

Women: The hidden voices in dementia

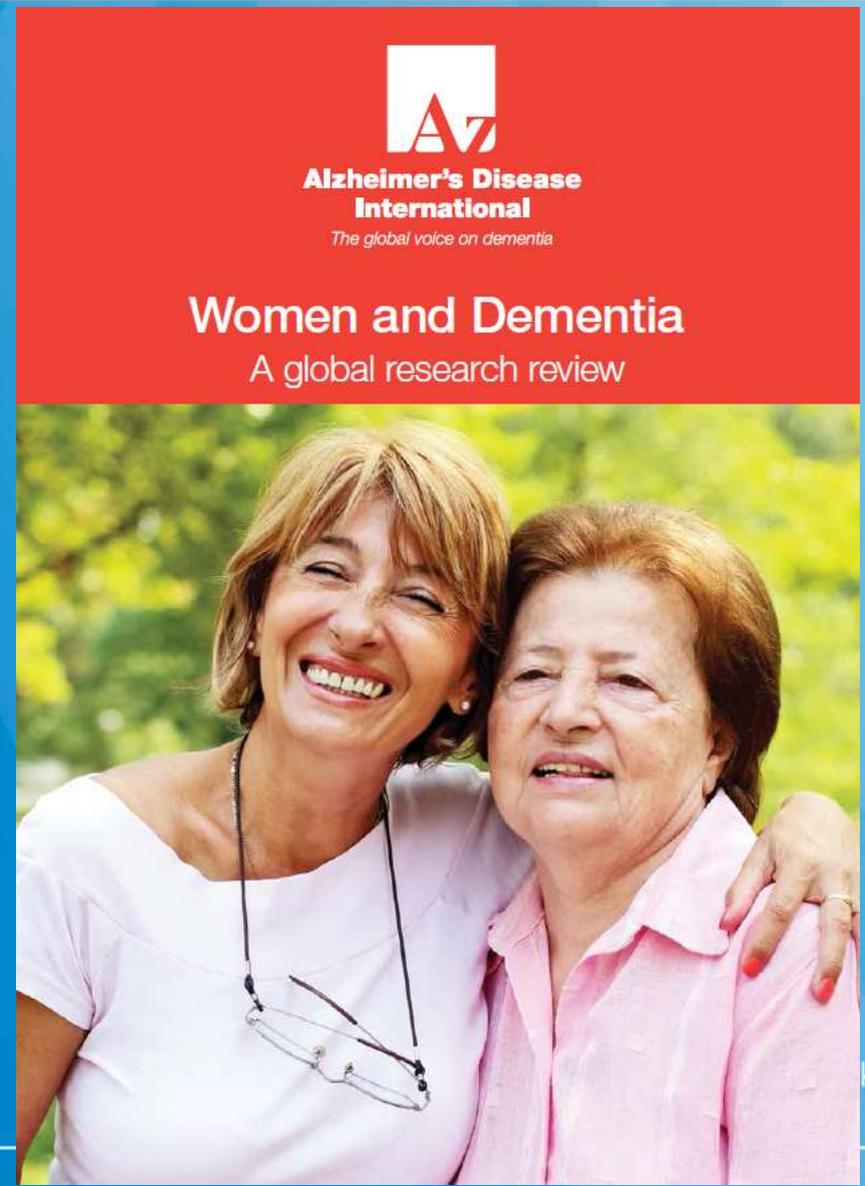
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Acknowledgements

Erol, R., Brooker, D. & Peel, E.
(2015) *Women and dementia:
A review of the research
literature*. London. Alzheimer's
Disease International

[http://www.alz.co.uk/women-
and-dementia](http://www.alz.co.uk/women-and-dementia)

Alzheimer's Disease
International funding and
guidance, case reports &
photos



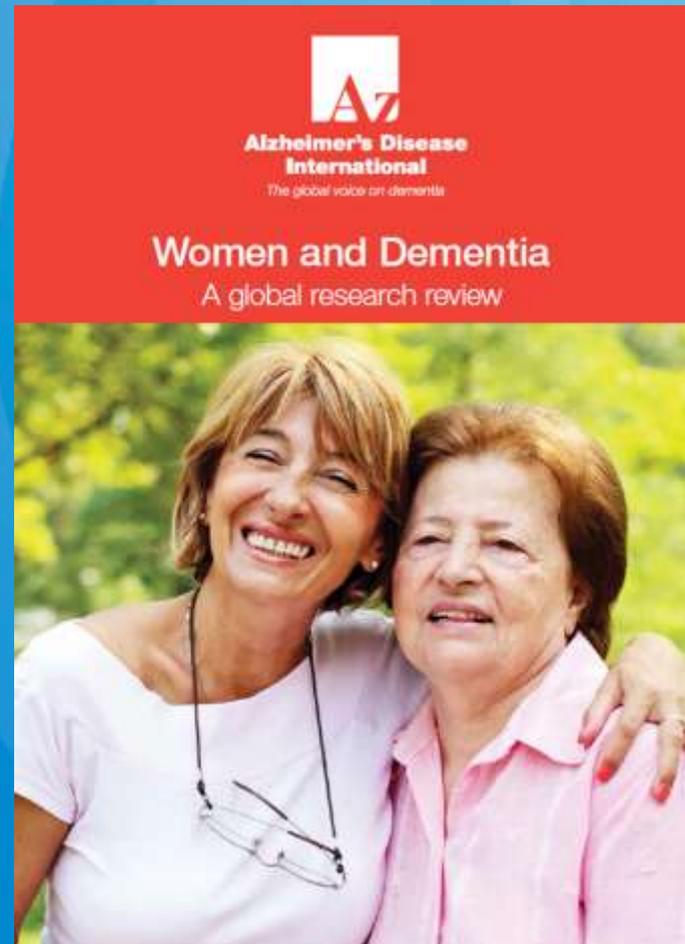
WHO Ministerial Conference on Defeating Dementia: Call to action March 17th 2015

