

The experiences of family caregivers of people with advanced dementia living in nursing homes, with a specific focus on spouses: a narrative literature-review.

Authors:

Jean Hennings and Katherine Froggatt

Faculty of Health and Medicine, Lancaster University, UK.

Corresponding author

Jean Hennings

Faculty of Health and Medicine, Lancaster University, Lancaster LA1 4YG, UK.

Email: j.hennings@lancaster.ac.uk

Abstract

Dementia affects individuals, families and their relationships. While there is increasing evidence about the experiences of family caregivers of people with dementia, relatively little is known of their experiences when their relatives are living in nursing homes with dementia. This narrative literature review aimed to synthesise current knowledge about family caregivers' experience of having relatives living in nursing homes with advanced dementia, particularly focussing on community-dwelling spouses. Using a systematic approach, textual narrative synthesis was undertaken. Four themes were identified: changing relationships, the need for companionship, adjusting to new roles and relationships and anticipating death/looking towards the future. Two additional themes were present only for spouses: changing identity – feeling married, being married; and alone but. . . The review demonstrates that some aspects of spouses' experiences are different from those of other family caregivers. Longitudinal studies are required to better understand spouses' motivations to continue caring in this context and to find ways of supporting them.

Keywords

dementia caregiving, end of life, nursing homes, review, spouses

Introduction

Estimates suggest that the number of people living with dementia worldwide is 46 million and that by 2050 that figure will be 131.5 million (Alzheimer's Disease International, 2015). A substantial amount of the care for people with dementia is provided by unpaid, informal caregivers (Wimo et al., 2010; World Health Organisation, 2012). Recent evidence suggests that, amongst those aged 65 and above, slightly more men than women undertake a caring role (ONS, 2013). Within long term co-habiting relationships caregiving tends to be regarded as an extension of that relationship (Gillies, 2012; Perry & O'Connor, 2002). It is now widely recognised that dementia is a condition which affects individuals and relationships (McGovern, 2011) and that the dementia and caregiving 'journeys' are dynamic processes which relate to the quality of the pre-morbid relationship (Hellström et al., 2007; Keady & Nolan, 2003). However due to the protracted, unpredictable, natural course of dementia (Mitchell et al., 2009), many people in the advanced stages spend at least their final year in nursing homes or long term residential settings (Houttekier et al., 2010; Mitchell et al., 2005). With the shift in emphasis of care from biomedical models to person centred (Kitwood, 1997) and relationship centred (Nolan et al., 2004) approaches, it would seem to be important to understand the perspectives of family caregivers for two reasons; to encourage and maintain their involvement where desirable and to identify and meet their needs. There appears to be lack of research surrounding community dwelling spouses of people with dementia nearing the end of their lives in nursing homes (Raymond et al., 2014). It is unclear whether this lack of research evidence is because the experience of spouses

is the same as that of family caregivers in general. The aim of this review was to synthesise what is known about family caregivers' experience of having a relative living in a nursing home with advanced dementia, to identify the commonalities and differences between the experience of family caregivers and that of community dwelling spouses and to highlight any knowledge gaps.

Methods

A narrative review of the literature was conducted as the aim was to identify the breadth and scope of available data, to identify similarities and differences between studies, to describe the diversity across them, and to identify any gaps in the literature (Lucas et al., 2007).

Evidence presented within both qualitative and quantitative papers was reviewed, taking a systematic and transparent approach (Popay et al., 2006). The search strategy was developed, and scoping searches conducted following methods recommended by The Centre for Reviews and Dissemination (2008). Nine electronic databases (Academic Search Complete; AMED; CINAHL; The Cochrane Library; EMBASE; Google Scholar; MEDLINE; PsycINFO; Web of Science) were searched. Search terms were developed and refined into three categories using thesaurus and MeSH headings and key words. These included MH "Dementia+" OR "lewy body dementia"; AND MH "Terminal Care +" OR MH "Terminally Ill Patients +" OR MH "Death" OR MH "Bereavement+" OR "Dying" OR "end of life" OR "dying process" OR "grieving" OR "social death"; AND MH "Caregivers" OR MH "Family Attitudes" OR "family caregiving" OR "wives" OR "husbands" OR "spouses" OR "spousal relationships".

The original scoping search included the line: AND MH "Residential Care" MH "Long term care" MH "Nursing home patients" MH "Institutional care+" OR "care homes" OR "residential aged care", but this was found to exclude important papers, narrowing the search too far. Therefore, this line was excluded from the electronic search but criteria surrounding the care setting were set in the inclusion and exclusion criteria (Table 1).

Peer reviewed empirical papers, reporting qualitative, quantitative or mixed methods studies, including case studies, published between 1980 and June 2016, written in English were included (Table 1). The primary focus of papers for inclusion was the experiences, views, and needs of family members and /or spouses (Table 1).

Table 1: Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Peer reviewed empirical papers. Qualitative papers, including case studies. Quantitative & mixed methods studies.	Opinion papers and letters to the editor. Not primary research/ review papers.
Papers written in English.	Papers not written in English.
Papers published between 1980 and June 2016.	Papers published before 1980.
Age groups: 65 and over.	Under 65 years.
Papers whose primary focus was the experiences/ views/ needs of family members including spouses.	Papers whose primary focus was decision making on behalf of people with dementia, burden or depression.
Papers whose context was end of life care of people with dementia from the caregiver's perspective.	Papers whose context was end of life care for people with a diagnosis other than dementia or clinical aspects of end of life care.
Papers in which the setting of care for the person with dementia was a nursing home, residential care home or equivalent.	Papers in which the setting of care for the person with dementia was their own home.

Further details of the search methods are available from the corresponding author.

Quality assessment of included papers was guided by Walsh & Downe (2006). This was not to exclude studies, but to be aware of any weaker studies when reporting findings, bearing in mind that appraisal itself is subjective (Spencer et al., 2003).

