MANAGEMENT OF DEMENTIA PATIENTS BY FAMILY CAREGIVERS:

A SOCIAL WORK PERSPECTIVE

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RESEARCH GUIDE
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PREFACE

It is impossible to stop the natural process of ageing but we can take care of the several factors that affect our health as one walks towards the twilight years. The main factors that become more important with the increased lifespan and social inclusion of the senior citizen are mental health and agility. Degenerative diseases like dementia, not only hampers the lives of those affected but also the overall contribution of this age group to the society.

World Health Organization's report on dementia published in 2012 reveals that around 35.6 million people suffer from dementia, which is projected to double by 2030. According to the Dementia India Report, the mortality rate due to dementia in India is 13.5 per lakh people in males and 11.1 per lakh in females. These statistics point towards the need to take mental health issues seriously. According to psychologist Dr. Deepali Pangaonkar, joint director of Central Institute of Behavioral Sciences, "medicines for dementia only slow down the progress of the disease, the person affected needs to be taken care of well. Everything from his diet to medicines and other aspects of life needs to be taken care by the caregivers". In terms of informal caring for those with dementia, India is better off than many western countries as we are still a close knit community and can expect help from neighbors and relatives, but lot needs to be done in the area of formal care services.

Further, an overview of mental health field and social work reveals that both have made significant advancements. We have travelled a long way from mental asylums to community participation to at home care services and human rights approach in dealing with mental health issues. The pace of growth of psychiatric and geriatric social work needs to gather momentum and undertake several initiatives locally, nationally and globally. The current study is a small step towards this Endeavour.

Awareness and understanding about the disease among common people is very important. There still is a lot of stigma and denial attached to the disease. What we all need to acknowledge is that dementia is a disease like many others and needs to be discussed about so that we can prevent it.

Sunita Jolly

DEDICATED TO

My mother-in-law late Mrs. Rose Raju (Amma) for making me the caregiver

And

My grandparents late Mrs. Laxmibai (Mai) & Mr. Motiram Dharpale (Aabba) for being my inspiration and teaching me to be humble and giving

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After experiencing various shades of care giving, while looking after my mother-in-law, I had a long desire as a social worker to do ‘something’ for the caregivers of patient with dementia. When I got an opportunity to boost up my ideas congregated from various sources, I decided to give my ideas a real shape and contribute to the profession.

I consider it my privilege to express my heartfelt gratitude and respect all those who guided, inspired, encouraged and stood by me in completion of this thesis. First and foremost I must thank my guide Prof. (Dr.) Aruna Khasgiwala, without her this thesis would not have seen the light of the day. She accepted me as her student, gave wings to my thoughts, guided me, made me work and worked with me at odd hours. A true mentor, who understood my strengths and weaknesses, pushed and pulled me to the limits and like a mother fed me while making me work in front of her eyes. Thank you is a small word for you madam! I am indebted to you for a lifetime.

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Towards end, I sincerely acknowledge the respondents of this study who in spite of their responsibilities spent hours with me narrating their experiences.

I end the thanks giving by offering my work to the Almighty, the strength he bestowed on me to complete this task and I pray he gives me further strength so that I contribute to the betterment of the society.

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"It was a busy morning, about 8:30, when an elderly gentleman, probably in his 80s, arrived to have stitches removed from his thumb. He said he was in a hurry as he had an appointment at 9:00 am.

I took his vital signs and asked him to take a seat, knowing it would be over an hour before someone would to able see him. I saw him looking at his watch and decided, since I was not busy with another patient, I would evaluate his wound. On exam, it was well healed, so I talked to one of the doctors, got the needed supplies to remove his sutures and redress his wound.

While taking care of his wound, I asked him if he had another doctor's appointment this morning, as he was in such a hurry. The gentleman told me no, that he needed to go to the nursing home to eat breakfast with his wife. I inquired about her health.

He told me that she had been there for a while and that she was a victim of Alzheimer's Disease. As we talked, I asked if she would be upset if he was a bit late. He replied that she no longer knew who he was, that she had not recognized him in five years now.

I was surprised, and asked him, 'And you still go every morning, even though she doesn't know who you are?'

He smiled as he patted my hand and said, 'She doesn't know me, but I still know who she is.'

CHAPTER -1

INTRODUCTION

> **And in the end, it's not the years in your life that count. It's the life in your years.**
>
> **- Abraham Lincoln**

The rationale of this chapter is to explain the nature of study and bring conceptual clarity on the basic concepts used in the study. It is divided in to five major sections and sub points under each major section. Since dementia is the disease related to elderly, their status has been covered in section number 1- backdrop information followed by section number 2 – Dementia which covers all the information related to dementia as a disease. In section number 3 an attempt has been made to explain what is meant by management of patients and covering aspects like Health care system in Indian context, caregivers and historical perspective of care giving and family caregivers. Section 4 covers management of dementia patients with aspects of care giving, management of dementia patients in general and in Indian context and care givers status in India. The last section 5 talks of social work perspective for the study.

1. BACKDROP:

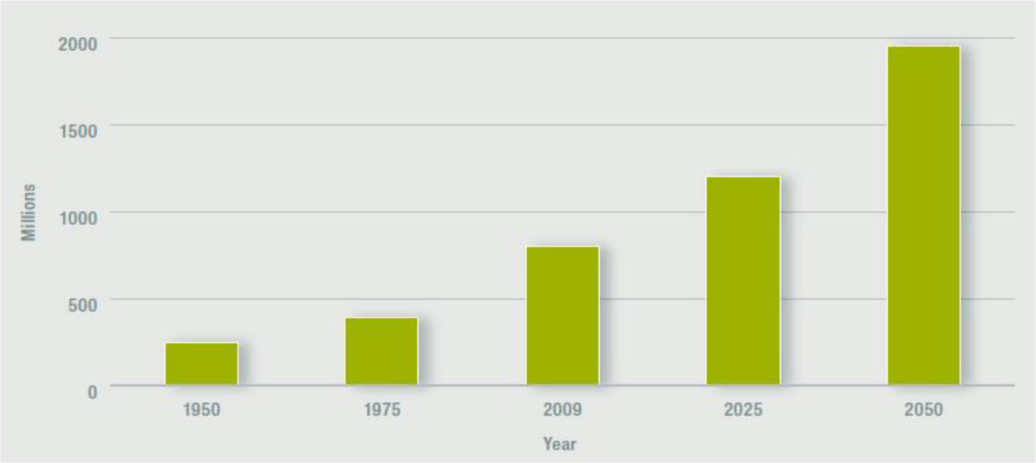
There are an estimated 605 million (20% of total population) older persons (age 60 and over) in the world, out of which nearly 400 million of whom live in low-income countries. By 2025, the number is expected to reach more than 1.2 billion (29% of total population) and by 2050 it will be 2 billion. (Fig 1) (WHO Report –Dementia a public health priority 2012).

While at the home front, as on 1st March, 2011 India's population stood at 1.21 billion comprising of 623.72 million (51.54%) males and 586.47 million (48.46%) females. India, which accounts for world's 17.5 percent population, is the second most populous country in the world next only to China (19.4%). Of the 121 crore Indians, 83.3 crore (68.84%) live in rural areas while 37.7 crore (31.16%) live in urban areas (the Census of India's 2011). Projections indicate that India’s population above 60 years will be double in size between 2001 and 2026, the elders will account for 12.17

percent of overall population in 2026, and being a vast country India may face the problems differently at rural and urban parts.

The above data clearly suggest that elderly population is increasing throughout the world and India is no exception to this. Older people, even those in generally good health, eventually need more care than they did earlier in their lives as they are prone to multiple Physical, Medical and Psychological problems.

Figure1 World population aged 60 years and above



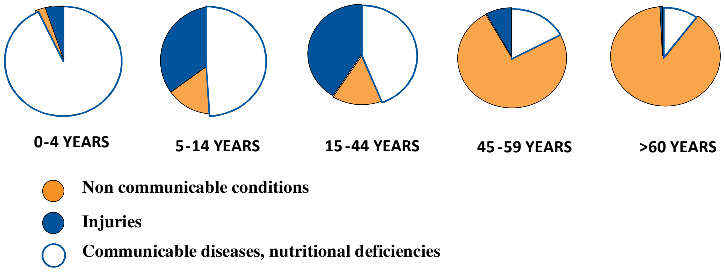
Source: WHO Report –Dementia a public health priority 2012

In addition to this, chronic diseases are significant and costly, that cause disability and reduced quality of life in both developing and developed countries. An elderly person’s independence is threatened when physical or mental disabilities make it difficult to carry out the activities of daily living. They are likely to encounter additional barriers related to the ageing process.

Other disabilities considered as incident to ageing are: Senile cataract, Glucoma, Nerve deafness, Bony changes affecting mobility, failure of special senses and changes in mental outlook. Along with this, longevity of aged persons gives rise to certain chronic conditions and is more frequent. Chronic conditions affecting older people worldwide reported by WHO are: Cardiovascular diseases (such as coronary heart disease), Hypertension, Stroke, Diabetes, Cancer, Chronic obstructive pulmonary disease, musculoskeletal conditions (such as arthritis and osteoporosis), mental health conditions (mostly dementia and depression**),** Blindness and visual impairment (WHO, 1999). These physical and mental health chronic conditions pose many challenges to the elderly themselves, health care system and both formal and informal caregivers.

Thus, as individuals age, non-communicable diseases (NCDs) become the leading causes of morbidity, disability and mortality in all regions of the world. NCDs, which are essentially diseases of later life, are costly to individuals, families and the public at large. Though many NCDs are preventable or can be postponed, Dementia is one such NCD which has no cure, neither stands good chances of prevention. Failing to prevent or manage the growth of NCDs appropriately will result in enormous human and social costs. Figure-2, below shows how NCD conditions increase along with the age.

Figure -2 Leading causes of death, both sexes, 1998, low and middle income countries by age



Source: World Health Report 1999 database

According to the World Health Report 2003, the Global Burden of Disease estimates for the dementia, contributed highest number of years lived with disability in people aged 60 years and older; Which is more than stroke (9·5%), musculoskeletal disorders (8·9%), cardiovascular disease (5·0%), and all forms of cancer (2·4%). The disability weight for dementia, estimated by an international and multidisciplinary expert consensus, was higher than for almost any other health condition**,** apart from spinal-cord injury and terminal cancer.

Dementia is one of the major causes of disability in later life. It accounts for 11.9% of the years lived with disability due to a non-communicable disease. It is also the leading cause of dependency (i.e. need for care) among older persons in both high-income countries and Low and Middle Income Countries. The estimated worldwide cost of dementia is estimated to have been US$ 604 billion in 2010. Direct medical care costs contribute to just 16% of the global cost. In low-income countries, most costs are due to informal care i.e. unpaid care provided by family members and others. (Source: WHO Report – Dementia a Public health priority 2012)

To summarize population ageing raises many fundamental questions for policy-makers, health care systems and social workers. The glaring data on non communicable health conditions becoming the leading cause for disability, morbidity and mortality along with the burden caused by it on the society; elderly and the caregiver pose many challenges. How can we strengthen health promotion and prevention policies, especially those directed to older people? How can their quality of life in old age be improved? How do we best balance the role of the family and the state when it comes to caring for people who need assistance, as they grow older? How do we acknowledge and support the major role that people play as they age in caring for others?

Hence the present study is rightly focused on studying the most important non-communicable disease of the elderly i.e Dementia and its management emphasizing family caregivers and Social Work perspective.

2. DEMENTIA:

2.1 Definitions:

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, judgment, impairment of cognitive functions accompanied and occasionally preceded by deterioration in emotional control, social behavior or motivation**.(International classification of disease.ICD 10).**

Dementia is characterized by progressive memory loss and additional cognitive deficits. **(Diagnostic and Statistical Manual of Mental Disorders 4th Edition.**)

2.2 Meaning and Characteristics:

Dementia is a common disorder in the later stage of life that is assuming increasing prominence with the demography shift toward an ever-increasing aging population. Throughout history, the disorder that we now think of as dementia was viewed as an inevitable consequences of aging. One of the early signs in the development of dementia is the loss of memory, which is often mistaken to be forgetfulness commonly seen in normal ageing. As a consequence persons with signs of dementia are seldom taken to medical professionals and therefore the disease goes undiagnosed.

It is a progressive brain dysfunction (in Latin 'dementia' means irrationality), which results in a restriction of daily activities and in the areas of cognition may be memory, attention, language, and problem solving and in most cases leads in the long term need for care. It is an organic brain syndrome characterized by loss of intellectual ability. Although many definitions of dementia exist, most include impairment of cognition, social and occupational functioning and performance in activities of daily living. Occasionally, deterioration in emotional control, social behavior or motivation is also seen. It is normally required to be present for at least 6 months to be diagnosed. Though often treatable to some degree, is usually due to causes which are progressive and incurable.

Thus, Dementia is characterized by multiple cognitive defects that include impairment in memory without impairment of consciousness. The cognitive functions that can be

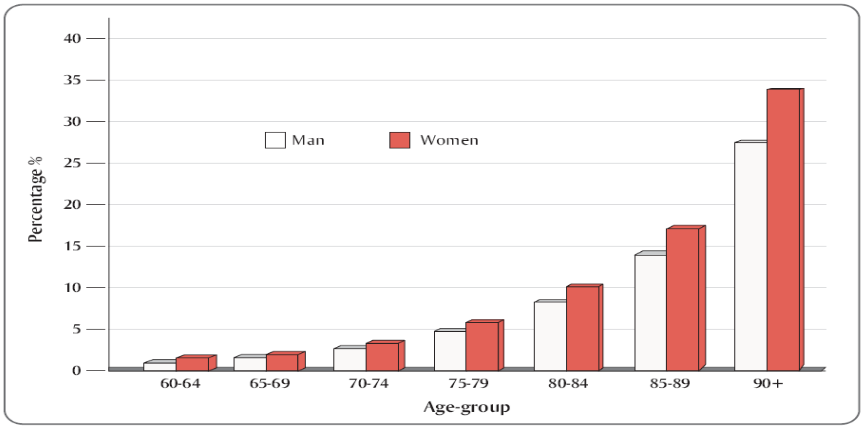


Figure 3 Prevalence of dementia in India 2010.

Source: ARDSI Indian Dementia Report 2010

affected in dementia include general intelligence, learning, memory, language, problem solving, orientation, perception, attention, concentration, judgment and social abilities and can be considered as a global impairment of intelligence, memory and personality in clear consciousness. It can occur at any age but become more frequent with age, with a prevalence of 5% - 10% in the over 65s and 20% in the over 80s. It is seen more frequently in women, due to their increased longevity living. Figure 3 Shows prevalence of dementia in India 2010.

2.3 Important indicators making a diagnosis:

There is a decline from previous mental ability (including intellectual, emotional and cognitive). The person's previous intelligence and educational level needs to be taken into account.

- The deficits are not exclusively during the course of a delirium, other neurological or psychiatric disorder.
- The deterioration is usually slow and progressive over months to years.
- The decline affects memory and at least one other area of brain function
    - **aphasia** (language disturbance),
    - **apraxia** (impaired ability to carry out motor activities despite intact motor function),
    - **agnosia** (failure to recognized or identify objects despite ,intact sensory function)
    - executive function (planning, organizing, sequencing, abstracting)
- The deterioration is severe enough to interfere with daily life such as working, organizing personal affairs, social interactions or personal care.

2.4 Memory Impairment and Dementia:

Older people commonly think their memory has deteriorated. Ageing can cause slower learning, mental processing and minor forgetfulness. These changes do not satisfy the criteria for dementia. People with MCI (Mild cognitive impairment) are often aware of some decline in memory, unlike dementia where insight is usually lost. MCI usually affects only one area of cognition, typically memory, and is not severe enough to interfere with daily activities. In contrast, dementia affects more than one area of cognition and does interfere with daily activities. MCI involves a heterogeneous group of conditions. About 10 -15% of people with MCI will progress to dementia over a year, higher than the general age matched population. Some with MCI will remain stable and while some will improve. People with MCI should be monitored over time.

2.5 Delirium and Dementia:

Dementia is different from delirium. Delirium is characterized by a rapid deterioration in mental function (usually over a few days) resulting in fluctuating cognition with inattention, disorganized thinking and disturbed consciousness. Early diagnosis of dementia enables the individual to plan for the future, for a time after they have lost capacity to make their own decisions. This will help the individual and care givers to understand the disease, reduce stress and maintain the preferred lifestyle as long as possible.

2.6 Signs and Symptoms of Dementia:

The early signs of dementia may be very subtle. Usually the first feature is memory loss. Other common symptoms include confusion, personality change, apathy and withdrawal, and loss of ability to undertake everyday tasks. Any of these features in an older person should trigger a formal cognitive assessment.

At the initial stages of dementia, a patient show fatigue, difficulty in sustaining mental performance, and a tendency to fail when a task is novel or complex or requires a shift in problem - solving strategy. The inability to perform tasks becomes increasingly severe and spreads to everyday tasks. Eventually, patients with dementia may require constant supervision and help to perform even the most basic tasks of daily living.

The major defects in dementia involve orientation, memory, perception, intellectual functioning and reasoning and all these functions become progressively affected as the disease process advance. Affective and behavioral changes, such as defective control of impulses and lability of mood, are frequent, as are accentuations and alterations of premorbid personality traits.

2.6.1 Intellectual deterioration with failure of:

a) Memory:

Memory impairment is typically an early and prominent feature in dementia, especially in dementias involving the cortex, such as dementia of the Alzheimer's type. Early in the course of dementia, memory impairment is mild and is usually most marked for recent events; people forget telephone numbers, conversations and events of the day. As the course of dementia progresses, memory impairment becomes severe and only the earliest learned information is retained.

b) Orientation:

In as much as memory is important for orientation to person, place and time, orientation can be progressively affected during the course of a dementing illness. For example, patients with dementia may forget how to get back to their rooms after going to the bathroom. No matter how severe the disorientation seems, however, patients show no impairment in their level of consciousness.

c) Language:

Dementing processes that affect the cortex, primarily dementia of the Alzheimer's type and vascular dementia, can affect patient's language abilities. Aphasia (language disturbance) is one of the diagnostic criteria of dementia. The language difficulty may be characterized by a vague and stereotyped elocution. Patients may also have difficulty in naming objects.

d) Thinking & Judgment:

Thinking becomes slower with reduced flow of ideas and impaired concentration; Judgment is impaired from early on and leads to poor insight; Paranoid thoughts and ideas of reference are common and may develop into delusions.

e) Comprehension of learning Capacity:

The brains ability to process incoming information is impaired.

f) Insight & Concentration

2.6.2 Emotional changes: Emotions become too easily stimulated, and have reduced control over laughter or tears.

2.6.3Deterioration of personality:

a) Increasing tendency to selfishness, b) lack of consideration for other people's feelings, personal habits, table manners, toilet, habits and hygiene deteriorate c) Sexual offences may be committed. Changes in the personality of a person with dementia are especially disturbing for the families of affected patients. Pre existing personality traits may be accentuated during the development of dementia. Patients with dementia may also become introverted and may seem to be less concerned than they previously were about the effects of their behavior on others. People with dementia who have paranoid delusions are generally hostile to family members and caretakers. Patients with frontal and temporal involvement are likely to have marked personality changes and may be irritable and explosive.

