



**Alzheimer's Disease  
International**

*The global voice on dementia*

# Women and Dementia

A global research review



Supported by



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**Red & Yellow Care** is a pioneering care provider for the over 50s. They are committed to dramatically improving health and wellbeing in later life, by developing smarter and better care solutions. They provide bespoke and responsive health and social care services in the UK, with a specialism in dementia and other long-term conditions prevalent in later life.

As a member of the USAgainstAlzheimer's Network, **WomenAgainstAlzheimer's** amplifies the powerful voice of women across the globe to find a cure for Alzheimer's. Our work is fuelled by a network of women who have grown impatient with the current progress and want to bring Alzheimer's out of the shadows and into the national spotlight. We empower women to speak up, we advocate for research funding, and we promote courageous research challenges to make finding a cure for Alzheimer's our new reality.

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# Contents

## **Recommendations 3**

## **Overview of findings 5**

### Chapter 1

#### **Introduction 10**

- The world is ageing 10
- Prevalence of dementia 11
- Impact of increasing prevalence 12
- Women and dementia 12
- The dementia care workforce 14
- Aim of this review 14

### Chapter 2

#### **How we conducted the review 16**

- Search strategy 16
- Articles identified 17

### Chapter 3

#### **Women living with dementia 20**

- Prevention and delaying onset 20
- Maintaining identity 21
- Maintaining independence 22

### Chapter 4

#### **The experience of women as family caregivers 23**

- Roles and identities 23
- Impacts of dementia care-giving on health 27
- Financial impact of caregiving 28
- Caregiver burden and stress 29

### Chapter 5

#### **The role of gender in managing and accessing support 33**

- Knowledge and education about dementia 33
- Coping strategies 34
- Care structures and support 35
- Informal support from family and friends 35
- Formal social and health support 37
- Institutional and residential care 39
- Decision making 39

### Chapter 6

#### **Women in the dementia care workforce 41**

- Migration and care work 41
- Distress in care work 42

### Chapter 7

#### **Conclusions 43**

- The perspective of people living with dementia is absent 43
- Research on caregiving is complex 43
- Caregiving in dementia is a gendered issue 44
- Family structures are changing worldwide 44
- Women and men access support in different ways 44
- Women approach dementia and caring in different ways 45
- Professionals and workforce need to be skilled in assessment and care 45
- National dementia strategies need to address the needs of women 45
- Limitations to this review 46

## **References 47**

## Foreword

Nearly everyone involved in the Alzheimer's movement is probably already aware that dementia impacts women more than men, not only because women make up over 60 per cent of the global ageing population, but even more because they are the main caregivers all around the world, both paid and unpaid. It's also fair to say that women are the main drivers for Alzheimer associations around the world, with the majority of ADI's 80 plus member associations currently being led by a woman, many of whom are current or previous caregivers for their husband or a member of their family.



It is about time we recognise this crucial role, which is why we wanted to produce this new global report on women and dementia. A group of women from the Alzheimer's Association in the USA started a great movement called WipeOut Alzheimer's and this will soon go global as well. Another international initiative is WomenAgainstAlzheimer's, and we thank them for the kind support they gave to the research for this project.

Professor Dawn Brooker and her team from the University of Worcester have carried out a comprehensive research review in putting this report together. We are really pleased with this overview, especially because it includes a lot of key recommendations for low and middle income countries (LMICs). I hope the report will find its way onto the desks of policy makers to help improve the quality of life for women living with dementia, as well as the millions of women all around the world who provide care and support for them.

A handwritten signature in blue ink, appearing to read 'Marc Wortmann'. The signature is stylized with a large loop at the beginning and a series of vertical strokes at the end.

**Marc Wortmann**

Executive Director  
Alzheimer's Disease International

## Recommendations



**A**cross 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 lower and middle-income countries (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. There was often reluctance amongst women caregivers to access help from formal and informal support services, due to conflicts between cultural and family expectations or the ability and willingness to seek help on the part of the caregiver. 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.

Women will continue to provide care, whether this is due to societal expectations, or an individual wish to support members of their family and friends. Whatever their motivation, there needs to be adequate and appropriate information and support in place to enable these women to provide care, and feel cared for themselves.

### Public Health Policy

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.

Health and social care policies need to be developed based on evidence of need identified within each country. Where policies are in place, these need to be prioritised and put into action, with adequate allocation of funding to facilitate this, both for the current situation and in planning for the future.

Support such as food, money, appropriate information and care centres in LMICs would help reduce the burden of care, whether provided directly by the state or through government support for organisations which deliver dementia care in the community.

A dependence on family care is in conflict with the advances in gender equality in education and employment, particularly in LMICs. Social care provision is needed for those without family caregivers, particularly older women with dementia.

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.

Interventions to provide support for caregivers need to be tailored to meet the individual needs of the caregiver-care recipient dyad.

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.

## Gaps in research

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

The vast majority of 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, both in how they experience dementia and how they are cared for.

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.



## Overview of findings



**T**his 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 per cent of people with dementia will live in low and middle income countries. 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. There is very little reported research into the long-term impact of dementia on women as family and formal caregivers.

## Reviewing the research

A systematic search process of academic databases was undertaken to identify relevant research, policy and other documents relating to the impact of dementia on women, either living with dementia, or caring for a person with dementia informally and in a professional care role. There was a specific focus on women in low and middle income countries (LMICs), family structures and the effects of migration.

A total of 38 searches identified 1689 papers which were screened for relevance; 133 papers were obtained for review. Of these, 22 papers focused on women and dementia, with a further 38 discussing gender and dementia more widely.

The majority of the research was conducted in North America and Europe; there were far fewer research papers (17 out of 133) relating to low and middle income countries.

## Women living with dementia

Relatively few papers focused specifically on the experiences of women with dementia from their own perspective. None of this research was from LMICs.

Factors that may delay the onset of dementia include physical activity and maintaining healthy body weight, along with mental activity, attaining higher education and socialisation. All of these factors impact differently within the lives of women than men. One of the main protective factors against developing dementia in later life is to develop good brain resilience in early life through intellectual development, usually provided by good education. Education has been shown to have a preventive effect on dementia. A study in Nigeria showed that any form of primary education was protective against dementia; it was also noted that women were less likely to have received education than men.

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. Recognising the need for help and accepting support is different for men and for women. Likewise, maintaining identity and independence is a strong personal driver for many experiencing the symptoms of dementia. There are wide individual differences in how this is experienced but gender roles are likely to impact on this experience.

For example, the concept of 'grateful guilt' was described in one study, looking at the dynamics of mothers being cared for by their daughters; there was a strong driver for mothers not wanting to be a burden on their families but at the same time being grateful for the help they received from daughters. This type of clashing emotional state can trigger conflict within families. When caring for a women with dementia and assessing care needs, the wider family dynamics and interactions, including her role prior to the onset of dementia should be considered. Social care needs to be provided in a way that meets the needs of the person with dementia without causing feelings of guilt.

## Women as family caregivers

### The caregiver role

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.

Dementia has a significant impact not only on the person diagnosed with the condition, but also their social networks of family and friends, who often provide increasing levels of care and support to enable them to continue living at home. In many countries and cultures there are social and familial expectations that women will take on the role of caregiver for older relatives within the family setting. Whilst this is often willingly accepted, caring for elderly parents with dementia often needs to be balanced against the competing demands of employment and caring for children.

Women caring for their husbands with dementia rarely identified themselves as “carers” or “caregivers”; instead this is a label given to them by service providers. Instead, the role of being a carer is seen as an extension of their lifelong commitment to caring for the family. The transition to the caregiving role can be difficult and confusing, requiring a reassessment of relationships, a need to understand their spouse’s behaviour changes, and a loss of reciprocal care.

Caregivers are required to take on roles traditionally undertaken by their spouse and learn new skills. For women this was generally seen as an extension of their existing work within the household; for men, taking on tasks such as cooking provided an insight into the work carried out by their wives that had previously gone unnoticed.

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. Religious reasons were also cited as being a factor in becoming a caregiver.

### The impact of caregiving on health

Being a long-term caregiver for a person with dementia has a significant impact on mental and physical health, and this may be experienced differently by men and women. Most studies have reported more extensively on the impact of psychological well-being than on physical health, although one Spanish study reported that female caregivers were more likely to smoke and describe themselves and physically inactive compared to female non-caregivers. This could have implications for long term health and targeted health education programmes.

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.

Cultural differences can also influence the health impact on family caregivers. Latina caregivers in the USA reported lower levels of burden than non-Hispanic white caregivers, whereas no differences found between burden in Chinese caregivers compared to American caregivers, despite differences in family traditions and expectations.

Some studies identified female spouses as being particularly vulnerable to caregiver burden and strain, being more likely to react emotionally to the situation, and spending a much longer time on caring related activities compared to male caregivers. Others found no significant difference in caregiver burden between husbands and wives. Longer term impact showed that wives continuing as caregivers over two years had more depressive symptoms than those remaining as non-caregivers, with approximately one in three wife caregivers in one study having depressive symptoms consistent with clinical depression.

## Financial impact

As well as the increasing global financial impact of dementia, the impact on individual caregivers is also significant, adding to the stress of caregiving. Access to assistance with social care appears to be very much influenced by the available resources, where there are no public funds to support this.

Caregivers of people living with dementia often have to make changes to their employment situation. Women were more likely than men to reduce their hours to part time, or stop work completely to be able to provide care. In high income countries, carers allowance may be payable; in LMICs, with no formal carer allowance available, a reduction in income and greater health costs can cause significant additional stress to the caregiver.

## Managing and accessing support

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.

There is a gender imbalance reported between the availability and take up of informal support for family carers. Women caring for husbands with advanced dementia in high income countries reported receiving less support from family and friends than men caring for their wives in similar situations, leading to poorer psychological and physical health. Where women did receive family help, this was not sufficient to significantly reduce their caregiving workload. However, research in LMICs found a trend towards lower levels of strain among carers who received additional informal support from other family members or friends, particularly in Latin American countries.

Male caregivers are more likely to receive formal practical support and use external resources than women to care for their spouses, and are more willing to accept help to enhance the level of support they could provide. Reasons for the wives' reluctance to access services included not wanting to place a burden on the support services, taking services away from someone with a greater need, or acknowledging personal shortcomings.

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. This has particular implications for the care of older women who live alone rather in the extended family set-up.

In some LMICs, changing family structures towards more nuclear families, along with changing migration patterns of younger family members due to employment in urban areas or overseas, has resulted in lower availability and dependence on the family (usually females) to provide long-term support.

Lack of availability of formal support for caregivers may result in poorer outcomes for the person with dementia. Rural communities in some LMICs face additional problems such as difficulty accessing necessary and adequate services, transportation and distance from services and a lack of awareness of available services.

Where the use of long term residential care was feasible and available, male and female spouse caregivers cited similar reasons for deciding to make use of this. Factors leading to early nursing home placement included caregiver burden, more family dysfunction and decreased social support. One study cited that those cared for by daughters were more likely to seek earlier care home admission.

Although there are huge individual differences, different coping strategies are reported by men and women within their caregiving role. Men focus on problem solving, accomplishing tasks and

preferring to make sense of their experiences at a cognitive level, whereas women focus more on the quality of task performance and emotional support. Given these differences, carer education programmes need to focus on different aspects depending on the gender of their target audience.

## **Women in the care workforce**

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. The care home workforce is predominantly female and the standing of this workforce both in terms of financial rewards and social status is low. Care home staff voice frustration at the inability to provide ideal care to people with dementia due to time pressure, workload, lack of emotional support from managers and difficulties in communication and lack of information about dementia. Lack of training and education in dementia mean that care workers deal with high levels of residents' distress with little support. The resulting emotional and physical exhaustion can in turn affect their own family life. 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 per cent lower than that of men in a similar role.

The situation regarding the paid work-force in LMIC is under-reported. In Latin America and China, the paid care workforce is overwhelmingly informal and unregulated, with untrained and inexperienced care workers being given responsibility for people with very complex needs.

## Chapter 1

# Introduction

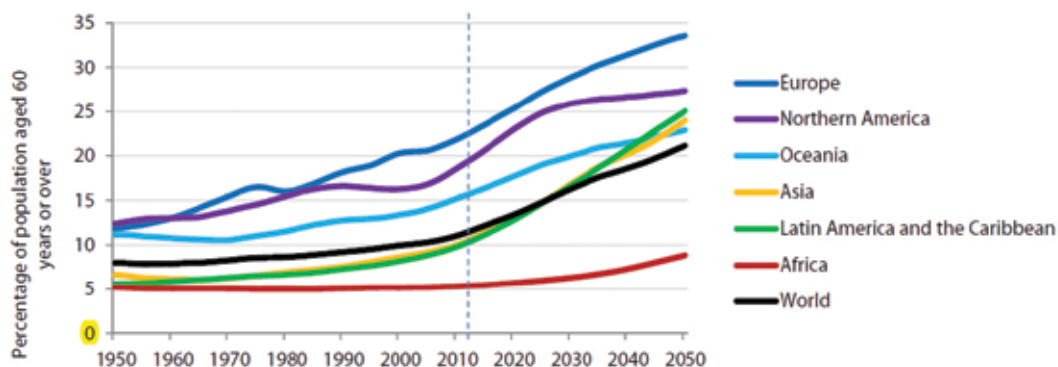


## The world is ageing

It is well documented that the world's population is ageing; the proportion of the global population aged 60 years or over has increased from 8.6 per cent in 1980 to 12 per cent in 2014, and is expected to rise further by 2050 to 21 per cent (United Nations, 2014) (figure 1.1). The number of people aged 80 or above is projected to increase by 19 per cent.

