Venus, Mars and Dementia - Gender perspectives on dementia

Values, Equalities, Rights and Dementia network (VERDe)

London - 2 June 2016

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Report of the second VERDe meeting

Summary

- The Values, Equalities, Rights and Dementia network (VERDe) connects people with dementia, carers, practitioners, policy makers, services, organisations and communities across the UK.

- VERDe aims to increase awareness and understanding about how values, rights and equalities affect people with dementia and can help improve dementia policy and practice.

- VERDe organises events and the second one of these events focused on how women and men may be affected differently by dementia.

- More women than men experience dementia and there are more women caring for people with dementia. The day discussed what this meant for men and women.

- Dementia policy and practice needs to be more sensitive to the differences in experience of dementia between women and men. If these differences are ignored it can create difficulties for both women and men.

- There are four more VERDe events to come. Please contact Jo Ackerman at jackerman@mentalhealth.org.uk if you want more information. We also want to hear about examples of where a focus on values, rights and equalities is having a positive impact.

Introduction

Two thirds of people with dementia are women. Caring is often seen as the role of women. Differences like these can also have implications for how men cope with dementia. But dementia is not often considered in terms of gender. This may mean that services for people with dementia do not take into account these important differences. What are the challenges for women and men affected by dementia, for practitioners, services and policy makers? How can a focus on equalities help with this?

The second meeting of the Values, Equalities, Rights and Dementia network (VERDe) in London on the 2 June 2016 focused on these issues.

Report on the day

43 people attended the day. Participants included people with dementia, carers, practitioners, academics and policy makers. The majority were from England. The day was co-chaired by **Toby Williamson**, Head of Development & Later Life at the Mental Health Foundation and **Joy Watson**, a Dementia Champion living with dementia.

Most of the presentations from the day can be found here.

The first session in the morning involved presentations and discussion by four women who had been active in the Women and Dementia project, supported by the Joseph Rowntree Foundation. **Ming Ho** spoke about her experience as a daughter and a carer for her mother who has Alzheimer's disease. **Nada Savitch**, a Director from Innovations in Dementia then presented key points from the project report. Nada's presentation also involved **Philly Hare**, who had commissioned the report, discussing it with **Joy Watson**. Joy described how her life had changed as a result of developing dementia and the impact this had upon her as a woman. Since being diagnosed with dementia her social life was spent less with female friends and more time with people she knew through having dementia. Yet she still retained a strong sense of herself as a woman, enjoying leisure activities associated with women like "having a laugh and a good old gossip", and still wanted opportunities to do these kinds of activities. This was followed by questions and comments from participants including:

- Dementia policy needs to take into account inequalities and the "care gap" that is increasing as public services shrink.
- There's a "sandwich generation" of women looking after children, parents, and often grandparents.
- Can personal budgets/self-directed support make a difference (for those that receive them) in terms of gender sensitive support? What can we learn from self-funders about how they deal with gender issues?
- Importance of people with dementia and cares speaking about their experiences, lobbying and influencing.

The second session of the morning started off with **Dr Simon Evans** from the Association of Dementia Studies at the University of Worcester presenting various research findings on gender and dementia.

This was followed by **roundtable discussions** identifying key issues involving gender and dementia. This included:

- Using the Scottish Government Equality Impact Assessment to improve dementia policies/services.
- Older lesbian women not keen to talk about their sexuality/sexual orientation because of historical context about Lesbian, Gay, Bisexual, and Transgender (LGBT) older people.
- Getting the balance right between inclusion and meeting gender specific needs.
- Focus on disability and dementia – loss or change in relationships (including carers/family members).
- Tension of being a woman and wanting to be a care giver but also aware that this is potentially reinforcing a gender difference and inequality. It’s ok to ask for help - people who provide care should not experience exclusions because of who they are or their role. How do professionals and practitioners respond to these roles in a way that doesn’t reinforce inequality?
- Some family members may not define themselves as a carer – but this then has implications for their rights and entitlements to assessment, support etc. Defining oneself as a carer may not feel right to some people.
- How to build resilience within families providing care, given the widening care gap? Communities supporting carers and the development of a carers’ social movement that can find solutions by working together.
- But care roles are changing where families are dispersed, complex, or different cultural norms exist, and it is less obvious who can provide care.
- Difficulty of including people with dementia who are living alone (especially older women).
- Are e.g. women MPs more “clued in” about dementia than men? Mixed views about journalists of different gender being more or less dementia friendly.
- Easy to offend and fall into stereotypes when talking about dementia and gender.
- Don’t want to change differences between women and men – but do need to think about gender as a characteristic and be person-centred.
- Gendered roles can be a problems e.g. form-filling traditionally seen as a male role – very relevant for people with dementia receiving welfare benefits and feelings of guilt (or inadequacy?) about not being able to complete forms.
- Changes in society and gender roles can be challenges e.g. the baby boomers becoming part of “them” i.e. older people who are at risk of developing dementia. But retirement expectations are also changing and people with degenerative diseases can still contribute – though knowing what one will need in 20 years’ time is difficult (role of advance decisions and living wills – to identify wishes and potential care needs).
- More communal living – reduces numbers living alone and dependency on immediate family members + adds reciprocity and value.
- Availability and quality of social care so variable that ensuring it’s also gender sensitive is very challenging.