2.6.4 Age - related body system changes

a) Cardio vascular system:

Decreased cardiac output, diminished ability to respond to stress, slower heart recovery, and increased rate of BP, Leads to fatigue with increased activity.

b) Respiratory system:

Increase in the residual lung volume, decrease in vital capacity, decreased gas exchange of diffusing capacity, decreased cough efficiency, leads to fatigue and breathlessness with sustained activity, impaired healing of tissue, due to decreased oxygenation, difficulty in coughing up secretions.

c) Genito-Urinary system:

Bladder capacity decrease, delayed sensation to void leads to urinary retention and difficulty to voiding.

d) Gastro - intestinal system:

Decreased salivation, difficulty in swallowing food, complaints of dry mouth. Delayed esophageal and gastric emptying leads to complaints, of fullness, heartburn and indigestion, reduced gastrointestinal mobility leads to constipation, flatulence and abdominal discomfort.

e). Musculoskeletal system:

Loss of bone density, muscle strength and size, degenerated joint cartilage leads to height loss, hypnosis, fracture, complaints of back pain, loss of strength, flexibility and endurance and joint pain.

f) Nervous system:

Reduced speed in nerve conduction, increased confusion with physical illness and loss of environmental cues, reduced cerebral circulation causes slowing of response and reaction. Learning takes longer, patient becomes confused with complains of forgetfulness and frequent falls.

2.6.5 Special Senses:

a) **Vision:** Diminished ability to focus on close objects, inability to tolerate glare, difficulty "in adjusting changes of light intensity, decreased ability to distinguish colours. As a result holds objects far away from face, complains of glare of poor night vision and confusion of colour.

b) **Hearing:** Decreased ability to hear high frequency sounds results in inappropriate responses, asks people to repeat words and strains forward to hear.

c) Taste and smell: Decreased ability to taste and smell, results in excessive use of sugar and salt.

2.6.6 Hallucinations and Delusions:

As estimated, 20 to 30 percent of patients with dementia, primarily patients with dementia of the Alzheimer's type have hallucinations and 30 to 40 percent have delusions, primarily of a paranoid or persecutory and un-systematized nature, although complex, sustained and well systematized delusions are also reported by these patients. Physical aggression and other forms of violence are common in demented patients who also have psychotic symptoms.

2.6.7 Other Signs and Symptoms:

a) Psychiatric:

40 to 50 percent of patients with dementia are having anxiety and depression, in addition to psychosis and personality changes patients with dementia may also exhibit pathological laughter or crying, extremes of emotions - with no apparent provocation.

b) Neurological:

In addition to the aphasias in patients with dementia, apraxias (The inability to perform correct movements because of a brain lesion) and agnosia (difficulty in recognizing familiar objects a symptoms of organic brain disease) are common. Other neurological signs that can be associated with dementia are seizures, seen in approximately 10 percent of patients with dementia of Alzheimer's type and in 20 percent of patients with vascular dementia and atypical neurological presentations, such as non-dominant parietal lobe syndromes, primitive reflex such as the grasp, snout suck, tonic may be present on neurological examination and cyclonic jerks are present in 5 to 10% of patients. Headaches, dizziness, faintness, weakness, focal, neurological signs and sleep disturbance are some of the additional neurological symptoms in-patient with vascular dementia.

c) Catastrophic reaction:

Patients with dementia also exhibit reduced ability in abstraction. Patients have difficulty in generalizing from a single instance, in forming concepts and in grasping similarities and differences among concepts. Catastrophic reaction marked by agitation is secondary to the subjective awareness of intellectual deficits under stressful circumstances.

d) Sundowner syndrome:

This is characterized by drowsiness, confusion ataxia and accidental falls. It occurs in older people who are overly sedated and in patients with dementia who reach adversely to even a small dose of a psychoactive drug. The syndrome also occurs in demented patients when external stimuli, such as light and interpersonal orienting cues are diminished.

2.6.8 Behavioral and Psychological Symptoms of Dementia (BPSD):

Behavioral and Psychological Symptoms of Dementia (BPSD) is an umbrella term for a heterogeneous group of non- cognitive symptoms associated with dementia, including: psychosis, delusions, depression, agitation and inappropriate sexual behaviour.

BPSD changes over time tending to become more troublesome as the dementia progresses. It may fluctuate over time, brought on by a change in the environment such as admission to residential care or hospital etc. If the change of behavior is of recent onset it should be reviewed with possible causes of distress or delirium e.g. pain, infection, dehydration, constipation, hearing and vision problems. Contributing environmental factors e.g. noise, poor lighting, and conflict with carers should be looked into. These are often the most distressing features and are often difficult to treat. Management requires a combination of strategies based on the individual's needs. Pharmacological approaches are often limited by intolerable side effects and are not the first line approach.

2.7 Causes of Dementia

Dementia is an (multifactor) illness having multiple causes. Dementia is the most common neurological diagnosis in old age and the third leading cause of natural death. Most popular studies (Skoog et al, 1996) report that 50 per cent to 70 percent of dementia cases have a diagnosis of Alzhiemers Disease while 20 per cent to 30 percent have a diagnosis of Vascular Dementia.

The greatest risk factor is age, followed by family history of the disease. Researchers are of the opinion that it is not caused by a single factor or gene, but by a combination of factors that are acting together.

Dementia usually is caused by degeneration in the cerebral cortex, the part of the brain responsible for thoughts, memories, actions and personality. Death of brain cells in this region leads to the cognitive impairment that characterizes dementia.

There are both treatable as well as untreatable causes for dementia. In order to make a definite diagnosis it is extremely essential to make sure that there are no reversible physical conditions that can cause dementia, like high fever, vitamin deficiency, bad reactions to medicine, thyroid problems, minor head injuries and the like. Other conditions that may cause dementia include AIDS, Parkinson's disease, Lewy body disease, Pick's disease, Huntington's disease, Creutzfeldt-Jakob disease, brain tumor, hydrocephalus, head trauma, multiple sclerosis, prolonged abuse of alcohol or other drugs, vitamin deficiency: thiamin, niacin, or $B_{12,}$ Infections, hypothyroidism, and hypercalcaemia.

Thus, Dementia has a variety of etiologies. The most common etiology is Alzheimer disease (AD), which accounts for approximately 60%-70% cases of late onset dementia. Dementia associated with cerebrovascular disease i.e. vascular dementia (VaD), dementia associated with Parkinson's disease (PD), and Lewy body dementia etc. are the most common causes of dementia in elderly.

2.8 Types of Dementia

a) Alzheimer’s disease:

In 1906, Dr Alois Alzheimer, a famous German pathologist, described a patient (51-year old Auguste De) who had died of an unusual mental illness. The name Alzheimer’s’ disease has been coined after him. Alzheimer’s disease has also been called primary degenerative dementia. It is referred to as ‘degenerative’ because the brain cells wither away and die. The rate of occurrence of the disease increases exponentially with age, which means that it occurs very rarely among those 40-50 years old, increases between 60 and 65 years, and is very common over 80 years.

In patients of Alzheimer’s disease, loss of intellectual capability progresses to such an extent that they cannot remember where they have kept their valuables, and have to search for hours to locate them; or they cannot recall the names of their own children or grand children. They tend to lose interest in their work, do not keep appointments, have difficulty finding words, or repeat the same questions that have been correctly answered. Occasionally, they forget having eaten and repeatedly ask for meals or lose their way when outside the house. Sometimes, there may be changes in their behavior or personality.

b) Vascular dementia:

Vascular Dementia (VaD) is related to various cerebrovascular disorders and different types of ischemic lesions in the brain, the most common forms of this being Multi-Infract Dementia (MID). VaD results from reduced blood flow to the brains’s nerve cells. The brain cells in a small area of the brain are killed, either because the blood supply to that area is blocked or because blood cells burst. The symptoms of vascular dementia tend to begin more abruptly than those of Alzheimer's dementia. Symptoms may progress stepwise with the occurrence of new strokes. Unlike AD, the incidence of vascular dementia is lower after age 75.

c) Dementia due to Lewy Body Disease:

The characteristics feature of dementia due to Lewy body disease is fluctuations of awareness from day-to-day and signs of Parkinsonism such as tremors and rigidity. Dementia due to Lewy body disease has similar pathological signs as Parkinson’s disease and both are associated with progressive cognitive disorder.

2.9 Symptoms and Stages of Dementia:

Symptoms of dementia vary considerably by the individual and the underlying cause of the dementia. Most people affected by dementia have some (but not all) of these symptoms. Every person is unique and dementia affects people differently-no two people will follow exactly the same course. An individual's personality, general health and social situation are all important factors in determining the impact of dementia on him or her. The problems linked to dementia can be best understood in three stages

(Box 1): early stage – first year or two, middle stage – second to fourth or fifth year and late stage – fifth year and after.

Some people deteriorate faster, and others more slowly. Dementia reduces the lifespan of affected persons. In the developed west, a person with dementia can expect to live for roughly 5-7 years after onset / diagnosis (Ganguli et al 2005; Fitzpatrick et al 2005). At times, diagnosis is often much delayed, and survival may be much shorter. The mortality rates could be higher in the absence of interventions (Dias et al, 2008) and the severity at the time of identification could also predict mortality. Patients with moderate to severe illness have a higher mortality than cognitively unimpaired elderly. Again, there is much individual variation because of health conditions and co-morbidity is very common in this age group. Not all patients will display all the symptoms which have been described. Knowing them makes care givers aware of potential problems and enable them to plan the future care needs.

People with irreversible or untreated dementia, present a slow, gradual decline in mental functions and movements over several years. Total dependence and death, often from infection, are the last stages. The box 1 below gives stage wise specific symptoms.

Box 1

Early Stage

The early stage is often overlooked. Relatives and friends (and sometimes professionals as well) see it as 'old age', just a normal part of the ageing process. The onset of the disease is gradual and difficult to recognize.

- Have problems talking properly (language problems)
- Have some memory loss, particularly of recent events
- Have difficulty in making decisions
- Become inactive and unmotivated, show mood changes, depression or anxiety and may react angrily or aggressively
- Show a loss of interest in hobbies and activities

Middle Stage

As the disease progresses, limitations become pronounced and more restricting. The Patient with Dementia have difficulty with day-to-day living.

- May become very forgetful - especially of recent events and people's names
- May become extremely dependent on their family and carers; unable to cook, clean or shop; needs help with personal hygiene
- Has wandering and other behavior problems such as repeated questioning and calling out, clinging and disturbed sleep
- Unable to recognize familiar and unfamiliar places at home or outside
- May have hallucinations (seeing or hearing things which are not really there)

Late Stage

This stage is one of near total dependence (confined to a wheel chair or bed). Memory disturbances are very serious with more physical complications. The person may:

- Have difficulty eating, walking and be incapable of communicating
- Not recognize relatives, friends and familiar objects
- Have bladder and bowel incontinence, breathing difficulties and respiratory infections

2.10 Epidemiology:

a) Global Prevalence of Dementia:

There is a growing body of evidence on the global prevalence and incidence of dementia. Most of the information is from high-income countries with some data becoming increasingly available from low- and middle-income countries (LMIC).

Prevalence and incidence projections indicate that the number of people with dementia will continue to grow, particularly among the oldest old, and countries in demographic transition will experience the greatest growth.

The total number of people with dementia worldwide in 2010 is estimated at 35.6 million and is projected to nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050. The total number of new cases of dementia each year worldwide is nearly 7.7 million, implying one new case every four seconds. Current estimates indicate 35.6 million people worldwide are living with dementia. This number will double by 2030 and more than triple by 2050. (Source: WHO Report – Dementia a Public health priority 2012)

b) National Prevalence of Dementia:

One out of every 50 families in India has a person suffering from dementia, a study by the Alzheimer's and Related Disorders Society of India (ARDSI) has found out. Dementia afflicts over 3.7 million Indians. This number is expected to increase manifold in the coming years.

According to the 'Indian Dementia Report 2010', released on 21st Sept, between 2006 and 2026, the number of people suffering from dementia in Jharkhand, Bihar and Delhi is expected to rise by 200 per cent or more. In Jammu and Kashmir, Uttar Pradesh, Rajasthan, Madhya Pradesh, West Bengal, Assam, Chhattisgarh, Gujarat, Andhra Pradesh, Haryana, Uttarakhand, Tamil Nadu, Karnataka and Maharashtra, the number may rise by 100 per cent.

By 2026, Uttar Pradesh and Maharashtra are estimated to have over 5 lakhs people with dementia. Gujarat, Andhra Pradesh, Bihar, Rajasthan, West Bengal, Madhya

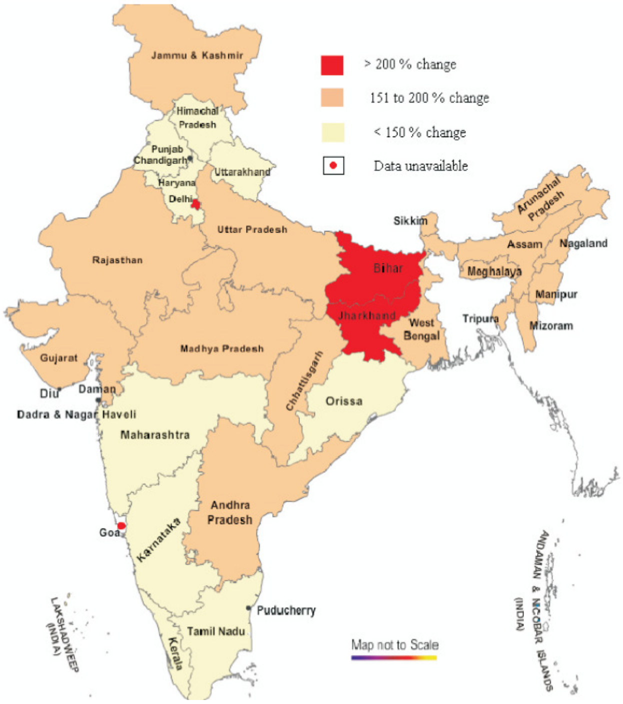
Pradesh, Orissa, Karnataka, Kerala and Tamil Nadu will have between 20,000 to 40,000 afflicted persons. Of the 36 lakh Indians who suffer from dementia, 21 lakh are women and the rest are men.

In India as reported above, one in every 50 households has a dementia, patient. (Alzheimer's and Related Disorders Society of India - ARDSI) the awareness of dementia is very low. Most cases go undiagnosed as people assume that it is just a normal ageing problem. In cases where the diagnosis is made, it is likely to be in moderately advanced stage.

Prevalence studies have indicated a lower prevalence of dementia in India than in high-income countries. The reported rates vary widely, from 1.4% to 4.4% (Shaji et al, 1996, 2005; Rajkumar & Kumar, 1996; Rajkumar et al, 1997; Chandra et al, 1998; Vas et al, 2001). It is estimated that there are already about 1.5 million people with dementia in India (compared with 2.9 million in the USA), but this number is likely to increase threefold over the next four decades (Ferri et al, 2005). This estimate is based on the premise that the Indian incidence rates are relatively low and will remain stable over time.

The relatively high prevalence of smoking and the high and rising prevalence of type 2 diabetes are matters of concern in India. These, coupled with anticipated lifestyle changes, could affect the incidence rates and lead to a higher than expected prevalence in the near future. The prevalence of vascular dementia and the importance of vascular risk factors for dementia need to be addressed in future research.

Figure 4 Projected changes between 2006 and 2026 in number of people living with dementia by State



Thus, the way societies provide or fail to provide the care, can have everything to do with an older person's as well as the caregivers' quality of life. Does care allow scope for independence and dignity? Is it equitably accessible to all? Who provides it? How is it paid? Are the caregivers efforts recognized? The questions need to be answered in the light of the rising prevalence of chronic diseases in ageing populations. It is a substantial burden not only for health care systems but also for social and family structures due to dependency resulting from chronic diseases.

Thus, as seen earlier in this chapter, Dementia is a complex disorder that afflicts primarily the elderly. The complexity of the disease makes treating dementia extremely difficult, involving a wide variety of social and health care interventions. There are no effective health care treatments for stopping dementia, that is why the social care aspect plays an important role in treating the disease, with family members an integral part of this process of management.

2.11 Diagnosis of Dementia:

Dementia is diagnosed when a patient presents with classical history of memory impairment which is slowly progressive with associated cognitive impairments. Diagnosis is mainly done on the basis of complete and detailed history from family members, physical examination, mental status assessment, routine investigations and other specialized investigation, such as MRI/PET scans depending on individual case.

1. History

Information is usually taken from reliable close relative who is in close contact with the patient. Components of history should include

- Complaints (e.g. memory impairment)
- Evaluation of every complaint with its onset, progression and current state.
- Cognitive impairment assessment on history (e.g. language disturbance, calculation difficulty, inability recognize objects or relatives, difficulty in planning, organizing impairment in abstraction)
- Associated impairments of roles and functioning and in activities of daily living.
- Cause of worsening or deterioration.

Past and coexisting medical condition.

- Medications
- Depression.
- Alcohol and other substance use.
- Family history.
- Associated psychological disturbances.

- Changes in previous personality.

The history should also focus on

- Living arrangements
- Supports available.
- Legal and any other issues if any.

2. **Mental Status Examinations:**

   Apart from routine mental examination, focus should be given on speech language disturbances, emotional disturbances, attention, concentration, memory, motor disturbances, intelligence, abstraction, orientation. In routine clinical practice, mini mental status examination should be done as a screening test to monitor progression and response to treatment of dementia. It tests various cognitive domains including attention, concentration, orientation, short term memory, language. Various other cognitive tests could also be done as per expertise of clinician.eg. Abbreviated Mental Test, General practitioner Assessment of Cognition, Neuro psychological testing can be considered in some cases. It assesses various aspects of cognitive function including memory, concentration, recognition, language, visio spatial ability and apraxia. This testing could provide a baseline that can be used to monitor change overtime.

3. **Physical examination**

   Detailed physical examination and neurological examination is must to diagnose specific type of dementia. This can lead to diagnosis of other associated conditions. Neurological examinations show signs of cerebro vascular disease (stroke) in cases of vascular dementia.

4. **Investigations**

   There is a need to undertake few blood investigations routinely in cases of dementia to rule out, reversible factors (causes) of Dementia. Along with routine blood investigation there is need to undertake

- Thyroid Function Tests
- Vitamin B 12 and folate levels
- HIV
- VDRL
- Liver Function Tests-RFT's

Specific other blood investigation can be done as per clinical judgment of individual case.

5. Other Specialized Investigations

CT scan or MRI scan can be done to exclude other condition like tumors, cerebro vascular disease, haematomas and hydrocephalus. CT or MRI is able to detect atrophic changes, but MRI' is more sensitive in detecting structural brain changes in Alzheimer's disease.

Single Proton Emission Tomography (SPECT) and Position Emission Tomography (PET) are functional imaging methods done rarely in clinical practice, but in future can be used in specific diagnosis detecting areas of brain affected where there is reduced glucose metabolism which are picked on SPECT and PET. Lumbar Puncture (CSF examination) can be considered in cases suspected to have infective etiology.

