Social Exclusion of Elderly Women suffering from Dementia: A Critique of Governmental Policies

Veena H. Kattegowdar[a], Sudeshna Mukherjee[b]
[a]Research Scholar, Centre for Women's Studies, University of Bangalore, Jnana Bharathi Campus, Bangalore 560056, Karnataka, India
[b]Assistant Professor, Centre for Women's Studies, University of Bangalore, Jnana Bharathi Campus, Bangalore 560056, Karnataka, India

Abstract

Dementia is a chronic illness where there will be decline in memory, thinking and ability to perform daily activities. This causes mostly among elderly people who are 60 years and above. In 2012 worldwide there was 35.6 million people had prone to dementia and this will increase every year for about 7.7 million cases and one new case for every 4 seconds. It is estimated that 3.7 million Indian people aged over 60 are suffering from dementia. In that 2.1 million are women and 1.5 is men. This shows that dementia is higher among older women than men and it is expected to be doubled by 2030.The people with this chronic illness are facing exclusion with respect to caring and economical aspect.

The globalization and its concurrent effect has led to privatization and cost escalation of health care, nuclearization of families and migration among younger ones for various purposes. This affects elderly people suffering from dementia, especially women who are primary care givers and often financially dependent on others in the family. Thus, when this primary care givers themselves are not well and in need for care but not protected either by State or by family, their exclusion become all encompassing. There are various old age homes to take care older people who are normal in their behaviour but very few looks into the dementia care of elderly people in the society. This is still the area where family plays the key role.

In this context this paper aims to study the social exclusion of women elderly suffering from dementia and also try to point out the lacunas in the state policies to include them in the paradigm of institutional care.

KEYWORDS: Dementia, Chronic illness, Globalization, Nuclearization, Migration, Exclusion

Introduction:

India has rich cultural heritage; it is the second most populous country in the world. It is the land of diverse people, religions, religious beliefs, cultural traditions, and customs. In Indian society the most important unit is "family". In India it is the practice of joint family system where everybody used to stay under same roof and the elderly people including women, occupies a prominent place. They are treated as the 'Head of the family' and respected by all by virtue of their age, experience and contributions towards family. But now there is an increasing Nuclearization of the family due to small family norms, urbanization and subsequent migration to urban areas and employment opportunities of the women outside home. This has inflicted

profound change in the geriatric care within the family system and transformed "elderly" from the most respected to most neglected, vulnerable and as liability. Women elderly suffered even badly because of their differential social status, economic dependence and unequal share in the property.

The Demography of Aging is alarming in India. 2001 census shows that India ranks second in its elderly population with 72 million (A.K.Ravishankar). The total population of elderly women in India is 3.88 corers. This is due to increase in the Life expectancy, literacy and improvement in the medical facilities available in India. During the old age the elderly people are prone to various illnesses including Alzheimer's, Schizophrenic, and Dementia etc which led to decline in their physical and mental capacity. Where this give rise to the exclusion of elderly people from the care and support, because the people who suffers from dementia needs a full time care. But due to the survival aspect both men and women should work to meet their needs of the family. Thus there is decline in the care taking and support from the family. This shows exclusion of the elderly people with special need is excluded.

The elderly women are those who are aged 60 and above are considered to be old, and the people who are prone to these illnesses are in need of special care. These elderly women are socially excluded from their health care and social support from their families and even the governmental initiatives respectively.

What is Dementia?

Dementia is a syndrome caused by disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, and orientation, and comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. Dementia mainly affects older people 2% of cases start before the age of 65 years. After this the prevalence doubles with every five-year increment in age. Dementia is one of the major causes of disability in later life (Neurological disorders: public health challenges pp.42). This shows that the life of the elderly women which is already vulnerable and turning it into worse. Since women are not financially independent from earlier to till they are aged, they are dependent on others for their living. Thus elderly women suffering from dementia are trebly vulnerable by virtue of their gender, age and the disease, since women are the primary care givers in any society when they themselves are in need of intense care, it become problematic. Thus this shows the social exclusion of elderly women who are prone to chronic illness is in need of special care.

