Chapter 13
Dementia and Women—Global Concerns

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Abstract Dementia is a common disorder involving memory loss, behavioral changes, and changes in personality that occurs after the age of 60 years. More women have dementia than men and often outlive men as well. This chapter looks at the interface of women and the dementia conundrum. We shall first look at women and some of the risk and protective factors that they have in developing dementia. The symptom differences and sociocultural factors that play a role in dementia in women are explored from a global perspective. The interface between hormonal replacement therapy and dementia is also looked at along with epidemiology of medical disorders in women and the propensity for dementia in the same population. Treatment and management differences with regards to dementia in women are highlighted, and finally, the chapter looks at the specific factors in women caregivers of patients with dementia.

Keywords Dementia · Women · Elderly · Geriatric · Caregivers

Introduction

Dementia is one of the greatest challenges to the geriatric healthcare scenario. It is a disorder with no known cure and limited treatments, and its onset redefines the collective experience of aging (Williams et al., 2009). Women all over the world have differing rates of dementia when compared to men in respect to the epidemiology, diagnosis, and management of dementia which is now required at a global level (Crooks et al., 2008). The subject of women and dementia remains under-researched and under-explored. While men and women may age in the same way and have similar needs, older women are particularly vulnerable and treated differently since childhood in many societies (Rosenthal, 2014). Several studies show

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the prevalence of dementia syndromes, and specifically Alzheimer's is showing an increasing trend in women as a global phenomenon (Vina & Lloret, 2010). The increase in life expectancy is in favor of women and also indicates that more women shall be prone to dementia (Wu et al., 2016). This chapter aims to explore the various facets of dementia and women from a global perspective.

Life Course Perspective

Assuming a life course approach, dementia in women is caused by various different pathological processes. It is a product of many trajectories, i.e., biological, psychological, social, political, cultural, and economic, and women need to be studied separately. As people age, women and men share same fundamental human rights. Older women are more susceptible to prolonged inequalities and discrimination in developing countries. Thus, from a life span perspective just like all physical and psychological disorders, dementia demands a separate perspective from a female point of view.

Terminology Used in the Chapter

In the following chapter, the term "***sex***" will be used to refer to "*differences which are biological, genetic, or phenotypic (genetic or physiological characteristics of being a man and woman)*" while the use of the term "***gender***" will be with regard to psychosocial factors such as social influences. "***Dementia***" will be used as the generic term in the chapter, to describe "*the symptoms that occur when the brain is affected by certain processes and aging*" rather than denoting a specific type of dementia.

Few Considerations

While we focus on dementia and women in this chapter, it does not imply that dementia in men is less important. The chapter is not a radically feminist viewpoint on dementia but rather based on scientifically supported facts on how dementia presents in women. Many factors mentioned in this chapter with regard to dementia and women apply equally for men. The role of gender and being a woman cannot be seen as the sole factor in health and well-being with the onset of dementia in later life. The gender lens cannot portray succinctly the complex, intersecting, and multilayered factors that go into the genesis of a neuropsychiatric disorders like dementia. Dementia is influenced by the interplay of a wide range of factors. Women are a diverse group, just as old age is dynamic and lies on a continuum of dependence

and interdependence (Tilly et al., 2016). Thus, just being a woman does not ascertain and determine risk or protection from disorders like dementia, and it would be morally and mortally incorrect to treat women as the same by stereotyping them.

Epidemiological Concerns

The growing aging population is a concern in all nations worldwide. In 2010, more than 83% of a global rise in the number older people was seen in developing countries (Pilkington, 2009). This trend will continue, and the number of women above the age of 60 years and more shall surpass 1 billion by the year 2050 (). In the population above the age of 80, there will be more women than men as well. Worldwide, by the age of 80, there are 189 women for every 100 men, and for age around 100, there are 385 women for every 100 men (). Paradoxically, women live longer but are not healthier in their old age. Research says larger number of women are compromised with age-related medical comorbidities as compared to men (Gelber et al., 2012).