Figure 1.1

Percentage of the population aged 60 years or over, estimated for 1950-2014 and projected to 2050



Data source: United Nations (2013) World Population Prospects: The 2012 revision

According to the UN (United Nations, 2014), the number of older persons worldwide is projected to be 2 billion by 2050, with particularly rapid growth in Africa, Latin America and the Caribbean, and Asia. Given the global differences in life expectancy between women and men, in 2014

women made up 54 per cent of those aged over 60, and 62 percent of those aged over 80.

The changing demographics of the population, along with changes associated with socioeconomic development, will have implications for the provision of health and social care for both developed and developing countries (WHO, 2011), to ensure there is an infrastructure to provide appropriate long term care available. According to the World Health Organisation (2011), many countries have been slow to make use of the available evidence to develop effective health care policies to respond to aging populations, particularly in low and middle income countries, with a lack of a strategic insight concerning their specific needs (Paraiso et al., 2011).

## Prevalence of dementia

As the population ages, the prevalence of dementia will increase, given that advanced age is the greatest risk factor for dementia (Alzheimer's Association, 2014). The number of people globally estimated to be living with dementia in 2013 was 44.35 million. This is predicted to rise to 75.62 million in 2030 and 135.46 million in 2050 (see table 1.1). The rates of increase across different parts of the world is not uniform, with rates increasing in India, China and South Asian and Western Pacific regions at three times the rate of increase in high income countries (Ferri et al., 2005).

In 2013, Alzheimer's Disease International estimated that around 38 per cent of people with dementia were living in high income countries, and 62 per cent in low and middle income countries (LMICs); this is predicted to rise to 71 per cent in LMICs by 2050 if current trends continue. These figures highlight the need for all countries, in particular low and middle income countries, to develop plans to ensure the provision of appropriate health and social care to manage the increasing need of the ageing population.

Table 1.1

**Estimates of the number of people living with dementia (source: Alzheimer's Disease International, 2013)**

Region	People with dementia millions (% of world total)			Proportionate Increase (%)	
	2013	2030	2050	2013-2030	2013-2050
G8	14.02 (32%)	20.38 (27%)	28.91 (21%)	45	106
G20	33.93 (76%)	56.40 (75%)	96.61 (71%)	66	185
OECD	18.08 (41%)	27.98 (37%)	43.65 (32%)	55	142
High income	17.00 (38%)	25.86 (34%)	39.19 (29%)	52	131
Low and middle income	27.84 (62%)	49.76 (66%)	96.27 (71%)	79	246
<b>World</b>	<b>44.35</b>	<b>75.62</b>	<b>135.46</b>	<b>71</b>	<b>205</b>

Women are disproportionately affected by dementia. As age is the greatest risk factor for dementia, and women having a greater life expectancy worldwide than men, a greater number of people with dementia will be women (Alzheimer's Association, 2014). There are also clinical differences between the genders in disease risk and severity, especially in relation to dementia and cognition. Women with Alzheimer's disease (AD) pathology have a three-fold risk of being diagnosed with AD than men. It has also been suggested that loss of oestrogen after the menopause can lead to deficits in brain metabolism, which may lead on to AD (Carter et al., 2012).

Bamford (2011) demonstrated that there is a significant association between age, gender and dementia in most areas of the world, with women showing a higher prevalence rate for dementia than men (Takeda et al., 2011). Almost two-thirds of Americans with dementia (3.2 million) are women. The risk of dementia doubles every five years after the age of 65. The prevalence of dementia demonstrates that this is an issue that disproportionately affects women, across both high income and lower and middle income countries (Braun, 2012).

## Impact of increasing prevalence

This is a cause of concern for many - a greater proportion of women (58 per cent) than men (43 per cent) in the United States were frightened about the prospect of being diagnosed with dementia, with the main reasons for this concern being forgetting loved ones, becoming a burden to their family and not being able to take care of themselves (Alzheimers Association, 2014).

In Africa, despite limited data, the prevalence of dementia is again higher amongst women than men (Ochayi and Thacher, 2006; Paraiso et al., 2011; George-Carey et al., 2012). Women had a weighted mean prevalence of 5.22 for age groups 70-79, and 19.68 for age 80+ compared to 2.60 and 16.8 respectively for men (George-Carey et al., 2012).

The current costs of dementia across the world are estimated to exceed US\$600 billion, including medical costs, social care workforce costs, and the significant contribution from informal caregivers (ADI, 2010). In high income countries, informal care accounts for 45 per cent of the costs, with formal social care accounting for a further 40 per cent, and medical care 15 per cent. For lower and middle income countries, informal family care accounts for the majority of the cost.

Therefore, the care burden associated with dementia disproportionately falls on family carers in much of the world. The health and financial impact of dementia worldwide means that dementia is a global public health priority that needs to be recognised and acted upon by individual countries, with investment needed to ensure appropriate policies and systems are in place to cope with the expected growth in numbers of people with dementia (WHO & ADI, 2012). Improved education, along with healthier environments and lifestyles is needed across the world to lessen the burden of dementia (Rizzi et al., 2014). However, if dementia is not made a public health priority by governments and health care authorities in low and middle income countries, it is difficult to secure funding to improve care and support for people with dementia and their families (Paraiso et al., 2011).

As part of the response to the need to take action to address dementia, the World Health Organisation prioritised dementia within its Mental Health Gap Action programme in 2008, which was designed to scale up the care provision for mental, neurological and substance use (MNS) conditions in LMICs (WHO & Alzheimer's Disease International, 2012). More recently, a ministerial conference hosted by WHO, involving 80 countries, launched the global Dementia Discovery Fund, with a promised investment of \$100 million. The need for coordinated global action was highlighted, with priorities to include raising awareness of dementia and its risk factors, building capacity for timely diagnosis, commitment to good quality continuing care and services, caregiver support, workforce training, and research<sup>1</sup>.

## Women and dementia

Given the greater prevalence of dementia amongst women, there is a growing recognition of the role of gender relating to dementia, with emerging evidence suggesting a need to acknowledge and prioritise dementia as a global women's health issue. In the literature about dementia, men and women are compared, but rarely in the context of gender roles and identities (Baker and Roberston, 2008).

A number of policy developments highlighting the need to address issues around gender and ageing have been developed, along with a more specific focus on the challenges faced by older women, given the changing demographics of this population. The Beijing Declaration was developed in 1995 to promote gender equality and the empowerment of all women, which led to the creation of a framework of 12 critical areas of concern for advancing women's rights. Older women were mentioned specifically within the framework. The existence of policy guidance does not necessarily result in action; a review of national reports has been conducted by UN Women to monitor progress in each area of concern across all 131 member states in relation to older women

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<sup>1</sup> <http://www.who.int/mediacentre/news/releases/2015/action-on-dementia/en/>



(United Nations, 2015). The review, conducted twenty years on from the implementation of the Beijing Platform for Action, showed very little has been done to address the challenges of older women. Very few reports mentioned the health challenges faced by older women; none of the reports referred to dementia or other mental health issues experienced by older women.

Collaborations between countries are developing policies around gender and ageing, to address gender inequality and in particular the needs of older women. More recently, the Gender and Aging Charter has been adopted at the 2nd International Longevity Forum held in Brazil (International Longevity Centre Brazil, 2014), which recognises the need for gender equality for a number of areas as the demographic profile changes. Within health, it specifies the need to acknowledge and support the role of caregiving, whether formal or informal, and the need for gender-appropriate health care where necessary.

### **Women as family caregivers**

In addition to there being a greater prevalence of dementia amongst women than men, a greater proportion of caregivers are women, reported by a number of studies to be between 60-70 per cent (Alzheimer's Association, 2014). There is a cultural expectation in all countries that women will assume caregiving roles (Godfrey and Warshaw, 2009). In many research studies on dementia caregivers, all or the majority of participants are women, reflecting the disproportionate extent to which they are relied upon as carers, although few of these look at gender as a specific issue (Robinson et al., 2014). In other words, the cultural assumption that women are, or should, provide informal or formal care to people with dementia is embedded in much of the research that is conducted in this area.

In the USA it is estimated that there are 15 million people acting as unpaid caregivers for family and friends (Carter et al., 2012). This is reflected in other countries - in Italy, it is estimated that 80 per cent of people with dementia live at home, with informal care provided by women in 70 per cent of cases (Lavarone et al., 2014). While there has been some increase in the number of male caregivers, women still provide the majority of family caregiving and carry the greatest burden of multiple caregiver roles (Lantz, 2009). According to the 10/66 Dementia Research Group (Prince, 2004), 71 per cent of caregivers of patients with dementia in developing countries are women.

It is also well understood that caregivers are at greater risk of physical and mental health problems such as fatigue, major depression and anxiety disorder (WHO and ADI, 2012). Given the disproportionate number of female caregivers across the world, this will have a greater impact on women, in terms of their own health and wellbeing. Whilst the majority of older heterosexual men can expect a spouse to provide care, this may not follow for many older women, due to women living longer than men (Godfrey and Warshaw, 2009). In England and Wales, 60 per cent of women aged over 75 were widowed compared to 29 per cent of men. Similarly, 59 per cent of those aged over 85 lived alone, three quarters of who are women (Office for National Statistics, 2014).

There are also differences in the burden of care associated with the gender of the caregiver. Women are more likely to experience social restrictions because of their caring role, and they experience higher levels of burden when compared with male caregivers with high levels of stress, tension, paranoid symptoms, increased perception of ill health and lower levels of quality of life (Papastavrou et al., 2007).

The financial impact of the economic downturn on family caregivers has been substantial, with caregivers in the United States reporting that they are more reluctant to take time off work to be able to provide care, or were having to take on additional work to cover caregiving costs, which increased as a result of the economic downturn (Evercare, 2009). Almost half of (48 per cent) of caregivers have full-time jobs above and beyond the time spent providing care (Godfrey and Warshaw, 2009). As a result, those who work outside the home are often forced to rearrange work schedules or take unpaid time off to provide care; the financial burden associated with this is an additional factor causing stress to women caregivers (Evercare, 2009).

Employed women caregivers have fewer resources yet are in caregiving relationships that place greater demand on the caregiver, including higher levels of stress and disruption to working patterns than for men who are caregivers (Dunham and Cannon, 2008). Women may also have the responsibility of caring for young children simultaneously with caring for a parent with dementia – sometimes referred to as the ‘sandwich generation’ (Solberg et al., 2014). Despite these problems, it often remains preferable, for a variety of cultural, obligational and practical reasons to continue to provide care at home (AARP, 2015).

## The dementia care workforce

In order to be able to provide adequate health and social support for people with dementia and their caregivers, the dementia care workforce needs to be established, with adequate numbers and appropriate training (Coogler et al., 2007; Elliott et al., 2012). Both low, middle and high-income countries are faced with the increasing need for provision of long-term care for the ageing population generally, and for people with dementia more specifically (WHO and ADI, 2012). Despite increasing numbers of people employed within the paid care workforce, in Australia a further threefold increase is needed to cope with the increased demand (Elliott et al., 2013). In LMICs in Africa, Asia and Latin America, formalized institutional care for the older people is rare, and long-term care remains a family responsibility to a great extent (WHO and ADI, 2012). Substantial investment in the mental health workforce, including for dementia care, in LMICs is needed to meet the growing demand (Bruckner et al., 2011). As with informal care providers, the majority of formal paid health and social care for people with dementia is provided by women, who make up over 85 per cent of this workforce (Cummings et al. 2013; Alzheimer’s Association, 2014).

## The need for this review

A roundtable discussion of experts in the field of Alzheimer’s disease (AD), reported by Carter et al. (2012) identified the need to understand more about the gender and sex differences in the mechanisms in the disease, and also the effects differences of sex and gender on those with the disease and on men and women caregivers. They recommended reviewing the literature on emotional and psychological impact of AD, and interventions designed to support carers. The predominance of women affected by dementia, both as experiencing dementia and as carers, makes dementia a gendered and feminist issue (Godfrey and Warshaw, 2009; Wilkinson, 2015).

Feminist inquiry offers the view that caring is an intergenerational process between two women, in case of daughters caring for their mothers, rather than being a case of a mother being a burden to her daughter (Ward-Griffin et al., 2006). Taking a feminist perspective can help develop knowledge to inform positive change with the aim of improving the lives of women living with, and caring for, someone living with dementia. This review of the literature goes some way to exploring the research that has been conducted looking at the impact of these issues on women.

## Aim of this review

The key aim of this review was to understand the main issues affecting women in relation to dementia from an international perspective.

