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(2015) *Dementia : through the eyes of women*. Research Report. Joseph Rowntree Foundation

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# **Women and Dementia: All But Forgotten? A literature review**

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**October 2015**

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**ISBN 978-1-907265-33-4**

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# Women and Dementia: All But Forgotten?

## Introduction

Dementia is an issue that disproportionately affects women. Of the estimated 800,000 people with dementia in the UK, two-thirds are women (Alzheimer's Society, 2014), three-quarters of family carers for people with dementia are women (Lindsay and Anderson, 2004), and it is mostly women who deliver paid care (Hussein and Manthorpe, 2012).

The conditions that lead to dementia are, of course, largely associated with older age. Thus, while women continue to live longer than men do, they will likely continue to be over-represented in the population of people with dementia. However, there is growing evidence that socio-economic circumstances, education and stress in younger life – all areas in which women as a group may find themselves more disadvantaged than men – may play a part in the genesis of conditions that lead to dementia (Basta et al., 2007; Johansson et al., 2013; Russ et al., 2013).

However, dementia is conceptualised primarily as a cognitive issue, with little attention given to the social conditions in which it evolves and is played out. The UK Mental Capacity Act (Department of Health, 2005), for example, which determines much of what happens to people with dementia (and how) 'primarily views decision-making as a cognitive process, [ignoring] how social inequality – particularly gender inequality – might constrain decision-making' (Boyle, 2013b: 239-240).

Women's voices within the dementia field are relatively quiet and we know little about their experiences, in relation to gendered issues such as power, control, choice and influence. There are three main issues here.

First, except in relation to carers, there is a very limited body of research literature concerned with gender and dementia suggesting, by implication, that dementia is a category not marked by gender. The title of a recent review of what evidence does exist – 'Women and Dementia: Not Forgotten' (Bamford, 2011) – clearly signals this historic neglect. However, most of the material reviewed there draws on quantitative studies that tell us little about what it is *like* to be a woman living with dementia, or caring for someone living with dementia, whether in a paid or unpaid role.

Secondly, one would have to look very hard indeed to see gender (or even sex) mentioned in the substantial numbers of policy documents and statements that have emerged from the English Department of Health since the inception, in 2009, of the Dementia Strategy (Department of Health, 2009). 'Service users' and 'carers' are construed as gender-neutral in policy discourse about dementia, as indeed they now are in health and social care policy discourse more generally. These sleights of hand serve to disguise where the impact, both of the condition itself and of the support that paid and unpaid carers provide, falls.

Finally, there is a growing user movement in dementia, but men tend to be overrepresented in acting as spokespeople for this movement. (see, for example, Bartlett, 2014).

As much of the work discussed here indicates dementia *is* a category marked by social location, including gender.

A project funded by the Joseph Rowntree Foundation and led by Innovations in Dementia has started to address this gendered gap in knowledge about women's experiences by consulting women and trying to use their stories to change the tenor of policy and practice debates and adjust the focus of research. The project has helped women living with dementia to give voice to how their lives are lived, through working with a professional storyteller and a photographer to create narratives that reflect their experiences *as* women.

Running in parallel with this work, we carried out a review of what, if anything, existing research says about women's experiences. The purpose of this was to provide an initial framework of issues to explore in the narrative element of the project; this would allow us to both build on and, where necessary, challenge what evidence currently exists. We report this review work in this paper, first explaining how we found and selected our material and then presenting our thematic analysis of it.

## Methods

This was a small project and we did not have the resources to carry out a full systematic review of research in the area. However, as well as using material already known to us, we did search systematically for other material published since 2000 and up to the autumn of 2014, using the main electronic sources where we would expect to find relevant material. Further, we were clear about the material we wanted to select to review; it should tell us something about the experiences and views of women with dementia, or those who care for people with dementia, whether in an

unpaid or paid capacity. We anticipated that such material would usually draw on qualitative research methods.

As the International Longevity Centre UK had published its review of research on women and dementia (Bamford, 2011) not long before our project, we started our search for material there. We each took two pages of the reference lists, randomly selected, and looked at the publications listed there. We were able to access the full text or abstracts of most of these electronically. This exercise suggested that only a very small proportion of the work reviewed would allow us to say anything about women's experiences and views. We did, however, pick up some references from this exercise that we identified for further appraisal (see below).

We then carried out simple searches of major electronic databases that covered health and social research: Medline, Embase, Psycinfo via Ovid, as well as the social science databases included in Web of Science. An example of the search strategy and its results (number of papers identified) in the Ovid search is at Appendix 1.

As is clear from the search strategy, we were interested in material where gender was central to the research being reported – with the terms 'women', 'female' or 'gender\*' appearing in the publication of the title, alongside 'dementia' and/or 'Alzheimer\*'. This tightly focused strategy was necessary given the short time we had available to us. We were aware that there is a substantial literature on carers and caregiving in relation to dementia (much of it focused on spouses and partners of people with dementia) and that some of this describes and sometimes compares the experiences of female and male carers. However, this literature, by and large, is not driven by a core interest in gender and it was this that we wished to pursue in our review.

After carrying out the searches, one of us (GP) read the results of the searches and selected publications that appeared relevant to our research question, based usually on published abstracts. Where abstracts were not available, GP accessed a version of the full paper, where possible, to inform the decision about its relevance. A total of 132 papers was included at this stage. Although we had de-duplicated the individual searches, further de-duplication was necessary when we combined the Ovid and Web of Science searches, which reduced the number of publications by 49.