Electroencephalography is not recommended in diagnostic evaluation of dementia, but can be considered if specifically indicated in some cases. It is useful in Creutzfeldt Jakob Disease where in it may show characteristics periodic sharp-wave complexes. So ultimately diagnosis in Dementia is usually clinical being added with specific investigation.

2.12 Treatment of Dementia:

The first step in the treatment of Dementia is to confirm the treatment. This is very important, because progression of the illness can be halted or even reversed, if appropriate treatment is given. Preventive measures are important, especially in vascular dementia. These include a change in diet, exercise and control of diabetes and hypertension. Treatment includes antihypertensive, anticoagulant or antiplatelet agents. Blood pressure should be kept at the higher end of the normal range, as it is known to improve cognitive function in patients with vascular dementia. Conversely, blood pressure below the normal range can further impair cognitive function in these patients. The general treatment approach to patients with dementia is to provide supportive medical care, emotional support for the patients and their families, and drug treatment for specific symptoms.

a) Drug Therapy:

Drugs are prescribed for insomnia, anxiety, depression and psychosis. However, care should be taken for possible idiosyncratic effects in the elderly (e.g., excitement, confusion and increased sleep). Generally drugs with high anticholinergic activity should be avoided. For people with mild to moderate memory loss, Donepzil, Rivastigmine, Galantamine, are commonly used. They produce a modest improvement in memory and global and directed thought. Psychological therapies are a major subject on their own and need to be discussed separately.

The goal of treatment is to control the symptoms of dementia. Treatment varies with the specific disorder. Hospitalization may be needed for a short time. The underlying causes should be identified and treated, including treatment for reversible organic lesions such as tumors.

Treatment of dementia begins with treatment of the underlying disease, where possible. The underlying causes of nutritional, hormonal, tumor-caused and drug-related dementias may be reversible to some extent. Treatment for stroke- related dementia begins by minimizing the risk of further strokes, through smoking cessation, aspirin therapy, and treatment of hypertension, for instance. There are no therapies which can reverse the progression of Alzheimer’s disease. Care for a person with dementia can be difficult and complex.

Two drugs, tacrine and donepezil are commonly prescribed for Alzheimer’s disease. These drugs inhibit the breakdown of acetylcholine in the brain, prolonghig its ability to conduct chemical messages between brain cells. They provide temporary improvement in cognitive functions for about 40% of patients with mild-to-moderate AD. Hydergine is sometimes prescribed as well, though it is of questionable benefit for most patients.

Psychotic symptoms, including paranoia, delusions, and hallucinations, may be treated with anti psychotic drugs, such as haloperidol, chiorpromazine, risperidone, and clozapine. Side effects of these drugs can be significant. Anti anxiety drugs such as Valium may improve behavioral symptoms, especially agitation and anxiety, although Buspar has fewer side effects. The anticonvulsant carbamazepine is also sometimes prescribed for agitation. Depression is treated with antidepressants, usually beginning with selective serotonin reuptake inhibitors (SSRIs) such as Prozac or Paxil, followed by monoamine oxidase inhibitors or tricyclic antidepressants. Electroconvulsive therapy may be appropriate for some patients with severe depression who are unresponsive to drug therapy. In general, medications should be administered very cautiously to demented patients, in the lowest possible effective doses, to minimize side effects. Supervision of taking medications is generally required.

b) Non Pharmacological Treatment of Dementia:

a. Memory aids

Memory aid such as the list diaries and clear written instructions can be helpful if the person is willing and able to make use of them. Displaying large clearly labelled picture of relatives will help the person to keep track of who is who. Labelling the doors of the rooms with words and bright distinctive colours can be helpful. Memory aids will not be so useful in later stages of dementia.

b. Reality orientation

Reality orientation is technique that is widely applied all over the world. There are two approaches to reality orientation. Class room reality orientation involves stimulation for the periods varying from 30-60 minute a day.

During these sessions the patient is given orientation to the day of the week, the month, the day of month, the year, what the weather is like and so on. Reality orientation (RO) board, writer instructions, cooks, calendars, maps and posters can be used to enhance reality orientation .the other form of reality orientation has been called 24-hours reality orientation. This usually takes place in a hospital ward or residential home. Instead of being presented with an intensive information session, the subjects are oriented in their relevant everyday activities throughout the day.

c. Reminiscence therapy

Reminiscence is looking back in over our lives, recalling past memories of the people, place and events. Our life experiences influence our personality; therefore our memories give us a sense of who we are.

A person with dementia begins to lose their memory. In the early stages short-term, memory is affected more than long term, or distant memory. At the last stage of dementia both long and short- term memory will be seriously affected. It is the duty of the caregivers to encourage people with dementia to talk about and share their memories and to help them enjoy these memories. Even for the people in the late stages of dementia it is often possible to fine some cue, a song of picture, which will give them pleasure.

Reminiscence activities include conversation, reading, singing, cooking, discussion, drawing, writing, question card, life story book, smelly box and rummage box etc.

d. Behavioral Therapy

Patient with dementia may have wide variety of behavioral disturbances, including depression, agitation, hallucinations and delusions, anxiety, violence, sleeplessness, and wandering. These behaviours can cause considerable distress to family members and professional care givers. Non- Pharmacologic approaches to behavioral problem should be tried before resorting to drug therapy. For example, treatment for depression may include encouraging simple activities that promote success and sense of usefulness (setting the table, gardening, cleaning) arranging comfortable social gatherings and encouraging activity can also help to improve the mood. Sleep disturbances in the patient that keep the caregiver awake in night can be particularly problematic. Keeping the patient active during the day with exercise and minimize wakefulness at night. Encouraging the patient to use the bathroom before bedtime may help prevent nocturnal and using night-light can help prevent nocturnal confusion.

Wandering poses a risk of physical injury to the patient and may be due to restlessness, confusion, boredom, or need for exercise. This needs to be tackled sometimes with medication. At some point, most Alzheimer's dementia patients experience agitation, and some experience hallucinations and delusions. Agitation can be managed by providing a calm, well structured, and predictable environment, as well as outlets for nervous energy. In many instances, a stimulus in the environment triggers the anxiety and agitation. Although the cause of anxiety may not be immediately apparent, identifying and eliminating the cause is the single best treatment. With patient who develops hallucination and delusion, the caregiver should avoid confrontation, especially if the delusion poses no danger. Simple, clam reassurance is often helpful. In general, avoiding confrontation is the best road to success for managing problematic behaviours.

e. Social interaction

Relatively simple environmental changes will increase the amount of interaction. Patients talked much more to each other at mealtimes if their chair were group around tables- instead of being in lines along with walls. Other studies have attempted to increase social interaction in small group setting. Good conversion stimulators include music, pets, children and reminder of younger days.

f. Domiciliary Care

Most of the patients have dementia live at their homes with their family. Many a times the support given by the family may be inadequate or inefficient due to the lack of understanding of the disease process, inability to deal with behavioral problems associated with dementia or due to interpersonal problems or caregiver's distress. Trained manpower is essential to look after the persons in the community. Imparting training to health workers to deal with this problem will be very useful.

g. Day care

The day care provides respite to the caregivers and rehabilitation to the patient. The programme is very helpful to those families where all the family members are working or those who are unable to take care of patients due to family disharmony or lack of personnel. Regular attendance in these programmes enables close monitoring of the physical and psychiatric status of the patients so that early intervention and treatment is possible.

h. Family intervention programme

Dementia does not simply affect the person who has it. It profoundly changes the lives of those family members who are close to that person. Care giving in dementia is time consuming, frustrating and a demanding task which can leave the care giver, frustrated, depressed angry and alone. Psychotherapeutic intervention with family members is the critical aspect of treatment. Psycho education is the most important component of the programme. Providing information about nature, course and prognosis of the illness help the caregivers to lowers their expectation about the patients, which in turn reduces the intensity of frustration. The programme is aimed to change the perception of the caregiver, to enhance problem-solving skills and to support.

i. Support Group- caregiver’s meeting

Caregiver’s meetings provide support in a group setting. Groups allow for the ventilation of feelings and the development of the group process. It provides opportunities for care givers to come together, empathies with each other, share their problems and solution and acknowledge and affirm each other’s care giving efforts. Living with and caring for a person with dementia newer coping strategies from the caregiver. Caregiver’s meeting provides an opportunity to learn how to cope better as demands are changing. Support group supports the relatives or friends so that they can cope more easily by sharing of common experience, problems and solutions. It works on the principles of sharing and co-operation, reduces feelings of helplessness and despair, provide a chance to discover that their situation is not unique, exchange of ideas and disseminate information. Also offers advice and support.

3. Management of Patients:

Illness and chronic illness can occur anytime to anyone regardless of the Age of a person. Across all the age group there are patients with various diseases and chronic illness both curable and non curable. It is always easier to manage or take care of the patients who are young and adult as compared to those who are old and children. Since dementia related to the elderly, management of patients who are elderly is emphasized further in this chapter.

Management of patient includes the prevention, treatment, and management of illness and the preservation of mental and physical well-being through the services offered by the medical and allied health professions.(The American Heritage® Medical Dictionary) It is co-ordination of patient registrations, updates, and movements for all clinical areas, unambiguous updating of historic patient movement events. It calls for a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual’s health needs through communication and available resources to promote quality cost effective outcomes.

Patient management for chronic illness is separately looked into in the medical field as it needs more professional help. It encompasses the oversight and education activities conducted by professionals to help patients with chronic diseases. This term is equivalent to disease management (health) for chronic conditions. It cannot be seen in isolation but in the context of overall Health care system.

3.1 Health care system:

Health care system has many stake holders – they are Hospitals, Medical Institutions (imagining centre, laboratories, Blood banks and special clinics), Pharmacist, medical and paramedical staff (doctors, nurses, attendants, and ward boys), Social workers, Case managers, Non-government offices, Government or state, Insurance companies, patients and their families. All these stake holders are actually service / care providers / caregivers except for the patients. There are two broad categories of care formal and Informal. Formal care is normally done by professionals at the hospitals or institutions while informal in mostly in the communities and families where care is given by family, friends, relatives and neighbors. Similarly there are categories of care recipient; those patients requiring the assistance of a caregiver generally fall into 2 categories:

a) Acute care patients:

Acute care is often a rehabilitative recovery from a hospital stay or it may be a recovery from a serious illness or injury. Recovery time is usually a matter of a few weeks or months after which the person–even if not completely whole-- is typically capable of not needing a caregiver to function normally.

b) Chronic care patients:

Certain diseases, disorders, accidents or injuries result in disabilities that last longer than a few weeks or months. Many of these become permanent problems and although the disabled person may eventually adapt to take care of himself, a caregiver is often needed. The location of where this care is given, either at the home or in an institution and whether the care is provided by informal or formal caregivers depends on the nature of the chronic condition and disability.

The treatments for chronic diseases are often complicated, making it difficult for patients to comply with treatment protocols also many of the chronic conditions as mentioned in point no b above are more prevalent with advanced ages and as a rule, care giving is a problem associated with aging.

3.2 Health care system – Indian Context:

The art of Health Care in India can be traced back nearly 3500 years. From the early days of Indian history the Ayurvedic tradition of medicine has been practiced. During the rule of Emperor Ashoka Maurya (third century B.C.), schools of learning in the healing arts were created, an attempt to give health care to all of his citizens, thus it was India which was the first state to give its citizens national health care.

In India, the hospitals are run by government, charitable trusts and by private organizations. The government hospitals in rural areas are called the (PHC)s primary health centre. Major hospitals are located in district head quarters or major cities.

Apart from the modern system of medicine, traditional and indigenous medicinal systems like Ayurvedic and Unani systems are in practice throughout the country. The Modern System of Medicine is regulated by the Medical Council of India, whereas the Alternative systems recognized by Government of India are regulated by the Department of AYUSH (an acronym for Ayurveda, Yunani, Siddha & Homeopathy) under the Ministry of Health, Government of India

In India there is scarcity in the terms of infrastructure related to specialty and supportive health care facilities. Unlike west, India lacks service systems like geriatric nursing homes, intermediate care facilities, assisted living, home care agencies, community services, hospice, religious or charity service groups, adult day care, senior centers, association services, state aging services, Geriatric wards, Memory clinics, support groups, caregivers associations and Help lines. Health care today is at crossroads.

It is proving beyond the reach of common man especially low and middle income group. It is estimated that around 10% to 12% of family income needs to be spent on taking care of emergency health care needs and age old problems. The emergency and specialty care is well beyond the reach of an average citizen. Awareness to create financial capability is shockingly lacking.

Since this study focuses on the care giving of the elderly (dementia patients), the help and services provided to the elderly is emphasized. Elderly care emphasizes the social and personal requirements of the aged who need some assistance with daily activities and health care with desire to age with dignity.

3.3 Caregivers- Backbone of Health Care System

Caregiver is a person who helps in identifying or preventing or treating illness or disability. He / she can be either a health care provider, health professional or primary care provider.

1. An individual, such as a physician, nurse, or social worker, who assists in the identification, prevention, or treatment of an illness or disability.

2. An individual, such as a parent, sibling, foster parent, or head of a household or family member, who attends to the needs of a child or dependent adult.

Caregivers navigate the often overwhelming health insurance system and communicate with multiple health care professionals. Coping with physical, emotional, spiritual and financial challenges affects caregiver health and quality of life as well as patients' health and quality of life. Caregiver is anyone who provides help to patients overcome chronic disabilities. Caregivers help with many things such as: grocery shopping, house cleaning, cooking, shopping, paying bills, giving medicine, bathing, using the toilet, dressing and eating. People who are not paid to provide care are known as informal caregivers or family caregivers.

3.3.1 Care giving –Historical Perspective

Care giving in old age is the provision of assistance to an elder when his or her health deteriorates, whether it is physical or mental health, or a combination of the two. Care giving typically refers to unpaid care from members of the family or friends. It is an aspect of social support but more generic in nature. Research in this area reveals diverse views as there is no precise scientific definition of the term care giving. For example, spouses less likely consider themselves as caregivers as compared to children and siblings who are providing assistance to their loved one with instrumental activities of daily living. Think of the instance where a daughter takes her mother grocery shopping. Either one or both may define it as a chance to socialize, or as assistance, or as simply something they do together. The literature adds to the confusion with the use of a variety of terms, including care giving, caring, assistance, interaction, and support, sometimes used synonymously and sometimes not. Despite these difficulties, the area of care giving in old age has received much research attention from 1970 onwards.

Interest in the area arose during the 1960s and 1970s as a practical concern. During this time, gerontologists documented care giving, during later life. This was important within the context of the times when it was commonly believed that seniors in Western industrialized societies were largely isolated from their family, living alone, and often housed in long-term care institutions. Further, during this time the prevalence of informal, unpaid caregivers as the dominant source of assistance for elders was also examined. It was established that when health declined the first resort for care was informal care network. This was important because it established the strength of the family as a major source of interpersonal support and care during old age (Chappell 1990).

By the late 1970s and especially in the 1980s, research on care giving rapidly increased. The critical role of spouses and children on death of spouse was studied and distinguished who provides support. The emotional aspects of care giving received little attention as it frequently focuses on tasks of activities of daily living, either instrumental activities of daily living (IADL) such as shopping and banking, and basic activities of daily living (ADL) such as going to the toilet, eating, personal mobility, and other activities necessary for survival. Yet it was recognized that it is this emotional element that distinguishes informal care from formal or paid care giving.

Public recognition of care giving raised and caregivers were labeled the 'hidden victims,' 'sandwich generation,' 'generation-in-the-middle' (Brody 1981). Cantor's (1979) hierarchical compensatory model, also known as the substitution model, also received much attention during this period. She argued that caregivers' selection followed and order of hierarchy. It was determined by the nature of the relationship between the giver and the recipient. According to this view, the most preferred caregiver was the spouse, followed by daughters, sons, other relatives, friends, and neighbors, in that order. Litwak's (1985) competing hypothesis of task specificity also gained popularity. In this instance, it was argued that persons differentially placed within society provide different types of assistance - spouses can provide emotional and other long-term needs on a continuous basis; neighbors provide short-term, sporadic, and instrumental assistance.

Most studies examined care from the spouse and children, who are the most prevalent care givers; there was less of a focus on support from siblings, friendships, and grandchildren. Significant gender differences in care giving were revealed: the fact that women tend to do the emotional and hands on work while men tend to provide advice and financial assistance (Horowitz 1981). Other studies reported that men are more likely to rely exclusively on their spouse for emotional support whereas women are more likely to rely on friends (Hess and Waring 1980); that caregivers experience burden as a result of their involvement in this role (Zarit et al. 1980); that there is generally one main care provider who does most of the work (Stone et al. 1987); and that working daughters do not provide fewer hours of care giving than those who are not in paid labor (Brody et al. 1984).

Other researches indicated that care giving differs from one ethnic group to other. However, variation due to ‘culture’ is difficult to establish. In a review of scientific studies, Kane and Kane (1985) estimated that between 75 and 85 percent of all personal care to seniors comes from the informal network. Chappell (1985) reported that almost all community living elders receiving any type of assistance do so from the informal network. The lack of recognition of the care provided by caregivers and the lack of support for caregivers within formal health care systems was also documented (George 1988).

Informal care giving emerged as the indisputable dominant system of care and sheer volume of research on care giving got established as a major area. It became obvious, that care giving is significantly a woman’s issue. Women predominate as the caregivers and the care-receivers. Caregivers are burdened and women who work do not go away from care giving.

By the late 1980s and early 1990s care giving had become a popular area of gerontological research, producing studies on a various facets of this topic. Studies on burden and stress continued, revealing a very important perspective that there is no difference in stress level between male and female caregivers. Research on male caregivers showed their more instrumental approach to the role than women have. Positive aspects of care giving such as feeling useful and bringing comfort to a loved one were being studied. Furthermore, care givers, were reluctant users of formal services.

There was heightened awareness from a feminist perspective that aging and care giving, as a woman’s issue. Indeed, family care emerged in the 1990s as a cornerstone in the health care.

The political awareness of caregivers brought urgency to research in this area, highlighting the need for an adequate understanding of care giving if policies and programs were going to make assumptions about their capacities and their needs. It led to a rediscovery of care giving. A concern with increased burden for caregivers became prominent. New questions were addressed. What is the impact of different service interventions on caregivers? How can the formal system support caregivers and how can caregivers be integrated with formal health care delivery?

Penning (1990) supports stages of care giving as a more apt descriptor of this phenomenon, since individuals are usually involved in raising their children, then caring for their parents, and then caring for their husband rather than being engaged in all of these roles at one time.

In addition to the characteristics of caregivers and the burdens of caring, researchers are beginning to study the meaning of caring. Wenger et al. (1996) suggest conceptualization care giving in terms of purposes and relationships rather than tasks, taking the everyday experiences of caregivers and care recipients into account. For example, to provide preventive care, such as ensuring the person eats well and exercises; and being involved in the supervision of care.

Interest in care giving in old age arose and has continued. It began with assumptions about supportive relationships and about the role of the family and over time has focused on the complexity of both the definition of care giving as well as its contextual fields. Only recently, has there been conceptual development in this area with current attempts to examine the meaning of the term ‘care giving’ and how that varies from group to group.

