

The Impact of Dementia Care on Women Caregivers with special reference to working women Caregivers

Veena H. Kattagowdar^a, Sudeshna Mukherjee^b

^aResearch Scholar, Centre for Women's Studies, University of Bangalore, Jnana Bharathi Campus, Bangalore 560056, Karnataka, India

^bAssistant Professor, Centre for Women's Studies, University of Bangalore, Jnana Bharathi Campus, Bangalore 560056, Karnataka, India

Abstract

The growth and increase in the life expectancy among the elderly population is giving rise to other health issues like chronic illness like Dementia. Dementia is observed in elderly people, the gradual decline in memory, reasoning and communication skills, and a gradual loss of skills needed to carry out daily activities, the person with dementia also experience changes in their mood or behavior and loss of control of basic bodily functions. It is one of the major causes of disability and dependency among older people especially for elderly women. It is very shattering not only for the people who are suffering from it but their caregivers. In India the caregiving is almost given by the family members, of course the primary caregivers are women. With increasing nuclearization, migration, of the families and women's participation in productive work outside home putting immense stress on dementia care givers and a lot of burden. Burden on caregivers associated with financially, physically, psychologically.

Materials and Methods:

“Triangulation” method is being adopted. Triangulation is the mixture of both the qualitative and quantitative data. In the qualitative method the tools adopted are ethnography method, participant observation, and case study, to study the patient's behavior. In quantitative data interview schedule is adopted to collect the data from the family caregivers. The Zarit Burden Interview Scale is adopted has a material to collect the data from the family caregivers.

Findings/Results:

- 100% of the caregiving task is given by the women in the families, as a primary caregiver
- 55% of them are working women, taking care as a prime caregiver in the family
- 60% of the family caregivers belongs to the category of 21-40 score Mild to Moderate Burden

KEYWORDS: Dementia, Nuclearization, Caregiving, Care Burden

Introduction:

India the developing country is growing with huge population. The share of the elderly population is rising rapidly. Elderly population has their contribution of 8.3 percent in 2011 and is going to be much higher in the coming days. As per the 2011 census, there are about 104 million elderly persons in India, 53 million are females and 51 million are

males. Since the last two decades the females has been outnumbered the elderly males¹. This manifests the changing trends among the elderly population by their gender. It is becoming a major concern for policy makers as elderly women are vulnerable on all fronts compared to elderly men. Since the growth or increase in the life expectancy of the elderly people due to advancement in the medicinal and pharmaceutical sector, the people are living longer. This longer life span is leading to the other chronic illness such as Dementia.

Dementia is a syndrome usually chronic, characterized by a progressive, global deterioration in intellect including memory, learning, orientation, language, comprehension and judgment due to disease of the brain. It mainly affects older people; about 2% of cases start before the age of 65 years. After this, the prevalence doubles every five years. Dementia is one of the major causes of disability in late-life². Dementia is used to describe a collection of symptoms, including a decline in memory, reasoning and communication skills, and a gradual loss of skills needed to carry out daily activities, the person with dementia also experience changes in their mood or behavior and loss of control of basic bodily functions. These symptoms are caused by structural and chemical changes in the brain as a result of physical diseases such as Alzheimer's disease. The factors, like age, genetic background, medical history and lifestyle, can combine to lead to the onset of dementia. Dementia is a progressive condition³. The changes are often small to start with but the symptoms become more severe over time⁴.

The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behavior, or motivation. Dementia is caused by a variety of diseases and injuries that primarily or secondarily affect the brain, such as Alzheimer's disease or stroke⁵. Dementia is one of the major causes of disability and dependency among older people worldwide. It is very shattering not only for the people who are suffering from it but their caregivers and families. It is due to lack of awareness and understanding of dementia, barriers to care and diagnoses. The impact of dementia on caregivers, family and societies can be physical, psychological, social and economic⁶.