Finally, we accessed full versions of all the papers that we had included for relevance and read these. Further selection then took place: we logged but did not analyse papers that full reading showed to have used quantitative methods with no description of women's experiences (n=22) or



that were solely concerned with sex differences in the epidemiology of dementia (n=17). We also excluded one foreign language paper, 16 that on full reading turned out not to be relevant to our research question, and two conference abstracts that did not report any findings.

After the first round of selection, we divided the papers reporting primary evidence between us and read them to identify what seemed to be the main themes emerging from them. We then discussed these and worked together to finalise a list. In some cases these themes were directly related to the issues that the primary research had been established to explore; in other cases we identified underlying themes that authors themselves had not identified. We used the main themes to structure our analysis of the material as well as sharing them with the group doing the narrative work with women in the other part of the project.

Where included papers suggested other references that might be relevant, and that we had not already found, we accessed these, where possible, and used the same criteria for deciding whether to include them. In some cases, this means that publications before 2000 have found their way into the review. We are aware that our restriction to papers published since 2000 may have excluded relevant studies carried out before then. However, our electronic searches did go back further than 2000 and a rapid look through the output for earlier years did not suggest that we had missed any major streams of work.

As a final check, towards the end of our work, we ran additional searches in the same databases but using a wider strategy (searching for our main terms not only in the title but also the abstract and key words of the publication). This process identified 1556 publications and one of us (GP) checked these against the material we had already found and included. This process identified some very recent papers of potential interest and some others that the original search had not found. The whole process led to a final selection, from the electronic and hand-based searches, of 44 papers reporting primary qualitative evidence, as well as three review papers.

We are aware that we are unlikely to have identified every issue that might be important to the experience of women living with dementia, given the relatively small literature that directly addresses this. Indeed, the narrative work with women that was also a part of the project flagged up issues that were not evident in the literature. However, we hope that our review will act as a stimulus not only to debate but also to new research that explores in depth women's experiences of living with dementia.

## The themes

We identified the following main themes from our initial reading of the included papers:

intersectionality; living alone; dementia and sexuality; gender dynamics in heterosexual marriage; issues of 'deservingness', control and burden; women living with dementia and their daughters; different reactions to dementia; and implications for services

### Intersectionality

While socio-culturally diverse older people with dementia may not use the language of intersectionality, their words and behaviours clearly indicate the relevance/applicability of this concept.

(Hulko, 2009: 141)

'Intersectionality' (Crenshaw, 1989) is a concept that seeks to explore how social locations and identities converge to create conditions of inequality and privilege. It acknowledges that we cannot usefully understand individuals in terms of single identity categories since everyone occupies multiple social locations that intersect to give more or less social capital and privilege.

From an intersectional perspective, particular attention is given to how simultaneous oppression or sites of disadvantage work. Calasanti and Slevin (2001) have argued the need for an intersectional 'gender lens' as a way to explore aging more generally, drawing on a 'feminist framework that requires us to explore old age and its intersections with gender, race and ethnicity, class and sexual orientation' (p.3). They stress the relational nature of their approach, acknowledging that women and men develop identities and gain power in relation to each other, and argue that 'sources of oppression can also be sources of resistance and strength' (p.3). Despite this, there is a tendency, in mainstream discourse, for older people to be reduced to their age and people with a dementia diagnosis primarily related to in terms of that diagnosis. Consequently, these intersections and their dynamics remain largely unexplored in dementia research. We therefore began our analysis by following Calasanti and Slevin's (2001) lead and discussing intersectionality in the dementia context as a useful framework to use in exploring women's gendered experiences.

Hulko (2004, 2009, 2011) has perhaps done the most so far in applying the concept of intersectionality to highlight the heterogeneous nature of people living with dementia and to challenge prevailing ideas about what it is like to live with the condition. She argues that there have been few attempts in the existing literature to 'diversify the group of insiders [people living with

dementia] and to analyse the influence of social location on their experiences of dementia' (2009: 132).

Hulko's empirical work used interviews, participant observation sessions and focus groups, alongside photography and photo elicitation, with eight older people with dementia, from a wide range of social circumstances. Her stated aim was to explore intersections of 'race', ethnicity, class and gender, although in her main empirical paper (Hulko, 2009) she tends to concentrate on aspects of disadvantage other than gender

Her overall conclusion is that people's appraisal of their experiences of dementia are diverse, ranging from 'not a big deal' to a 'nuisance' to 'hellish'. She argues that this diversity is 'associated with the respondent's social locations, with the multiply privileged older people holding the most negative views of dementia and the multiply marginalized older people largely dismissing the significance of dementia' (2009: 135). Henderson (2002) makes a similar point.

She further argues that this diversity of opinion is greater than that seen in earlier literature, which has tended to concentrate on people who are middle-aged, white, well-educated, married professionals in the early stages of dementia, with strong religious or ideological beliefs and a supportive family. She suggests that the less privileged respondents who were part of her project had had to acquire resilience through their lives and therefore 'dementia [became] one more hurdle to overcome or just another thing to be getting on with in life.' (ibid: 141). As a result, she argues, the less privileged people had to concentrate more on instrumental rather than 'socio-emotional preoccupations' and that this correlated with their views of dementia. As we see later, however, other researchers have come to different conclusions about the intersections of disadvantage and dementia.

