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Dementia: through the eyes of women

by Nada Savitch, Emily Abbott and Gillian Parker

Women are disproportionately affected by dementia, whether they are living with dementia, or caring or working for people with dementia. But the voices of women are missing.

Dementia: through the eyes of women

Nada Savitch, Emily Abbott and Gillian Parker

Dementia disproportionately affects women but the experiences and voices of women are missing from the research and literature. This project provides a snapshot of the experiences, thoughts and opinions of women affected by dementia: women with a diagnosis of dementia, women who are caring for family or friends, and women working in one of the caring professions which support people with dementia. This report aims to inspire people to think differently about women and dementia by using stories and reflections from individual women to inform the debate in a unique and insightful way.

The report shows:

- there is often resistance to talking about dementia as a women's issue;
- research needs to focus on the voices, experiences and perceptions of women affected by dementia;
- service provision needs to reflect the needs, skills and attributes of women with dementia, female carers and the female care workforce;
- the way women experience dementia is affected by gender, but also by many other factors including education, ethnicity, sexuality, class, age, and disability;
- particular consideration needs to be given to issues that are specific to women – such as the large number of women with dementia who live alone;
- women are expected to take on caring responsibilities but women can experience caring as a duty;
- organisations and individuals can think differently about dementia if they consider women as a marginalised majority.

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1 Executive summary

Dementia disproportionately affects women but the experiences and voices of women are missing from the research and literature. This project aimed to inspire people to think differently about women and dementia by using stories and reflections from individual women to inform the debate in a unique, inspiring and insightful way.

This report is a snapshot of the experiences, thoughts and opinions of dementia of women affected by dementia: women with a diagnosis of dementia, women who are caring for family or friends, and women working in one of the caring professions which support people with dementia. It is not intended as a scientific analysis of women's roles, policy or practice, or as the start of a campaign.

There is no one experience that can represent women affected by dementia. The project set no agenda for how people could contribute and so has been able to capture both academic research and highly personal stories. It used a variety of methods to shine a spotlight on these experiences, including a literature review, a proactive piece of work which invited women affected by dementia to share their often unheard experiences and thoughts in an illustrated booklet, and the Women and Dementia Conference (WDC) in November 2014 in York that brought together women from across the country. All these resources, along with individuals' thoughts and opinions from around 50 different women, have been brought together on a project website – www.dementiawomen.org.uk.

Women and dementia is a complex issue and the differences between women, however they are experiencing dementia, may be as important as the similarities. There is huge variety in women's origins, education, ethnicity, access to paid work and income, sexuality, partnerships, children, and health. These differences are likely to interact and affect how dementia is experienced.

Throughout this project, issues and experiences affecting women have been raised irrespective of whether the woman has a diagnosis of dementia, is caring for a family member or is in paid care work. Therefore, it is unhelpful to think separately about women who have a diagnosis of dementia and those who are caring for someone.

The overarching themes that arose through the project are common to many women, including lack of voice, visibility and power, the importance in women's lives of emotions, friends, physical appearance, roles and relationships, and sexuality and sexual identity. Many of the women who contributed to the project defined themselves and other women by their caring roles, but the project has also thrown a spotlight on the expectations, stereotypes and sense of duty that can accompany caring and the status of caring (both paid and unpaid) in society.

Voice, visibility and power

Women's voices within the dementia field are relatively quiet and little is known about their experiences in relation to gendered issues such as power, control, choice and influence. There is very little research that tells us about what it is like to be a woman living with dementia. There is more about caring for someone living with dementia in an unpaid role, but virtually nothing about caring in a paid role. And regardless of how much research there is, almost none of it focuses on the gender issues of living with dementia. Gender is also largely missing from policy documents and statements about dementia.

Certain women seem to have even less of a voice and their needs are not met by many services. This includes women from ethnic minority communities, lesbians and bisexual women, and sections of the care workforce.

Pervasive negative stereotyping around dementia and around women affects how women with dementia are treated and how services are provided. Women can feel invisible to services that are meant to support them, but there is also evidence that women often feel that they don't deserve to be listened to. Living alone is a major factor that can contribute to women with dementia feeling powerless, although

living alone can also sometimes bring benefits. Female family carers often do not receive the support they need because they take on caring roles as part of their family duties.

Dementia and women's lives

Although women's roles, qualities and attributes are subject to stereotypes and misunderstandings, many women feel that these attributes, such as kindness and empathy, are important to them. Thus while gender roles are highly linked to societal norms and are often socially constructed, these gender roles were mentioned frequently, and obviously have a meaning to many women who contributed to the project.

Emotional support is seen as particularly important for both women with dementia and female carers but the perception is that practical support is easier to obtain. On the positive side, if a strength of women is their ability to form informal networks and relationships, this can help other women to cope with dementia.

Appearance, especially clothing, is important to many women's sense of identity, but stereotyping around dementia may lead to assumptions about what matters to individual women. Women with dementia may thus be denied choice around their appearance.

Women affected by dementia (whether women with dementia or carers) are often defined in terms of their family and their roles within the home. Relationships are often damaged by dementia, and more often by the personal care that can accompany it.

Women and caring roles

Throughout this project women have defined themselves and other women by their caring roles. Many women feel naturally drawn to caring for others and fulfilled by this role. Society should celebrate that many women have the emotional intelligence and empathy to enjoy and be good at caring. However, society and in particular health and social care professionals, should be aware that it is unrealistic to expect that all female relatives will be happy to take on caring responsibilities. Women often have feelings of guilt when they find caring difficult or do not want to take on caring responsibilities.

Related to this, there is a perception that the low status of caring is linked to a feeling that caring comes naturally to women and is therefore not skilled work. There is a need for policy-makers and service providers to value the more 'feminine' attributes of empathy and kindness.

Conclusions and reflections

This project has begun to hear the voices of women affected by dementia. Contributors to the project have called for people to think differently about women and dementia.

There is a need for more and different research. Research needs to focus on the voices, experiences and perceptions of women affected by dementia. More fundamentally there is a need to more fully understand the reasons why more women develop dementia. There also needs to be more emphasis on issues that affect women such as living alone, safety and finances. In addition, data from existing and future studies needs to be analysed with respect to gender. Conference organisers are in a powerful position to open up the discussions around dementia to encourage research about the issues.

Services tend to persist in an assumption that people with dementia are a homogenous group. But if services are to be person-centred, gender needs to be taken into account. Groups for only women are felt to be beneficial. Services need to think about how women and men cope with dementia.

Policy-makers need to acknowledge the fact that dementia disproportionately affects women, and take gender into account in policy, including health inequality studies.

However, discussing women and dementia is in itself difficult. Many people find the language of feminism challenging and think it is unhelpful to discuss dementia in terms of women. Some feel that it is men who

are marginalised in service provision. Others feel that society has changed and that future generations of women will not have the same issues. However, others acknowledge that dementia is a feminist issue and that dementia care is a 'woman's world'. More work is needed to widen this debate to younger women.

This project has thrown a spotlight on the experiences and perceptions of women affected by dementia. By acknowledging that dementia does disproportionately affect women, we can start to think differently about dementia research, service provision, and policy and also to encourage women generally to think about dementia as an issue that affects them.

1 Introduction and methodology

Introduction

2015 has been the year when the dementia spotlight has finally turned onto women. This report is the third on the topic to be published in the UK in this one year.

But this report is unique. It focuses on the experiences and reflections of individual women who are affected by dementia – whether they have a diagnosis of dementia, are caring for a family member or friend, or are working in one of the many professions which support and care for people with dementia.

The project was inspired by several individuals with dementia, not least Manuela who was known to the authors and who would continually ask why dementia affected more women than men. She thought dementia was ignored because it is a condition that affects women – and older women at that.

Although there has been a lot of attention drawn to the facts and figures around dementia, the missing link is the voices and experiences of women affected by dementia.

This report is about a different sort of project. The project was subtitled ‘The personal is political’ because the team wanted to draw on the work of feminists, who have long argued that what happens in women's personal lives, i.e. access to health care, being responsible for all of the housework, possibly being sexually assaulted in their own homes, was a political issue.¹

The basis of this idea is that women's lives matter and women's experiences can inform the debate in a unique, inspiring and insightful way.

The aim was to start a debate that thinks differently about women and dementia. So the focus has been first on women and second on how they are affected by dementia. Unless otherwise specified, when this report talks about women affected by dementia, this includes women with a diagnosis of dementia, women caring for or supporting family or friends with dementia, and all the women who work in health and social care around dementia.

It is hoped that this focus on personal individual stories will help to continue the debate, inspire more people to get involved and enable people to think differently about women and dementia.

Background

The project is part of the wider Joseph Rowntree Foundation (JRF) work on dementia under the collective title ‘Dementia Without Walls’. Since 2012 JRF has been working to strengthen the collective voice of people with dementia, support dementia-friendly communities and encourage people to think differently about dementia. The contribution of people with dementia is always at the heart of this work. This project has also sought the views of female family carers and care workers which are also not always heard.

When this project started at the beginning of 2014, a Google search for ‘women and dementia’ would have produced barely anything besides some statistics and an Alzheimer's Society information sheet on the risk of developing dementia.² Here it is stated that women are slightly more likely to develop Alzheimer's disease than men, even if the fact that women are more likely to live longer is discounted – but that the reasons for this are unclear.

In early 2015, the issue of women and dementia really hit the headlines.

On the weekend of 14 February 2015, *The Observer* published an article with the headline ‘Dementia hits women hardest – study’.³ The article previewed the Alzheimer's Research UK (ARUK) report *Women and dementia: A marginalised majority* which was officially published in March 2015.⁴ ARUK's report had two main conclusions: that dementia is the biggest killer of women in the UK, and that women are far

more likely than men to end up as carers of people with dementia, experiencing physical and emotional stress and job losses in the process.

ARUK is calling for more support for scientists who are investigating women and dementia.

On its release in spring 2015, the film *Still Alice* created more general conversation about women and dementia – especially after its star, Julianne Moore, picked up award after award for best actress. In a world with so little understanding of dementia, such representations of dementia in mainstream art can be very powerful. As Dr Alice Hall from the University of York points out, cultural representations of dementia have the potential to encourage reflection and can also help shape public attitudes towards dementia.

In June 2015, Alzheimer's Disease International (ADI) published a global research report (Erol *et al.*, 2015). This report focuses on the English language published literature, but takes an international perspective. The authors look at women living with dementia, women as family caregivers, the role of gender in managing and accessing support, and women in the dementia care workforce.

The statistics

Women and dementia: A marginalised majority brings together a wealth of statistics from existing research to illustrate how dementia disproportionately affects women.

The conclusions from this report are:

- dementia is the leading cause of death among women in the UK;
- women over 60 are twice as likely to develop Alzheimer's disease than breast cancer;
- between 60 and 70 per cent of all unpaid dementia carers are women;
- 2.5 times more women than men provide intensive, 24-hour care for people with dementia;
- 62 per cent of female carers said that the experience was emotionally stressful;
- 20 per cent of women carers have gone from working full time to part time;
- 17 per cent felt they had been penalised at work because of their caregiving duties;
- 19 per cent of women who care for someone with dementia have had to quit work.⁴

The published research

Women's voices within the dementia field are relatively quiet and little is known 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. This suggests, 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 and Walker, 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.

Second, one would have to look very hard indeed to see gender mentioned in the substantial numbers of policy documents and statements that have emerged from the Department of Health since the inception, in 2009, of the National Dementia Strategy. 'Service users' and 'carers' are construed as gender-neutral in policy discourse about dementia, as indeed they 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.