More specifically the study had the following objectives:

- To explore research that has been conducted relating specifically to women and dementia
- To examine the effect of gender on three specific groups: women living with dementia; woman caring for people with dementia in a professional caring role; women undertaking an informal caregiving role for someone with dementia.
- To understand the issues affecting women in relation to dementia across these groups, with specific focus on cross-cutting issues including factors affecting women in lower and middle income countries; family structures and kinship; and the effects of migration and immigration.

**Debbie Benczkowski, Canada**

*I feel like I live and breathe at the epicentre of dementia – because I work at the Alzheimer Society of Canada and I make a long round trip every weekend to take care of my aging parents. My mother is in her late nineties and is living with vascular dementia. Virtually everyone I know who has a parent or a partner living with dementia is female. We know that women represent 72 per cent of Canadians living with Alzheimer’s disease – we know that women live longer than men, and we know that age is the biggest risk factor.*

*As a female leader in the Alzheimer’s movement, it disturbs me that the biological differences between men and women are not routinely addressed in matters of research and care and that women are dangerously under-studied in dementia research. Issues relating to the menopause, such as sleep deprivation, are understood to have the potential to raise the risk of dementia, so why is this not studied more closely?*

*Last but not least, I believe that most female executives feel a greater duty of care to nurture their staff than their male counterparts – so, the circle of care for a female executive/leader is effectively widened beyond immediate and extended families to include their staff as well. Couple that with the fact that staff are dealing with their own personal caregiving issues and the inevitability that we are beginning to have staff in our workplaces in the early stages of dementia themselves, and we’ve got a perfect storm happening. We need to act now.*

## Chapter 2

# How we conducted the review



### Search strategy

**A** systematic search process was undertaken to identify relevant policy, research and other documents relating to dementia, with a focus on women and gender. The search strategy aimed to identify as wide a range of published papers and reports as possible in the time available. The databases searched included Academic Search Complete, CINAHL, PsychINFO, Medline, Web of Science, PubMed and Google Scholar along with a search of relevant government department and third sector organisations websites and a general internet search.

### Search terms included

- Dementia, Alzheimer's
- Women, gender, female, feminis\*
- caregiving, care work, professional
- family carer, partner, spouse, daughter, mother, caregiver
- migration, immigration, language
- famil\*, structure, kinship, culture

### Exclusions

The review excluded papers relating to medical intervention, clinical treatment, and biomedical research.

### Limitations

The papers retrieved were limited by the following criteria:

- Time period for search: 1 Jan 2005- 31 Dec 2014

- Language: English
- Setting: worldwide
- Type of articles: research, reviews
- Search within title, keyword, abstract

### Data extraction and synthesis

The papers identified were assessed to check that the study was relevant and focused, and an appropriate method has been used to answer the research question. A data extraction tool was developed to collate relevant information about aims and objectives, method, findings, conclusions and recommendations, and limitations of the study. The proposed approach is adapted from by the EPPI-Centre approach to assessing and synthesising research evidence resulting from various methodological approaches (Harden and Thomas, 2005; Jackson et al., 2008).

### Articles identified

A total of 38 searches of the relevant databases were conducted, from which 1689 papers were screened for relevance, from their title and abstract.

The search results are summarised in Table 3.1.

Table 3.1

#### Search results

Search Results	
Searches completed	38
Titles/abstracts checked	1689
Potentially relevant abstracts (minus duplicates)	217
Dissertations (excluded)	13
Potentially relevant but not accessible within the time available	35
Not directly relevant	36
Papers obtained	133

The 133 papers obtained through the search process were reviewed and categorised into different groups, according to the relevance to the aims and objectives of the review (Table 3.2). Just under half of the papers were focused on gender, focusing specifically on women (n=22) or on gender issues more generally (n=38). For one quarter of the papers reviewed gender issues were not discussed, despite all or the majority of respondents being female.

Table 3.2

#### Categories of papers

Category	Number of papers
a. Focused specifically on women and dementia	22
b. Focused on dementia and gender as a specific issue	38
c. Gender issues/differences not the focus but discussed within the paper	23
d. All or majority of research participants are female but gender not discussed	35
e. Gender discussed but not focused on dementia	8
f. Focused on other areas & background info	7
<b>Total</b>	<b>133</b>

The papers represented research studies from a wide range of countries or geographical areas.

These have been grouped according to the World Bank country income groupings<sup>2</sup> (see Table 3.3). The majority of the research has been conducted in North America and Europe; there is far less research relating to low and middle income countries.

Table 3.3

**Country/area of focus**

Low income economies		Lower-middle-income economies		Upper-middle-income economies		High income economies		Others	
Benin	1	Nigeria	2	Brazil	2	USA	57	Africa	1
		Sri Lanka	1	China	2	UK	16	Middle Income	1
				Iran	2	Canada	10	International	1
				South Africa	2	Spain	6		
				Turkey	2	Australia	4		
				Mexico	1	Japan	4		
						Italy	3		
						Cyprus	2		
						Finland	2		
						Sweden	2		
						Israel	2		
						Czech Republic	1		
						Denmark	1		
						Germany	1		
						Netherlands	1		
						Norway	1		
						Portugal	1		
						Republic of Korea	1		
<b>Total</b>	<b>1</b>		<b>3</b>		<b>11</b>		<b>115</b>		<b>3</b>

The papers were also categorised to look at the participant group on which they were focused: people with dementia, informal family carers or the formal care workforce (Table 3.4). Three quarters of the papers focused on informal dementia caregivers as the main participant group for the research. There were similar numbers of papers focusing mainly on the person with dementia, and on the formal care workforce, which both received far less attention in the literature through this search strategy.

Of the 15 papers published from the low and middle income countries, nine focused on caregivers, four looked at prevalence and two focused on the workforce.

2 World Bank economy groups <http://data.worldbank.org/about/country-and-lending-groups>

Table 3.4

**Participant group or research focus**

Participant group/focus	Number of papers
Caregivers	96
Person with dementia	9
Workforce	9
Prevalence	9
Specific population groups/nationalities	4
Person with dementia and caregivers	3
Older people and caregivers	2
Person with dementia and caregivers and workforce	1
<b>Total</b>	<b>133</b>

The report draws on the findings of all the papers retrieved, focusing on the issues for the three main groups identified: women with dementia, caregivers and the formal care workforce.

### **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.*

*It's vital we address these factors in Uruguay as part of a larger programme to tackle the lack of policies for dementia, comprising prevention, early diagnosis and better provision of health and social care.*

## Chapter 3

# Women living with dementia



**O**ur search highlighted relatively few papers focused specifically on the experiences of women with dementia, which actually included the views and perceptions of the women themselves, rather than the perspectives of their caregivers or clinical aspects of care or treatment. Issues around prevention and delaying onset were touched upon. The main themes that emerged from the literature on the experience of having dementia from a woman's perspective were around identity, and maintaining control around decision making.

### Prevention and delaying onset

The importance of the prevention agenda in delaying the onset of dementia or slowing cognitive decline is gaining ground as evidence emerges of effective preventative measures. There is little evidence currently on gender differences but it is likely that in health education programmes will need to be targeted differently towards male and female health behaviours.

Godfrey and El-Badri (2009) suggest a number of factors, focused on women, that can delay onset of Alzheimer's disease. Diet (Pinder, 2008) and physical activity, as well as body weight, seems to have a positive impact on the risk of future dementia and cognitive decline; however these factors do not appear to slow or reverse dementia once women reach their 70s (Godfrey and El-Badri, 2009). Mental activity (such as reading, playing games), attaining higher education, socialisation and an active lifestyle have the greatest potential for avoiding or reducing risk of developing Alzheimer's disease or other forms of dementia.

Education can have a preventive effect on developing dementia. In a study in Nigeria, Ochayi and Thacher (2006) noted that whilst none of their participants had an education beyond primary school, any form of primary education was protective against dementia. They also noted that females were less likely to have had any education than males.



## Maintaining identity

Borley et al. (2014) described the experience of an 83 year old woman going through a transition from a carer to being cared for through a case study. She expressed denial of her condition, maintaining that she was “just the same”. She experienced difficulty in accepting the change in her role from being the central carer for the family, to being the one who was being cared for. Having always been the one who was responsible for caring for her home and family, she did not want to become a burden on her husband and family. Borley et al. (2014) suggest that maintaining her identity as a central figure in her family life, and reinforcing perceptions of self, usefulness and value within the family unit was a key factor in maintaining her quality of life as the disease progressed. The identity of the person with dementia therefore needs to be considered as part of a whole family system (Beeber and Zimmerman, 2012), to understand their wider role prior to the onset of dementia, and looking at how the dynamics of the family interactions change when caring for a person with dementia.

As well as reinforcing the identity of the person with dementia through their role within the family, material objects and possessions can offer people with dementia continuity with past social identities and roles, as well as providing a sense of comfort and security. Buse and Twigg (2014) in their study of women with dementia and their handbags in the UK in both their home setting and a care home setting, found that handbags were linked to connections to memories and identities, and also offered a means of containing personal items and keeping them safe. Women living at home kept collections of handbags that were no longer used, again linked to their identity as being part of a wider social world. Keeping the bags symbolised resistance to loss of identity. Buse and Twigg (2014) concluded that the no longer having the need to carry a handbag signified loss of independence as the disease progressed.

Spousal carers also supported their partner with dementia to retain their identity, through maintaining a level of gendered appearance, and through maintaining a gendered sense of self (Calasanti and Bowen, 2006), for the benefit of both spouses. Men described maintaining their wives appearance, learning to apply their make-up and buying the same brands of beauty products they used previously. Likewise wives helped their husbands to dress appropriately, and made sure they had shaved and combed their hair, to maintain appearances. This represents having to learn to think in terms of a different gender identity and understand why certain grooming patterns were followed by their partners. There was also evidence of action taken by female caregivers to maintain their husbands masculine identity; Calasanti and Bowen (2006) describe how one wife caregiver ensured her husband still had a drivers licence even though he could no longer drive, to maintain his identity and still ‘feel like a man’.

Maintaining the identity of the person with dementia was important not only for that individual, but also for the carer, whose own identity was related to that of the care recipient. Decisions of caregiver wives’ to decisions to withhold the diagnosis of dementia from their cognitively impaired husbands might have helped protect the status and identity of husbands and, in turn, women’s own identities as wives (Hayes et al., 2010).

For lesbian and bisexual women, having their identity recognised and acknowledged can be problematic within the context of community and residential care where heteronormative assumptions are made about the person with dementia and their support needs. This may lead to avoidance of support services in the community, with the associated risks of early admission to residential care (Westwood, 2014), which brought about additional problems around identity.

In some countries, maintaining identity is not possible where those in communities in which the person with dementia belongs do not understand dementia or what is happening to them, resulting in extreme stigmatisation (Spittel, 2014). In Ghana, for example, Alzheimer’s and Related Disorders Ghana (2012) report that elderly women displaying signs of memory loss, forgetfulness, or disorientation are excluded from their communities and sent to ‘witch camps’, with their symptoms being mistaken for witchcraft.

## Maintaining independence

There are difficulties in adapting to changing needs as the dementia progresses, and relinquishing the traditional gender roles and positions held by individuals within the family (Borley et al., 2014). Recognising the need for help and accepting support was difficult when maintaining identity and independence were still important to the person with dementia. Mothers with dementia described their gratitude for daughters taking care of them, but at the same time felt they were a burden to them – the concept of “grateful guilt” has been used to describe this situation (Ward-Griffin et al., 2006). Parents needing care from their daughters wanted to keep some degree of control and independence over the caregiving relationship (Watt et al., 2014), and maintain their dignity as an adult (Ward-Griffin et al., 2006; Dunham and Cannon, 2007). Ward-Griffin et al. (2006) described a level of avoidance and deception on both sides to try to maintain control, with the mothers withholding information from their daughters about how they were feeling, thereby not wanting to make too many demands of them (Ward-Griffin et al., 2006, Watt et al., 2014), and the caregiving daughter needing to adopt deceptive practices to maintain the safety of the care recipient (Dunham & Cannon, 2008). Alternative provision of social care, which meets the needs of people with dementia and their families without prior assumptions about the gender roles within the family, would remove the need for these feelings of guilt.

### Kate Swaffer, Australia

*Two thirds of the five million seniors with dementia of the Alzheimer’s type are women, they are twice as likely as men to develop dementia at the same age, and women have a more severe and rapid decline than men (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. The stigma, the discrimination and the characteristic isolation that a diagnosis of dementia brings with it ensures hopelessness. The Prescribed Disengagement™ (Swaffer, 2014) still given to most people following diagnosis potentially also creates a learned helplessness and exacerbates the hopelessness; it is unhelpful and also in my opinion, unethical. The emotional devastation of such a diagnosis can be crippling and so disempowering, it is easy to give up and not to fight for our lives. With a rehabilitative and disability-enabling approach to our care, our sense of well-being and quality of life potentially is increased significantly; despite the fact these approaches are not a cure. Living better with dementia, with improved support for the assets we still have, is imperative.*

#### References

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- Swaffer, K 2015, Reinvesting in life is the best prescription, Australian Journal of Dementia Care, <http://journalofdementiacare.com/reinvesting-in-life-is-the-best-prescription>

## Chapter 4

# The experience of women as family caregivers



Dementia has a significant impact not only on the person diagnosed with the condition, but also their social networks of family and friends. The decline in cognitive function experienced by people with dementia means that they will require increasing levels of care as the disease progresses, and will need support from an informal carer or carers to enable them to continue living at home. Around two thirds of people with dementia in developed countries live in the community in their own homes (Alzheimer's Society, 2011; Alzheimer's Association, 2014). The proportion in LMICs is much higher, where care is typically provided by family members at home (Alzheimer's Disease International, 2009).