Further, the lack of a specific focus on gender issues in Hulko's earlier (2009) analysis perhaps obscures some gender related impact of dementia. For example, she talks about one of her privileged (male) respondent's traditional (instrumental) gender roles in his household (managing the family accounts) being challenged by his memory problems but does not raise the challenge to an equally instrumental gendered role, reflected in the obvious distress caused by talking about cooking with one of her less privileged (female) respondents.

In her 2011 analysis, Hulko draws on de Beauvoir's concept of the 'other' ('he is the subject, he is the absolute – she is the Other') (de Beauvoir, 1952: xxii) as a way to draw parallels and explore

intersectionality between dementia, gender, and other social locations. Building on her arguments in the earlier paper, she suggests that ‘the degree to which participants were subject to othering as a result of their dementia status varied by social location’ (Hulko, 2011: 210): the more marginalised social locations people occupied, the more ‘othered’ they became.

Sexual identity is another point of intersection that may influence women’s experience of dementia but one that is also under-researched. Price (2008) interviewed 20 gay and lesbian carers of people with dementia, using the data to ‘examine the theoretical intersections between a non-heterosexual sexual identity, increasing age and dementia’ (p.1338). In her overview of the literature on aging and LGBT individuals, Price draws out an argument similar to Hulko’s about those with less social privilege coping better with dementia because of pre-established strategies for managing social marginalisation. Price (2008) argues that the literature on ageing and minority sexualities suggests that ‘gay men and lesbians are apt to age more successfully than their heterosexual counterparts, as, having learned to successfully manage a stigmatised identity [...] the ageing gay man or lesbian woman faces the stigma attached to old age with a well prepared set of psychological defences’ (p.1344). Calasanti and Bowen (2006) argue similarly, (see section below on heterosexual relationships), that women carers cope better with caring for a male partner with dementia because they are already doing much of what that role involves. They are subjugated in a hierarchy of gender arrangements in which men who undertake caring tasks are viewed as exceptional whereas women are just expected to get on with it. In contrast, Price (2008: 1344) argues that ‘for older gay men and lesbians, dementia may become the hub around other intersections of identity turn, rendering ineffectual the privilege and carefully constructed coping mechanisms that may be associated with their other social identities’.

However, if Hulko’s and Price’s analyses are taken together, then logically we might expect men caring for men with dementia to experience **more** difficulty adjusting to change if the privilege of both (as men) is threatened.

### Living alone

It is estimated that one-third of people with dementia live alone but that this is more likely for women, because of both differential survival into older age and differential age at marriage between men and women (Wilson and Smallwood, 2008); Miranda-Castillo et al., 2010). There have been a number of studies about living alone with dementia, but the majority of these have been quantitative and have focused on risk. Even those that draw on qualitative approaches tend to have

focused on risk and usually represent the views of family and care providers rather than the person with dementia (see de Witt et al., 2009, 2010 for review of this earlier research). There have been recent studies attempting to fill this gap, but they do not use gender as an analytical tool (e.g. Gilmour et al., 2003; Duane et al., 2011; Harris, 2001). We did find and review two studies of women with dementia who live alone based on qualitative exploration, but while both took highly theoretical approaches to analysis (Frazer et al., 2011; de Witt et al., 2009 and 2010) neither could be said to offer a gendered analysis.

The first of these was the study of Frazer et al. (2011) which involved semi-structured interviews with eight women with a diagnosis of Alzheimer's Disease who were living alone. The aim was to explore how 'women who live alone with dementia see themselves and how they cope in their day-to-day lives, in the absence of someone a) to reflect their identities back to them, and b) to help them with day-to-day living' (Frazer et al., 2011: 678). Sabat et al.'s (1999) tripartite social constructionist conception of self was used to explore the data. In this model, self 1 is 'the self of personal identity expressed through the indexical 'I'. It is not reliant on others for its existence, and hence should not be damaged by dementia'. Self 2 comprises the person's attributes, while self 3 is 'the social presentation of selfhood, or person. A person can be a friend, neighbour, spouse, or parent, and have different personae associated with each of these social relationships' (Frazer et al., 2010: 678).

The research focused on how 'parts of our identities are constructed from our interactions with others' (ibid: 191) and considered what the impact on identity might be when positive social contact is limited.

Analysis identified four primary themes that could be related to Sabat et al.'s (1999) tripartite self: living with a changing sense of self; fluctuating awareness of memory problems; seeking sanctuary versus risking danger; and being with others – connection versus disconnection. If social contact is an important part of the ongoing project of constructing identity, then identity and sense of self come under jeopardy in this scenario.

The point is supported more broadly in the literature, which highlights the importance of the social environment in enhancing or detracting from personhood and individuals' sense of identity (e.g. Sixsmith et al., 1993; Kitwood, 1993). However, Hulko (2004: 103) makes an interesting point here in relation to identity, that 'Person-centred care, with its call for maintenance of personhood and

continuity of identity [...] may lock older people, especially older women, into rigid gender roles, which may be contrary to their wishes at that stage in life’.

