p. 173). Interestingly, some female participants explicitly stated that having an independent lifestyle away from their husband with dementia was more difficult as a woman. One participant expressed her frustration at the judgements made by others due to her gender,

> But the men who have wives there (in the nursing home)… they have girlfriends… And that's fine. That's accepted. But if a woman does it, then it's frowned upon. We still have a double standard in spite of all the things we try to do. (Kaplan, 2001, p. 94).

As a result, many participants felt guilty if they did not visit their partner as often as they previously had done and instead spent time meeting their own needs. Therefore, partners of people with dementia often had to compromise on their investment in each role to ensure that they were balancing their own needs and the expectations of others.

Some participants suggested that being able to separate successfully their different roles and identities had a positive impact on their relationship with their partner. In particular, participants noted that they experienced fewer feelings of guilt when they were able to maintain interests and relationships outside of the care home environment. As a result, participants felt that they were more resilient to manage the emotional demands of visiting their partner and consequently could enjoy spending more quality time together. One participant acknowledged how engaging with her hobbies prevented her from resenting the time she spent visiting her husband,

> I sometimes realize how much I did give up, I guess I was thinking of my art. And I found I wasn’t doing anything but going to the nursing home, and I didn’t like that. So, it was up to me to change that so I wouldn’t blame him. (Braithwaite, 2002, p. 169).

Furthermore, some participants were able to manage their time by recognising that some activities were meeting their own needs rather than benefitting their partner in any way. For example, one participant acknowledged that she had visited her partner on Christmas day because she had felt that she should, despite her partner being unaware that it was Christmas nor recognising that his wife had visited him. Consequently, this participant ensured that new routines were developed for her partner on Christmas day and that she did not feel guilty about spending time with her children instead (Braithwaite, 2002). Moreover, participants whose partner had been in residential care longer reflected on advice that they would give to other people about looking after their own wellbeing when visiting their partners without feeling guilty. For example, one participant encouraged others to pursue their own life as well as supporting their partner, ‘I think it’s important to be there for yours…But I can leave without feeling guilty that I’m going out and do what I call “freedom” and I would encourage people to go on with their life.’ (Kaplan, 2001, p. 93). Therefore, creating a positive separate identity for the person with dementia enabled partners to enjoy other aspects of their lives without experiencing feelings of guilt.

## Discussion

The analysis of data from thirteen selected papers resulted in the development of four third order constructs which described the experiences of individuals who had a partner with dementia in long term care. Within each of the themes participants described how their experiences changed as they and their partner transitioned through different stages of dementia. For example, within the theme of 'negotiating a new sense of self', some participants acknowledged that creating a new identity for themselves was difficult when their partner first moved into long term care. However, this became easier and more important for their own emotional wellbeing the longer their partner remained in care. Specifically, the circumstances surrounding their partner's dementia, level of care required, other people's understanding and their own lifestyle had changed considerably with the passage of time. Consequently, partners experienced multiple role and identity changes in response to the changing situation of having a partner with a progressive illness.

Furthermore, following an admission to long term care the experience of partners can be understood as a series of significant life transitions. In particular, life transitions occur when an individual's 'current reality is disrupted, causing a forced or chosen change that results in the need to construct a new reality' (Selder, 1989). Moreover, life transitions describe changes in an individual's sense of self, identity and perception of their current situation rather than a single external event (Bridges, 2004). As a result, there is a growing body of research exploring the experiences of living with chronic health conditions such as HIV and renal disease, in the context of a transitional process (Kralik, Visentin & van Loon, 2006). Similarly, the experience of having a partner with a chronic illness also results in a disruption of their reality, including their roles, identity and responsibilities, all of which have to adapt to the new situation. Moreover, the experiences of participants within the current review described the importance of 'negotiating a new identity' following their partner's admission to long term care. Specifically, participants acknowledged that attempting to continue with existing roles (e.g. specific roles and responsibilities within the marital relationship) would cause them further distress. Therefore, having a partner with dementia can be viewed within a life transition model whereby partners' identities and sense of self are no longer compatible with their new situation and as a result they need to find a way to adapt.

