



Women and Dementia – Not forgotten

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About this Report

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1. Executive Summary

Dementia now represents one of the greatest challenges to our economic, health and social care landscape. It is set to not only irrevocably change the lives of ageing citizens across the world, but also shake the tenets of the systems and structures that underpin our societies. With no known cure and with limited treatments available to counteract the insidious impact on an individual's personhood, dementia will redefine our individual and collective experience of ageing.

Against this backdrop, this report posits that women will disproportionately bear the burden of dementia and a gendered approach and response to dementia is now required at the regional, national and international level. The 'feminisation of ageing' is a widely recognised trend and yet hitherto a comprehensive approach to the impact of dementia on women remains largely under explored. Invariably women and men, as they age, share many of the same fundamental needs. Yet, as is acknowledged in many parts of the world, older women are particularly vulnerable and are subject to prolonged inequalities experienced since childhood, for example, lower levels of education and a greater risk of poverty. This report assumes a life course approach to the challenge of dementia and women, arguing from a global perspective that women face a 'triple jeopardy' as a result of the associated stigma attached to their age, gender and decline in cognitive functions.

Dementia is set to be a particularly foreboding reality for many women. Several studies show the prevalence of dementia syndromes, specifically Alzheimer's disease, is increasing among women and this appears to be a cross-cultural, cross-national phenomenon (Kukall at al, 1994). Indeed the near-universal gender gap in life expectancy in favour of women, with this imbalance increasing with age, demonstrates women have most to fear from dementia. It is widely accepted that advanced age is the main risk factor for most forms of dementia syndrome, with prevalence roughly doubling every five years over the age of 65. This pattern is evident across most parts of the world; in Europe for example, one study cites there are approximately over five million women with dementia, compared to two and half million men (EuroCoDe, 2006-2008).

Thus the numbers alone suggest a need for policy interventions and frameworks that include sex (from a biological perspective) and gender (as a social construct). This need is particularly pertinent if one considers the risk factors - which are sex and gender specific - that can increase an individual woman's likelihood of developing a dementia syndrome, these include: sex-

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specific genes, reproductive hormone levels, depression and education, to name just a few. It is therefore essential that health policies and practices reach out to women throughout the life course, not only in terms of the prevention agenda, but also to close the gap in inequalities that exist in terms of the role and position of women in certain societies. The latter point is critical in terms of women with dementia having the opportunity and resources to access health and social care.

The report also explores the gender-specific nature of unpaid care and argues family care is in most cases a euphemism for female care, with women shouldering the responsibility of dementia care in most parts of the world. This aspect of unpaid care exposes the individual and collective cost of dementia to women, and, as noted in the opening paragraph, many women will experience the profound hardship of dementia initially through their caring responsibilities, before they experience the possible onset for themselves. Across the developed and developing world this pattern seems to be borne out, for example, just over 80 per cent of carers for people with dementia in Venezuela and Cuba were women, (World Alzheimer Report, 2009). As a result of these caring responsibilities, women are subject to financial hardship, social isolation and mental and physical health problems on an individual level. At the societal level, women remain a forgotten and largely invisible workforce, their contribution unrewarded and overlooked.

Thus the key questions we need to ask from this report is what will be the consequences and costs of failing to address the problem dementia poses for this growing cohort of older women? And to what extent will dementia compound the persistent inequalities women have already faced through their life course in many parts of the world? Furthermore, several demographic and societal trends in some countries imply a dramatic shortfall in informal care provision, so an even more pressing question for the next generation of women is who exactly will care for them in the future?

This report is in no way intended to be a comprehensive gendered analysis of what is arguably a complex, at times contradictory, and vast topic; rather it is intended to draw together some of the main arguments and provide a roadmap for future research and discussion. Through assembling parts of the jigsaw, it demonstrates that we ignore at our peril the unpaid contribution of women propping up our families and health and social care systems by caring for people with dementia. It also exposes the prescient need for further research on the role of sex and gender with regards to dementia in order to develop more targeted and effective policy interventions to help the many millions of women affected.

Overarching Recommendations of the Report

- 1, Dementia health policies and programmes should incorporate a gender dimension in their design, delivery and evaluation.
- 2, Gender should be included as a key health determinant in the promotion and disease prevention of dementia.
- 3, Dementia research at the regional, national and international level needs to be disaggregated by gender and age.
- 4, Women and men should be equally represented and involved at the micro and macro level of decision-making with regard to the development of health and social care policies and resource allocation as they pertain to dementia.
- 5, There is a need for greater interdisciplinary research incorporating the biological and social models of health for men and women to improve health interventions and outcomes.

ILC-UK ‘Calls to Action’ for the International Community

- 1) The ILC-UK calls on the United Nations Committee on the Elimination of Discrimination against Women (CEDAW) to ask national governments through their reporting mechanism to provide information on national actions and measures with regard to promoting gender equality and equal access to health and social care for women with dementia.
- 2) The ILC-UK calls on the United Nations Committee on the Elimination of Discrimination against Women (CEDAW), to produce a general recommendation to raise awareness of the disproportionate impact of dementia for women and how dementia will affect the rights of older women to health and social protection in the coming years. This could require national reports to include statistical data on the numbers and impact of dementia for women and information on legislative interventions, policy measures and programmes that address these gender concerns.
- 3) The ILC-UK calls on the Department of Gender, Women and Health at the World Health Organisation to produce and commission specific research, publications and awareness raising information to highlight the gender inequalities for women and dementia in line with other health conditions and problems currently highlighted.

2. Introduction

Overarching Aims of the Report

The overarching aim of this report is to inform our understanding of gender, sex and dementia for women's health and highlight both current and emerging issues. Within the context of a human rights and social justice agenda, the purpose of the report is to provide policymakers with an improved understanding of the sex-specific and gender dimensions that exist to help formulate more effective and targeted health and social care policies. This is also salient as women and men approach their health differently and services need to respond and communicate accordingly.

Setting the Scene

The inexorable growth of our ageing population has led to a significant rise in the global prevalence of dementia syndrome. The word dementia coming from the Latin *de* meaning "apart" and *mens* from the genitive *mentis* meaning "mind", is a descriptive term, describing the pattern of symptoms of brain disorder which involve the progressive damage and eventual death of brain cells. The result is the devastating loss of cognitive and intellectual functions that is often accompanied by changes in psychological and emotional states such as depression, agitation, aggression and apathy.

As the average life expectancy of women exceeds that of men, dementia is a particularly foreboding reality for women across the developed and developing world. Not only is the average life expectancy generally longer for women than men, but the most rapid increase in the population is in the 'oldest old' aged 85 and over – the age group with the highest risk of dementia. There is also growing recognition at the international level that the burden of disease from dementia will be shouldered increasingly and disproportionately by women.

While the numbers alone suggest a need for policy interventions and frameworks that include a sex and gender dimension, if one considers health in terms of the specific biological and social processes that affect women, the need for further research becomes compelling. Several research studies suggest women are at greater risk of Alzheimer's disease, cognitive decline is often accelerated in women after the menopause and care-giving is gendered with women heavily represented across the developing and developed world. Thus sex and gender

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differences are relevant to dementia not only with regard to prevalence and incidence, but also in terms of awareness and diagnosis, risk factors, treatment and response, care and care giving.

A Life Course Approach to Dementia

Assuming a life course approach, this report will argue women's health is mediated by a range of experiences. If we define health as a product of many factors: biological, psychological, social, political, cultural and economic, the evidence shows that older women warrant separate and specific attention. As we age, women and men share the same fundamental needs related to the protection of human rights and the need for food, shelter, access to health and social care services, dignity, independence and freedom from abuse. The evidence shows however, that when judged in terms of the likelihood of being poor, vulnerable and lacking in access to affordable health care, older women are particularly susceptible and may be subject to the prolonged inequalities and discrimination experienced since childhood, particularly in low to middle income countries.

The Research

While gender differences in health have been well-documented, gender differences of older people have tended to be neglected in research in favour of other stages of the life course. Similarly hitherto a comprehensive approach to gender and sex-specific differences and factors concerning the incidence, prevalence, mortality rate, disease burden, diagnosis, risk factors, treatment and response, care and care giving of dementia has been largely invisible. Using secondary analysis, this report sets out a new conceptual framework that can guide efforts to improve dementia diagnosis, treatment and care of ageing women in developed and developing countries alike.

This report is not intended to cover all facets of the health status of women and dementia. The subject areas addressed are limited by their relevance, the availability of reliable and topical data and the availability of data in a sex-specific format.

All in the Name of -

'Dementia and Women - Forgotten Women' – the title of this report - signifies the many millions of women across the world, either forgotten or literally lost, as a result of discrimination and

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persistent inequalities. Women as a group for example, are largely forgotten or excluded from decision-making, policy formulation and research at the micro and macro level. As this report has adopted a life course approach to older women's health, the role and status of child, youth, adult and older person are all pertinent. Indeed the provision of care is yet another area where the contribution of women is often forgotten. The majority of care-givers are women and yet this valuable contribution is often undervalued in terms of recognition, reward and support. Throughout the report, subject areas where women's contribution and role appears to be forgotten, overlooked or ignored will be highlighted.

Structure of the Report

The report is divided into chapters. This first chapter is the executive summary, and Chapter 2 introduces the report, setting out the general aims, ambitions and objectives of the report. Chapter 3 focuses on the methodology and the methodological issues and limitations which may arise. Chapter 4 sets the scene, exploring the changing demographic and socio-economic trends that are pertinent to women's health. Chapter 5 provides an overview of the current and future size and scale of dementia for women, exploring prevalence, incidence, mortality rates and disease burden. Chapter 6 considers awareness and diagnosis and how women's own subjective experiences' and approaches to health care may influence their care and health pathways. Chapter 7 explores the specific risk factors and health determinants for women, Chapter 8 examines the differential outcomes in treatment and response for women and Chapter 9 considers the growing challenge of dementia care and the impact of caring for women. Chapter 10 concludes the report with a summary of the key findings of the report, the conclusions of the gender lens tool and recommendations for key actions on dementia and for the promotion of women's health across the globe.

3. Methodology

This report aims to bring together the current evidence on dementia and women, identifying key issues and highlighting areas which merit further public policy, medical or clinical research or intervention. The report is presented in the form of an evidence review, composed from a literature review of a range of quantitative and qualitative data including: academic, clinical and research papers and grey literature.

By approaching dementia through the prism of sex and gender, the report attempts to understand the complexities of the interaction between biology and socially constructed roles. Health research it has been argued has traditionally failed to adequately explore the combination of social and biological sources of difference in men's and women's health (Bird et al, 1999). The report, *Women, Ageing and Health: A Framework for Action* by the World Health Organisation (2007) highlights the need to consider social, economic, physical, and behavioural determinants when assessing women's health. This report will follow a similar approach assisted by using an adapted tool developed by Dr. Anna Day at the University of Toronto. The tool is intended to provide a health based framework to consider the possible sex and gender differences and factors for dementia and women. It will also facilitate analysis of what factors might contribute to these differences in the form of biological and social, cultural, economic, political and educational factors (under the umbrella term of psychosocial).