Third, the ADI report highlights gaps in the research. There is very little research in any context involving women with dementia as participants which focuses on the gender issues of living with dementia. There is also a need for longitudinal studies to research the impact of dementia on women.

The authors of the ADI report point out that the existing research base is limited. They explain that only 22 of the 133 papers of the papers they reviewed related directly to women and dementia, and a further 38 looked at wider gender and dementia issues. Unsurprisingly, most research that the authors found had been conducted in high-income countries, yet by 2050 more than 70 per cent of people living with dementia will be living in low- and middle-income countries. At present, little is known about the long-term impacts of dementia on women, either as family carers or as dementia care workers.

The ADI report emphasises that dementia caregiving needs be viewed through a gendered lens, and national dementia strategies need to explicitly address the needs of women. The gendered pay gap in health and social care professions also needs to be addressed to ensure that the care workforce is properly remunerated for the important and challenging work it undertakes. As long as cultural and societal expectations of women as carers remain, women will be disproportionately affected. Their physical health, mental health and financial implications should be front and centre stage in the global efforts to provide the best possible care for people living with dementia.

The ADI report (Erol *et al.*, 2015) has a number of conclusions:

- the perspectives of people living with dementia are absent;
- research on caregiving is complex;
- caregiving in dementia is a gendered issue;
- family structures are changing worldwide;
- women and men access support in different ways;
- women approach dementia and caring in different ways;
- professionals and the workforce need to be skilled in assessment and care;
- national dementia strategies should address the needs of women.

The issues

The pervasive negative stereotyping around dementia has caused much damage. Alise Kirtley (a researcher and consultant in innovation in older person care) is not alone when she talks about how people describe older adult care as stuck in a time warp of sexist attitudes, where older women are viewed as 'your quintessential little old lady' and all care is seen derogatorily as 'women's work'. She hopes and believes – as most women do – that these social stereotypes melt away in the face of respectful and compassionate care.

But this project is about much more than counteracting stereotypes. It is about opening up a debate and throwing a spotlight on women.

This gendered issue is not going away. The writer and blogger Beth Britton describes the last nine years of her father's life as being surrounded by women, and argues that dementia is set to remain – both positively and negatively – dominated by women for the foreseeable future. Professor June Andrews from Stirling University points out that the older women we care for now lived without a lot of the rights and benefits younger women take for granted. She argues that for the next 30 years at least, dementia will be a feminist issue.

Purpose and methods

The project team set out to capture and record the experiences and reflections of women living with and affected by dementia, in order to reveal the stories of women behind the statistics.

The aims of the project were to:

- help women living with dementia to have a voice in how their lives are lived;
- begin to change public and personal attitudes towards women affected by dementia;
- put women at the heart of the project;
- begin to influence a range of people in the field.

The project set no agenda for how people could contribute. The fact that dementia disproportionately affects women was presented to potential contributors, who were asked to tell their stories and give their thoughts and opinions. Therefore the project has been able to capture both academic research and highly personal stories.

To capture as many perspectives as possible they worked in a number of different ways:

- a literature review focusing on women's experiences;
- proactive work to find the often unheard experiences of women affected by dementia, and showcase them in a booklet;
- a website to collect thoughts and opinions of women;
- the Women and Dementia Conference (WDC) – bringing together women from across the country;
- *thinking differently about women's experiences*: more specific work with organisations and projects outside the project team.

The project team brought together all these perspectives to think differently about women's experiences. In the later stages of the project the team worked with specific organisations and individuals to see how they could think differently about women and dementia.

Literature review

This was a small project: time and resources did not allow a full systematic review of research in the area. As well as using material already known to the project team, they searched systematically for other material published since 2000. Material selected to review had to be about the experiences and views of women with dementia, or those who care for people with dementia, whether in an unpaid or paid capacity. This material would usually draw on qualitative research methods.

As the International Longevity Centre (ILC) had published its review of research on women and dementia (Bamford and Walker, 2011) shortly before the project began, the literature review started there. However, only a very small proportion of the work reviewed in the ILC report includes women's experiences and views.

Simple searches of major electronic databases that covered health and social research were carried out looking for material where gender was central to the research. There is a lot of research on carers and caregiving in relation to dementia (much of it about spouses and partners of people with dementia) and some of this describes and sometimes compares the experiences of female and male carers. However, by and large, this work is not focused on gender, as such. Publications were read, leads to other work followed and themes identified. The project team does not expect that every issue that might be important to women living with dementia has been identified, because there is not much research that talks about women's experiences directly. 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, the review will contribute to the debate and new research that explores women's experiences of living with dementia.

The literature review can be found on the project website www.dementiawomen.org.uk.

Women's Experiences of Dementia booklet

As the literature review found, women's voices are largely missing within the dementia field. To redress that imbalance, the project team talked to women affected by dementia: to hear their voices and share them in a meaningful, accessible way. The aim was to bring women's voices into the heart of dementia discourse.

Recruitment of women for this part of the project was through a combination of existing and new contacts. Health and social care agencies, third sector organisations, professional bodies and unions were contacted and also care homes, day centres and support groups.

Interviews were arranged with women who have dementia, with family carers and paid carers. Women were interviewed in York, Bradford and Reading. Some interviews were conducted one to one, and others in groups.

The project team spoke to members of Meri Yaadain in Bradford (a support group for people from Asian communities affected by dementia); members of The Club (for younger people with a diagnosis of dementia) at Woodley Age Concern in Reading; Nicola, a social care manager and family carer; Susan, a daughter living abroad; NW, a manager of a domiciliary care agency; Audrey, a woman with dementia in York; Ming, a writer, blogger and carer; and LS, a care assistant and medical student.

The purpose of the interviews was to understand the interviewees' experiences of dementia from their own perspective.

This was not a piece of academic research. The interviewees are not a representative sample of women affected by dementia. And as writer Helen Cadbury pointed out when she spoke at the WDC, it is important to consider the silence – the voices that are absent from the booklet.

The outcome was a 30 page booklet, *Women's Experiences of Dementia*.⁵ It is illustrated with Eloise Ross's photographs, and is a collection by Helen Cadbury of comments from the women who were interviewed over a period of about four months in 2014. The prime value of the booklet is its authenticity as a testament of the voices of the interviewees. It avoids abstract generalisations and is more like a series of snapshots. The booklet serves as a physical record for the participants themselves: an object of beauty and meaning and power; a paper manifestation of the value the project places on these women and what they have to say. All the words in the booklet are direct quotes from the women who were interviewed. The voices in the booklet are rarely solitary ones, but are full of interconnection with others. They reflect the cluster of individuals around each person.

The purpose of the booklet is to trigger conversation among people who up to now have given these matters little consideration. The booklet is also a useful tool for education and training. Feedback since the booklet's publication indicates that it is still a novel thing for readers to hear people with dementia talking about it. For most of the women interviewed, it was also new for them to be asked for their thoughts.

Project website www.dementiawomen.org.uk

The main purpose of the website was to act as a repository of information produced via the Women's Experience of Dementia project, and a place to encourage people to think about women and dementia in their own lives.

The website encouraged contributions from a wider group of people, sharing their thoughts and opinions on the site in the form of blogs based on personal or professional experiences. More than 40 women contributed their thoughts and opinions, many of which have informed this report. Contributors included women with dementia, family carers, nurses and other professionals, care and support workers and professors and academics (see acknowledgements).

The website will continue to act as a place where thoughts and experiences of women and dementia can be shared.

Women and Dementia Conference (York, 2014)

The Women and Dementia Conference (WDC) took place at the University of York on 6 November 2014 and brought together more than 70 women and three men from across the country. These included women with diagnoses of dementia, carers and health and social care professionals. The event was chaired by Professor Jo Moriarty from Kings College London.

The WDC aimed to:

- share the thoughts and experiences of women living with dementia, women who are caring for family members with dementia, and the female workforce;
- debate the underlying issues about dementia from a women's perspective;
- decide what more needs to be done to change attitudes, policy and practice.

Discussion continued later that month at a UK Dementia Congress workshop, attended by approximately 40 people.

'I will use my influence to promote equality for family carers in relation to gender.'

'I will capture women's stories to shape our service and share.'

'I will remain vigilant to moments of collusion with the expectation that women service as carers.'

'I will take forward the exploration of feminist perspectives within our research agenda.'

Pledges made by delegates to the event

Project advisory group

The project advisory group was made up of eight women with different experiences and backgrounds (see acknowledgements). Their advice, suggestions and commitment to the project and especially the conference were invaluable in steering the project.

Thinking differently about women's experiences

The final stage of the project was to work with individuals and organisations outside the project team to develop ways of influencing the agenda in priority areas identified by the project.

This work included working with:

- Dementia Engagement and Empowerment Project (DEEP), to explore the needs of women with dementia who want to influence others and have their voice heard (see case study in Chapter 5);
- Social Care Institute for Excellence (SCIE), to examine their online resource 'The Dementia Gateway' and how it reflects the statistics, and to explore how SCIE might encourage good practice in services for women affected by dementia (see case study in Chapter 5);
- University of Bradford and Hawker Publications, to think about the role that conferences and conference organisers can play (see case study in Chapter 5);
- The IDEAL research project, to think about how researchers can add to the knowledge about women affected by dementia (see case study in Chapter 5).

In addition, the project team worked with other organisations to publicise both the issue and the project. For example:

- an article was published in the online feminist magazine *The F-word* in April 2015 to raise awareness of this issue (Savitch, 2015);
- ARUK to publicise both reports at events such as the Women of the World festival (WOW) on London's South Bank, where ARUK had a stand promoting their report and the booklet from this project;
- Alzheimer's Europe Conference in 2015, where a presentation of both pieces of work was presented.

The importance of using stories

The use of people's individual stories should have a key position in dementia care. As Valerie Freestone argues, the biomedical model of dementia has disempowered women. The concept of person-centred care reinforces our human need to tell our stories and most importantly the need for others to listen to our stories.

The power of stories has been pointed out by many people working with people with dementia and researching their lives. Andrea Capstick and Katherine Ludwin from the University of Bradford describe a film-making project with women in long-term dementia care. They point out that the filmed stories speak volumes about what women with dementia have endured and survived during their lifetimes.

The ADI report highlights how women's experiences are missing from much of the research around dementia (Erol *et al.*, 2015). Dr Lorna Warren argues that it is crucial that women's experiences of dementia are captured 'in the round' to show the profound and highly nuanced impact of gender. She believes that women's personal narratives, both oral and visual, are the best place to start.

Other contributors (such as researcher Isabella Luthra) argue that stories should be used in education and training to help medical students and other professionals to really appreciate the lived experience of dementia. Valerie Freestone (a nurse and Health Service Journal Inspirational Woman 2014) argues passionately that if we lose these stories we will find caring for women with dementia so much harder – and more importantly we will also miss out on meeting some of the most inspirational women of our lives.

Dr Alice Hall from the University of York highlights the value of fiction in this process. She argues that although short stories, novels and films cannot be relied upon to tell us verifiable facts, they can make us think in new and creative ways about how life stories are constructed – and value the process of storytelling. She also champions the role of fictional stories. She says that fiction can bring debates about dementia to new and large audiences in an accessible way, especially because it is not subject to the often restrictive rules of ethics committees or the requirements for anonymity that come with published academic research.

It is for these reasons that this report is made up of perceptions, reflections and anecdotes. How women are perceived and how they perceive themselves is of great importance.

A note about men

Many contributors to the project have been keen to point out that talking about women should not exclude men.

As Professor June Andrews says, it is really important that what is said here is not misrepresented as an angry feminist diatribe from people who hate men and refuse to recognise their contribution, which is often as significant as women's. Rachel Thompson (Dementia UK) has questioned whether considering dementia as a feminist issue risks creating a separate agenda for women that could leave men feeling excluded. But she also points out that feminism should be seen as an issue for society – not just for women.