Currently complex conceptual issues are starting to be addressed—whose definition of care giving counts? How are caregivers taken into account within the health care system? How can they be taken into account? Whose definitions of care giving are appropriate for service delivery? How can the autonomy of caregivers be maintained? The conceptual issues relate to methodological issues. If the mother does not consider the daughter’s effort to be care giving but the daughter does, whose definition does the researcher accept, if either? If the wife is cooking the meals anyway and always has, is this part of care giving when her husband’s health declines? When computing the economic value of care giving, do we include those times and tasks governments would not provide? Future directions for care giving research in the short term seem more or less clear.

3.3.2 Family Caregiving – Theoretical Perspective:

Family responses are extensively studied and conceptualized in severe mental illnesses. The three major conceptual frameworks commonly used are: family care giving burden, expressed emotion, and family stress and coping models. Each has distinct limitations.

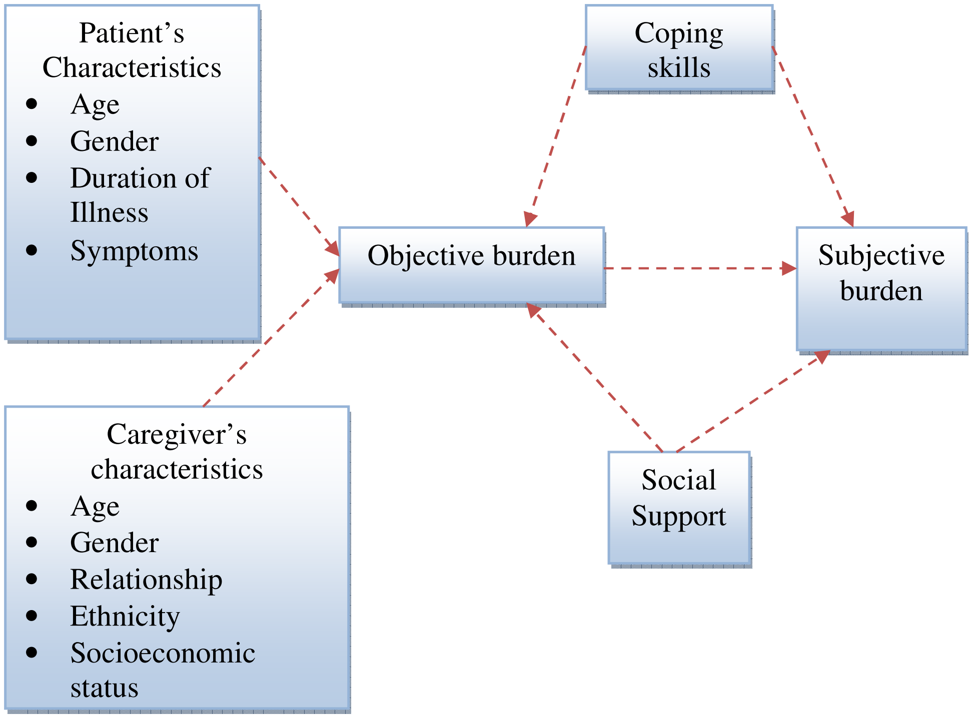
1. Family Care giving Burden

Studies of family responses to mental illness have pointed to the burden placed on family members (Reinhard, 1994; Salleh, 1994; Solomon & Draine, 1995). Care giving to a mentally ill person is assumed to have a negative impact on the family and is perceived as a family burden. Further burden in divided into two Objective burden and Subjective burden.

Objective burden arises due to disruption in everyday life in the household, financial problems, limitations on personal activities, and social interactions. Subjective burden is the individual personal appraisal of the situation and the extent to which caregivers perceive they are carrying a burden. Subjective burden results from the care giving experience and includes feelings, attitudes, and emotions (Maurin & Boyd, 1990; Reinhard, 1994). Further, care giving burden is predicted by ill family members characteristics, such as age, gender, duration of illness, functional status or extent of disability, and symptoms (Solomon & Draine, 1995; Veltro, Magliano, Lobrace, Morosini, & Maj, 1994), and caregiver demographic characteristics, such as gender, age, socioeconomic status, ethnicity, health status, relationship with the patient, and living situation (Cook et al., 1994; L. S. Jones et al., 1995; Scazufca & Kuipers, 1996).

Reported mediating factors include social support (Solomon & Draine, 1995) and coping skills (Birchwood & Cochrane, 1990; Solomon & Draine, 1995) family care giving burden framework is illustrated as in Figure 1.

Figure 1 Family Care giver Burden Framework



Source: Journal of Family Nursing 2000 Vol 6 No. 4

Critical Review:

This approach is incomplete as it does not address positive and rewarding experience of the care giving. It emphasizes only negative perspective towards care giving of the chronically ill patient is taken. However, Research suggests that there are both gratifications and rewards in care giving (Greenberg, Greenley & Benedict, 1994). These are overlooked here. Plus some burdensome activities, such as household routines, are the same as those that occur whenever families experience any change in their normal life. This means caregivers might experience burden regardless of the presence or absence of an ill family member. Hence we cannot confidently say that the burden is attributed to the illness of the family member.

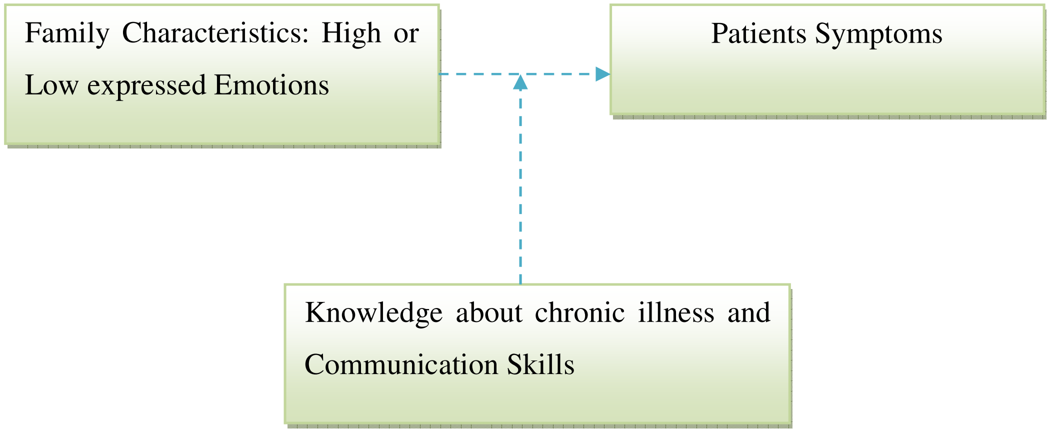
Thus, the assumption underlying the family care giving burden perspective is that caring for a family member with severe mental illness imposes a care giving burden, and the degree of the burden will vary according to other factors. Conceptualization of the burden framework should include the possibility that gratifying, positive aspects of caring can also result from the care giving experience.

2. Expressed Emotions Framework

The expressed emotion framework (Figure 2), developed by Brown, Birley, and Wing (1972), has been used in studying a factor influencing the patient with mental illness, that is emotional environment of families. Expressed emotion is a clinical concept derived from composite ratings from an audiotape of a semi structured interview of the family (Camberwell Family Interview -CFI) (Brown et al., 1972). It talks of two different attributes of family members: 1) Criticism and hostility and 2) Over Emotional Involvement. Further, families are classified as high or low expressed emotion according to these two areas. Low-expressed-emotion families tend to be warm, concerned, understanding, and tolerant, whereas high expressed- emotion families tend to be either highly over involved or critical or both.

Studies have found that the persons from high-expressed-emotion families were at greater risk for psychiatric relapse than those from families with low expressed emotion. Within the framework of expressed emotion, family psycho education programs have been developed to increase family members' knowledge about mental illness and communication skills (i.e., to lower expressed emotion) (Falloon et al., 1985; Hogarty et al., 1986). Figure 2 displays the basic relationships within the expressed emotion framework.

Figure 2 Expressed Emotions Framework



Source: Journal of Family Nursing 2000 Vol 6 No. 4

Critical Review:

The expressed emotion concept cannot be used to explain entirely the complexities of family life because it lacks consideration for other variables that may affect illness For instance, other sources of stress could be occurring during the same time the family is taking care of the ill relative (e.g., financial problems or changes in mental health care system policies). The expressed emotion framework does not consider these contextual influences.

Although research findings reported that there was a positive correlation between high expressed emotion and patient relapse, the expressed emotion framework is often perceived as blaming families for causing mental illness or relapse (Malone, 1993).

The expressed emotions may be the outcome of the personality of the caregiver or the situation, personal issues apart from the patient, gender bias, family dynamics that may be affecting emotional climate of the family. At times High expressed emotions are also due to patient’s intolerable behavior. Family burden, stigma, and isolation may influence the expressed emotion and coping capacities of family members as well as the behavioral difficulties imposed by the illness. Lefley (1996)

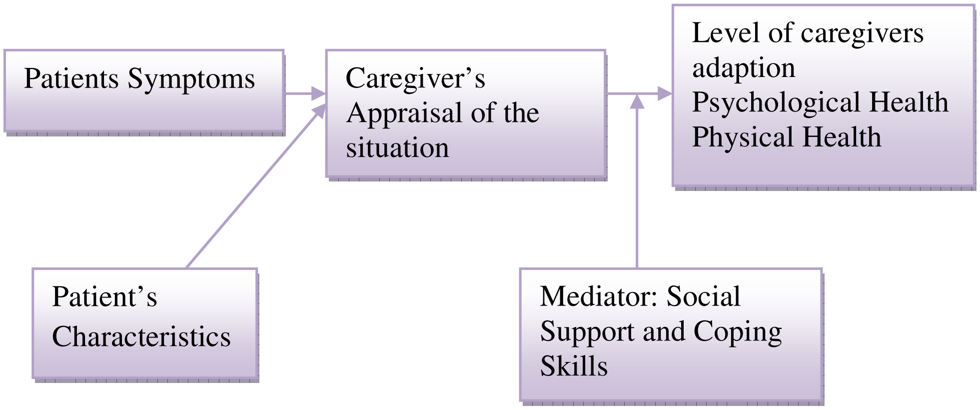
3. Family Stress and Coping

Systematic investigation of the assumption that all families of persons with psychiatric illness experience stress, based on the concepts of family stress and coping, is sparse. Very few studies of family caregivers of a person with a mental illness has used family stress and coping models compared to the extensive use of this framework to study other areas of family care giving.

Hatfield (1981, 1987) proposed a conceptual framework of coping and adaptation for understanding families of persons with mental illness, and his studies have often been cited in literature on family caregivers in the context of chronic mental illness (Doornbos, 1997; Fisher, Benson, & Tessler, 1990).

There are three major concepts in the model: crisis, coping, and adaptation (Figure 3).

Figure 3 Family Stress and Coping Framework



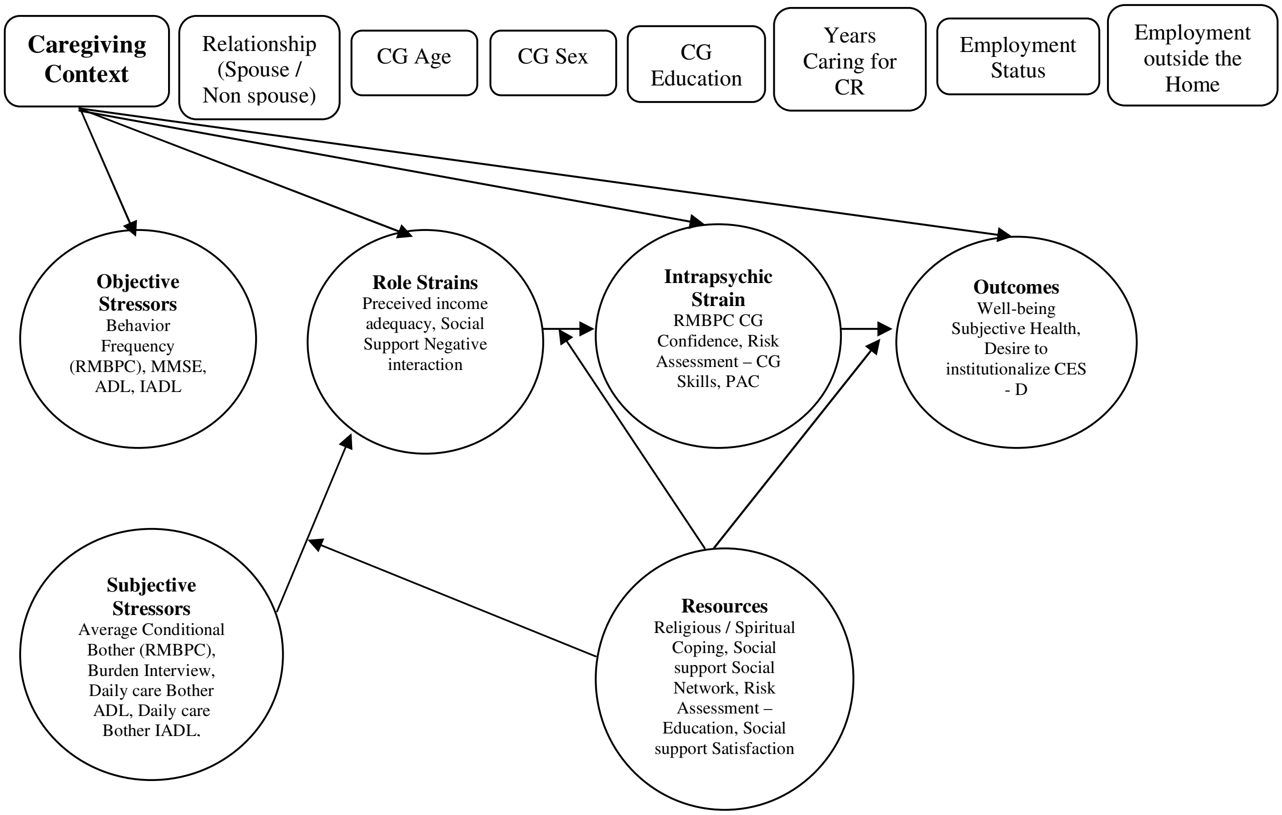
Source: Journal of Family Nursing 2000 Vol 6 No. 4

The state of crisis for the family is produced on the onset of mental illness of the family member. The term crisis refers to any intensive, rapidly changing, sudden, or unexpected events that are beyond the individual's habitual modes of response and ability to keep a balanced state. Coping refers to the problem-solving efforts people make to master the stressful situation. Adaptation refers to the relationship of external demands and the person's resources for dealing with them. When coping is insufficient to reduce the appraised stress, the result is psychological or physical morbidity (Szmukler et al., 1996). However, this model is situated within the context of the individual, not the family system. For example, how family functioning affects the family caregiver's coping is not addressed in the model. It is inadequate to explain the family process. Rather, it produces a collection of individual responses.

After looking in the above three frameworks, further this chapter documents the state of current knowledge and explores the current theoretical frameworks that have been used to describe the care giving process from the field of geriatrics especially review of the studies of dementia family caregivers was done. As it is known care giving for elderly with dementia is an enormous responsibility, one that can far exceed that of typical care. While most family members adapt well to the situation of caring for a person with other chronic illness, some do not, especially if the disease is dementia. To understand family caregivers' adaptations to their patient's behavior, the complex nature of stress processes must be accounted for and the constructs and factors that play a role in the care giving must be considered.

The most comprehensive model of stress and coping (SPM Figure-4) in the process of care giving indicating the mediating factors was developed by Pearlin et al in 1990. The SPM proposes that care giving context variables affect each part of the stress developed in care giving process. This can have implications on the care givers perception or appraisal of the stressful situation and its outcomes such as depression and physical health. Contextual factors /variables specifically, age; gender, employment status, and relationship to the care recipient affect care giving outcomes within the SPM.

Figure 4 Stress process model based on Pearlin and Colleagues (1990)

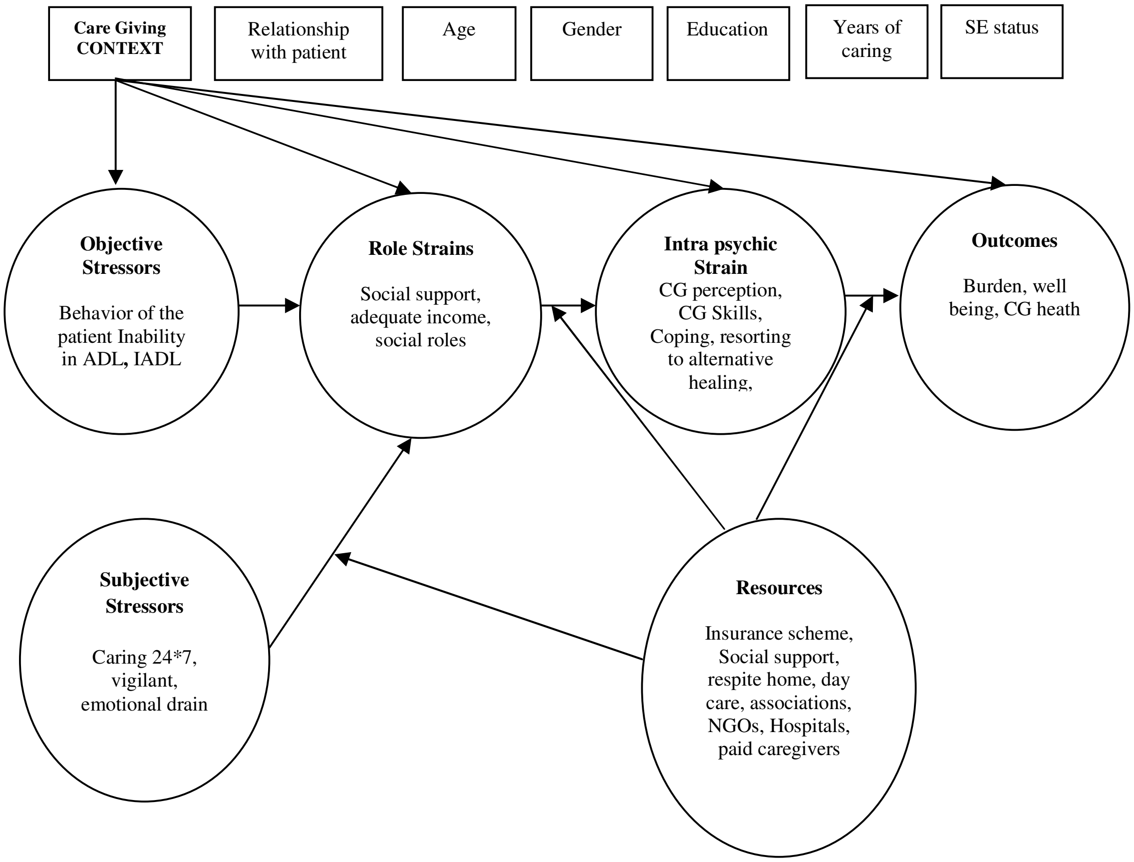


Source The Gernotologist 2009 April 9(2) 248-261

However, the model has not considered race / ethnicity of a caregiver as a variable which has a potential of affecting care giving process. It is an important variable as perception of stressors, availability of resources, social support and coping strategies may vary from one race/ ethnic group to other race/ethnic group. This may possibly be true in Indian context as India is the country with varied cultures, religions, with many caste and sub caste.