Conversion in the Society:

A recent change over in the structure of the family, joint families has made the way for nuclear families and a tremendous decrease in the number of family members. Migration among the families like from rural to urban places, urban areas to metropolitan cities and metropolitan cities towards abroad a rapid change due to urbanization. Globalization is one of the reasons because the globalization has changed

¹Elderly in India, 2016

²The Dementia India Report, 2010

³Dementia UK

⁴https://www.alzheimers.org.uk/info/20007/types_of_dementia/1/what_is_dementia retrieved on 22/6/2017

⁵<http://www.who.int>

⁶ibid

the society a lot, the life style of the people have changed. To balance the life style and to lead secure and decent life both the couples in the family will be working. This was not the condition faced by the people earlier because women's in the families used to take the responsibility of the elderly people, children and household chores. Women used to dedicate her full time in caring people of the house. But in the present situation women are into jobs heading towards the empowerment. Here lies the gap and lacks the geriatric care at the family level. These inferences gives rise to vulnerability among the elderly people especially the status of elderly women with dementia deteriorates.

Dementia: Indian Situation

In India there are for about 4.1 million dementia patients as per 2015. In 2010 Dementia India Report 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 2030⁷. In India it is estimated that the cost of taking care of a person with dementia is about 43,000 annually as per the dementia India report much of which is met by the families as the state is virtually non-existent. Presently the Institutional cost in private clinics ranges from Rs30, 000-40,000 which is prohibitively high for common citizen. The financial burden will only increase in the coming years making it impossible for the poor.

Table: 1 shows the estimated cases of dementia in top 5 states in India 2001 census:

| Sl.No | States | Total Population | %>60Years | Estimated People with Dementia |
|-------|----------------|------------------|-----------|--------------------------------|
| 1 | Uttar Pradesh | 166197921 | 7 | 221043 |
| 2 | Maharashtra | 96878627 | 8.7 | 160140 |
| 3 | Andhra Pradesh | 76210007 | 7.6 | 110047 |
| 4 | West Bengal | 80176197 | 7.1 | 108158 |
| 5 | Tamil Nadu | 62405679 | 8.8 | 104342 |

The estimation of dementia patients in all the states of India as per the 2001 census data⁸, The highest population of dementia patients is seen in Uttar Pradesh with 2,21,043 persons with dementia. Extended with the states like Maharashtra, Andhra Pradesh, West Bengal, and Tamil Nadu. Karnataka is in the top eighth region or state in having dementia patients by 77,320 persons suffering from dementia.

⁷ Dementia India Report, 2010

⁸ Amit Dias, VikramPatil, 2009

Dementia care in India is almost entirely home based. It is prudent to strengthen home based care for more than one reason. Greater focus on the households in India is required since they hold the key to the care and support of Person with Dementia. With increasing nuclearization of the families and women's participation in productive work outside home putting immense stress on dementia care givers. The estimated number of Person with Dementia in India in 2010 is 3.7 million. Assuming that it is very unlikely that there is more than one Person with Dementia in a given household, it means that 3.7million households have with a Person with Dementia. This would indicate that 1 out of 50 normal households will have a Person with Dementia and 1 out of 16 households with at least one older member will have a Person with Dementia. These figures indicate that dementia is not uncommon among Indian households. Dementia, directly or indirectly affects all members of a household. The estimated number of people indirectly or directly affected by dementia would then be around 20 million⁹.

Materials and Methods:

For the data collection "Triangulation" method is being adopted. Triangulation is the mixture of both the qualitative and quantitative data. In the qualitative method the tools adopted are ethnography method, participant observation, and case study, to study the patient's behavior. In quantitative data interview schedule is adopted to collect the data from the family caregivers. In the following study 30 samples were examined.

The Zarit Burden Interview Scale is adopted has a material to collect the data from the family caregivers. The aim of this interview schedule is to know the level of burden faced by the dementia caregivers. Zarit Burden Interview (ZBI) Scale was developed by Steven .H. Zarit (USA) in the year 1980¹⁰. The objective is to assess the level of burden experienced by the family caregivers of older persons with dementia.