## Roles and identities

### Transition to the caregiver role

The experience of transition to a carer, and the changing roles and identities associated with this, differed depending on the relationship between the person with dementia and the carer. Individuals rarely identify themselves as “carers” or “caregivers”. This is a label that is given by service providers. Nonetheless, most spouses or adult children who provide long-term support for someone living with dementia will go through a process of relationship change whereby they will eventually see themselves as a carer or caregiver. The dynamics within the transition from spouse or adult child to that of carer is likely to be different for men and women. The primary caregivers of people with dementia, who take on responsibility for the overall care of the person with dementia and spend most time with them are often women, usually wives, daughters, or daughters in law (WHO and ADI, 2012).

The period around diagnosis, beforehand when unusual behaviour is noted but not understood and on receiving a formal diagnosis of dementia is a difficult time, with the need to have a period of adjustment and transition to come to terms with the diagnosis (Potgieter and Heyns, 2006).

Receiving a diagnosis of dementia necessitates a reassessment of identity and roles between the carer and the person receiving the diagnosis to understand the implications of this within the relationship. Potegieter and Heyns (2006) described how caregivers, in this case female spouses, experienced a loss of control during the early stages after diagnosis, caused by a lack of knowledge about dementia, their husbands behaviour, and an incomprehensibility of the overall situation. Understanding the initial emotional reaction to the diagnosis can be confusing, although the emotions experienced in caregiving and care receiving are fluid, and are continually changing and being redefined as the disease progresses (Boylestein and Hayes, 2012).

In a number of cases, women saw the role of being a carer for their husbands as an extension of their lifelong commitment to caring, and providing a caregiving role in varying circumstances throughout their lives (Eriksson et al., 2013), and they continued to draw on support from networks of other women as an important resource for sharing the caring responsibilities, as they had done in previous caregiving roles. Alongside this, women reassessed and restructured their social networks to adapt to the new and complex environment of dementia care to which they now belonged, and needed to understand and influence (Neufeld et al., 2007).

In interviews from research studies and the wider media, the behaviour of the person with dementia has been described as becoming more 'childlike', therefore daughters and sons in a caring role experienced a role reversal with the parent becoming cared for and wives described their role as changing to be more like a mother (Dunham and Cannon, 2007; Boylestein and Hayes, 2012; Toepfer et al., 2014).

### **Maintaining relationships**

In a number of the studies looking at spousal caregiving, the difficulties in maintaining a relationship within the marriage was highlighted, although a number of mechanisms were described to try and retain some of the previous qualities of the marriage. Many of the women were profoundly negative about their marital closeness and companionship since the onset of their husband's dementia (Boylestein and Hayes, 2012). They described a deep sense of loss about who and what their spouse had become, and the loss of reciprocal care and relational discontinuity (Walters et al., 2010). Wives experiencing a reversal of roles in terms of authority within their traditional marital relationship, distinct from the challenges faced by men, may also experience greater burden and stress (Hayes et al., 2010).

Wives taking on the role of carer for their husbands had experienced changes to how they perceived their marriage, as the partnership became increasingly unequal as the disease progressed, redefining their role within the marriage in terms of closeness and companionship (Boylestein and Hayes, 2012). As the dementia progressed, caregivers increasingly described their relationship in non-sexual terms (Dourado et al., 2010). The decrease in satisfaction from sexual intimacy within the relationship for female caregivers, was related to a decreased emotional and physical connection with their partner, resulting in more emotional distress and diminished well-being (Davies et al., 2012).

Boyle (2013) described how carer-spouses highlighted how giving their partners emotional support was just as important as giving them practical support, with the importance of demonstrating patience, acceptance, trust, love, partnership and honour, as part of their relationship and marriage. Continuing to share activities such as shopping or gardening helped to maintain a sense of closeness or "maintain a connection" for both men and women, with women being more likely than men to mention humour as a way of maintain marital closeness (Boylestein and Hayes, 2012).

### **Taking on new tasks**

As the dementia progresses, particularly within a heterosexual spousal caring relationship, the transition to the role of carer required crossing gender boundaries and taking on additional tasks and developing new skills, that the person with dementia was responsible for prior to diagnosis. Spouses engaged in caregiving perform similar tasks, regardless of gender (Calasanti and Bowen 2006), though the view of what counts as care work differed. These involved tasks that were seen

as gendered within the marriage, with women mainly taking on daily household chores, and men doing more 'outside' work (Calasanti and Bowen, 2006).

The perception of which roles were traditionally taken on by men and which were done by women, have many similarities across countries, cultures and ethnicities, with caring traditionally seen as being a woman's role. The tasks seen as being part of the woman's role included food preparation and personal care (Botsford et al., 2012); women reported having to take on their husbands tasks, such as putting petrol in the car, household finances and gardening (Calasanti and Bowen, 2006). Not all couples shared tasks according to 'normal' pattern, and there were cultural and ethnic differences in some gender allocated tasks. For example, Afro Caribbean respondents in one study reported that dealing with family finances was a woman's responsibility, unlike in other cultures where it was a man's role (Botsford et al., 2012).

The ability to take on these new tasks and overcome the gendered association of the tasks depends on how the carer has to learn tasks that were previously carried out by their spouse, and the extent to which carers relate this to their own sense of self as a gendered person (Calasanti and Bowen, 2006), and their perception of gender role conflict (Baker et al., 2010). Men taking on the tasks previously carried out by their wives were provided with an insight into the work that had previously gone unnoticed and unacknowledged (Russell, 2007). Whilst men were involved in fewer caregiving tasks than women (Friedemann and Buckwalter, 2014), the main tasks taken on included maintenance of their spouse's personal hygiene, doing the shopping and preparing meals (Pretorius et al., 2009). For example, cooking was not viewed by women caregivers as care work, as it was part of their day to day role within the marriage, whereas men do include this within the tasks they undertake within their caregiving work (Calasanti and Bowen, 2006). A number of studies highlighted the concerns of men taking on the role of being the food provider and managing food, as few had experience in doing this (Russell, 2007; Fjellstrom et al., 2010, Boyle, 2013). Often, due to the gendered split between tasks, the complexity of the processes involved in planning and producing food was unseen and unknown prior to their new role as carers (Russell, 2007).

Providing personal care for their wives was described by their carer husbands as being daunting and unfamiliar, according to Russell (2007). However, the accounts by men of taking on the role of carer for their wives were not negative, but instead relayed a sense of transition, commitment, devotion and confidence with regards to personal care.

Whilst husbands appeared to find it more challenging to adapt to taking on daily household tasks, adding to the stress they felt in this caregiver role, they were more likely to ask for help to perform these tasks. Women seemed more prepared to take on additional gendered tasks, and it was often viewed as a gradual extension of their existing work within their household (Calasanti and Bowen, 2006). Despite the daily time and effort involved in performing these tasks, and their invisibility, successfully managing these tasks can also alleviate some potential stresses of care work, and maintain a sense of continuity (Calasanti and Bowen, 2006).

Successfully taking on tasks associated with caring can support the identity of the carer; Hayes et al. (2010) found that men's involvement in caring for their wives affirmed their identity as male protector and provider, and those with traditional beliefs about masculinity were more likely to articulate the positive aspects of being a carer for their wife (Carter et al., 2012).

There were difficulties in adapting to the role of caregiver in some cases, and taking on the necessary tasks associated with caregiving. Some Hispanic males providing care to their female relatives felt they could not provide support in helping bathe or toilet their mothers. Others had no choice but to overcome this taboo, as there no-one else to do it (Evans et al., 2011). The tasks undertaken as a caregiver also varied according to the gender of the care recipient, reflecting traditional gender values. Daughters support their mothers in performing traditional gender roles (cooking, cleaning, being around to provide companionship), whereas the support for fathers was aimed at supporting their dignity, such as engaging in jointly making puzzles, and driving them to appointments (Flores et al., 2009).

## Motivation for providing care

The reasons for becoming a carer for a person with dementia vary; the extent to which they have a choice in taking on the role of the primary caregiver can have an impact on the health and ability of the caregiver to cope with the caring process. This may depend to some extent on the relationship between the carer and the person with dementia, their gender and whether they live in the same household (Toribio-Diaz et al., 2013). A higher percentage of women (39 per cent) than men (33 per cent) said that they had no choice in becoming an informal caregiver, with women being two and a half times more likely than men to provide full time care to a person living with dementia when they live with the care recipient (Alzheimer's Association, 2014).

The reason for becoming a caregiver may be in response to assumptions made about traditional gender approaches, with women being seen as the natural choice to be carer, with a "natural aptitude for caring" (Toepfer et al., 2014), and a wish to protect and enhance the wellbeing of their family members (Ducharme et al., 2011). The assumptions about differences between men and women caregivers were highlighted in a number of studies (Papastavrou et al., 2007) with gendered cultural and societal expectations about the caregiver role.

For heterosexual married couples, where one partner develops dementia, the main reasons for becoming a carer was a sense of obligation (separate from marriage) to their partner and through love for the person they married, and concern for their well-being (Rivera et al., 2009; Egset and Myklebust, 2011). The decision to become a carer may not be articulated, instead being seen as an extension of the existing gendered caring role within a marriage; in describing one wife taking on the caregiver role, Calasanti and Bowen (2006) indicated that "to her, no decision to give care or what type was ever made; she just gradually did more for him over time". In one study men caring for their wives did so out of a sense of duty; however the duty was replaced by devotion as the husbands identified an emotional connection as a significant factor in the caregiver role (Russell, 2007).

There are positive factors associated with becoming a caregiver, giving a sense of pride and satisfaction (Watt et al., 2014). Reasons for becoming a caregiver included feeling a complex mix of expectation and obligation, along with love, and gratitude for the person with dementia, to repay the care they received as children; this feeling was reciprocated by the parents (Price, 2011; Dunham and Cannon, 2008, Olazaran Rodriguez et al., 2011; Toribio-Diaz et al., 2013). A sense of duty was the main motivating factor for daughters caring for their mothers in a study by Ward-Griffin et al (2007), where there were expectations within the family that the daughter would care for the mother with dementia. Religious reasons were also cited in more recent papers as being a reason to provide care voluntarily (Watt et al., 2014; Wezel et al., 2014; Friedemann and Buckwalter, 2014). Having fewer additional family responsibilities may also be another factor in becoming a carer for a parent with dementia. Friedemann and Buckwalter (2014) suggested that as the proportion of unmarried caregivers was highest amongst male adult children, being single could be a decisive factor for men becoming caregivers.

A number of lesbian women respondents in one study (Price, 2011) reported feeling family pressure to provide care, not only due to gendered expectations, but also because their relationships were perceived as being less important compared to those of heterosexual siblings. All respondents had experienced challenges within biological family relationships around acceptance of their sexuality; the necessity to provide care for a family member with dementia was often a catalyst for renegotiation.

## Cultural influences

There are many cultural factors that impact on the decision to become a caregiver for a person with dementia, with many social and familial expectations of women to take on the role. In Cypriot society the caring role is ascribed to women through social expectation; many women undertake this not by choice but because it is socially imposed on them, with the belief that they will be able to take on the task because it is part of their "female nature" (Papastavrou et al., 2007). Latina women living in the United States and Spanish women in Spain spoke of a conflict of cultures felt

a family obligation to provide care for elderly parents with dementia, which they wanted to fulfil, whilst balancing this with the needs of their own families and children (Flores et al., 2009; Romero Moreno 2014). The sensed of obligation to care was present even when there had been previous conflictual relationships with parents and irrespective of the gender of the parent.

Expectations and traditions vary in different countries. In Sri Lanka and some other Asian countries the provision of elder care is the legal responsibility of family members, especially adult children (SEARO, 2012; Watt et al., 2014); this system exists in a society with multigenerational households, and intergenerational care is widely acceptable to all members of the family. Caregiving for an ageing parent was considered as an unquestioned moral obligation, and the care-givers in this study said that they performed their role willingly and that it gave them great rewards. Challenges existed for daughters and daughters-in-law, who were predominantly responsible for providing direct care whilst juggling employment and caring for their own children with their caregiver role; sons were relied upon more for financial support (Watt et al., 2014). Likewise in Korea, daughters-in-law, spouses, and daughters are typically the caregiver for the family member with dementia, resulting in female caregivers having a greater burden than male caregivers (Kim, 2013)

Traditions of responsibility for caregiving continue in immigrant communities. A study of female caregivers in the USA found that Hispanic/Latino caregivers were the youngest group, with a higher proportion of daughters or daughters-in-law providing care (78 per cent) compared with 63 per cent and 49 per cent daughters in the Chinese-American and white groups respectively (Gray et al., 2009). Family care is seen as a duty, but then above all, a duty that is primarily a task for women.