Many epidemiological studies have reported arise in the prevalence of dementia, and it is reported to double for every 5 years increments in age post 65 years (Chêne et al., 2015). It is known in medicine that dementia is not age dependent and rather age related and can be prevented by the reduction of various risk factors that lead to dementia (Rocca et al., 2014). The relationship between gender and dementia is confounding with lack of regularity and discrepancies across studies based on methodology that was used and other statistics of the region in which the study was conducted (Beydoun et al., 2014). There are many factors that make dementia a significant concern for women. The average life expectancy is more in women than men. Thus, dementia would be more common in women than men in the coming years (Rizzi & Rosset, 2014).

A recent meta-analysis on dementia suggests a strong epidemiological relationship age, gender, and dementia. The incidence and prevalence of dementia increased exponentially with age and gender had an effect in most regions of the world. Men had a lower predicted prevalence than women and was in the range 19–29% (Mitchell et al., 2014). In some studies done in Europe and Asia, dementia incidence rates are higher in women than in men. There are significant gender differences in European nations after the age of 85 where older women have a greater risk than men. Studies have demonstrated a great incidence of dementia in women in very old age for Alzheimer's, while the reverse is true for vascular dementia (Fiest et al., 2016; Pendlebury & Rothwell, 2009).

Dementia and Its Global Burden

Dementia makes up 0.8% of all disability adjusted life years in worldwide studies. As dementia is seen more in older populations, the contribution is higher in the age

group 60 years and above with a burden being twice as higher in women than men (Nichols et al., 2019). The disease burden is greater in developed nations, and no uniform patter has been reported. Varied results have been reported from studies in Asia, and women with dementia above the age of 60 years are also at a greater risk for the development of depression (Alladi & Hachinski, 2018; Wimo et al., 2010). Thus, the burden of dementia is greater in women, because they live longer and because they outlive men in older cohorts. Greater medical issues like poor vision, cataract, hypertension, arthritis, and depression also impinge on the burden in dementia (Launer, 2019).

Many women with dementia fail to receive adequate care and may not even be diagnosed properly by their treating doctors due to lack of training. Many may not receive adequate treatment and may not get the care needed and the rehabilitation needed for the disorder (Venketasubramanian et al., 2010).

Lack of Access to Dementia Care

Women suffer more than men with regard to dementia care and its access. Discrimination against women is well-documented in many societies, and they are rarely brought for treatment and diagnosis early. Dementia as a diagnosis is powerfully stigmatizing both in the public health and residential care settings, as many patients have disturbed behavior, poor self-care, memory loss, and incontinence. There are prejudices that exist toward women getting the right care and medical help (Giebel et al., 2015).

Caregivers can also be a cause of discrimination and prejudice to patients. The majority of caregivers are women, and women often have to bear the brunt for the demented state of their spouses and elder men in their families with dementia. In many countries, dementia and psychiatric disorders is considered akin to "*madness*" which renders the individual not getting access to care or getting it with stigma and ridicule (Garand et al., 2009). Women may be taken to traditional healers which further promotes stigma and isolation. Stigma in mental health and fear of admission may serve to act as barriers to women seeking care and getting diagnosed with dementia, and the awareness of dementia is also low in some countries (Herrmann et al., 2018).

Lack of Diagnosis in Women

Diagnosis rates in women also depend on their ability to access dementia care and successfully use the healthcare system. The multiple medical problems faced by women with old age such as lack of mobility, hearing impairment, memory loss, and depression may serve as barriers to going to a healthcare professional (Religa et al., 2012). Older women in various countries live alone and are lonely, and the death of

the spouse is a stressor that makes it further difficult. Some studies on diagnosis rates of dementia have shown slightly lower rates in people living alone than those with a family and caregivers (Bunn et al., 2012).

Risk Factors for Dementia in Women

There are many risk factors for dementia that have been identified. While there are differences in the risk factors for men and women with regard to the development of dementia, sex and gender differences are seen in this domain regard. There is no single risk factor but rather multiple complex modifiable and non-modifiable and modifiable risk factors that play a role in the development of dementia (Chen et al., 2009).