For the purposes of this report, the identified areas of interest (on the left hand side of the table) have been extended to include: prevalence, incidence, mortality, disease burden, diagnosis and awareness, risk factors, treatment and response and care and care giving. As intended the tool will be used to identify issues related to the sex and gender of women and assist in the exploration of this subject area. The overarching guiding questions which will be employed to complete the tool are: (i) Are there gender differences in dementia with regard to the areas identified on the left hand side of the table for example prevalence? (ii) If there are, what factors might contribute to these differences, with regard to biological and gender factors? For example, if there are identified gender differences in risk factors, what role may educational background occupy to explain these differences? This process will also aid the identification of gaps in the literature. The tool will be used as a framework to assist internal analysis and will be completed and incorporated into the final chapter of conclusions and recommendations.

Gender lens tool

Differences in	Existing Gender Differences	Factors that may contribute to gender differences					
		Biological	Social	Cultural	Psychosocial		
					Economic	Political	Educational
Prevalence	Yes/No						
Incidence	Yes/No						
Mortality Rates	Yes/No						
Disease Burden	Yes/No						
Awareness	Yes/No						
Diagnosis	Yes/No						
Risk Factors	Yes/No						
Treatment/Response	Yes/No						
Care	Yes/No						
Care Giving	Yes/No						

Thus this report assumes an integrated and interdisciplinary approach, which will facilitate a more holistic analysis of the basis of differences in women’s health and how health is shaped across the life course. It will help detect manifestations of gender inequality and inequity for example, in the role of caregiving or cultural practices which may hinder access to diagnosis or treatment. As it is the a priori assumption that gender inequalities and inequities play a role in older women’s experience of dementia, the research is broadly feminist in its approach. Based on an anti-foundational ontology, the emphasis of the report will be on understanding and exploration as opposed to explanation. However the report will attempt to identify key areas which merit further investigation.

Throughout the report the term ‘sex’ will be used to refer to differences which are primarily biological in origin and may be genetic or phenotypic (genetic or physiological characteristics of being a man and women) and ‘gender’ will be used when referring to psychosocial factors such as social or economic influences based on sex (based on Pinn, 2003).

Dementia will be used as the generic term throughout the report, to describe the symptoms that occur when the brain is affected by certain diseases or conditions. However caution will be

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exercised to distinguish the different types of dementia (named often according to the condition that has caused the dementia) as the risk factors, symptoms, response and treatment can be different. Some of the main types of dementia are: Alzheimer’s disease, Vascular dementia, dementia with Lewy bodies and Fronto-temporal dementia. It should also be noted that there are rarer forms of dementia and many individuals have ‘mixed dementia’ which is increasingly common.

3a. Methodological Issues and Limitations

While this report focuses on the sex and gender aspects of dementia as they pertain to women, it is not to imply the impact of dementia for men is any less important. Indeed while it was beyond the scope of this report to compare gender differences between men and women, or isolate the specific challenges men face, there is clearly a case for further research in this area. Furthermore while this report is framed within a feminist paradigm, it should not be assumed and is not the intention to suggest oppressive patriarchy alone is responsible for the discrimination and inequalities women face, contrary to radical feminist thought. Similarly it is acknowledged within certain cultures and communities, women themselves can be the perpetrators of oppression or discrimination against other women. It should also be noted that some of the issues highlighted and recommendations in the report equally apply to men, thus reinforcing the range of variables which influence an individual’s experience of dementia.

Indeed gender should not be viewed as the fundamental determinant of health and well-being in later life; rather for the purposes of this report it has been isolated as a key variable. It should also be noted, the application of the adapted gender lens is not particularly helpful in demonstrating the complex, intersecting and multilayered inequalities and discrimination women face. As an analytical tool, the interplay of a wide range of biological, economic, sociological, political factors and membership of equality groups or strands in terms of gender, but also disability, race/ethnicity, religion or belief, fall beyond the report’s scope and reach.

Similarly there is an awareness of the potential dangers of conceptual reductionism when undertaking gendered analysis of this nature. Women are not a homogenous group, just as old age is not a static form, but constitute a “continuum of independence, dependence and interdependence” (WHO, 2007, p. 2) Thus one’s status as a ‘woman’ can not be an all-purpose explanation. It would be a descriptive misrepresentation to treat women as a monolithic entity by the simplifying process of stereotyping. Furthermore while this report stresses through a life course approach the structures of society in the form of economic or political factors, it is not the

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intention to suggest women are passive agents, responding and being shaped by external forces alone.

Thus just as caution has been exercised to avoid treating women and older people as a homogenous group, acute awareness must also apply to the representation of different parts of the world. Global in its approach, this report aims to provide an overview of developments across the world and tries to refrain from sweeping platitudes, generalisations and assuming a westernised model of analysis. Indeed even the dichotomous terms of “developing” and “developed” fall far short of the complex reality of the global picture, and in many respects almost all countries are still ‘developing’ in terms of their policy interventions and responses to dementia. There is also a distinct paucity of research on dementia in developing countries (Prince et al, 2007) and thus there may be unintended bias towards analysis of women living in middle to high income countries. Particular attention throughout has been exercised to stress if any issues raised are isolated to particular parts of the world or are more universal in their application or impact.

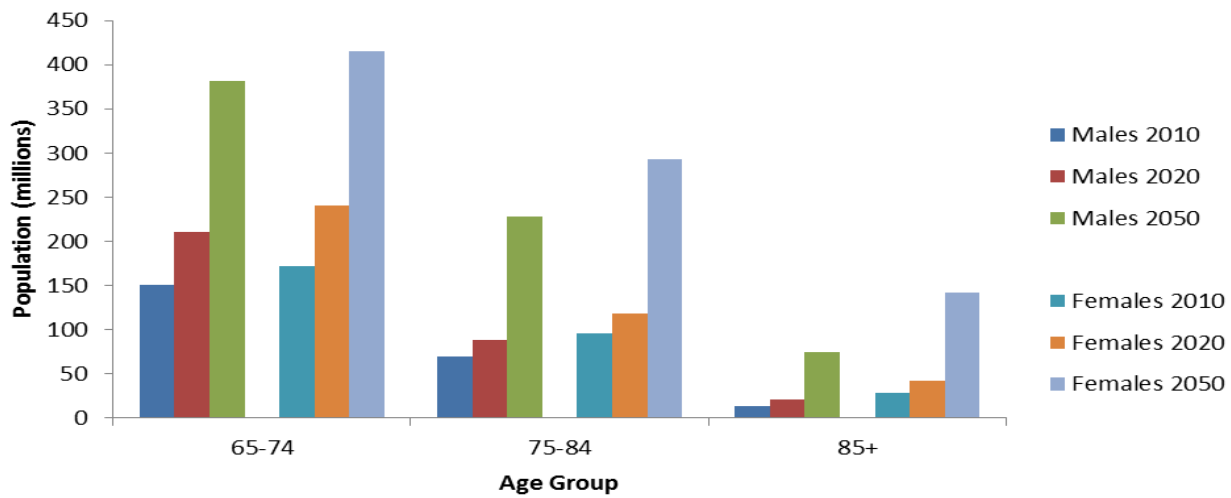
4. Ageing, Gender and Health – The Female Paradox

Demographic change and medical and technological advances have heralded a new dawn in the population landscape with a wave of ageing across the developed and developing world. The rate of growth is rapid with both overall numbers and proportions of older people rising rapidly and women constitute a majority of this population due to their increased life expectancy relative to males. However simply because women are living longer than men does not infer they are necessarily enjoying healthier lives, with old age ushering in gender common and gender distinct challenges.

In 2007, 55 per cent of adults aged 60 years and over were women, a proportion that rises to 58 per cent at age 70 and above (WHO, 2009) with the majority of older women from the developing regions of the world. In 2007, there were 270 million women aged 60 years and over living in low and middle income countries compared with 115 million in high income countries (WHO, 2009). Indeed it is a common misnomer to assume ageing is a concern only in countries with low birth rates, high incomes and effective geriatric health care. In 2008 more than 80 per cent of the global increase in older people in the year up to July 2008 was seen in developing countries (Pilkington, 2009). Though it should be noted the current level and pace of population ageing varies widely both within and by geographic regions (US Census Bureau, 2008).

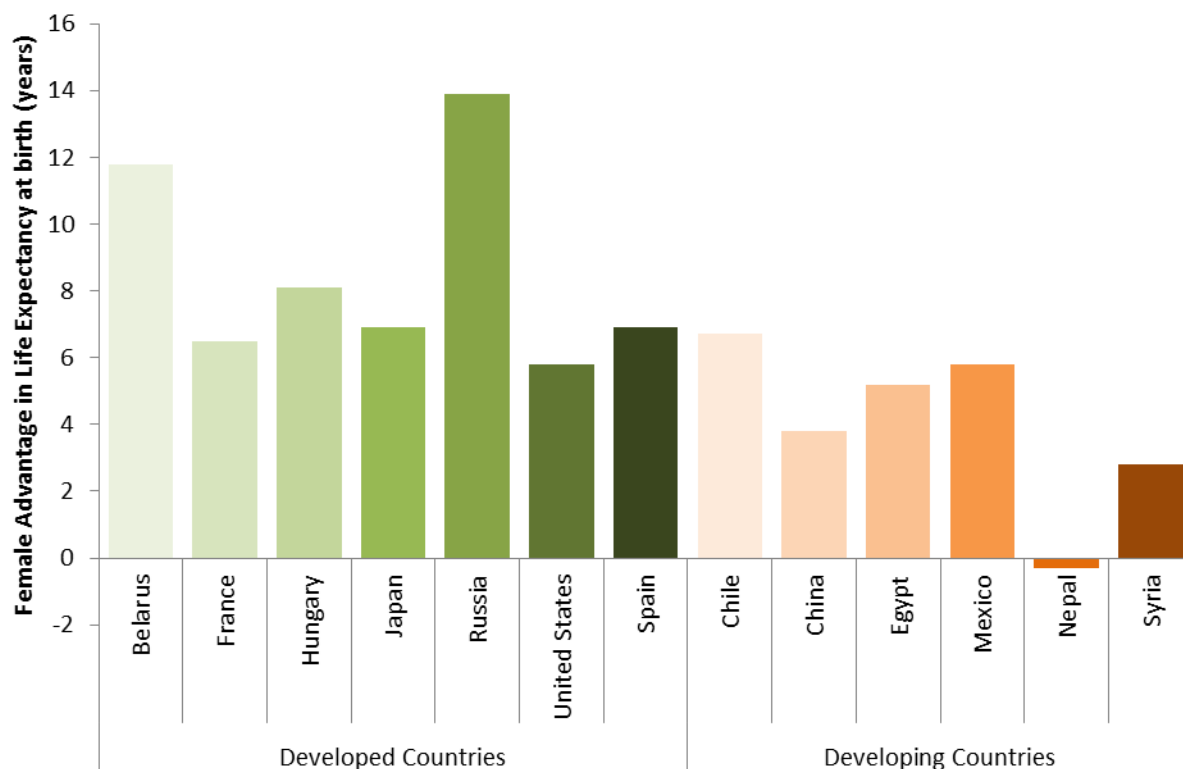
In the future this trend will continue, with the number of women aged 60 and over predicted to grow to just over 1 billion by 2050 (WHO, 2007). A predicted increase in the numbers of the oldest old across the world's population will also mean there will be more women than men in the oldest cohorts. In all older age groups women outnumber men with this imbalance increasing with age. Worldwide, by aged 80 and over there are 189 women for every 100 men and by age 100 and over, this gap is widened to 385 women for every 100 men (WHO, 2007). Data obtained from the US Census Bureau conforms to the trend termed the "feminisation" of ageing. Projections obtained from their population database disaggregated by gender for 2010, 2020 and 2050 (see Figure 1) clearly demonstrate women are and will increasingly form the majority of all older people across the world. The projections are particularly striking in the oldest old categories.