Furthermore, a review by Kralik et al. (2006) suggested that the process of transition can be positive, in which emotional distress can be reduced or alleviated. Specifically, it is acknowledged that the event which triggered the need for change may have been distressing (e.g., having a partner diagnosed with dementia) and subsequently individuals may feel relieved that they have been able to cope with the new situation (Kralik et al., 2006). Similarly, within the current review the experience of 'embracing the changing the boundaries of marriage', highlighted how individuals who were fixed in their perception that they had a duty or obligation to remain involved in their partner's care, often felt their lives were restricted by their marital commitments. Conversely, individuals who acknowledged and accepted that their relationship dynamics and identities had changed continued to feel part of a committed relationship and were able to better adjust to their partner living in long term care. As a result, it is suggested that individuals were able to regain some control following a disruptive event by engaging in activities which promoted experiences of mastery and achievement, such as continuing to have a positive interactions with their partner.

Conversely, the process of transition can be socially isolating for many people (Kralik et al., 2006). Specifically, individuals who underwent a period of transition due to chronic illness found that other people did not always recognise the need for role and identity changes which had a negative impact upon their relationships (Kralik, 2002). Similarly, participants within the current review described a 'continuation of social isolation' due to a lack of understanding of their current situation by existing family and friends. Moreover, some participants described how they had personally changed to adapt to the new dynamic of their partner living in long term care, however other people did not understand or accept these changes. Additionally, participants sometimes felt isolated from care home staff who did not understand their personal experiences. Similarly, feelings of isolation after a family member has been admitted to residential care have been reported by other populations, such as parents of children with learning disabilities (Werner, Edwards & Baum, 2009) and family members of people in mental health facilities (Ewertzon, Lützén, Svensson, & Andershed, 2010). Specifically, parents of children with learning disabilities described feeling isolated from their family who did not understand their decision to place their partner in residential care and also placement staff who did not understand their specific family circumstances (Werner, Edwards & Baum, 2009). Therefore, the process of identity and role adaptation is necessary for personal adjustment however this can sometimes be divergent from the perceptions other people hold about the individual and the relationship they have with them.

However, being able to adapt and adjust to the new situation of a partner living in long term care requires the acknowledgement that a previous way of living/being has ended (Bridges, 2004). Specifically, prior to adapting to new roles and identities, many participants experienced a period of grieving for a lost future or previous relationship but while their partner is alive (Holley & Mast, 2009). Moreover, this can contribute to feeling isolated and not understood by others as partners can be reluctant to express these feelings through fear of appearing selfish or ungrateful. Furthermore, the process of becoming aware of personal and lifestyle changes can be exposing and feel threatening. As a result, participants within the current review found it safer and more comfortable to change as few things as possible, certainly in the initial stages of their partner living in long term care. However, for the majority of participants this was only a short term coping strategy. Consequently, engaging in identity and role changes can only occur when partners feel safe and prepared to do so, which requires consistent support from others.

## Strengths and Limitations

The current review used a meta-ethnography approach to synthesise the studies, which provided a framework for an in-depth and comprehensive analysis of the results (Atkins et al., 2008). Additionally, the quality of papers was assessed using a quality appraisal tool, CASP. As previously discussed, there remains an active debate regarding the use of quality appraisal tools and the subsequent exclusion of literature based on this. As a result, within this review papers were not excluded based on their quality as all studies can contribute something to the overall understanding of a particular research area (Downe, 2008). However, it is acknowledged that some papers may contribute more than others to the development of specific themes. Furthermore, there are currently a limited number of studies which specifically focus upon this particular subject and therefore conducting a review aims to develop the current limited understanding.

Additionally, this review only included the experiences of partners of individuals with dementia. While this decision was based on the assumption that partners may have specific experiences due to their intimate relationship, it also assumes that partners are the primary caregivers to individuals with dementia. In particular, in other cultures adult children are the primary caregivers of elderly relatives and not their partner (10/66 Research Group, 2010). Moreover, studies which included the combined experiences of partners and other individuals were excluded from this review. While this may have ensured that the review focused upon the experiences of a specific population, further research should be sensitive to the changing cultural and social caregiving roles.

## Conclusion

In summary, this review aimed to explore the experiences of individuals whose partner with dementia was in long term care. The results from this review suggest that partners struggle with the ambiguity and isolation that having a partner with dementia often creates. Consequently, partners attempt to regain some control by developing meaningful identities that are distinct from being a partner to someone with dementia and promote social relationships. Therefore, in order to support this process understanding the dementia journey for both partners and the individual living with dementia is crucial. However, providing continuity of care across an individual's dementia journey can be resource intensive, even with collaboration between public and third sector organisations. As a result, it is important that specific peer support groups and networks are supported and promoted within local areas. Specifically, peer support groups can enable people to have a role in supporting others, receive support themselves and potentially sharing their experiences with health care staff through training workshops. Consequently, it is anticipated that developing and sharing the experiences of partners would facilitate more empathic relationships that enable important role and identity changes to occur.