At the WDC, different understandings of feminism were expressed. There is some feeling that framing the issue in terms of women's rights is not helpful, and the language used can be misunderstood; care needs to be taken not to exclude or criticise men. But the statistics don't lie – dementia is an issue that disproportionately affects women. Ignoring this will help neither men nor women.

In fact, much of the discussion recognised that women's issues and experiences are mirrored by those of men. There is recognition that care work is not an easy profession for men. Many male care workers are underused, because of an expressed or assumed preference for female carers from people with dementia and their families. As blogger Darren Gormley has highlighted, there is a feeling that care work is 'women's work' (Gormley, 2013). Women are calling for more men to be encouraged to be carers/care workers. Male carers need to be given the confidence to care and it is recognised that men who find themselves caring may be learning new skills and may need support networks.

About this report

The voice of women with dementia has been central to this project. Reflecting this, the report records and amplifies many voices of the women who have given generously of their time, thoughts, experiences and emotions. These women include: women living with dementia, female carers (daughters, partners and mothers), journalists and bloggers, paid carers, medics and researchers.

As part of this project a wonderful group of women with dementia from DEEP groups met in June 2015 (see case study). They expressed a wish that the project encourage a sense of sisterhood, bringing together women affected by dementia, and this report has been structured to reflect this wish. Issues are discussed in terms of women as a whole rather than separately as women with a diagnosis of dementia, carers or care workers. As Catherine Ross (former editor of the Journal of Dementia Care) points out, the fate of women in the dementia care workforce and the fates of the women with dementia for whom they care are fundamentally linked. Many of the issues that arose for the women who contributed to the project are similar whether they have a diagnosis of dementia or they are caring for someone with dementia – either paid or unpaid.

This report has been drawn together from all aspects of the project including the literature review, the Women's Experiences of Dementia booklet, the Women and Dementia conference and the website. Unless stated otherwise, opinions and comments expressed in this report come from contributors to the website available at <http://www.dementiawomen.org.uk/thoughts.html> where the debate continues.

2 Women and dementia: voice, visibility and power

Introduction

Women's voices in dementia are relatively unheard, whether they be the voices of women with dementia, family carers or the paid workforce. There are various barriers to be overcome in order for these voices to be heard. These include reaching out to women with dementia who live alone, giving confidence to **women** who do not feel they deserve to be listened to, supporting women to support other women, and encouraging more research into women's views. We need to acknowledge different experiences and different viewpoints.

Throughout the project, there is a strong perception that women's voices are not heard as loudly as those of men – whether they are women with dementia, female carers or people in the care workforce. This lack of voice is reflected both personally and politically.

The popular press is often filled with stories of women over 50 being invisible, but this is usually trivialised to refer to men not noticing older women. This project found that women are often 'invisible' to people who matter.

The literature review also showed that women's voices within the dementia field are relatively quiet and little is known about their experiences in relation to gendered issues such as power, control, choice and influence. And the first conclusion of the ADI report on women and dementia globally (Erol *et al.*, 2015) is that the perspectives of people living with dementia are absent from the research.

Being invisible

"...women who are carers on low income are invisible, old people are invisible and people with dementia are invisible."

NW, Yorkshire

"Sometimes the medical people talk to your family. They don't talk to you."

Pauline, The Club, Woodley

"In the acute hospital they were not aware of dementia at all, which was quite shocking. She was on a ward full of elderly people, many of whom had quite obvious dementia symptoms, but they weren't geared up to deal with it...None of them actually looked at her."

Ming, London

"Older people in hospital are overlooked all the time."

LS, care assistant and medical student, Newcastle

"Some who are in their own home, with family, they are actually being neglected."

Ghazala, Bradford

"Often it's the daughter-in-law who has the caring role, because she's living in the house...But she has no voice."

Ghazala, Bradford

"...people need to recognise it is an illness, rather than just being a batty old aunty or whatever."

Pat, The Club, Woodley

Often women feel unnoticed. Ming Ho argues that women's identities and the great bulk of their lives are often hidden in the domestic realm. And as a result, no one notices or cares when they develop dementia (or start caring for someone).

The feeling of invisibility is something that many women experience. In her 2013 report Imogen Blood (Blood, 2013) points out that 'old dears' are typically women. Being patronised, marginalised or made to feel invisible (and not feeling able to challenge or even identify when this is happening) is more of a danger when this has been experienced throughout a whole lifetime. It can be difficult to demand that one's voice is heard in older age if it has not been heard much throughout one's life.

Rachel Thompson points out that, although the numbers of people with dementia speaking openly about their experiences and campaigning about the rights and needs of people with dementia has increased, the voice of men seems more prominent than women. One very active woman with dementia, Agnes Houston, feels that women with dementia need support to find their voice. She believes that women with dementia need to be heard – both on the campaigning stages but also in their own care.

Women are also often missing from research and new projects. Alison Macadam says that 65 per cent of people involved in the NDTi Circles of Support project (Macadam and Savitch, 2015) were men. This surprised her given the statistics on the percentages of women living with dementia. She observed that partners and family members supporting people with dementia to be part of the project were almost entirely female. She wonders whether women are more likely to take an active role in encouraging family members who are living with dementia to take part in activities and opportunities – perhaps because women usually have the role of organising or co-ordinating family activities and support. Some of the research reviewed for the project found that women with dementia are more likely to be assumed to lack capacity to remain involved in household decisions (Boyle, 2013a). However, the wives of men with dementia may support them so that they can stay involved in this household decision-making, while husbands of women with dementia may supervise and monitor their wives (Boyle, 2013a; Hirschman *et al.*, 2005).

Women are often literally invisible to services – services are not aware that they exist. To some extent, this may be because older women are more likely to live alone and therefore have fewer people to help them get access to diagnosis and services.

Dr Karan Jutla from the University of Worcester has worked extensively with the Sikh community in Wolverhampton. She says that research into South Asian communities in the UK tells us that the majority of family carers are in fact daughters-in-law, but they tend to be hidden from services because their husbands are usually being classed as the carer.

But listening to women's experiences can and should be inspiring for other women. Valerie Freestone highlights the importance of listening to women with dementia. She talks about Lily, who is the reason she became a nurse, and who taught Valerie more about being person-centred than any book or lecture. Lily taught her to listen and to see past the verbal and physical aggression, the screaming, the biting and the punching, to the person underneath and the fear that caused it.

'Deservingness', control and burden

Several studies that were reviewed raised questions about women's sense of 'deservingness'. This included their right to complain, to be listened to, to be in control and to have their feelings recognised as being as important as those of others in the family and elsewhere. Related to this was feeling a 'burden' to others.

Some research shows that women with dementia feel that they have no right to complain, that their feelings are not important and that they are not listened to. If women are expected to care for others perhaps it is difficult for them to talk about their own worries, and they silence their own voices (Proctor, 2001).

One study that directly looked at the experiences of women with dementia and their daughters used the idea of 'grateful guilt' to sum up the findings. First, mothers talked about how they kept themselves independent by 'doing care' for themselves, but this was often because they did not want to impose their

needs on their daughters or to be a 'burden' to them. Second, women kept their needs hidden, by not asking for help from daughters who had busy lives. The researchers came to the conclusion that, 'For fear of asking too much of their children, the mothers sometimes found it easier to ask for nothing' (Ward-Griffin *et al.*, 2006 p.134).

The third theme was about women trying to balance independence with accepting that help was actually needed. Mothers did this by restricting the type of help they were prepared to receive from their daughters, and accepting help only if it did not interfere with the daughters' own independence.

The final theme was 'accepting care', where mothers accepted their daughters' assistance whether they felt they needed it or not. The researchers argue that these women seemed gradually to have given up control, either because they did not want to seem ungrateful or because they did not want to risk losing their daughters' help.

Choice and control

"I can't go home, can I? I haven't got a home to go to, the children are going to sell it."

Audrey, York

"I felt guilty about going behind her back to arrange the care place."

Ming, London

"It's often imposed on women...I wouldn't say they are forced into their roles, but it just happens, doesn't it? Even though we don't like it."

Audrey, York

Apart from feeling invisible, women report a lack of power to make choices or to control the course of their lives generally.

Choice and control are of course big issues in the women's movement and also in the current narrative around received services. This is the time to start to think about what choice means for older women.

Dementia is seen mainly as a cognitive issue, with little attention given to the social context in which it exists. For example, the UK Mental Capacity Act 2005 determines much of what happens to people with dementia. But it mainly sees 'decision-making' as a cognitive process, [ignoring] how social inequality – particularly gender inequality – might constrain decision-making' (Boyle, 2013a).

When women develop dementia, they can find their relationships and position within the family changing. Andrea Lemard from Nubian Life, an organisation in west London for African and Caribbean older people living with complex health conditions including dementia, says: 'As women we are complex, manifold creatures and demand respect, but if we have lost the very things that give us that respect where does that leave us?' She gives examples of two women with dementia she supports. One woman was displaced from the position of matriarch within her family and another feels her position as wife is under threat, perhaps because she no longer feels the equal of her spouse.

Feminists have for many years described how gender influences the division of labour and of power in male/female relationships, particularly in marriage. Some evidence suggests that these patterns persist after a dementia diagnosis (e.g. in relation to housework, cooking, or financial management) although this is a largely unexplored area.

The power dynamic in relationships is often affected by dementia. Dr Lorna Warren from the University of Sheffield argues that in her experience there are clearly gendered patterns in everyday decision-making between couples where one of them has dementia.

The literature backs this up. For example, in one study some women with dementia felt that they were not adequately involved in financial decision-making, despite having retained capacity. This was felt to reflect and continue gender dynamics established early in the marriage. However, sometimes both men and women with dementia who had managed the household money in the past were helped by their

partners to stay involved (Boyle, 2013b). This emphasises the importance of decision-making and capacity.

Women who live alone and have dementia are often the least heard. Janet Dean tells us of an aunt who lives alone and who desperately wanted to stay at home. For Janet the case was clear: her aunt was an adult and independent and Janet knew this meant more to her aunt than her safety. But the story can be different for the many women who have no one to advocate on their behalf. Barbara Twinney shared a moving story of a good friend who developed dementia. She was happily living alone with help from care workers, family and friends. But her life changed quickly after she left her home one night, leaving the door open and cash in the house. A 'best interests' meeting called for her to move into residential care. Barbara beautifully describes her friend's loss of control over her life – 'a free spirit punished for doing what she realises was a silly thing'.

As mentioned earlier, the research reviewed for this project also suggested that different assumptions are made about women's and men's capacity to make decisions.

Living alone

"I live on my own, so I'm still looking after the house..."

Pat, Woodley

"I've got nobody. Nobody."

Sandra, Woodley

"It's just me and Susie. She's beautiful! If you'd told me years ago that I was going to get fond of a cat I'd have told you to f... off!"

Audrey, York

It is estimated that one third of people with dementia live alone but that this is more likely for women. This is because women live to a greater age than men and because they tend to marry men older than themselves (Wilson and Smallwood, 2008; Miranda-Castillo *et al.*, 2010). Studies about living alone with dementia have mostly been quantitative and focused on risk. Even those that use qualitative approaches have focused on risk and represented the views of family and care providers rather than the person with dementia (see de Witt *et al.*, 2009 and 2010 for review of this earlier research). Recent studies attempting to fill this gap do not use gender to examine their findings (e.g. Harris, 2011; Gilmour *et al.*, 2003; Duane *et al.*, 2011).