De Witt et al. (2009, 2010) interviewed eight women with dementia who lived alone, six of these on two separate occasions separated by eight to ten weeks. Heidegger’s notions of space and time were used as a framework for the analysis. The analysis related to space explored how the women ‘lived on the threshold’ in a number of ways, working to maintain activities and, to some extent, their identities to enable them to continue living in their own homes. Among other things, the analysis related to time showed the importance of control for some of the women, ‘of doing what [they] wanted when they wanted, in the temporal experience of living alone’ (de Witt, 2010: 1703). The women were aware of the limited time for which they might be able to live in their own homes and identified three factors that might influence how long that time might be – ‘being trouble’, ‘being worse’ and ‘being exhausted’.

### Dementia and sexuality

‘Older’ people tend to be seen as non-sexual (Bauer et al., 2007) and, at the same time, the social world remains broadly structured according to institutionalised heterosexuality which is ‘not just about what does or does not happen between the sheets’ but also relates more broadly to the ways in which social relationships are organised and understood (Jackson, 1995: 21). This extends to assumptions that might be made about how people have lived, or do live; that everyone has been, or aspires to be, heterosexually married, monogamous, and reproductive. In a care context, these dynamics may be especially damaging for lesbian, gay, and bisexual people since – as with heterosexuality – being lesbian, gay or bisexual ‘is about more than defining your sex life. It shapes the way you have experienced life, your interests, dislikes, humour, friendships and attitudes. It is part of assessing people’s ‘social interests’ and ‘cultural needs’ as well as their ‘social contacts/relationships’ (Smith and Calvert, 2001: 14). According to Ward et al. (2010: 12), where there is funding to explore sexuality in this population, it tends to focus ‘on (mainly men’s) sexual health with less information available on older bisexual and lesbian women’ leading to an erasure of experience.

Research points to ways in which service providers fail to recognise marginalised sexuality (Ward et al., 2010). Indeed, according to the Commission for Social Care Inspection report (2006), only nine per cent of social care providers consulted had carried out work focused on promoting LGB equality (Chartered Institute of Housing, News, 2012). Although ‘[l]esbian, gay and bisexual people are

nearly twice as likely as their heterosexual peers to expect to rely on a range of external services as they get older<sup>1</sup> (Guasp, 2011), this is an area that remains largely unaddressed. A study by Heaphy et al. (2003: 12) found that lesbian, gay and bisexual people aged between 50-80 'generally believed that health care and service providers [...] operated according to heterosexual assumptions'. Of their participants, 78 per cent of women and 63 per cent of men viewed residential care homes as particularly undesirable with 'notable distrust about respect for their sexual identities and relationships in such contexts' (Heaphy et al., 2003: 3). When gay, lesbian, and bisexual people do end up in residential care settings – away from their communities of choice - these dynamics may result in a 'return to the closet' as a strategy for avoiding the psychic (and sometimes physical) trauma of homophobia. At the same time this return may also involve significant levels of trauma to the self.

A return to the closet may be motivated by fear of homophobia from care staff. Ward et al. (2010: 19) draw on two such examples from the literature: one where the staff group in a care home 'reacted with a mixture of mirth and disgust at the possibility that a female resident may have been a lesbian' and another where 'an older woman with dementia in a Scottish care home had support withdrawn from her during the last months of her life after she was labelled a lesbian by staff'.

While there is little research considering the dynamics of sexuality as they relate to 'older' people, there is an even greater dearth of work in this area related to people with a dementia diagnosis (Ward et al., 2010). When sexuality is discussed in relation to this group, it is most typically in relation to the 'problem' of 'hypersexuality' associated with diminished inhibitions, rather than focusing on the important connections between sexuality, intimacy, social relationships, identity and sense of self. This may further lead to the diminishing of sense of self, which is already a key issue in relation to people with dementia living in care homes (and in general since this group of people face significant social stigma) where activities tend to focus on stereotypical things that 'older' people are interested in, and care plans tend to focus on heterosexual relations for background information, rather than adopting an individualized approach to care. These assumptions rely on presupposed traditional gender roles.

In 2013 the Labrys Trust – a registered charity based in West Yorkshire concerned with promoting the visibility of older lesbians – published the findings of a small-scale study that explored 'the

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<sup>1</sup> This is because, for the current generation of 'older' LGB people, rather than relying on family networks including children, nieces and nephews, informal networks of support tend to be made up of peers who are possibly in need of care themselves and less likely to be able offer the type of practical support often needed.

impact of sexuality on the assessment of care needs and the quality of care delivered to older lesbians in residential homes' (Walker et al., 2013: 16). The research involved a questionnaire and interviews with care managers and care staff in two West Yorkshire districts. Most respondents said that information on sexuality/sexual orientation was not recorded in care plans, with one manager describing this as 'still a bit of a taboo subject' (p.28). Key findings from the study were that care providers were not interested in addressing the needs of older lesbians; prevailing cultures in the care environment were heteronormative and focused on treating everyone the same (i.e. as heterosexual); and care need assessments did not facilitate identification/disclosure of sexuality. Price (2008: 1347), similarly discusses the 'heteronormative nature of assessment and recording procedures' in care settings.