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# Appendices

Figure 1

*Flow chart of literature search strategy*

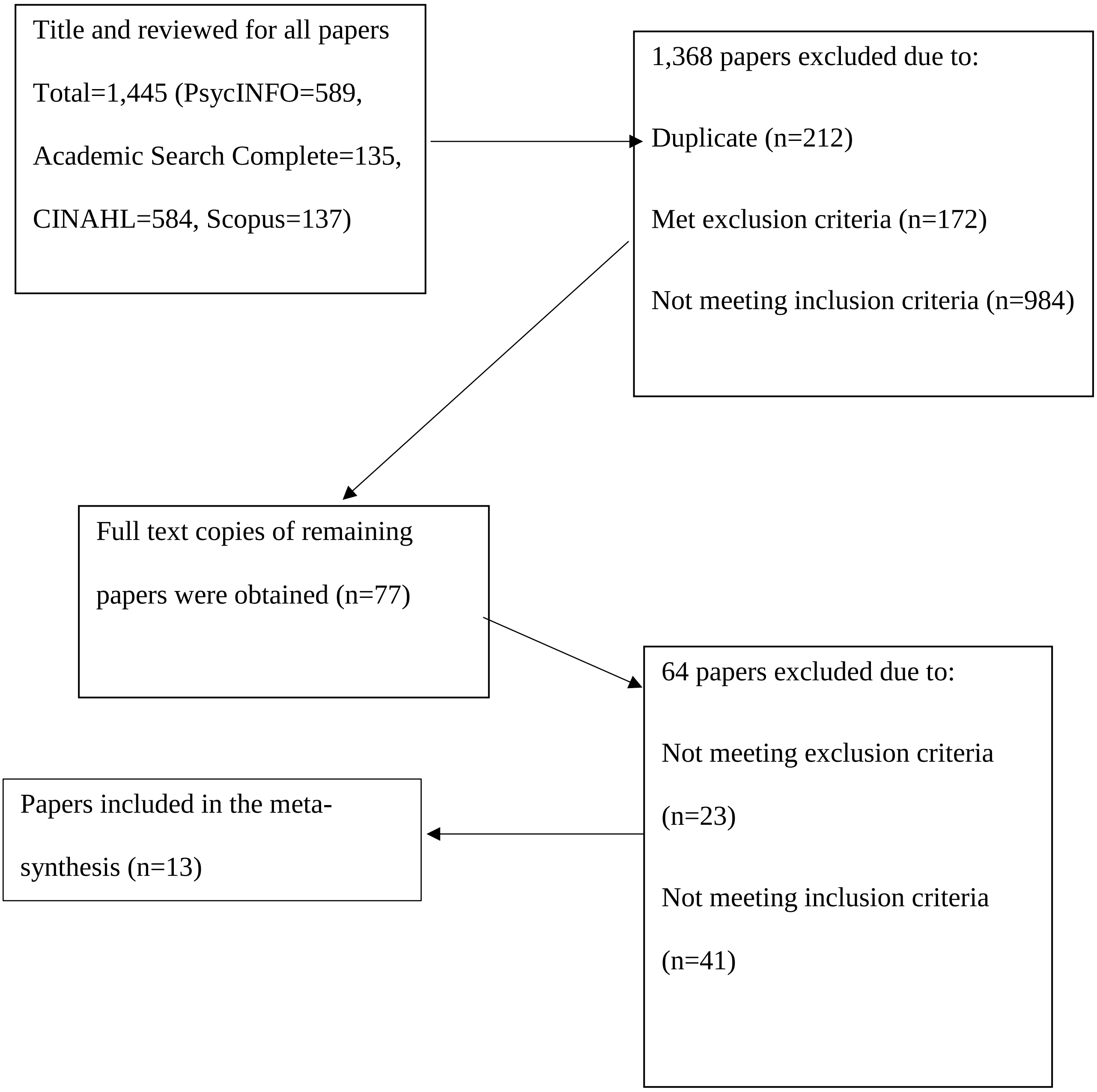

Table 1

*Characteristics of studies included in meta-synthesis*

| **Paper** | **Aim(s)** | **Sample** | **Country** | **Data Collection** | **Design/Analysis** |
|---|---|---|---|---|---|
| Baxter, Braithwaite, Golish & Olson (2011) | To explore the perceived contradictions that organise interaction between wives and their husbands with Alzheimer's disease and related conditions. To explore how wives manage these contradictions. | 21 wives (mean age of 77.1 years) of whom 15 husbands were alive and six were deceased (mean age 81.3 years). Average length of marriages was 49.1 years. 20 women were Caucasian and one was African American. All husbands had Alzheimer's disease or dementia and resided in a nursing home. | USA | Semi-structured interviews | Qualitative content analysis |
| Bonnel (1996) | To explore spouses' experiences of late stage Alzheimer's disease. | A 79 year old gentleman, 'Ben', who had cared for his wife with Alzheimer's disease for 12 years; six years at home and six years at a nursing home. 'Ben' was retired and had a daughter and son. He lived by himself in the family home he shared with his wife. | USA | Three open-ended interviews with 'Ben'. | Case study content analysis |
| Braithwaite (2009) | To explore the role changes for wives whose husbands live in nursing homes. To explore how wives represent their | 21 wives (mean age 77.1 years) of whom 15 husbands were alive and six were deceased (mean age 81.3 years). Average length of | USA | Semi-structured interviews | Qualitative content analysis |

| | | | | | |
|---|---|---|---|---|---|
| | perceptions of self-identity and marital relationship. | marriages was 49.1 years. 20 women were Caucasian and one was African American. All husbands had Alzheimer’s disease or dementia and resided in a nursing home. | | | |
| Cahill, Doran & Watson (2012) | To investigate the experiences of spouses whose partners died in care settings in Ireland. To develop guidelines for nursing home staff based on these experiences. | 16 spouses (12 females, four males) of deceased patients with dementia. 8 participants from Northern Ireland, 8 from the Republic of Ireland). Mean age of bereaved spouse was 77 years. Spouses had died six months-two years prior to the interviews. Participants were recruited through carers centres, private nursing homes, dementia units and state funded nursing homes. Mean stay in residential care was 33 months. | Northern Ireland and Republic of Ireland | Semi structured interviews containing seven separate sections. | Thematic analysis |