The questionnaire includes 22 questions with 5 points response scale, namely;

1. Never – 0
 2. Rarely – 1
 3. Sometimes – 2
 4. Quite Frequently – 3
 5. Nearly Always – 4
- The total score of the Zarit Burden Interview (ZBI) is a summation score of all 22 questions (range – 0 to 4). The score range is within 0 to 88. The interpretation of the score is as follows;
 - 0-21 – Little or No Burden
 - 21-40 – Mild to Moderate Burden

⁹ ibid

¹⁰<http://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/zarit.aspx>

- 41-60 – Moderate to Severe Burden
- 61-88 – Severe Burden

Findings/Results:

Among the 30 samples, there were total of 18 women dementia patients. For about 12 elderly women dementia patients were taken care by the family caregivers. Around 06 elderly women dementia patients were given care in the institutional care 03 patients are taken care by the domestic assistance at home Only 01 elderly women is taken care by the day care centers Only 01 elderly women dementia patient is getting professional care. In an institutional care only 01 dementia women dementia patient has special individual care. These are the different kinds of social and health care support receiving by the elderly women suffering from dementia.

Through the participant observation I could analyze that when the patient is fully bedridden and psycho-motor activity is nil, the families hire the professional care services. When the family caregiver is emotionally and psychologically drained, frustrated and depressed they have opted for day care centers for dementia patients. The family caregiver utilizes those free times for themselves. When the patient is a bedridden, often due to vascular kind of dementia – stroke and motor activities does not work, the caregiver is hired for the full time for special individual care. Apart from this, individual special caregiver is hired when there is no other female member to take care of the patient and the patient needs to be assisted 24x7.

Cost of Care:

- The institutional care is costly cannot afford for the poor and middle class families because the cost of taking care a dementia patient starts from the minimum amount of 750 rupees per day. The cost increases as the disease increases where the demand is more for the caregivers. Since the disease increases the patients with dementia will have a gradual decline in their bodily movements, where there is a need of personnel individual care is required
- With a good facility and care can cost more than 1000/- rupees per day, since it reaches approximately around 30,000/- per month. It is a again a burden to the family members, until an individual has his/her own source of income
- The economic burden will be less at home compare to institutional care because the amount is spent for the medicines which costs within 5000/- rupees.

Care Burden:

By adopting the Zarit Burden Interview (ZBI) have come up with the following results and interpretations;

Table: 2 Shows the Care Burden of Family Caregivers and Interpretation of Scores

| Interpretation of Scores | Frequency | Percentage |
|---------------------------------|------------------|-------------------|
| Little or no Burden | 04 | 20.0 |
| Mild to Moderate Burden | 10 | 50.0 |
| Moderate to Sever Burden | 03 | 15.0 |
| Severe Burden | 03 | 15.0 |
| Total | 20 | 100.0 |

1. 0-21 score Little or no burden

- ✓ Out of 20 family caregivers 04 family caregivers have got their interpretation of little or no burden.
- ✓ In this category there were 2 patients each men and women
- ✓ In the Little or no burden category ,
 - Patients are physically independent in doing their work by themselves
 - One of the women patient is sent to Alzheimer’s center from 9am to 4pm
 - One of the male patient has taken professional care services
 - In other 02 patients since the condition is in the initial stages the family members don’t feel burden
 - When the family caregivers have opted for the day care centers, professional care, there physical and mental stress or burden is less in taking care of dementia patients.

2. 21-40 score Mild to Moderate Burden

- ✓ Out of 20 family caregivers 12 family caregivers have got their interpretation of mild to moderate burden.
- ✓ In all these 12 cases of dementia patients need assistance in their day to day activities. Some times it depends on the patients behavior and mood swings of that day. e.g. sometimes patients need to be fed , give bath etc. and sometimes patients will be hyper active that they themselves do their work

- ✓ The patients in the family care 50% of them are getting source of income as family pension, property or fixed deposits. The other 50% of the dementia patients are dependent on others financially, the burden slightly increases among the caregivers
- ✓ 03 of the family caregivers have got 24x7 care services at home as well as 40% of the significant care is shared by the more than one person at family care, since women are the prime caregivers, even men in the family support for women which is a significant change.

3. 41 - 60 score Moderate to Severe Burden

- ✓ Among 20 family caregivers only 01 of the family caregivers has the interpretation of moderate to severe burden
- ✓ The caregiver is a working women where there is a dual role is expected both working outside and inside the home, which is difficult to manage.
- ✓ Though the patient is sent to Alzheimer’s center for a half a day, family caregiver feels exhausted because the symptoms of repetitive talks, asking for food again and again, patients talk continuously, the family caregiver will be exhausted working outside, having stress, work pressure etc.