Figure 1, World Midyear Population by Age and Sex for 2010, 2020 and 2050. (Obtained from the US Census Bureau Database)



It is therefore evident, as the figures and projections show, the near-universal gender gap in life expectancy in favour of women (see Figure 2). A recent US Census Bureau report states female life expectancy now exceeds 80 years in more than 45 countries and is approaching this level in many other nations (2008). The gender differential was also found to be less significant in developing countries in the three to six year range (2008). However it has been suggested while the gender gap in longevity favours women, life expectancy in men in certain developed countries is relatively greater (Newman and Brach, 2001). It must also be noted there is geographical variation, with the trend reversed in some societies in southern Asia and Sub-Saharan African societies. Here cultural, economic and social determinants most notably with regard to the social standing of women in these societies, has led to higher male than female expectancy (Newman and Brach, 2001).

Figure 2: Females Advantage in Life Expectancy at Birth for Selected Countries in 2008 (Obtained from the US Census Bureau Database)



Paradoxically, while women are living longer, they are not necessarily enjoying a ‘healthier’ life in their old age. The adage “men die and women become disabled” is still widely considered to ring true. It is well documented that a larger percentage of women than men are disadvantaged in terms of age-specific disabilities and co-morbidities as a result of living longer. Despite these assumptions being challenged by several recent studies, which argue the gender differences in self-reported health are much more modest than hitherto reported (Macintyre et al., 1996) the paradox arguably remains in terms of numbers. As the WHO Women and Health report argues, the overall prevalence and severity of disability among older women will continue to rise due to not only the ageing of the population, but because higher proportions of older women will be in the oldest age groups where disability levels are higher (2009).

While it is beyond the scope of this report to explore the complex interplay of factors which have contributed to the reasons behind this paradox, it is worth noting cultural, economic and social determinants have a role to play. While biological factors are significant in explaining the disability burden older women face, arguably gender based discrimination and prolonged

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inequalities will also influence the incidence and prevalence of disability. Poor nutrition in early life for example would clearly be a risk factor for the onset of diseases such as osteoarthritis and osteoporosis, both of which disproportionately affect women in older age.

5. Prevalence, Incidence, Mortality Rates and Disease Burden of Dementia

As a result of our enhanced longevity, dementia syndromes are set to blight the landscape and lives of individuals and families across the world. This chapter explores the prevalence, incidence, mortality rates and disease burden of dementia syndromes and argues why dementia is set to be a particularly foreboding reality for many women.

Prevalence of Dementia

The steady and future growth of our ageing population will herald an increase in the number of people with dementia. The World Alzheimer Report (2009) produced by Alzheimer's Disease International reports that there are currently 35.6 million people with dementia with the numbers set to nearly double every 20 years to 65.7 million in 2030 and 115.4 million in 2050. 58 per cent of all people with dementia at the moment live in low and middle income countries with this set to rise to 71 per cent by 2050.

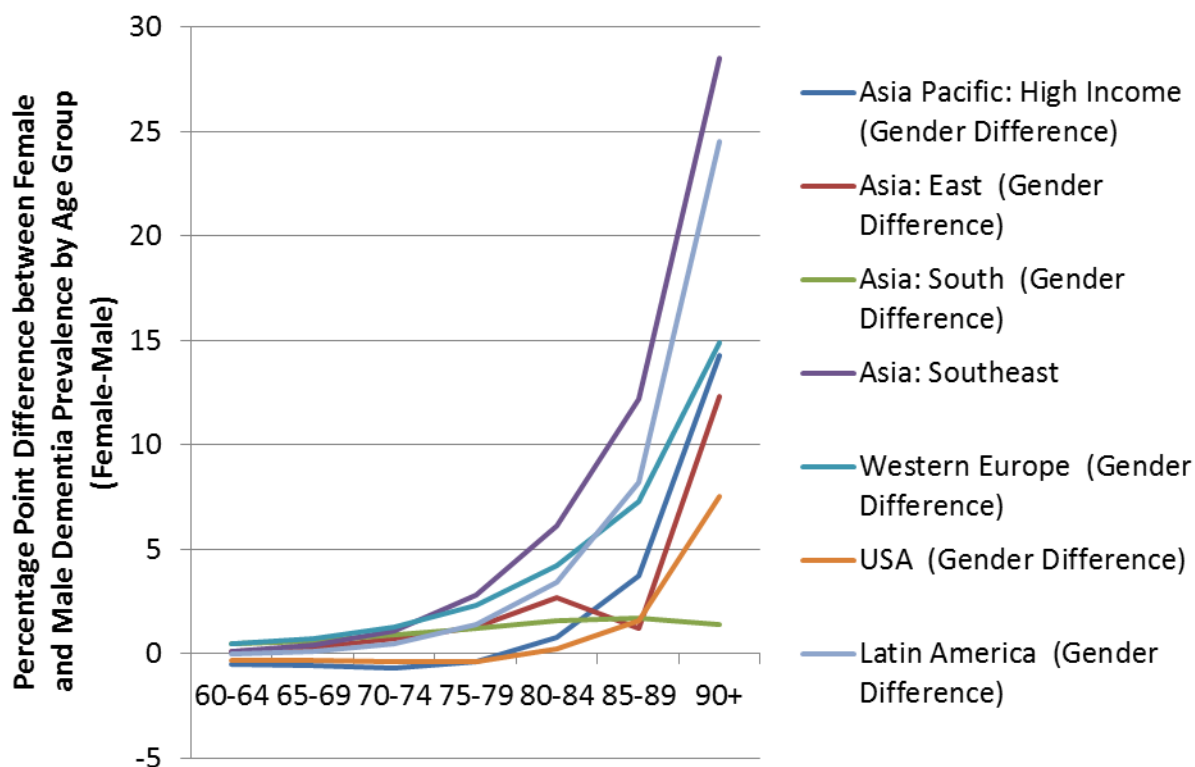
Many prevalence studies report a sharp rise in prevalence rates with age, it is reported to double for every five year increase in age after the age of 65 (Chandra et al, 2006). However this association with age has been the subject of recent discussion, with the suggestion that the relationship between age and dementia is not age dependent but age related, thus implying the disease could be eliminated by the removal of risk factors (Gao et al, 1998). The latter, it should be stressed, remains a relatively minority view.

The relationship between gender and dementia is yet more complex, with considerable inconsistencies and contradictions across studies. Indeed, examining the sex distribution of dementia can be a fraught process, yet some tentative assertions can be pulled from the quagmire of academic opinion. At the most simplistic level one could argue two factors combine to make dementia a significant concern for women. First, as average life expectancy is generally higher for women than men and, second, as the most rapid increase in the population is in the 'oldest old' aged 85 and over (this is the age group with the highest risk of dementia), one could conclude there will be more women than men developing and living with Alzheimer's disease and other forms of dementia (Lindsay and Anderson, 2004). However, it should be noted this is,

once again, by no means a universal view (See Gambassi et al (1999) and Lautenschlager et al (1996)).

A meta-analysis of dementia prevalence in the World Alzheimer Report 2009 by Global Burden of Disease (GBD) world regions suggests there is a relationship between dementia and age and gender. The strong effect of age and gender was evident in the models, with the prevalence of dementia increasing exponentially with age and an independent gender effect in all regions except for North America and Asia Pacific being similarly prominent. The predicted prevalence for men was observed at between 19 per cent and 29 per cent lower than that for women. As the figures below (see Figure 3) demonstrate, there is higher age-specific prevalence rate for women than men, with a tendency in all regions for the divergence in prevalence between men and women to rise with age, particularly after the late 70s, though it should be noted this was only statistically significant for the Asia Pacific region.

Figure 3, Gender differences in dementia prevalence per 100 persons (additional female burden based on difference between female and male age specific prevalence). Data taken from meta-analysed estimates of dementia prevalence generated from Poisson random effects models by Global Burden of Disease Region. (Original Source: ADI Report 2009)



Several studies have shown that the prevalence of dementia syndromes, specifically Alzheimer's disease, is increasing among women and this appears to be a cross-cultural, cross-national phenomenon (Kukull et al, 1994). As the chart above and data on dementia prevalence from OECD countries as well as Latin America, India and China demonstrate (Table 1),

prevalence increases with age and the increase is significantly more rapid for females for whom prevalence is much greater in the oldest old (see Table 1). However, some exceptions are found in the oldest age group, notably in rural China and urban India. One European study cites there are 5,230,421 women with dementia compared to 2,525,644 men with dementia (EuroCode, 2006) (alternative figures from the Eurodem study exhibit a lower gender differential, with an estimated 4,287,867 women and 2,617,766 men living with dementia, although these figures are based on data from the 80's and 90's).

Table 1, Prevalence of dementia per 100 persons by age and sex.

	65-69		70-74		75-79		80-84		85-89		90+	
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
Australia*	0.8	0.3	2	1.3	3.2	3.1	5.8	7.4	16.4	23.9	-	-
Canada*	-	-	4.5	4.6	8.2	9.1	15.1	17.4	22.6	28.1	30.4	41.1
England and Wales*	2.2	1.8	-	-	8	10.3	-	-	18	26	-	-
France*	-	-	-	-	7.7	5.7	12.5	16.6	22.9	29.9	27	52.8
Germany*	-	-	-	-	-	-	-	-	-	-	-	-
Japan*	-	-	-	-	-	-	-	-	-	-	-	-
Spain*	1	0.4	1.2	2.9	2	2.4	4.3	8.9	9.3	14.8	15.4	28.1
Sweden*	3.4	2.5	-	-	7.7	9.6	-	-	21.9	26.1	-	-
USA*	1.6	1.3	2.9	1.3	7.2	7.7	15.5	15.1	23.5	28.4	29.9	42.2
EuroDem**	1.6	1.0	2.9	3.1	5.6	6.0	11.0	12.6	12.8	20.2	22.1	30.8

	65-69		70-74		75-79		80+	
	Male	Female	Male	Female	Male	Female	Male	Female
Cuba***	2.9	2.9	5.9	6.1	6.6	9.8	23.2	26.6
Dominican Republic***	4.8	3.5	6.2	7.1	14.4	11.7	17.2	25.5
Peru Urban***	3.6	2.3	3	2.2	8.3	7.9	19.3	27.2
Peru Rural***	1.3	5	3.5	7.2	8.3	5.7	6.9	17
Venezuela***	3	2	2.3	3.5	6.5	5.1	17.2	20.7
Mexico Urban***	0	0.5	5.1	4.3	3.8	13.5	16.3	25.2
Mexico Rural***	0	2	2.9	6	6.9	9.7	20.7	22.9
China Urban***	0	2.9	3.7	3	6	8	14.7	24.4
China Rural***	1.6	1.6	3.1	4.2	9.1	9.6	19.6	14.7
India Urban***	2.9	5.5	5.5	7.4	4.5	8	25	21.2
India Rural***	4.3	7.8	5.8	14.8	5.7	15.7	11	29.4

Notes:*OECD numbers taken from Moise and Schwarzinger (2004), Eurodem numbers represent figures taken from Mathers & Leonardi (2000) ***Numbers for Latin American countries, India and China taken from Rodriguez et al (2008) and represent prevalence within 10/66 project sites

The Cambridge study similarly confirms a higher risk of dementia and Alzheimer's disease among women (Fratiglioni, 1997) and recent research from developing countries also highlights women have more to fear from Alzheimer's disease compared to vascular dementia, which is found to be more common in men. Though it must be stressed this is in no way a universal view, and some studies report no gender difference in the overall prevalence of dementia (See

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Access Economics Party Ltd, 2006). Similarly, as significant differences between the sexes usually occur, it has been argued, in the oldest-age categories where there are few men and even fewer with Alzheimer's disease, estimates can be unreliable (Gao et al, 1998). It is also worth noting that mixed pathologies are more common than 'pure' pathologies, this is particularly the case for Alzheimer's disease,vascular dementia and dementia with Lewy bodies, thus adding another diagnostic hurdle to analysis (Neuropathology Group, Medical Research Council, 2001).