In both the Turkish and Moroccan communities living in the Netherlands, family care was primarily handled by the eldest daughter or the wife of the eldest son. In the Surinamese Creole community, it was also often a daughter who is involved in the care of a parent with dementia, but not necessarily the eldest daughter (Wezel et al., 2014). Family care is seen amongst these groups to be superior to professional care – including residential care – as it is more loving and secure, and the family understands the cultural background of the patient.

## Impacts of dementia caregiving on health

Being a long-term caregiver for a person with dementia can have a significant impact on the psychological and physical health of the caregiver. Caregiver burden is the term used to encompass the stress experienced as a result of caregiving, although there is no singular definition of the concept (Kim et al., 2011; Bastawrous, 2013). The combination of loss, complexity of treatment, prolonged distress and the physical demands of giving care in older caregivers increases the risk of psychological and physical health problems (Zvěřová, 2012).

Family caregivers of people with dementia are more likely to develop affective disorders such as major depression and anxiety disorder, with female caregivers having higher levels of depressive and anxiety symptoms and lower life satisfaction (WHO and ADI, 2012; Godfrey and Warshaw, 2009, Toribio-Diaz et al., 2013). Compared to caregivers for people with conditions other than dementia, caregivers to adults with dementia had increased prevalence and incidence of depressive disorders (Cuijpers, 2005), had higher mean levels of perceived stress, and experienced more behaviour and cognitive problems from care recipient (Bertrand et al., 2006).

Providing care to a person with dementia is a long term commitment with a potential long term health impact on the caregiver. Women provide care for a longer period of time than men; 36 per cent of women had been providing care to their family member or friend for over 5 years, compared to 29 per cent of men (Shriver and Alzheimer's Association, 2010). They also spent more hours per day helping with tasks associated with activities of daily living (ADL) and instrumental activities of daily living (IADL) and were more likely to feel captive in the caregiving role (Kim et al., 2011). ADLs include basic self-care tasks, such as feeding, toileting, getting dressed, bathing and walking. IADLs include the more complex skills needed to live

independently, such as preparing meals, shopping, managing finances and housework.

There are gender differences in caregivers' outcomes in relation to health (Pöysti et al., 2012). When compared with male caregivers, female carers may face higher levels of stressors; have fewer social resources and report lower levels of psychological and physical health. The suggested reason why women reported higher burden levels is that female and male caregivers differ in their conceptualization and approach to the caregiving role and respond differently to it (Papastavrou et al., 2007). Caregiver gender, satisfaction with intimacy, and caring for a person with mild AD have all been found to be significant predictors of caregiver depressive symptoms (Davies et al., 2012).

Many factors influence carer burden and strain across different countries, ethnicities and cultures. In a survey of 11 sites in middle income countries (Latin America, China and India) the factors leading to carer strain were found to be the primary stressors of behavioural and psychological symptoms of dementia (BPSD), dementia severity, the care needs of the care recipient and time spent caring (Prince et al., 2012).

Cutting back on paid work to undertake care was significantly associated with higher carer strain in most countries. There was no consistent evidence for an association between socioeconomic status or the level of education of the carer and carer strain. Peel and Harding (2014) found that most participants in their UK study (78.5 per cent, n=142) were 'under strain'. No significant associations were found in chi-square analyses on demographic variables, dementia diagnosis, severity of dementia, medications prescribed or where the person with dementia lives which would account for these high levels of carer strain. Elsewhere, in Iran, factors increasing the risk of psychological morbidity in dementia carers included being a spouse, having an affected person at home, and living together (Javadpour et al., 2008).

The socio-cultural stress and coping model has been used to explain ethnic differences in caregiver stress (Montoro-Rodriguez and Gallagher-Thompson, 2009; McCallum et al., 2007). According to this model, the impact of stress of caregiving on the mental and physical health outcomes of caregivers can be mediated by the caregiver's views and approaches to manage the caregiving situation. Reactions of the caregiver to stress are affected by the structural (socio-economic status) and cultural (ethnicity) context in which they live, such as strong family bonds and the sensibility of caregiving for the elderly at home in particular societies (Akpinar et al., 2011).

## Financial impact of caregiving

On a global scale, the financial impact of dementia is significant, with current costs estimated at US\$ 604 billion per year at present and set to increase as the prevalence soars. In the USA, the costs associated with dementia are comparable to that of heart disease and cancer, with the value of informal care provided by family and friends being almost equal to the direct care costs of dementia (Hurd et al., 2013).

Dementia also introduces a significant financial impact for individuals and families coping with and caring for a person with dementia, which in turn can add to the stress of caregiving (Diel et al., 2010; Prince et al., 2012). The financial strain comes from the costs of obtaining health and social care, particularly over the longer term, and also from a reduction or loss of income due to the nature and extent of the caregiving need (WHO and ADI, 2012). Access to assistance with social care appears to be very much influenced by the available resources, where there are no public funds to support this. A study of women being cared for by their daughters indicated that other care options were not feasible, as most did not have the financial resources to purchase caregiving assistance (Ward-Griffin et al., 2006). Providing long-term dementia care can seriously compromise or threaten an older couple's financial savings and stability, leaving little for the caregiver if they become ill at a later stage, and family conflicts can arise where potential inheritance is seen to be used to cover care costs (Sherman and Bauer, 2008).

Caring for a person with dementia also had an impact on the employment of the caregiver, with



women being more likely than men to experience difficulties with employment once they had become caregiver, particularly in the more advanced stages of the disease. Three quarters of caregivers in the USA were employed, although many had to make significant changes to their employment situation to cope with the demands of caregiving. This was particularly apparent for women caregivers (Alzheimer's Association, 2014). One fifth of female caregivers reduced their working hours to part time, compared to three per cent of men. Eighteen per cent of women took leave of absence compared to 11 per cent of men, and more than twice as many women as men had to stop working entirely (Alzheimer's Association, 2014). Whilst the loss of income has an immediate impact on the economic situation of the family, not continuing with or reducing the level of employment limits the caregivers personal development and the opportunity to gain support from and build social networks through work, or take up new offers of employment (Toribio-Diaz et al., 2013).

The impact on finance is also significant in LMICs, where the fewer than half of the people with dementia received any kind of pension; this proportion was lower in India and Nigeria (Prince et al., 2004). However, some LMICs have adopted policies of non-contributory pensions as part of social welfare programme, or have wide access to healthcare services, addressing some of the problems faced by the older population (HelpAge International, 2013). The majority of caregivers in the 10/66 Dementia Research Group study (Prince et al., 2004) had to cut back on paid work, or stop working altogether, in order to care for the person with dementia, with no provision of any kind of state caregiver allowance. In Tanzania, with no state care available, it was suggested that provision of community day care for people with dementia, either by the state or religious organisations, would allow caregivers to undertake more "productive work" (Mushi et al., 2014).

Financial difficulties may be particularly significant for women where the male care recipient has younger onset dementia. For women with younger onset dementia (onset under the age of 65), male caregivers often continued to work; as the main household earner this meant the financial impact on the family was relatively small. Female caregivers were faced with having to work to support the family with the loss of their husband's income, having to provide care for their husband, holding down a job and caring for children (Takano and Arai, 2005; Boylestein and Hayes, 2012). These multiple demands may constitute a serious care burden for female caregivers (Takano and Arai, 2005).

Help with financial planning, wider access to social support through pensions and insurance schemes, such as in Japan (Ono, 2010), could provide protection to people with dementia (WHO and ADI, 2012), along with caregiver support where financial difficulties exist due to in being unfeasible to work at the same time as provide care.

## Caregiver burden and stress

The impact of burden and stress associated with caring for a person with dementia is a common theme across the research papers around dementia caregiving. Several studies have been conducted looking at which groups of caregivers are most vulnerable or susceptible to the negative impact of caregiver burden, and to identify factors which account for the differences observed.

### Impact on females and males

There appears to be an overall consensus that female caregivers reported higher levels of burden, stress and depressive symptoms than male caregivers, with similar outcomes being reported across different countries and settings (Prince et al., 2012; Davies et al., 2012; Papastavrou et al., 2009; Takano and Arai, 2005; Diel et al., 2010; Akpınar et al., 2011; Stewart et al., 2014; Zhang et al., 2006). This is independent of their relationship to the care recipient and their characteristics and care structures in place (Prince et al., 2012). However, the quality of the relationship between the caregiver and the care recipient, along with their sense of obligation to provide care, has been identified as a predictor of the outcomes of caregiving on women's health; a poor relationship prior to diagnosis, along with caregiving being undertaken from a sense of duty can lead to poor

health outcomes for women (Hodgins et al., 2011). Ducharme et al. (2011) found that compared to men, women caregivers experienced more problems controlling disturbing thoughts about their caregiving role and experience more family conflicts and psychological distress, although male caregivers had worse physiological risk and reported better physical health than women (Zhang et al., 2006)

Differences between male and female caregivers for particular types of burden have been highlighted. In Turkey, for female caregivers the higher levels of burden are associated with time dependence, developmental, physical and social burdens, with emotional burden found to be similar in both genders (Akpınar et al., 2011). A possible explanation for the differences offered by Akpınar et al (2011) included women experiencing greater burden from the additional responsibility of taking on further caregiving after raising children. A study in Italy concurred that developmental predominated in women caregivers, but also found higher emotional burden in women compared to men (Iavarone et al., 2014). The sense of coherence of the caregiving situation was found to be higher in male caregivers than women (Valimaki et al., 2009).

Papastavrou et al. (2009) suggest that the differences noted may be as a result of response bias in which females and males may have similar levels of psychological morbidity, but males are less likely than females to report within the surveys that they are experiencing emotional discomfort. It has been noted that there is a tendency for women to be willing to report health and psychosocial problems especially if they are under chronic stress; women may be more aware of their problems, and may have a higher burden in general from their professional and family roles (Zhang et al., 2006).

### **Impact on wives and husbands**

A number of studies looked at spousal care, and the differences in the health impact of caring for a husband or wife on the spousal caregiver. Female spouses were identified in some studies as being particularly vulnerable to caregiver burden and strain, being more likely to react emotionally to the caregiver situation (Friedemann and Buckwalter, 2014, Forbes et al., 2008), and having a greater burden through spending a much longer time on caring related activities. Husbands with dementia received 31 per cent more hours of care than wives did from their husbands (Carter et al., 2012). Despite this, other studies showed no significant difference between husband and wife caregivers in terms of caregiver burden (Papastavrou et al., 2009).

Depressive symptoms were significantly higher in some studies for female spouse caregivers than for men providing care for their wives (Papastavrou et al., 2009; Friedemann and Buckwater, 2014). In spite of being the most spiritually focused, which might be seen to mediate the depressive symptoms, they had the highest depression scores, experienced more burden than male spouses, and reported less optimal physical health. Again there is some discrepancy between studies, with Croog et al. (2006) reporting that husband caregivers showed significantly higher scores for depression than wife caregivers, whereas wife caregivers showed higher scores on anxiety than husbands.

Longer term impact showed that wives continuing as caregivers over two years have more depressive symptoms than those remaining as non-caregivers; for husbands there is no difference between caregivers and non-caregivers (Dunkle et al., 2014). This may be explained by traditional differing gender roles of wives and husbands, with a greater expectation that women take on caregiving tasks, their coping strategies (emotional rather than problem solving approaches), and having additional caregiving responsibilities. Approximately one in three wife caregivers in a longitudinal study had a number of depressive symptoms throughout the study period consistent with clinical depression (Taylor et al., 2008).

Male spouses manage to maintain a relatively high level of wellness despite the challenges posed by the caregiving situation, in part due to the additional support they had for daily care-related activities. The main challenges the men experienced were to do with diminishing communication, cognitive and behavioural changes, loss of companionship and financial burden (Pretorius et al., 2009).

### Impact on spouse carers and adult children

A few studies considered the level of burden experienced by parent caregivers compared to adult children carers, in particular the differences experienced between caregiver wives and caregiver daughters. In the study by Stewart et al. (2014), spouses reported more severity of distress than adult children caregivers, but there was no difference in perception of burden based on type of relationship. This is unpicked further in the same study, where wives reported more role burden (demands of the role), whereas daughters reported more personal burden (difficulty fulfilling their role due to competing demands). In other studies, wives providing care for their relatives expressed lower levels of burden than daughter caregivers (Montoro-Rodriguez and Gallagher-Thompson, 2009), whilst another found no significant difference in the burden and depression levels of wives and daughters (Papastavrou et al., 2009).