In the current study, the SPM model is adapted for conceptual framework. The study though in Indian setting where culture may affect the coping mechanisms and care giving process on the whole as stated earlier, as considered in this model because during extensive review of literature not many studies were found on care giving of dementia patient in India more so in Gujarat. Secondly, possibility of getting data on the basis of variable of culture and caste was less. Figure 5 below is the conceptual framework model adapted for the current study of management of dementia patients by the family caregivers.

Figure – 5 Stress Process Model of Care giving



The conceptual framework highlights the study areas.

- **Caregiver Context:**

  Care giving does not occur in isolation from one's social and experiential past or present. The construct is included to address the setting in which care giving takes place, with emphasis on socio-demographic and economic characteristics of the caregiver.

- **Objective Stressors:**

  Objective stressors represent the stimuli or behaviors related to the patient that trigger the emotional response or reaction in the caregiver. They are disturbed behaviors like wandering away, sleep disturbances, self harming behaving.

- **Role Strains:**

The role strain encompasses the stressors related to maintaining multiple social and work-related roles.

- **Caregiver Intrapsychic Strain:**

  The Intrapsychic factors construct pertains to the caregiver's internal state. Self-evaluation of how well one performs the role. Self-perception is thus considered an important intra psychic factor. It also refers to ability of maintaining confidence in care giving, care giving skills, and rewards associated with care giving.

- **Subjective Stressors:**

  Subjective stress included care giving demands, emotional bother related to providing for the patients daily care needs(activities of daily living), behavioral botheration, and constant vigilance.

- **Resources:**

  People differ in their access to and use of coping factors. Factors included under this construct are social support, family function, and stress management, resorting to alternative healing etc.

- **Outcomes:**

  This construct will help understand the outcome of the care giving – well being of the caregiver or the burden and related health problems.

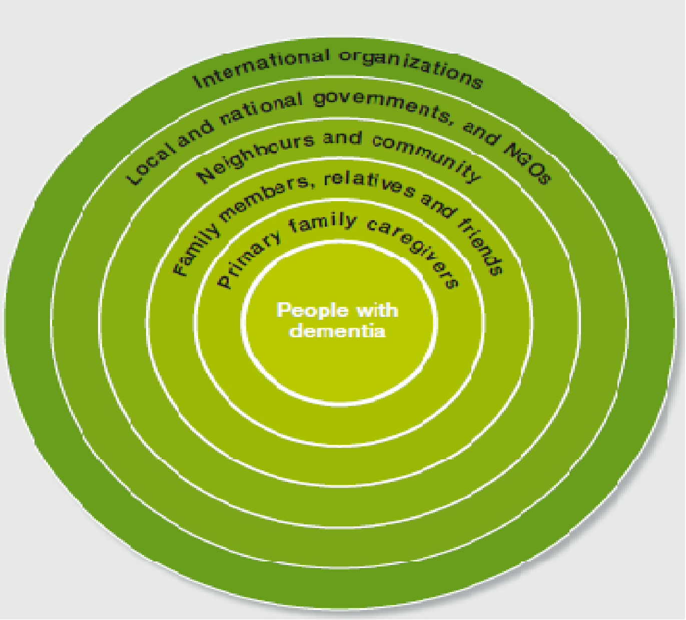
3.3.3 Family Caregivers – Integral part in Health care system:

Care giving and support is not the responsibility solely of the family and others in the immediate network of the person with dementia. It should also be a concern for communities, governments and society as a whole, although lack of awareness or commitment may mean that this is not the case in practice. Figure 5 illustrates levels of care (some very direct, such as that of family and neighbours; others less direct, but nevertheless crucial, such as the supportive role of government and society) and their proximity to the person at the centre of the arrangements for care, i.e. the person with dementia. The key role of family caregivers is often neither supported nor properly acknowledged.The family is one of the most important providers of care for the elderly. In fact, the majority of caregivers for the elderly are often members of their own family, most often a daughter or a granddaughter. Family and friends can provide a home (i.e. have elderly relatives live with them), help with money and meet social needs by visiting, taking them out on trips, etc.

Family caregivers have become an integral part of the health care system, working in partnership with patients and health care professionals. Family caregivers play a major role in maximizing the health and quality of life of elderly patients. Patients depend on family caregivers for assistance with daily activities, managing complex care, navigating the health care system, and communicating with health care professionals. Physical, emotional and financial stress may increase caregiver vulnerability. Geographically distant family caregivers and health professionals in the role of family have separate challenges to face.

Family caregivers as defined include relatives, partners, friends and neighbors who assist with activities of daily living and complex health care needs that were once the domain of trained hospital personnel. Approximately 30 – 38 million family caregivers over the age of 18 help patients manage illnesses and treatment recommendations.

Figure -5 The integrated care giving system



Source: WHO Report – Dementia a Public health priority 2012

4. Management of Dementia Patients:

Management of Dementia Patient can be difficult and complex. Physical care is only one part of the process. It may additionally require accompanying the patient to the hospital, bringing food to the hospital and supplementing nursing care. Furthermore, patients are often immobile and disoriented, requiring the caregiver to provide a range of care services and activities including physical, clinical, psycho-social, emotional, spiritual, financial and practical care.

This being practically difficult in Institutionalized setting care more often family members assumes increasing responsibility for the patient's physical, emotional and psychological needs. There is reliance upon families as the cornerstone of support and care. However, surprisingly little is known of the care arrangements for people with dementia and the strain experienced by their family caregivers. Women provide the majority of informal care to spouses, parents, parents-in-law, friends and neighbors, and they play many roles while care giving—hands-on health provider, care manager, friend, companion, surrogate decision-maker and advocate.

4.1 Care giving and Management of Dementia Patients:

Caregiver support is important in the management of Dementia patients. Management of disabled older people with behavioral disturbance can be very stressful for the families. Studies have highlighted the importance of identifying and managing behavioral symptoms of dementia.

As dementia patients decline cognitively and become increasingly dependent, the role of the caregiver is critical in their care. While care giving is required whenever a person is ill/ dependent, care giving for a dementia patient is considered more stressful than care giving for patients suffering from other disease. This is further compounded because as dementia Progresses, the patients also suffer from other diseases and care giving involves handling challenges posed by a combination of disease.

People who end up becoming caregivers of dementia patients are usually people like you and me, people in various jobs and professions, with no clue about dementia or what care giving involves for a patient with declining cognitive ability. Many of them had never envisaged that they would end up in this role, and have no mental or emotional preparation for it. They don't have a clue on how to handle the behavior problems a dementia patient poses.

Dementia patients lose their cognitive abilities, but remain aware emotionally of their surroundings, and are quick to notice the emotions of the people around them. Patients will notice that the caregiver is irritated/ frustrated/ angry, even if he/ she are careful not to utter anything hurtful. Thus, it makes sense to understand all about care giving, what are the multiple skills required, treat it like a project and very significant area of study.

Dementia care giving is different from other care giving for patients with other chronic conditions, in terms of activities and time required and the impact on caregivers. Table 1 below shows the comparative picture about difference in care giving to dementia and non-dementia patients.

Sr No	**Patient with Dementia**		**Patient without Dementia**
1	Incapable of understanding his/ her health condition and unable to make decisions due to cognitive impairment.		Patients with other medical conditions need assistance, but are aware of their problem and are able to communicate and also make choices.
2	Dementia patients, unable to understand that treatment is needed, hardly co-operate and often view caregivers as intruders.		Patients understand that treatment is needed, and cooperate, in spite of difficulties faced. Understand that the caregiver is doing what is required, and is helping them
3	Patients get paranoid, and are extremely suspicious of caregivers, accuse them/ inform visitors about such alleged injustice/ persecution.		Other medical conditions except for psychiatric conditions don't show this behaviour
4	Dementia patients, over time, no longer recognize the family caregiver. This can get very heart-wrenching.		Other medical conditions except for psychiatric conditions at times don't forget family members & caregivers.
5	Patient fade away as a person, lose his /her personality, or become a (apparently) different person.		Other medical conditions except for psychiatric conditions don't show this behaviour

Sr No	Patient with Dementia		Patient without Dementia
6	In dementia, the progression sometimes stretches for years. It is, as they say, a very long goodbye.		In most diseases, care giving is for a short period till the patient recovers. Or, it lasts for some months if the patient is at the end-life stage.
7	Patient is completely dependent and uncooperative is physically extremely tiring. It is almost a 36-hour job.		In other diseases patient though dependent is most of the time co-operative.
8	Patients can harm themselves, are dependent & wander away cannot be left alone, needs constant supervision		Patients in some case may harm themselves or be dependent for some time but don't wander away.

4.2 Care giving and Illness Situation:

Caregivers are important to the management of Dementia disease: a breakdown in care giving leading to institutionalization is as likely to be the result of a breakdown in the caregiver's health, as to be caused by the Patient with Dementia (PWD) being too ill to be cared for. Patient symptoms and behavior have an effect on the care giver and the characteristics and behavior of both patient and caregiver predict caregivers distress levels. Patient outcomes are influenced, naturally by the illness itself, but also by the care they receive. Therefore it is imperative that care givers are recognized as being part of the illness process, and do not remain hidden patients.

There is increasing recognition of the importance of the caring for caregivers as a society, and the fact that many of them need high-quality, reliable and responsive support from statutory or voluntary services to continue their role and maintain their own health and well-being.

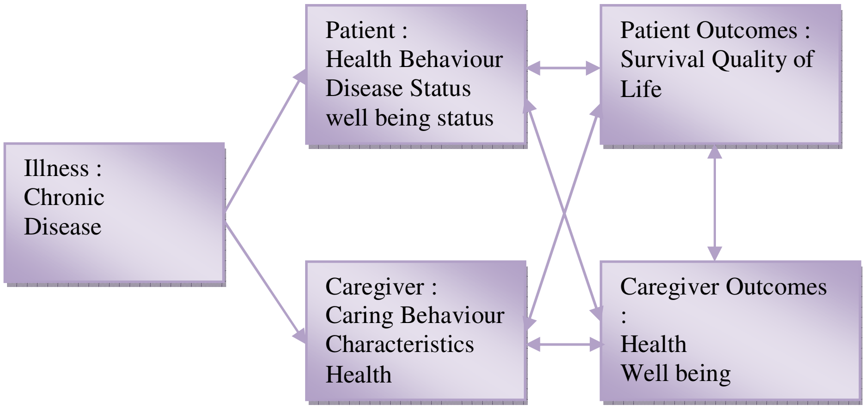
The focus of much care giving research has been to provide predictors of distress, depression, burden and, more lately, well being (Aarsland D-2001, Thommessen B,et al 2002). These studies have clearly shown that there are care giving-specific predictors of caregiver distress, as well as non-specific predictors such as an emotional personality. As caregiver distress is a multi dimensional concept, interventions should be targeted to a care givers particular needs (Cousins R, et al-

2002). This is especially true in Dementia, which, as a progressive illness, impacts upon caregiver differentially according to stage. It was reported as early as 1972 that when institutionalization does occur, it is usually because of a break down in caregivers' health.(Isaacs B, et al 1972)

Model of the illness situation:

The notion that Dementia is a family illness can be illustrated by an adaptation of Young's model of illness in later life (Figure 6). Young argues that the consequences of illness in the family should be conceptualized as a mutual encounter, since both the patient's response and the caregiver's response to the illness situation, in turn, affect the situation. The patient-caregiver interaction model shows the way in which quality of life in dementia is dictated by the complex dynamic interplay of patient and caregiver responses to the illness situation.

Figure -6 Patient-Caregiver Model



Source: Young's Model of Illness In Later Life Young RF. Elders, families, and illness. J Aging Studies. 1994; **8**: 1–15.

Caregivers bring their own characteristics into the caring situation. As indicated in the model, care givers characteristics have an effect on outcomes, (Pinquart 2003) as well as on their response to the demands of the PWD. Caregivers' emotionality and coping style are major predictors of care giver outcomes (Cousins R.1997) Coping style, however, is amenable to change. There is also evidence that relationship strain predicts caregiver depression and negative health outcomes. (Lyons KS, Zarit SH,) Caregivers are not well informed about Dementia, particularly the psychological aspects of the disease. Objective tests of physical demand and psychological demand indicate that those caregivers who look after more advanced PWD are those who know more, suggesting that they are learning while giving care.

4.3 Caregivers and Management of Dementia Patients: Indian Context

The growing number of aged population as a result of the increase in the life span of the individuals, and the continuing preference of older persons to stay with their young are some of the reasons which led to the emergence of care giving as an important aspect of family life (Bali, 1999). In India, home based care with family members as primary caregivers still remains as the first and often the only option for a majority of the elderly (Puri, 2004).

Indian families tend to view caring for the older family members as their obligation and sending them to long-term care institution is regarded as a violation of cultural norms. Caring for the elderly care recipients in India has traditionally been family based but care giving is increasingly more demanding with the fast-changing social system in contemporary India. Urbanization, changing role and status of women, decrease in family size, and small living space are all factors that may influence the care pattern of the elderly people and the demand on and coping ability of informal caregivers.

Of late the trend towards caring for chronically ill patients by family members at home is a common phenomenon because of the high costs of institutional care, dissatisfaction with the lack of personalized care in long term settings and the institutions' rejection of some clients as unsuitable due to the nature of their illness or the behaviors that result from the illnesses. The trend of deinstitutionalization places considerable burden for family caregivers who takes the sole responsibility in taking care of chronically ill patients especially in India.

In India, some amount of senility is expected, and elders are expected to pass on their chores to youngsters as they age. As they do not live independently, minor deterioration is not visible and a visit to a specialist is not even thought of. It would be downright rude to tell an elder, "I think you need to go to a memory clinic".

Awareness of dementia is very poor, and dementia is seen as either a slightly accelerated aging or (at the other extreme) mental illness (gone mad, paagal). It is socially unacceptable for children to point out memory lapses or mood swings or suggest a trip to a specialist. Diagnosis is therefore unlikely in early stages.

When the immediate family continue to treat the dementia patient as a person competent to handle decisions, and not understand that the person may be suffering memory lapses places a lot of stress on the dementia patient, and on the persons thus accused/ subjected to mood swings. Doctors rarely advise the family on the behavioral impact of dementia; they do not give tips on how to handle the problem with dignity and consideration for all concerned. Care giving is not recognized as a skill or a vocation/ profession. The family is supposed to take it all in its stride.

The person who ends up care giving keeps dipping more and more into his/ her time to perform required chores, but this is not recognized or appreciated by anyone. While judgmental people exist everywhere, our society encourages comments and judgmental/ critical comments, which the receiver is supposed to accept in all humility.

In India there are limited numbers of studies in the field of burden whereas it has been reported extensively in studies done abroad. Owing to diversity and difference in economical, social, cultural and family dynamics compared to western countries, researcher felt the need to explore management of dementia patients by caregivers from the social work perspective of Indian families.

Family burden has been extensively explored for illnesses like Schizophrenia, Dementia and Cancer by researchers. The cost families incur in terms of economic hardships, social isolation and psychological strain are referred to as family burden. Review of literature available suggest that family burden in mental and neurological diseases have some common characteristics such as the fact that several cognitive and behavioral symptoms may occur both in psychiatric disorders and dementia and these have been found to be strong predictors of anxiety and depression in patient's relatives because of the inability of the relatives' difficulty in understanding the meaning of some psychiatric and neurological symptoms. Relatives of patients with neurological or mental disorders tend to overestimate a patient's capacity to control symptoms and disabilities.

Data on the impact of care giving on caregivers' and their burden or satisfaction in India is limited. Moreover, existing published studies have mostly been based on small samples in some pockets of India or on different disease categories.

Lack of reliable data at the national level makes the awareness and working on dementia a difficult exercise. Hence, there is a rising concern to look into the caring of dementia patients, have systematic data on the impact of care giving on informal caregivers (family context) and gauge the impact of care giving to facilitate the planning of social and health support services and government policies.

This study would give much needed insights into care arrangements, challenges and satisfaction faced by the caregivers in caring of dementia patients. This study would also explore and understand various dimensions of care giving and coping strategies adapted by the caregivers of dementia patients in Indian context. No governmental effort has been seen to update data on the number of dementia cases in the country though the threat has been widening. Despite the prevalence, there is gross ignorance, and is often neglected in our country.

The western world has already prioritized this area of intervention, and actively taken initiatives in this direction. In Asia, Japan and Australia have already prioritized national level research work and action projects in the field of dementia and Alzheimer's, much research and field projects are needed in the Indian context. (Source: ADI, Access Economics study 2006)

These facts strongly suggest that there is a need for more research studies, to know possible interventions and strategies, to have insight about the disease and the psychosocial challenges it poses to families, society and the nation at large.

4.4 Caregivers Status – Indian Context:

According to the 'Indian Dementia Report 2010', released on 21st Sept, lack of trained caregivers remains the biggest problem for treating dementia patients in the country.

The care is almost entirely given at home. Most of the primary caregivers are women (75%), and the vast majority of them are co-residents (98%). Several studies conducted in India have revealed negative impact of dementia -- physical, psychological and economic -- on caregivers. Prolonged stress and physical demands of care giving, coupled with biological vulnerabilities of older caregivers, may increase their risk for serious health complications.

According to the World Alzheimer's report, 40%-75% caregivers had significant psychological illness, resulting from the nature of their work and 15%-32% had clinically diagnosable major depression. Caring is a full-time job -- an average of around eight hours per day for a relative with moderate to severe dementia. In India, over 50% of people with dementia require caregivers to take care of them. If dementia care were a country, it would be the world's 18th largest economy. If it were a company, it would be the world's largest. (Source Indian Dementia Report 2010)

To summarize Care giving has many outcomes and impact on the care givers, however, one of the outcomes of care giving is caregiver stress and burden. Several questions come to our mind when we think of care giving and caregiver burden in family context. Who are the primary caregivers of the older persons in Indian family context? Which factors are associated with caregiver stress or lack of it? What measures are used to assess these variables and so on. Studies show that caregiver stress is reported to be associated with such variables as family income, age of caregiver, kinship relationship, caregiver’s attitude and certain attributes of the care recipient i.e. the elderly (Jamuna, 1997).

5. Management of Dementia Patient - Social Work Perspective

Social work is a social science involving the application of social theory and research methods to study and improve the lives of people, groups and societies. It incorporates and uses other social sciences as a means to improve the human condition and positively change society’s response to chronic problems. Social Work is a profession committed to the pursuit of social justice, to the enhancement of the quality of life and to the development of the full potential of each individual, group and community in the society, especially focusing the poorest of the poor and sick.

Further, the profession of social work is dedicated to a set of core values. These values include social justice, service, dignity and worth of the person, importance of human relationships and integrity. These form the foundation of social work. This study being in the health setting and also a part of mental health, it becomes imperative to understand the social work in health care.

Social work in health care helps these people who are dealing with a medical problem to function within their situation. Social workers work with clients and their families to provide services necessary to make their lives easier for the duration of client's illness and to help them deal with consequences directly related to that specific illness. The main concern of the social worker is to assist the client and the client's family in coping with their health care situation. Medical social work being subpart of social work, they typically work in hospital, skilled nursing facility or hospice. They work with patients and their families in need of psychosocial help. Medical social workers assess the psychosocial functioning of patients and families and intervene as necessary. Intervention may include connecting patients and families to necessary resources and supports available in the community; providing psychotherapy, supportive counseling or grief counseling; or helping patient to expand and strengthen their network of social supports.

