

## **“A Study on Social and Emotional Reactions of Care - Givers of Elderly Demented Persons”**

**Prasita Nair\* & Dr. Pratiksha Patrick\*\***

*\*Ph.D Scholar (Nursing) Malwanchal University Indore (M.P)*

*\*\*Guide, S.S Institute of Nursing college Bhopal (M.P)*

### **INTRODUCTION**

*India with an elderly population of nearly 76 million, constituting 7.7% of the total is amongst the top ten nations in this category. At present one out of every seven elderly persons in the world is an Indian. By the year 2020 it is estimated that the population of the elderly will be increased to 142 million or about 11% of the country's population. Our life expectancy was only 40 years at the time of independence in 1947 with a very high birth rate. This resulted in a pyramidal demographic pattern, in which children constituted the broad base, while the apex of the pyramid was made up of a small number of aged people. As health parameters have improved, this pyramid has become smaller at the base, acquired a broader middle and a higher apex. It reflects the present birth rate which is lower, a broader, economically active young and middle aged population, and a larger number of ageing people, which is growing even large as we advance Life expectancy in India for males is 57.7 years and for Females is 58.1 years; in USA for males it is 73 and for females it is 79*

*Prior estimates of dementia prevalence in India were based on samples from selected communities, inadequately representing the national and state populations.*

*An estimated 8.8 million Indians older than 60 years have dementia. The burden of dementia cases is unevenly distributed across states and subpopulations and may therefore require different levels of local planning and support. (Jinkook Lee January 2023)*

### **PROCESS OF AGEING**

As a person grows older, there is a process of natural dying of various cells and a slow erosion of one's faculties, physical & mental. In fact, from the moment of our birth, there is a biological death clock that starts ticking. This determines the rate of natural growth and dying out and is programmed into the genetic code of each cell. How this dying out process is calibrated and set still a great mystery, except that genetic factors are primarily responsible. Environmental and toxic factors also have a role in this process. The brain cells are no exception to this and with age, they too gradually undergo a process of natural ageing & death. However, the rate at which this process occurs is never severe enough to affect the person's daily mental and thinking faculties so that he is never incapacitated in his routine day to day activities.

Occasionally, however, this process of brain cell attrition and death may occur faster than usual, resulting in the impairment of one's faculties, severe enough to be detrimental to one's

daily activities. This is the abnormal brain-cell death, which may be the result of identifiable diseases or toxic factors (multiple strokes, alcohol abuse, syphilis or AIDS), inherited diseases (like Huntington's chorea) or diseases of as yet unknown causes (like Alzheimer's disease).

As one grows older, the chance of developing dementia becomes higher. This is understandable as the dementing process seems to be a result of accelerated ageing (due to multiple causes). Between the ages of 60 and 65, (the young old), the chances of developing dementia are about 5%. This increases by 5% for every 5 years of advancing age, so that by 80 years of age, a person has a 20% chance of being demented. It is estimated that by the 2011 census, 10% of India's population will be above 60. This gives us an idea of the magnitude of the imminent problem.

### WHAT IS DEMENTIA?

Dementia is a syndrome due to the disease of the brain, usually of chronic or progressive nature in which there is disturbance of multiple higher cortical functions including memory, thinking, orientation, comprehension, calculation, learning capacity, language, judgement, impairment of cognitive functions accompanied and occasionally preceded by deterioration in emotional control, social behaviour or motivation. (International classification of disease .ICD 10).

Dementia is the gradually progressive, acquired loss of cognitive faculties of the brain, in multiple domains of functions, in an alert, fully conscious patient. Each of these terms requires a little elucidation. Cognition is the ability to act reasonably and logically in a given set of circumstances and it is the loss of this logical, deductive process that occurs in dementia. Moreover, normal brain functioning involves various domains-memory, logical thinking and planning abstract thinking, visuospatial integration and the processing of various incoming stimuli in the visual Tactile and auditory areas. Dementia results in the loss of more than one of these realms. Study conducted by **Soraia Teles (2022)**, with the **Aim:** To explore how informal caregivers of persons with dementia perceive training needs and preferences in the context of online training and support interventions.