Data were extracted systematically from each of the included papers and tabulated using a method described by Popay et al (2006) (Table 2).

[Insert Table 2: Tabulated Research Summary]

The second stage of textual narrative synthesis involved grouping papers according to country of origin, design, methodology and methods used, and the context of care (Creswell, 2014). Finally, narrative synthesis of presented data was developed (Arai et al., 2007; Lucas et al., 2007). Narrative synthesis of textual data is akin to thematic analysis of primary qualitative research data: in which common themes across studies are systematically identified, noting any contradictions or outliers (Arai et al., 2007). Themes are defined and refined by the review researcher, rather than using themes identified by individual authors.

Review findings

[Insert Figure 1]

Figure 1: *Summary of sources contributing to the narrative synthesis*
From: Moher et al (2009)

The search yielded 901 abstracts from which nineteen were retained following title and abstract review. Seven papers were excluded after reading the full text.

Reasons for these exclusions were that they did not report primary research (3), or that the focus of the research was:

- the early stages of dementia (1)
- focus on ethics, decision making and advanced directives (1)
- carers' views regarding end of life for relatives with dementia (1)
- the way in which carers spoke about dementia compared with media portrayals of the condition (1)

Reference lists of relevant papers were hand searched, revealing two papers for inclusion (Figure 1). A total of twelve papers were included in the narrative review.

Of the included studies, eight were conducted in North America or Australia (Ford et al., 2013; Hemingway et al., 2014; Kaplan, 2001; Meuser & Marwit, 2001; Moyle et al., 2002; Peacock et al., 2014; Sanders et al., 2009; Shanley et al., 2011), three in Scandinavia (Førsund et al., 2015; Hellström et al., 2007; Høgsnes et al., 2014) and one in the United Kingdom (Mullin et al., 2013).

Seven studies used a cross sectional design with current caregivers (Ford et al., 2013; Førsund et al., 2015; Høgsnes et al., 2014; Kaplan, 2001; Meuser & Marwit, 2001; Moyle et al., 2002; Mullin et al., 2013), and one used a cross sectional design with bereaved caregivers (Shanley et al., 2011). Four studies were longitudinal with data generation over periods of between ten months (Sanders et al., 2009) and five years (Hellström et al., 2007).

The settings of care were, or had been, nursing homes, long term dementia care units, long term care homes, care homes, group home, veteran's hospital or hospice (with a long term care element) (Table 2). Several studies included a variety of care

settings, reflecting the research design and nature of the disease process (Hellström et al., 2007; Peacock et al., 2014; Shanley et al., 2011).

Seven papers included participants who were exclusively spouses or long term partners of people with dementia (Ford et al., 2013; Førsvund et al., 2015; Hellström et al., 2007; Hemingway et al., 2014; Høgsnes et al., 2014; Kaplan, 2001; Mullin et al., 2013). The remaining five papers included a variety of family members and spouses in various proportions.

The method of choice for data generation was structured or semi-structured interviews: with ten of the twelve studies using it. The other two studies used focus group interviews (Meuser & Marwit, 2001; Moyle et al., 2002).

Reporting methods varied, some used brief, unattributed quotes, offering little contextual detail (Hemingway et al., 2014; Meuser & Marwit, 2001; Moyle et al., 2002), and others preserved detail and context surrounding participants (Mullin et al., 2013; Shanley et al., 2011).

To retain the richness of original data, in the included papers and for clarity, data direct from research participants are distinguished from author interpretations, as outlined by Lucas et al (2007). Direct verbatim participants' quotes are given, as presented in the original paper, in '*quotation marks and italicised Calibri font*'. Author interpretations or commentary are presented in '*quotation marks and italicised normal font*'. In cases where there is lack of clarity the format for author interpretations is used. Where possible the relationship of quoted participants to the person with dementia is reported.

The following themes were common across all included papers:

1. Changing relationships
2. The need for companionship
3. Adjusting to new roles and relationships
4. Anticipating death/ looking towards the future

Two further themes were identified that were present only for spouse caregivers:

5. Changing identity - feeling married, being married
6. Alone but...

Changing relationships

Physical deterioration and cognitive decline in the relative with dementia was understood by family caregivers as a series of ongoing losses. Those losses included loss of conversation, communication and recognition (Meuser & Marwit, 2001; Moyle et al., 2002; Mullin et al., 2013; Peacock et al., 2014; Sanders et al., 2009): *'...there is no interaction anymore. There is nothing there.'* (wife) (Sanders et al., 2009 p541).

Communication difficulties affected relationships:

'Everything about the relationship is gone' (unattributed) (Sanders et al., 2009 p536)

'... the relationship has (.) has gone because you can't converse and can't talk and can't share experiences anymore.' (male spouse) (Mullin et al., 2013 p183)

Spouse caregivers were reported to have *'felt invisible'* when their partners failed to recognise them (Mullin et al., 2013 p183), but they gained strength on occasions when they were recognised:

'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 several weeks ... life's simple pleasures.' (wife) (Ford et al., 2013 p141)

Episodes of lucidity in the relative with dementia were treasured (Meuser & Marwit, 2001), but were also discouraging, because in such moments they frequently expressed a wish to die (Meuser & Marwit, 2001). However, one spouse was of the

opinion that having thoughts and feelings but being unable to express them would be 'pure hell' (wife) (Ford et al., 2013 p141) she therefore hoped that 'her husband was void of thought or feeling' (Ford et al., 2013 p141).

There could however be beneficial effects of cognitive decline and loss of recognition. Leaving the person with dementia in the nursing home became easier as the disease advanced and there was little or no recognition or emotional response (Mullin et al., 2013). Also, some people with dementia were reported to have expressed their emotions more freely and to become less inhibited, a trait which caregivers found to be comforting (Meuser & Marwit, 2001).