This becomes challenging when clients contract or are diagnosed with a chronic /life threatening disease. Social workers help them assess these problems, identify their immediate and long term needs. Since dementia being the most debilitating disease of the elderly and having immediate effect on the family, the social workers presence to deal with these patients and their family members becomes inevitable.

CHAPTER -2

REVIEW OF RELATED LITERATURE

It is when you give of yourself that you truly give

Khalil Gibran, The Prophet

This chapter presents narrative review of studies related to family care giving and dementia. Empirical studies which are published are, reviewed to enable further understanding of challenges and satisfaction experienced by Family caregivers while managing dementia patients and interventions to help these caregivers.

To have a wider search of literature and conceptual clarity first studies on caregivers (generic) were looked into. Then the focus was shifted to dementia care giving studies. A literature search was carried out using the databases of Google Scholar and Pub Med/ Psyc INFO. Journals on Gerontology both Indian and International were extensively referred. PhD thesis and studies done for academic purposes were looked into, libraries of The M S University of Baroda, Tata Institute of Social Sciences (TISS) and National Institute for Mental Health and Neuro Sciences (NIMHANS) were searched. For Indian Studies written permissions were sought from scholars, researchers and Institutes of repute to get the study material and researches carried out by them.

Search terms included ‘dementia’, ‘management of dementia’, ‘Social Work and care giving’ ‘family care giving’, ‘family caregivers’, ‘burden’, ‘stress’, ‘caregivers satisfaction,’ ‘rewards of Care giving’ and ‘care giving in India’. The reference lists of identified papers were also searched. The title and abstracts were reviewed. Papers are included if they are peer-reviewed, published in English and focused on family care giving issues for persons with dementia and other diseases. The researcher has attempted to look into studies at both National and International level along with one book review. At national level, studies purely related to dementia were less and hence studies on family caregivers of other chronic diseases are also reviewed. Following gives the idea of total number of studies, articles and books literature reviewed.

- **International Studies - 9**
- **National Studies – 11**
- **Articles – 2**
- **Books -1**

These studies/ articles are further covered under the specific themes/ section of this chapter as per the relevance. For the purpose of understanding, the chapter is divided into three sections such as:

1. Dementia and Family Caregivers (Arrangements, characteristics, primary caregivers)
2. Care giving Burden and Coping Mechanism by Family Caregivers
3. Caregiving Satisfaction and Well Being of Family Caregivers

1. Dementia and Family Caregivers (Arrangements, characteristics, primary caregivers):

Interest in the area arose during the 1960s and 1970s as a practical concern. During this time, gerontologists documented care giving during later life. There is a great amount of research and literature concerning the situation for family caregivers of persons with dementia. By the late 1970s and especially in the 1980s, research on care giving was rapidly increasing. While caregiving frequently focuses on tasks of activities of daily living, either instrumental activities of daily living (IADL) such as shopping and banking, and basic activities of daily living (ADL) such as going to the toilet, eating, personal mobility, and other activities necessary for survival, the emotional aspects received little attention. Yet it was recognized that it is this emotional element that distinguishes informal care from formal or paid caregiving.

Shultz (2004) defines the role of care giving as: “Care giving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting” As stated in the earlier chapter, family caregivers are a core part of health care and long-term care, in spite of that the significance of their role, and their own care-related strain and compromised health, is often overlooked. The challenges and pressures of family care giving are a reality of daily life. Today, family caregivers monitor chronic and sometimes acute medical conditions as well as provide long-term care at home. Hence it is important to recognize, respect, assess and address family caregivers' needs.

The stressors which affect the quality of care giving are work demands, availability of social support and health status of the caregiver (Jamuna and Ramamurthy, 1999). Studies shows that family members who provide care to persons with chronic or disabling conditions are themselves at risk. Emotional, physical and financial problems arise from the complexities and strains of caring for frail or disabled relatives, especially when the care is for a person with dementia. These burdens and health risks can impede the caregiver's ability to provide care, lead to higher health care costs, and affect their quality of life and those for whom they care.

1.1 Who gives care?

Care giving and support is not the sole responsibility of the family and others in the immediate arrangements of the person with dementia. It should also be a concern for communities, governments and society as a whole. However, because of lack of awareness or commitment the concern is not beyond the family. Nevertheless the support from government and society is crucial. These direct and indirect levels of care and their proximity to the person with dementia are illustrated in Figure no 5 in first chapter.

Family caregivers can be defined by the relationship (spouse, adult children, daughters- and sons-in-law, friends, neighbours), primacy (primary or secondary caregiver), living arrangements (co-resident with the care recipient or living separately) and care input (regular, occasional or routine). Family caregivers can be involved in providing care or in organizing care delivered by others, sometimes from a distance. Primary caregivers are persons, who spent most of the time with the person with dementia and secondary caregivers, are those family and friends who play a supplementary role to the care of a relative. (Gaugler et al. 2003). In the 10 / 66 Dementia Research Group population-based study in 11 sites in Latin America, China and India, women predominated as caregivers, except in rural China. In the care givers study of the elderly in rural families (not for dementia patients) around 64 %

of the caregivers were women, 25.7 % were wives, 23.3 % were sons followed by 22% daughters-in-law and 13% daughters and 8% were husbands. (Deviprasad & Indirarani 2007).

In India it is found that women are traditionally caregivers in Indian families. (Prakash, 1999)Women report greater levels of stress as they are often engaged in the care giving of two generations– rearing their own children and providing long term care to the elder relatives which results in great cost to their well-being both physical and psychological (Prakash, 1999; Hirst, 2005). Caregiver stress is reported to be high among daughters-in-law followed by spouse and daughter (Jamuna, 1997). Thus, there is a clear ‘feminization of caring’. On the other hand research on male caregivers shows their more instrumental approach to the role than women have i.e. there role is seen in context of providing help in the Instrumental activities of daily living e.g. Providing financial support, taking care of shopping of necessary items etc. For men the most common caregiver was the wife followed by daughter-in-law and in the case of women, it was mostly the daughter-in-law followed by the daughter (Prakash, 1999; Sharma, 2003).

1.2 Caregiving arrangements

As dementia is a progressive disease, typically the level of support increases as the disease progresses, starting with support for instrumental activities of daily living (household, financial and social activities) at the early stage and expanding to include personal care and eventually almost constant supervision during advanced stages. This support and care needed changes with the progression of the disease over time, depend on many factors such as the clinical profile (types and severity of cognitive impairments and behavioral and psychological symptoms, which may vary by subtype of dementia), the presence of comorbid physical and psychological problems, the custom and habits of the person with dementia, the person’s personality and relationships. Over and above this at home, family caregivers have other responsibilities along with multiple tasks of care giving. Thus, the role of caregiver may vary according to the impairments of person with dementia, which varies considerably from person to person. Dementia care is difficult and requires time, energy and, often, physical exertion from the caregiver. As the disease progresses slowly, the patient lives with the disease for minimum 3 to more than 8 years. Family members often provide care for many years with long durations and are under high levels of stress. Providing long hours of care without periods of relief, causes chronic fatigue and thus intensifies high level of stress, this is more so in the late stage. To enable the caregivers to continue in their role for as long as possible requires respite especially when physical input and the emotional impact increases.

Further, when a person is diagnosed with dementia, service providers for people with dementia often speak of family caregivers as second patient in the making. This draws attention to give equal priority to the needs of the primary caregiver who is a crucial resource in the long-term care arrangements for the person with dementia.

An epidemiological, study by Chandra, V et al (1998) conducted a community survey of a cohort of 5,126 individuals aged 55 years and older. The overall objectives of this Indo-US Cross-National Dementia Epidemiology Study were: (a) to determine the prevalence and incidence of, and risk factors for, Alzheimer's and other dementias in a defined Indian community (Ballabgarh), and (b) to compare these results with those found in a reference U.S. community (Monongahela Valley).

The cohort was screened by using Hindi cognitive and functional screening instruments, developed for and validated in this population. A total of 536 subjects (10.5%) of 5,126 total populations, who met operational criteria for cognitive and functional impairment and a random sample of 270 unimpaired control subjects, underwent standardized clinical assessment for dementia using the DSM-IV- the Clinical Dementia Rating Scale (CDR). It was found that overall prevalence rate for all dementias was 0.84% in the population aged 55 years and older with a CDR score of at least 0.5, and an overall prevalence rate of 1.36% in the population aged 65 years and older. While for Alzheimer’s (AD) the overall prevalence rate was 0.62% in the population aged 55+ and 1.07% in the population aged 65+. Greater age was associated significantly with higher prevalence of both AD and all dementias, but neither gender nor literacy was associated with prevalence.

The study concluded that in this population, the prevalence of AD and other dementias was low, increased with age, and was not associated with gender or literacy. Possible explanations include low overall life expectancy, short survival with the disease, and low age-specific incidence potentially due to differences in the underlying distribution of risk and protective factors compared with populations with higher prevalence. It is clear that there are regional differences in prevalence within India.

The study has not determined the cause of the differences i.e is it due incidences of dementia or due to survival or both. If prospective studies show age-specific incidence to be different across populations, this finding will promote the search for new risk and protective factors. Further implication will be that, as average life expectancy and standards of living will improve, the societal and public health burden of dementia will increase concurrently.

Yet another prevalence study by Shaji, Bose, & Varghese (2005) aimed to investigate the prevalence, psychosocial correlates and risk factors of various dementing disorders in an urban population in Kerala, southern India. The community chosen for the study was the Ernakulam constituency for the legislative assembly, which is a part of the city of Kochi (Cochin). The population aged 18 years and above was 183 977 according to the electoral list. The list of voters and the area map constituted the sampling frame. The Ernakulum constituency was divided into 178 parts, each of which has a population of 800-1000. For operational purposes, each part was designated as a cluster, and a cluster sampling technique was used. Thirty of 178 parts were randomly selected and in each a door-to-door survey was conducted to identify residents aged 65 years and above. The community survey was conducted by a group of six psychiatric social workers who were trained by a psychiatrist. They explained the purpose and procedures of the study to the family members and obtained their informed consent.

The study was conducted in three phases.

- During phase I, all identified people aged 65 years and above were screened with the vernacular adaptation of MMSE. The survey identified 2031 elderly people aged 65 years and above. Of these, 1934 people were screened with the vernacular adaptation of MMSE. In phase II, those who scored 23 or below on the MMSE had a detailed neuropsychological evaluation with CAMDEX Section B to confirm the impairment in cognitive function. For each individual a caregiver or relative was interviewed with CAMDEX Section H to confirm the history of deterioration in social and occupational functioning or activities of daily living. This was done by a clinical psychologist.

- In phase III, a psychiatrist visited the homes of participants whose impairments were confirmed by the CAMDEX Sections B and H for diagnostic evaluation according to DSM-IV criteria. Ten per cent of the negatively screened population were randomly selected and evaluated at each stage. Evaluation in phase III included a detailed medical history, physical and neurological examination. Necessary investigations were done to rule out conditions such as hypothyroidism, HIV infection, brain tumors and vitamin B_{12}deficiency.

Cases of dementia were categorized according to ICD-10 criteria. Age- and gender-specific prevalence rates of dementia, Alzheimer's disease and vascular dementia were calculated. The Alzheimer's disease group and the vascular dementia group were compared with control groups matched for age, gender and education and with one another on various socio-demographic and clinical parameters. Caregivers were asked whether the individual had a known history of high blood pressure, diabetes mellitus, cardiac disease, cancer, Parkinson's disease, Down's syndrome, head injury, fits or any psychiatric disorder. The control groups were selected by group matching of the cases with respect to age, gender and level of education. For this purpose the entire population was stratified according to these categories and the required number of controls was selected from each group at random.

Results indicate that the prevalence rate obtained from this urban study was lower than that found in an earlier rural study in which the prevalence of dementia in people aged 65 years and above was 44 per 1000 (Shaji et a 1996). Comparison of the prevalence rates of dementia in these rural and urban populations indicates that there is little variation in the prevalence of Alzheimer's disease (15.5 per 1000 in the urban population and 17 per 1000 in the rural population), but that the higher prevalence of vascular dementia contributes to the greater total prevalence in the rural community.

It was also found that people with Alzheimer's disease more often had an increased family history of dementia. Identification of hypertension as a risk factor for vascular dementia indicates the need for changes in lifestyle and better monitoring of blood pressure. In nut shell:

- The prevalence rate of dementia in people aged 65 years and above in this urban community was 33.6 per 1000.
- Alzheimer's disease was the most common cause of dementia, followed by vascular dementia.
- Identification of risk factors such as hypertension points towards some possible methods of intervention to reduce the total prevalence of dementing disorders in this community.

Overview of the Prevalence (Epidemiological) studies in India so far:

Sr. No	Study By	Place	Age Group	Prevalence Rate per 1000
1	Rajkumar et al 1996	Chennai	60 years & above	27
2	Rajkumar et al 1997	rural block of southern India	60 years & above	36
3	Shaji e al 1996	rural community in Kerala	60 years & above	44
4	Chandra et al 1998	Balabhgadh -rural	55 years & above	8.4
			65 years & above	13.6
5	Vas et al 2001	Mumbai Urban	65 years & above	18
6	Shaji et al 2005	Ernakulam urban Kerala	65 years & above	33.6

The overall prevalence rate of 33.6 per 1000 in this study is well within the range of prevalence rates reported from other studies conducted in India (Rajkumar and Kumar 1996; Shaji et al, 1996; Chandra et al, 1998; Vas et al, 2001). Prince (2000) reviewed seven published prevalence surveys from the developing world and reported that the prevalence of dementia ranged from 13 per 1000 to 53 per 1000 for all those aged 60 years and over, and from 17 per 1000 to 52 per 1000 for all those aged 65 years and over (Li et al, 1989; Zhang et al, 1990; Phanthumchinda et al, 1991; Hendrie et al, 1995; Rajkumar & Kumar,1996; Shaji et al, 1996; Chandra et al, 1998). In general, estimated rates for the Asian nations have been lower than rates for the USA and Europe (White 1992)

Similar to this study Rajkumar and Kumar (1996) reported a higher prevalence of dementia in the rural community than in urban settings. Shibayama et al (1986) also found higher prevalence rates of dementia in rural areas of Japan compared with urban areas. Differences in lifestyle, health awareness and healthcare delivery systems may be the factors contributing to this difference. Moreover, people in urban areas are better educated and more in touch with current events, and so perform better on cognitive testing. One of the consistent findings across studies is that the prevalence of dementia increases proportionately with age. This study confirmed the same finding.

Robinson et al (2001) examined the relationships between problematic behaviours and caregiving impact in 30 primary caregivers of persons with AD. He explored two things:

1. Relationship between frequency of problem behaviour and impact; and
2. The relationship between caregiver reactions to problem behaviours and impact from care giving.

A convenience sample of 30 persons caring for family members diagnosed with Alzheimer's disease and related dementia (ADRD) were interviewed in their homes. Persons caring for a family member diagnosed with AD were selected through caregiving programmes, chapters of the AD Association, home health agencies, church newsletters, and senior citizens centres.

The frequency of problem behaviour and the caregiver reaction was measured using The Revised Memory and Behaviour Problem Checklist (Teri et al. 1992). The impact from caregiving was operationalized using the Cost of Care Index developed by Kosberg and Cairl (1986). Results indicate that out of 20, significant associations were found for 11 subscales that measured the association between the frequency of problem behaviour in the patient and the impact from caregiving experienced by the caregiver. While, the association between caregiver's reaction to problem behaviours and impact from caregiving was even more significant as out of 20, 15 subscales were significant. Female caregivers experienced a greater reaction to disruptive and depressive behaviour when compared with male caregivers even though both genders reported similar frequencies of problem behaviours. Personal characteristics of the caregiver have been thought to impact family care giving. Female caregivers also had higher impact of caregiving in four of the six indicators when compared with men (restricted activity, decline in health, provoking nature of the care recipient, and total impact of care).

Thus, it can be concluded from the study that caregiver reaction to problem behaviours was more highly associated with impact from caregiving than the actual frequency of the behaviours. These findings have great implications for intervention programs. Caregivers, especially females, need to receive individualized, specific education/training on how to understand and manage disruptive and depressive behaviour in persons with AD. Caregiver knowledge and understanding about anger and frustration management may be important interventions for women.

Korean Family Caregivers' Perceptions of Care in Dementia Care Units a study by Myonghwa Park (2002) aimed to describe Korean family caregivers' perceptions of stress and satisfaction with care, their caregiving roles, their relationships with staff, and their involvement in care. The objectives of the study were: What are Korean family caregivers' perceptions of satisfaction with the care of patients with dementia provided by facilities? What are Korean family caregivers' perceptions of stress from their caregiving roles in the care of their patients with dementia in facilities? The study involved data collection from 10 long-term care facilities The facilities included 6 geriatric hospitals, 2 dementia care centers and 2 nursing homes. Primary family caregivers were defined as persons who took the chief responsibility for family caregiving.

Findings reveal that most family caregivers were daughters, sons, and daughters-in-law. It should be noted here that the percentage of sons in this study was considerably higher and that of daughters-in-law was lower compared to other studies with family caregivers in the community by Son (1998) (28.2%), and Lee (1999) (41.7%). Another notable finding was that a relatively higher percentage of female caregivers, especially daughters-in-law, having full time jobs. Over 85% of family caregivers had full time job. Family caregivers in this study reported moderately high feelings of captivity. Differences in family caregivers' stress were related to caregivers' relationships with patients. It was found that wives reported the highest feelings of loss and Daughters-in-law reported higher feelings of captivity than other family caregivers.

WC Chan, et al. (2004) explored the lived experience of caregivers of persons with dementia in Hong Kong, and their service needs. A qualitative study conducted over 4 months. The study utilized focus group discussions. Four focus group interviews, each group comprising 6 to 7 informal caregivers, were conducted. A total of 27 participants were recruited. With the participants' consent, interviews were audio taped and transcribed verbatim. Subjects selected were the informal caregivers, i.e. unpaid family members who offered a substantial amount of care for older persons with dementia. Reasons for non-participation included: caregiving responsibilities, domestic commitments, poor mobility, and long distances to travel. A topic guide consisting of broadly focused open-ended questions. In addition, socio-demographic data about the caregivers and care recipients were collected.

A topic guide consisting of broadly focused open-ended questions was designed based on the framework drawn up by Pearlin et al. This model divides caregiving experiences into 4 domains: background and contextual factors; stressors; mediators of stress; and outcomes. Socio-demographic data about the caregivers and care recipients were collected. Caregivers also completed a checklist of common experiences related to caregiving for persons with dementia that had been previously identified in literature. This was done on completion of the focus group interviews, so as to avoid bias from exposure to checklist questions.

Results indicate that among the 27 informal caregivers, 10 were spouses of care recipients (5 wives and 5 husbands), and 17 were their children (16 daughters and 1 son). Their ages ranged from 36 to 82 (median, 52) years. They provided care for their mothers (n = 15), fathers (n = 2), wives (n = 5), and husbands (n = 5) respectively.