All reports demonstrate striking geographical differences in dementia prevalence at the present time, finding it is particularly less common in rural than urban areas. Ferri et al, suggest genetic, environmental and lifestyle factors may underlie these regional variations (2005).

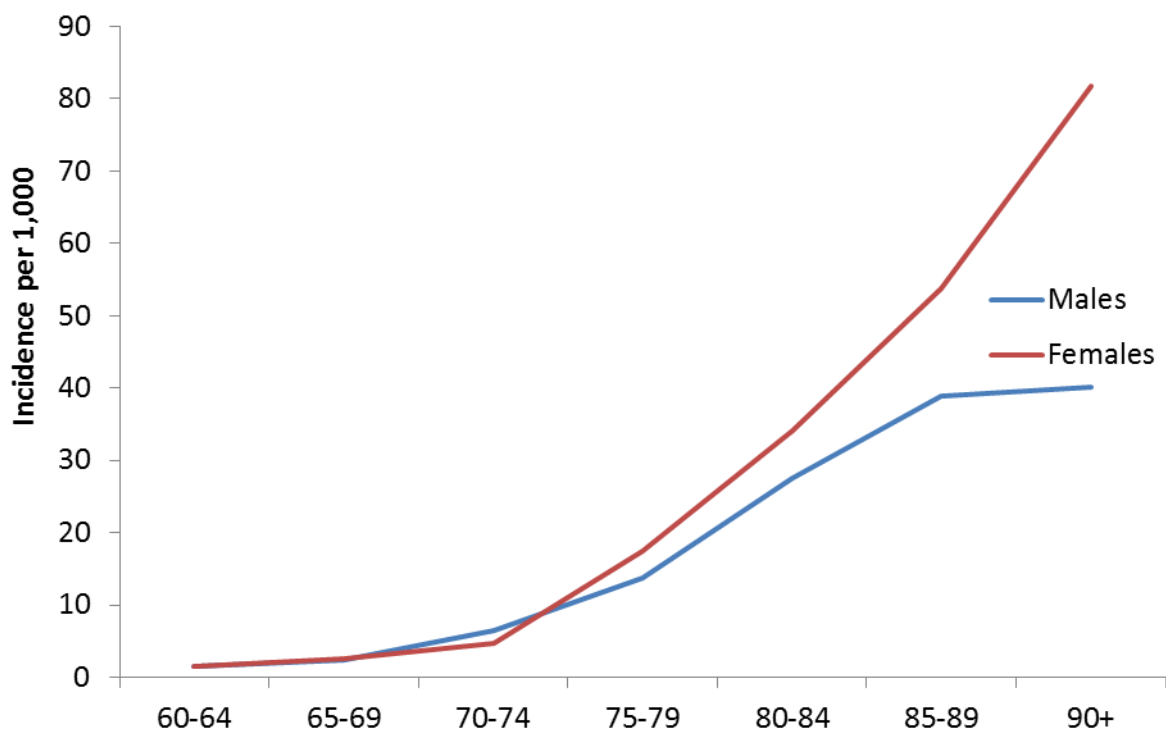
Incidence of Dementia

Incidence - the rate of new cases occurring in a population in a given time period - is generally considered a more effective measure of disease risk and almost all incidence studies report a positive association between age and dementia. However yet again, the relationship between age and sex is far from conclusive.

In some European and Asian studies the incidence rates of Alzheimer's disease were found to be higher in women than in men. The Eurodem studies showed significant gender differences in the incidences of Alzheimer's disease after 85 years of age, with a higher risk in older women than men (see Figure 4). A meta-analysis of age-specific incidence by Jorm and Jolley of 23 published studies globally, similarly found a higher incidence of Alzheimer's disease for women in very old age, but no significant overall sex difference in dementia incidence (Jorm and Jolley, 1998).The incidence of dementia reported in the Rotterdam Study also concurs with these findings, with dementia incidence after 90 years of age higher for women than men. It also found the incidence of vascular dementia is higher for men than women in all age groups (Ruitenber, 2001).

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Figure 4, Incidence of dementia from the EURODEM meta-analyses. (Obtained from Leonardi and Mathers, 2000)



However one cohort study from the United States reported no difference in incidence rates between men and women. The Rochester Study found there were no consistent differences between men and women, and women were not at an increased risk of incidence of Alzheimer's disease. The findings suggest in this instance sex or gender determinants did not play a major role in the causation of Alzheimer's disease for the American population sampled (Leonardi and Mathers, 2000).

This global variation in findings is further hampered by the inherent problems associated with incidence studies in terms of methodological differences, small scale samples and finding common clinical diagnostic criteria. At the present time a lack of available data on the incidence of dementia renders certain national and particularly cross-country comparisons a non-existent or risky venture, to say the least. A greater understanding of the incidence rate for all populations disaggregated by gender is essential if policy-makers are to understand and respond appropriately in determining and allocating health and social care resources. Incidence data is also critical in helping to identify critical risk factors that may lend themselves to preventable interventions (Gao,S, 1998).

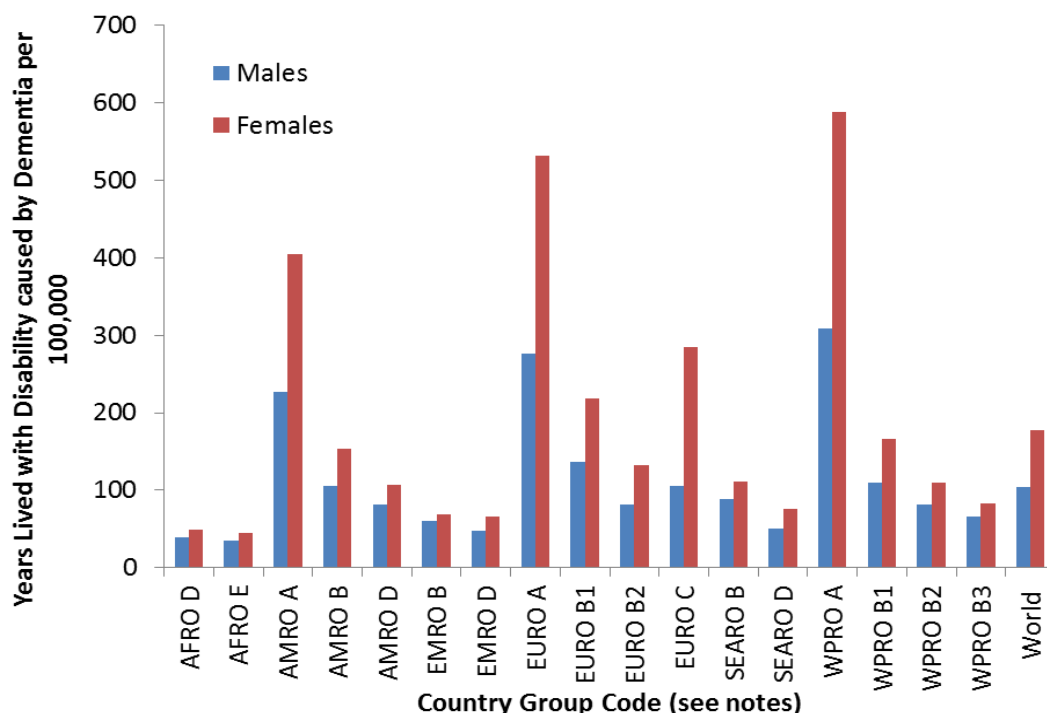
Disease Burden

Dementia is considered to be among the most disabling of all chronic diseases. The middle to late stages of the disease in particular signal a loss of autonomy, physical and cognitive function and independence for most individuals affected. In order to quantify disease burden in 1990 the World Health Organization introduced a new metric – the Disability-Adjusted Life Year (DALY). DALYs for a disease or health condition are calculated as the sum of the Years of Life Lost (YLL) due to premature mortality in the population and the Years Lost due to Disability (YLD) for incident cases of the health condition.

According to the most recent Global Burden of Disease report (2004), as cited in the World Alzheimer Report (2009) dementia contributes 0.8 per cent of all DALYs worldwide, 1.6 per cent of Years Lived with Disability and just 0.2 per cent of Years of Life Lost. As dementia is a disease which primarily affects the older population, the proportionate contribution is considerably higher among those aged 60 and over, accounting for 4.1 per cent of DALYs, 11.3 per cent of Years Lived with Disability and 0.9 per cent of Years of Life Lost (Alzheimer's Disease International, 2009). Mathers et al (2003) estimate DALYs for all dementias as 17,108,000 with the burden being almost twice as high for females (11,016,000) as for males (6,092,000) (As cited in Chandra et al, 2006). The disease burden is found to be more pronounced in higher income countries, though this pattern is by no means uniform with a high burden in East Asia and some of the Pacific regions (Chandra et al, 2006). According to the WHO, Dementia causes 13 per cent of years of healthy life lost among women over 60 years of age and women with dementia also face an increased risk of depression (2009).

Figure 5 demonstrates the added burden facing women compared to men based on the years lived with disability due to dementia. It shows that for each country grouping, women face a higher number of years living with dementia than men, with the difference being highest in European, North American and Western Pacific nations.

Figure 5: Years Lived with Disability due to dementia per 100,000 person years (Source: Mathers & Leonardi 2000)



Notes: see WHO (2000) for country codes:
http://www.who.int/whr/2003/en/member_states_182-184_en.pdf

Thus the burden of dementia will be particularly pronounced for women, due to their longer life expectancy and because higher proportions of older women are in the oldest age groups, thereby being most at risk of dementia. Furthermore as a result of their longer life expectancy, older women will be living with increasing levels of co morbidity, The main health problems faced by older women, as cited in the WHO report are poor vision (including cataracts), hearing loss, arthritis, depression and dementia (2009). Thus women will have to cope with a range of potentially disabling and debilitating health problems which will invariably impact on their autonomy, independence, dignity and quality of life. This is an issue we consider in more detail in the latter part of this report.

Mortality Rates

While dementia is more commonly associated with disability and cognitive impairment, dementia is slowly being recognised as an underlying cause of death (See Aguero-Torres, Fratiglioni et al.1999, **Joly et al, 2001). The Global Burden of Disease Report ranked Alzheimer’s disease and other dementias to be the seventh most common cause of death for women over 60 and to be the third leading cause of death for women in high income countries

(2004). Chronic non-communicable diseases are now the major cause of death among older people in both the developed and developing world. Coined the “epidemiologic transition,” a phrase used to refer to a long-term change in leading causes of death, from infectious and acute to chronic and degenerative conditions, developing countries are currently in various stages of the transition. This is reflective of the fact that dementia does not feature as one of the top ten causes of death for women in low to middle income countries (see Table 2 below). However, as noted above, given the anticipated increase in ageing populations and dementia in the developing world, this will invariably change. Also it has been argued that dementia is rarely cited or recognised as a cause of death in many countries.