The need for companionship

Continuing to care for a relative in the nursing home required high levels of time and commitment, resulting in lack of time to maintain other relationships (Shanley et al., 2011). In addition, some friends and family were reported to distance themselves from both the caregiver and the person with dementia, resulting in loneliness (Meuser & Marwit, 2001; Shanley et al., 2011).

'Friends we've had for thirty and forty years I've never seen one of them since.' (husband)
(Shanley et al., 2011 p333)

Some caregivers experienced increased family cohesion as a result of having a family member with dementia, whilst others reported increased tension (Peacock et al., 2014).

Whilst there was evidence that caregivers had problematic relationships with friends and family, and struggled to communicate their needs, there was also evidence that they wanted social support and meaningful relationships. Participants particularly valued carer support groups, where they found acknowledgement of their role,

empathy, information and advice (Shanley et al., 2011). Group members were able to give and receive mutual support (Ford et al., 2013; Moyle et al., 2002; Sanders et al., 2009; Shanley et al., 2011). It appears that the much needed support and empathy was only found within support groups, as family and friends tended to be otherwise engaged.

Adjusting to new roles and relationships

Participants acknowledged that home caring had been difficult, but said that they had been comfortable in their role (Moyle et al., 2002). They expressed relief that the day to day demands and stresses of caregiving were over:

'... they did everything, all I had to do was go and visit and feed her. Didn't even have to feed her but I liked to.' (husband) (Shanley et al., 2011 p332)

Their caregiving role within the nursing home involved a delicate balance between many, often conflicting, needs and emotions. Whilst relationships with the person with dementia, family and friends were changing and at times challenging, family caregivers needed to develop relationships with nursing home staff and negotiate new roles (Moyle et al., 2002).

Caregivers wanted to be with their relative, to check that standards were maintained, to retain some control, and to play an advocacy role within the nursing home (Hemingway et al., 2014; Moyle et al., 2002; Mullin et al., 2013; Peacock et al., 2014; Shanley et al., 2011). This was particularly because their relatives were no longer able to verbalise their own needs.

The emotional effect of the physical distance of partners could be profound:

'They are not really yours anymore. On paper they are, but they are not really yours.' (unattributed spouse)(Hemingway et al., 2014 p7)

Family caregivers tended to feel guilty at having placed their relative in the nursing home (Moyle et al., 2002), regarding it as a failure of home care (Peacock et al., 2014). Staff were focussed on the care of residents rather than on their relatives (Moyle et al., 2002). As a result, family caregivers often felt lost and alone in their caring role, receiving little support from nursing home staff (Moyle et al., 2002).

Anticipating death/ looking towards the future

Some participants regarded their relatives with dementia to be in some ways already dead. As a result of the losses, their relative *'no longer seemed to be the person they once knew'* (Moyle et al., 2002 p30). Losses were reported to have occurred at various stages:

On receiving the diagnosis:

'So really we lost our mom just like that.' (daughter) (Peacock et al., 2014 p6)

On admission to long term residential care:

'his life had ended, you know his death at that point of (being my) Dad was at that moment.' (son) (Peacock et al., 2014 p6)

'He died when he went into the nursing home.' (wife) (Kaplan, 2001 p92)

And at an ill-defined point earlier in the disease and caring process:

....'our lives had separated down the track. In actual fact you lose them a bit earlier than that if you know what I mean, figuratively speaking.' (husband) (Shanley et al., 2011 p333)

The impending death of the person with dementia was typically viewed with mixed feelings: as both a blessing and feared (Moyle et al., 2002), with relief and sadness (Meuser & Marwit, 2001), longed for and dreaded (Mullin et al., 2013; Shanley et al., 2011). Some wished for the death of the person with dementia, regarding it as marking the end of suffering and preferable to the continuance of life (Peacock et al., 2014). In some ways death was regarded as the final, but not the most painful loss;

watching the person with dementia *'fade away'* being equally, if not more difficult (Shanley et al., 2011 p333). Some felt that bereavement would be easier to cope with than the ongoing losses experienced as a caregiver (Høgsnes et al., 2014; Mullin et al., 2013). But others were reported to have felt that they would never be *'ready'* for the death (Peacock et al., 2014 p6). Spouse caregivers wanted to be relieved of their problems (Meuser & Marwit, 2001; Mullin et al., 2013), but did not regard the death of their spouse as a solution to those problems (Meuser & Marwit, 2001).

Sanders et al (2009) defined four typologies with regard to the caregivers' approach to their situation: questioning, reconciled, all consumed and disengaged. Questioning caregivers had limited knowledge and did not recognise their relative to be dying, even in the most advanced stages. Similarly, Shanley et al (2011) described some caregivers who, having been warned in advance, were still unprepared for the death of their relative. In contrast, *'reconciled caregivers'* were characterised as being prepared for their relative's death, which would come as a relief (Sanders et al., 2009):

'Let's keep him comfortable and let nature take its course' (unattributed) (Sanders et al., 2009 p541)

The *'all consumed'* family caregivers would typically state that they were ready for the death of their relative, but would also express feelings of loneliness and loss (Sanders et al., 2009). *'Disengaged caregivers'* were exclusively adult children of people with dementia, of either gender, with a mean age of 50 years (Sanders et al., 2009). They were also prepared for their parent's death, but had minimal involvement and were emotionally disconnected (Sanders et al., 2009).

The concept of time was difficult and confusing for some and spoken about with mixed and conflicting emotions (Peacock et al., 2014). There was conflict between what caregivers wanted for themselves, and what they wished for their relatives in the nursing home. One caregiver said that she was *'marking time'* (unattributed female) (Sanders et al., 2009 p541), as if standing still. Some felt that this phase of life would never end (Peacock et al., 2014; Sanders et al., 2009). Some wanted time to go faster, yet they also wanted to *'hold onto'* time (daughter) (Peacock et al., 2014 p6), being aware that life for their relative was limited. Others were passive in relation to the future, *'simply waiting for the time to come'* (Sanders et al., 2009 p544), recognising that they were unable to affect the natural course of events.