One major factor in feeling, and literally being, invisible to services is living alone. Janet Dean's moving story of her grandmother reinforces the idea that women can be largely ignored. People remarked on how 'negative' her grandmother had become, without wondering why. This invisibility is compounded because she lived alone, so as Janet says, 'nobody really had to tolerate her difficult behaviour for long'.

The literature backs this up. De Witt *et al.*, (2009, 2010) interviewed eight women with dementia who lived alone, six of these on two occasions separated by eight to ten weeks. This small study of women with dementia who lived alone talked about the women living 'on the threshold', working to keep up their activities and their identities so that they could continue living in their own homes. Among other things, the study 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 *et al.*, 2010). The women were aware of the limited time they might have to live in their own homes. They identified three factors that might influence how long that time might be – 'being trouble', 'being worse' and 'being exhausted'.

Wider issues around having a voice

Women may also feel alone because of the stigma surrounding dementia. Karan Jutla argues that lack of knowledge and understanding of dementia in some communities means that carers get very little support and find themselves dealing with the stresses of caring in silence. Sue Westwood has highlighted the lack of voice for older lesbians who may not have family, and fear that they will have no one to speak up for

them should they be less able to due to dementia. Research in this area is almost non-existent. What there is suggests that assessment and recording in care settings assume that everyone is heterosexual.

But it is not only women with dementia who lack choice and control. Karan Jutla found in her research that daughters-in-law in some Sikh communities are expected and presumed to conform to the responsibilities associated with their role – including caring – and that for many women this position is one of subjugation.

Rachel Thompson has also pointed out the imbalance of decision-making in the care professions where the leadership in the field (often male) does not reflect the workforce they represent (mostly female). And Catherine Ross points out that people with dementia depend daily on a workforce that is lacking in power or a collective voice. The reputation of the female care workforce is that workers are unlikely to complain, let alone strike, and are therefore being ignored.

Some contributors have highlighted the need to listen and hear what women are saying – however unpalatable it may be. Sue Wilkinson, Professor of Feminist and Health Studies at Loughborough University, told the story of the feminist psychologist Sandra Been who took her own life four years after receiving a diagnosis of Alzheimer's disease. Sue feels strongly that, although many women with dementia will decide that life is still worth living, the choices of those few who decide otherwise should not be denied or hidden from view, and we should honour and respect more challenging choices.

Summary

Many women are still hidden from view with their voices unheard. In dementia, this is linked to women's feelings that they have no right to complain and fears of being a 'burden' to others. Choice also becomes a more complex issue for women affected by dementia – an issue that is compounded when women live alone or without traditional families. The lack of voice may affect the services that women receive and the place of women in the workforce.

3 Dementia and women's lives

Introduction

Although women's roles and qualities are subject to stereotypes and misunderstandings, many women feel that these attributes are important to them and are part of the rich life experiences that make up their personhood. They should not be ignored. Every woman is different and every person with dementia is different. However, any discussion about women will perhaps inevitably be couched in language that includes stereotypes, generalisations and assumptions. Like it or not, these stereotypes and ways of thinking about women's roles are ingrained in many of the societies we live in. Undoubtedly these perceptions affect the choices that are made in the dementia field.

When Professor June Andrews talks about the benefits won by the generations of women now needing care and support, she provides an eclectic list including: maternity leave, equal rights at work, laws against rape and violence, recognition of the need for education, decent sanitary products, washing machines and disposable nappies. This list illustrates the complex nature of 'women's issues', and, although they cannot be addressed by this project, it is important to remember the broad nature of women's experiences. This list also serves to remind us that, by working together, women can achieve much for other women.

This chapter starts by addressing some of the ways in which society and women themselves have described what it means to be female, and how so-called female attributes, qualities or issues affect how women react when dementia is part of their lives. This leads on to the roles that women play in society, in families and in dementia care, and how relationships change because of dementia. Almost inevitably this means a discussion about caring – but caring as it affects the woman, not the 'person with dementia' or 'the carer'.

The importance of emotions

"Women wear their hearts on their sleeves more."

Pauline, Woodley

The perception in society as a whole, and among many women, is that women are more in touch with their emotions, have more empathy and follow their feelings more. In contrast, being task orientated, focusing on the practical, and being scared of showing emotions, are perceived as masculine traits. There is also a feeling that these feminine nurturing traits are not valued by society.

This divide may have an effect on how services have been habitually designed. Many services for people with dementia and support for carers focus on the practical. The emotional support that is seen as important by women is not easily available.

And this also has an effect on how care workers are perceived. Because kindness and empathy are seen as female attributes they may not be valued in assessments of care workers' skills. Likewise, career progressions that involve less time to spend with people who have dementia may not be attractive to women who want to care and believe that caring is about relationships. Beatrice Goodwin feels that 'living kindness' is an essential quality, but points out that management tends not to value this quality in their care staff.

Informal networking

"I felt that I was just going to be up front with everybody."

Pat, Woodley

"When we have the men here, they don't talk about it. They don't talk about their dementia. If we start talking about it, they just take themselves off into the garden."

Pauline, Woodley

Maureen: Oh yes, as a group we all laugh at each other.

Pat: We're not laughing at you, but with you.

Margie: Yes, we're laughing with each other.

Maureen: We've got to laugh, you've got to laugh, haven't you?"

Another 'female attribute' is seen as the ability to form groups, make friends easily and share emotions and experiences. Often referred to as 'tend and befriend', this model for women's reactions to stress contrasts with the more masculine model of 'fight or flight'. The 'tend and befriend' model leads to nurturing behaviour in stressful situations. Differences in the way women and men handle interactions are also prominent in popular perceptions about how women and men work in business – with men tending to use a 'transactional approach' and women using a 'relational approach', getting to know people and building relationships before doing business.

At a basic level this ties women together. Jen Marks, a one-to-one support worker with Young Dementia UK, talks about the 'girly gossip' she has with the women with dementia she works with, and how they create a female bond. She believes that, although they have different personalities, experiences, beliefs and interests, simply being women means they have an intuition and appreciation of each other. Frances has shared with us a moving account of her friendship with Sally who has advanced dementia. Frances knows that her presence in Sally's life greatly enhances Sally's quality of life.

Researchers such as Andrea Capstick and Katherine Ludwin from the University of Bradford have noticed that, when they have been working with people with dementia, the women developed a distinct group identity during the study and liked to spend time sharing memories.

The DEEP paper *Women with dementia – our voices*, which was written by women with dementia as part of this project, emphasises the importance of women's networks.⁶ They cite their own experiences of having close female relationships and liking to be in group situations with other women. They also place importance on their role in supporting other women with dementia to be engaged (see case study).

Physical appearance

"There are issues that only women really understand – like what it means to you to be feminine."

*Women and dementia – our voices*⁶

For many women their clothes, hair and make-up are undeniably a big part of how they perceive themselves. Dr Julia Twigg (2010) has written about the link between clothing and identity in women with dementia. And for this project, Sarah Reed's daughter Poppy talks about her grandmother teaching her mother to sew and the importance of clothes to them both when her grandmother developed dementia.

At the WDC, people thought that many women with dementia might benefit from having female care workers, not just in terms of personal care, but in helping them to maintain their identity, for example through appearance and dress.

However, physical appearance is an area where stereotypes can be damaging. Dr Lorna Warren talks about the 'dark images of dementia' which are still pervasive. Her research 'Look at me' studied images of older women in popular culture. She reports that many of the participants identified 'images of old women with Alzheimer's' as images they did not like – conceding that it was because they did not want to be reminded of their own ageing process.

Agnes Houston feels that an emphasis on appearance is important but must avoid stereotyping. Women should be asked what makes them feel feminine and happy being women. She fears that unless women speak up about how they feel and write things down, when a woman is being helped to dress in the morning it will be all about make-up. For Agnes, perfume is what makes her feel good and confident.

Isabella Luthra reminds us about the concept of 'embodied self' – meaning the body's natural power of expression using basic body movements. She believes that a society and care system that shows less reliance on cognition and language could enable women to express themselves and their wishes more through their bodies.

Women's roles

"It's usually their role in the family to care for the less capable members of that family. It's always been expected that this is the role of women."

Audrey, York

"Unfortunately it usually falls to the woman of the family to play more than one role."

Audrey, York

"The difference is, probably for Dad's generation, the division of chores and labour, and the way husbands and wives lived, so Mum had done the cooking, done the shopping, and been the social organiser as well."

Nicola, York

"Day and night I look after my husband. My son and daughter-in-law live here too. She looks after the children."

Farida, Bradford

"I was a nurse. It's very odd to be a patient. Not frightfully enjoyable really."

Audrey, York

The complex nature of women's roles has been a key theme in this project. Gender roles are strongly linked to societal norms and are often socially constructed. In this study gender roles have been mentioned frequently and obviously have a meaning to many women.

Isabella Luthra argues that developing dementia means that a woman's role in society – as wife, carer, friend or sister – is often occluded, and that this lack of a recognised role threatens the woman's sense of stability and in turn the preservation of her personhood. The writer and blogger Ming Ho says that this loss of identity is also felt by women who take on caring roles. She suggests that society more readily grasps the loss of identity experienced by men – living with dementia or in a caring role – because it still equates the man's self with his public role: doctor, engineer, lawyer, sportsman, driver, head teacher, famous author – as someone active and respected, the loss of which is visible to the outside world. Women living with dementia and their female carers are, she argues, less likely to be identified by public status than their husbands, brothers or fathers. So when a woman starts to withdraw from professional life because of her dementia or because of caring for someone else, it will often pass without notice.

This is backed up by the literature. Women tend to be diagnosed later in the dementia journey and some researchers have wondered if this is because stereotypes about gender lead to earlier diagnosis for men: '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' (Hulko, 2004).

This supposition seems to relate, in particular, to gendered arrangements within traditional heterosexual marriage. This researcher also suggests that women might be more likely than men to see some of the symptoms as a normal, almost inevitable, part of being 'dotty old women'. However, other research challenges this and says that women may take longer to recognise or acknowledge change in their husbands than men do in their wives (Beard *et al.*, 2012). But, of course, older women are more likely to live alone and less likely to access services, and both might reduce the chances of others recognising change associated with dementia.

It is interesting how many contributors to the project talked about women's roles in terms of the family and roles within the home. As Andrea Capstick and Katherine Ludwin point out, it is too easy to assume that women of older generations did not do paid work. In fact, all the women participants in their project

with people in long-term care had been in paid employment after their marriage as well as before it. Other contributors have pointed out the diverse roles that women have had in their lives. Andrea Lemard from Nubian Life in London refers to the women she supports as strong, proud women; women who have had their own businesses, raised families and cared for others.

Dementia forces women's roles in life to change. Roles for women are often defined by our relationships with others. Andrea Lemard asks how we as women can be expected to make sense of the changes brought about by dementia when we have learnt to define ourselves by other's expectations.

Sarah Reed, from an organisation called Many Happy Returns, which promotes conversation between generations, describes her mother occupied in a variety of roles – preparing fruit and vegetables, sewing or knitting – and how she was often sitting but always busy. She contrasts this with her mother later on and now with dementia – she sits in a nearly identical chair, but this time with little to do but watch and wait. Janet Crampton talks about the importance that women's roles in life still have as dementia progresses. She points out that the brain may hold on to time-honoured roles even though people's lives, perceptions and actions may change. She therefore applauds the staff in her mother's care home who talk to women residents about household tasks and acknowledge that the routines of daily life such as getting the children to school, getting a meal on the table, and doing the washing on a Monday, are habits that die hard. Janet believes that acknowledging this role gives a woman with dementia a sense of herself.

Gillian Drummond reports that two of the three wives she supported to contribute to the project said that more and more of the roles previously undertaken by their husbands had now devolved to them. Agnes Houston feels that her life skills as a woman, which she defines as organiser, nurse and caregiver, have helped her to cope with dementia. She sees being a person with dementia as just the next challenge, the next role she had to take on.