Table 2, Ten leading causes of death in women aged 60 years or over by country income group, 2004 (WHO, 2004).

	World		Low income countries		Middle income countries		High income countries	
	Rank	% of total deaths	Rank	% of total deaths	Rank	% of total deaths	Rank	% of total deaths
Ischaemic heart disease	1	19.2	1	19.9	2	19.8	1	17.1
Stroke	2	17.5	2	14.7	1	21.7	2	12.1
COPD	3	8.2	4	7.5	3	11	6	3.3
Lower Respiratory infections	4	5.3	3	9.7	5	3.4	4	4.4
Diabetes mellitus	5	3.3	5	3.4	6	3.2	9	3.1
Hypertensive heart disease	6	3	6	2.1	4	3.7	10	2.4
Alzheimer's and other dementias	7	2					3	5.3
Breast cancer	8	1.9			9	1.5	7	3.1
Trachea, bronchus and lung cancers	9	1.9			8	1.8	5	3.6
Colon and rectum cancers	10	1.6			10	1.4	8	3.1
Cervical cancer			7	1.9				
Nephritis and nephrosis			8	1.8				
Diarrhoeal Diseases			9	1.7				
Stomach cancer			10	1.5	7	1.9		

6. Awareness and Diagnosis of Dementia

There is a distinct paucity of evidence on awareness and diagnosis of dementia and how the gendered experience differentially contributes to health interventions and outcomes. It is thus extremely difficult to examine the relationship between gender and dementia in this regard. Any analysis at the global level is rendered particularly difficult given just how little is yet known about the response of communities and individuals to dementia, particularly in the developing world. The 10/66 Dementia Research Group has identified the urgent need for well-designed epidemiological research in low and middle income countries and also developed an approach to diagnosing dementia, known as the '10/66 Dementia Diagnosis'. However despite these endeavours, there remain significant knowledge gaps with regard to understanding the complex interplay of behavioural and psychological attitudes, awareness and response to the symptoms of dementia in developing countries (Prince, 2004). Nevertheless out of this quagmire, this chapter will suggest and highlight some potential areas linked to awareness and diagnosis where the impact for women may be particularly pronounced.

At the present time, it is impossible to quantify how many people at the global level have received a diagnosis of dementia, due to lack of epidemiological data from many countries. Where diagnosis rates are available, they offer little comfort, for example across the European Union, it is estimated fewer than 50 per cent of people with dementia receive a diagnosis (Bamford, 2010), though it should be stressed there are variations across the EU Member States. Furthermore the majority of people with dementia do not receive a specialist diagnosis at any time during the pathway of the disease or do so only in the latter stages or at point of crisis. Thus low levels of diagnosis, poor quality diagnosis and often late diagnosis all have profound repercussions not only for the individual's access to treatment and care, but also the intensity and level of care they need. Indeed early diagnosis is gradually being recognised as providing significant fiscal, social and health benefits, as explored in a recent paper by the ILC-UK on the efficacy of various policy interventions for dementia (Bamford, 2010).

Diagnosis rates are driven by a range of clinical, cultural, health and social factors which are often country specific. In many countries dementia remains inextricably linked to the process of ageing, thus general awareness of dementia in these countries is low with poor diagnosis rates. Higher diagnosis rates can be found in countries where the 'normal ageing' explanation is challenged. Moreover diagnosis rates of dementia are not only influenced by dementia per se

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and the disability that derives from it, but also by the wider social prejudice, discrimination and stigma surrounding ageing and dementia more generally.

It is this facet of awareness and diagnosis where women may suffer greater disadvantage than their male counterparts. Age discrimination against women is well-documented in many societies and therefore it seems that older women affected by conditions such as dementia are exposed to what we could term a 'triple jeopardy' (Graham et al, 2003) discriminated against as a result of their age, sex and condition. It is still the case that specific symptoms of dementia are powerfully stigmatising both in the community and in care settings, for example disturbed behaviour, poor self care and incontinence. As there will be a greater number of women with dementia as expounded earlier, women will not only be at greater risk of discrimination and prejudice as a result of the stigma attached to dementia, but such practices may act as a disincentive for women coming forward for help or a diagnosis (if such services are available in the community setting). Care givers can also be vulnerable to discrimination and prejudice. As the majority of carers are women, as will be discussed later, women may find themselves blamed for the apparent state of neglect of their older relatives with dementia (WHO-WPA, 2002). Indeed in some developing countries dementia is still equated with 'madness' which renders the individual affected and their family in an extremely vulnerable position. Some individuals in these instances are taken to traditional healers (Chandra et al, 2006), which further enshrines the isolation and stigma. While there needs to be recognition of the diversity of cultural practices and traditions across the world, community education is arguably required to safeguard the wellbeing of vulnerable older people, particularly women, in these communities.

However while it does appear that stigma and fear may serve to act as a barrier to women coming forward for a diagnosis in certain countries, where there are low levels of awareness of dementia, one could argue the reverse may be true, particularly in certain high income countries. Research on gender differences in terms of self-reported health and contact with health-care services more generally, suggests where there are health and social care services available, women are more likely than men to report poor health and access medical care (Stoverincket al, 1996). Thus gender disparities in health can be explained by psychosocial factors. In some high income countries the 'sick role' is deemed to be more socially acceptable for women and therefore they are more predisposed to notice changes in terms of illness (Ladwig et al, 2000). Furthermore high levels of self-reported symptoms among women could be the result of a greater awareness and interest in health education, which may lead them to have greater contact with health care services:

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According to a study by the World Health Organization, women are consistently more likely to use mental health services than men, who seek care at a later stage or until symptoms become severe (2002). However one explanation for higher levels of reported poor health among women could be linked to gender stereotyping by clinicians. In terms of the institutional response in the treatment of mental health problems, different studies found that doctors were more likely to diagnose depression in older women than men presenting the same symptoms. Similar research highlighted that being diagnosed with a psychological disorder has a lower likelihood of being associated with a male gender attribute (WHO, 2002). However given the complexities of the diagnostic pathway of dementia and the interplay of factors involved, it should not be assumed that women display uniformity in their health seeking behaviour or the evidence above necessarily applies to women in this instance.

Diagnosis rates are also influenced by an individual's ability to access and navigate successfully the health and social care pathway. As noted earlier, with advanced age many older women suffer from multiple impairments or disabilities such as mobility problems, hearing loss or depression, all of which, may serve as a mental and/or physical barrier to seeking help from a GP. Furthermore older women in many countries are more likely to live alone; the death of one's spouse becomes increasingly common in older age, particularly for women. In the UK, for example, 22 per cent of women aged 65-74 were widowed compared to 9 per cent of men of the same age. Among women aged 75 and over the percentage widowed increases sharply to 60 per cent; and the percentage of men widowed increases to 29 per cent (ONS 2011). Some studies of dementia and diagnosis rates have shown the potential repercussions of living alone in terms of seeking out a timely diagnosis, and are less likely to be diagnosed than an individual living with their spouse or a resident caregiver (Consuelo et al, 2007).

As highlighted above, trying to understand the relationship between dementia diagnosis and gender is extremely difficult and any firm conclusions remain far from our analytical grasp. As this report has assumed a definition of health that looks at the psychosocial determinants of women's health, it is evident women's respective role and standing in their society will influence their awareness and access to health care services. Therefore without improving women's overall position, then for many women in certain low income countries, dementia will pose a significant challenge in their age old. As a starting point there needs to be greater work on improving overall awareness of dementia in all countries so women do not have to face a 'triple jeopardy'. In societies which have advanced health and social care services, then, a timely diagnosis is essential in order to open the gateway to the appropriate treatment and support

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available. Consideration should also be given to how health and community based services can reach out to women living on their own and try to circumvent some of barriers which may prevent or delay a diagnosis of dementia. Finally there is also a need for further research to unpick the different health seeking behaviour of men and women and understand to what extent gender bias within clinical settings may influence health outcomes.

7. Risk Factors for Dementia

While the causes (aetiology) of dementia are not completely understood, certain risk factors are known. According to several studies there are different risk factors for men and women that contribute to the development of dementia, thus both sex and gender prove influential in this regard. There is no one risk factor that can be solely attributed, but rather it is the complex interaction and interplay of various non-modifiable and modifiable risk factors which contribute to their development. Indeed as dementia is a descriptive term used to describe various different brain disorders, any generalisations on the risk factors for dementia must be approached with caution and every effort will be made to distinguish the factors pertinent to the relevant disorder.

Age

As noted in the previous chapters, it is widely accepted that advanced age is the main risk factor for most forms of dementia syndrome, with prevalence roughly doubling every five years over the age of 65. As women live longer and form a greater proportion of those in the oldest old age group, where the risk of dementia is greater, women will be disproportionately affected.

Sex

Several studies have suggested women are at a slightly higher risk of Alzheimer's disease, particularly in the oldest old categories. The previous chapter on the incidence of dementia discussed this in more detail. However as Alzheimer's disease is the most common form of dementia responsible for more than 50-60 per cent of all cases (Blennow and Zetterberg 2006) and in light of women's longer life expectancy, then we may witness the 'feminisation' of dementia in the forthcoming years. According to data from the Framingham Heart Study as cited in the Journal of Women's Health, the estimated lifetime risk of developing any form of dementia is one in five for women, compared with one in seven for men (Liebert, 2009).

Genetic

Genes also contribute to dementia risk. Several genetic causes for dementia syndrome have been identified, and some of which specifically for women. It has been proposed that there is a sex apolipoprotein genotype interaction with women who are e3 e4 heterozygotes being at

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greater risk for Alzheimer's disease than men who are e3 e4 heterozygotes (Gao et al, 1998) The results of the meta-analysis suggest that women have a higher degree of susceptibility than men regardless of apolipoprotein genotype (Gao et al, 1998). Though it should be noted these findings have not been tested in larger sample studies.

In the first study of sex-specific genes in Alzheimer's disease, a strong association for late-onset Alzheimer's disease is evident in individuals who have a mutation on the PCDH11X gene. The key variant of the gene which appeared to be closely linked to a higher risk of the disease was found on the X chromosome, of which females have two copies, but males have only one. The raised risk of Alzheimer's disease was not statistically significant in men who carried one copy of the rogue gene variant, and only marginally so in women with just one copy. But the raised risk was more significant in women who carried two copies - one inherited from each parent. In women who carry two of these chromosomes, the risk of Alzheimer's disease is 75 per cent higher; one copy of the gene confers a 26 per cent increased risk compared to an 18 per cent increase risk in men (Godfrey et al, 2009).

Hormones

A significant biological factor for women and dementia is linked to reproductive hormone levels (Godfrey J R et al, 2009). It has been suggested that the lack of estrogen or other hormonal changes in postmenopausal women either by themselves or in association with other factors account for an increased risk of Alzheimer's disease in women (Gao et al, 1998). Therefore estrogen therapy has historically been considered to reduce the risk of Alzheimer's disease. Several studies suggest estrogen replacement therapy for postmenopausal women reduces the risk of cognitive impairment and Alzheimer's disease.

Two meta-analyses of estrogens and dementia reported risk reductions of 29 per cent and 34 per cent (Nelson et al, 2002 as cited in Shumaker et al, 2003). Recently, however, the orthodoxy of this theory has been challenged, with data from the Women's Health Initiative (WHI) Memory Study raising doubts about the benefits of hormone therapy in diminishing the risk of dementia in older women (Craig et al, 2005). The study of 4532 women showed estrogen plus progestin therapy increased the risk for probable dementia in postmenopausal women aged 65 years or older. In addition, estrogen plus progestin therapy did not prevent mild cognitive impairment in the sample group of women (Shumaker et al, 2003). Thus while the preventative effects of estrogen replacement therapy for Alzheimer's disease seem increasingly

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debatable, the growth of academic interest in this area has at the very least pushed to the fore the question of the significance of risk factors for women.