The following section focuses on two themes which were unique to spouses. They were: 'Changing identity - feeling married, being married,' and 'Alone but...'

Changing identity - feeling married, being married

With the deteriorating condition of the spouse and altered living arrangements, spouse caregivers tended to increasingly define their status as no longer being one of a couple (Førsund et al., 2015; Hellström et al., 2007) with a perceived need to build a new single identity (Meuser & Marwit, 2001). Some spouses already felt divorced or widowed, and were mourning the loss of their partners as fully active people in relationship (Hemingway et al., 2014; Kaplan, 2001; Meuser & Marwit, 2001).

'As far as I'm concerned there's no future [for the marriage]. No. I feel pretty much almost like widower in that respect.' (husband) (Kaplan, 2001 p94)

Some participants were at least thinking about seeking new dyadic relationships:

'...I hope that there will be somebody for me, somebody that will care about me as much as [my husband] did ... That would almost ... scares me, because I don't think there's another one like that out there that had such high esteem for me. Uh, but I feel that I really need that.' (wife) (Kaplan, 2001 p93)

Motivation to seek new relationships was driven by loneliness and the need for close companionship.

Whilst some regarded their marriage to be over, this did not always indicate that they had ceased to care for and about their spouse:

'I don't have a wife anymore. ...I still love her but it isn't her anymore.' (husband) (Kaplan, 2001 p92)

This was replicated by Høgsnes et al (2014) and Mullin et al (2013). However, some spouse caregivers continued to express strong feelings that their marriage and relationship was unchanged by disease and changed living arrangements, describing themselves in relationship as 'we' (Kaplan, 2001 p92).

Alone but...

Participants were frequently reported to feel alone, and be alone, but were unable or reluctant to make changes. This was referred to as an *'uneasy individuality'* (Meuser & Marwit, 2001 p666). Spouse caregivers were found to regard *'living as a single person'* as a frightening and confusing situation (Meuser & Marwit, 2001 p666).

Participants questioned how life as an individual was possible, when their partner was still alive and their caring obligations continued (Meuser & Marwit, 2001). This finding was replicated by both Kaplan and Hemingway:

'And life goes on for me, and I have to make the best of it ... but that thought of that spouse is never far from your mind.' (unattributed spouse) (Kaplan, 2001 p93)

'It is just that you have to learn to be on your own, you know. I think that the hardest thing is that you have a husband, but you have nothing.' (unattributed spouse) (Hemingway et al., 2014 p7)

There is also evidence that spouses were alone and lonely in their own homes (Hemingway et al., 2014; Mullin et al., 2013).

'You come home to an empty house. You have nobody there.' (unattributed spouse) (Hemingway et al., 2014 p7)

'I'd been coming home and living on my own, with [wife] still alive, but she was separated from me [in the nursing home].(husband) (Shanley et al., 2011 p333)

Participants were described as being in a *'life-death limbo'*: as being *'stuck and unsure how to proceed with life'* (Meuser & Marwit, 2001 p666). Marriage was described as being *'stagnant'* (unattributed spouse) (Kaplan, 2001 p93) and life as *'frozen'* (female spouse) (Førsund et al., 2015 p127). These sentiments were mirrored by others:

'No we take one day at a time.' (wife) (Hellström et al., 2007 p397)

'I am just living day by day' (unattributed spouse) (Hemingway et al., 2014 p8)

Life continued for the community dwelling spouses, but they were living in a transitional state which was confused and confusing, presenting an uneasy tension.

Three of the included papers referred to change over time, but findings were inconclusive. The ethnographic study of ten months duration with family caregivers (four of whom were spouse caregivers) reported little change over time (Sanders et al., 2009). A second study reported change to be both temporal and linear (Meuser & Marwit, 2001). The third, a longitudinal study of spouse caregivers reported change to be temporal but non-linear (Hellström et al., 2007).

Discussion

Many of the experiences of caregivers related to the effects of the dementia disease process, changed living arrangements and associated changes in the caregiver role. This was a confused and confusing period of transition embodied by uncertainty and

disorder. Family members in general understood the deteriorating health of their relative in terms of a series of losses over a prolonged period. Loss of communication, interaction and recognition resulted in loss of companionship, loss of opportunities for companionship, and loneliness. However, some perceived positive effects as their relatives with dementia expressed their emotions more freely and some reported increased family cohesion. A variety of reactions and emotions were expressed in response to the changes and losses: including deep sadness, regret, distress, burden and resigned acceptance of the situation.

Whilst the relationship with the person with dementia was changing, relationships with others were also affected. It was recognised that carers were busy and preoccupied in their role, leaving little time or energy for others. There was evidence of distancing of friends and family from the person with dementia and from their caregivers. However, participants had a desire for social support and meaningful relationships. They found empathy and support from their peer group and in support groups. There was evidence of both increased family cohesion and increased family tension.

Difficulties were experienced as new roles and relationships were negotiated within the nursing home. Surveillance of care, to ensure that standards were maintained, had to be balanced against nurturing relationships with staff and avoiding conflict. Feelings of guilt were reported in relation to caregivers' inability to continue home caring, and when they were unable to visit.

Some family members understood their relative to be dead prior to their physical death, reflecting the degree of loss and perception of the losses. When these sentiments were present in spouses, the way in which they felt about their marital

relationship was affected. Death of the relative with dementia was anticipated with mixed and confused emotions.

