

# What is an older husband's experience of caring for his wife who has dementia? A Literature Review.

## Abstract

There are a significant number of informal carers looking after people who have dementia. Women's caregiving experiences are well documented. However, there is a substantially smaller amount of research specifically investigating the male carer perspective. This literature review considers older husbands' perceptions of supporting their wives who have dementia.

The findings suggest that husbands are committed to their caregiving role but can feel socially isolated. The caregiving role of older men has altered the dynamic within the marriage. Husbands continue to show commitment towards their spouses but feel that male-only support groups could offer some respite from their responsibilities.

Nurses need to take time to listen to husband's experiences, offering emotional support and signposting them to other services that can offer assistance.

Further research on the long-term effects and support needs of older male carers is needed.

Key words: dementia, older husbands, male spouse, caregivers, experiences, perceptions

## Introduction

There are 831,000 people aged 60 years or older living with dementia in the UK (Lewis et al 2014). Many of those people are supported in their own homes by family members (Alzheimer's Research UK 2019). The majority of literature on dementia caregiving focuses on females undertaking this role, predominantly wives and daughters looking after their relatives (Sharma et al 2016; Ruiz and Nicolás 2018). Despite the increasing emphasis on gender equality, the research into male spouse caregivers remains fairly limited (Sharma et al. 2016). However, Alzheimer's disease is more likely to develop in women than men (Alzheimer's Society 2018). As a result, this review poses the question: What is an older husband's experience of caring for his wife who has dementia? Acknowledgement is made of Spendlow et al's (2017) and Robinson et al's (2014) reviews of male caregivers. These papers utilise a different approach to the male experience. Robinson et al.'s (2014) findings compare the differences in male and female experiences of dementia caregiving whereas Spendlow et al. (2017) include sons caring for parents who have dementia. This review differs by looking specifically at the experiences of older husbands as caregivers to their wives who have dementia. It is anticipated that by identifying the views and feelings of this group of individuals, a greater understanding can be reached to inform nursing practice.

## Method and search strategy

A review of the literature was undertaken in December 2018 using online health databases PsycINFO, CINAHL, Complimentary Index, SOCIndex and MEDLINE Complete. Boolean phrases 'and' and 'or' were used in addition to key search terms to identify relevant research (Aveyard 2014) (Table 1).

| Search Terms   |
|--|
| Dementia or Alzheimer's<br>AND male spouse OR husband OR man<br>AND Experiences OR perceptions OR attitudes OR views OR feelings OR opinions<br>AND caregiver* |

Table 1

Publication dates were limited to **2001** – 2018 to explore current evidence on the experiences or views of older male spouses providing a caring role. This eliminated women, family members and other informal caregivers from the search strategy (Table 2). A PRISMA (Moher et al. 2015) flowchart is provided (Appendix A), detailing the search process. The initial search resulted in n=708 papers and only peer reviewed literature was considered (Hames 2007). To ensure easy replication of the findings by others (Bettany-Saltikov 2012), full text articles were used and limited to English language only (n=421). Once these limiters were put in place and duplicates removed, n=198 papers were left for consideration. As a result of these omissions and further exclusion criteria (Table 2), n=192 papers were eliminated, leaving n=6 papers to analyse.

| Inclusion criteria  | Exclusion criteria               |
|---------------------|----------------------------------|
| Dementia            | Cognitive impairment             |
| Alzheimer’s Disease | Literature reviews               |
| Male caregivers     | Women / family caregivers / sons |
| Men                 | Incontinence                     |
| Older caregivers    | Nursing homes                    |
| Husbands            | Patients with dementia           |
| Male spouses        | Companion animals                |
|                     | Singing                          |
|                     | Young on-set dementia            |

Table 2

### Findings

From the six papers selected for the review (Russell 2001; Knutson and Rahlm 2009; Pretorius et al. 2009; Sanders and Power 2009; Han and Jupri 2013; Simpson et al. 2018), five used qualitative methodologies and one used a mixed methods approach see table 3. Three of the papers had been translated into English (Knutson et al. 2009; Pretorius et al. 2009; Han and Jupri 2013), this may have resulted in some loss of the original context. The papers were predominantly qualitative and so there were small participant numbers (Russell 2001, n=14; Knutson and Rahlm 2009, n=9; Pretorius et al. 2009, n=10; Sanders and Power 2009, n=17; Han and Jupri 2013, n=5; Simpson et al. 2018, n=6) and perhaps not representative of the wider population. However, as qualitative research is rich in its descriptive content, only a small purposeful sample size is required (Merriam and Tisdell 2015). In all the studies, the men’s experiences were only captured for a brief period of time. Only one of the papers mentioned interviewing their participants on more than one occasion (Sanders and Power 2009). More longitudinal studies, or participatory led research, could identify the long-term effects and support needs of older male carers.