| Ford, Linde, Gigliotti & Kim (2012) | Explore meanings caregivers attribute to their caregiving experience. | Three wives of military veterans, whose husbands lived in military residential hospital. All husbands had a dementia diagnosis and their ages were 51, 71 and 84 years old. | USA | Semi structured interviews (30-60 minutes). Separate quantitative data collected using MM-CGI. | Case study content analysis |
| Forsund, Skovdahl, Kirk & Ytrehus (2014) | Explore and describe spouses’ experiences of losing couplehood with their dementia- affected | 10 married spouses (five men and five women) of individuals with dementia in four different nursing homes. Seven | Norway | Thematic Interview Guide was used to structure | Grounded theory |

| | | | | | |
|---|---|---|---|---|---|
| | partner living in residential care. | participants were older than 80 years old, all spouses had been married for more than 40 years. All couples, except one, had adult children. Individuals with dementia had been living in the nursing home between 8-48 months and their degree of dementia ranged from moderate to severe. | | interviews, lasting between 50 minutes and two and a half hours. Two participants submitted unprompted written reflections. | |
| Hemingway, MacCourt, Pierce & Strudsholm (2016) | To identify and describe the experience of spousal caregivers caring for a partner who is resident in a care facility. | Twenty eight spousal, including common-law caregivers. The average age of participants was 74.8 years. 19 participants were female. Average length of their marriages was 50.6 years. Participants' spouses had been resident of long term care facility for an average of 32.2 month. | Canada | Structured interviews were conducted with spouse participants on three occasions over 2 years. Focus groups were also held with care facility staff. | Thematic analysis |
| Hennings, Froggatt & Payne (2013) | To explore the caregiving experiences of spouse carer of people with advanced dementia living in nursing homes. | 10 spouse caregivers (Seven females and three males), aged between 65 and 89. Number of years married ranged between 27 and 67 years. Age of spouse with dementia ranged from 66 and 97 years old. Number of years since diagnosis ranged from one year and four months to 15 years. All partners with dementia resided in a nursing | UK | Eight participants were interviewed on three occasions (one was interviewed once and one was interviewed twice). Data was collected via interviews (nine-69 minutes) and | Narrative analysis |

