

## Review

# Gender, citizenship and dementia care: a scoping review of studies to inform policy and future research

Ruth Bartlett BA (Hons) MA PhD, Trude Gjernes PhD, Ann-Therese Lotherington PhD and Aud Obstfelder PhD  
Faculty of Health Sciences, University of Southampton, Southampton, UK

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### Correspondence

Ruth Bartlett  
Faculty of Health Sciences  
University of Southampton  
Highfield Campus  
Southampton SO18 1QB, UK  
E-mail: r.l.bartlett@soton.ac.uk

### What is known about this topic

- Gender is a neglected dimension in public discourse about dementia.
- Gender is a key factor structuring the lives of those living with dementia.
- There are gender differences in the care-giving experience.

### What this paper adds

- A critical review of the research literature on gender differences in dementia care from a feminist citizenship perspective.
- Insights into the gaps in the research literature.
- Recommendations as to how policy makers can incorporate gender into national plans.

### Background

There is an urgent need to improve the delivery of health and social in the community for people living with dementia. The number of people diagnosed with dementia in 2015 worldwide is estimated at 46.8 million, reaching over 74 million by 2030 and 131 million in 2050 (Alzheimer's Disease International 2015a). The establishment of a World Dementia Council, appointment of a World Dementia Envoy following the G8 dementia summit in London in December 2013, and fact that the WHO hosted the

### Abstract

Gender is a neglected dimension in public discourse related to people with dementia. Those living with this condition are typically portrayed in policies and strategies in gender neutral terms as 'people with dementia' and 'family carers' as if gender does not matter, when clearly it does. The purpose of this scoping review was to take stock of knowledge about gender differences in relation to dementia care to inform policy and future research. The work is grounded in a feminist perspective to citizenship, as this provide a lens with which to expose and examine gendered assumptions within dementia studies. A search of four databases, including CINAHL, Web of Science, Medline and Cochrane was conducted using systematic techniques between May and July 2014. A repeat search was conducted in February 2015. We found a significant amount of valuable research concerned with gender differences in relation to dementia care published from 1990 to 2014; the majority of which lacks a feminist citizenship perspective. Moreover, a disproportionate number of studies focused solely on caregivers rather than citizens with dementia. As such, questions about gender equality are not being raised and the voices of men and women with dementia are silent. Thus we argue for increased gender-sensitivity in policy making and recommend that social scientists inject a feminist citizenship perspective into their work.

**Keywords:** citizenship, dementia care, feminist theory, gender, health policy

first ever Ministerial Conference on dementia in March 2015, demonstrates the growing importance worldwide of improving care services for the millions of people living with dementia.

Generally speaking, the majority of people affected by dementia are women. It is estimated that 61% of people with dementia are women and 39% are men. This is likely to be because women live longer than men, as age is the biggest known risk factor for the condition (Alzheimer's Disease International 2015b). However, different dementias sub-types may have different prevalent rates and so life expectancy is not

the only factor to consider. Furthermore, as with other major health conditions, it is predominantly women who take on the role of caring for someone with dementia; studies suggest that in most countries up to three quarters of family caregivers are women (Bamford 2011). For these reasons, dementia has recently come to the attention of feminists (Wilkinson 2015); in that, it represents a struggle for resources and an unequal division of labour (Freedman 2001).

Because age is the single biggest risk factor, the majority of people living with dementia are also older, aged 65 years and above. Thus, it is important to consider gender in the context of ageing when discussing this topic. Since the late 1990s, scholars have been arguing for more critical feminism in gerontology – that is, focusing on how patriarchal practices and assumptions affect people in later life (see, for example, Ray & Fine 1999). This work has paved the way for increased critical attention on older woman. For example, there has been research into older women's contribution to civic society (McHugh 2012), and work on the role of older women as 'transmitters of values' (Quéniart & Charpentier 2013). However, little attention has been paid to older women with dementia within this area of feminist enquiry, as a dementia diagnosis tends to exclude people from mainstream ageing studies. This is a significant oversight, as we need a critical feminism for people with dementia too.

Gender clearly matters in the context of illness, impairment and care-giving (Annandale and Hunt 2000). It is especially important in respect of people with a disability like dementia where 'forms and impacts of disability are always refracted in some way through the prism of gendered locations and gender relations' (Thomas 1999, p. 28). For example, the loss of a handbag is thought to symbolise the loss of independence for a woman with dementia (Buse & Twigg 2014); and a man with dementia in a care home may feel socially excluded because there are so few other men to relate to (Bartlett 2007). Thus, gender, as well as age, will inevitably be a factor structuring the lives of those living with dementia.