### Gender dynamics in heterosexual marriage

The gendered division of labour and gender power imbalance in the context of heterosexual relationships has been well documented by feminist scholarship since at least the 1960s (e.g. Friedan, 1963; Oakley, 1974; Bernard, 1972; Dobash and Dobash, 1979). Some evidence suggests that this frequent feature of heterosexual marriage often persists after a dementia diagnosis (e.g. in relation to housework, cooking, or financial management) although this is a largely unexplored area. Based on small-scale qualitative research, Geraldine Boyle (2013a; 2013b; 2013c; 2013d) has written most extensively on this topic. Her study involved researching ways in which heterosexual couples, in which one partner has dementia, negotiate decision-making on a daily basis. Her findings were based on a qualitative study in which 21 couples were included. The research involved ethnographic participant observation and interviews with both partners (using an adaptive approach for partners with dementia). Boyle found that 'social factors, particularly gender, influence decision-making in dementia' (Boyle, 2013a: 560). In reference to financial decisions, some women with dementia in Boyle's (2013a) study felt that they were not adequately involved in financial decision making, despite retained capacity, and this 'reflected and was often a continuation of a gender dynamic established early in the marriage' whereby husbands desired control over decisions in this area. However, 'people with dementia [including women] were more likely to be involved in financial management [facilitated by their partner] when they had undertaken this role prior to their disability' (Boyle, 2013a: 560).

Boyle (2013a: 240) and others have shown that gender influences 'whether people with dementia [are] given the support necessary to exercise their capacity'. Gendered assumptions may also mean



it is more likely for women to be assessed as lacking capacity (Boyle, 2013b). Thus, female carers appear more likely to involve men with dementia in decision-making (Boyle, 2013b; Hirschman et al., 2005). For example, Boyle (2013b: 239) found that wife-carers were more likely to use facilitative approaches whereas 'husband-carers were more likely to use supervision and monitoring strategies'. However, the difference was less apparent in relation to major decisions where carers more generally tended to exclude partners with dementia regardless of gender or capacity (Boyle, 2013b).

Focusing on heterosexual couples in which one partner has Alzheimer's disease, Calasanti and colleagues (Calasanti and Bowen, 2006; Calasanti and King, 2007) sought to explore 'the extent to which gender may influence how spouses experience care work' (Calasanti and Bowen, 2006: 253). They did this by analysing data from in-depth interviews with 22 carer spouses. Unlike Boyle's research, Calasanti and Bowen did not consult partners with dementia in their study. They found that male carers 'appeared at a greater disadvantage in some respects. Because the tasks their wives typically performed [that they now undertook] were those that involved daily work, their increased workload, in this realm, seemed greater' (Calasanti and Bowen, 2006: 261). However, male carers were more likely to accept help or pay for help since they were concerned with getting things done, whereas women-carers were more likely to see increased caring as an extension of their existing caring responsibilities and to therefore assimilate the work into what they were already doing. Male carers often found themselves taking on daily tasks that they had not previously done and characterised this as 'care work'. By contrast, 'women who have traditionally cooked and cleaned may not include these tasks in their list of caregiving since they "would have been doing it anyway"' (Calasanti and Bowen, 2006: 253).

Where Calasanti and Bowen (2006) found that carers often crossed gender boundaries, taking on atypical tasks as part of their caring responsibilities, Boyle (2013a, 2013b) found spouse-carers often trying to preserve gendered dynamics associated with tasks of daily living. This was particularly true of husbands who often seemed to expect their wives to continue to undertake gendered tasks (e.g. cooking, housework) even when this seemed difficult or problematic for their wives. Husband carers tended to refuse to cook or took over cooking all together, thereby either placing an unhelpful burden on their wives or excluding their wives from an activity they enjoyed and were skilled in (Boyle 2013c). A similar dynamic arose in relation to housework with husband carers often being reluctant to take on housework tasks (Boyle, 2013d). Thus, Boyle's work suggested that habituated decision-making, which tended to be based on gender-stereotyped roles

in marriage, continued to inform marital dynamics post diagnosis. Couples found it very challenging to make adaptations based on cognitive and physical abilities rather than persisting with deeply entrenched gender norms, which tended to disadvantage women.

Discussing a study that had found that women had a longer duration of dementia symptoms at presentation, Hulko (2004: 95) wonders if an 'adherence to stereotyped gender roles resulted in the earlier recognition of men's cognitive impairment [...]. For example, dementia may interfere with performance of work roles for men while women who perform traditionally female roles such as homemaking may find their cognitive impairments are less noticeable or easier to mask'. This supposition seems to relate, in particular, to gendered arrangements within traditional heterosexual marriage. Hulko (2004: 95) also suggests that women might be more likely than men to construct some of the symptoms as a normal, almost inevitable, part of being 'dotty old women'.

However, both this argued patterning of diagnosis and Hulko's interpretation of it are challenged by other research that suggests that women may be slower to recognise or acknowledge cognitive change in their husbands than men are in their wives (Beard et al, 2012). A more parsimonious explanation of the finding about the duration of dementia at presentation may be that older women are more likely to live alone and less likely to access services – in both cases reducing opportunities for others to recognise cognitive problems.

## **Deservingness, control and burden**

Several studies that we reviewed raised questions about women's sense of deservingness: their right to complain, to be listened to, to be in control and to have their feelings recognised as important as those of others (in the family and elsewhere). Related to this were issues of psychological distancing, silencing one's own voice and feeling a 'burden' to others.