| | | | | | |
|---|---|---|---|---|---|
| | | home for between six months and five years. | | participant diary entries. | |
| Hogsnes, Melin-Johansson, Gustaf-Norbergh & Danielson (2014) | To describe the existential life situations of caregiver spouses before and after relocating their partner with dementia to a nursing home. | 11 spouses of people with dementia (Alzheimer's, vascular or frontal-temporal dementia) living in a nursing home. All spouses were married and the majority had children, 8 female and 3 male. The time living in a nursing home varied between 1 week and 2 years with a median of 8 months. | Sweden | Semi structured interviews (40-60 minutes). | Interpretative content analysis |
| Kaplan (2001) | To understand the term couplehood and the impact of separation through institutionalisation on an individual's feeling of being married. | 68 individuals (42 females and 26 males) whose married spouses were in long term residential care. Average age of participants was 74.3 years and their partners was 77.9 years. Average years married was 47.1 years and average time spent in care home was 1.7 years. 99% of participants were Caucasian and for 75% this was their first marriage. | USA | Quantitative and qualitative data was collected. Qualitative data was collected through semi-structured interviews (30 mins- two hours). | Thematic Analysis |
| Kraijo, Leeuw & Schrijvers (2014) | How partners of people with dementia feel about their decision to place their partner in a nursing home. | 14 spouses of people with dementia diagnosis, living in nursing home. Participant ages ranged from 57 to 87 years old. Six females and eight males. | Netherlands | Semi- structured interviews approx. 18 months after partner was | Grounded Theory |

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|---|---|---|---|---|---|
| | | Partner ages ranged from 70-89 years old. | | admitted to nursing home. | |
| Mullin, Simpson & Froggatt (2011) | To explore the experience of spouses of those with dementia in long term care. | Nine married spouses and one long term partner of individuals with dementia, living in a care home for at least one year (range one year to four years and six months. Participants were six males and four females; ages ranged from 54 to 89 years old. Spouses with dementia ages ranged from 67 to 89 years old. | UK | Semi-structured interviews (50 minutes- one hour 20 minutes) | Interpretative Phenomenological Analysis |
| Tilse (1998) | Exploring the meaning of placing a spouse in long term care. | 18 spouses whose partner had been placed in residential care- 10 participants (five males and five females) had diagnosis of dementia and had been placed as a result of this diagnosis. | USA | Semi-structured interviews (average two hours) | Qualitative content analysis |

Table 2

*Quality appraisal of included studies using Critical Appraisal Skills Programme (CASP)*

| **Paper** | **Design, methods** | **Recruitment strategy** | **Data collection** | **Relationship between participants and researcher** | **Ethical issues** | **Rigorous analysis** | **Clear findings** | **Valuable contribution** |
|---|---|---|---|---|---|---|---|---|
| Baxter et al. (2011) | B | C | B | C | C | C | B | B |
| Bonnel (1996) | C | C | B | C | C | C | B | C |
| Braithwaite (2009) | B | C | B | C | C | C | B | B |
| Cahill et al. (2012) | B | B | B | C | C | B | C | B |
| Ford et al. (2012) | C | C | C | C | B | C | C | C |
| Forsund et al. (2014) | B | C | B | C | C | B | B | B |
| Hemingway et al. (2016) | B | B | B | B | B | C | B | B |
| Hennings et al. (2013) | B | C | B | C | B | B | B | B |
| Hogsnes et al. (2014) | C | C | C | C | B | C | B | B |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Kaplan (2001) | B | B | B | C | C | C | B | B |
| Kraijo et al. (2014) | B | B | B | C | C | B | B | B |
| Mullin et al. (2011) | B | C | B | C | B | B | B | B |
| Tilse (1998) | C | C | C | C | C | C | B | B |

Key to quality rating Downe, Simpson and Trafford (2007):

A- No or few flaws. The study credibility, transferability, dependability and conformability is high.

B- Some flaws, unlikely to affect the credibility, transferability, dependability and/or conformability of the study.

C- Some flaws, which may affect the credibility, transferability, dependability and/or conformability of the study.