Researchers have begun to focus on gender differences in relation to the lived experience of dementia and significant findings are emerging. For instance, one qualitative study has found that male carers are less likely to facilitate the autonomy of their partners than their female counterparts (Boyle 2013a,b, p. 240). While it is unclear whether this situation is due to dementia, or more of a reflection of the spousal relationship through the life course, such results are significant in terms of understanding the restrictions placed on a woman's agency. Other research shows

that husbands and wives respond differently to signs of dementia in their spouse; with men being slower to recognise the symptoms than women, and women quicker to recognise subtle changes but failing to take action quickly (Hayes *et al.* 2010). Such work underscores the importance of incorporating gender into the design, delivery and evaluation of dementia care policies (Bamford 2011). Moreover, it shows that research into gender in the context of dementia care is growing and producing results that warrant the attention of policy makers.

Given what we know about gender, it is curious why the topic is not more prominent in dementia care research and policy. Influential texts use gender-neutral terms such as 'people with dementia' and 'family carers' rather than distinguishing between men and women (e.g. Kitwood 1997, Sabat 2001). Even literature reviews on self-identity (Caddell & Clare 2011) and relationships (Ablitt *et al.* 2009) – topics deeply connected with gender – there is no reference to gender, either in relation to the studies reviewed or the review itself. It would seem that the dementia care literature is gender blind.

Gender is neglected in national dementia strategies too. In 2015, 17 countries, namely Australia, Denmark, England, Finland, France, Israel, Republic of Korea, Luxembourg, Malta, Netherlands, Norway, Northern Ireland, Switzerland, Taiwan, Scotland, USA and Wales, had developed a national dementia strategy (<http://www.alz.co.uk/alzheimer-plans>). Other than referring to female sex as a risk factor for dementia, no distinction is made in these national plans to men and women. The incidence and prevalence of dementia is not even considered from a gender perspective, as numbers of *people* with dementia are given, rather than numbers of men and women. Given the strategic importance of these plans, which provide the language and set the agenda for the development of healthcare services, it is both curious and of concern that national dementia strategies throughout the world should neglect gender.

There are signs of gender moving into the dementia care landscape, with the publication of new reports about women and dementia. For example, Alzheimer's disease International recently produced a report on the extent to which dementia affects women across the globe (e.g. Alzheimer's Disease International 2015b). Also, in the UK, the Joseph Rowntree Foundation has published a piece called *Dementia Through Women's Eyes*, as part of its *Dementia Without Walls* programme (Savitch *et al.* 2015). Although not overtly political or feminist in tone, such work does show a growing awareness of

gender. However, as feminist gerontologists have pointed out, the risk with focusing on women is that men become invisible, and the relational aspects of gender, privilege and oppression are overlooked (Calasanti 2004). A risk that is recognised to some extent within current work, but nonetheless, women remain the focus. It is important, therefore, to consider gender as an influential force in everybody's lives.

In this review, we therefore take stock of existing research into gender differences in the context of dementia care to inform policy and reflect on future research directions. The review is grounded in a feminist perspective to citizenship, as this provides a lens with which to expose and examine gendered assumptions implicit within dementia care studies. Such a lens also encourages us to think beyond care practices to broader issues of knowledge production and power relations. All of which are important if we want to promote the citizenship of people living with dementia, as it draws critical attention to the problem of binary thinking – e.g. men and women are different (Lister 2003) and how the processes of research affects the results of that research (Letherby 2003). We recognise that there is no single or unified approach to feminism, and so for us the project is about analysing how gender differences are investigated and handled by researchers to determine the extent to which the field of dementia studies is working to achieve a social (gender) justice – gender differences being cultural, as opposed to sex differences, which are biological. Essentially, this article seeks to examine the relationships between feminist theory, citizenship and dementia care.

The scoping review includes the vast number of studies on gender differences among male and female caregivers and the small but growing area of research related to the gendered nature of the lived experience of dementia. We highlight the lack of a feminist citizenship perspective in dementia studies and argue for greater gender sensitivity in policy and research arenas related to dementia care.

## Method

A scoping review of published studies on gender differences in the context of dementia care was conducted between May 2014 and February 2015. Scoping reviews aim to provide a comprehensive coverage of the literature on a given topic area and are primarily concerned with the breadth and depth of existing knowledge rather than its quality (Arksey & O'Malley 2005). The threefold aim of this scoping review was to (i) summarise and discuss research

findings on gender differences in the context of dementia care and through a feminist citizenship lens, (ii) identify research gaps in the existing literature, to (iii) inform policy and future research. Criteria for inclusion in the scoping review were that the study was: published in a peer-reviewed journal; addressed gender differences in the context of dementia care [including Alzheimer's disease (AD); Lewy body dementia, vascular dementia and 'senile dementia']; and written in English. The criteria for exclusion in the review were: non-research articles (including thought pieces, meeting abstracts and letters to the editor), reporting on gender as a risk factor for dementia and biological studies on sex differences. No date restrictions were imposed. We wanted to locate and review all relevant studies to identify any trends in research and to avoid making recommendations for future research if similar work had been carried out previously.