| Author, Year, Country         | Title   | Sample Size | Participant age | Data Collection  | Approach to data analysis |
|-------------------------------|---|-------------|-----------------|--|---------------------------|
| Russell (2001), New York, USA | In sickness and in health. A qualitative study of elderly men who care for wives with dementia. | 14          | 68-90 years     | Interviews in various locations<br>Duration: 1.5-2 hrs | Qualitative               |

|  |  |    |                   |  |                                |
|--|--|----|-------------------|--|--------------------------------|
| Knutsen and Rahlm (2009), Norway         | The dialectic movement between suffering and reconciliation: Male caregivers' experience of caring for their wives suffering from dementia | 9  | 65 – 87 years     | Interviews in own homes<br>Duration: 55 mins – 1 hr 15 mins  | Phenomenological / qualitative |
| Pretorius et al.(2009), South Africa     | Sense of coherence amongst male caregivers in dementia: A South African perspective  | 10 | 61-86 years       | Semi structured interviews in own homes<br>Duration: 1 hr  | Salutogenic / mixed methods    |
| Sanders and Power (2009), Midwestern USA | Roles, responsibilities and relationships among older husbands caring for wives with progressive dementia and other chronic conditions     | 17 | 66-85 years       | Semi-structured interviews in a 'safe' setting<br>Duration: 1-2 hrs<br>2 interviews 4 months apart | Phenomenological/ qualitative  |
| Han and Jupri (2013), Singapore          | Caring for my wife: voices from Malay older husbands in Singapore  | 5  | 65 years or older | Semi-structured interviews in own homes<br>Duration: 50-60 mins                                    | Grounded theory/ qualitative   |
| Simpson et al. (2018), North western USA | Support groups for Alzheimer's caregivers: Creating our own space in uncertain times.  | 6  | 74-85 years       | Semi-structured interviews in various locations<br>Duration: 1.5-2 hrs                             | Phenomenological/ qualitative  |

Table 3 Summary of papers

Three overarching themes emerged in response to what is an older husband's experience of caring for his wife who has dementia. These were commitment, perceived loneliness and support groups.

#### Commitment

A predominant theme running through all six papers is the bond that the older men felt towards their spouses. Commitment is expressed through wording such as loyalty or taking on a nurturing role within the partnership. Knutson and Rahlm's (2009) participants expressed a lifelong mutual respect for their wives and perceived their caregiving role as an ethical duty. Sanders and Power's (2009) interpretation of their phenomenological findings was nurture. The men felt that they were able to demonstrate their commitment to their spouse through their role as a critical caregiver. Russell (2001) describes the devotion of husbands towards their wives. Devotion appears to be a cross-cultural concept as the participants in this study included an African-American and two Eastern European immigrants. Equally, Han and Jupri's (2013) grounded theory study of five Malay husbands portrayed caregiving as a reciprocal process. This theme of 'paying back' their spouse for looking after them is mirrored in Russell's (2001) findings. Furthermore, the participants in Simpson et al.'s (2018) study mentioned the marriage vows 'til death do us part' as a way to express the bond of love and dedication they had towards their wives. Some of the men did not speak about love, preferring words such as loyalty and commitment instead (Knutsen and Rahlm 2009; Simpson et al. 2018). Suggestion is made that this is a generational concept where expressions of emotions in earlier decades were disapproved of (Knutsen and Rahlm 2009). Although reference is made to love and

reciprocity in Pretorius et al.'s (2009) paper, this does not form a main theme. The article appears to favour the men's cognitive approach to caring which could be perceived as a cultural characteristic for these individuals.