Table:1Estimated cases of Dementia in various States of India [census 2001]

State/UT	Total Population	%>60Years	Estimated People with Dementia
Jammu & Kashmir	10143700	6.7	12913
Himachal Pradesh	6077900	9	10393
Punjab	24358999	9	41654
Chandīgarh	900635	5	856
Uttaranchal	8485349	7.7	12414
Haryana	21144564	7.5	30131
Delhi	13850507	5.2	13684
Rajasthan	56507188	6.7	71934
Uttar Pradesh	166197921	7	221043

Bihar	82998509	6.6	104080
Sikkim	540851	5.4	555
Arunachal Pradesh	10979668	4.5	939
Nagaland	1990036	4.5	1701
Manipur	2166788	6.7	2758
Mizoram	888573	5.5	929
Tripura	3199203	7.3	4437
Meghalaya	2318822	4.6	2027
Assam	26655528	5.9	29881
West Bengal	80176197	7.1	108158
Jharkhand	26945829	5.9	30206
Orissa	36804660	8.3	58041
Chhattisgarh	20833803	7.2	28501
Madhya Pradesh	60348023	7.1	81409
Gujarat	50671017	6.9	66430
Daman & Diu	158204	5.1	153
Dadra Nagar Haveli	22490	4	17
Maharashtra	96878627	8.7	160140
Andhra Pradesh	76210007	7.6	110047
Karnataka	52850562	7.7	77320
Goa	1347668	8.3	2125
Lakshadweep	60650	6.1	70
Kerala	31841374	10.5	63523
Tamil Nadu	62405679	8.8	104342
Pondicherry	974345	8.3	1536
Andaman & Nicobar Island	356152	4.9	332
Total	1454679		

The above table shows the estimated cases of Dementia in various States of India according to the 2001 census (Amit Dias, Vikram Patilpp 94).

In 2012 worldwide there was 35.6 million people had prone to dementia and this will increase every year for about 7.7 million cases (Fact sheet N°362 April 2012)and one new case for every 4 seconds. It is estimated that 3.7 million Indian people aged over 60 are suffering from dementia. In that 2.1 million are women and 1.5 is men (Public Health Foundation of India pp.8). This shows that dementia is higher among older women than men and it is expected to be doubled by 2030. The people with this illness are facing exclusion with respect to caring and economical aspect.

Financial Impact of Dementia

The World Alzheimer Report (2010) focused on the economic impact of Dementia. A dementia is already significantly affecting every health system in the world, and large amount of money are being spent in caring people with dementia. Alzheimer's and other dementias are imposing huge societal and economic burdens, both through direct (medical and social care) and indirect (unpaid care giving by families and friends) costs. Evidence is just beginning to emerge of the extent of the economic burden in middle income countries (Anders Wimo, 2010)

It is estimated that the cost of taking care of a person with dementia is about 43,000 annually; much of which is met by the families as the state is virtually non-existent. The financial burden will only increase in the coming years making it impossible for

the poor. In the present modern days, family support is shrinking and very few institutions has come forward to fill this wide. Such as Alzheimer's and Related Disorders Society of India (ARDSI) and the national voluntary organization dedicated to the care, support and research of dementia has been in the forefront to improve the situation since 1992 (The dementia India report, 2010).

In India during early days there was an existence of joint family system elderly people was given more prominence and well taken care by the family members especially women who were staying back at home taking care their do's and don'ts but in the present day context the structure of the family has now changed to nuclear family system, where the younger ones are migrating to cities for various reasons due to the effect of globalization, the cost of living and survival has become difficult this consequence has led both the couples to work outside the home to meets their needs so due to lack of enough time, patience the younger people are not able to spend time and look after them as earlier. (Older Persons Maintenance, Care and Protection Bill 2005).
This affects elderly people and led to join old age homes either it is due to forcefully, family disturbances at home, sometimes it's willingly people join themselves to old age homes. There are number of old age homes to take care or to look after elderly people, who are normal in their behaviour and who can do their work themselves. So, when the people are not looking after the elderly people who can perform their work without depending on others, the elderly people who needs special care is vulnerable, and especially women who are often financially dependent on others for their living. Thus elderly women suffering from Dementia are trebly vulnerable by virtue of their gender, age and the disease, since women are the primary care givers in any society when they themselves are in need of intense care, it become problematic. In developed countries, in the field of geriatric care the vacuum created by the absence of family is duly filled in by the social security measures provided by the state. In India a clear absence of required social security measures for the elderly turns the field of geriatric care extremely challenging.