We searched for primary studies on gender differences in the context of dementia care. This included studies that reported exclusively on gender differences in relation to the care-giving role, and studies that differentiated between men and women's experience of living with dementia. We took the decision to include a wide range of studies because we felt it was important to gain a comprehensive picture of the research arena in order to summarise what is currently known about gender differences in the context of dementia care. Initially, we searched the Cochrane Library using the terms 'dementia' and 'gender' and found no relevant reviews. A controlled vocabulary and key word search was then conducted using the following databases: CINAHL, Medline, The Allied and Complimentary Medicine Databases, Web of Science and International Bibliography of the Social Sciences. The controlled search terms were 'dementia, including Alzheimer's disease; Lewy body dementia, vascular dementia', 'pre-senile' and 'senile dementia'; gender, gender roles, gender differences, caregivers. The key word search terms were 'gender', 'men', 'women' and 'dementia'. Relevant additional studies identified from lateral searching of references were also reviewed. The literature search was carried out in May 2014. A total of 23 publications satisfied the inclusion criteria and were selected for a full-text review. Reference lists of the selected articles were visually scanned to ascertain whether any key studies had been missed. Ten additional publications were found in this way. The search was repeated in February 2015 (with the date limit 2014–2015) and three further studies were found, bringing the total amount of papers to review to 35. Retrieved articles were stored and shared between authors using the digital

reference manager Mendeley. A template for extracting data and reviewing studies was developed and agreed by the authors. It contained the following categories: (i) full details of citation; (ii) knowledge established; (iii) theoretical perspective; (iv) study design and methods; (v) sample size and profile; (vi) methodological strengths and limitations; (vii) key findings related to citizenship and gender; (viii) recommendations for research.

## Findings

Publication dates were from 1990 to 2015. Studies included in this review were conducted in the United States, Canada, the United Kingdom, Finland, Sweden, Norway, Spain, Germany, Cyprus and Japan. An early finding was that researchers have been sensitive to gender differences in relation to dementia care since the early 1990s. Several studies published at this time discuss gender differences in the context of dementia care. The studies reviewed used either qualitative methods, predominantly interviews ( $n = 17$ ), quantitative methods, predominantly large-scale surveys ( $n = 15$ ), or mixed methods ( $n = 2$ ). Four studies were literature reviews. The majority of the studies focused solely on gender differences in relation to the care-giving role, primarily husbands. Eight studies focused on gender differences in relation to the experience of living dementia. We identified two main themes in the studies reviewed by taking into account both the sample and whose perspective researchers had taken; these were (i) gender differences among caregivers and (ii) the gendered nature of the lived experience (Table 1). The 35 papers are presented in Table 1.

### Gender differences in relation to care-giving

Twenty-eight of the 35 studies reviewed studies focused on gender differences in relation to care-giving. This is clearly an established and growing field of enquiry, with one literature review dating back to the early 1990s (Corcoran 1992) and another study published last year (Gibbons *et al.* 2014). With the exception of the study by Gibbons *et al.* (2014) and another recent study reported in two papers (Boyle 2013a,b), the perspective of the person with dementia (or care recipient) is completely absent from these studies. These findings will be reported in relation to three subthemes: care-giving from a male perspective; care-giving from a female perspective; and differences between male and female caregivers.

### Care-giving from a male perspective

Eleven of the studies focused on care-giving from a male perspective, usually the husband. Six studies were qualitative in design, three were quantitative and two were reviews of the literature on men caring for wives with dementia (Baker & Robertson 2008, Robinson *et al.* 2014). These studies present valuable findings in respect of an older man's experience of caring for his wife with dementia.

Some studies provide evidence of the interplay between care-giving and masculinity. This research reveals tensions between being a caregiver (a feminised activity) and being a man. For example, one study found that caring responsibilities can make it difficult for a man to maintain contact with their male friends (Kirsi & Jylha 2000, Kirsi *et al.* 2004). In another study, it was found that 'gender role conflict' is more significant than 'gender identity' as 'some men may connote care as a feminised activity and may struggle to construe themselves as in the caring role. This may explain why some men are reluctant to access services' (Baker *et al.* 2010, p. 326).

In contrast, an early study suggests that some men with 'traditional views about masculinity may view care-giving as an opportunity to express gratitude for the care their wives provided as a spouse and mother' (Borden & Berlin 1990, p. 609). More recently, it has been found that some husbands may want to take control to feel good about the care-giving role, especially if they are highly educated (Kramer 1997, 2000). Some evidence is contradictory. In one qualitative study it was found that men may experience isolation and invisibility because other family members do not see or recognise what they are doing (Russell 2001). Whereas another study found that male caregivers are likely to be supported by other family members, usually women (Brown *et al.* 2007). In sum, male participants report wide variations in their experiences of care-giving.