Proctor's (2001) qualitative study examined the experience of service use with four women with dementia, with a particular emphasis on relationships between the women, all of whom appear to have had experience of being in mental health hospital settings and clinical staff. Although based on so few interviews, possible themes related to areas of feminist analysis did emerge. One of these was women with dementia feeling that they had no 'right' to complain, that their feelings were not important and, overall, that they were not listened to. The presumption that women are expected to care for others perhaps made it difficult for them to talk about their own 'worries', meaning that they silenced their own voices. Proctor reinterprets this as an example of Brown and Gilligan's

(1992) concept of psychological resistance, which she earlier explains as 'resistance to the dominant cultural voice, when women (or other Others) bury their feelings and thoughts, and manifest confusion, uncertainty and dissociation' (Proctor 2001: 366).

Ward-Griffin et al. (2006) highlight similar issues in informal relationships, in a paper from their study of mother-daughter dyads where women with dementia were receiving care from their adult daughters. This paper expressly explores the perspectives of the women with dementia and develops the notion of 'grateful guilt' to sum up the findings. The analysis identified four inter-related themes within the mothers' accounts. First, mothers talked about how they kept themselves independent by 'doing care' for themselves, but this was often explained within the context of not wanting to impose their needs on their daughters or to be a 'burden' to them (p.133). The second theme was about keeping need in check, by '[w]ithholding requests for assistance' from daughters who had busy lives, and mothers preventing daughters 'from doing too much by suppressing their own wishes and needs (p.133). Ward-Griffin et al. suggest that, 'For fear of asking too much of their children, the mothers sometimes found it easier to ask for nothing' (p.134).

The third theme was related to trying to balance independence with the acknowledgement that assistance was actually needed. Mothers did this by 'determining' the type of care they were prepared to receive from their daughters, applying certain conditions and accepting help 'only if it did not restrict or jeopardise the daughter's [own] independence' (p.134). For some, this meant thinking about residential care in the future, if their needs became greater than they felt their daughters could or should provide.

The final theme was 'accepting care', where mothers were said 'passively' to accept their daughters' assistance 'whether, in their [the mothers'] experience they needed it or not' (p.135). Here, the authors argue, mothers seemed gradually to have given up control of their care to their daughters, either because they did not want to seem ungrateful or because they did not want to risk losing their daughters' help.

Ward-Griffin et al. (2006) place these themes in a social context, originally outlined by Gillian Dalley (1996), and argue that 'individualism' and 'familism', shaped the mothers' responses. Within the notion of privacy of the family unit and minimal state interference, women's caring role within the family is perceived as 'natural' and freely given. The participants respected these prevailing assumptions and values with regard to women's role as primary caregiver within the family.

However, the tensions for women with dementia of receiving care when individualist and familist ideology suggests that they should be providing it, led to 'grateful guilt' being 'at the centre of the mothers' experiences' (p.138). The mothers thereby questioned whether they deserved or were entitled to their daughters' care and tempered their needs for fear of becoming a 'burden'.

Other papers from the same study did not directly identify the issue of deservingness, though a reading of them suggests that it is there, either implicitly or explicitly. For example, a second publication from Ward-Griffin et al. (2007), based on material from the study referred to earlier (Ward-Griffin et al., 2006) explored mother-daughter dynamics and identified four different 'states' that these dyadic relationships can take - custodial, combative, co-operative and cohesive. To some extent these appear to reflect the pre-existing quality of the relationship, with some clear suggestions that having vied for 'deservingness' over the years, some mothers and daughters take this contested state into the 'dementia-d' relationship. As a consequence, only those relationships based on a degree of reciprocity (which suggests that mother and daughter have been able successfully to negotiate deservingness) - co-operative and cohesive - allow the mother-daughter dyad to function in a way that does not emphasise the 'deficits' (Ward Griffin et al., 2007: 21) of the mother, while at the same time allowing the daughter to care in a way that also meets her needs. In 'combative' relationships, in particular, the issues of power and control loom large, with Ward-Griffin et al. arguing that in such relationships the main focus is on addressing 'the cognitive deficiencies of the mother' (2007: 22) but with a distinctive feature of 'power over', where both mother and daughter 'compete for control or authority over the dementia care process' (p.23). Such conflict, they state, has been a dominant feature of the lives of the two women. Only in cohesive relationships, the authors conclude, is 'power with' not 'power over' a 'dominant feature' (p.26).

The importance of the quality of past relationships, and the way in which they influence or determine the balancing of power and control in relationships in dementia, is also evident in other research.

Power and control are raised (though not always explicitly) in other research, too.

Hulko (2009) for example, in the study referred to earlier, examines the experiences of both women and men, focusing on socio-economic differentials, in particular, to explore how dementia is perceived and experienced. A somewhat counter-intuitive conclusion emerges from this work. It is argued that those who have had *least* control or power in their everyday lives (people from

minority communities, those of lower socio-economic status and, by implication women, although this is not actually analysed in the paper directly) are more likely to see dementia as less of an 'issue' than those who have experienced more privilege. Hulko (2009: 138) suggests that people from less privileged circumstances were focused more on instrumental than on socio-emotional preoccupations and that this correlated, as we saw earlier, with viewing dementia as 'not a big deal' or a 'nuisance' rather than 'hellish' ...'.