Age: We all know that advancing age is a major risk factor for all forms of dementia. Women live longer than men and form a large part of adults in the oldest old age groups, and hence, where the risk of dementia is greater, more women than men have dementia (Song et al., 2011).

Sex: Several studies have suggested that women are at greater risk of Alzheimer's disease. However, as Alzheimer's is the most common form of dementia and due to women outliving men, we may have more women than men having dementia in the years to come. The risk of developing dementia in women compared to men is 5–7 times greater (Bamford & Walker, 2012; Podcasy & Epperson, 2016).

Genetic Factors: There are numerous genetic studies conducted to determine the genetic risks for dementia. Several genetic causal theories have been put forth for dementia and many with genes seen more in women. Research has proposed that there is an Apolipoprotein E genotype interaction with women who are thus at a greater risk for Alzheimer's than men in older age groups (Rosvall et al., 2009). Results of these studies taken together suggest that women are more susceptible than men to dementia irrespective of apolipoprotein genotype (Bäckman et al., 2015).

Hormonal factors: A biological hormonal factor for women and dementia is linked to some blood reproductive hormone levels (Whitmer et al., 2011). It has been proposed that low estrogen levels with other factors account for an increased risk of Alzheimer's disease in women (Georgakis et al., 2016). Estrogen replacement therapy has been considered to reduce the risk of Alzheimer's disease. Many studies suggest estrogen to serve as a protective agent for postmenopausal women and reduces the risk developing Alzheimer's disease (Rasgon et al., 2014).

Cardiovascular factors: Cardiovascular factors have been implicated in the causative pathway of dementia in women and include stroke-related factor that may contribute to the onset of vascular dementia. There are risk factors associated with coronary heart disease and stroke like chewing tobacco, smoking, hypertension, raised cholesterol, obesity, lack of exercise, and a poor diet. Women also have higher rates of silent ischemic episodes and cerebral white matter degeneration. Diabetes is a risk factor in women associated with the development of dementia (Alonso et al., 2009; Fillit et al., 2008).

Physical Activity: A number of risk factors and lifestyle associated factors influence the risk of developing dementia. The associations between walking regularly and protection from Alzheimer's and related dementia syndromes have been noted in women (Aarsland et al., 2010). There have been reported reductions of the risk of dementia by 50–60% in women with greater levels of physical activity as compared to those with less or no physical activity (Blondell et al., 2014).

Diet and lifestyle: Dietary factors considered in the same study yielded the protective effect of regular red wine consumption. Moderate amounts of wine consumption were associated with a reduced dementia risk in women (Stockley, 2015). Women who are obese seemed to be at a greater risk for dementia than men (Hassing et al., 2009).

Depression: For women, a higher risk of dementia has been associated with subclinical depression and even presence of depression increases the risk of dementia development in women. Untreated depression is at a greater risk to cause dementia in women due to brain based and neurochemical theories beyond the scope of this chapter (Byers & Yaffe, 2011).

Language and education: The Nun study which was a longitudinal study based on 678 American Roman Catholic sisters demonstrated how early life experiences and educational status along with linguistic abilities showed that cognition like poor idea density and lower grammar complexity was found to be liked to dementia (Mortimer, 2012).

Most studies on risk factors in dementia are marred by their small sample sizes, geographical circumscribed locations, and small population bases that make national and international comparisons difficult (Barnes et al., 2009).

Treatment Response in Women

Women have not been a part of early studies and most clinical trials due to safety issues. There are limited studies on gender specific effects of drugs used in the management of dementia. Many older women have medical problems and may be on multiple drugs with diverse medication combinations causing the chance of drug reactions. With regard to dementia, the problem is further compounded by cognitive decline where response to therapy can never be measured by the subject's response but rather one has to rely on the caregiver. The male subject bias in dementia research may have gender-based implications in studies on the medical management of dementia (Johnell et al., 2013; Patterson et al., 2008).