### Care-giving from a female perspective

Three of the studies reviewed focused on care-giving from a female perspective. These were all qualitative in design. Research conducted by Perry (2002) uncovers a 'process of interpreting caring', beginning when the wife recognises the husband is changing, moving to a phase when the wife takes over the husband's roles and responsibilities (p. 307). The researcher found that the women construct a new daily life through the process, as new identities and roles take root for the husband. Similarly, another study found that women view their care-giving role

**Table 1** Studies on gender difference in the context of dementia care

Study	Sample	Study design	Key findings	Comments
<i>Male caregivers</i>				
Baker <i>et al.</i> (2010)	Husbands ( $n = 70$ ) currently caring for their wives with dementia	Survey methodology; explores gender identity using questionnaires	Male caregivers with traditional beliefs about masculinity are more likely to say that (i) they are not feeling burdened; (ii) they feel uncertain about caring; and (iii) they are more likely to articulate positive aspects to being a spousal carer than men with less traditional beliefs about masculinity (p. 326)	Male perspective is privileged; women's perspective is absent
Kramer (1997)	Husbands ( $n = 74$ ) caring for their wives with dementia	Cross-sectional analysis using structured interviews	Social resources and good health help men feel better about care-giving; highly educated men were least likely to feel good about care-giving	Some discussion of structural inequalities in the workplace; women's voices are absent
Kramer (2000)	Husband caregivers ( $n = 74$ ) (same sample as study above). 60% participated in this follow-up study	Longitudinal study using interview method; scales were used to measure stressors and well-being, including depression	Men adapt to care-giving role over time	Women's voices are absent
Kirsi and Jylha (2000)	Sample of 159 caregivers: 58 wives, 47 daughters, 36 other female carers (sister, friend, daughter in law), 3 sons and 15 husbands	A discourse analysis of 15 stories written by husbands about their wives with dementia	There is a tension between being a caregiver and a man	No discussion of how this is produced or what might be done to change it
Kirsi <i>et al.</i> (2004)	Written accounts ( $N = 44$ ): 11 husbands/33 wives and other female carers Interviews ( $N = 36$ ): 13 husbands/23 wives and other female carers	Qualitative study conducted in Finland; 13 focused interviews with husbands who had given care to their wives with dementia	Men's experiences of care-giving are diverse	Questions raised about how gender is reproduced; voices of women are absent, but the authors recognise this is problematic
Knutsen and Råholm (2009)	Nine men caring for their wives with dementia took part in interviews	A phenomenological study conducted in Norway	Care-giving is a daily struggle; men do not like not being able to fulfil themselves and loss of control	Taking on household responsibilities and caring role is assumed to be a burden for men; voices of women are absent
Neufeld (1998)	Male caregivers ( $N = 22$ ) (husbands, sons, brothers) were interviewed four times. One focus group with 7 interviewees	Qualitative component of a larger study conducted in Canada which involved female caregivers	Most men gave care on the basis of obligation, which was accompanied by negative or mixed feelings	Provides an example of men's citizenship within the private sphere

Table 1 (continued)