It is also suggested that the less privileged respondents have had to acquire resilience through their lives and therefore 'dementia becomes one more hurdle to overcome or just another thing to be getting on with in life ...' (p.141). Taken to its logical conclusion, this seems to imply that women, being largely in the less privileged group, will be less likely to see dementia as an 'issue'.

This is in contrast to the analysis of Ward-Griffin et al. (2007), who suggest that inter-relationships between family and financial resources play a part in the quality of mother and daughter relationships in dementia, as '... daughters involved in a custodial or combative relationship tended to have fewer resources than those women in cooperative or cohesive relationships' (p.29). This might lead us to the conclusion that for less privileged daughters, dementia is, indeed, 'a big deal', regardless of what their mothers might think.

We saw earlier the study from de Witt et al. (2010) that involved interviews with eight women (aged between 58 and 87) with dementia, all of whom lived alone. The theme of 'holding back time', in the sense of holding back the disease progression and, thereby, maintaining control and continuing to live alone was identified. However, despite the all-women group, there is little analysis that is gender specific. Some material is presented about women not wanting to be 'a burden' on their families or giving others 'trouble', but there is no discussion of whether this might be a gendered response.

The issue of the role of financial resources in enabling women to maintain control comes up in a tantalising case example in Hulko (2009). Here, a woman is described who displays an interesting trade-off between instrumental concerns (which she meets via paying a personal support worker) and social ones; having the support worker enables her to maintain her independence and continue to have visitors and entertain.

## Women with dementia and their daughters

We have already mentioned the work by Ward-Clifton and colleagues (2006, 2007), which was based on interviews with 15 mother-adult daughter dyads and explored the relationships in the context of the mothers' having dementia. Two interviews were carried out with each pair, about 6-9 months apart and 13 dyads completed both interviews.

As outlined above, the analysis revealed four different types of relationship - custodial, combative, cooperative, and cohesive. Custodial and combative relationships largely focused on the provision and receipt of instrumental tasks, and tended to be based on the mothers' 'deficits'. By contrast, cooperative and cohesive relationships were emotion focused and tended to be based on the mothers' strengths. The authors argue that contextual factors, such as expectations of care and levels of support from both formal and informal sources shaped the development of these relationships, often in interaction with pre-existing dynamics.

In custodial relationships, the 'defining characteristic was "duty"' (Ward-Griffin et al., 2007: 21) and family-based expectations about caring drove the relationship. Perhaps as a result, the 'main experience for mothers and daughters of a task focused, deficit based custodial relationship is the objectification of the mother, leading to potential caregiver and/or care-recipient burden ...' (p.22).

In combative relationships, the main focus was on addressing 'the cognitive deficiencies of the mother' (p.22) but with a distinctive feature of 'power over' where both mother and daughter 'compete for control or authority over the dementia care process' (p.23). Such conflict had been a dominant feature of the mother's and daughter's lives. The authors argue that increasing hostility, plus high caregiving demands and limited formal or informal support from elsewhere, may lead to neglect or abuse.

In cooperative relationships, by contrast, the basis of the relationship was strength, with the defining feature of reciprocity, rather than a focus on the cognitive status of the mother. This meant that the mother and daughter tried to work together as 'a team', which was seen to 'facilitate[.] rather than impede[.] the care process' (p.25). Dyads in this group tended to have strong family networks for support and could thus handle most demands.

Finally, cohesive relationships were 'emotion focused and strength based' (p.25), with a strong and positive attachment between mother and daughter. Rather than 'focusing on the deficits of the disease, the daughter ... [was] cognisant (sic) of her mother's strengths and need for independence'

(p.25). 'Power with' and not 'power over' was said to be 'the dominant feature of a cohesive relationship' (p.26).

The authors discuss the importance of identifying these different types of relationships and thereby recognising 'the various types of relationships among persons with dementia and their caregivers, which differ in perceptions of deficits, strengths, tasks and emotions' (p.27). They suggest that service providers need to be aware of these differences and how they lead to different experiences for both people with dementia and carers. They also argue that the types of relationships are dynamic, not static, and may alter 'depending on a number of intrinsic and extrinsic contextual factors: intimacy between mother and daughter, familial care expectations, and informal and formal care support' (p.28).

### **Possible different reactions to dementia**

In the absence of any directly comparative, in-depth research with both men and women with dementia, it is difficult to come to any conclusions about possibly different reactions to the condition that are gendered. We saw earlier that Hulko et al. (2009) suggested that marginality in more than one domain might alter the appraisal of dementia as a 'big deal' or otherwise. If this is indeed the case, then we might expect, say, women from poor economic circumstances to be less likely to see dementia as a 'big deal' than men from similar circumstances. This might explain the suggestion, included in a footnote to the Hulko (2009) paper, that the men interviewed for this study were more likely to reflect an approach that was about 'struggling against' dementia and 'tackling' things that 'oughta be done' (p.140, footnote 9).

Hulko et al. also talk about dementia challenging traditional gender roles for men. The example is given of a privileged male respondent whose traditional roles in the household are being challenged by his memory problems (he was experiencing difficulty managing the household accounts). Oddly, however, a similar challenge to a female gendered role is not highlighted. A substantial verbatim extract of a conversation with a (less privileged) woman with dementia shows clearly the distress that talking about cooking (and not really being able to do it anymore) caused her, yet this is not constructed as a challenge to this woman's traditional roles.