Dementia Care for Women

In developing countries, proper care for dementia is not available, and even if it is, it is expensive and beyond the reach of all. Thus, most patients are managed by the

family or neighbors and in some cases by charitable non-governmental organizations. The developing nations neither have the capacity nor the healthcare infrastructure to rise up to the increasing graying population that shall soon suffer from dementia. Elderly women are in a more vulnerable position than elderly males when it comes to dementia and quality of life (Witt et al., 2010). Lower educational status in women and lack of attention given to their care are other factors. Education of women is not a priority in many countries (Bott et al., 2017). Many situations arise where women may either work within the family environment or maybe involved in low-skilled and poorly paying work. A United Nations Human Development Report mentions that "*poverty accentuates gender gaps, and when adversity strikes, it is women who are often the most vulnerable*" (Frazer et al., 2012).

Elder Abuse and Dementia in Women

In respect to elderly women, topics like elder abuse are important as this applies to any form of care that they receive. Women with dementia are more susceptible to elder abuse due to deteriorating cognitive function, poor memory causing a vulnerable state where they may be taken advantage of Dong (2015). Elder abuse manifests as elder bullying, physical violence, intimidation, emotional and physical neglect, and even financial abuse. In most nations, elder abuse is under-reported and has always received poor attention and priority in both developing and developed countries. Women are more susceptible to elder abuse given many live longer and older and are also more likely to be lonely and at the mercy of the caregiver. Elder abuse studies across the globe report higher rates in women as well as under reporting of the same (Dong et al., 2014; Yon et al., 2017).

Women as Caregivers in the Dementia Process

Caregivers of patients with dementia are an invisible workforce and are neglected in terms of healthcare support. Family members as caregivers remain the mainstay for elder care in dementia. Women may derive happiness and satisfaction from their role, and caution must be sued when we refer to caregiver burden for them (Zauszniewski et al., 2015). Population studies report chances that particularly in developing countries indicate a shortfall in informal care provision. The proper education of women and their increasing participation in the healthcare force, their migration causing mobile populations, and a breakdown of traditional families as well as more couples reducing the number of children, they have shall affect caregiving for the future. In the future, there may be less women available, who are keen to assume caregiver responsibilities, and this will have huge repercussions for the future of informal dementia care at home (Stewart et al., 2016).

Future Research Needs

The following, we feel, are the future research needs in the area of women and dementia and their interface:

1. Dementia health policies should inculcate a female- or women-based dimension in their design, delivery, and execution.
2. Gender-specific risk factors should be included as a key health indicator in the primary prevention of dementia.
3. Gender- and age-based dementia research at a regional and national level.
4. More research across disciplines shall combine biological and social aspects of dementia care in women.
5. Women and men should be recruited in drug trials and treatment studies in dementia care.
6. Women must be considered at healthcare policy level and resource allocation in dementia.
7. Drug response studies to treatments in dementia.
8. Genetic studies for dementia in women.
9. Specific studies of women caregivers in dementia.
10. Specific studies on elder abuse and women with dementia.
11. Phenomenological and qualitative studies of women with dementia.

Conclusions

Though there is a greater risk for dementia among women, several factors are also protective in nature and can play a role in the well-being of aging women. Interestingly, the biologically determined sex as well as the gendered aspect of being a woman can pose risk factors as well as protective factors in the development of dementia. There are unique challenges that women (and men as well) face as a result of developing dementia that demands for an adequate health infrastructure in order to address those. While there is a need for the health sector to provide for holistic dementia care, the psychosocial care received from the family can aid in preventing dementia to a fair extent. Genetically underpinned dementia can also be managed well at the family level to a decent extent. Psychoeducation and awareness are key to understanding and addressing dementia at the family level. While a more comprehensive nature of research will help address the nuanced challenges of dementia among women, there is a lot one can do in order to delay dementia. However, there is a need for understanding the phenomenon of dementia better in women by including greater number of women subjects in research.

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