Existing Governmental Policies to tackle Dementia:

In India Dementia remains a largely hidden problem and it is not considered as a health care priority, especially in those disadvantaged parts of India where poverty and illiteracy levels are high. In most parts of India institutionalised care for dementia patients is not available. Even if relevant services are available, their affordability would become a burden for many families, resulting in the majority of older people with dementia being cared at home by their families. Although dementia has been reported as a well-established cause of dependency among older people, no clear system has been developed for ensuring the social protection of older people with dementia

According to the National Dementia initiatives, Alzheimer's and Related Disorders Society of India (ARDSI) with the support from The Ministries of Social Justice & Empowerment and Health & Family welfare have recently undertaken consultative meetings across India with the aim to identify the gaps in diagnosis, treatment, care, support, and research for people affected by dementia in India.

While there is currently no direct policy for the care of people with dementia, there are a number of government and voluntary initiatives that support the health and social care needs of the elderly in India. They include:

The National Policy for Older Persons (1999) aims to promote the health and welfare of senior citizens in India and encourages individuals to make provision for their own as well as their spouse's old age. This policy enables and supports voluntary and non-governmental organizations to supplement the care provided by the family and provide care and protection to vulnerable elderly people. Health care, research, creation of awareness and training facilities to geriatric caregivers have also been enumerated under this policy. The main objective of this policy is to make older people fully independent citizens. (http://www.archive.india.gov.in)

This policy has resulted in the launch of new schemes such as-

1. Strengthening of primary health care system to enable it to meet the health care needs of older persons
2. Training and orientation to medical and paramedical personnel in health care of the elderly.
3. Promotion of the concept of healthy ageing.
4. Assistance to societies for production and distribution of material on geriatric care.
5. Provision of separate queues and reservation of beds for elderly patients in hospitals.
6. Extended coverage under the Antyodaya Scheme with emphasis on provision of food at subsidized rates for the benefit of older persons especially the destitute and marginalized sections.

The Integrated Programme for Older Persons (2007) is a scheme that provides financial assistance to non-governmental organizations to establish and maintain old age homes, day care centres, mobile Medicare units and that provides non-institutional services to older persons.

The National Mental Health Programme (1982) focuses on prevention and treatment of mental and neurological disorders and their associated disabilities and use of mental health technology to improve general health services. Despite there being a focus on the needs of senior citizens who are affected with Dementia, it failed to make adequate provision for specific dementia treatments and services.

When we look at the services for People with Dementia in India the Alzheimer's and Related Disorders Society of India (ARDSI), established in 1992, is a Non-Government Organisation which has spearheaded the dementia movement in India. It is the first Afro-Asian organization to get officially affiliated with Alzheimer's disease International, UK which is the umbrella organization for all organizations working for the welfare of people with Alzheimer's and related diseases around the globe. In addition a few other organizations like Help age India, Dignity Foundation, Nightingales Medical Trust, the Dementia Society of Goa, Sangath, Voluntary Health Services and Silver Innings Foundation are also providing such care services either in association with ARDSI or by themselves. A majority of them are in the South Indian

States (The Dementia India Report 2010).The numbers of services available in India that cater exclusively to people with dementia are as follows:

Type of Services	**Approximate no of facilities in India**
Day Care centres - Dementia Day Care facilities are designed for Person with Dementia who have a need for medical attention or supervised daytime care, but who do not require institutionalization in a nursing home.	10
Residential care facilities - This facility is to manage the basic day-today activities of the Person with Dementia. This may be long term care in a nursing home or short respite care.	6
Domiciliary care services - Provided to the Person with Dementia at the residence. Services could range from caregiver training to formal nursing care. Could be provided by geriatric home nurses or other trained personnel	6
Support groups - Support groups for caregivers of Person with Dementia. Members share experiences and get support and coping strategies.	Exact data not available
Memory clinics - Specialized clinics that offer clinical assessment, support, information and advice to persons with memory problems	100
Dementia Help Lines - Dedicated phone lines to address queries on dementia 24/7. Handled by trained personnel.	10

Sources: (Dementia India 2010pp 56, 57).

