



**Alzheimer's Disease
International**

The global voice on dementia

Women and Dementia

A global research review

SUMMARY SHEET

Key findings

The purpose of this report is to understand the main issues affecting women in relation to dementia from an international perspective. The report examines the effect of gender on three specific groups: women living with dementia; women caring for people with dementia in a professional caring role; women undertaking an informal caregiving role for someone with dementia.

The report also focuses on cross-cutting issues, including factors affecting women in low and middle income countries (LMICs); family structures and kinship; and the effects of migration.

This report reviews the published English language research literature on the issues affecting women in relation to dementia from an international perspective. Women make up a larger proportion of the older population. In 2014, women accounted for 62 per cent of people aged over 80. Population ageing is particularly rapid in Africa, Latin America, the Caribbean, and Asia. The prevalence of dementia worldwide is increasing. By 2050 over 71% of people with dementia will live in LMICs. The impact on women will be greater than for men.

- More women live with dementia than men. The prevalence is higher for women than for men; women are more at risk of developing dementia and the symptoms they live with are more severe.
- Women provide a substantial proportion of informal care to people with dementia, with around two thirds of primary caregivers overall being women. The proportion in LMIC countries is much higher. The effects of being a caregiver, on health and wellbeing as well as the financial impact is therefore likely to be greater for women.
- The formal care workforce is predominantly female, particularly in dementia care, providing the majority of health and social care in the community as well as in hospitals and care homes.

The vast majority of reported research about the impact of dementia on women has been conducted

in high income countries. There is a need for a much better understanding of the issues facing women in LMICs. There is very little research involving women affected with dementia as participants which focus on the gender issues of living with dementia.

For women who develop dementia, it can be difficult for themselves and others to accept the change in their role and identity. The shift from being the main caregiver within the family to the one now needing to be cared for is a profound one that is often resisted.

Around two thirds of people with dementia in higher income countries live in their own homes. Dementia care is primarily undertaken in the community. In LMICs this is often a much higher figure, although difficult to quantify. Care is typically provided by family members (often daughters or daughters-in-law) at home.

Positive factors associated with becoming a caregiver included having a sense of pride and satisfaction; motivations for taking on the carer role often involved 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.

Family caregivers of people with dementia are more likely to develop mental health problems such as major depression and anxiety disorders.

Female caregivers report overall higher levels of burden, stress and depressive symptoms than male caregivers, with similar outcomes being reported across different countries and settings.

Caregivers of people living with dementia often have to make changes to their employment situation. Women



The full report can be downloaded from the ADI website

alz.co.uk/women-and-dementia

were more likely than men to reduce their hours to part time, or stop work completely to be able to provide care.

Care pathways and structures of support offered to caregivers of a person with dementia vary widely across countries, and also within countries depending on setting and location. Whilst the majority of high income countries have community services available to help people with dementia, very few services were available in LMICs, particularly in rural areas.

Traditional extended family structures, with cultural expectations that family members would be cared for within the family setting, were described in many countries. However, as family structures change due to divorce, remarriage, falling birth rates, greater mobility, and an increase in female employment, traditional structures can no longer be relied upon to provide care to the same extent.

Women make up the largest proportion of the professional care workforce in dementia care, and providing formal health and social care and support for the person with dementia and their caregiver. Many females working in care are often supporting children and older parents. This then interacts with their ability to provide family care, impacting on the quality of life of the whole family including those living with dementia. The gender pay gap for people working within the health and social care environment means that the median hourly earnings for women is 10% lower than that of men in a similar role.

Recommendations

Across all regions of the world, dementia disproportionately affects women. More women than men develop dementia, and a large proportion of carers are women, in both informal and formal capacities.

While the higher prevalence of dementia amongst women is noted in the research, there is little evidence of policy being put into place and actioned in response to this.

In the few papers focused on LMICs, there was often no governmental organisation or programmes to address the problems associated with dementia, either for the person with dementia or to support the caregiver.

Expectations are made in many countries that families will look after older relatives, including those with dementia. This expectation often extends to it being the women in the family who take on this direct caregiving role. In LMICs in particular it was seen to

be important to ensure that community services were made more easily accessible to women with little or no education.

Dementia is a public health issue that will become increasingly visible in LMICs as the population ages. All countries need to understand the current and predicted prevalence and acknowledge that dementia disproportionately affects women; the impact on women needs to be ascertained in individual countries, along with a review of the support available currently and what is needed to meet future needs.

The needs of people with dementia and their family caregivers must be addressed in rural areas in LMICs, where fewer health and social care services were available, and accessing health services was more difficult, due to lack of infrastructure, local availability and difficulties associated with transport.

Women provide a significant amount of unpaid care to those with dementia across all settings. Adequate support needs to be in place to enable women to continue within this caregiving role, taking into account the health and financial difficulties associated with the caregiving role.

Women need to be made aware of assistance that is available to them through greater awareness raising and better signposting by health and social care organisations of the formal and informal services available and how to access these.

Dementia training should be in place for all community based health professionals, to enhance their confidence in understanding behaviours of those with dementia, and the impact this has on their carers, to enable them to provide effective support.

The low status, financial rewards and inadequate training and support for paid care work impacts on women, their families and people living with dementia. There is a need for skilled care competencies for health and care staff and professionals working with people living with dementia with complex needs and co-morbidities.

There is very little research in any context involving women with dementia as participants which focus on the gender issues of living with dementia.

There is a need for further research into the impact of dementia on women as caregivers through longitudinal studies, to understand the longer term impact of the dementia journey, with a greater focus on cohort studies to compare women in different settings over time. Research should focus on what helps to build resilience to help people adjust and to cope long term.

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Our vision is an improved quality of life for people with dementia and their families.

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