Study	Sample	Study design	Key findings	Comments
Russell (2001)	Men ( $n = 14$ ) currently caring for their wives with dementia	Qualitative study using interviews conducted in USA near New York	Men are capable, nurturing and innovative carers	The need for gender-sensitive services is highlighted and female perspective is considered
Brown <i>et al.</i> (2007)	Men ( $n = 9$ ) caring for their wives with dementia at home for an average of 6 years	Qualitative grounded theory study	Help-seeking by older husband caregivers is complex and gender-specific (p. 352)	Voices of women are absent
Baker and Robertson (2008)	Reviewed 93 articles	Systematic review of literature to assess the status of knowledge about men's coping with the role of dementia caregiver	Male caregivers are still poorly understood compared to female caregivers	The emphasis on coping is individualistic; hence, wider socio-political relations are overlooked
Robinson <i>et al.</i> (2014)	Reviewed 30 articles	Scoping review of articles published between 2007 and 2012	None of the studies use a gender framework to inform study design or analysis	A gender lens is needed to critique society and develop an understanding of what needs to be done and changed
<i>Female caregivers</i>				
Eriksson <i>et al.</i> (2013)	Women ( $n = 12$ ) caring for their husbands with dementia	Qualitative study; used interview method to explore meanings of home, their partner's condition and everyday life	The commitment and responsibilities that women experience in their day-to-day caring must be acknowledged (p. 159)	Goal here is to raise gender awareness rather than achieve gender justice
Perry (2002)	Wives ( $n = 20$ ) all but one of whom lived at home with their husband with dementia	Qualitative study conducted in Canada	Wives took over their husbands' roles and responsibilities	Provides an example of women's citizenship within the private sphere
Strang (2001)	Women caregivers ( $n = 8$ ) were interviewed twice	Qualitative study conducted in Western Canada using repeat interviews	The women were committed to the welfare of their family members	Draws explicitly on a feminist perspective but no discussion of women's citizenship or agency
<i>Caregivers per se</i>				
Winter <i>et al.</i> (2011)	Male (35) and female (202) caregivers ( $n = 237$ ) of community-dwelling people with dementia	Used baseline data from participants enrolled in a randomised study of non-pharmacological intervention to manage behavioural symptoms	Stronger desire to institutionalise was associated with lower quality of relationship for male but not female caregivers	Needs of male caregivers are privileged; the citizenship of women, including those who are institutionalised, is not discussed
Romero-Moreno <i>et al.</i> (2013)	Caregivers ( $n = 351$ ) (58.97% daughters, 10.54% sons, 19.66% wives and 10.38% husbands)	Questionnaire-based study conducted in Spain	Daughters with higher levels of guilt who do not engage in leisure activities may be especially vulnerable to psychological distress	No discussion of why daughters should feel guilty; or how feelings of guilt might play a role in women's oppression

**Table 1** (continued)

Study	Sample	Study design	Key findings	Comments
Chappell <i>et al.</i> (2015)	Caregivers ( $n = 873$ ) as part of a larger research program on drug therapy for people with AD	Quantitative study using structured interviews conducted in British Columbia, Canada	Gender as social positions/categories can work together and in opposition to shape experiences of caregivers' burden	Draws explicitly on an intersectionality framework but only in terms of gender and relationships
Gibbons <i>et al.</i> (2014)	Spouses/carers ( $n = 65$ ) of people with dementia – 45 (69.2 female) and 20 (30.8) male	Used survey methodology and measures to clarify differences in the experiences of wives and husbands in respect of burden and health. Conducted in Canada	Female gender is a marker that places caregivers at increased risk of high burden and less support	Hints at social injustices but not explicit about it
Hooker <i>et al.</i> (2000)	Spouse caregivers ( $n = 175$ ) of people with AD (88–59% women) and Parkinson's disease (87–64% women)	Quantitative study using structured interviews/questionnaires conducted in USA	AD care-giving wives tended to report greater depression and were significantly more stressed and anxious than were AD care-giving husbands (p. 571)	Gender lens is not apparent but calls for future research to investigate how gender differences are (re) produced
Schiffczyk <i>et al.</i> (2011)	People with dementia ( $n = 212$ ) and their proxies – primary proxy was the spouse in 180 of 194 dyads (93%)	Quantitative study using questionnaires conducted in Germany	Found a higher score of depression in female proxies than men	A gender-specific analysis is taken but it might have skewed results, as you will not see the effects of other variables (e.g. socioeconomic status) if the sample is split according to gender
Hayes <i>et al.</i> (2010)	Men ( $n = 13$ ) and women ( $n = 15$ ), all of whom cared for their spouses with dementia, took part in intensive qualitative interviews	An interview study conducted in the USA	Husbands/men were slower than the wives/women to recognise the symptoms of Alzheimer's disease and related disorders within their spouse	The gender relations within the context of marriage are presented as quite stereotype. The authors do not problematise this
Miller and Kaufman (1996)	Spouse caregivers ( $n = 215$ ). Male and female, African-American and white	Qualitative study conducted in USA using a grounded theory approach and interview method	Men were less likely to refer to care-giving in terms of emotional work	Participants were asked three open-ended questions about gender; such directedness is unusual in dementia care research
Papastavrou <i>et al.</i> (2009)	Primary caregivers ( $n = 172$ )	Cross-sectional descriptive study where all data were obtained from questionnaires. Conducted in Cyprus	Women use emotional coping strategies (such as day dreaming and wishful thinking) more often than men, who used more practical strategies	Voices of people with dementia are absent
Pöysti <i>et al.</i> (2012)	Dyads of wife–husband couples. Mean ( $n = 335$ )	Quantitative study conducted in Finland; Participants were from two intervention trials	Male caregivers of people with dementia experienced lower burden than female caregivers despite care recipients; more severe disease	Differences between men and women highlighted; persons with dementia positioned as having no agency

Table 1 (continued)