The balancing act between roles has also been a recurring theme throughout the project. Jane Gilliard shared her personal experiences of the 'family tug of love balance' between caring for a parent with dementia and enjoying being a grandparent or parent. Jane points out that grandchildren are precious, tiny for such a short period, making it difficult not to feel resentful if one cannot be there to enjoy them. But she also says that parents hold a special place and need support as their lives come to their end. In Jane's experience, it is often the woman who is somewhere in the middle, holding everything together.

All this shows that differences between women's experiences of dementia may be as important as the similarities. This was a theme identified in the research that was reviewed through the project, although evidence about it is scarce. Women are not just women; they are women whose origins, education, ethnicity, access to paid work and income, sexuality, partnerships, children, and health all differ and interact, affecting how dementia is experienced. Perhaps a woman with significant financial resources of her own might find it easier to maintain independence and control in the dementia journey than one without? Or perhaps a woman with a large and loving family might fare differently from one who is single?

Relationships

'We don't want our relationships with our families to be ruined by them being carers. We especially want our daughters to be our daughters – not our carers.'

Women and dementia – our voices⁶

Relationships were very important to most women in the project. And women often defined themselves in terms of their relationship to others – mother, wife, carer, friend. Indeed Sarah Reed from Many Happy Returns and her daughter Poppy, based their contribution on the experiences of three generations of women.

Being labelled as a carer is often seen to be detrimental to relationships. Three wives of men with dementia who contributed to the project all considered that their role as a wife was more important than that of a carer, and two of the three did not consider themselves to be carers at all.

But dementia can bring about changes in relationships, emphasising both difficulties and strengths. A study of women with dementia and their daughters identified four different types of relationships – custodial, combative, co-operative and cohesive. To some extent these reflected the earlier quality of the relationship between mother and daughter. Only relationships that were based on reciprocity allowed the mother and daughter to function in a way that did not emphasise the 'deficits' of the mother. At the same time, these more balanced relationships helped the daughter to care in a way that also met her needs. By contrast, in 'combative' relationships, the issues of power and control loomed large. The researchers argue that in these relationships the main focus was on addressing 'the cognitive deficiencies of the mother' with a strong feature of 'power over', where both mother and daughter 'compete for control or authority over the dementia care process' (Ward-Griffin *et al.*, 2007). They argue that this type of conflict had usually been a dominant feature of the lives of the two women. Only in cohesive relationships, they conclude, is 'power with' not 'power over' a 'dominant feature'.

But the same research also showed that family expectations, and access to financial resources and other types of informal and formal support, influenced the type of relationships that developed between mothers and daughters. The relationships between mothers and daughters were not set in stone, but could be influenced. This underlines again the importance of other factors that can alter the experience of dementia.

Family relationships can become blurred in dementia. Janet Crampton talks about how her mother seems to have lost a sense of relationships between people, sometimes believing that she is the child and Janet is the mother. Linda Lamont talks about her experiences of caring for her husband who lives in residential care. She talks about how the small number of residents who share the sitting room with her husband have become his extended family – and, because she visits every day, hers too.

Relationships can also change for the better. Jane Garner contributed a moving real life account of a mother and daughter relationship which was not close before dementia. The relationship improved as the dementia progressed and the daughter was able to see with compassion the positive aspects of her mother that had previously been hidden from her. Her mother was able to express the warmth and love which it is assumed must have underpinned her previously critical attitude. The wives who talked to Gillian Drummond also reported that, despite the stress and distress of caring, they felt that their husband's illnesses had brought them closer together.

Relationships with care staff have been highlighted as particularly important. Frances, who cares for her friend with dementia, has seen that what people with dementia need are members of staff who have the capacity and willingness to develop good, supportive, caring relationships with them as unique individuals. Linda Lamont also talks about how the care workers in her husband's residential home are his other very important family. In Jane Garner's account, the relationship between mother and daughter only improved when professional care workers were there, not just to remove the strain of practical caregiving, but to bear the criticism from the mother in a way that the daughter could not, because of the emotions involved. Frances also points out the importance to her friendship with Sally, a woman with dementia, of not giving physical care – this would have changed the nature of their relationship.

Sexuality and sexual identity

Sue Westwood has pointed out that older lesbian and bisexual women are less likely than heterosexual-identifying women to have partners, to have children or to be in regular contact with extended family members. This means that services may not be appropriate for these women.

'Older' people tend to be seen as non-sexual (Smith and Calvert, 2001). At the same time, the social world remains broadly structured according to institutionalised heterosexuality. This 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, 2005).

Service providers largely fail to recognise marginalised sexuality (Ward *et al.*, 2010). The 2006 Commission for Social Care Inspection report said that only 9 per cent of social care providers consulted had carried out work focused on promoting LGB equality (Thornhill, 2012). Although lesbian, 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 (Taylor, 2012) this is an area that remains largely unaddressed.

There is little research about the dynamics of sexuality in 'older' people and even less about people with a dementia diagnosis (Ward *et al.*, 2010). When sexuality is discussed in relation to this group, it is usually about the 'problem' of 'hypersexuality' associated with diminished inhibitions, rather than the important connections between sexuality, intimacy, social relationships, identity and sense of self. This may lead to the diminishing of sense of self. This is a key issue for people with dementia living in care homes. Care plans tend to focus on heterosexual relations for background information, rather than adopting an individualised approach to care, and activities tend to focus on stereotypical things that 'older' people are interested in. These assumptions rely on presupposed traditional gender roles.

A small-scale study has looked at how sexuality affects the assessment of care needs and the quality of care delivered to older lesbians in residential homes in two districts of West Yorkshire (Walker *et al.*, 2013). Most of the managers and care staff 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'. Key findings were that:

- care providers were not interested in addressing the needs of older lesbians;
- culture in the care homes was heteronormative and focused on treating everyone the same (i.e. as heterosexual);
- care need assessments did not facilitate identification/disclosure of sexuality.

Summary

Many women's lives are focused on roles within the home, relationships, friendships, emotions and physical appearance. All these aspects of women's lives can easily be stereotyped. The extent to which dementia can have positive or negative impacts on women's lives depends on how they, the people who support them, and policy-makers react to and use these aspects of women's lives.

4 Women and caring roles

Introduction

For many women caring is an integral part of their identity. Society should celebrate that many women have the emotional intelligence and empathy to enjoy and be good at caring. However, society, and in particular health and social care professionals, should be aware it is unrealistic to expect that all female relatives will be happy to take on caring responsibilities.

Throughout this project women have defined themselves and other women by their caring roles. Ming Ho argues that, on an emotional level, our society still expects women to be nurturers, the 'supporting cast'. And she thinks that this means that a woman's identity is always bound up with those she cares for. It was especially interesting to note that the women with a diagnosis of dementia who attended the Women and Dementia Conference also defined themselves as still supporting and caring for others (as well as often continuing to work in paid or voluntary roles).

It is perhaps useful to think about caring roles of women in terms of socialisation in infancy. The perception is that girls are handed dolls to play with and encouraged to show nurturing and caring behaviours, whereas boys are given superheroes and toy soldiers, encouraging fighting and protecting behaviours.

However, labels such as 'carer' or 'caregiver' are often difficult for people. The ADI report (Erol *et al.*, 2015) points out that for many the role of carer is seen as an extension of a lifelong commitment to caring for the family.

Many women feel naturally drawn to caring for others and feel fulfilled by this role. This means that many women who have found employment as care workers do this job because they love it and feel drawn to it. However, some women worry that, because caring is seen as a natural feminine attribute, it is not valued by other people or society in general. Other women feel there is an assumption they will take on caring roles whether they want to or not, and that the support they might need is not forthcoming because of this assumption that caring comes naturally to women.

The ADI report (Erol *et al.*, 2015) sees motivations for taking on the carer role as a complex mix of expectation and obligation, along with love, and gratitude for the person with dementia, or to repay the care they received as children.

The research reviewed in this project highlighted the tensions for mothers who want to care but are now being cared for. Ward-Griffin *et al.* (2006) argue that 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 in their study respected these prevailing assumptions and values. But this created tensions for women with dementia who were now receiving help when, according to the prevailing ideology, they should be providing it. This led to feelings of 'grateful guilt' being 'at the centre of the mothers' experiences'. The mothers asked whether they deserved or were entitled to their daughters' care, and managed their needs for fear of becoming a 'burden'.

Women who want to care

Many women do want to 'make a difference' and do not think of caring as a burden but as a positive choice. Dr Lorna Warren talks about her friend and neighbour who has spent a 'life caring' and still continued to care for her neighbours' children even when she displayed signs of having dementia. In her contribution to the project website, Jo Moriarty from King's College London highlights ethnographic research by Pia Kontos which showed the nurturing side and tender concern of a female resident of a care home. The ADI report also highlights positive factors associated with becoming a caregiver, including having a sense of pride and satisfaction.

Many contributors to this project also felt that women's caring instinct was a good thing. Beth Britton, for example, thinks this instinct should be a cause for celebration. Sophie Dishman, a young carer, talks about

her feelings about caring for her grandparents. She explains that she doesn't resent them for the difficulties of being a carer and celebrates the extra time she spends with them as they inspire her. Dr Karan Jutla, talking about her work in Sikh communities in Wolverhampton, confirms that some women have a very high level of satisfaction with the role and feel very proud that they have been able to 'fulfil their duty positively'.

The three wives of men mentioned earlier observed that women tend to be more resilient and cope better with caring than men. The women in focus groups and interviews conducted by Professor Peel and Dr Harding never felt the need to justify or account for why they engaged in caring for their relative or friend with a dementia, whereas male participants were more likely to talk about 'obligation'.

Beatrice Goodwin praises the women – mostly middle-aged – who work in care. They have few academic qualifications but they do react to people with dementia intuitively, imaginatively and empathetically.

Some women who attended the Women and Dementia Conference acknowledged that women may also 'mother' people and over-care. It is acknowledged that some women become serial carers – caring for generations.

Over many years research about caring has shown that, in general, men and women see caring activity in different ways. But it has also shown that there is no clear dividing line between all women's and all men's views about, and commitment to, caring. This is particularly the case within heterosexual partnerships (Parker, 1993). Research about this issue that is specific to dementia is relatively scarce, but there is some evidence about the ways in which gender may influence caring in marriages where one partner has dementia. This echoed more general research on caring. The review of the research carried out for this project concluded that male carers seemed more disadvantaged because the tasks they took on 'were those that involved daily work. This meant that their increased workload, compared to women in a similar position seemed greater'. However, male carers were more likely to accept 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 responsibilities and to 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).

Lack of caring skills can affect how people cope with dementia. June Andrews points out that, when an older woman has a husband with dementia, she often has the life skills to care for him. For this reason he is more likely to end his days in reasonable comfort at home. But when an older woman has dementia, the reverse is often true.

Expectations and stereotypes

"As the carer of a younger husband with dementia I was aware of an expectation that I should give up work to care for him."

Delegate at WDC

"I nursed my father...I nursed my mother...I nursed my younger sister...I suppose looking back on it there wasn't any other poor sod to fill the role...I'm a filler-inner, a stand-in, for whoever's needed at the time."

Audrey, York

There are still stereotypes about male breadwinners and female home-makers. Throughout this project there has been a perception that women are socialised from a young age into caring roles and so are expected to be competent carers.