#### Perceived loneliness

Loneliness was expressed as isolation from family members and friends in three of the papers (Russell 2001; Knutsen and Rahlm 2009; Simpson et al. 2018). Words including 'invisible' and 'unappreciated' appeared in the narratives of Russell's (2001) study. Grievances also resulted from the lack of support that was offered by family members compounding feelings of abandonment and disconnection from the community (Simpson et al. 2018). A loss of meaningful interactions and companionship with their spouses is reflected in Knutsen and Rahlm's (2009) research. Pretorius et al.'s (2009) findings echo the absence of support from friends and the loss of companionship within their marriages. However, the researchers propose that, predominantly, the men preferred to make sense of their situation in a cognitive rather than an emotional way, therefore it is not apparent to what extent loneliness was experienced. Loneliness was not mentioned in Sanders and Power's (2009) findings. Their participants recognised the finality of the relationship with their spouse but exhibited feelings of anger, sadness and guilt and there was no evidence to support the notion that they felt lonely. In comparison, within the Malay culture, loneliness is not perceived as a factor due to the communal, social importance placed on family bonds (Han and Jupri 2013).

#### Support groups

Access to a support group was a source of coping utilised by men in three of the papers (Pretorius et al. 2009; Sanders and Power 2009; Simpson et al. 2018). Being able to express needs, concerns and share caregiving experiences in a safe, all-male environment allowed men to connect with community resources and offered a setting to share frustrations openly without reproach (Simpson et al. 2018). Men's perception of their survival as a caregiver was ensured by prioritising themselves some personal time (Sanders and Power 2009). Only one of the ten South African men claimed to be actively involved within a support group (Pretorius et al. 2009). The remaining men viewed this type of group as being highly emotive and primarily established for female caregiver needs as reasons not to participate. However, they remained frustrated with the lack of opportunity for temporary respite from their care-giving burden. Conversely, the opportunity to be able to talk to other men in a similar situation in a strictly male-only group setting was expressed in Knutsen and Rahlm's (2009) study. Russell's (2001) participants viewed support in a more informal manner but still expressed the requirement of respite to conserve their emotional and physical strength. In contrast, the Malay men (Han and Jupri 2013) perceived their families as their main source of social support, preferring to keep personal issues within this framework.

#### Discussion

Women are more likely to develop Alzheimer's disease, accounting for 61% of cases in the UK (Alzheimer's Research UK 2015). Potentially, therefore, men could be considered more likely to become carers. However, caregiving is still primarily provided by women (Corden and Hirst 2011). Today's society continues to hold onto the traditional representation of women as caregivers

despite changes in societal norms (Sharma et al 2016), this of course may change over time and further exploration in future research would be useful. Nevertheless, there has been a growth in the number of men providing care for their spouses (Robinson et al. 2014). The proportion of UK male spouse caregivers over the age of 75 years is higher than women giving unpaid care (Storey 2013).

Much of the existing literature (Davis et al 2011; Hemingway et al 2016; Wang et al 2017; Cheung et al 2018) accounts for husband and wife caregiving roles. However, the ratio of male to female participants tends to be disproportionate. The bias towards female participant numbers does not truly represent the male experience.

Sabey et al (2014) propose that older couple's beliefs on the sanctity of marriage builds a foundation of compassionate love for one another, enhancing their marital satisfaction. Suggestion is made that the spiritual support offered through the bond of marriage is reinforced through faith. In the early 20th century, marriage was valued and perceived as a lifelong union, with duties and responsibilities therein. References towards a close communion through marriage are made in all of the review papers which suggest a strong commitment to this institution. Moreover, the men have taken on a less traditional role, compared to the masculine identity (Hurd Clarke and Lefkovich 2018) of their generation, which shows no sign of abating. Russell's (2001) paper suggests that devotion and responsibility reaffirmed the changing role in the partnership, leading to a strong sense of purpose. Furthermore, mastering caregiving skills brought men gratification (Knutson and Rahlom 2009).

The loss of companionship is prevalent in the review's findings expressed through the 'loss of golden years' (Simpson et al 2018) and grief about the wives' declining health. However, resilience is reflected through the loyalty and devotion expressed by the men towards their partners. This is a contrast to a younger population as identified by Johannessen et al (2017). Their study on young onset dementia suggests that the loss of marital relations and friendship within a marriage, coupled with a lack of time for socialising, leads to loneliness and isolation. The men in this review had a median age of 75 years whereas in Johannessen et al's (2017) research the median age of the men was 61 years, a younger cohort. Although there is not a wide difference in age, the younger carers were still working. This suggests that trying to maintain employment added to the strain on the younger couple's relationship. In addition, some of the couples had considered getting divorced before the diagnosis but now felt obligated to stay together. Wawrziczny et al's (2016) study offers similar findings. The loss of intimacy had left some spouses feeling that their relationship was over and now saw themselves purely as caregivers. Conversely, Kimura et al (2019) argue that a high level of resilience enables carers of this demographic to cope. Whereas this paper reviews older male caregiver's perspectives, Black et al (2008) acknowledge that younger generations' changing perspectives on commitment and present divorce rates may lead to a different approach to spousal caregiving. As this population ages, consideration needs to be given to how their partner's declining condition could influence their caregiving responses in the future. Further research could identify why attitudes towards marriage have changed over the years and why some younger carers are more resilient than others. Providing more emotional support for this group may alleviate some of their burden and help them to cope as they progress through their caregiving journey.