Study	Sample	Study design	Key findings	Comments
Boyle (2013a)	21 dyads of wife–husband couples in which one partner had a diagnosis of dementia, took part in the study which examined the gendered nature of support	Qualitative study conducted in the north of England	Gender inequality in relationships persists even when women develop dementia	A gender perspective is implicit and recommended to shift focus from women's capacity to an analysis of interdependency
Boyle (2013b)	Same study as above	Same study as above	Gender influenced whether people with dementia were given the support necessary to exercise their capacity	
Borden and Berlin (1990)	Spousal caregivers ( $n = 61$ ) of older adults with dementia	Completed a questionnaire and more than half participated in a follow-up interview	Women are more prone to psychological distress than men in the context of the care-giving experience	Gendered assumptions are made about the way men and women approach illness and are affected by it
Corcoran (1992)	Scope of review is unclear	Literature review of gender differences in dementia care-giving and consequences of each approach for dementia management plans	Gender differences may influence spousal caregivers' definition and resolution of care management problems	The need for gender-sensitive practice is acknowledged
<i>Men and women with dementia</i>				
Ono <i>et al.</i> (2010)	Hospitalised patients ( $n = 325$ ) with dementia; 294 were divided into men and women	Longitudinal study carried out over a 7-year period	Most women did not return to their homes	Neither the reasons for this, nor what needs to be done to promote equal health outcomes are explored
Buse and Twigg (2014)	People with dementia ( $n = 32$ ): nine men and 23 women took part in the study	Qualitative study conducted across three care homes in Kent and with people with dementia living in their own homes	The loss of a handbag can signify the loss of independence for women with dementia	Men's perspective is absent
Ward <i>et al.</i> (2014)	People with dementia (7 women and 5 men)	Qualitative interviews using 'appearance biographies' method	Men and women reveal themselves through their appearance and the processes of managing it	Findings on gender are not fully utilised
Lindesay and Skea (1997)	Older people with dementia ( $n = 36$ ) (19 men and 17 women) and 37 care staff (30 women and 7 men) were observed interacting over 6 weeks	Non-participant, time-sampling observation and coding of interactions between staff and residents in single setting in the UK	Residents and staff are more likely to interact with male residents than female residents	Reference is made to feminist theory but it is not used to analyse findings
O'Connor <i>et al.</i> (2010)	One aboriginal woman with dementia living with a same-sex partner	Individual case study, which generated data over a 1-year period through in-depth interviews, participant observation and access to health records. Conducted in Canada	Gender as social positions/categories can work together and in opposition to shape the dementia experience	Intersectionality is considered in relation to post-structuralist and social constructionist concept of subjectivity, subject position and discourse

**Table 1** (continued)

Study	Sample	Study design	Key findings	Comments
Forbes <i>et al.</i> (2008)	Sample of 467 (males = 247; females = 220)	Cross-sectional survey design using data from the 2003 Canadian Health Survey Cycle 2.1	Although women reported receiving more services and rated the availability of community services higher than their male counterparts, they also reported greater unmet home care needs than the men	A gender perspective was used throughout the study
Baron <i>et al.</i> (2015)	Data from 21 European and North American countries were pooled	Reviewed 73 high-quality RCTs on psychosocial interventions (PSI) outcomes in AD and mild cognitive impairment (MCI) with respect to gender distribution and gender differences	Three key findings. <ol style="list-style-type: none"> <li>1 Only 45 (62%) of the RCTs reported gender ratios. In these studies women were under-represented</li> <li>2 Only 19% of the RCTs analysed and reported on gender effects. In these studies women were under-represented</li> <li>3 In 40% of RCTs reporting gender analyses, gender effects on treatment outcomes were reported</li> </ol>	The study raises questions about equal opportunities for women to get involved in research
Zuidema <i>et al.</i> (2009)	People with dementia ( $n = 1319$ ) were recruited from 26 nursing homes across the Netherlands	Cross-sectional cohort study conducted within a 4-week period	Physically aggressive behaviour more common in men, whereas female patients demonstrated more verbally agitated behaviour	Behaviours are attributed to the condition rather than to the quality of care or wider societal factors

and responsibilities as paramount to other duties and concerns in everyday life, including care for themselves and need for support (Eriksson *et al.* 2013). This was echoed in the third study which found that women are so motivated by family obligations and ethics of care that they hesitate to access services; hence, the authors call for a 'female/care burden-liberation' to solve the problem (Strang 2001). These studies show a sensitivity to gender dynamics and social power structures.