Cardiovascular risk factors

Cardiovascular risk factors, stroke-related and atherogenic causes (referring to the ability to initiate or accelerate atherogenesis—the deposition of atheromas, lipids, and calcium in the arterial lumen) are all known to contribute to the onset of vascular dementia, which some studies argue is more common in men (see previous chapter on incidence). However there is increasing evidence that the above factors may also contribute to the development of Alzheimer’s disease. There are many risk factors associated with coronary heart disease and stroke, they include: tobacco use, alcohol use, high blood pressure (hypertension), high cholesterol, obesity, physical inactivity and an unhealthy diet (World Heart Federation, 2011). Gender has been shown to be significant in this respect. The prevalence of hypertension has been proved to be greater in men than in women until the age of 60 years and then it is higher in women. In the Framingham cohort, nearly 75 per cent of those over 80 years of age were hypertensive and the majority were women (Kearney et al, 2005 as cited in Azad and Power 2008). Women also have a higher rate of silent ischemia and cerebral white matter changes associated with hypertension and diabetes (Azad and Power 2008). Diabetes mellitus in women is associated with a substantial risk factor of cognitive impairment (Azad et al, 2007). Women who have suffered from diabetes for more than 15 years in one study were shown to have between a 57 per cent to 114 per cent greater risk of major cognitive decline than women without diabetes (Gregg et al, 2000).

Modifiable Risk Factors

An area of research which has also started to slowly lead to the variability in the expression of dementia between men and women is the rise in interest of modifiable risk factors. There are a plethora of lifestyle factors which influence the risk of developing dementia syndromes, with men and women demonstrating different risk profiles. While it is beyond the scope of this report to explore these in any greater depth, certain factors stand out for women.

Physical activity

The associations between physical activity and increased levels of protection from Alzheimer’s disease and other dementia syndromes have been demonstrated to be particularly important for

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women. A study of the longitudinal data from the Canadian Study of Health and Aging showed the associations between physical activity and risk of dementia and Alzheimer's disease were strongest in women. It found there was a reduction in risk of Alzheimer's disease of 60 per cent among women with high levels of physical activity, as compared with no physical activity. Though the author of the study notes that while the literature is not entirely consistent, these findings have been supported by other studies (Lindsay et al, 2002).

Diet and lifestyle

Another factor considered in the same study was the protective effect of 'regular' wine consumption. Moderate wine consumption was associated with a reduced risk of Alzheimer's disease and the protective effect appeared to be even stronger in women. These findings were found to be consistent with a longitudinal study in France (Lindsay and Anderson, 2004). Some studies have suggested midlife obesity seems to be a slightly greater risk factor for dementia in women than in men (see Goble, 2005). However this is by no means a uniform view, with some academics arguing as dementia has a lower prevalence in men than in women, the power to detect effects may therefore be slightly reduced in men (Witmer, Quesenberry, Yaffe, 2005).

Other Modifiable Risk Factors

A French study on the risk profiles for developing mild cognitive impairment and dementia also showed gender differences. Some potentially reversible risk factors for progression to dementia were identified which were different for men and women. For women a higher risk was associated with subclinical depression, for men a higher risk was linked to low levels of education and a loss of independent living for example following a stroke (Artero et al, 2008). However some of these findings contradict other incidence studies, which reported the association of higher educational levels with a reduced risk of Alzheimer's disease to exist only for women or to be stronger in women. The Nun study (a longitudinal study of 678 American Roman Catholic sisters set up to examine the onset of dementia) showed the importance of early life experiences and educational attainment in the form of linguistic abilities, as measured by an analysis of an essay written on entrance to a convent, to predict later life cognitive function. Among the 14 sisters who died, Alzheimer's disease was present in all with low idea density and low grammatical complexity but in none of those with high idea density (Snowdon et al, 1996).

The Importance of Risk Factors for Women

As discussed at the start of this chapter, one of the intrinsic problems associated with the identification of sex or gender specific risk factors for dementia syndrome is the wider complexities attached to our understanding of the specific disorders or disease. While, as illustrated above, it is possible to isolate possible key risk factors for women, the research and clinical community as yet, have no way of evaluating their influence, interplay and respective importance in most cases. While it may be possible to isolate certain variables, we must remember we are not working from a level playing field and there remains a considerable lack of epidemiological data particularly from certain parts of the world. As Prince notes, there is a need for more research in developing countries to help increase the environmental variance, facilitating the identification of environmental risk factors and gene-environment interactions (Prince, 1997). Studies on risk factors tend to be small scale, limited in their geographical scope and population base (for example failure to include representative samples of ethnic minorities), thus making cross-country comparisons in particular extremely difficult.

However the relative importance of risk factor based studies should not be underestimated. There is a prescient need for further research in this area and for a greater understanding of the gender dimension, in order to promote preventative strategies to the appropriate population cohort, be they male or female. This may also lead to the development of gender-specific clinical intervention programmes for dementia.

Indeed the policy and public importance attached to preventing dementia remains low to non-existent compared to other NCDs. This may be partially accountable to the fact that dementia is linked more to disability than to mortality and is often viewed as an inexorable part of the ageing process. There also needs to be a greater emphasis on health based interventions earlier on in the life cycle, highlighting once again, the importance of assuming a life course approach for women and men.

8. Treatment and Response of Dementia

While there is no cure for dementia, there are treatments available which can help the cognitive, behavioural and psychological symptoms of dementia. Yet again, there is an absence of research on the sex and gender dimension of treatments particularly with regard to differentiated responses to cholinesterase inhibitors, which have become the main pharmacological approach to symptomatic treatment. At the present time, primarily in middle to high income countries these drugs have been used to help delay the loss of brain function for Alzheimer's disease, thereby lessening the impact of confusion and memory loss. Further studies are needed to fully understand the long term effects of these drugs and others in both sexes. This is important for not only clinical outcomes and the individual in terms of function and behaviour, but also their potential to reduce levels of informal care. In most developing countries however treatment tends not to be pharmacological given a lack of access to affordable health care.

There is also the wider issue pertaining to gender bias against women in several areas of clinical research. Women historically have been excluded from early studies of most drug trials due to reasons of safety. As a result there has been and to a large extent remains limited knowledge of the different drug efficacy and the side effects of drugs for women (Royal Society of Medicine, 2007). Older women may also be taking multiple drugs and following complex medication regimens, which create additional risks for the individual. All these aspects of research continue to be neglected, despite an increase in the numbers of women participating in clinical trials. There are also significant social and economic barriers for women in research today, both as researchers and subjects. With regard to dementia, the problem is further compounded by the prescient need for more clinical studies and the recruitment of older people with cognitive decline and dementia in clinical trials. This gender bias in research may have potential repercussions for evidence based medicine and the future disease management of dementia syndromes.

Indeed very few studies have addressed the gender specificity of the expression of dementia. In a study of individuals with Alzheimer's disease, female patients were recorded as performing worse than male patients with the disease on tests related to names, vocabulary and word recognition skills (Rafii, 2008). Henderson and Buckwalter (1994) have also found gender differences on the Mini-Mental status examination score related to language dysfunction, though no gender differences were found using the Blessed test (a cognitive screening

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instrument), and the rate of deterioration was similar in both sexes (1994). At the moment the biological basis for the difference in language abilities is not clearly understood, though several theories have been proffered, linked to cortisol levels, metabolic rates and regional cerebral blood flow. Gambassi et al suggest the most plausible explanations may be the different patterns of cerebral organisation that could influence cognitive deterioration of Alzheimer's disease (1999).

It is also critical that there is greater understanding of the different behavioural and cognitive manifestations of dementia between the sexes to improve and tailor non-pharmacological approaches. A cohort study from five US States found significant differences in the prevalence and type of behaviour between men and women with Alzheimer's disease. The results of their study, the authors suggest conform to the finding from several similar investigations which highlight a relationship between specific types of behaviour and gender (Gambassi, 1999). Men, they suggest more commonly demonstrate verbal incoherence, apathy and excessive sleeping and a propensity for aggressive behaviour including sexual aggression, compared to women with Alzheimer's disease. In comparison women showed more reclusive behaviour and intense mood changes, with behaviours such as hoarding, refusing help, and inappropriate laughter and crying (Moritz et al, 1997 as cited in Lerner, 1999). Differences in baseline behaviour may contribute to these findings, and differences in levels of androgens and estrogens may help explain the differences in behavioural expression between men and women (Lerner 1999). However associations between sexual aggression and men remain tenuous with a divergence of academic opinion on the subject. It may simply be the case that sexual behaviour by men is more likely to be judged to be inappropriate, in contrast, sexual expression by female residents is often overlooked or prompts a more protective response by care workers and families within certain environments (Bamford, 2011). Thus we do need to bear in mind the gender dimension in care and nursing setting, as there are a higher number of women as staff but also as residents, which will invariably lead to different gendered outcomes and responses.

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9. Dementia Care and the Impact for Carers

9a. Dementia Care

Reliable and comparable data on access to health care across the world is limited and as there are no effective health care treatments for stopping dementia, social care plays an important role in treating the disease, with family members playing an integral part in this process. In the developed world, the model of care for individuals in the moderate to severe stages of dementia is often based on long-term care in institutions. Though it should be noted, given the high disability burden of dementia a significant proportion of care particularly in the early to middle stages of the disease is provided by unpaid carers and, as will be explored, mainly by female members of the family.

In developing countries, formal care provision for dementia is virtually non-existent and even if it were available, it would be beyond the financial grasp of most of the populace. The public health sector is primarily focused on curative and preventative health care, private health services are few and far between and do not meet the costs of continuing care (Prince, 1997). Thus the model of care is based on informal care provided by the family or the close community or in some cases Non-Governmental Organisations. It should also be noted that as dementia is a relatively new phenomena for the developing world, the care for people with dementia has received little attention as historically it has been an uncommon condition with few people surviving into the age group most at risk (Prince, 1997). Hence developing countries have not established the capacity or health or social care infrastructure to respond to what is now a looming threat for their populations.

In the developed world, it should be stressed that there is not universal access to adequate and affordable health and social care provision and there is evidence to suggest there are gender differentials in this regard. In Europe, some of the most comprehensive available data comes from the 2007 Eurobarometer Survey on health and long-term care in the European Union, which is a public opinion survey and sufficient to suggest potential trends. While it reinforces the disparity in health and social care provision across Europe, it stresses there is evidence of unmet need with some discrepancy among income quintiles, with the poorest women much more likely to report unmet need (European Commission, 2007). Indeed several studies have shown that the disparity in access and health outcomes in developed and developing countries, is closely associated with the wider disadvantage women experience in society, in terms of

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human capital, location, economic and social resources (Sen, 2010). In many countries access to health and social care is dependent on social security and health insurance schemes, which in turn are linked to previous employment history.

Across the life course, societal structures and norms can render women in a more vulnerable position than their male counterparts and this disadvantage may well be compounded as they enter old age. The value of girls and women in some societies is deemed to be considerably lower than that of boys and men. Primary and secondary education for example, is less frequent for girls than for boys, especially in underdeveloped and developing countries. Parents with limited resources are more likely to invest in the education of their sons because they do not understand the advantages of giving an education to girls since their future role has to be found within marriage, family and domestic life. As a result of such norms, at the global level it is estimated that women make up two-thirds of the estimated 960 million adults worldwide who cannot read or write and this gender gap between men and women is predicted to persist (Save the Children, 2000).