Dementia is a syndrome, a cluster of signs and symptoms with myriads of possible causes. It is therefore the acquired global impairment of intelligence, memory, judgment and personality. Dementing disorders are the most common causes of psychopathology in the elderly. About 15 percent of persons above 65 years of age suffer from dementia. This ratio increases dramatically with further ageing. In India, the rough estimate of dementia at present is about 4 per cent of the elderly population over the age of 60. This means that more than four million elderly people in India now have dementia. By 2020, nearly 7.5 million Indians over the age of 60 will be victims of this terrible condition. It is commonly held that caring for an elderly person who is mentally ill is far more of an emotional drain than caring for a person with physical disabilities (Poulshock) As in many chronic patients, the patients having dementia cannot be considered in isolation from his/her family. Both the patient and the family are the victims of this devastating ailment. As the disease progresses, the demented individual in many ways starts behaving like a difficult child and most often the family member takes the lead role in the patient's care. The primary care giver is the person, most heavily affected due to the disease. The most common problems faced by primary care - givers are the difficulties with activities of daily living (ADLs), difficulties in handling the

behavioral problems of patients and emotional outbursts in the form of anger, hostility, anxiety and depression. This study mainly concentrates (i) on the extent of emotional and social reactions experienced by the care givers in their :are-giving process, such as restlessness, hostility, anger, grief, depression, anxiety, social rejection, social isolation and (ii) various problems faced by the care - givers in the care-giving process. Besides, the study explores (iii) the extent of reduction of social participation and extent of burden of care givers in the various areas of family functioning.

## **EPIDEMIOLOGY OF DEMENTIA**

The number of people with dementia is rising quickly in the world. It is estimated that by 2025, there will be four times the number of people with dementia in the developing world as there were in 1980. Besides 71% of all people with dementia will be in developing countries 2025 i.e., 24 million people.

Caregivers for people with dementia (PWD) have reported needing emotional and social support, improved coping strategies, and better information about the illness and available support services. Elizabeth G. Birkenhäger(2020)

## **SCOPE OF THE STUDY**

One of the advantages of this study is that it helps one to understand the magnitude of various problems that the care - givers undergo while caring for the dementia patients in the family setting. The current demographic trend indicates a steady increase in the number of dementia patients in Haryana Gurgaon and very few studies on career's issues have been conducted on this subject. Thus, the study analyses the social and emotional reactions of care givers in a systematic way.

The study aims at providing useful insights to the mental health professionals in planning suitable strategies for the effective implementation of programmes for the care - givers and dementia patients. Besides, the findings throw light on the need for improving the quality of care - givers as well as patients and develop ;I culturally suited intervention model for the Care givers. This study also brings forth concrete suggestions to organize continuous awareness programmes and counseling facilities to ameliorate the burden of care givers in different areas of family functioning.

### **Difficulty in performing familiar tasks:**

People with dementia often find it hard to complete familiar everyday tasks that usually do not require any thought. A person with dementia may not know in what order to put clothes on or the steps for preparing a meal.

### **Problems with language:**

Occasionally everyone has trouble in finding the right word but a person with dementia often forgets simple words or substitute unusual words making speech or writing hard to understand.

### **Disorientation to time and place:**

We sometimes forget the day of the week for where we are going, but people with dementia can become lost in familiar places such as the road they live in forget where they are or how they got

there, and not know how to get back home. A person with dementia may also confuse night and day.

**Poor or decreased judgment:**

People with dementia may dress inappropriately, wearing several layers of clothes on a warm day or very little on a cold day.

**Problems with keeping track of things:**

A person with dementia may find it difficult to follow a conversation or keep up with paying their bills.