### Differences between male and female caregivers

Twelve of the studies focused on gender differences in the care-giving role and included both men and women in their samples. Five studies were qualitative in design, five were quantitative, one was a mixed methods design and one was a review of spousal differences in dementia care plans (Corcoran 1992). Most of these studies are about the 'burden' of caring and

report on coping strategies and the adverse effects of the care-giving role; critically in these studies '(f)emale gender is a marker that places (female carers) at increased risk of high burden' (Gibbons *et al.* 2014, p. 6). For example, in one of the earliest studies reviewed, gender was found to be a significant 'correlate of psychological well-being, in that men reported lower levels of psychological distress than women' (Borden & Berlin 1990, p. 608). Similarly, researchers found that caregiver wives of people with AD reported more depression, anxiety and stress than caregiver husbands (Hooker *et al.* 2000). The same finding was reported from a study conducted in Greece where gender differences resulted in overall burden depression, with females experiencing higher levels than men (Papastavrou *et al.* 2009).

Some studies examine the relationship between burden and severity of impairment. One study found that male caregivers of people with dementia experienced lower burden than female caregivers despite

care recipients more severe disease (Pöysti *et al.* 2012). Similar findings were reported by Norwegian researchers who examined 27 'text pieces' from a survey of adults providing care to people with dementia in their own homes and found that men, more than women, say that they are satisfied with formal care and the collaboration with the rest of the family (Aasgaard *et al.* 2007).

One quantitative study explored the relationship between feelings of guilt and depression in the context of dementia caregivers (Romero-Moreno *et al.* 2013). This study found that 'daughters with higher levels of guilt who do not engage in leisure activities may be especially vulnerable to suffering psychological distress' (p. 1), thus providing useful evidence on how care-giving affects younger women.

Only one study addressed the issue of power dynamics between couples. This was reported in two papers by Boyle (2013a,b). Findings from this study show that men may take over certain household tasks (such as cooking) when their wife develops dementia in order to gain a sense of control (Boyle 2013a). Furthermore, as previously noted, male carers are less likely to facilitate the autonomy of their partners than their female counterparts (Boyle 2013a,b, p. 240). As the researcher explains, this shows that gender inequality in relationships persists even when women develop dementia.

### Gender differences in the lived experience

Nine of the 38 studies reviewed focused on gender differences in relation to the lived experience of dementia. Findings from these studies will be reported in relation to three subheadings: effects of gender on health outcomes; effects of gender on participation; and effects of gender on use of services.

#### Effects of gender on health outcomes

One study conducted in Japan focused on the effects of gender on health outcomes. The researchers explored health outcomes after discharge from a hospital ward, and found that the length of hospital stay was longer for women than men, and women were more likely than men to be institutionalised (rather than return home) on discharge from the hospital (Ono *et al.* 2010).

#### Effects of gender on social participation

Two studies examined the effects of gender on social participation. One of these examined men and women's participation in interactions in care homes,

while the other was concerned with participation in clinical trials. In the study of interaction contacts between staff and residents in a long-term care facility, it was found that men initiated significantly more interactions with staff than female residents did. Women did not initiate any interaction with male staff. Female staff initiated more interaction with residents than male staff; and finally, both male and female staff initiated higher proportions of interaction with male residents than with female residents (Lindesay & Skea 1997). In the other study, it was found that gender can affect levels of participation in clinical trials (Baron *et al.* 2015). Three key findings are reported here: (i) only 45 (62%) of the randomised controlled trials (RCTs) reported gender ratios. In these studies, women were underrepresented (ii) only 19% of the randomised controlled trials (RCTs) analysed and reported on gender effects. In these studies, women were underrepresented (iii). In 40% of RCTs reporting gender analyses, gender effects on treatment outcomes were reported. While these are very differently designed studies carried out over 20 years apart, they both show how gender can affect a person's opportunity to participate in social life.

#### Effects of gender on service use

Three of the studies reviewed examined the effects of gender on service use. One mixed methods study conducted in Canada examined gender differences in relation to the use and availability of home and community-based services for people with dementia (Forbes *et al.* 2008). In this study, women with dementia reported greater difficulty moving about the home and were more likely to receive personal care and respite care from family members. Men were more likely to report sub-optimal functional health and to suffer the effects of a stroke (p. 44). Another interesting finding was that women with dementia visited the dentist and eye specialist less frequently than men. The study also found that men with severe dementia and comorbidities were living in their homes longer than women with dementia. This implies, the authors suggest, that although men with dementia are in poorer health, their caregivers (usually their wives and/or other family members) are willing and able to care for them longer than those who are caring for women with dementia. As a result, caring for men with dementia (usually wives) may be particularly vulnerable to negative health outcomes (Forbes *et al.* 2008, p. 52).

In two separate Canadian studies, intersectionality theory is used to explore the position of one younger aboriginal woman with dementia (O'Connor *et al.*

2010) and relations between caregivers and relatives with dementia (Chappell *et al.* 2015) in respect of using support services. Using intersectionality theory meant that these researchers explored gender as one of several factors affecting a person's experience of dementia and use of services. For example, in the individual case study, the women described 'feeling out of place' in the Alzheimer's support group because others were much older than her and she was the only person with childcare concerns (O'Connor *et al.* 2010, p. 36). Likewise, the results from the other study revealed that daughters experience the highest burden but also the highest esteem, suggesting that the care-giving role is less salient for their self-identities, perhaps because of their younger age (Chappell *et al.* 2015). The findings of both these studies highlight the complexity of women (and men's lives) and the importance of taking into account other differences, such as age, ethnicity and sexual orientation, as well as gender, when researching the lived experience of dementia.