### **Implications for services**

An intersectional focus attempts to counter the tendency for people with dementia to be viewed as a homogenous group, and seeks to explore the heterogeneous nature of people living with a

diagnosis. Services nevertheless tend to persist in their assumption that people with dementia are a homogenous group or, as Cooper et al (2010) put it in their review of evidence about dementia, ethnicity and service use:

Generic services are geared to the majority group in any society and this disadvantages ME [minority ethnic] people who may not consider them to be culturally appropriate.  
(p.201)

Those occupying a marginalised sexuality may also be reluctant or hesitant to access services for similar reasons (discussed in the section on sexuality and dementia below).

For those who are ageing and have dementia, living alone, which is more likely for women (Miranda-Castillo et al., 2010), can add an additional barrier in terms of social and service contact. In Frazer et al.'s (2011) study those living alone appeared at danger of becoming 'lost in the system', particularly if without family support. People with dementia who live alone were less likely to make use of hospitals, day centres, or nursing homes (Frazer et al., 2011). Unmet needs also involve social care; Miranda-Castillo et al.'s (2010) study of 152 people with dementia, found that those living alone had 'significantly higher unmet needs in the areas of looking after the home, food, self-care and accidental self-harm' (p.616).

Class and gender may combine to create conditions in which women with dementia feel de-personalised and alienated from services. Proctor's (2001) small-scale qualitative study of the experiences of four older women with dementia about using services explored the women's relationships with medical staff. She focused on the ways in which power operated in this context since 'Older women in the mental health system face a 'double jeopardy' (Rodeheaver & Datan, 1988) being vulnerable to sexist and ageist attitudes' (Proctor, 2001: 363). Her data suggested that power dynamics operate to 'silence' voices in relationships with professionals as a result of gendered hierarchy but, also, in relation to education-levels and, by implication, socio-economic status, creating – at least – a 'triple jeopardy'. Again, despite the small numbers involved, there was a suggestion of the importance of differentials in education and social class, which also made it difficult for women to challenge the decisions and worldviews of people that were more educated and, in this particular context, those of medical staff.



## Conclusion

As we have seen throughout the material we reviewed, individuals with dementia are marked by the social locations and identities they occupied prior to diagnosis; these axes of identity may form important parts of individual sense of self. Failing to recognise them in interactions and provision of support may thus contribute to an erosion of personhood and perpetuate marginalisation.

As Hulko (2011) argues, ‘the lives of older adults continue to be shaped by social divisions based on gender identity and gender expression, race and racialisation, ethnocultural group membership, social class, sexual orientation, faith and religious affiliation, (dis)ability and marital status’ (p. 198). Thus, while gender is important, it also runs alongside other aspects of women’s lives to generate experiences that are both shared *and* unique.

Adopting an intersectional approach provides a useful lens through which to consider the relevance of gender to the experiences of dementia, exploring the particularities of women’s experiences. Because of pre-existing power relations connected to gender, women experience dementia differently from men. Women with dementia may have better coping strategies for dealing with a dementia diagnosis based on having developed strategies to manage prior experiences of inequality. Of the group of people with dementia living alone, the majority are women. This group is especially at risk of social isolation, which may affect their sense of identity and personhood since these aspects of individuality are achieved, at least in part, through social engagement with others. However, Hulko warns, and other researchers’ work underlines, that a focus on the importance of continuity of identity may lock women into traditional gender roles.

Women with dementia are more likely to have lived and be living in conditions of socio-economic deprivation, which have been linked to higher levels of dementia.

Additionally, women may experience multiple ‘jeopardies’ – e.g. based on gender, class, ethnicity – which may silence their voices in relation to health providers and access to services. Lesbian women face particular issues related to stigma within care environments that are overwhelming heteronormative. This may result in a ‘return to the closet’ and reluctance to access services.

In the context of spousal relationships, gender hierarchy - which is often a feature of heterosexual marriage – may persist after a dementia diagnosis, particularly in relation to daily tasks of everyday life such as housework and cooking. The literature makes a clear case for considering dementia as a category marked by social locations, including gender, as a way to explore the heterogeneity of the

group of people living with the condition and more fully understand individual experiences within this group.

However, given the relative dearth of empirical research in this area, the themes we have outlined here and those explored in the report from the whole study (Savitch, Abbott and Parker, in press) remain to be explored and confirmed in future studies.

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## Appendix 1

Database: Embase <1996 to 2014 Week 40>, Ovid MEDLINE(R) without Revisions <1996 to September Week 4 2014>, PsycINFO <1987 to October Week 1 2014>

Search Strategy:

- 1 women.m\_titl. (305396)
- 2 female.m\_titl. (102196)
- 3 "gender\*".m\_titl. (90384)
- 4 dementia.m\_titl. (70991)
- 5 "alzheimer\*".m\_titl. (104638)
- 6 1 or 2 or 3 (491095)
- 7 4 or 5 (166054)
- 8 6 and 7 (1244)
- 9 remove duplicates from 8 (669)
- 10 from 9 keep 2,5,13-14,16,26,42,48,52,57-58,63-64,70,73,76,94,101,112-113,137-139,145-146,155-156,158,172,177,183,193,196,217,222,230,248,267,271,275,285,319,335,349,351,353,361-363,371-372,383,406-407,420,428,432 (57)