4. 61 – 88 score Severe Burden

- ✓ In this category out of 20 family caregivers 03 of them has got the interpretation of feeling severe burden
- ✓ In this category there is double burden for the family caregiver because women caregiver is taking care of 2 dementia patients at home without any others helps including in the family she is not getting support from other family members.
- ✓ Physically and financially both the patients are dependent on caregiver which is over burden.
- ✓ In this case caregivers are not able to afford for any extra help due financial inconvenience among the families, and needs to look other responsibilities at home.

Problems of working women caregivers:

Table: 3 Shows Working Women and the type of job opted

| Women working full time | Women working in flexible jobs | Women changed the profession | Women quite their jobs |
|--------------------------------|---------------------------------------|-------------------------------------|-------------------------------|
| 04 | 04 | 03 | 03 |

- 55% of the working women are the caregivers, out of 11 working women only 4 are in to full time job, 4 of them are into flexible job and change their profession for balancing the caregiving as well as continuing with their profession
- 3 of the caregivers have quit their jobs to take care the dementia patient at home.
- The problems of both working and home maker are as follows;
 - ✓ Dual role responsibility for the working women, balancing both family and professional career.
 - ✓ Problems of not having personal space for themselves as well as to meet other responsibilities in the family
 - ✓ Social life has been very much hindered cannot attend any of the gatherings, cannot go anywhere living the responsibilities on others.
 - ✓ It is problematic for both the patients as well as the caregivers, since patients could not adjust to the environment.
 - ✓ Problem for the working women with the timings (time management is difficult)
 - ✓ Lack of time and patience to spend with the patients
 - ✓ Women who are into flexible jobs feels that relatives in the family takes into granted that they have time and always will be at home. So visiting relatives at home frequently feels burden
 - ✓ Feeling of restlessness, lack of time to concentrate on their profession and lack of personnel space.
 - ✓ One of the caregiver have joined the flexible job, going for a kindergarten play home to cope up with her frustration, emotional stress, spending time with the children for half a day she feels more joyful.

Conclusions:

In the institutional care patients feels isolated, depressed, and missing their family members. But in the families the behavior is not seen among the patients. In the family the hygiene is maintained and the patients are secured when they are around the family members which lacks in the institutional care. Though the family caregivers are hired professional caregivers, or sent to the day care centers, when the patient is having his own source of income. Since who have hired professional care or hired the full time domestic assistance at home have less burden on family caregivers. By this we can say or propose a health care through the combination of both professional care givers as well as family caregivers working with alternatives can help the family caregivers as well as dementia patients, with less burden for the family members at their own residence. Since elderly people can also lead a good quality and dignified life.

Suggestions:

1. Need to have specialized training for the care takers to take care dementia patients
2. Need to have a more manpower for the geriatric care
3. All the hospitals should have the prior test on the onset of dementia for the people on or after the age of 50 years
4. The State should come up with the affordable geriatric care in order to help the poor and a middle class people
5. State should come up with providing awareness about the problem of dementia through various means of mediums
6. There should be a Private and Public Partnership in providing facilities to reach the bigger number of people in facilitating and providing domiciliary care services

Reference:

1. Amit Dias, VikramPatil. (2009). "Closing the Treatment gap for Dementia in India".
2. Dementia UK, the Full Report. (2007). Alzheimer's Society: Dementia care and research. Kings College London. A company limited by guarantee and registered in England no. 2115499.
3. Elderly in India (2016). Published by Central Statistics Office, Ministry of Statistics and Programme Implementation, Government of India.
4. <http://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/zarit.aspx>
5. <http://www.who.int>
6. https://www.alzheimers.org.uk/info/20007/types_of_dementia/1/what_is_dementia retrieved on 22/6/2017
7. Shaji KS, Jotheeswaran AT, Girish N, SrikalaBharath, Amit Dias, MeeraPattabiraman, Mathew Varghese. (2010). "The Dementia India Report 2010: Prevalence, impact, costs, and services of dementia". Published by Alzheimer's and Related Disorders Society of India, New Delhi.