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Women and dementia:All but forgotten? A literature review. Research Report. Social Policy Research Unit, University of York

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DEMENTIA: THROUGH THE EYES OF WOMEN

Women are disproportionately affected by dementia. But whereas the statistics relating to women and dementia are clear, the voices of women affected by dementia – whether they are living with dementia or caring for or working with people with dementia – are missing.

This project collected the experiences and reflections of women affected by dementia: women with a diagnosis of dementia, women caring for family or friends with dementia and women employed in the dementia field.

Key points:

- There is often resistance to talking about dementia as a women's issue.
- More and different research is needed. In particular, women's experiences are missing from research.
- Women's experiences of dementia reflect women's experiences in society – they are affected by stereotypes of women, their lack of a voice in decision-making, and the low value placed on 'feminine' attributes such as kindness and empathy.
- Service provision needs to reflect the needs, skills and attributes of women with dementia, female carers and the female care workforce. Being person-centred means taking gender into account: gender-blind policy and services are unhelpful for both women and men.
- The way women experience dementia is affected by their gender, but also by many other factors including education, ethnicity, sexuality, class, age, and disability.
- Special consideration needs to be given to issues that are specific to women – for example the large number of women with dementia who live alone.
- Many women's identities are tied into their caring roles. Although this can be a positive thing, it can also lead to unhelpful expectations around women taking on caring responsibilities. Women can also experience caring as a duty.
- Organisations and individuals can think differently about dementia if they consider women as a marginalised majority.

The research

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NOVEMBER 2015

BACKGROUND

Although women are disproportionately affected by dementia, their voice is often unheard. This project aimed to work with women to collect their views and experiences and to start a debate on women and dementia that is long overdue.

What's the issue?

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

Pat, The Club, Woodley

The 2015 Alzheimer's Research UK report *Women and Dementia: A Marginalised Majority* (Alzheimer's Research UK, 2015) brings together a wealth of statistics from existing research to illustrate that dementia disproportionately affects women. The Alzheimer's Disease International global research review (Erol *et al.*, 2015) confirms that this is true worldwide.

However, the voices and the experiences of women affected by dementia are missing.

In spite of the advances of 40 years of feminism, women with a diagnosis of dementia are still stereotyped as 'old dears' and 'batty old women'. What is more, society expects women to take on caring roles within families, and also to have caring professions, while at the same time undervaluing the attributes that inspire women to take up these roles.

Society's attitude to women is not going to change overnight. Many contributors to the project hoped or presumed that the issues highlighted through the project will change as society becomes more equal. However, the project has shown how well established some assumptions about women are.

This project has concentrated on the stories of individual women in different circumstances and affected by dementia in different ways, in order to put the spotlight on women and dementia and start a debate.

The views of women affected by dementia

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

NW, Yorkshire

The project used a variety of methods to collect the views and experiences of women around dementia. However many contributors found it difficult to separate general concerns about dementia from specific issues around experiencing dementia as a woman.

Feedback through the project is that it is still a novel thing for people to hear or talk about women's issues around dementia. For most of the women who were interviewed for the project, it was the first time they had been asked for their thoughts.

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 of us that we lack a useful, accessible feminist or gender vocabulary. Contributors to the project did not want to be seen as criticising or ignoring men and their contribution to dementia care.

In many ways, the issues around women finding their voice around dementia are just a reflection of women's place in wider society. There was a strong perception throughout the project that women's voices are not heard as loudly as those of men – whether they are women with dementia, female carers or women in the care workforce. Women's experiences of living with dementia or caring for someone with dementia are also linked to many other factors in their lives, such as education, ethnicity, education, class or wealth.

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.

Person-centred services and policies need to think about gender

“Women wear their hearts on their sleeves more.”

Pauline, Woodley

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.

“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

In the interests of 'equality' many services and policies will pride themselves on being gender-blind. However, this project has shown that viewing people with dementia or their carers as a homogenous group may not be the most person-centred approach.

Some issues around women are not going to go away. More women than men have dementia. The number of women with dementia living alone is probably going to increase. Women have health issues in later life that will affect their ability to cope with living with dementia or caring for someone with dementia.

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 define themselves by their caring roles, assumptions, stereotypes and expectations about women caring can lead to women feeling unsupported in these roles.

More and different research is needed

It is clear that there are gaps in the research which means that the views of women are not heard. Women's issues are not being researched – including the issue of why more women develop dementia than men. In addition, there is concern that women are not represented in research.

The project has also highlighted that little is known about many aspects of women and dementia:

- very few research projects or service evaluations are analysed in terms of gender;
- the experiences of women have not been sought widely;
- decision-makers do not know about good practice around services for women with dementia or women carers. Little is known about what women want or need in terms of services or dementia friendly communities.

Implications for research, policy and practice

“We want the experiences of women with dementia to be followed over time to see if what we are saying has an impact on women's lives in the future. We hope that this project has a legacy for future generations of women with dementia.”

Women and dementia – our voices (Dementia Engagement and Empowerment Project, 2015)

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

- Acknowledge the facts about women and dementia

While dementia clearly disproportionately affects women, 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, and to lack of recognition for caring skills and services that do not support women effectively.

References

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About the project

This report is a snapshot of women's experiences of dementia in the UK, whether having a diagnosis or being a carer, over the last 18 months. This project was conducted by Nada Savitch and Emily Abbott (Innovations in Dementia CIC), and Professor Gillian Parker (Social Policy Research Unit, University of York). It ran from January 2014 to September 2015. Writer Helen Cadbury and photographer Eloise Ross worked with women with dementia, women carers and female professionals to capture their stories in a booklet (available at <http://www.dementiawomen.org.uk/experiences.html>). The project also included a short literature review, a call for women to submit their thoughts and opinions via the project website, a conference in York, and several pieces of work with smaller groups. The debate continues at www.dementiawomen.org.uk

FOR FURTHER INFORMATION

The full report, *Dementia: through the eyes of women* by Nada Savitch, Emily Abbott and Gillian Parker is available as a free download at www.jrf.org.uk

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ISSN 0958-3084

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