After lunch participants heard from **Anna Buchanan**, Director of Dementia Programmes for the Life Changes Trust in Scotland (presentation unavailable). Anna talked about the different dementia projects that the Trust was supporting and gave examples of how gender roles were both expressed and affected by living with dementia or caring for someone with dementia. This included creative uses of self-directed support and positive uses of reinforcing personhood among people with dementia through reminiscence and recreating more traditional gender roles (e.g. tea making rituals). She talked about how people's occupations or roles are so important to identity and personhood, and therefore affect people's experience of dementia. Work was being done with Age Scotland, the Scottish Trade Unions Congress, trade union representatives and human resources departments to identify signs of dementia among employed people.

Anna's presentation was followed by two men, speaking from personal perspectives about dementia. **Keith Oliver** has been diagnosed with Alzheimer's disease and is a dementia envoy for Kent and Medway NHS and Social Care Partnership Trust. Keith spoke about his perspective as a man with dementia. **Tony Watson** spoke next about his experience as Joy Watson's husband but also her carer (presentation unavailable). Although there are more women with dementia than there are men, male carers tend to be less visible – this may make it difficult for male carers to fully participate in carers groups which are female dominated. So some men (like some women) may prefer gender specific carers groups.

A final roundtable discussion enabled participants to consider what they had heard and share examples of positive practices and experiences. These included:

- Refreshing to have men's perspectives as well as women's.
- Importance of a cognitive-emotional approach and emotionally intelligent/emotionally informed approaches towards dementia.
- Importance when doing social research to be aware of the voices one is not hearing – if we only hear from one gender then things may be missed. And some groups may be more or less willing to participate in social research. "Gender blind" social research may not always be the best approach e.g. parents/carers work tending to focus on women (although they are the majority taking on these responsibilities).
- Memory clinics doing follow up sessions that are gender sensitive.

A final summary and question from **Toby Williamson**:

- Although gender roles are changing in society we are still in a traditionally patriarchal society (what would the experience of dementia look like in a matriarchal society?). That causes/contributes to inequalities which can be exacerbated when dementia is also a factor.
- But if person-centred care is to be meaningful the lived experiences of both people with dementia and carers is important - and this applies to both men and women.
- Dementia policies and services should not reinforce stereotypes around gender roles.
- Dementia and gender is definitely where the personal meets the political, but also where the experiential meets the factual!
- Are gender differences in dementia care the challenge that needs addressing (given that its gender skewed towards women as people with dementia, as family carers, and as paid staff)? Or is the problem that gender sensitive support and services are not provided to care givers and people with dementia?

Feedback from the day was very positive and from 22 feedback forms 16 people rated the day as "extremely useful". Hearing about and discussing the issues involved in dementia and gender, hearing from people with lived experience, together with perspectives from practice, policy and research were all positively commented on. Getting a perspective from Scotland was also welcomed. Some people wanted more time for discussion (it's nearly always difficult getting the balance right between presentations and discussion time) but overall the organisation of the day, together with the venue (Friends Meeting House, Euston Road) was rated highly.

Some quotes from the feedback forms

"*Finding out about gender perspectives of Martians and Venuses, differences, commonalities, and how to reconcile. Networking. Today's meeting shows dementia is not a dull subject, but interesting to talk round and share about*"

"*All the speakers were very good and very interesting, really good to hear voices and perspectives of people with dementia and carers. Very informative and thought provoking. Good roundtable discussions*"

"*I thought the speakers were inspirational, and will impact on the dementia related projects that I am working on*"

"The enthusiasm of needing to move the agenda forward, and raising this agenda. Now we want to move forward and put it into practice"

One theme that came out from some comments was the question of 'what next?' What learning and practical steps could be taken from the day to influence policy and practice? One of VERDe's objectives is to embed different thinking and approaches in policy and practice affecting people with dementia so it has been agreed that the fourth meeting of VERDe (date and venue to be confirmed but likely to be towards the end of 2016) will focus on how VERDe can increase its impact. **If you have examples of how a focus on equalities, rights, or values are having a positive impact on people with dementia and carers that you would be willing to present at a VERDe meeting, please let us know** by contacting Jo Ackerman at jackerman@mentalhealth.org.uk.