Two narrative themes, exclusive to spouses, were 'Changing identity - feeling married, being married', and 'Alone but...'. They were unique, but central themes, reflecting the way in which dementia in a partner and their changed living arrangements influenced community dwelling spouses' feelings about their own identities and their marital relationships. The theme 'Alone but...' reflected the uneasy feelings of spouses who were living alone and felt alone, but still had caring responsibilities and were still committed to their relationship. There was a strong sense that their own lives must continue, but they also felt unable to make changes or to think about the future.

More generally, there appears to be a particular shortage of studies conducted with community dwelling spouses whose relatives are resident in nursing homes with advanced dementia. From the review findings, spouses in this context and setting appear to suffer from what we have termed 'triple invisibility' or 'triple silencing'.

There are three major reasons why knowledge of this particular group is limited. First, this literature review highlighted that this group of carers tend to be regarded as no longer caring or to have relinquished care (Bond et al., 2003; Eloniemi-Sulkava et al., 2002). As a result, in some cases, their participation in research on caregivers is not sought. Where their views have been sought it has usually been in their capacity as proxy decision makers, or to provide proxy evaluations of quality of life, or quality of death.

Second, dementia research tends to focus on the person with dementia rather than their caregivers, and on the early stages of dementia rather than the end of life. The views of family caregivers in their own right have rarely been elicited, particularly in relation to end of life dementia caregiving (Hennings et al., 2010).

Third, where spouse caregivers were included in studies, their data tend to be aggregated along with that of other family caregivers (Graneheim et al., 2014). It appears that researchers have made the assumption that the experiences of all caregivers in this setting will be comparable. In the reviewed papers, many quotations were unattributed, sparse or non-existent. This may be due to limits set by journals and their editors, but teasing out differences and making comparisons was difficult as a result. This review has illustrated that the experiences of community dwelling spouses do not map those of other family caregivers, and therefore deserve to be the focus of further research.

Earlier research suggests that in the early stages of dementia, couples within previously good relationships, work together to maintain connectedness and communication (Hellström et al., 2007; Keady & Nolan, 2003). Caregiving spouses use in-depth knowledge of their partners with dementia to preserve their personhood and maintain continuity (Hellström et al., 2007; Perry & O'Connor, 2002). Caregiving spouses also adapt over time in response to their partners' changing abilities and levels of engagement (Hellström et al., 2007). By working to support their partners' competence and protect them from incompetence, home caregiving spouses are known to create a 'façade of normalcy' which preserves their own and their partners' identities (Perry & O'Connor, 2002 p59). From a cross sectional study of six women caring for their spouses with dementia at home, Walters et al (2010) suggested that

the extent to which caregiving spouses can maintain elasticity of connection is a crucial factor in their perception of continuity. The degree of change in the person with dementia, and the relationship are less critical, with some seeking signs of continuity and others repelling the idea that the spouse with dementia may be the same person (Walters et al., 2010). Similarly, a recent cross sectional study of twelve family caregivers of people with dementia, ten of whom were home caregiving, suggested that in the context of previously positive relationships, a positive caring relationship 'involves emotional connectedness and open communication' (Quinn et al., 2015 p1266).

There is further evidence that in the home caring situation, the changing social identity of the spouse with dementia affected their partners' perception of marital closeness (Boylstein & Hayes, 2012). In support of these findings, a recent review of the literature surrounding the impact of dementia on marriage, in the context of home caring, suggested that there is transition of relationships, roles and intimacy as dementia progressively affects individuals and their relationships (Evans & Lee, 2014).

These findings were supported in a more general review of the literature surrounding family relationships and dementia which suggests that the history and quality of relationships and communication within them tended to result in caregiver/receiver dyads either working together and openly communicating or working apart and using minimising and denial as coping strategies (La Fontaine & Oyebode, 2014).

There is evidence that the meanings associated with caregiving, and the motivation to continue are affected by the quality of relationships (Quinn et al., 2015) with caregivers interpreting their experience in the context of life experience as a whole

(Lewis, 1998). Quinn et al (2015) presented findings from a cross sectional study of twelve family caregivers (of whom ten were home caring and eight were spouses), in which caregivers indicated that they would continue home caring until the relative with dementia no longer recognised them. Quinn et al (2015) suggested that at this point caregivers would no longer be able to derive meaning from their caring role.

As a result of this literature review, and a consideration of the wider literature, several questions remain unanswered. How and why do community dwelling spouses derive meaning through caregiving when their spouses (with advanced dementia living in nursing homes), demonstrate intermittent emotional connectedness and poor communication? What strategies do they use to maintain connectivity?

Implications for practice

Health and social care services in general could assist by moving away from the use of labels such as 'carer' or 'caregiver' which tend to be ascribed by others (Ribeiro et al., 2007; Smith, 2001). Such terms fail to recognise persons in their own right and do not define them or their relationships.

Nursing home staff could assist community dwelling spouses by recognising their potentially difficult position. Activities used to support person centred care and relationship centred care can also be used to retain involvement of community dwelling spouses and keep lines of communication open.

Conclusion/ Future research

The majority of studies conducted with family caregivers in this review were retrospective and cross sectional, a trend previously observed by van der Steen

(2010) and La Fontaine & Oyeboode (2014). Longitudinal studies are essential if the dynamic journey of caregiving, particularly for a spouse with dementia, is to be fully understood and the underlying motivations interpreted.

To date research has tended to focus on the early stages of dementia in the home setting (e.g. Walters 2010). This is an observation supported by a review of the impact of dementia on marriage, in which none of the included 19 papers involved spouses residing in long-term care (Evans & Lee, 2014). In the case of non-co-habiting spouses the day to day pressures of direct caregiving have reduced, but the opportunities for intimacy and potential satisfaction of caring have largely been removed. Little is known of the motivations and strategies employed by community dwelling spouses to maintain or rebuild connectivity with a spouse later in the disease trajectory. In addition, the differences in those who choose to sever ties and those who continue caring when no longer co-habiting appear not to have been investigated.