**Misplacing things:**

Anyone can temporarily misplace his or her wallet or keys. A person with dementia may put things in unusual places such as an iron in the fridge or a wristwatch in the sugar bowl.

**Changes in mood or behavior:**

Everyone can become sad or moody from time to time. A person with dementia may become unusually emotional and experience rapid mood swings for no apparent reason. A person with dementia may also show less emotion than was usual previously.

**Changes in personality:**

A person with dementia may seem different from his or her usual self in ways that are difficult to pinpoint. They may become suspicious, irritable, depressed, apathetic or anxious and agitated especially in situations where memory problems are causing difficulties.

**Loss of initiative:**

At times, everyone can become tired of housework, business activities or social obligations. However, a person with dementia may become very passive, sitting in front of the television for hours, sleeping more than usual, or appearing to lose interest in hobbies.

**FOUR STEPS TO RECOGNIZING DEMENTIA**

- **Recognize the early symptoms**
- **Listen to the person**
- **Listen to the care giver**
- **Seek professional advice**

**OBJECTIVES OF THE STUDY**

a) **General objective:-** The main aim of the study is to understand the social and emotional reactions of caregivers of elderly demented persons in the care giving process.

b) **Specific Objectives:-** The present study is carried out with the following specific objectives. –

- To find out the socio-economic status of the care givers and patients - To study the emotional reactions experienced by the Care givers

- To study the social reactions experienced by the Care givers
- To study the nature of various problems faced by the care - givers
- To understand and measure the level of psychological distress of the c'are- givers.
- To find out the association between selected socio-economic profile of the care givers and the family burden and psychological distress of the Care givers.
- To explore the extent of reduction of social participation of the. Care givers
- To measure the extent of burden of care givers in the various areas of family functioning
- To suggest suitable measures for reducing the burden and psychological distress of the care - givers.

### **HYPOTHESES:**

The following null hypotheses have been formulated for the present study.

1. Dementia patients from different age groups, educational groups do not differ with regard to their Total Emotional Reactions, Awareness about the Illness, Social Reactions, Expressed Emotions, Social Participation, Level of Burden in different areas of Family Functioning and the Extent of problem that they have.
2. Male and Female dementia patients do not differ with regard to their Total Emotional Reactions, Awareness about the Illness, Social Reactions, Expressed Emotions, Social Participation, Level of Burden in different areas of Family Functioning and the Extent of problem that they have.
3. Alzheimer's disease (AD) and Multi-infarct dementia (MID) patients do not differ with regard to their Total Emotional Reactions, Awareness about the Illness, Social Reactions, Expressed Emotions, Social Participation, Level of Burden in different areas of Family Functioning and the Extent of problem that they have.
4. Care -Givers of Dementia Patients from different Age groups, different Marital status do not differ with regard to their~ Total Emotional Reactions, Awareness about the Illness, social Reactions, Expressed Emotions, Social Participation, Level of Burden in different areas of Family Functioning and the Extent of problem that they have.
5. Dementia Patients from different Age groups, Educational level, Occupation level, - do not differ with regard to their level of Family Burden and their level of Psychological Distress.
6. Male and Female Dementia Patients do not differ with regard to their level of Family Burden and their level of Psychological Distress
7. Alzheimer's disease (AD) and Multi-infarct (MID) dementia patients do not differ with regard to their level of Family Burden and their level of Psychological Distress
8. Dementia Patients from Urban and Semi Urban area do not differ with regard to their level of Family Burden and their level of Psychological Distress
9. Care -Givers of Dementia patients from different Age groups, Educational levels, Religious groups, Occupational groups, and Monthly Income groups do not differ with regard to their level of Family Burden and their level of Psychological Distress



10. Care Givers such as Male and Female, Unmarried and Married, from Joint and Nuclear families do not differ with regard to their level of Family Burden and their level of Psychological Distress

11. There is no association between the Level of Family Burden and the Level of Psychological Distress of the Care givers.