Culturally, support groups appear to be a western phenomenon (Janevic and Connell 2001). The Malays (Han and Jupri 2013) preferred to utilise family networks for respite and all but one of the South African men (Pretorius et al. 2009) sought help from their housekeepers, perceiving support

groups to be too demonstrative. O'Shaughnessy et al (2010) propose that peer support groups give caregivers emotional and social support. As the physical stamina of caring for a spouse with dementia increases with age (O'Rourke 2007), support groups could help alleviate carers' negative mental and physical health problems, allowing them to continue in this role (Smith et al 2018). Shanks-McElroy and Strobino (2001) suggest that the physical demands placed on dementia caregiving can lead men to neglect their own well-being in favour of looking after their spouse. The endorsement of traditional male roles in society results in men suppressing or channelling their emotions. In contrast, women are perceived as nurturers (Spendelov et al 2017) and are encouraged to express their feelings (Levant 1996). The Alzheimer's Society (2017) suggests a range of interventions including respite care and support to aid caregivers' emotional wellbeing. The National Institute for Health and Care Excellence ([NICE] 2018) proposes that carers may be socially isolated and not be aware of the support available to them. They recommend that support interventions are necessary to offer emotional assistance and are more likely to be effective within a group setting.

Given the increase in a global, ageing population (World Health Organisation 2018) and the trend to continue to offer care within the home (Prince et al 2013), the experiences of older male caregivers should not be overlooked. Inclusion of more research into male caregiver experiences will normalise the ideology of male caregivers in what is still predominantly perceived as a female role. Longitudinal, observational studies could potentially offer a broader perspective of husband's caregiving experiences of this phenomenon.

#### Implications for practice

Dementia does not just affect the person who has the condition (Alzheimer's Society 2019). This review highlights how husbands, as caregivers, are affected emotionally. There is a sense of needing to own responsibility in all the review papers. Evidence suggests that older carers are reluctant to seek support, citing reasons including pride, duty and the belief that they are not entitled to receive help (Greenwood et al 2019). This indicates the requirement to incorporate a holistic approach to carer's needs and work in collaboration with them (Bull 2014). Therefore, implications for nursing practice include taking the time to listen to husbands' experiences, offering emotional support and signposting them to other services who can offer assistance (NICE 2018). Nurses can support the mental and physical health of caregivers (Hannan 2014) by listening to their concerns and offering alternative options for support within the community if required. Specialist nurses can explain how the progression of dementia is likely to affect the couple's marriage and the emotional experiences that may be faced (Dementia UK 2019). Guidance may be offered by suggesting options of help such as respite and long-term residential care. However, this should be guided by individual circumstances (NICE 2018) and based on an assessment of how the husband is coping with his caregiving role. Coping strategies can be put in place (Dementia UK 2019) to allow the husband to continue looking after his wife for as long as he wishes. In order to prevent the marginalisation of men in groups dominated by female carers (Kirsi et al. 2004), nurses can advocate for male caregivers' needs by promoting screening for referrals to male-only support groups in the community (Hemingway et al. 2016). Hellstrom et al. (2017) concur, proposing that health professionals need to remain sensitive to men's doubt regarding their role as a caregiver. The support male caregivers are offered may be better targeted by focussing on the significance and value they give to their everyday care activities.

## Conclusion

This review has highlighted some of the experiences men have faced whilst looking after their wives who have dementia. Perceptions about their marriage have altered and they have adapted to a less traditional role compared to the masculine identity of their generation. The findings speculate that older husbands are nurturing towards their spouses, acknowledging that the dynamic of the relationship has changed. The perceived loneliness felt by the men suggests that support groups are a way forward to offer emotional support to likeminded individuals. Nursing implications have been addressed, proposing guidance to support their caregiving role. By adopting a holistic approach to male carers, nurses will have a deeper awareness and appreciation of the experiences of husbands and be able to offer productive emotional support and guidance to these citizens and enable them to continue in their role as carers. Overall, the lack of original literature into older male caregiver experiences needs to be addressed. This will balance the gender bias currently in favour of female caregivers and provide a broader perspective into the older male caregiver role.