The research reviewed provided contradictory messages. Calasanti and Bowen (2006) found that carers often crossed gender boundaries, taking on atypical tasks as part of their caring responsibilities. By contrast, Boyle (2013a, 2013b) found that husbands and wives who were carers tried 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 either refuse to cook or took over cooking all together. This could either place an unhelpful burden on their wives or exclude them 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). In Boyle's study, decision-making based on gender stereotyped roles in marriage continued to influence 'who did what' after the diagnosis of dementia. Couples found it very challenging to make adaptations based on cognitive and physical abilities rather than persisting with deeply entrenched gender norms – and this tended to disadvantage women.

In July 2015, *The Daily Telegraph* reported Princeton University, US study of the family networks of 26,000 Americans, which found that men do as little as they can get away with in terms of caregiving and that their sisters have to overcompensate for this.⁷

Dr Karan Jutla argues that in South Asian communities in the UK, but also more universally, norms around gender roles and division of labour predispose women naturally to nurture and take care of the daily activities within the home, while traditionally men take care of matters outside the home. Interestingly, she notes that these stereotypes are more pronounced in South Asian communities in the UK because some of the communities are living within the cultural norms of a time before their migration to the UK. Professor Peel and Dr Harding have also found that there is an implicit or explicit expectation that it is women who care, in both emotional and practical terms. At the WDC there was a perception that women do hands-on caring while male family carers often deal with financial and practical matters.

The stereotypes of women as first and foremost wives and mothers may influence how women with dementia are treated and what services are offered to them. The ways in which gender and marital status influence what and what level of support services are received was a key issue for researchers in the 1980s and 1990s (for example, Arber *et al.*, 1988; Parker and Lawton, 1994). Now, however, these issues have largely disappeared in work that explores receipt of services.

The project discussions have also highlighted the difficulties of the ingrained assumptions that women are 'naturally' good at caring and that society expects women to find the caring role easy.

However the assumptions mentioned above often mean that there is an expectation from family and professionals that the women (wives, daughters and even daughters-in-law) in the family will do the caring. There is a feeling of duty and obligation which is not seen so much with male carers.

Sense of duty

"At work, I deal with the care assessments and the biggest thing I see there is just a massive sense of duty...No choice in it. No wanting to."

Nicola, York

"...there were at least three women in my support group who were having to cope with caring for somebody that they despised, because that person was never a good mum, but they're now stuck with the duty of care of somebody that they don't care for."

Alison, daughter, living abroad

"I am struck by my own assumptions concerning duty of care – being dismayed when a daughter faced with a parent's diagnosis chose not to care."

Delegate at the WDC

Assumptions about caring leave women who are not natural carers, or who do not wish to be a carer, in difficult positions and full of guilt whichever choice they make. In November 2014, BUPA reported that women are pushing themselves to breaking point because they are caring for relatives out of feelings of duty and guilt.⁸ Women at the Women and Dementia Conference reported feeling *guilty* if they cannot or do not want to care for someone, whereas men who take on a caring role expect *acknowledgement* for their work and what they have given up.

There was also a feeling that, if women develop dementia or take on a caring role, they have less to 'give up' in their lives than men – in terms of career, status or finances.

Such expectations can have consequences for the quality of support that women carers receive. Professor Peel and Dr Harding argue that women carers are assumed to find it easy or natural and are therefore not offered the support from professionals they might need. As Rachel Thompson points out, there are plenty of men who provide care and support for people with dementia and do so incredibly well. But she believes that male spouses providing care tend to receive a disproportionate amount of help compared with their female counterparts, and she questions why this is so. She thinks that as a society we seem to empathise more with the difficulties of personal caring for men.

Status of caring – both paid and unpaid

"The carer is often the person who knows the person best, but the decision-maker in the family often doesn't want her as next of kin, so she's not allowed to make decisions."

Abida, Bradford

"It's difficult getting male care staff...Caring is not a valued profession. If you can, you're going to try and get in at a higher level...So it's seen as okay for men to do nursing, but not to do care work as such."

Nicola, York

"It's the money. It's not a career that's appealing to people because of the money...if they can earn the same money in the local supermarket, why would they stay?"

Nicola, York

Research on the workforce in dementia care is difficult to find, and particularly that which explores the feelings and experiences of women who are part of it. However, recent work that has examined existing statistics shows that the dementia care workforce is more likely to be female, to work part-time, to be employed by agencies, and to be less qualified than in other parts of the social care workforce (Hussein and Manthorpe, 2012).

A useful concept might be 'emotional labour', which has been used to describe work such as care work which includes an emotional element, which can be stressful and demanding. Female workers are particularly susceptible to performing emotional labour because of the jobs available to them and because they are socialised to be pleasant and amicable.

Although discussion about the status of caring – both paid and unpaid – is not new, looking at it through the lens of society's views about the role of women can help to develop the debate.

The views of people at the WDC echoed many studies and reports that have highlighted the need for caring to be valued. There were calls for: more training, more qualifications, a career pathway, financial rewards (not least the living wage for care workers), and for caring to be valued as a profession. The question was raised as to whether the status of caring work would rise if more men were involved in direct care provision. The perception voiced at the WDC was that men (especially male decision-makers) do not value caring because they have never done it. The status of the female dementia care workforce needs to be improved and service providers and policy-makers should examine the value of female attributes and emotional labour.

The assumptions outlined above have a real impact on the perceived value of caring for someone with dementia – in either a paid or non-paid role.

The fact that caring is undervalued can be linked to the language of caring and the caring role reflecting 'natural female' attributes. Caring is a woman's domain, not just because of female traits but because care work often is – or can be – part-time, and made to fit with family commitments. It was also felt that women care workers might 'go the extra mile' i.e. exceed the requirements of their paid role in terms of hours worked and the type of work undertaken.

It has also been pointed out during the project that men who want to work in care are often disadvantaged because of ideas around gender roles, and because people with dementia or their families want a care worker to be female.

Our review of the research identified no recent work on the experiences of women who work in dementia care in a paid role.

Summary

Caring skills are often undervalued by society and it is difficult not to conclude that this is because of assumptions that caring comes naturally to women. This project has found that, while many women do have caring instincts and defined themselves by their caring roles, assumptions, stereotypes and expectations about women caring can lead to women feeling unsupported in these roles.

5 Reflections and conclusions

This report is a snapshot of women's experiences of dementia, whether having a diagnosis or being a carer. It is not intended as a scientific analysis of women's roles, policy or practice, nor as the start of a campaign. The project aimed to throw a spotlight on women's experiences of dementia, to hear directly from women about what it feels like to have dementia, or be a carer, in their own voices.

The project set no agenda for how people could contribute. The fact that dementia disproportionately affects women was presented to potential contributors, who were asked to tell their stories and give their thoughts. In this way, the project has been able to capture both academic research and highly personal stories.

The facts about the numbers of women affected by dementia have been known for many years, but too often they have been ignored. Until very recently dementia has not been seen as an issue that particularly affects women.

This project was important because it sought to work with women affected by dementia in a different way, bringing their voices and reflections directly into the heart of the discourse.

Themes arising from the project

It's a complicated issue

The project debates were nuanced and varied and the narrative of this report might seem over simplified. It is clear that this is a complicated issue. The complexities of dementia, the need for person-centred care, and the need to recognise individual needs and experiences which are often *not* related to gender – all these resist simplification.

Other issues – such as age, ethnicity, disability, class, education – may interact to influence the experience of dementia. Looking at these other issues may help us to consider the relevance of gender to the experiences of dementia, by exploring different 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 because they have developed strategies to manage earlier experiences of inequality.

The majority of people with dementia who are living alone are women. This group is especially at risk of social isolation which may affect their sense of identity and personhood. However, it is also true that, if we focus on the importance of continuity of identity, we may lock women into traditional gender roles (Hulko, 2011).

Women with dementia are more likely to be living in deprived socio-economic circumstances, conditions which have themselves been linked to higher levels of dementia (Basta *et al.*, 2007). Additionally, women may experience multiple 'jeopardies' – for example 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 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 – can persist after a dementia diagnosis, particularly in relation to daily tasks of everyday life such as housework and cooking. The research reviewed makes it clear that we have to think of the experience of dementia as something that is influenced not only by gender but also by other social and economic factors. This would help us to explore the differences as well as the similarities of people living with dementia and better understand individual experiences within this group:

'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' (Hulko, 2011).

More and different research is needed

Research is vital. As Jo Moriarty points out, too often we have to rely on guesswork to understand how people's experiences of dementia are profoundly influenced by gender. This project's findings are similar to those of the ADI report on global research perspectives. There is a need for more and different research.

The perspectives of women living with dementia are absent from the vast majority of research, and the perspectives of women working in the field are also overlooked.

Ming Ho sums up the issue, calling for researchers to 'shine a light' on the deeper losses of self that are felt by so many women behind closed doors. Professor Peel and Dr Harding highlight the need for more research into the perspectives of women who are caring for a person with dementia and their need for sensitive support. They want more research to focus on whether there is still a gendered duty to care and whether and why women are still expected to undertake the lion's share of the caring work. Erol *et al* (2015) talk about the complexity of researching caregiving with respect to gender.

Research to hear the voices of women should not be limited to how they experience dementia and the services they receive. Alison Macadam wants more investigation into the experiences of how well women and men are being supported to be active in their local communities.

Another issue is that women are seen as more vulnerable than men. Dr Lorna Warren worries that some women are being denied opportunities to represent their lives because of the rules around ethics committees and university research.

Why do more women develop dementia than men?

Many of those involved in this project called for an answer as to why dementia disproportionately affects women.

The conditions that lead to dementia are, of course, largely associated with ageing. Thus, while women continue to live longer than men do, they will probably continue to be over-represented in the population of people with dementia. However, there is growing evidence that socio-economic circumstances, such as poorer 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).

Beth Britton calls for a better exploration of those psychological and lifestyle aspects unique to women. She mentions hormones, stresses relating to motherhood and other caring responsibilities. June Andrews from the Dementia Services Development Centre (DSDC), University of Stirling, also links dementia in women to stress and the stressors associated with women's lives such as depression and poverty.

More specific research is needed on issues that affect women

This project has highlighted that women with dementia are affected by many other issues that are associated with dementia. However, research in these areas is limited.

Some ideas for research that arose through the project include:

- Women with dementia who live alone: the literature review found that most of the research concentrates on risk rather than the experiences of women and their needs.
- Other health issues: older women have other health issues, for example osteoporosis, that will affect how they cope with developing dementia or being a carer.
- Finances: financial considerations, especially around caring and reduced incomes, were a major topic at the WDC. The ADI report on women and dementia (Erol *et al*, 2015) highlights the financial impact of caring for women. Women are more likely than men to reduce their hours to part-time or stop work completely to be able to provide care

- Safety: Sue Westwood and others have highlighted issues around safety and fear especially in residential care (Westwood, 2014). The research has ignored how women (including some lesbians and others who have constructed lives apart from men) may feel especially vulnerable in shared living spaces.

Analysis of data by gender

The literature survey found that many studies did not offer a gendered analysis of their data. The ADI report (Erol *et al.*, 2015) highlighted the lack of longitudinal studies.

Many participants at the Women and Dementia Conference questioned the lack of information and knowledge with which to start the debate.

Case study

IDEAL research project: thinking differently about women in research studies

'Improving the experience of dementia and enhancing active life: living well with dementia': The IDEAL study (www.idealproject.org.uk) is a longitudinal study of 1,500 people with dementia, and their carers when they have one, across the UK. Its aim is to find out what makes it easier or more difficult for people to live well with dementia, and what can be done to help more people to live well with dementia. This ESRC-funded project started in January 2014 and will run for five years.