Daughters' acting as the primary caregiver also reported higher burden levels than sons providing care and higher depression levels (Papastavrou et al., 2009; Takagi et al., 2013). Sons and daughters in wider support roles were more concerned about the wellbeing of the parent who was the caregiver than the one who had dementia (Egset and Myklebust, 2011). Daughters providing care were more likely to have caring responsibilities for children as well as their parent with dementia – and concern for the well parent acting as primary caregiver – and hold down employment, leading to a conflict between multiple and competing roles (Egset and Myklebust, 2011; Simpson and Carter, 2013).

Additional sources of stress may be pertinent to caregivers in non-traditional roles. For some gay and lesbian carers, the maintenance of control of information about their sexuality was of central importance and the ability to manage sensitive information about themselves was clearly compromised in some situations. As such, the choice (or necessity) to come out to service providers often increased anxiety and stress (Price, 2009), exacerbating feelings of isolation and marginalisation when dealing with the care workforce and their preconceptions about family relationships.

### Impact of cultural differences

Cultural differences can also have an impact on the burden score of family caregivers. Latina caregivers in the USA reported lower levels of burden than non-Hispanic white caregivers (Montoro-Rodriguez and Gallagher-Thompson, 2009), whereas no differences were found between burden in Chinese caregivers compared to American caregivers, despite variances in family traditions and expectations. (Chen and Levkoff, 2010). Differences in caregiver burden have been seen between similar population groups in different countries; Potgieter et al. (2006) found a high degree of carer burden in a study in South Africa, comparative to countries such as Greece, Portugal, Austria and France.

### Impact on wider health issues

There appears to be little research on the health promotion of caregivers, with the focus instead on self-care behaviours (Hodgins et al., 2011). Targeted health promotion may benefit caregivers; although overall physical health of female caregivers caring for a person with dementia was similar to non-caregivers, the caregiver group smoked more and did less physical exercise than non-caregivers, with 74 per cent of caregivers classifying themselves as being physically inactive (not walking for 30 minutes per day) compared to 30 per cent of non-caregivers (Gusi et al., 2009). However, although female caregivers report having less leisure time exercise than non-caregivers, their physical health was similar, due to the physical demands of caregiving.

There were also differences in terms of ethnicity and kinship of female caregivers in terms of physical health issues. Daughter caregivers were more likely to have experienced recent weight gain, to have high blood pressure, or a chronic lung condition than spousal caregivers (Rabinowitz et al., 2007). White caregivers were significantly more likely to smoke, have a heart condition, and experience gastrointestinal difficulties than Latina caregivers, although Latina caregivers were less likely to rate their health as very good or excellent and more likely to rate their health as good, fair, or poor (Rabinowitz et al., 2007).

**Faraneh Farin, Iran**

*In many parts of the world, the structure of societies predefines the role of women as “caring for the families and the sick”. Women are emotional by nature and more family oriented than men. To achieve this goal, the girls are denied of meaningful education and are disciplined in traditional ways of older women. Later, as adults, the lack of education contributes to societal discrimination making them more vulnerable to disease and poverty. Despite the issues women face today, the evidence shows that in the 21st century women live longer than men, but not necessarily healthier. It is estimated that there will be a bigger population of women who will be afflicted by dementia and therefore more daughters, daughter in-laws have to cope with the burden of care. Nowadays, more women are working to support their families but should they need to care for a family member, then it is expected that they quit their jobs resulting in their marginalisation. It seems that either way, whether a woman has dementia or she cares for a loved one, she is trapped in the cycle which has been constructed by the society. Dementia is an issue that engages a woman's entire life.*

## Chapter 5

# The role of gender in managing and accessing support



**T**he approach to managing and organising the caregiving process and coping with the demands of caregiving appear to differ according to the gender of the caregiver. Navigating the health and social care systems and networks to support the person with dementia and their caregiver, understanding what help is available, and accessing appropriate formal and informal services has been described by carers as difficult and confusing (Peel and Harding, 2014). As the person living with dementia becomes less able to make decisions themselves about their care situation and the support they need to access, the responsibility for this increasingly lies with the caregiver (Bamford, 2011). Having a supported decision-making model in place which involves the person with dementia as much as possible, for example by documenting their care preferences, should ensure that the caregiver has a good understanding of the person's views when decisions about care need to be made on their behalf (WHO and ADI, 2012). However, caregiving is becoming more complex, with caregivers caring for multiple family members and experiencing their own health problems (Lantz, 2009).

## Knowledge and education about dementia

The attitudes, knowledge and experiences of dementia vary in the general population. According to the survey conducted by the Alzheimers Association (2014), over half of the respondents reported knowing someone with dementia, and were more likely to have heard or read about it than those who did not know anyone with the disease. They found similar levels of knowledge about the disease between women and men, but found larger differences between ethnic groups, and concluded that more education was needed about risk factors for dementia across the population, with particular need for certain ethnic groups. Some ethnic groups saw dementia as a normal part of the ageing process, and therefore not a health problem (Botsford, 2012; Turner et al., 2005); this may affect understanding of when a person has dementia, and may delay seeking professional help to support the person with dementia and their families (Gray et al., 2014).

A lack of understanding about dementia in some cultures can lead to inappropriate practices, and greater community education is required to safeguard the wellbeing of vulnerable older people, particularly women (Bamford, 2011). A study in Tanzania noted that the majority of people with dementia and caregivers did not know what dementia was, and related it to stroke, high blood pressure, diabetes, old age, curses or witchcraft (Mushi et al., 2014). In one study of Asian-American males and females, women seem to know less about the prognosis of dementia than men (Siri and Woo, 2014), and were more likely to worry about developing dementia than their white counterparts (Gray et al., 2014). Given the disproportionate effect of dementia on women, both in developing dementia and as caregivers, efforts need to be made to ensure women know about and recognise dementia as a disease, and understand the need to access professional help (Siri and Woo, 2014).

As well as identifying the need for more education about dementia amongst the wider population, there also appears to be a lack of information and education available for those who become caregivers after a diagnosis of dementia has been made (Olazaran Rodriguez et al., 2011). Toribio Diaz et al. (2013) noted a lack of dementia education with just over a quarter of principal caregivers (26.2 per cent), and secondary caregivers (27.3 per cent), the majority of whom were women, receiving any training in dementia care. This figure was even lower for formal caregivers (13.6 per cent) providing care in the home (Toribio Diaz et al., 2013). Ducharme et al. (2011) also noted the almost absence of informational and instrumental support when for a caregiver going through the transition to and adapting to this new role.

Providing caregivers with knowledge about dementia and methods for coping and better knowledge of the care structure are amongst some of the interventions which can help to alleviate some of the stress of caregiving and improve outcomes and quality of life for both the caregiver and the person with dementia (WHO and ADI, 2012; Toribio Diaz et al., 2013).

## Coping strategies

Finding ways to understand and cope with the stresses and strains of dementia caregiving can help the caregiver maintain control and not feel overwhelmed by their situation, which can impact on the caregivers health outcomes (Montoro-Rodriguez and Gallagher-Thompson, 2009). Coping styles can influence health outcomes; active coping styles, including avoidance and positive coping are can mediate the impact of background stressors such as managing the care-recipient behavioural problems on caregivers' psychological outcomes (Montoro-Rodriguez and Gallagher-Thompson, 2009).

Much of the literature suggests that different coping strategies are adopted by men and women within their caregiving role, with men focus on problem solving and accomplishing tasks and preferring to make sense of their experiences at a cognitive level, whereas women focus more on the quality of task performance and emotional support, albeit with some cross over between the different approaches (Calasanti & Bowen, 2006; Pretorius et al., 2009; Egset and Myklebust, 2011, Etters et al., 2008).

The focus for men on practical solutions to problems encountered during the caring process was seen to make it easier to take on responsibility for the house and home, and adapt to being a caregiver (Ducharme et al., 2011). Male caregivers also tend to adopt mechanisms that help them to create a psychological distance from the care recipient, focusing on practical tasks, thus reducing the stress of care (Papstavrou et al., 2007). The more methodological approach to caregiving used by men suggest that this role is seen as a 'new job' (Takano and Arai, 2005). It has been suggested that the previous experience of men in paid employment has enabled them to develop a stronger and wider repertoire of managerial techniques, and develop a more positive approach to problem-solving (Hong and Coogole 2014). Men appeared to be more logical in preserving self-identity/role, and proactive in pursuing innovative activities (Hong and Coogole, 2014).

Female caregivers were found to follow more emotion-focused coping strategies, with more

negative responses to the stress of the caregiving situation (Iavarone et al., 2014, Eters et al., 2008, Papastavrou et al., 2007) and lead to higher levels of distress. Emotion-focused strategies are influenced by gender, and strongly related to burden, trait anxiety and, to a lesser extent, dementia severity (Iavarone et al., 2014). This is thought to be related to the cultural traditions that they are expected to provide care, unlike men who receive greater recognition and endorsement from the community for taking on the caregiving role (Iavarone et al., 2014).

Given the differences in the coping strategies adopted, caregivers, especially women, would benefit from specific training in how to understand and manage the behaviour of relatives with dementia and how to cope with their own feelings. (Papastavrou et al., 2007)

Cooper et al. (2008) found that caregivers using emotion focused caregiving strategies had the same level of anxiety at the follow up one year later, unlike using problem solving approaches, which were associated with higher anxiety a year on. It was suggested that as the dementia worsened, problem solving strategies were harder to implement as the condition of the person with dementia deteriorated. Also, applying the problem solving coping mechanism to long term planning may be difficult, given the unpredictable nature of the disease (Egset & Myklebust, 2011; Ducharme et al., 2011).

Despite the apparent gender split between the different coping strategies, there were exceptions to this, and it would appear that coping strategies such as active problem-solving skills are beneficial in caregiving irrespective of caregiver gender (Baker and Roberston, 2008; Poysti et al., 2012; Iavarone et al., 2014). Spouses were found to have a more emotion focused approach and problem solving approaches less often (Ducharme et al., 2011). In one study where the care-receiving wives were more impaired as a group than the care-receiving husbands, using an emotional coping strategy allowed the caregiver husbands to care for spouses at home longer than might otherwise have been the case (Calasanti and Bowen, 2006).

A reliance on religion was also linked to emotional coping strategies, with female Turkish and Moroccan caregivers indicating that they gained a great deal of strength and support from their religious faith in relation to caregiving, enabling them to sustain their caregiving activities (Potgieter, 2006; Wezel et al., 2014)

## Care structures and support

The approach to caring for a person with dementia will depend on the family structures of support that are in place, cultural norms and expectations, understanding what formal and informal support services are accessible locally, and having the necessary financial and other resources available. 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. Six of seven (85.7 per cent) WHO dementia survey respondents from high income countries reported that community services are provided to people with dementia, compared with 3 of 21 (14.2 per cent) respondents from LMICs. Fewer services were available to those living in rural areas; China and Russia, for example, reported that services are limited to major cities (WHO and ADI, 2012). In Korea, despite the recognised importance of support services for families caring for people with dementia, few such services available (Kim et al., 2009).

In high income countries, people with moderate to severe later stages of dementia often have the option of being cared for within long term care facilities; this provision of service rarely exists within low and middle income countries, which lack the infrastructure of health and social care (Bamford, 2011). Family structures are often relied upon to provide informal care and support, with the person living with dementia co-residing with their primary caregiver.

## Informal support from family and friends

As we discussed earlier, many people with dementia are cared for by family members in their own homes, at least in the mild to moderate stages of the disease. Often the main caregivers are

spouses or adult children, in many cases co-residing with the person with dementia. Providing care is difficult, and the main caregiver often relies on support from a wider network of family and friends. The experiences of providing informal care within the home appear to be broadly similar across developed countries. The EURO CARE study looked at the experiences of 280 spouse carers from 14 European countries. In this, the respondents talked about their experiences, satisfactions and difficulties with caregiving in broadly similar terms, showing consistency across gender and national boundaries despite differences in patterns of informal care and formal services (Murray et al., 1999).

Traditional extended family structures and strong family bonds, with cultural expectations that family members would be cared for within the family setting were described in a number of studies in a number of different countries (Akpınar et al., 2011; Kim, 2013, Toribio-Diaz et al., 2013). With extended families and the complex nature of the family set-up, family members took on roles to deliver care (Beeber and Zimmerman, 2012), with examples of grandchildren providing direct help to their grandparents with dementia, most notably when their parents were engaged in a greater number of hours of caregiving (Hamill, 2012). The young people who provided more care to grandparents demonstrated more positive attitudes toward the provision of long-term care to older parents in general (Hamill, 2012). However, having larger households and traditional extended family care networks did not necessarily reduce the strain experienced by the main carer (Prince et al., 2012).

Family structures are changing more widely from the traditional model, due to divorce and remarriage, falling birth rates, greater mobility and an increase in female employment (Schneider et al., 1999). In American Indian communities, this has meant that family care relies on individuals – often women – to provide care, rather than relying on an extended family network (Ryser et al., 2014). Likewise in urban areas of Africa, the evolving family structures toward western models and the nuclear family, has resulted in lower availability and importance of family support compared to rural areas (Paraiso et al., 2011). Migration patterns are also having an impact on the availability of family caregivers (Watt et al., 2014).