The age of the care recipients ranged from 66 to 98 (median, 78) years. The female-to-male ratio for caregivers was 3.5:1, and for care recipients it was 2.9:1. Most of the caregivers had only a basic education. Three (11%) had received no formal education, 10 (37%) finished primary school, and 12 (44%) finished secondary school; only 2 (7%) had received tertiary education. About a third of carers did not disclose their incomes. Around half were recipients of the Comprehensive Social Security Assistance Scheme. The majority of the families earned HK$10,000 / month or less per household, which was lower than the median household income for Hong Kong families (HK$15,500 in the year 2004). Caregivers had provided daily care for their family members for mean (range) duration of 64 (12-168) months. More than half of them were residing with their care recipients and the remainder paid frequent visits. Five key themes around the personal experiences of carers of persons with dementia emerged from the focus group discussions.

1. **Confusion Regarding Diagnosis:** Although all caregivers agreed that their family members were suffering from a health condition, they had significantly diverse views about its nature. One carer insisted that his wife was suffering from schizophrenia while another coined a new Chinese terminology which literally means 'an illness of forgetfulness' to describe the problems that her father suffered. Their comments suggested a lack of information given to caregivers and confusion regarding the health problem. Especially for those who had no prior encounter or knowledge about mental health problems, the comments may be related to the lack of acceptance of mental illnesses and its associated stigma. Others, however, welcomed the diagnosis of dementia because they were relieved when the diagnoses were confirmed by doctors, rather than relying on their own opinion.

2. **Emotional Impact:** The emotional burden experienced by family members was the strongest theme that emerged from the focus groups. As shown in the checklist of caregiving experiences, 70% of the participants reported psychological distress and 56% reported disturbed mood. A wide array of negative emotional responses were identified, notably grief, sadness, anxiety, anger, guilt, blame, fear, and embarrassment. Nevertheless, several carers also reported the positive aspects of

caregiving, which included: companionship, adding meaning to life, and having opportunities to care for their close ones.

3. **Difficulty in coping with the care recipient's behaviours:** Caregivers gave a detailed account of various behavioral and psychological problems they encountered during caregiving of their family members. These comprised a wide range of symptoms but agitation, irritability, aggression, obstinacy, withdrawal, insomnia and abnormal perception were the most common.

4. **Provision of care recipient's daily care needs is demanding:** The functional deficits associated with dementia increased as the illness progressed. Most caregivers found it very demanding to help their family members with their activities of daily living. Provision of care 24 hours a day all year round constituted one of the major sources of burden.

5. **Conflicts among social roles:** Caregiving posed a significant strain on carers as it frequently clashed with other social roles. In the questionnaire, 37% of respondents indicated problems with their social life, 26% with their relationships with other family members, and 15% with their jobs. Some caregivers described major conflicts between their different social roles. For example, several were unable to have regular work because they had to attend to the care recipients almost round the clock. A carer used the term 'shattered family' to describe the crisis in relationships among family members. Lack of support from other family members, including the grownup children who usually lived separately from the persons with dementia was another significant problem.

The study concluded that **c**aregiving in dementia in Hong Kong is as demanding and challenging as reported in other developed communities. 'Confusion regarding diagnosis', 'Emotional impact', 'Difficulty in coping with the care recipient behaviors', 'Provision of care recipient's daily care needs is demanding', and 'Conflicts among social roles' were themes pervasive across every focus group. In addition, the needs of carers changed as the disease of their care recipients progressed. Most caregivers found it very demanding to help their family members with their activities of daily living. Provision of care 24 hours a day all year round constituted one of the major sources of burden.

Amit and Ravi et al (2004) studied the impact associated with caring for a person with dementia, at two centers Goa (rural/semi-urban) and Chennai (urban) by:

- Comparing economic and psychological status and perceived strain with those of co-residents of older persons from the control groups free of dementia (60 in each centre), with caregivers and co-residents of older persons with moderately severe depression (30 in each centre).
- Also comparing use of health services by the older people, and associated costs.

Findings reveal that in both centers care givers of people with dementia provided care for significantly longer time than did caregivers and co-residents of depressed person and controls. Most of the time was spent in communicating, supervising, and helping with eating and toileting. Caregiver strain was notably higher among caregivers of people with dementia. They were 16 times more likely to have a common mental disorder than co-residents of controls and twice as likely as co-residents of people with depression. Economic strain was indicated by the high proportion of dementia caregivers giving up work to care, coupled with the increased likelihood of high health care costs. This was explained by the frequency of people with dementia to use expensive private medicine rather than free government services.

This confirms that the Problem behaviour to be the most stressful aspect of caregiving (Coen et al. 1997, Payne & Caro 1997) and contributes to increased burden for caregivers. Problem behaviours can have major impact on caregivers. How caregivers react to these behaviours may determine the total impact experienced from care giving. The following study emphasizes the impact of problematic behaviour.

Dias A, et al (2008) developed and evaluated the effectiveness of a home based intervention in reducing caregiver burden, promoting caregiver mental health and reducing behavioral problems in elderly persons with dementia. This was a randomized controlled trial in which the person with dementia-caregiver dyad was randomly allocated either to receive the intervention immediately or to a waiting list group which received the intervention after 6 months. It was carried out in communities based in two talukas (administrative blocks) in Goa, India. Mild to moderate cases with dementia (diagnosed using the DSM IV criteria and graded using the Clinical Dementia Rating scale) and their caregivers were included in the trial. Community based intervention provided by a team consisting of Home Care Advisors who were supervised by a counselor and a psychiatrist, focusing on supporting the caregiver through information on dementia, guidance on behaviour management, a single psychiatric assessment and psychotropic medication if needed. The caregiver mental health was measured by using General Health Questionnaire, caregiver burden by Zarit Burden Score, distress due to behavioral disturbances by using Neuropsychiatric Inventory (NPI-D), behavioral problems in the subject by using Neuropsychiatric Inventory (NPI-S) and activities of daily living in the elder with dementia by using Everyday Abilities Scale for India (EASI). The study concluded that Home based support for caregivers of persons with dementia, which emphasizes the use of locally available, low cost human resources, is feasible, acceptable and leads to significant improvements in caregiver mental health and burden of caring.

The qualitative study conducted at Engandiyur Panchayath of Thrissur District, in Kerala, India by Shaji, George, Prince and Jacob (2009) aims to examine the prevalence of Behavioral and Psychological Symptoms of Dementia (BPSD) in a community sample of patients with dementia and its impact on the caregivers. Sample consisted of 29 cases that were assigned DSM IV diagnosis of dementia and were rated as having dementia of mild to moderate severity as per clinical Dementia Rating (CDR). Cases of dementia were identified using a novel case identification method; this method makes use of trained women health workers to identify potential cases of dementia in the community. Tools used in the study were Clinical Dementia Rating, BEHAVE – AD, Questionnaire (GHQ-12) as a measure of psychiatric morbidity, Zarit Burden Interview (ZBI) as a measure of caregiver strain.

Findings reveal that: Behavioral disturbances were extremely common. Paranoid and delusional symptoms along with activity disturbances were the most frequently identified. Hallucinations (both visual and auditory) were reported to be present in 12 (41.3%) patients. Further it was also found that majority of caregivers were young women, often daughters-in-law of patients affected by dementia. The mean age of the sample was 78.3 years. There were 23(79.3%) women in the sample. The principal sources of caregiver strain were Behavioral problems associated with the dementia syndrome, and incontinence. Strain was aggravated by the lack of supportive response by local health services, and by lack of support and, sometimes, criticism from other family members. Family conflict was commonly encountered. The majority of caregivers experienced significant deterioration in their mental health. Symptoms like delusional thinking, activity disturbances and aggressiveness were more likely than other symptoms to be rated as troublesome to the caregiver

The study concluded that there is every reason to believe that BPSD is present across cultures in the developed as well as developing regions of the world. But, the prevailing low levels of public awareness about dementia in India and other developing regions of the world these symptoms are stressful for the co-resident caregivers, who lack support and guidance from the health care delivery system. To be effective, dementia care services in developing countries need to focus on management of BPSD at home. Development of a low cost, effective and sustainable dementia care service should be given due importance by the policy makers in the developing world.

International study by Kaufman & Kosberg (2010) examined the experiences of African American and White family caregivers of older persons with dementia who live in rural communities. The Objective of the study was to find out whether there were relations between informal social support, caregiver burden, and life satisfaction for study participants. The study used a cross-sectional survey design. Data were gathered from 141 rural-dwelling dementia caregivers (52% White, 48% African American) through structured telephone interviews conducted by highly trained interviewers. All survey respondents were self-described primary family caregivers who provided at least 10 hr a week of face-to-face assistance to meet the physical and/or emotional care needs of the care recipients. All respondents had to be cognitively intact, have access to a telephone, and be conversant in English. Caregiver and Care recipient socio demographic details were obtained.

Findings revealed that Women comprised 85% (n = 120) of the total sample. Most participants (60%, n = 85) were married, and most (61%, n = 86) were not employed outside of the home. The largest subgroup of caregivers in the sample were adult children (59%); 10% of the sample were spouses. Most participants (82%, n = 115) had at least a high school education, most reported (73%, n = 103) family incomes of

$40,000 a year or less, and half (50%, n = 71) of the sample reported some degree of economic difficulty meeting basic needs. The most important finding to be noted in this study is that no relations were found between social support and caregiver burden. This finding is contrary to the findings of other caregiving studies in which informal social support has been found to mediate the stress and burden experienced by caregivers. Caregiver stress, which we did not measure in this study, and burden, although likely related, are qualitatively different psychological states. It may be that burden, as an emotion, may not be responsive to the types of social support provided by informal social networks. The finding that the female caregivers in the study reported higher levels of social support than their male counterparts is consistent with similar findings in other caregiver research studies.

Findings reveal that caregivers reported providing an average of 50 hr of care a week to their older dementia care recipients. For the total sample, respondents reported moderately high scores on each of the four dimensions of social support (the availability of concrete help and material assistance from social network members); for appraisal (the availability of persons to obtain advice from and with whom to discuss problems); for belonging (the availability persons to talk to or socialize with); and for self-esteem (receipt of positive regard and self-esteem from others).

Further findings also support the popular perception that rural communities contain active and supportive social networks and have the potential of helping persons who live in these communities so that they can deal better with some of the challenges. More specifically, in this study, two dimensions of social support—the availability of having persons with whom to talk or to socialize, and the receipt of feelings of positive regard and self-esteem from others—appear to have a mediating effect upon our respondents' feelings of life satisfaction. This finding has several potential practice implications for social workers working with dementia caregivers in rural communities. It is important that when working with caregivers who live in rural areas, social workers not automatically assume that such caregivers are recipients of high levels of informal social support from their families, friends, and neighbors. Social workers should consider the extent and the nature of the caregivers' network relations, and to identify the types of social support that they actually receive from network members.

2. Care giving Burden and Coping Mechanism:

The two most common words seen with care giving are ‘Burden’ and ‘Coping’. The term ‘burden’ is a common English word, which has become quite popular in psychiatry with de-institutionalization. There are some minor differences in the way; the term has been defined by different investigators. According to Platt (1985), “burden refers to the presence of problems difficulties or adverse events that affect the lives of psychiatric patients.” While, Braithwaite (1990) defined caregiving burden as “distress arising from dealing with the Dependant’s physical dependence and mental incapacity and over the effects of caregiving on one’s life”.

Similarly, “Coping’, in general, refers to a person’s cognitive and behavioral response to a stressful situation. Lazarus and Folkman (1985) have defined coping as “coping refers to the constantly changing thoughts and behaviours that people use in order to manage stressful situations. “Ways of both patients and relatives, and depend on relatives’ appraisal of their patients’ situation.

Braithwaite (1990) proposed that caregiving burden is very much a subjective phenomenon and that the carer’s perception of their situation is the most reliable predictor of the impact of caregiving. Mediating factors include the carer’s attitude to caregiving; their preparedness for role; the nature of their relationship with the dependant, and the availability of formal and informal support. Caregiving burden may be at its most acute when caregiving does not follow its desired path; when it does not make things better, and when it accompanies losses rather than gains in the well-being of the dependant, which makes her model of caregiving burden highly relevant for dementia care. Three variables were suggested, the expectation being that if the level of demand or workload is great, personal, social and material resources are few and the crises of decline are present, care giving burden will be extreme:

1. 'Level of demand and workload': the activities in which carers engage and the responsibilities they accept in order to promote the physical well-being of their dependant and preserve their mental health and quality of life.

2. ‘Availability of personal, social or material resources’: the coping style of the carer; their personality; health, and access to support from family or services can help sustain the carer.

3. ‘Crises of decline’: carers perceiving degeneration; the unpredictability of symptoms; time constraints and competing demands; interpersonal difficulties between the carer and dependant and others, and a lack of choices in care can undermine the carer.

Other studies have shown that problem behaviours can have major impact on caregivers. It has been reported to be the most stressful aspect of caregiving (Coen et al. 1997, Payne & Caro 1997) and contributes to increased burden for caregivers.

Thus, caregiver burden is one of the most studied topics in gerontological literature. The burden upon caregivers with responsibility for a mentally ill relative living at home was first acknowledged by Grad and Sain bury in the early 1960s. Since then, burden has been a central concept in family care giving research and conceptualized in several ways. However, in India, few studies have attempted to directly determine the relationship between coping mechanisms and burden; in the West, studies have found that improved coping in family members can decrease the perceived burden. Thus, Caring for a person with dementia can have a negative effect on the caregiver’s psychological (Pinquart M, Sorensen 2003, 2006) and physical health (Vitaliano et al 003), life expectancy (Schulz et al 1999), quality of life and economic security. The disease can have profound and often adverse impacts on family dynamics and role functioning.

Jayakumar, Jagadheesan and Verma (2002) compared burden of care between the caregivers of patients with OCD and schizophrenia. A cross-sectional study conducted at the OPD. A sample of 30 OCD and 41 schizophrenia patients’ caregivers. Caregiver's burden was assessed with burden assessment schedule (BAS) (Thara et al., 1998) The findings reveal that Caregivers of patients with OCD experienced a high degree of burden in spouse-related areas. The key relatives in OCD group often encountered problems such as poor support from spouse in Family responsibilities, inadequate satisfaction of emotional and sexual needs, and deteriorated marital relationship. Impairment in caregiver's routines such as time to look after one's health, sleep, and time for relaxation. Caregivers of both OCD and schizophrenia group had similar level of financial burden.

O’Donovan (2004) investigated the phenomenon of dementia caregiving burden and breakdown in community caregiving situations. 109 care givers formed the study sample. The sample comprised mostly adult children 54.4% and spouses 38.9%. Majority of them were female 78.9%. Most care givers had been providing care for more than 3 years (46.6%), and 18 (20%) of these had been care givers for more than 6 years, 80% of them caring for moderately to severely demented dependants.

Impact on health: The majority of care givers (54.4%) were providing care in the face of disability, illness or disease; only (44.9%) thought themselves to be in good health. (22.5%) carers were suffering from non-life threatening conditions, e.g. chest infection, and (2.2%) had a diagnosed life threatening illness, e.g. cardiovascular disease. Depression in carers was associated with higher levels of caregiving burden.

Relationship: The majority of carers reported deterioration in the quality of their relationship with their dependant right from the onset of illness and due to night-time wandering, irritability and depression. This increased care giving burden exponentially.

Coping strategies used by caregivers: The caregivers in this study used a range of coping strategies which were positive. Carers, for the most part, had become highly skilled in providing person-centered care for their dependants, often without professional guidance. Many used recognized therapeutic techniques, such as reassuring the dependant that everything is all right (n=13); prompting the dependant in order to retain self-care skills (n=7); being patient (n=7); walking away from the dependant when angry (n=5); keeping to a daily routine (n=5); talking through/explaining caring procedures (n=5); engaging the dependant in reminiscence (n=5) etc, which could be termed ‘direct action’ strategies, aimed at preventing stressful situations from occurring. The power of information as a coping resource was evident in the 9 statements relating to the benefits of talking with other carers as role models; 4 on the benefits of internet/chat rooms; 3 on the benefits of reading about the illness and coping; 3 on the benefits of talking to a doctor, and 3 on the benefits of individual counselling. Such strategies are termed as ‘cognitive strategies’, as they aim to create a different perception of the stressful situation. Similarly, strategies such as ensuring social contact with friends (n=11) or taking personal time to read novels/listen to music (n=8) highlighted the importance of carers taking ‘time out’ from the stressful care giving environment for themselves. Those strategies used which concerned ‘reframing the meaning of events/problems’, such as remembering it is not the dependant’s fault (n=6), accepting symptoms as part of the illness (n=4), and looking beyond the illness to the person (n=3), demonstrated the importance of carers perceiving their efforts as meaningful. Similarly, responses such as trying to predict/avoid problems (n=5) and gradually learning to cope (n=5) demonstrated the importance of carers ‘developing a sense of competence and mastery’. It is worrying that 8 carers (11.3%) stated that they were unable to cope with caregiving and 4 (5.6%) stated that they felt ill equipped to provide care for their dependant, having no specific caregiving strategies. Furthermore, 46 of 421 statements related to inappropriate caring/coping strategies used, such as colluding with confusion (n=4), fighting with the dependant during personal care (n=4), shouting at the dependant (n=4), and using alcohol or smoking as a means of coping (n=3). Carers who perceive they are unable to cope or who engage in negative care are more likely to be near to breakdown in their caregiving situation.

A study by Creado, Parkar, Kamath (2006) aimed to evaluate the burden and coping of primary caregivers of patients with chronic schizophrenia living in the community. Specific objectives were to assess the burden of illness and coping mechanisms of the primary caregiver. The relation between the level of functioning in patients, the coping styles used by caregivers and their perceived burden of illness. The study design is Clinical, instrument-rated and cross sectional. A sample of 100 primary caregivers regularly accompanying patients diagnosed as having chronic schizophrenia as per the DSM criteria and who attend the follow-up OPD was randomly selected. The primary caregiver was identified as an adult relative living with a patient, in the same environment, for at least 12 months and was involved directly in giving care to the patient and most supportive either emotionally or financially, i.e. felt most responsible for the patient. Tools consisted of a semi-structured interview covering the socio demographic profile, details of illness and functioning of the patients as defined by the DSM criteria for schizophrenia. Patients were assessed on the Global Assessment of Functioning (GAF) scale while caregivers were administered the Burden Assessment Schedule (BAS) and Mechanisms of Coping (MOC) scale.

Findings reveal that Fatalism and problem-solving were the two most preferred ways of coping. Problem-focused coping, i.e. problem-solving and expressive-action decreased the burden of caregivers, while emotion-focused coping, i.e. fatalism and passivity, increased it. As the level of functioning of the patient decreased, the significance with which the coping mechanisms influenced the burden, increased. The use of problem-solving coping by caregivers showed a significant correlation with higher level of functioning in patient. Among caregivers, about two-thirds were either parents or spouses, over 35 years old. 61% were women and approximately 50% of the caregivers were unemployed, daughter-in-law and husbands.

Gupta, Nancy & Pillai (2007) explored the influences of selected social and psychological factors that are associated with perceived caregiver burden in a sample of 263 primary caregivers of the elderly in Allahabad City in northern India. The multistage probability sampling method was used to generate a sample of primary caregivers in the city of Allahabad.