- Raising the priority at a global level
- Strengthen capacity, leadership, governance and partnerships
- Promote understanding, public awareness and engagement
- Advance prevention, risk reduction, diagnosis and treatment.
- Facilitate technological and social innovations
- Collective efforts in dementia research
- Coordinate delivery of health and social care, including capacity building of the workforce, supporting mutual care taking across generations on an individual, family and society level, and strengthening support and services for their caregivers and families
- **A gender-sensitive approach**
- Strengthen international efforts to support plans and policies at all levels in particular in low- and middle-income countries;

Aims of the research review

Explore research relating specifically to women and dementia

1. Women living with dementia;
2. Women in family care situations
3. Woman in the dementia care workforce



What we reviewed

- **Systematic search on a number of databases:** Academic Search Complete, CINAHL, PsychINFO, Medline, Web of Science, PubMed and Google Scholar and general internet search.
- **Publications 2005-2014, English language, worldwide**
- **Utilised EPPI-Centre approach to assessing and synthesising evidence**
- **38 searches; 1,689 abstracts; 217 papers/reports**
- **133 included in the review**

Top line

- More women live with dementia than men.
- Women live longer with dementia and they have more severe symptoms.
- Around two thirds of primary caregivers are women: Much higher in low & middle income countries.
- Impact on health, wellbeing and finances is therefore likely to be greater for women.
- The formal care workforce is predominantly female, particularly in dementia care

Women living with dementia

- Very few papers. None from Low and middle income countries.
- Protective factors such as physical, mental and social activity, and education levels differ between men & women.
- The shift from “care-giver” to “cared for” is often difficult.
- Concept of ‘grateful guilt’ can lead to conflict
- Family dynamics, interactions and family roles
- Providing guilt-free care?

Women in the care-giving role

- Two thirds of people with dementia live in their own homes, supported by (female) family members
- Between 60-70% of family caregivers are women
- Social and cultural expectations that women will provide care
- Complex mix of reasons for providing care: love, gratitude, expectation, obligation, religious factors
- Difficult transition to 'carer' role, additional tasks and responsibilities, reassessing relationships

The impact of care-giving

- Physical and mental impact of caregiving experienced differently by men and women
- Female carers report higher levels of burden, stress and depressive symptoms than men
- Poorer physical health than non-caregivers
- Financial impact is greater for women – more likely to stop working or work part time

Managing and accessing support

- Care pathways and support structures differ widely between and within countries
- Men and women adopt different coping strategies
- Women caring for their husbands received less family support than men caring for their wives
- Male caregivers are more likely to accept formal help and access support services than women

Women in the care workforce

- Women make up 75% of the healthcare work force; this is higher for dementia care
- Care home workers often have low status and pay, and insecure contracts
- The dementia workforce has a higher proportion of migrant workers compared to other health sectors
- Improved skills, education and working conditions would reduce the stress of caring for people with complex needs

Recommendations

- Health and social care policies need to be developed based on evidence of need within every country
- Adequate, accessible support is needed to provide guilt-free support to women
- Access to prevention, diagnosis, and formal and informal health and social care needs to be targeted in a way that respects gender difference.
- Improving the skills in dementia care for all health & social care professionals will help women at home and in the work-force
- Need further research: impact on women in LMICs, longitudinal studies, the experience of women with dementia and gender data collection analysis

Kate Swaffer, Australia (Szoeki, 2015). *I am a woman but with a diagnosis of younger onset dementia, and although not in the senior bracket I do know the effect on women. Whilst younger women have a few unique issues such as having to care for young children, elderly parents and being employed, we still have many of the same roles as any aged woman, and experience the same grief and losses of dementia. Many more women are living alone, and many of us would also normally be providing care for others. Dementia means this is no longer possible, and the psychological impact of our nurturing and other roles being taken away by the progression of the disease has a negative and disabling effect.*

Victoria Repiso, Uruguay

Although dementia occurs in both men and women, it has a higher incidence in females and is a very important health issue in Uruguay. Women are often so busy with the many different tasks they are expected to perform, such as employment, motherhood, homemaking and of course as the primary family caregiver. As a result, they often neglect their own health and go to see the doctor very late on for any issues. Much like the rest of the world, in Uruguay the primary care for children, grandchildren and the elderly is undertaken mostly by women, which, when coupled with the other tasks they are expected to perform, can make for a very stressful lifestyle. Many women with dementia live alone in Uruguay. They often forget to take medications, or do not eat well and can become lonely.

At the moment, Uruguay is also not doing enough to encourage women to lead healthier lifestyles. With such busy lives, many women in Uruguay cannot find the time to undertake physical exercise, which puts them at a higher risk of developing dementia themselves. There is also a high prevalence of smoking among young women in our country, another very strong risk factor for dementia.

Thank you for listening!

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