## **METHODOLOGY OF THE STUDY**

**Universe and Geographical Area** The universe of the study comprised of all care givers of dementia patients in the geographical area of Haryana Gurgaon

### **The Inclusion Criteria:**

- \* The care givers of diagnosed dementia cases
- \* The family care givers who regularly look after the patients.
- \* Male and female Care givers.

### **Exclusion Criteria:**

- \* The professional Care givers.
- \* The care givers of patients who were institutionalized.
- \* The family care givers with severe neurological and psychiatric problems.

**Sample Size** A sample of 150 care givers of dementia patients who fulfilled the inclusion and exclusion , criteria was selected for the study.

**Methods and Procedure of Sampling** The researcher selected 150 care givers of dementia patients using simple random sampling from the list of 230 Care givers identified by Alzheimer's and related disorders society of Hope who were satisfying the exclusion and inclusion criteria.

**Pilot study** The researcher conducted pilot study at Alzheimer's and Related Disorders in dementia hope society Haryana Gurgaon. The objectives of the study were-

(1) To find out the feasibility of the study (2) To get the permission and cooperation of the concerned institutional authorities to gather the relevant data (3) To gather information for framing a suitable sampling design (4) To find out which method of data collection would be effective and (5) To fix the universe of the study. The pilot :study helped the researcher to modify and design the study appropriate to the research problems and objectives.

## **RESEARCH DESIGN**

The research design was descriptive in nature focusing on the various emotional and social reactions of care givers of dementia patients.

### **Tools of Data Collection**

1. Interview Schedule prepared by the researcher to find out the socio - demographic profile and to measure the social and emotional reactions bf the Care givers.

2. The Family Burden Assessment interview schedule by Pai and Kapur. (1981) . 3. General Health Questionnaire (GHQ - 28) by Goldberg & Hillier 1979 for assessment of psychological distress.

### **Data Collection**

The researcher visited each family of care givers of dementia persons and personally interviewed the Care givers. Each interview lasted for an average 1 to 1.5 hours. It took 10 months to complete data collection. Thus a total 150 care givers from the Hope corporation area were interviewed during this period and data were collected.

### **Data Analysis and Interpretation**

The collected data were edited, coded and then entered in to the master chart manually prepared by the researcher. Each item of data was strictly checked for accuracy before being entered in to the master chart. After the coding and tabulation of data, it was analyzed and interpretations were made according to the sequence of the objectives of the study.

### **Setting of the STUDY**

The setting of the study was Cochin Corporation, which belongs to the State of Haryana Gurgaon state of India.

### **Limitations Of Study**

The present study, like any other studies of its nature has its own limitations. Some of the limitations are as follows:-

1. The study could include the urban population and the rural scene still remains in darkness
2. The study was focused on a number of problems present among the care givers. However, the impact of these problems on the care givers lives and their effects on interpersonal relations with others were not focused.
3. It is suggested that the data collection may involve all members of the family so that the views obtained pertaining to various issues would be more objective, collective and representative.
4. Most of the time, the interviews with care givers were disrupted due to the disturbances from the patients. Hence, the researcher had to spend more time and pay two or three visits to finish up with interviews.
5. Since some of the questions in the interview schedules and questionnaires were difficult to understand for care givers more explanations and examples had to be given to elicit complete information. These limitations are to be borne in mind while generalizing the findings of the study to the issues related to burn out among the Care givers.

### **CONCLUSION**

The study has brought to the attention that the dementia patients get less support from the community, which further deteriorates their condition. This may be due to lack of awareness about dementia and negative attitudes of general public towards them. Dementia is still, is considered as a mental illness and various myths, misconceptions and stigmas are attached to it. Hence it is imperative to take effective steps by the professional social workers to educate the general public

about dementia and its impact on care givers through awareness classes, seminars, lectures and workshops. The continuous awareness programmes would definitely help for the early diagnosis, better treatment and rehabilitation of dementia victims.