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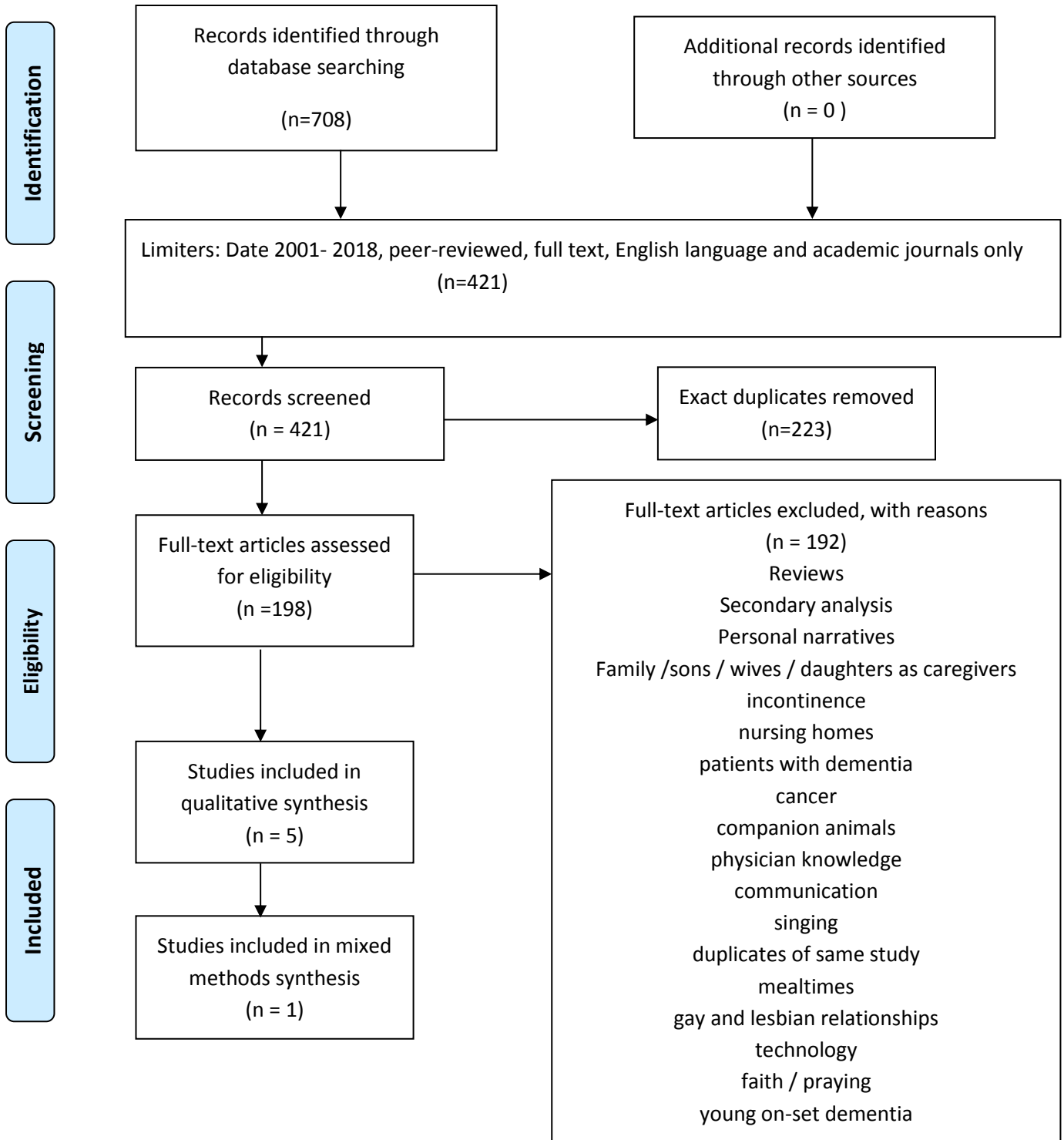
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**PRISMA 2009 Flow Diagram**



Adapted from Moher et al. (2015)