### Limitations

We only included studies written in English and therefore acknowledge a publication bias. The review has not included work on gender published in Japanese and cited by (Ono *et al.* 2010), or the research into gender differences in respect of care-giving published in Korean (Lee *et al.* 2009). It is possible that other international studies have been excluded. The review did not account for study quality.

### Discussion and conclusion

The findings of this review show that men and women respond differently to the care-giving role and that gender affects the lived experience of dementia. The reviewed studies provide valuable evidence of how gender differences matter in the context of dementia care, and findings reinforce the point that others have made about factoring in such differences when policies and strategies are developed (Brown *et al.* 2007, Forbes *et al.* 2008, Boyle 2013a,b, Dao & Woo 2014). In particular, it is recommended that 'policy needs to be more gendered in order to promote the equality of women with dementia' (Boyle 2013a, p. 347). Much more emphasis is needed on influencing the policy agenda to ensure it is gender-sensitive – a point researchers have been making for over a decade (Russell 2001).

Integrating a feminist perspective into health policy is a global priority; it is widely recognised that 'gender-based differences in access to and control

over resources, in power and decision-making, and in roles and responsibilities have implications for women's and men's health status, health-seeking behaviours and access to health services (World Health Organisation 2010, p. 14). Studies in this review have clearly established the fact that as regards dementia care 'female gender is a marker that places caregivers at increased risk of higher burden and less support' (Gibbons *et al.* 2014, p. 16). Moreover, findings show that people with dementia are not being included or represented in studies; their experiences are not valued and so they have fewer opportunities than caregivers to say what it is like to live with this illness and receive care. Applying a feminist citizenship perspective to dementia care research in the future may help to explain why such inequalities persist, and provide a framework with which to work towards social equality and justice.

We found that research into gender differences in relation to dementia care lacks a feminist perspective – that is, few researchers start from the premise that society tends to be unequal, hierarchical and based on masculinised values and that this needs to change (Letherby 2003). Instead, masculinised tools and measures which subjugate participants are commonly used, especially in care-giving studies (Schiffczyk *et al.* 2011, Romero-Moreno *et al.* 2013), and findings related to gender are not fully utilised or extended to discussions about what needs to change structurally and politically to end oppression. A case in point is that women's socialisation for care-giving is a long-standing feminist issue, yet several of the studies reviewed on this topic did not problematise the position that women found themselves in (e.g. Ono *et al.* 2010). Moreover, the disproportionate number of studies on male caregivers identified in this review raises questions about whether the traditional view that women are 'natural carers' is being challenged or reproduced in dementia care research. Richer interpretations are therefore needed that link the personal experience of dementia with wider inequalities and social locations, including gender.

It is worth emphasising here that gender does not equal women: men are at risk of oppression too. But not from being a man (Calasanti 2004). The studies reviewed here show how one social identity can intersect with another to create disadvantage. So, for example, in the same way as the voices of women with dementia were silent in most of the care-giving studies, the voices of men with dementia were silenced too. Men were thus disadvantaged by their health status rather than gender. Additionally, some studies found variations in peoples' experiences of care-giving based on education (Kramer 1997), ethnic-

ity (O'Connor *et al.* 2010) and age (Romero-Moreno *et al.* 2013) as well as gender. Such evidence highlights the need for a feminist citizenship lens in the field of dementia studies; people living with dementia will then be recast as political agents and oppressive power dynamics can be challenged (Lister 2003).

Our aim in this work has been to take stock of knowledge about gender differences in relation to dementia care to inform policy and future research. We conclude that while there is a growing body of work concerned with gender differences in the context of dementia care, most of it fails to address the marginalisation of people living with dementia. Furthermore, the field tends to focus on the individual experiences of men and women rather than wider gender relations. As feminist disability scholars point out, 'the experiences of individuals tell us not simply about the particular, the micro-environments, in which individuals live out their lives, but also about the general, the macro-environments which make up the broader social context of these lives' (Thomas 1999, p. 84). Fundamental questions remain therefore as to how policy makers can act now to address inequalities and promote citizenship. Moreover, how should health and social care professionals incorporate gender awareness into the support they provide (Alzheimer's Disease International 2015b). Such questions will remain unanswered unless social scientists inject a critical gender perspective into their work, and use findings about gender differences to influence the policy arena.

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