There are inevitably wide disparities between countries, in Africa for example South Africa and Zimbabwe have a literacy rate close to 80 per cent, while in some of the poorest countries, such as Niger and Burkina Faso, only 10 per cent of women can read and write (Save the Children, 2000). Education and literacy are one of the most important drivers for human development and are strong determinants for an individual's life chances.

Education is not the only future barrier to health and social care, in some developing countries women and indeed children either remain working within the family environment or are involved in low-skilled, poorly remunerated activities. Property ownership and inheritance laws in certain countries also enshrine women's economic and social disadvantage, acting as yet another barrier to autonomy or financial independence. It is no surprise therefore, women of all ages make up 70 per cent of the world's 1.3 billion poor and absolute poverty is often further entrenched in old age (WHO, 2007). This has been termed by some the 'feminization of poverty', as women on average not only sufferer greater financial hardship than men, but also suffer more intensely as a result. In India, it is estimated that women and children account for 73 per cent of those below the poverty line, with female-headed households and poor women in general forming the primary poverty groups (Barrett and Beardmore, 2000 as cited in Thukral, 2002). As a United Nations Human Development Report states poverty accentuates gender gaps, and when adversity strikes, it is women who are often the most vulnerable, this increased

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vulnerability is most visible in cases of disaster, conflict, or involuntary resettlement (UNDP, 1997: 64 in Thukral, 2002).

Another important facet of health care is the responsiveness of systems to respond to gendered needs. Responsiveness is not, as the WHO (2007) argues, a direct measurement of the quality of health outcomes, but rather refers to the non-health features of the health care system and whether a population's expectations for care provision are met. The system should respond to the need for personal dignity, confidentiality, respect, autonomy to participate in choices about one's own health, and freedom in the selection of facilities and care providers. Responsiveness the WHO argues is especially relevant for women already facing barriers to the utilisation of the health care system.

In this respect issues such as elder abuse are important, and apply to both the formal and informal care sector. People with dementia are particularly susceptible to elder abuse given their lack of cognitive function and memory problems, rendering their mistreatment arguably all the more pernicious given their vulnerable status. Elder abuse can take the form of bullying, violence, intimidation, neglect or financial abuse. Whether it is in an institutional or family environment, elder abuse is under-reported and until recently received insufficient attention or priority in both developing and developed countries. Women one could argue are particularly susceptible to elder abuse given their increased numbers in old age and the greater likelihood they will be living alone. A survey of elder abuse in private households (NatCen, 2007) carried out in the UK found that women were more likely than men to report that they had experienced mistreatment: 3.8 per cent of women and 1.1 per cent of men. Research from a report from Canada similarly suggests the older women are more likely to be the victims of abuse than older men, with women constituting two thirds of victims in the abuse or neglect cases (Pittaway and Gallagher, 1995). However, on per capita basis the report found the rates of abuse and neglect appeared to be equivalent for older men and older women, but as women live longer than men they are disproportionately represented. As elder abuse of women is under-reported and it is often carried out within the private or closed spheres, arguably the above findings can be challenged. Indeed as the title of this report suggests women in this regard are to a large extent 'forgotten'. A report in 2004 from the United States confirmed that the abuse of older women was more common than expected and women were at greater risk given their more vulnerable position in later life. Out of 92,000 women surveyed aged 50-79 years of age, 11 per cent reported experiencing some form of abuse in the past year (Mouton et al, 2004). It is also worth noting that certain groups of women may be particularly vulnerable to abuse, for example, an

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older lesbian woman with dementia, particularly when entering residential care. Thus care plans need to respond to the plurality of an individual's affiliations and identity, respecting their age, sex and sexuality.

Indeed in many communities women are at greater risk given the entrenched inequalities and discrimination they face as older women. While research on elder abuse in developing countries is still in the nascent stages, several reports on the status of older women highlight it as an emerging and underestimated phenomenon. As a report from the WHO (2004) on women's health predicates, older women in many countries are prone to greater abuse, with some traditional practices for example relating to widowhood resulting in violence and the abuse of older women. Indeed interpersonal violence can be common within certain communities and is closely entwined and entrenched in individual and societal norms of attitudes and behaviour. However it should be noted in some societies older people are esteemed and greatly valued for their past contributions and the wisdom they have bestowed upon their communities.

9b. The Impact for Carers

In many settings across the world the bedrock of dementia care is provided by family members. The disease burden of dementia is profound and carers play a critical role in providing part or all of the care individuals require as the disease develops. The conceptualisation of caring varies across cultures and communities, but can comprise of assistance with practical tasks, such as shopping, physical assistance in the form of dressing for example or psychological support through listening and support. Perhaps one of the most difficult aspects of care provision for dementia is the deterioration of the sense of self, which renders individuals affected unable to participate in decision-making regarding their health and social care and thus can increase the weight of responsibility experienced by carers.

Gender differences in the sphere of unpaid care are well attested, with women widely recognised as the primary care givers in the informal home setting. Family care is often considered a euphemism for female care and women do form the cornerstone of care in many communities. With regard to dementia care, this pattern seems to be borne out. Studies of Latin America, India and China by the 10/66 Dementia Research Group and the EURO CARE study which included 280 spouse carers from 14 European countries, found in almost all settings most carers were women (ADI, 2009). In the 10/66 study (see Figure 6), other than in rural China, they found the overwhelming majority of carers were women, usually daughters or daughters-in-law caring for a parent. A study from Canada similarly demonstrated women's strong care

giving role, three quarters of carers for people with dementia in the community were women, as were 71 per cent of primary care givers of people with dementia in health or social care settings. In the community they found 24 per cent were wives and 29 per cent were daughters (Lindsay and Anderson, 2004). However there is evidence particularly in developed countries of cross-sex personal care within the marital relationship. A study based on data from the annual General House Survey in the UK found that men and women were equally likely to provide care for someone in the same household, 3.8 per cent of men and 3.9 per cent of women (Arber and Ginn, 1995). Thus one should not discount men's caring contributions especially in later life when men often care for their marital partner. The research however did not include data on the reasons behind the caring relationship, as dementia poses many specific challenges for carers, one can not assume the transferability of these results for dementia care. It should also be noted that women often have multiple caring responsibilities for other family members.

Figure 6, Household living arrangements and characteristics of the main carers for people with dementia in 11 sites in Latin America, China and India (10/66 Dementia Research Group population-based studies)

	n	Household Living Arrangements				Characteristics of the main carer			
		Alone	Spouse only	Adult children	One or more children under 16	Spouse	Child or Child-in-law	Non-relative	Female carer
Cuba	316	6.3%	10.2%	54.7%	33.7%	17.3%	67.7%	5.8%	80.0%
Dominican Republic	235	8.5%	10.2%	48.5%	39.9%	21.4%	44.6%	11.6%	81.3%
Venezuela	140	5.7%	4.9%	68.1%	53.8%	13.7%	68.4%	2.8%	80.7%
Peru (urban)	129	1.6%	9.4%	54.3%	27.1%	13.0%	41.6%	30.1%	83.7%
Peru (rural)	36	13.9%	8.3%	63.9%	38.9%	16.7%	58.4%	2.8%	86.1%
Mexico (urban)	86	14.0%	9.3%	55.8%	38.4%	5.8%	79.1%	3.5%	83.7%
Mexico (rural)	85	16.5%	11.1%	55.3%	31.8%	12.9%	68.2%	2.4%	76.5%
China (urban)	81	2.5%	34.5%	38.3%	7.4%	36.1%	47.3%	13.9%	66.7%
China (rural)	56	3.6%	8.9%	75.0%	60.7%	42.9%	57.1%	0.0%	35.7%
India (urban)	75	4.0%	13.3%	72.0%	49.2%	26.7%	40.0%	0.0%	69.3%
India (rural)	106	15.1%	5.7%	67.0%	52.8%	23.3%	70.0%	0.0%	80.2%

The cost of caring for many women though is profound, women as a result of their caring responsibilities are subject to financial hardship, social isolation and mental and physical health problems. Carers' own health often suffers as a result of their caring activities. Research into the impact of care-giving in the UK shows that one-third to one-half of carers suffer significant psychological distress and experience higher rates of mental ill health than the general population (Shah et al, 2010). There is also some evidence to suggest that a diagnosis of depression can be causally related to the care-giving situation. Dura et al (1991) found that

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nearly one quarter of caregivers met the criteria for depression whilst in the care-giving role. Dementia can be a particularly challenging disease for female carers, and possibly as a result of their perceived role as caregivers within society, may struggle before trying to access help and possibly delay placement of a family member even at the expense of their own health and wellbeing.

Carers are thus arguably a forgotten and invisible workforce and are overlooked in terms of health and social care support. Unpaid carers provide a prop for ailing health and social care systems in the developed world and remain the bedrock of most forms of elder care in the developing world. While many women derive enjoyment and satisfaction from their role and caution should always be exercised to refrain for pejorative terms such as 'care burden', it is evident that women require greater support and interventions in order that they can carry on this valuable role without damaging their own health and well-being.

The question however that looms large on the horizon which perhaps poses an even greater threat to the next generation of women is just who will care in the future? Several demographic and societal threats particularly in developing countries imply a dramatic shortfall in informal care provision. The World Alzheimer's Report (2009) identifies four trends which could have dramatic consequences: the education of women and their increasing participation in the workforce; migration which leads to increasingly mobile populations and a breakdown of traditional family and kinship structures; declining fertility rates in the final state of the demographic transition; and in Sub-Saharan Africa, the HIV/Aids epidemic which has led to 'orphaned' parents as well as children. Evidently with almost non-existent awareness of dementia in many of these developing countries and the predicted growth of dementia particularly among women, urgent interventions and initiatives are required. It cannot be assumed that in the future there will be sufficient women available, ready and willing to assume caring responsibilities which will have dramatic repercussions for the future of informal care.

10. Conclusion

The fundamental aim of this report is to present the current evidence on dementia and women, identifying key issues and highlighting areas which merit further public policy, medical or clinical research or intervention. Based on analysis of the available data and assisted by the gender lens tool, this report posits that women across many parts of the world are and will disproportionately bear the burden of dementia, with particular regard, to either living with dementia and/or caring for family members with dementia.

As this report has highlighted, the shifting demography of all nations has led to a marked increase in the older population globally both in relative and absolute terms. If we assume the age-specific dementia prevalence rate remains constant, the ageing of the populations will result in an almost doubling in the prevalence of dementia world-wide, from 35.6 million people with dementia to 65.7 million in 2030 (ADI, 2009). Therefore while dementia syndromes affect men and women, this report has highlighted that women will disproportionately bear the burden of dementia. Dementia is a particularly foreboding reality for women, with average life expectancy generally higher for women than men. Furthermore, higher recorded prevalence rates of certain dementia syndromes in the 'oldest old' categories of people aged 85 and over place older women at greater risk than older men.

It has been argued that the figures alone suggest a need for policy interventions and frameworks that include a sex and gender dimension. This need is particularly pertinent if one considers those risk factors that are sex and gender specific, which can increase an individual's likelihood of developing a dementia syndrome. Similarly in terms of disability and disease burden, dementia is considered to be among the most disabling of all chronic diseases. As noted in the previous chapter, dementia causes 13 per cent of years of healthy life lost among women over 60 years of age. Therefore there is a growing cohort of older women whose everyday activities and ability to lead an autonomous and independent life will be severely restricted by dementia.