The changing family support structures have particular implications for women. In Japan, most elderly people live alone or with their spouses, and gender differences were apparent in the family care structures for people with dementia. According to Ono et al. (2010) most men with dementia (59 per cent) had been cared for by their spouses, compared to 11 per cent of women. The women were divided into two groups: those who had been living alone, most of whom had been cared for by their children and women who had been living with their families, mostly being cared for by their daughters-in-law (Ono et al., 2010 and 2011). A different model of care has been reported in Spain, where 15 per cent of the people with dementia in one study area were living with different members of the family in rotation, rather than using care homes (Rivera et al., 2009; Toribio-Diaz et al., 2013). Living in rotation was most commonly associated with low socio-economic neighbourhoods, the majority of people were women (80 per cent), and all were widowed.

A number of studies noted that male primary caregivers, in the majority of cases caring for their wives with dementia, often depended on additional support from daughters or other female members of the family, reinforcing traditional female caregiver expectations (Brown et al., 2007), and possibly influencing the lower levels of burden found in men (Papastavrou et al., 2007 & 2009; Alzheimer's Association, 2014). Likewise in South Africa, the white middle class male caregivers depended on their daughters and/or housekeepers as their most accessible and dependable sources of support, particularly in the upkeep of their domestic environment (Pretorius et al., 2009).

Some caregivers noted that their role was rarely acknowledged by other family members, with assumptions that the caregiver daughter is obliged to take on the role without relying on support from other family members rather than it being an obligation to be shared by all family members (Flores et al., 2009). In another study in Spain, whilst only just over half of the caregivers received help from other family members, two thirds felt that their caregiving role was acknowledged



(Olazaran Rodriguez et al., 2011). Not all family contact was positive; non-supportive interactions, such as criticising and refusing requests for support were sometimes experienced by women carers from family members, but this was sometimes used as a stimulus for change (Neufeld et al., 2007). Being given positive feedback from others could enhance self-esteem and have an impact on the life satisfaction of caregivers (Kaufman et al., 2010). There was also a recognised reluctance to ask for help, with some caregivers being afraid that friends and family members will see such a request as a sign that they are incompetent (Ducharme et al., 2011).

There is a gender imbalance between the availability and take up of informal support for carers, and was found to differ between women looking after their husbands and men looking after their wives. Women caring for husbands with advanced Alzheimer's disease reported receiving less support from family and friends than men caring for their wives in similar situations, linked to experiencing poor psychological and physical health (Alzheimer's Association, 2014). Where women did receive family help, the level of help was not sufficient to significantly reduce their caregiving workload or their burden (Friedemann and Buckwalter, 2014). However, research in LMICs found a trend towards lower levels of strain among carers who received additional informal support from other family members or friends, particularly in Latin American countries. Few Chinese or Indian carers reported receiving additional informal support (Prince et al., 2012).

Support from wider networks of friends outside the biological family was identified as an important factor, especially for caregivers for whom family relationships have been strained prior to the diagnosis (Price, 2011). This is particularly relevant for lesbian and bisexual women who are less likely than heterosexual women to have children, and may not have access to the same intergenerational support networks (Westwood, 2014). Women were more likely to use informal social networks for support including emotional support, especially from networks of other women (Eriksson et al., 2013). Men reported having fewer relatives, friends and confidants than women, which may explain the lower use of informal support (Sun et al., 2008; Pretorius et al., 2009; Kaufman et al., 2010). It has also been highlighted that policy decisions need to be taken about whether to prioritise care for those without closely related caregivers in response to changing family structures, where family caregivers do not exist, or cannot be expected or relied upon to provide the necessary level of care (Egset and Myklebust, 2011).

## Formal social and health support

The take up of more formal health and social care varies depending on the availability and accessibility of the service, and a willingness to access these services (Flores et al., 2009) and this differs for men and women (Brown et al., 2007). Formal care defined by Schneider et al. (1999) as being the services provided by statutory or voluntary agencies to support the person with dementia living in the community, which include cleaning, personal care, some elements of home nursing, shopping and laundry. For this review this definition was extended to health professionals and the support specifically for caregivers as well as for the person with dementia.

Male caregivers were more likely to receive formal practical support and use external resources than women in caring for their spouses and were more likely to be willing to accept help to enhance the level of support they could provide (Brown et al., 2007; Sun et al., 2008; Pretorius et al., 2009; Boylestein and Hayes 2012). This included receiving assistance with personal care and respite from family members and to use formal services such as overnight hospitalization, personal care and housework assistance (Forbes et al., 2008). Looking at specific services available, female caregivers were more likely to use transportation services than men (Sun et al., 2008).

Support groups played an important part of the informal support network. Women often used regular attendance at support groups and informal group meetings as a support mechanism; these were an important factor in the comprehension of the caregiving situation, their sense of coherence (Potgieter et al., 2006) and for sharing information (Kazmer et al., 2013). These support groups were used far less frequently by men (Brown et al., 2007), as they saw them as being aimed at more women, and having an "emotionally expressive climate" (Pretorius et al., 2009). However, Sun et al. (2008) found no significant gender differences in the use of day care or

support group services.

There did appear to be a reluctance to seek out help where it was available. For example, the need for external support for spouses taking care of their husbands was downplayed, both by the wife caregiver and by the health professionals she encountered (Eriksson et al., 2013). Reasons cited for not wanting to use support included not wanting to place a burden on the support services, taking services away from someone with a greater need, or acknowledging personal shortcomings (Eriksson et al., 2013). Also, caregivers were not aware of the services that were available (Ducharme et al., 2011), making it difficult for the caregiver to give any thought to long term planning for meeting the longer term needs of person with dementia. In the study by Forbes et al. (2008) the respondents who reported that their health care and home care needs had not been met in the preceding year, gave the main reasons to be that the services they needed were not available, followed by cost, decided not to seek care, and did not know where to go.

This may be particularly pertinent for women – a study in Turkey indicated that women had significantly fewer follow up appointments with specialist health professionals than men (Yaman and Yaman, 2014). In the context of migration, for U.S.-born Latinos caregiving is kept within the family due to both cultural expectations and limited access to social services (Flores et al., 2009). However, for the Chinese American community in the USA, women were disproportionately bearing the burden of dementia caregiving, but were still likely to access health services as a result despite the stigma around this and taboos about discussing problems with someone from outside the family (Leung and Gallagher-Thompson, 2005; Dao and Woo, 2014).

Lack of access to formal paid support for caregivers may result in poorer outcomes for the person with dementia. Where paid carers were employed in Benin in Africa, China and Latin America it was primarily in urban areas; rural communities in low and middle income countries face additional problems such as difficulty accessing necessary and adequate services; transportation and distance from services; lack of awareness of available services (Crosato and Leipert, 2005; Prince et al. 2012), although in high income countries a relatively high level of social support was available in rural areas with a high level of active and socially supportive networks (Kaufman et al., 2010).

Support is needed to enable informal caregivers to be able to continue in their role for as long as possible; the use of paid carers in LMICs was generally associated with lower carer strain for the main family caregiver (Prince et al., 2012). In Australia, carer changes were found to be a significant predictor of formal service use, including older age, sleep difficulties, needing care themselves and needing co-resident care (McKenzie et al. 2014). As well as supporting the person with dementia with regular ongoing caring tasks, access to temporary respite care enables the caregiver to maintain their identity outside that of the caregiver role, and to engage in other activities (WHO and ADI, 2012). Respite care includes a range of services and settings, from a few hours in-home help, attending a day centre, or residential care for several weeks.

As women caregivers are the most exposed to social isolation and to the burden of care, they may experience the greatest benefit from having respite from caring, in maintaining her identity in relation to others and the environment in which she lives (de la Cuesta-Benjumea, 2010; Romero Moreno et al., 2014). As with other forms of formal services and support, the availability and cost of respite care differs widely in different areas. In the WHO dementia survey, whilst 5 out of 8 (62.5 per cent) high-income countries provided respite services, this was the case for only 3 out of 22 (13.6 per cent) LMIC respondents, although in a further three LMICs, respite was provided through a private provider or from the local Alzheimer organization (WHO and ADI, 2012).

Raising awareness of appropriate services for caregivers is important in achieving the best outcomes for both the caregiver, and the person with dementia for whom they are caring. There also needs to be a strategy to “reframe” the reluctance to seek help, to support caregivers to view help and support as a necessary resource rather than a sign of incompetence or an inability to cope (Ducharme et al., 2011). Health professionals need to understand the significant benefit that they can provide for both people with dementia and caregivers through their help; medical

professionals could have a very positive effect on the comprehensibility and manageability that caregivers experience in this situation (Potgieter et al., 2006). There is a need to have gender specific support from professionals, to take into account different approaches of men and women to providing care (Boylestein and Hayes, 2012). However, health professionals also need to consider the individual groups with diverse social identities with specific needs, and offer professional and culturally appropriate responses to caregiver's lifestyles (Price, 2009).

A number of interventions have been developed to deliver the best support caregivers by health and social care professionals. Although many of the studies identifying gender differences between coping and support mechanisms, and many highlighted the importance of developing interventions that were tailored to the individual needs of the care recipient and the caregiver as a unit (Etters et al., 2007; Ono, 2010), there were few evaluations of interventions with a specific focus on the influence of gender that emerged in this review process.

## Institutional and residential care

Supported residential care was available in the majority of high income countries and one third of LMICs (WHO and ADI, 2012). For many caregivers, the use of institutional care or care homes was a last resort, when not rejected as a concept outright. Moroccan and Turkish carers saw home care as being superior to that provided by care homes, as they could provide adequate access to religious and other social factors. Whilst the high costs of nursing homes were often prohibitive anyway, cultural factors dictated that care would be provided in the home, almost certainly by a female caregiver (Wezel et al., 2014). Early nursing home placement was associated with a number of factors, including caregiver burden, more family dysfunction, and decreased social support, along with female gender of the caregiver (Etters et al., 2007).

The decision to place a person with dementia into a care home is never easy, with a number of factors leading up to the decision. Davies et al. (2012) found that male and female spouse caregivers reported similar reasons for choosing to place their spouse in a residential care home. The most common reasons were the functional status of the person with dementia (55.6 per cent), cognitive function (51.6 per cent), or problems with incontinence (44.4 per cent). Once the decision had been made for the person with dementia to go into residential care, spouse carers, the majority of whom were women, found that their caring role became ambiguous and liminal, leaving them coping with a transitional situation that may last a significant amount of time (Hennings et al., 2013).

## Decision making

All respondents, regardless of gender, found it difficult to make decisions regarding professional care (Egset and Myklebust, 2011). However according to the literature, the process of decision making about the care of the person with dementia appeared to be gendered, with different approaches to decision making being used by male and female caregivers. Boyle (2013) found that wife carers were more likely to use facilitative approaches to make decisions than male caregivers whereas husband carers often adopted supervisory or overseeing roles. Boyle suggests that as caring and nurturing are often seen as feminine characteristics these were taken for granted by wife carers, whereas husband carers emphasised their approach in order to demonstrate competency in their new caring role.

These observed gender differences tended to disappear when major decisions were being made about care for the person with dementia (Boyle, 2013). Alongside this, family relationships and dynamics influence how the bigger decisions are made and who is involved in making these decisions, involving a larger number of family members and people other than the primary carer (Yektatalab, et al. 2012). Difficulties were experienced by women caregivers who made decisions in day to day care, but were disregarded or had less influence in making longer term care decisions. These experiences included wives in second marriages encountering problem situations with their husband's children from an earlier marriage (Sherman and Bauer, 2008), and also in situations where male relatives got involved in decision making about longer term care, but

were generally 'absent carers' not involved in day to day aspects of care (Dunham and Cannon, 2008). This was also the case for Iranian families who described a large number of family involved in decision making acting on behalf of the person with dementia. The person with dementia often appears to be excluded from the decision making process, even when they have the capacity to make decisions (Yektatalab, et al. 2012; Boyle, 2013).

Given the gendered differences found between decision making processes, and also preferred support strategies, these differences should be recognised by nursing and care staff, and taken into account where appropriate in discussing and agreeing the most appropriate support for each family. Caregiving interventions and support should be gender specific (Boylestein and Hayes,

### **Kate Gordon, USA**

*As the disease progresses, people with dementia are rendered totally dependent for all activities of daily living and the burden of care falls to others. Thus, the impact of dementia involves not only those living with the disease, but also their primary caregivers, who, most often, are female. Globally, most people with dementia live at home. It is in the home where they are cared for by daughters, granddaughters and female siblings and other members of their family. The global effect of increased life expectancy means that we will continue to see the numbers of multi-generational caregivers increase, who will be faced with the daily demands of dementia care needed by their grandparents (in late to middle stages) and parents (in early to middle stages), all the while still managing to raise their own children. These challenges are compounded as caregivers may face negative impacts upon: their own health; their ability to meet obligations to others (e.g. spouse); and their finances. Caregiving clearly impacts their ability to fulfil all obligations simultaneously, which serves to increase the burden on the family as a whole.*

*Whether caregiving for multiple generations or only a single family member, female caregivers bear a two-fold financial burden: in the short-term due to lost wages and added household costs (e.g. prescription drug costs and payment for services to provide additional caregiving services) and long-term due to the negative impact on employment-based pensions. Financial assistance to the elderly is determined on prior work and earning history. Caregivers, and in particular the traditional roles of women as caregivers, are particularly vulnerable as it is more difficult for caregivers to build sufficient contribution or official work records for pensions in systems that require long vesting periods.*

## Chapter 6

# Women in the dementia care workforce



**W**omen make up about 42 per cent of the estimated global paid working population. Within the health sector, in many countries women comprise over 75 per cent of the workforce (WHO, 2008). Women make up the largest proportion of the professional care workforce in dementia care, and provide formal care and support for the person with dementia and their caregiver. Health and social care covering all stages of the dementia journey are essential, including post-diagnostic support, community support, services for continuing care and end-of-life palliative care (WHO and ADI, 2012). The people involved in delivering care as part of the care workforce include those in primary care, domiciliary care, social work, hospitals, community health, care homes, covering a range of roles and qualifications and working in a variety of statutory, for-profit and charitable funded organizations.