This project will examine how social and psychological factors influence the possibility of living well. It will identify what changes could be made at individual and community levels to make living well more possible, and will result in recommendations for social and health care purchasers, providers and planners and advice and guidance for people with dementia and those who support them. The study will look at social factors (such as social contact, relationships, availability of help and support), economic factors (such as income), physical factors (such as health and diet), and psychological factors (such as self-esteem or optimism).

It is very important to the study team that the sample of people with dementia represents the population of dementia in the UK. Therefore they are aiming to recruit 998 women with dementia to represent 66.5 per cent of the population.

Recruitment for the study is via memory services and other NHS services at a number of sites across the UK. At the beginning of the study many more men than women were recruited. The number of people with dementia living alone was also below target. The research team is committed to redressing this balance, and in conjunction with the research sites are putting in place a number of measures to address the problem. In addition, they are committed to analysing the data by gender. It is hoped that this large longitudinal study will be able to provide some answers to some of the questions raised by this project.

Dissemination of research about women

Conference organisers are in a powerful position to open up the discussions around dementia to encourage research about the issues.

During the project, analysis was undertaken of the women involved in one of the major UK dementia conferences, UK Dementia Congress 2014 run by Hawker publications. It showed that:

- approximately 75 per cent of the work of running Congress was done by women;
- none of the plenary speakers named on the programme were women;
- women made up nearly 80 per cent of Congress delegates;
- male delegates were more likely to be speakers.

The project team took these statistics to Hawker Publications, who were very open to thinking differently about the inclusion of women at their conferences. At the 2015 UK Dementia Congress women and

dementia will take centre stage at the opening plenary session, and the plenary speakers and chairs are predominantly women.

Case study

Hawker Publications: thinking differently about conferences

During discussions with the project advisory group, the issue of women's visibility at conferences was raised. Andrea Capstick from Bradford University did a quick analysis of the UK Dementia Congress in 2014 and found:

- approximately 75% of the work of running Congress was done by women;
- none of the Plenary speakers named on the programme were women;
- women made up nearly 80% of Congress delegates;
- male delegates were more likely to be speakers.

The project team took these findings to Hawker Publications (organisers of the Congress) who were keen to redress the balance. The 2015 UK Dementia Congress will feature 'women and dementia' as part of the opening plenary session and the plenary speakers and chairs are predominantly women. Conference organisers are in a powerful position to open up the discussions around dementia to encourage research about the issues.

The project team, together with the School of Dementia Studies, University of Bradford, have produced the following thoughts for conference organisers to consider:

The number of female delegates should reflect the proportion of women in the field

Women should be encouraged to attend conferences about dementia. Women who attend conferences about dementia should be made to feel welcome, and that their own specific contribution is valued – not that they are only there to listen and learn from others. Practical issues to consider include:

- the facilities – especially number and availability of toilets at the venue, including disabled toilets;
- child care options and other caring responsibilities;
- creation of a programme that encourages women to attend; for example topics that address women's issues, but also sessions designed to facilitate a wide range of communication styles, as opposed to traditional lecture-style presentations.

Conference programmes should reflect the proportion of women in the field

- Women speakers and presenters should be represented throughout the programme.
- Participation of female carers and women with dementia in the programme should be encouraged.
- Session chairs should ensure that women's voices are heard from the floor in any debates.
- There should be representation of women throughout the conference, including high profile roles – not only administrative roles behind the scenes.
- When developing conference programmes organisers should acknowledge the value of contributions that increase our knowledge of gender issues in dementia

Hawker Publications is supporting this initiative.

Andrea Capstick from University of Bradford, Nada Savitch and Sue Benson from Hawker Publications will be writing an article for Journal of Dementia Care to coincide with the UK Dementia Congress 2015 around the importance of inclusive conferences – which include women, and involving people with dementia and carers.

Services for women

Services tend to persist in their assumption that people with dementia are a homogenous group. But people with dementia are no less varied than any other group of people. Rachel Thompson has called for us all to acknowledge the imbalance and to initiate positive discrimination so that women receive the

amount of care, support, services and recognition they deserve. In order to provide person-centred services, gender needs to be taken into account.

Specific services for women

The DEEP group of women agreed that specific groups for women with dementia would be helpful. They believe that women's groups offer a safe place where women can talk to each other in a relaxed atmosphere, where they do not feel they have to worry about what they say.⁶

The ADI report (Erol *et al.*, 2015) highlights the different coping strategies that are reported by men and women within their caregiving role. Their findings echo sentiments expressed at the WDC that men focus on problem-solving and accomplishing tasks, whereas women focus more on the quality of task performance and emotional support. These gendered differences need to be understood by health and social care professionals working with family carers.

Throughout the study there has been a perception that many of the services offered to people with dementia do not suit men. There are various initiatives around the country that seem to focus on specific services for men (for example Men and Sheds⁹ and Sporting Memories¹⁰), but few for women. Helen Stirk, a clinical psychologist at the Ealing Cognitive Impairment and Dementia Service, is optimistic about services for women, and explains why they are thinking of setting up men-only groups. Many of the dementia groups she runs are women-only because men decline to attend. As the involvement meetings and services themselves are dominated by women, she feels that the groups and services she runs are largely shaped by women. She also points out that most of her team and the people supporting the groups are women, and consequently women's voices are integral to the development of services (personal communication, 2015).

Case study

SCIE: Thinking differently about good practice

The Social Care Institute for Excellence (SCIE) aims to improve the lives of people who use care services by sharing knowledge about what works. SCIE is a leading improvement support agency and an independent charity working with adults', families' and children's care and support services across the UK.

SCIE develops and maintains online resources for people working in dementia care through the Dementia Gateway (www.scie.org.uk/dementia). The Dementia Gateway contains supportive information and resources, including videos, e-learning material and downloads, for care workers, people living with dementia, and their friends and family. Some resources on the Dementia Gateway are mapped to the Qualification and Credit Framework (QCF) units to support learning.

SCIE has a long tradition and a reputation for working alongside people who receive services. Practice Development Manager, Pamela Holmes, who manages the Dementia Gateway, is keen to highlight the disproportionate impact of dementia on women throughout SCIE resources. This work includes:

- co-presenting with Nada Savitch at the 2015 Alzheimer's Show in London to raise awareness and flag up how SCIE is developing its work;
- updating the Dementia Gateway with facts about dementia and women;
- blogging about the issue on the Women and Dementia website;
- putting out a call for good practice via the SCIE bulletin and other networks to ascertain the range and diversity of services run for women living with dementia or for women who care for people living with dementia;
- considering the need for new resources in the light of the findings above.

Policy

Policy around dementia and dementia care and support services is gender-blind. This is unhelpful when dementia is affecting so many more women than men.

The project has highlighted the need for a more nuanced approach to policy in dementia care and also to public health inequalities messages.

Following the WDC the project team attempted to influence the government's new vision for future dementia policy to recognise and reflect the issues around women affected by dementia.

The main points were that policy should:

- acknowledge the fact that dementia disproportionately affects women: that two-thirds of people with dementia are women, that the majority of family carers are women, that the vast majority of the care workforce is female, that women have fewer resources in old age and that they are more likely to live alone;
- make sure that equality discussions include those around the needs and experiences of women (not of course implying that if men are the minority they should receive inferior services);
- recognise that policy so far has been gender-blind and reflect that policy, practice and services need to take gender into account;
- encourage researchers and service evaluators to collect data on and investigate issues around gender and dementia – for example in attitudes towards care and who takes on caring roles;
- highlight that personalised health and social care must take into account the needs of women (both women with dementia and carers); we know that gender may affect carers' feelings about applying for and accepting help, therefore those who assess needs should bear such gendered issues in mind;
- acknowledge that the dementia workforce is predominantly female and propose adaptations in development of the workforce to reflect this (for example by valuing traditional 'feminine attributes').

At a global level, the Call for Action adopted by the participants of the First WHO Ministerial Conference on Global Action against Dementia included the commitment to support a gender-sensitive approach in the elaboration of plans, policies and interventions aimed at improving the lives of people living with dementia.¹¹

Dementia as a feminist issue

The numbers are clear: dementia affects women more than men. But there is more to it than that. Many of the issues highlighted by this project mirror issues that have been on the feminist agenda for years: representation of women, stereotypes, undervaluing women's contribution, gender roles, choice and control over women's lives and bodies, and how 'emotional labour' is undervalued in society.

However, the project has highlighted how difficult it is to present a complicated condition such as dementia as a feminist issue.

The project team found they were continually defending themselves for conducting a project whose sole focus was women. They found it hard to talk about looking at dementia through a gendered lens without people assuming that an active, hostile criticism of men was implicit in their stance.

It has been interesting to see how many women were not comfortable talking about women's issues. Throughout this work people found it difficult to relate to dementia as a feminist or even a women's issue.

The biggest hurdle met in creating the booklet was the problem of the f-word: feminism. It proved far harder than anticipated to explore a feminist perspective with prospective participants, overtly or covertly. Many people find the language around feminism intimidating and obstructive. Talking and thinking in terms of feminist discourse is so far removed from the experience of many that we lack a useful, accessible feminist or gender vocabulary.

During the production of the booklet the project team found the silences very telling. It was particularly hard to engage care home managers. One manager cancelled a series of creative workshops with residents in the later stages of dementia, because she didn't think the residents could contribute to our project. She also cancelled planned interviews with staff. Two care home managers agreed to be

interviewed, only to pull out at the very last minute. Not only were those managers' voices lost, it also meant losing the voices of their residents and staff.

A complicating factor in trying to bring the voices of women into dementia discourse is the continuing absence of voices of people with dementia in general. People with dementia are rarely consulted or listened to. Their voices are little heard or valued. Perhaps we need more of a culture change in this regard before we can focus our gaze with more effect.

Case study

Dementia Engagement and Empowerment Project (DEEP)

Thinking differently about the voices of women with dementia

Five women with dementia attended the WDC in November 2014. One of the breakout sessions was reserved just for these women to get together. It was important to find out if women with dementia themselves thought that this was an issue worth talking about.

These women all want to make it easier for the women who are getting diagnosed after them. They all found that the way they coped with their dementia and how it was received and perceived by others could be affected by their gender.

Most importantly there was a feeling that there is room for women with dementia to support other women about women's issues.

This led to a link with DEEP.⁶ DEEP works to link together groups of people with dementia from around the UK who want to influence policy and practice around dementia. DEEP is keen for as many voices of people with dementia to be heard as possible and works hard to think of different ways to include people. Therefore it was an easy partnership to work with DEEP to explore this issue further.

In June 2015, seven women with dementia from DEEP groups in Scotland and York got together to discuss the issues. The group described themselves as a sisterhood of women working together to empower women and support them. They hope that this approach might help women with dementia.

In addition, they support the idea of men sometimes needing separate support. Key messages were:

- women-only groups could be very useful for many women with dementia
- women with dementia themselves can play a big part in supporting other women with dementia
- women's voices should be heard and women should be encouraged to get involved.

The conclusions from the meeting are published on the DEEP website⁶ and further feedback will be sought from women and men across the network. The group of women in York will continue to be supported and with the backing of DEEP will encourage women from other DEEP groups to make contact.

There were also comments throughout the project, and especially at the WDC, that society has changed and that future generations of women will not have the same issues.

2015 has been a key year for the issue to be raised. But Pamela Holmes from SCIE asks: would the male-dominated fields of politics have been quite so interested if it had been highlighted earlier on that it is women who are mainly affected by dementia? Would the knowledge that two out of every three people with dementia are women have made male-dominated professions less determined to focus on dementia? These are interesting questions.