Policies for Dementia patients United Kingdom

When we look at the care and policies for Dementia people in developed countries like UK, it provides a special care and services for dementia patients, It specifies the need for comprehensive specialist Older People's Mental Health [OPMH] services and is explicit about the need to identify and treat people with dementia early in their illness as well as providing high quality health and social care across dementia severity. However, as we have seen, evidence has been accumulating that suggests a failure of services for older people with mental disorders. The Audit Commission's (AC) Forget Me Not (2000) and Forget Me Not 2002 (2002) reports identified multiple areas for service improvement. In 2003 the national inspection reports by the Social Services Inspectorate(SSI) Improving Older People's Services: an overview of performance and the Commission for Health Improvement This service development guide for integrated mental health services for older adults was published by the Care Services Improvement Partnership (CSIP) in 2005 with a particular emphasis on informing the commissioning of [OPMH] services. The fundamental challenge is that

at present it may be the case that less than a quarter of people with dementia come into contact with old age psychiatry services at any time in their illness (Holmes et .al 1997). Services are not available for a large majority of the population to deliver the memory assessment and care services. Currently demand has been managed by health purchasers not providing funding for service development and services continuing to act reactively. With the publication of definitive statements on the content and value of good quality care, such as the NICE Clinical Guideline, and positive changes in public attitudes and understanding of dementia, demand can be predicted to grow. This is a profound challenge for both service providers and commissioners (Dementia UK).

Conclusions:

In developing country like India there are policies for elderly people but the government fails to form policies especially for the Dementia patients. At present only day care service is provided for the dementia patients only at the selective institutions and hospitals. Hence the Nation needs a special policy towards the special need care patients such as dementia, because in future days it will be in demand and the patients are going to be doubled. Thus this shows that the social exclusion of elderly people especially elderly women suffering from dementia is excluded with respect to caring and policies initiatives by the state. So this has to be included in the paradigm shift to institutional care.

The Dementia UK report identifies:

1 People with dementia are substantial users of health and social care services.
2 The number of people with dementia and families affected by dementia is set to increase rapidly and we will therefore see increasing demand for support services.
3 Increased demands for support services will be driven both by the increases in the numbers affected and the shift in the age distribution towards a preponderance of the oldest people, who tend to be frailer and to have more limited informal support networks (Dementia UK, pp81).

The Dementia India report 2010 identifies:

1. The number of Persons with dementia and families affected by dementia is set to increase rapidly.
2. The impact of dementia on the individual, the family and society will increase exponentially in terms of the burden, disablement, and costs of care.
3. Persons with dementia do not access and use health and social care services.
4. Dementia care is characterised by a significant lack of service delivery and evidence on outcomes with interventions.
5. A small portion of persons with dementia and families access private health services due to absence of or unsatisfactory public services.
6. There will be an increase in demand for support services.
7. Increased demand for support services will be driven both by the increases in the numbers affected and the shift in the age distribution towards a preponderance of the oldest people, who tend to be frailer and to have more limited informal support networks.
8. Lack of awareness among professionals, the family and community, policy makers and agencies to the needs of Persons with dementia has led to dementia care being absent or delivered piecemeal and in an inefficient fashion in India.

9. More investment and careful planning will be needed to maximise the quality of life of
Persons with dementia and their families, and to accomplish that in an efficient manner with the available resources.
10. There are hardly any standard practice guidelines and treatment centres in India and the current health and social care system is characterized by a widespread failure to support Persons with dementia and their families (Dementia India Report 2010, pp71).

Recommendations:

1. Make dementia a national priority
2. Increase funding for dementia research
3. Increase awareness about dementia
4. Improve dementia identification and care skills
5. Develop community support
6. Guarantee carer support packages
7. Develop comprehensive dementia care models
8. Develop new health Policies towards dementia patients
9. Early Identification, Assessment tool should be made available in all the health clinics

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