Declaration of Conflicting Interests

None declared

Funding information

This research received no specific grant from any funding agency.

References

- Alzheimer's Disease International. (2015). World Alzheimer Report 2015: The global impact of dementia. An analysis of prevalence, incidence cost and trends. London: Alzheimer's Disease International.
- Arai, L., Britten, N., Popay, J., Roberts, H., Petticrew, M., Rodgers, M., & Sowden, A. (2007). Testing methodological developments in the conduct of narrative synthesis: A demonstration review of research on the implementation of smoke alarm interventions. *Evidence & Policy*, 3(3), 361-383.
- Bond, M. J., Clark, M. S., & Davies, S. (2003). The quality of life of spouse dementia caregivers: Changes associated with yielding to formal care and widowhood. *Social Science & Medicine*, 57(12), 2385-2395.

- Boylstein, C., & Hayes, J. (2012). Reconstructing marital closeness while caring for a spouse with Alzheimer's. *Journal of Family Issues*, 33(5), 584-612. doi: 10.1177/0192513x11416449
- Centre for Reviews and Dissemination. (2008). *Systematic reviews. CRD's guidance for undertaking reviews in health care*. York: CRD University of York.
- Creswell, J. (2014). *Research design. Qualitative quantitative and mixed methods approaches*. London: Sage.
- Eloniemi-Sulkava, U., Rahkonen, T., Suihkonen, M., Halonen, P., Hentinen, M., & Sulkava, R. (2002). Emotional reactions and life changes of caregivers of demented patients when home caregiving ends. *Aging & Mental Health*, 6(4), 343-349.
- Evans, D., & Lee, E. (2014). Impact of dementia on marriage: A qualitative systematic review. *Dementia*, 13(3), 330-349. doi: 10.1177/1471301212473882
- Ford, J. L., Linde, B. D., Gigliotti, C., & Kim, K. Y. (2013). Grief experiences of 3 caregiving wives of veterans with dementia. *American Journal of Hospice & Palliative Medicine*, 30(2), 137-145. doi: 10.1177/1049909112446847
- Førsund, L. H., Skovdahl, K., Kiik, R., & Ytrehus, S. (2015). The loss of a shared lifetime: A qualitative study exploring spouses' experiences of losing couplehood with their partner with dementia living in institutional care. *Journal of Clinical Nursing*, 24(1-2), 121-130.
- Gillies, B. (2012). Continuity and loss: The carer's journey through dementia. *Dementia*, 11(5), 657-676.
- Graneheim, U., Anneli Johansson, A., & B-M, L. (2014). Family caregivers' experiences of relinquishing the care of a person with dementia to a nursing home: insights from a meta-ethnographic study. *Scandinavian Journal of Caring Sciences*, 28, 215-224.
- Hellström, I., Nolan, M., & Lundh, U. (2007). Sustaining 'couplehood': Spouses' strategies for living positively with dementia. *Dementia*, 6(3), 383-409. doi: 10.1177/1471301207081571
- Hemingway, D., MacCourt, P., Pierce, J., & Strudsholm, T. (2014). Together but apart: Caring for a spouse with dementia resident in a care facility. *Dementia*. Retrieved from <http://dem.sagepub.com/content/early/2014/07/15/1471301214542837.abstract>
doi:10.1177/1471301214542837
- Hennings, J., Froggatt, K., & Keady, J. (2010). Approaching the end of life and dying with dementia in care homes: The accounts of family carers. *Reviews in Clinical Gerontology*, 20(2), 114-127. doi: 10.1017/S0959259810000092
- Høgsnes, L., Melin-Johansson, C., Norbergh, K. G., & Danielson, E. (2014). The existential life situations of spouses of persons with dementia before and after relocating to a nursing home. *Aging & Mental Health*, 18(2), 152-160. doi: 10.1080/13607863.2013.818100
- Houttekier, D., Cohen, J., Bilsen, J., Addington-Hall, J., Onwuteaka-Philipsen, B. D., & Deliëns, L. (2010). Place of death of older persons with dementia. A study in five European countries. *Journal of The American Geriatric Society*, 58(4), 751-756. doi: 10.1111/j.1532-5415.2010.02771.x
- Kaplan, L. (2001). A couplehood typology for spouses of institutionalized persons with Alzheimer's disease. Perceptions of "We" – "I". *Family Relations*, 50(1), 87-98.
- Keady, J., & Nolan, M. (2003). The dynamics of dementia: working together, working separately or working alone? In M. Nolan, U. Lundh, G. Grant & J. Keady (Eds.), *Partnerships in Family Care* (pp. 15-32). Maidenhead: Open University Press.

- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press.
- La Fontaine, J., & Oyeboode, J. (2014). Family relationships and dementia: A synthesis of qualitative research including the person with dementia. *Ageing & Society, 34*(07), 1243-1272. doi: 10.1017/S0144686X13000056
- Lewis, R. (1998). The impact of the marital relationship on the experience of caring for an elderly spouse with dementia. *Ageing and Society, 18*(2), 209-231.
- Lucas, P., Baird, J., Arai, L., Law, C., & Roberts, H. (2007). Worked examples of alternative methods for the synthesis of qualitative and quantitative research in systematic reviews. *BMC Medical Research Methodology, 7*(4). doi: 10.1186/1471-2288-7-4
- McGovern, J. (2011). Couple meaning-making and dementia: Challenges to the deficit model. *Journal of Gerontological Social Work, 54*(7), 678-690. doi: 10.1080/01634372.2011.593021
- Meuser, T. M., & Marwit, S. J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist, 41*(5), 658-670. doi: 10.1093/geront/41.5.658
- Mitchell, S., Teno, J., Kiely, D., Shaffer, M., Jones, R., Prigerson, H., . . . Hamel, M. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine, 361*(16), 1529-1538.
- Mitchell, S., Teno, J. M., Miller, S. C., & Mor, V. (2005). A national study of the location of death for older persons with dementia. *Journal of the American Geriatric Society, 53*(2), 299-305.
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D., & The PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Med, 6*(6), e1000097. doi: 10.1371/journal.pmed1000097
- Moyle, W., Edwards, H., & Clinton, M. (2002). Living with loss: Dementia and the family caregiver. *Australian Journal of Advanced Nursing, 19*(3), 25-31.
- Mullin, J., Simpson, J., & Froggatt, K. (2013). Experiences of spouses of people with dementia in long-term care. *Dementia, 12*(2), 177-191. doi: 10.1177/1471301211418096
- Nolan, M. R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond 'person-centred' care: A new vision for gerontological nursing. *Journal of Clinical Nursing, 13*(3a), 45-53. doi: 10.1111/j.1365-2702.2004.00926.x
- ONS. (2013). 2011 Census Analysis: Unpaid care in England and Wales, 2011 and comparison with 2001. Newport, Wales: Office for National Statistics.
- Peacock, S., Duggleby, W., & Koop, P. (2014). The lived experience of family caregivers who provided end-of-life care to persons with advanced dementia. *Palliative & Supportive Care, 12*(2), 117-126.
- Perry, J., & O'Connor, D. L. (2002). Preserving personhood: (Re)membering the spouse with dementia. *Family Relations, 51*(1), 55-62.
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, A., Rodgers, M., . . . Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. A product from the ESRC Methods Programme. Lancaster: Institute for Health Research, University of Lancaster.
- Quinn, C., Clare, L., & Woods, R. (2015). Balancing needs: The role of motivations meanings and relationship dynamics in the experience of informal caregivers of people with dementia. *Dementia, 14*(2), 220-237.

- Raymond, M., Warner, A., Davies, N., Manthorpe, J., Ahmedzhai, S., & Iliffe, S. (2014). Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family carers. *Dementia*, 13(1), 96-110. doi: 10.1177/1471301212450538
- Ribeiro, O., Paul, C., & Nogueira, C. (2007). Real men, real husbands: Caregiving and masculinities in later life. *Journal of Aging Studies*, 21(4), 302-313.
- Sanders, S., Butcher, H. K., Swails, P., & Power, J. (2009). Portraits of caregivers of end-stage dementia patients receiving hospice care. *Death Studies*, 33(6), 521-556. doi: 10.1080/07481180902961161
- Shanley, C., Russell, C., Middleton, H., & Simpson-Young, V. (2011). Living through end-stage dementia: The experiences and expressed needs of family carers. *Dementia*, 10(3), 325-340. doi: 10.1177/1471301211407794
- Smith, P. (2001). Who is a carer? Experiences of family caregivers in palliative care. In S. Payne & C. Ellis-Hill (Eds.), *Chronic and terminal illness; new perspectives on caring and carers* (pp. 83-99). Oxford: Oxford University Press / Published to Oxford Scholarship Online: Nov-2011.
- Spencer, L., Ritchie, J., Lewis, J., & Dillon, L. (2003). Quality in qualitative evaluation: A framework for assessing research evidence. Government Chief Social Researcher's Office, London: Cabinet Office.
- van der Steen, J. T. (2010). Dying with dementia: What we know after more than a decade of research. *Journal of Alzheimer's Disease*, 22(1), 37-55.
- Walsh, D., & Downe, S. (2006). Appraising the quality of qualitative research. *Midwifery*, 22(2), 108-119.
- Walters, A. H., Oyebode, J. R., & Riley, G. A. (2010). The dynamics of continuity and discontinuity for women caring for a spouse with dementia. *Dementia*, 9(2), 169-189. doi: 10.1177/1471301209354027
- Wimo, A., Winblad, B., & Jönsson, L. (2010). The worldwide societal costs of dementia: Estimates for 2009. *Alzheimer's & Dementia*, 6(2), 98-103. doi: <http://dx.doi.org/10.1016/j.jalz.2010.01.010>
- World Health Organisation. (2012). Dementia. A public health priority. Geneva: World Health Organisation.

Table 2: Tabulated research summary

Study and Location	Aim or Question	Sample	Methodology	Key Findings
Ford, Linde, Gigliotti, Kim ^{2012.} USA	To gain a deeper understanding of the meanings constructed and assigned by caregivers to their caregiving experience.	3 wives of military veterans	Cross sectional. Phenomenology case study and grief inventory (MM-CGI).	Themes: Relationship history; Story of developing dementia; previous caring experience; Thoughts re professional carers; Emotional coping and support; Caregiver grief. Participants gave meaning to their situation through past events and knowledge of their partner.
Førsund, Skovdahl, Kiik, Ytrehus ^{2015.} Norway	To explore and describe spouses' experiences of losing couplehood with their dementia-afflicted partner in institutional care.	10 spouses (5 women, 5 men)	Cross sectional. Qualitative interview.	Themes: Loss of shared everyday life; loss of shared past; loss of joint future. Participants fluctuated between identifying themselves as 'I' and as 'we' in relationship with their spouses. Moments of continuity or glimpses of reciprocity from partners were infrequent but highly valued.
Hellström, Nolan, Lundh ^{2007.} Sweden	To explore the ways in which people with dementia and their spouses experience dementia over time, especially the impact it has on their interpersonal relationships and patterns of everyday life.	20 couples, one of whom had dementia.	Longitudinal. Qualitative interviews.	Phases: 1. Sustaining couplehood. 2. Maintaining involvement 3. Moving on. Although the phases were temporal they were not linear involving delicate, interactive, iterative relationship.
Hemingway, MacCourt, Pierce, Strudsholm ^{2014.} Canada	To identify and describe the experience of spousal caregivers caring for a partner resident in a care facility.	28 spouses of people with dementia	Longitudinal. Qualitative interviews.	Overarching theme: 'together but apart' related to both the relationships between participants and their spouses and between participants and nursing home staff.