Many participants hoped or assumed things would get better as society becomes more equal. Ming Ho hopes the presence of women in public roles today will mean expectations for women as they age will change and be more equal. At the WDC many people expressed the hope that any issues around gender are based on generational assumptions; that people from older generations had more gendered roles. They hope that younger women carers are different from older ones and that young fathers (who may be more hands-on with their children) will more probably care for their older relatives automatically. However, others fear that this is wishful thinking. On 10 March 2012, Tracy McVeigh, writing in *The Guardian*, claimed that the gender imbalance in British households is alive and thriving.¹² She based this on a report from the Institute for Public and Policy Research which showed that eight out of 10 married women do more household chores and just one in 10 married men does the same amount of cleaning and washing as his wife.¹²

Through this work, the project team has also been in touch with the organisation Ageing without Children (AwC). AwC recognises dementia as one of the issues that frightens both women and men who are ageing without children, as they worry who will advocate for them if they get dementia.¹³ The project team hopes that this project will begin to put dementia onto the feminist agenda, but are concerned that the current wave of feminism appears to be dominated by the young.

Many researchers expressed the view that, while gender issues used to be at the forefront when talking about caring, this is no longer the case.

Interestingly, in the USA Maria Shriver (executive producer of the film *Still Alice*), has launched her Wipe Out Alzheimer's challenge, which encourages women to become innovators, agitators and instigators. It is a joint initiative with the US Alzheimer's Association and the non-profit organisation A Woman's Nation.¹⁴

The project team have found it hard to engage the interest of active feminists and feminist groups and organisations. However, an article was published in the online magazine *The F-Word* in April 2015, highlighting many of the issues from our project, including spelling out the statistics. In addition, June Andrews' piece in the *Feminism and Psychology* issue on feminism, suicide and assisted dying (prompted by the death of feminist Sandra Bem) (Andrews, 2015) drew heavily on her contribution to the project website. The project team also joined forces with Alzheimer's Research UK to focus on the issue at the Women of the World event on the South Bank in London.¹⁵

Summary – implications for policy, research and practice

In order to start thinking differently about women and dementia, individuals and organisations need to:

Acknowledge the facts about women and dementia

There is no doubt that dementia disproportionately affects women. However it is often difficult to talk about dementia as a women's issue. The issues can be complex and depend on many other factors such as education, ethnicity, sexuality, class, age and disability.

Investigate what the facts mean

There is a lack of research into how and why dementia disproportionately affects women or whether gender-specific services are needed or effective. In particular, the experiences and voices of women

affected by dementia need to be heard. Special consideration needs to be given to issues that are specific to women, for example living alone, safety and finances.

Celebrate the positive aspects of women's lives and personalities

There are many aspects of women's lives which are important to their identities and may enable them to cope well with dementia – either as a woman with dementia or a paid or unpaid carer. Society, service providers and policy-makers should celebrate attributes traditionally seen as 'female' such as kindness, empathy, building relationships and caring.

Challenge stereotypes and gender-based expectations

Stereotypes around women can lead to unrealistic expectations, for example that all women will be good at caring. Stereotypes can also lead to lack of recognition for caring skills and services that do not support women effectively.

Notes

- 1 Available at <http://www.feminist.com/askamy/feminism/fem153.html>
- 2 Available at http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=102
- 3 Available at <http://www.theguardian.com/society/2015/feb/14/dementia-hits-women-hardest-study>
- 4 Available at <http://www.alzheimersresearchuk.org/about-us/policies-reports/women-and-dementia/>
- 5 Produced by the project and available at <http://www.dementiawomen.org.uk/experiences.html>
- 6 Dementia Engagement and Empowerment Project (DEEP). See website <http://www.dementiavoices.org.uk>
- 7 Available at <http://www.telegraph.co.uk/women/womens-life/11043452/Caregivers-are-more-likely-to-be-women-says-American-study-as-daughters-take-responsibility-over-sons.html>
- 8 BUPA press release. Available at: <http://www.bupa.com/media-centre/press-releases/uk/women-say-feelings-of-duty-and-guilt-delay-care-decisions/>
- 9 For Age UK initiatives see <http://www.ageuk.org.uk/professional-resources-home/services-and-practice/health-and-wellbeing/men-in-sheds/>
- 10 For information about the Sporting Memories Network see <http://www.sportingmemoriesnetwork.com/>
- 11 See WHO news release, 17 March 2015, available at <http://www.who.int/mediacentre/news/releases/2015/action-on-dementia/en/>
- 12 Available at <http://www.theguardian.com/society/2012/mar/10/housework-gender-equality-women>
- 13 Find out more about Ageing without Children at <http://awoc.org/>
- 14 See <http://wipeoutalzheimers.org/>
- 15 Find out more about Women of the World at <http://wow.southbankcentre.co.uk/>

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Acknowledgements

Project Advisory Group

Andrea Capstick, Professor, School of Dementia Studies, University of Bradford
Linda Gomila, Membership Officer, The Cooperative Group
Philly Hare, Programme manager, Dementia without Walls, Joseph Rowntree Foundation
Agnes Houston, woman with dementia, campaigner and activist
Helen Roberts, Lecturer, Department of Health Sciences, University of York
Elisabeth Storrs, informal carer, former mental health nurse, PhD student, Department of Theology and Religious Studies, University of Chester
Pam Turpin, family carer, PhD student and former Research Programme Manager, ARUP
Dr Lorna Warren, Senior Lecturer, Department of Sociological Studies, University of Sheffield

Literature Review

Katherine Ludwin, Researcher, University of Bradford. Katherine has a background in gender and sexuality studies with a focus on heteronormativity and life stories.

Women's Experiences of Dementia booklet

Helen Cadbury, writer. Helen has experiences of finding the voices of seldom-heard women. She brought a fresh approach to the dementia fields that did not assume that women in this area have lost their voice. Her role was to create meaningful and interesting booklet that told the truth about women's issues in dementia and also celebrated their roles.

Eloise Ross, design and photography. Eloise is a professional photographer who captured the every-day lives of women. Her documentary photography captured the power of a moment. Her photography gave meaning, colour and drama to the apparently mundane and is a powerful visual tool that allows a story to be told in an instant.

Alison, daughter, abroad
The Club, Woodley Age Concern: Maureen, Pat, Sandra, Margie, Pauline, Chris, Jenny, Sue
Audrey Greaves, artist
Ming Ho, writer, blogger, carer, dementia campaigner
LS, care assistant and medical student
Nicola, daughter, York
NW, home care agency manager, Yorkshire
Meri Yaadain, Bradford: Vidya, Athma, Ghazala, Riffat, Qamar, Farida, Abida

DEEP Dementia Women Network meeting participants

Margaret H, woman with dementia
Donna Houston, personal assistant, dementia campaigner and activist
Eileen Jaques, woman with dementia
Anne McDonald, woman with dementia, campaigner and activist
Wendy Mitchell, woman with dementia, blogger, campaigner and activist
Elaine Stephenson, woman with dementia
Clare Tasker, photographer
Liz White, woman with dementia

Dementia Women blog contributors

All contributors to the project website blog did so in a personal capacity. We are grateful to them for sharing their thoughts, opinions and experiences.

June Andrews, Professor, Dementia Services Development Centre, University of Stirling
 Dr Hazel Boyd, User Interface Engineer, Designability
 Beth Britton, writer, blogger, carer, freelance dementia campaigner
 Dawn Brooker, Professor of Dementia Studies, Director of the Association for Dementia Studies, University of Worcester
 Andrea Capstick, School of Dementia Studies, University of Bradford
 Janet Crampton, consultant, AESOP Consortium
 Janet Dean, consultant, Dean Knight Partnership
 Sophie Dishman, family carer
 Gillian Drummond, Dementia Quality Lead, Greater Manchester West Mental Health NHS Foundation Trust
 Dr Rosie Erol, Research Associate, Institute of Health and Society, University of Worcester
 Nina Evans, Occupational Therapist, Designability
 'Frances,' friend
 Valerie Freestone, Clinical Specialist Dementia Nurse and HSJ Inspirational Woman 2014
 Jane Garner, Consultant Psychiatrist and non-executive director of Innovations in Dementia CIC
 Jane Gilliard, daughter and dementia expert
 Beatrice Godwin, dementia researcher and PhD student, University of Bath
 Dr Rosie Harding, Birmingham Law School, University of Birmingham
 Pamela Holmes, Practice Development Manager, Social Care Institute for Excellence
 Linda Lamont, family carer
 Katherine Ludwin, Researcher, University of Bradford
 Dr Alice Hall, Department of English and Related Literature, University of York
 Philly Hare, Programme manager, Ageing Society team, Joseph Rowntree Foundation
 Dr Karan Jutla, Association of Dementia Studies, University of Worcester
 Alise Kirtley, independent dementia care and culture change consultant
 Andrea Lemard, Nubian Life Resource Centre, Hammersmith & Fulham, London
 Isabella Luthra, medical student, King's College, London and researcher at the International Longevity Centre
 Alison Macadam, Project Manager, Circles of Support Project, National Development Team for Inclusion
 Jen Marks, One to One Support Worker, Young Dementia UK
 Jo Moriarty, Research Fellow, Social Care Workforce Research Unit, King's College London
 Elizabeth Peel, Professor of Psychology and Society Change, Institute of Health and Society, University of Worcester
 Sarah Reed, daughter, founder of Many Happy Returns and CQC Expert by Experience
 Catherine Ross, former editor of the Journal of Dementia Care
 Rachel Thompson, Admiral Nurse Professional Lead
 Barbara Twiney, buddy and supporter of DEEP group EDUCATE, Stockport
 Dr Lorna Warren, Senior Lecturer, Department of Sociological Studies, University of Sheffield
 Sue Westwood, Lecturer, School of Health Sciences, Department of Sociology, University of Surrey, Guildford
 Sue Wilkinson, Professor of Feminist and Health Studies, Loughborough University

About the authors

Emily Abbott works as an associate of Innovations in Dementia and is based in York, where she also runs the social enterprise Here Now Dementia. Here Now develops projects that support people with dementia to flourish, and does in consultancy work. Current projects include The Secret Garden Project – a supported volunteering project for people with dementia, and Vocal Flourish – an inclusive, accessible choir for people who have dementia (and carers), which works to challenge low expectations with high quality sound. Emily also co-facilitates (with Damian Murphy) the DEEP group York Minds and Voices – York’s forum for people who have a dementia. Her involvement in the Women’s Experiences of Dementia project has inspired Emily to apply to do an MA in Women’s Studies at York University. Fingers crossed...

Gillian Parker is Professor of Social Policy Research at the University of York. She was Director of the Social Policy Research Unit at York until summer 2014. She is part of the NIHR-funded Evidence Synthesis Centre at York and a member of the Health and Social Care in the Community editorial board, NICE Quality Standards Advisory Committee 3, and the Multiple Sclerosis Society Research Commissioning Group. Dementia care is one of Gillian’s main research interests. She has recently worked on a NIHR-funded project about Life Story Work with colleagues in York, Dementia UK, Innovations in Dementia and the Life Stories Network. She has also worked on a joint project with the Universities of Sheffield, Leeds and York using knowledge about how the brain works to help develop good dementia care, and is starting work on a project looking at how Admiral nurses help people with dementia and those who support them at home. Gillian is also interested in music in dementia care.

Nada Savitch is a director of Innovations in Dementia, a community interest company that works collaboratively with people with dementia. Innovations in Dementia works nationally with people with dementia, partner organisations and professionals with the aim of developing and testing projects that will enhance the lives of people with dementia. Outcomes from such projects will influence approaches to dementia care and support to help them become more creative, positive and enabling. Innovations in Dementia facilitates the Dementia Engagement and Empowerment Project (DEEP). This project has enabled Nada to keep her promise to Manuela.

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Joseph Rowntree Foundation
The Homestead
40 Water End
York YO30 6WP
www.jrf.org.uk

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