This study has shown that awareness about dementia has helped the care givers of both Alzheimer's and Multi infarct dementia patients to provide better care to their relatives. Hence it is suggested that more voluntary organizations are to be encouraged to work for dementia patients and sufficient fund should be made available to them.

The study has brought to the attention that the housewives are more psychologically distressed than other Care givers. It may be due to their multiple responsibilities of looking after their children, husband and other family members. It has also revealed that they also get very less time to visit their relatives. Home care service is

an alternative in many areas. Home care is sometimes called a sitting service, but good home care is a lot more than just sitting service. The home care worker look after the person with dementia while the carer can have a rest, visit friends, and do the household chores.

The study shows that care givers face various emotional distress in relation to care-giving in the family setting. The social workers need to identify such care givers with psychosocial stressors and organize family intervention programmes and crisis intervention techniques to strengthen family resources and support systems.

The study reveals that social dysfunction is high among low income groups and it is recommended to provide supportive services to care givers from lower income groups, which would help to ameliorate their social dysfunction.

In the study it has been mentioned that care givers undergo immense stress and strain in the caring process. In order to deal effectively with these psycho-social problems the *need* of professional counsellors become imperative. The services of the professional counsellors may be made available to the care givers at individual and family levels to ameliorate their burden. Besides opportunities should be made available for carer's assessment in order to organize appropriate respite provision to the carers.

The study has revealed that the Care givers highly expressed emotion is loneliness, which leads to psychological distress. Day centres can allow carers to continue to work or to have some time to themselves, while providing appropriate care away from home. Besides, appropriate measures may be taken to provide intensive training course to the care givers either in the day centres or community centres by mental health professionals with the purpose of improving the quality of care of the patients.

The starting of self-help groups of care givers could provide immense opportunities to the care givers to get together, empathies with each other, ventilate their feelings, share their problems and obtain remedies from mental health professionals

## REFERENCES

- i. Elizabeth G. Birkenhäger(2020), Effects of caregiver dementia training in caregiver-patient dyads: A randomized controlled study, Int J Geriatr Psychiatry. 2020 Nov; 35(11): 1376–1384. Published online 2020 Jul 22. doi: 10.1002/gps.5378



- 
- ii. Jinkook Lee **January 2023**)Lam, KY, Tsang, NWH, Han, S, Ng, JKY, Tam, SW & Nath, A 2015, ‘SmartMind: Activity Tracking and Monitoring for Patients with Alzheimer’s disease’.
  - iii. Soraia Teles (2022), Dementia caregivers training needs and preferences for online interventions: A mixed-methods study J Clin Nurs 2022 Jul;31(13-14):2036-2054. doi: 10.1111/jocn.15445. Epub 2020 Aug 31.
  - iv. Saxena , N 2014 ‘Economic Load Dispatch Using Firefly Algorithm’ Doctoral dissertation, Thapar university, Patiala.
  - v. World health organization <https://www.who.int/news-room/fact-sheets/detail/dementia>
  - vi. Zhang, X, Hu, B, Ma, X & Xu, L 2015,‘ Resting-State Whole-Brain Functional Connectivity Networks for MCI Classification Using L2- Regularized Logistic Regression’, IEEE Transactions on NanoBioscience, vol.14,no.2, pp.237-247. **Net**
  - vii. National Indian health <https://www.nia.nih.gov/health/whatdementia#:~:text=Dementia%20is%20the%20loss%20of,and%20their%20personalities%20may%20change>.
  - viii. Mayo clinic <https://www.mayoclinic.org/diseases-conditions/dementia/symptoms-causes/syc-20352013>
  - ix. National institute on aging <https://www.nia.nih.gov/health/what-are-signs-alzheimers-disease#:~:text=For%20most%20people%20with%20Alzheimer's,30s%2C%20although%20this%20is%20rare>.
  - x. Alzheimer’s association <https://www.alz.org/alzheimers-dementia/what-is-dementia>