<p>Høgsnes, Melin-Johansson, Norbergh, Danielson ²⁰¹⁴. Norway</p>	<p>To describe the existential life situations of spouses who care for persons with dementia before and after relocation to nursing homes.</p>	<p>9 spouses of people with dementia and 2 bereaved spouses (8 women, 3 men)</p>	<p>Cross sectional. Qualitative interview.</p>	<p>Themes before relocation: Feelings of shame and guilt; Being isolated in the home; Being exposed to psychological threats and physical violence; Feelings of placing one's own needs last. After relocation: Feelings of guilt and freedom; Living with grief and thoughts of death; Feelings of loneliness in the spousal relationship; Striving for acceptance despite a lack of completion</p>
<p>Kaplan ²⁰⁰¹. USA</p>	<p>To ascertain to what degree community dwelling spouses of institutionalised people with dementia perceive themselves to be married.</p>	<p>68 spouses (42 women, 26 men) of people with advanced dementia</p>	<p>Cross sectional, Mixed methods study. (Quantitative data not presented in this paper)</p>	<p>Couplehood typology proposed: 'We'; 'We but'; 'Husbandless wives/Wifeless husbands'; 'Becoming I'; 'Unmarried marrieds'</p>
<p>Meuser, Marwit ²⁰⁰¹. USA</p>	<p>To define a model of dementia caregiver grief to aid clinical intervention and further research. And to identify differences and similarities between spouse and adult-child caregivers.</p>	<p>87 caregivers or bereaved caregivers of people in various stages of dementia (42 spouses and 45 adult children)</p>	<p>Mixed methods. Postal questionnaire (quantitative) and Focus groups (qualitative semi-structured)</p>	<p>Adult child caregivers of a parent with 'severe' dementia expressed interpersonal regret at loss of relationships and opportunities. Their focus was on loss of a parent. Dominant feelings were sadness, longing and loneliness. Spouse caregivers of partners with dementia at the same stage focussed on their uncertain future and the need to build a new single identity. Dominant feelings were confusion, aloneness and frustration. Their losses included loss of identity as a member of a couple and distance from family & friends.</p>

<p>Moyle, Edwards, Clinton 2002. Australia</p>	<p>To investigate family caregivers' perceptions of having a relative with dementia living in an institution.</p>	<p>15 Family caregivers (9 wives, 5 daughters, 1 son-in-law)</p>	<p>Cross sectional. Qualitative focus groups.</p>	<p>Major theme; Living with Loss. Sub themes; Relief v Burden of loss; Loss from observation of cognitive decline; Loss of companionship; Loss creating fear & frustration; Loss of personhood; Anticipation of death.</p>
--	---	--	---	--

<p>Mullin, Simpson, Froggatt ^{2013.} UK</p>	<p>What are the experiences of spouse/ partners of people with dementia in care homes? What meanings do the participants give to their experiences?</p>	<p>9 spouses & 1 long term partner.</p>	<p>Cross sectional. Semi-structured interview.</p>	<p>Themes- 1. Identity: 'til death us do part' - few self identify as carers most with the term husband/wife. Commitment to marital relationship. 2. Making sense of change - loss of conversation, recognition make communication difficult. Unable to share past and current stories. 3. Relationship with care provided, surveillance of care - active in providing aspects of care and surveillance of care by others. Yet also praised staff. 4. Relationship to the future: hope v despair - worried re partner's deterioration and own health. View that death will be better than continued life with ongoing losses.</p>
---	---	---	--	---

<p>Peacock, Duggleby, Koop ²⁰¹⁴. Canada</p>	<p>To uncover the meaning of this end of life care experience (advanced dementia in long term CH) from the perspective of bereaved family caregivers</p>	<p>11 bereaved family caregivers (4 wives, 3 husbands, 3 daughters, 1 son).</p>	<p>Semi-structured interviews (2-3 with each carer).</p>	<p>Essences: 'being there', 'being with'. Nursing home as home, welcoming and supporting the renewal of old relationships or not home, unwelcoming and a failure of home care. Time as precious and wanting to hold on to it and time standing still wanting suffering to be over. Social death of people with dementia prior to physical death.</p>
--	--	---	--	--

<p>Sanders, Butcher, Power, Swails ²⁰⁰⁹. USA</p>	<p>To explore the experiences of caregivers for patients with end stage dementia enrolled into hospice care.</p>	<p>27 Caregivers (22 adult children, 1 grandchild, 4 spouses) of 25 people with dementia living in long term care facility & 2 receiving home care.</p>	<p>Ethnomethodology. Semi-structured interviews (2-4 with each carer) & chart review.</p>	<p>Four caregiver portraits: Disengaged (minimal involvement, self focussed, busy); Questioning (struggled to understand the disease & progression, in denial, guilt re using hospice resources); All consumed (highly involved with care, expressed grief ++); Reconciled (still engaged, but ready for, and see death as a relief, realistic re disease process)</p>
---	--	---	---	--

<p>Shanley, Russell, Middleton, Simpson-Young ²⁰¹¹. Australia</p>	<p>To better understand the end of life experiences and needs of persons with dementia and their family carers.</p>	<p>15 Bereaved family caregivers (5 wives, 5 husbands, 3 daughters, 2 sons).</p>	<p>Cross sectional. Qualitative, semi-structured interview.</p>	<p>Themes: Getting support (sought acknowledgement of caring role and empathy. Joined support groups). Having to trust professionals in the nursing home. Surveillance of care. Family & friends distanced themselves. Loss of connection and intimacy. Witnessing loved one fade away. Anticipating and witnessing death. Re-establishing life post bereavement.</p>
--	---	--	---	---