While sex and gender factors were found to play a role with regard to diagnosis, treatment and response, at present there is a paucity of evidence to draw any firm conclusions on the prominence and potential importance of them. It is however evident that women's role and position in society and access to health care will determine to a large extent their care pathway as the disease progresses, and further research in this area is urgently required.

The report has also explored the gender specific nature of care in terms of how women with dementia receive care, women’s role as primary care-givers and how underlying social and economic determinants affect women’s health. The nature of women’s role as largely hidden and forgotten care givers, and older women’s vulnerability to the care they receive in certain parts of the world, demonstrate the persistent inequalities many women face across the life course. This will require responses that are tailored to women’s needs and wider consideration of how policy interventions can improve women’s health and social position more generally.

Results from the Gender Lens

Differences in	Existing Gender Differences	Factors that may contribute to gender differences					
		Biological	Social	Cultural	Psychosocial		
					Economic	Political	Educational
Prevalence	Yes	x	x	x	x	?	x
Incidence	Yes	x	x	x	x	?	x
Mortality Rates	Yes	x	x	x	x	?	x
Disease Burden	Yes	x	x	x	x	?	x
Awareness	Further research required		x	x	x	?	x
Diagnosis	Further research required		x	x	x	?	x
Risk Factors	Yes	x	x	x	x	?	x
Treatment/Response	Yes	x	x	x	x	?	x
Care	Yes		x	x	x	?	x
CareGiving	Yes		x	x	x	?	x

While the gender lens has been a useful tool for aiding, clarifying and structuring internal analysis throughout this project, it should be noted that the application of the gender lens is not particularly helpful in demonstrating the complex, intersecting and multilayered inequalities and discrimination women face. As an analytical tool, the interplay of a wide range of biological, economic, sociological, political factors and membership of equality groups or strands in terms of gender, but also disability, race/ethnicity, religion or belief, falls beyond its scope and reach. Furthermore some areas where it was not possible to identify if certain psychosocial factors played a role may be more of a reflection of the limitations of the scope of this report, and the

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research available. Thus it should not necessarily be assumed that political factors are not an influencing factor in certain respects, see results above. Further clarification and investigation in terms of how we define political factors particularly at the macro and micro level and how they may influence policy development in particular, would merit further investigation. Indeed the results of the gender lens should be merely used as a guide and as a discussion point for further research and it is acknowledged, that due to the paucity of evidence in certain areas linked to dementia and gender, some of the judgments made could be considered subjective and open to debate.

Thus, just as finding an appropriate and suitable analytic tool to approach the subject of dementia and women is a conceptually fraught process, so is in turn the process of producing recommendations given the magnitude and scale of the dementia challenge ahead.

Recommendations

This report aims to provide an overview of the main topics as they pertain to dementia and women, as a necessary first step for further work. The findings suggest the urgency for global, national and regional responses to the specific challenges dementia poses for women. The recommendations below are based on priority areas, identified throughout the report.

Incidence/Prevalence/Disease Burden/Mortality Rate

1, Epidemiological studies are required for many world regions (Prince et al, 2008) and are not always disaggregated by age and gender or differentiate between the different forms and stages of the condition. Further research is required to address this.

Awareness/Diagnosis

1, There continues to be a pressing need to raise awareness of the impact of discrimination, exclusion and stigma associated with dementia and the impact this may have for women in particular.

Risk Factors and Prevention

1, With regard to non modifiable risk factors, there needs to be further research on the sex differences in the manifestations of Alzheimer's disease and other dementia syndromes. 2, With regard to modifiable risk factors, further research on gender differences on the different impacts

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of health conditions and the social determinants of health and dementia for women are urgently required.

3, There is a need to highlight the importance of the prevention agenda of dementia and protective risk factors by gender through improved public health campaigns and information provision.

Treatment/Response

1, While gender-inclusive guidelines have been implemented in some countries, greater inclusion of women in clinical trials is required, as is further research on the effect of multiple drugs and complex medication regimens for women.

2, There needs to be increased awareness of gender issues across the development and delivery of health and social care services.

3, There needs to be further research on the response of health services and systems and the need for a gendered response in certain areas as an essential step in identifying relevant issues for women and for analysing the efficacy of current measures.

4, Further research needs to be commissioned on health and social care expenditure by gender, in particular health care costs and health insurance coverage for women is weak in many countries.

Care/Care Giving

1, There needs to be greater recognition across all echelons of civil society of the role of women as the primary caregivers of people with dementia across many parts of the world and the need to ensure adequate support and social protection for this group.

2, There needs to be further research commissioned on the extent of the contribution of women as caregivers and the cost to their own wellbeing in terms of finances, health and social wellbeing.

Overarching Recommendations of the Report

1, Dementia health policies and programmes should incorporate a gender dimension in their design, delivery and evaluation.

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2, Gender should be included as a key health determinant in the promotion and disease prevention of dementia.

3, Dementia research at the regional, national and international level needs to be disaggregated by gender and age.

4, There is a need for greater interdisciplinary research incorporating the biological and social models of health for men and women to improve health interventions and outcomes.

5, Women and men should be equally represented and involved at the micro and macro level of decision-making with regard to the development of health and social care policies and resource allocation as they pertain to dementia.

The ‘Calls to Action’ for the International Community

1) The ILC-UK calls on the United Nations Committee on the Elimination of Discrimination against Women (CEDAW) to ask national governments through their reporting mechanisms to provide information on national actions and measures with regard to promoting gender equality and equal access to health and social care for women with dementia.

2) The ILC-UK calls on the United Nations Committee on the Elimination of Discrimination against Women (CEDAW), to produce a general recommendation to raise awareness of the disproportionate impact of dementia on women and how dementia will affect the rights of older women to health and social protection in the coming years. This could require national reports to include statistical data on the numbers and impact of dementia for women and information on legislative interventions, policy measures and programmes that address these gender concerns.

3) The ILC-UK calls on the Department of Gender, Women and Health at the World Health Organisation to commission and produce specific research, publications and awareness raising information to highlight the gender inequalities for women and dementia in line with other health conditions and problems currently highlighted.

It should be noted that these recommendations are in no way intended to be exhaustive and merely reflect the priorities identified throughout the report. It is thus evident, any comprehensive framework for action needs to adopt a life course approach in order to truly identify and address the multifaceted inequalities girls, young women and older women face. The priority areas for action, as identified in the WHO report, ‘Women, Ageing and Health: A framework for Action’ produced by the WHO in 2007, address the scale and complexity of this

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challenge and are recommended reading in this regard. Similarly, the recommendations refrain from more general recommendations with regard to dementia, however it is evident any improvements in the field of dementia, will invariably improve outcomes for both men and women alike. In this regard, the latest recommendations from Alzheimer's Disease International in their 2010 Alzheimer World Report and the Dementia Declaration from the International Longevity Centre Global Alliance merit further investigation.

Last word...

While the overarching aim of this report is to highlight how women may be affected by dementia, it is not the intention to view older women with dementia and indeed the ageing of our populations more generally through the traditional prism of public discourse as a 'burden' to current society. There is arguably a need to move away from framing the health and social care debate merely in terms of cost and consumption, and widen the debate to consider the possibilities and opportunities of a productive and healthy older population. It is worth remembering that the disease progression of dementia varies greatly from individual to individual and particularly in the early stages it should not be assumed older women can no longer contribute to their family and indeed wider civil society. Women with dementia should continue to be valued and respected within their communities for the life they lived and for the life they can still live.

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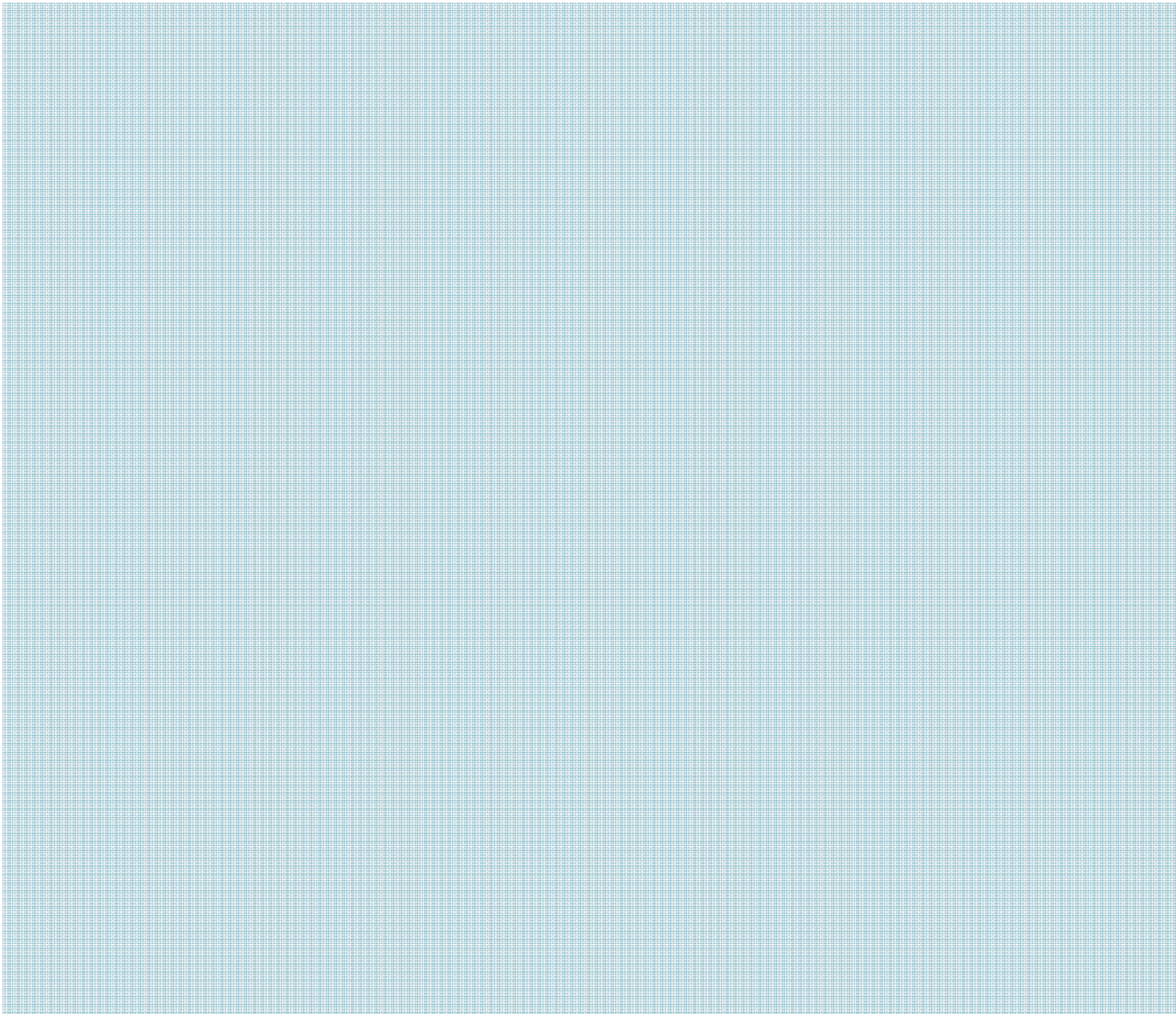
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