In the UK, 87 per cent of the dementia care workforce is female, a greater proportion than the care workforce overall (Hussein and Manthorpe, 2012). Almost three quarters were involved in providing direct care, and three quarters were employed by private sector organisations. A larger proportion of dementia care workers worked for employment agencies, with fewer on permanent contracts. The dementia workforce contained significantly more non-British workers (19.1 per cent vs. 15.3 per cent;  $p < 0.001$ ) than other sectors of the care workforce. There was also a noted lack of training within the dementia care workforce, with fewer people with qualifications. The gender pay gap for people working within the health and social care environment means that the median hourly earnings for women is 10.1 per cent lower than that of men in a similar role (Perfect, 2012).

### Migration and care work

The employment of migrant workers, predominantly females, within the care workforce was mentioned in a number of studies (Rosa, 2007; Solari, 2006). In Italy, the use of full time care

assistants living with the family are associated with significant improvements in the primary caregivers' objective and subjective burdens (Rosa et al., 2007). A similar arrangement was becoming more frequent in Israel (Ayalon, 2010), where is subsidised by the government to keep older adults in their home environment for as long as possible, as a cheaper alternative. Of the relatively few men employed as carers, there were concerns about the low status of care-work, with one Russian migrant worker in the USA noting that care-work and domestic labour was not part of the "gendered expectations for men" (Solari, 2006). Women care-workers in the same situation some saw it as an extension of their domestic caring experience or as a professional job, and emphasised work contracts, technical skills, and qualifications, creating boundaries between professional and personal roles. One third of migrant workers in care suffered from depressive symptoms, with half of these identified as being severe.

## Distress in care work

Barbosa et al. (2013) identified two sources of negative impacts on well-being of care workers looking after people with dementia in care homes. The first was the inability to provide ideal care due to time pressure, workload, lack of emotional support from managers, difficulties in communication and lack of information about dementia. The second related to problems managing residents behaviour, and the emotional and physical exhaustion that resulted from that, and was reported to have an impact on their own family life, indicating a conflict between their personal and professional life. The need to have more training and information about dementia was noted (Lee et al., 2013), along with developing specific competencies for health professionals working in the field of dementia (Barbosa et al., 2013). Having an increased skills and knowledge in how to provide care for people with dementia and complex needs can help nurses and other professionals in the care workforce in reducing work related stress, along with additional support from managers (Isaia et al., 2010).

## Education and training

There appears to be an overwhelming need to provide specific training and education to the formal workforce about dementia, as indeed is the case for informal carers. In Latin America and China, the paid care workforce is overwhelmingly informal and unregulated, with untrained and inexperienced care workers, usually recruited from people moving from rural areas to cities (Prince et al., 2012). The majority of migrant workers in care (86 per cent) do not have any dementia-specific training before they start work, although most (80 per cent) would like training to feel better prepared for and cope with the challenges of providing dementia care.

### Li-Yu Tang, Taiwan

*Formal caregivers in the Taiwan workforce are mostly women, including nurses and care workers in dementia day centre or dementia special care units. In Taiwan society, women are the key caregivers in the households, and most people with dementia are taking care by their wives, daughters and/or other female relatives. According to the studies in Taiwan, around 70-80 per cent of the family caregivers are female and we believe the figure will continue to grow in the future. Contrary to women's role as caregiver in the family, their own health may be placed in the lower priority or even be neglected. Generally, women are an economically disadvantaged group in Taiwan, especially in rural communities, so it's obvious that dementia is a women's issue. We need to support women who are dementia caregivers without any resources inside or outside the family. We need to support women to help reduce their own risk of dementia. Community health program should pay more attention in the early screening of dementia, especially women especially in rural communities and health care deprived areas.*

## Chapter 7

# Conclusions



**T**his report provides an overview of the international research evidence that highlights the extent to which women are disproportionately affected by dementia. More women develop dementia, and a large proportion of carers are women, in both informal and formal capacities. Despite the review of the research evidence confirming the impact of dementia on women, public health and social care policy developments, particularly in LMICs, still need to be developed and implemented to address the issues facing women.

### The perspective of people living with dementia is absent

The vast majority of the research relating to gender and issues of dementia affecting women focused on caregivers. In many cases, the perspective of people with dementia appeared to be overlooked – especially during the early stages of the disease, getting this perspective on the type of care they would prefer, and their expectations of the relationship with their carer, including the level of care provided, would be beneficial in understanding the needs of all those involved. The decision making process should include the person with dementia. A number of studies indicated that decisions were made for them with no consultation, even when they were capable of expressing their preferences (Goodman, 2010; Boyle, 2013). The research on caregiving and the decision to become a carer makes very little reference to the preferences of the person with dementia.

### Research on caregiving is complex

The review highlighted a number of variations between studies of the impact of caregiving on physical and emotional health and wellbeing, making it difficult to compare studies directly and present an accurate picture of the true impact of dementia on women compared to men. There is variability in how participants were recruited to research studies and the instruments used to gather data about the impact of their caregiving. Few studies presenting quantitative measures of burden and health impact present comparative data about levels of burden, depression and anxiety before the diagnosis of dementia.

The majority of studies used a cross sectional design, with no longitudinal data about how the situation changed over time. Cultural contexts are not always taken into account when looking at analysing the data collected. Although there are several longer term, large scale studies, these need to be revisited as changing demographics and family structures have an impact on caring for people with dementia. Even where longitudinal data is available, the follow up periods are relatively short in relation to the dementia journey. 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.

## Caregiving in dementia is a gendered issue

Despite some ambiguity in some of the data, the overwhelming outcome from the research is that across all regions and settings, women bear the brunt of the incidence of dementia and the responsibility for caring for people with dementia. There is a consensus across the research evidence reviewed that caring for a person with dementia and the process in general is stressful, with implications for the physical, emotional and financial wellbeing of caregivers. As women make up the largest proportion of caregivers the overall impact on women will be greater. Much of the evidence points to how men and women approach and react differently to changes in their roles and identities, realigning their expectations within the relationship, and the need to take on different tasks associated with caregiving. The gender differences need to be understood by health and social care professionals working with the caregivers, and will have implications for the design and implementation of interventions to assist them; there is less evidence about the impact of the interventions on the caregiving role in terms of gender, although that was not the primary focus of this review. Despite many intervention studies having all of mostly female participants, few discussed the issue of gender within their findings.

Women will continue to provide care, whether this is due to societal expectations, or an individual wish to support members of their family and friends. Whatever the motivation, there needs to be adequate and appropriate information and support in place to enable these women to provide care, and feel cared for themselves. Women need to know what support is available, and understand that accessing support is not a sign of weakness or inadequacy, rather creating the best environment to provide care.

## Family structures are changing worldwide

Much of the research conducted to date has focused on family care, and dependency on the wife or husband, or children (mainly daughters) to provide care. There is a growing recognition that family structures are changing, particularly with migration to urban areas in LMICs and the number of people living alone or with a partner rather than in extended family structure is increasing. One study suggested that policies should focus priority on those without closely related family – very little research emerged on women with dementia without family caregivers, or the impact of migration of younger family members on care provision for the older family members remaining behind. Research and policies to support dementia also need to take account of those not living in heteronormative family contexts: lesbian, gay, bisexual and trans people with dementia, who may have ‘families of choice’ rather than relationships recognised legally or societally. Health professionals need to incorporate the important contributions of families of choice into assessment and care provision processes, procedures and practices. Further research would be welcomed with caregivers who do not fit the categories that are predominantly covered in the current research (such as friends, in-laws, unmarried partners, both same sex and different sex).

## Women and men access support in different ways

It emerged that there was often some reluctance amongst women caregivers to access help from formal and informal support services. This may be due to conflicts between cultural and family expectations or the ability and willingness to seek help on the part of the caregiver. Women



caregivers need to be supported by health professionals to seek help at an earlier stage, and to enable the caregivers needs to be assessed soon after diagnosis, during the difficult and often confusing transition period, to ensure that the caregiver is aware of services and how to access them, and if there are unmet support needs (Ducharme et al., 2011). In LMICs, it was seen to be particularly important to ensure that community services were more easily accessible to women with no or lower levels of education, who were more reluctant to seek help outside the home.

## **Women approach dementia and caring in different ways**

Women living with dementia have complex needs that are often difficult to manage. Where possible, support should be provided from a competent health-care provider who is knowledgeable about dementia, experienced in the management of the condition, and is aware of the individual needs of the person with dementia and her caregiver (Forbes et al., 2008); this includes sensitivity to the gender differences of persons with dementia and their caregivers. Many studies noted the importance of avoiding a one-size-fits-all approach to understanding caregiving or in intervening to help by care workers, recommending the need to provide approaches to care and interventions for specific groups, whether these are wives, men, daughters with feelings of guilt, gay and lesbian carers. The term 'women caregivers' does not refer to a homogeneous group; instead it covers a wide variety of people in different roles and with a wide variety of characteristics: wives, daughters, daughters-in-law, working, retired, mothers with young children, single, married, lesbian etc. All these factors, along with cultural, religious, financial and other socio-economic factors, together with their own personal perspectives, make it difficult to generalise about the requirements of the caregiver, and highlight the importance of assessing individual needs.

## **Professionals and workforce need to be skilled in assessment and care**

Recommendations from much of the research focuses on the need to tailor interventions and support to individual needs – this means that appropriate resources and training need to be in place to assess the individual needs of the caregiver-care-recipient dyad, and take into account relationship of caregiver to care recipient, past relationship, reasons for taking on the caregiving role, and social support networks. Many researchers highlighted community nursing staff as being in the best position to undertake this assessment, and inform carers of the support available. This assumes that healthcare professionals are confident and well trained in dealing with dementia, and are aware of the issues around caring. A sufficiently resourced formal workforce, educated about dementia and caring for someone with dementia is needed to ensure carers are well supported, thereby minimising the health impact of being a caregiver for a person with dementia. This may involve the care worker being confident to encourage family caregivers to overcome cultural taboos about discussing family health problems, or admitting a need for support.

## **National dementia strategies need to address the needs of women**

The needs of women with dementia and women caring for a person with dementia are extensive and varied, and need to be acknowledged and supported. There are a number of ways this needs to be addressed. For every country at a national level, the impact of caregiving on women needs to be fully understood and acknowledged; health policies need to be in place to ensure that the health and social care workforce in the community is trained and knowledgeable about dementia and the types of intervention that would usefully reduce the burden on female caregivers. Given the benefits of respite care, particularly for women caregivers who may be isolated within this role, provision should be available for respite care, to help caregivers maintain their identity outside that of being a carer, and provide some sense of continuity beyond caregiving.

## Limitations to this review

There are a number of limitations of this study. A number of papers were not available within the timescale of the review, and may have additional findings to add to the knowledge gathered within this report. All the papers that were found to be relevant to the focus of this review were included in this report, to give a broad overview of the issues affecting women in relation to dementia.

There are notable gaps in the literature from low and middle income countries around gender and dementia, with the few papers that were identified mainly focusing on prevalence and issues for caregivers. There were also gaps in the literature on the financial impact for women in relation to dementia, and on the availability and level of education. More research into the complexity around changing family structures resulting from migration, changing employment patterns, and divorces and remarriages is also needed to ensure changing needs are recognised and understood. While this report provides a broad overview of the recent research evidence relating to women and dementia, there is still much to do to understand the needs of women and the impact of dementia on their lives in all areas of the world.

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## **About Alzheimer's Disease International**

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Each of our 83 members is a non-profit Alzheimer association supporting people with dementia and their families.

ADI was founded in 1984 and registered as a non-profit organization in the USA. Based in London, ADI is in official relations with the WHO since 1996 and has consultative status with the UN since 2012.

ADI's vision is an improved quality of life for people with dementia and their families throughout the world. ADI aims to make dementia a global health priority, to build and strengthen Alzheimer associations, and to raise awareness about dementia worldwide.

Alzheimer's Disease International:  
The International Federation  
of Alzheimer's Disease and  
Related Disorders Societies, Inc.  
is incorporated in Illinois, USA,  
and is a 501(c)(3) not-for-profit  
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