D- Significant flaws, which are very likely to affect the credibility, transferability, dependability and/or conformability of the study

Table 3

*Table of constructs from meta-synthesis analysis*

| **Themes from Selected Studies** | **Key Concepts** | **Second Order Constructs** | **Third Order Constructs** |
|---|---|---|---|
| Wanting better communication with staff (Bonnel, 1996)<br>The complexity of relations with staff (Tilse, 1998)<br>Becoming an I (Kaplan, 2001)<br>Relationship with care provided: visiting as surveillance (Mullin, Simpson & Froggatt, 2011)<br>Satisfaction with care (Cahill, 2012)<br>Relationships (Cahill, 2012)<br>Decision-making relationships and trust (Cahill, 2012)<br>Feelings about formal caregivers (Ford et al., 2012)<br>Caregiving (Hennings, Froggatt & Payne, 2013)<br>Roles in decision making (Kraijo et al., 2014) | New relationships (self, marriage, spouse, care staff, friends) | a) Partners strive for certainty and control | e) Ambiguity prevents acceptance<br>(Challenges in planning for the future) |
| The precursors of the placement (Tilse, 1998)<br>We but (Kaplan, 2001)<br>Certainty-Uncertainty (Baxter et al., 2002)<br>Making sense of change (Mullin, Simpson & Froggatt, 2011)<br>Hospital Care (Cahill, 2012)<br>Status (Hennings, Froggatt & Payne, 2013)<br>Striving for acceptance despite a lack of completion | Ambiguity (present roles, future, identity, wanting clarity) | b) Partners cope by separating lives and re-defining marriage | f) Isolation can protect from feelings of guilt<br>(Continuation of social isolation) |

| | | | |
|---|---|---|---|
| Preparing for the future (Kraijo et al., 2014) | | | |
| The nature of relocation (Tilse, 1998)<br>Husbandless wives/wifeless husbands (Kaplan, 2001)<br>Emotional coping and social support (Ford et al., 2012)<br>Loss of shared everyday life (Forsund et al., 2014)<br>Feeling of loneliness in the spousal relationship (Hognsnes et al., 2014)<br>Separate lives (Hemingway et al., 2016) | Isolation (keeping others at a distance, lack of connectedness and understanding, lonely) | | |
| Seeking permission to gradually withdraw (Bonnel, 1996)<br>Giving to others (Bonnel, 1996)<br>Openness-Closedness (Baxter et al., 2002)<br>Staff training (Cahill, 2012)<br>Continued caregiving (Hemingway et al., 2016) | Restriction (partner, own life, expectations of others) | c) Negotiating new and old relationships- can be isolating or protective | g) Meaning and understanding of marriage evolves<br>(Embracing the changing the boundaries of marriage) |
| Seeking positive affirmations (Bonnel, 1996)<br>Decision-making and marital discontinuity (Tilse, 1998)<br>Experiences of visiting (Tilse, 1998)<br>Til death do us parts (Kaplan, 2001)<br>The presence-Absence Contradiction (Baxter et al., 2002)<br>Previous caregiving experiences (Ford et al., 2012)<br>Feelings of guilt and freedom (Hogsnes et al., 2014)<br>Actions of the informal caregiver (Kraijo et al., 2014) | Responsibility and Guilt (obligation to wedding vows, wanting to care, ending home care) | | |

| | | | |
|---|---|---|---|
| Wedding vows (Hemingway et al., 2016) | | | |
| Unmarried marrieds (Kaplan, 2001)<br>Past-Presence (Baxter et al., 2002)<br>Relationship to the future (Mullin, Simpson & Froggatt, 2011)<br>Time of death (Cahill, 2012)<br>Pain and symptom control at end of life (Cahill, 2012)<br>Story of developing dementia (Ford et al., 2012)<br>Loss of a shared future (Forsund et al., 2014)<br>Living with grief and thoughts of death (Hogsnes et al., 2014)<br>Disease progression (Hemingway et al., 2016) | Concerns about future (partner, marriage, own life, waiting for death, freedom) | d) Responsibility and perceived expectations lead to increased guilt | h) Partner establishes new identity consistent with the needs of themselves and partner (Negotiating a sense of self) |
| Typology of couplehood (Baxter et al., 2002)<br>Identity: ‘til death do us part (Mullin, Simpson & Froggatt, 2011)<br>Person-centred care (Cahill, 2012)<br>Exploring relationship history (Cahill, 2012)<br>Caregiver grief (Ford et al., 2012)<br>Loss of a shared past (Forsund et al., 2014) | Emotions towards partner (stable across time, love, sympathy, resentment) | | |