In this study, the term caregiver refers to a man or woman aged 18 or older who takes care of a parent or parent-in-law, grandparent, or relative who is aged 60 or older and has lived in a joint household with the recipient of elder care for more than a year. Among these caregivers, the primary caregiver is the one who self identifies as the person who provides at least 4 hours of care per day and assists the recipient of care with at least one activity of daily living (ADL) or two instrumental activities of daily living (IADLs). Along with the structured face to face interview, perceived care giver burden was adapted from Stommel, Given and Given. The dependent variable was perceived caregiver burden and three independent variables were gender of the caregiver, adherence to Asian cultural norms, and role overload.

The results indicate that although male caregivers' perceived burden depends only on the size of the role overload, female caregivers' perceived burden depends on the interrelationship between the size of the role overload and adherence to Asian cultural norms. Implications of the findings for social work are discussed. The results suggest that there are gender differences in the social processes that contribute to perceived caregiver burden. Even though it is generally believed that sons are expected to be primary caregivers of the elderly in India, a high proportion of the primary caregivers in the study were female. Social workers may offer courses and facilitate support groups that provide guidance and information on the efficient division of care giving tasks and household chores and that teach caregivers how to manage their time and establish priorities.

Ganguly, Prof. Chadda, Dr. Singh (2009) studied Socio Cultural Perspectives of Care Givers in Burden Coping Behavior in Bipolar Disorder and Schizophrenia Cases**.** This study assessed the qualitative dimension of care giving and burden coping strategy by doing Focus Group Discussion (FGD). Thereafter appropriate educational interventions were designed to help improve quality of coping strategy and reduce the burden of the care givers. The researchers have presented qualitative dimensions of care giver-patient relationship, coping of burden by care giver and various subtle hints adopted as strategy to deal with the issue of coping of burden while giving care to patients as well as ways and means to defend self esteem under stressful situation.

Focus group discussions were primarily conducted to elicit the nature of burden, coping strategies and problems faced by the caregivers in day to day interaction with the patients and how they found out solutions to such problems.

The results showed that caregivers generally felt that the society does not sympathize and they lack in understanding of mental patients. They are often unappreciated, blamed and misunderstood by the general public and such attitude makes the situation more complicated as the backlash of patients anger is felt by the care givers.

Ten FGDs and twenty two intervention sessions brought out, how efficiently the care givers (the spouses /children /parents) evolved in the process of care giving and had positive bearing as well. The process of intervention in particular was done in the presence of the patients. The study helped assess the burden and coping strategies used by caregivers of patients with schizophrenia and bipolar affective disorder (BPAD) in a prospective design. While carrying out the study different psycho social issues came up regarding care giving and strategies to cope up with the burden of care giving.

David Karp in his “Mental Illness, Care giving, and Emotion Management” has explained in great detail about care giving and emotion management in mental illness. Based on 50 odd in-depth interviews, his paper considered how caregivers to a spouse, parent, child, or sibling suffering from depression, manic-depression, or schizophrenia manage their emotions over time. Four interpretive junctures in the caregiver-patient relationship are identified. Before diagnosis, respondents experience emotional anomie. Diagnosis provides a medical frame that provokes feelings of hope, compassion, and sympathy. In the present situation the intervention sessions raised hope and confidence of the care givers, as their patients were not only diagnosed but also supported through different sessions.

Realization that mental illness may be a permanent condition ushers in the more negative emotions of anger and resentment. Caregivers’ eventual recognition that they cannot control their family member’s illness allows them to decrease involvement without guilt. Decreased involvement and no guilt feeling of the care giver were not allowed to creep in by constant boosters of different types (mainly moral) by the research team. Karp's thesis is that the moral boundaries of care giving necessarily shift as the mental illness emerges over time, and that it is imperative to balance the needs of the mentally ill person with the needs of those who provide care and support. Karp reminds readers of the 4 C's: (1) I did not cause it, (2) I cannot cure it, (3) I cannot control it, (4) all I can do is cope with it. The FGDs were replete with such coping strategy and as a result the intervention running over twenty sessions and adherence to the suggestions by the care givers yielded positive result. And even those who were not so optimistic about the whole process were seen to be changing in their thought process.

A cross sectional study of a long term project by Jathanna, Latha, et al (2010) involves face-to-face interview with family caregivers of patients with diagnosed cases of dementia. Participants willing were recruited through convenient sampling from psychiatry outpatient clinics from three hospitals, one university hospital, a district hospital and a private centre which runs a “memory clinic” once a week. Most of the clients were seen at their respective homes. The study comprised of 125 informal caregivers.

In this study reports on brief measure of coping reactions, based on the COPE inventory are used. The Brief COPE includes only 28 items, which measure 14 conceptually differentiable coping reactions. Some of these reactions are known to be generally adaptive; others are known to be problematic. The Brief COPE thus provides researchers a way to assess potentially important coping responses quickly. Caregiver Burden Scale, a self-administered 22-item questionnaire with a five-item response set ranging from “never” to “nearly always” is also used. The numbers for the responses are added to obtain the total score, with higher scores indicating greater caregiver distress. (0 to 20 = little or no burden; 21 to 40 = mild to moderate burden; 41 to 60 = moderate to severe burden; 61 to 88 = severe burden.) For the analyses SPSS package (version 11.5) was used. Descriptive statistics is used for continuous variables for the demographic data. For data analysis cross tabs and paired t tests were done for correlating burden with the coping methods employed, selected patient related variables & selected care giver related variables.

Results indicate that 54.4% (68) of the persons with dementia were males and 45.6% (57) were females. Most of the patients were from the age group of 71 to 80 years (35.2%) followed by age group of 61-70 years (32.8%). 16.8% (21) of the them were from the age group of 51 to 60 years and 13.6 % (17) were above 80 years of age. While, most of the caregivers i.e., 59.2% (74) were females and 40.8% (51) were males. 44 (35.2%) care givers were of 36 to 50 years, and least care givers were of 71 – 80 years of age.

Further, Out of total sample of 125 care givers 43.3% (54) of them experienced severe burden, 28% (35) moderated to severe burden, 24% (30) mild to moderate burden and only 4.8% (6) had little or no burden. Each dimension of coping strategies was correlated with the burden experienced by the care givers. Test of significance shows positive reframing, use of emotional support, venting, behavioral disengagement and self blame was found to be significant when correlated with burden experienced by the informal care giver.

- 12 care givers adapted an active coping strategy, eight (66.6%) out of them reported to experience severe burden when compared to care givers who adapted this method more often. That is 12 out of 32 care givers experienced severe burden (37.5%).

- Out of 19 care givers who less frequently planned for their care giving role 11 (57.89%) have experienced severe burden. And 12 out of 43 (27.9%) care givers who frequently planned for care giving role have reported to have experienced severe burden. This is less when compared to the care givers who did not plan for care giving.
- Only seven care givers reported to adapt Positive reframing strategies and out of this one care giver experienced severe burden.
- Other strategies reported by the caregivers were:
    - Humor as coping strategy
    - Religion
    - Using Emotional Support strategy
    - Using instrumental support strategy
    - Self distraction strategy
    - Denial strategy
    - Venting strategy
    - Substance use as coping strategy.
    - Behavioral disengagement
    - Self blame

The study concluded that burden was related to patient's behavioral problems, gender, family type and the years of care giving. Principal component analysis of Brief Cope revealed 6 major dimensions: acceptance, humor, religion, substance use, behavioral disengagement and self blame as significant coping skills. Care giving was associated with more psychological complaints and a poor quality of life both physical and psychological. Self blame, behavioral disengagement, venting & emotional support emerged as an important variable as the care giver relation differ in the kind of care giving and care giving burden.

3 Satisfaction of Care giving and Well being of caregivers:

Folk man and Lazarus (1985), in the transactional model of stress has explained that the stress experienced by an individual is determined by the way an individual perceives situations in relation to his/her own available resources, the circumstances in person's life is per say is not stress provoking otherwise. i.e. stress is inversely proportionate to the ability of an individual to respond. Nolan et al. (1998) extended this model to cover coping and rewards of care giving. The individual selects a coping response or resource to deal with the threat, harm or challenge. If no appropriate response can be made, stress is likely to occur. If the threat, harm or challenge is met, it implies coping in successful and if it remains as it is, results into reduced morale, loss of control and deterioration in physical health. This helps explain why individuals react differently to similar caregiving events, e.g. some caregivers cope successfully with the onset of incontinence whilst others do not. Further they derived that rewards and satisfactions are associated with:

- Improved caregiver well-being
- An increased commitment to the caregiving relationship
- Reduced likelihood of institutionalization of the patient
- Perception of the patient as a valued person
- Evidence of a good prior relationship with the patient
- A more positive attitude about the future, and
- Successful coping.

It is often thought that large intergenerational families in traditional societies cope well with dementia and are relatively immune from caregiver strain. However, the pilot studies of the 10 / 66 Dementia Research Group in 25 countries in Africa, Latin

America, China and India revealed levels of caregiver strain as high as those typically seen in European and North American studies.

Linda & Lisa (1986) examined the well-being of family caregivers of older memory-impaired adults in four dimensions: physical health, mental health, financial resources, and social participation, thus assessing impact of care giving. Data was obtained from a large, heterogeneous sample of family members caring for memory-impaired older adults. Caregiver and patient characteristics were examined as correlates of well-being, providing information about the personal circumstances that mediate the impact of caregiving and the sensitivity of the well-being measures to variations in the caregiving context.

The sampling frame for this research consisted list of Family Support Program. Caregivers known to FSP were identified from variety of sources including a media campaign; contacts with community physicians, social service agencies, and nursing homes; health fairs, and other outreach activities. Survey instruments were mailed to all persons on the FSP mailing list who were currently providing care to a memory impaired older adult. The final sample consisted of 510 family caregivers. The survey included multiple indicators for four well-being dimensions.

- Physical health was measured by two indicators: number of physicians visits in the past 6 months and self-rated health (i.e., as poor, fair, good, or excellent).
- Mental health was measured using four indicators: a checklist of psychiatric symptoms, a measure of affect, a single-item measure of life satisfaction.
- Financial resources were measured by two indicators: household income, a multi-item scale measuring respondents' subjective assessments of their economic well-being
- The final well-being dimension, social participation, also was measured using both objective and subjective indicators.

Findings reveal that caregiver burden is experienced primarily in the areas of mental health and social participation. Overall, spouse caregivers exhibit lower levels of well-being in all four dimensions than adult child caregivers or, especially, other relatives. Findings indicated that three of the four dimensions of well-being had at least one indicator significantly related to patient living arrangements. Patient illness characteristics were minimally related to caregiver well-being.

The study concluded that care giving has different effects upon well-being, depending upon the characteristics of the caregiving context and the resources available to the caregivers. Many personal and situational characteristics may be related to well-being. The relationship between patient and caregiver was coded into three categories: (1) spouse caregivers (54%), (2) adult child caregivers (32%), and (3) other relatives (e.g., siblings, grandchildren) (14%), and caregiving was associated with lower well-being when the patient was a close relative. Patient living arrangements also was coded into three categories: (1) patient lived with the caregiver (53%), (2) patient lived in a nursing home (34%), and (3) patient lived with someone else (13%), it was found that caregiving had the greatest impact upon those caregivers who lived with their patients and presumably had full-time or nearly full-time care giving responsibilities. Perceived need for more social support from friends and family was measured by a single-item question. 59% of the sample expressed the need for more social support and 41% indicated that they were receiving sufficient support from friends and relatives. It was established that the relationship between the patient and caregiver is one important aspect of the caregiving context. Overall, spouse caregivers exhibit lower levels of well-being in all four dimensions than adult child caregivers or, especially, other relatives.

Resources available to the caregiver, rather than the condition of the patient, that most directly affect caregiver well-being. From public health and practice perspectives, these findings reiterate the conclusions of previous research that caregivers are an at-risk population and are especially vulnerable to emotional discomfort. Beyond that, however, efforts are needed to strengthen the social networks of caregivers as well. Given the perceived need for additional assistance reported by this sample, the alternative may well be serious family conflict or estrangement.

Family functioning in the caregivers of patients with dementia was studied by Heru, Iqbal, and Ryan (2002). The study examined family functioning, caregiver burden and reward and quality of life in 38 family members caring for a relative with dementia. The marital relationship has been suggested as a meditational model through which variables influence the caregiver and contribute to the experience of burden or reward. Caregivers of out-patients with dementia completed self report questionnaires. 63% of caregivers were female with a mean age of 62 years. Patient mean age was 73 years. The average number of caregiving years was 3.1.and most of caregivers were spouses (61%) than children (29%) or other relatives (11%). Despite the fact that caregivers reported that their relatives were moderately disabled, they perceived more reward than burden. Caregivers who reported poor family functioning had higher ratings of strain and burden. Family functioning in these caregivers was poorest in the dimensions of affective responsiveness, problem solving and communication but it was also impaired in roles and affective involvement.

Some comments made by the caregivers were; ‘Feeling needed and responsible’, ‘Feeling good inside, doing for someone what you want for yourself and knowing I’ve done my best’, ‘Being able to help’, ‘To brighten her days’, ‘I know he is being cared for the way he is used to’ and ‘I feel that she is loved and not alone.’

The study concluded that although caregiving is undervalued by society, it can be personally rewarding. It is important to look for factors that will enhance satisfaction and reward. These can be identified at the initial family assessment and sources of satisfaction and reward can be sustained as part of the family treatment. There has been little prior research on the rewards of care giving and this is an area worthy of future exploration. Secondly, If caregiving can be carried out without significantly affecting quality of life, caregiving can be perceived as more rewarding than burdensome.

Stanley, Shwetha (2006) assessed the caregivers of patients with schizophrenia before and after psychosocial intervention with regard to Family burden & Quality of life. A quasi-experimental study since no control group has been deployed. A sample consisted of 30 cases at community based care center, Gunaseelam, TN

This study aims at comparative pre and post intervention analysis to determine the extent of change in psychiatric symptomatology in schizophrenic patients attending a community based rehabilitation programme and the family burden and perceived quality of life of their caregivers. An integrated intervention package comprising of pharmacotherapy, psychosocial therapies and spiritual therapy was provided to the patients and their caregivers. Instruments to assess the psychiatric status of the patients as well as family burden and quality of life of their caregivers were administered.

Self-prepared interview schedule was administered to elicit socio-demographic data and clinical particulars. All instruments were administered twice; first at the time of admission and later after intervention during the first follow up. Results indicate that majority of the caregivers were female (53.3%), married (70%) and their age ranged from 23 to 75 years age of 54.9 years. Their mean income per month was Rupees.1408.80. Significant reduction in patient symptomatology as well as caregiver burden and enhanced QOL of the caregivers following intervention. Further, a significant negative correlation between the family burden and QOL scores of the caregivers was obtained. It is suggested on the basis of this study that spiritual therapy specific to the religious orientation of patients combined with pharmacotherapy and other psychosocial therapies may enhance the effectiveness of intervention in schizophrenia. Psycho education programs for caregivers need to focus on empathic engagement, education, ongoing support, better access to clinical resources, social network enhancement, and increased problem-solving, coping and communication skills

B. Devi Prasad and N. Indira Rani (2007) assessed the burden and satisfaction experienced by the caregivers of the older persons in Indian rural family context and association between the caregiver burden and caregiver satisfaction with relevant variables of the caregivers. A census survey with sample of 300 (176 women and 124 men) caregivers having at least one older person (60+years) from 7 villages in of Visakhapatnam district, AP was drawn.

Around 64 % of the caregivers were women. 25.7 % were wives, 23.3 % were sons followed by 22% daughters-in-law and 13% daughters, 8% husbands. Burden and satisfaction of care giving is associated with sex and age of caregiver, and family income. As a whole, a large percentage of caregivers expressed satisfaction about the care-giving role played by them. More specifically, the trend shows that on caregiver esteem subscale a slightly less percentage of women, as compared to men expressed satisfaction about their care-giving role. At the same time, more men i.e. 76 per cent reported resentment for having to take care of the elder relative than women caregivers (57 percent). Similarly, with regard to impact on health, more women caregivers reported tiredness and worsening health because of stress arising out of their care giving roles. Moreover, more women reported interruption of schedule, constraints on social interaction, less visiting of relatives, and strain on financial resources. On the whole, the reason for lower percentage of women expressing satisfaction over care giving and reporting of higher levels of burden on other scales could be because the major burden of caring the elderly is actually shouldered by women rather than by men.

Similarly caregiver satisfaction appears to come down significantly with the financial constraints experienced because of care giving and this impact appears to scale up with the increase in the age of the caregiver. More importantly it was found that both the age of the caregiver and family income are weakly related to care giver satisfaction. A significant finding is that the sex of the caregiver is one of the strong explanatory factors for caregiver stress and women reported higher levels of caregiver stress as compared to men. This may be probably because the major burden of caring the elderly is actually shouldered by the women who are the conventional caregivers in the family. Though a considerable number of caregivers expressed satisfaction over care giving role played by them, only a small percentage of women expressed their satisfaction about their care giving role. The caregivers from nuclear households reported higher levels of burden as compared to joint or extended households. Next, the caregiver burden was found to increase with the increase in the age of the caregiver. Similarly, caregivers from lower income households reported higher levels of burden and it decreased as the income level of the caregiver increased. Further analysis revealed that the age of the caregiver was an important contributing factor than the family income. That is, with the increasing age, the caregiver is likely to experience more stress irrespective of their income levels. Also, evidence shows that the lower the income of caregivers, the greater the impact of care giving burden on health of the caregiver. And that is found to bring down the caregiver satisfaction significantly.

Overall Synthesis:

From the above studies reviewed concepts like Caregiving burden, Satisfaction, Quality of life of caregivers, Community based interventions and coping mechanisms have emerged. Most of the studies are cross sectional while few are clinical and surveys. Two studies are purely epidemiological. It is also found that five studies are highlighting the Social Work significance wherein two of the studies are taken by professional social workers and others have related social work concepts in their studies. Social workers may offer courses and facilitate support groups that provide guidance and information on the efficient division of care giving tasks and household chores and that teach caregivers how to manage their time and establish priorities (Gupta, R 2007).The studies have also brought out the standardized measures and instruments used widely in Indian context especially for dementia patients.

Dementia is emerging as an important health problem in India. It is apparent form the above reviewed studies. Two epidemiological studies of dementia conducted in residents aged 60 years and over, one study conducted in a rural community in Kerala yielded a prevalence of 34 per 1000 in people aged 60 years and above (Shaji et al, 1996) and another study reported a prevalence rate of 8.4 per 1000 in a population aged 55 years and above and an overall prevalence rate of 13.6 per 1000 in a population aged 65 years and above from a rural community in Ballabgarh in northern India (Chandra et al 1998). Vas et al (2001) reported an overall prevalence of 18 per 1000 for those aged 65 years and above in an urban population in Mumbai

The much of the literature reviewed above has focused on negative aspects of giving care. This has been evident in all the three types of care giving studies i.e .for elderly without any particular illness, more women as compared to men caregivers reported tiredness and worsening health due to stress arising out of their care giving roles (B. Devi Prasad et al, 2007) perceived care giving burden depends on the size of the role overload and adherence to cultural norms in Indian context (Gupta, R 2007). For second type of care giving for Schizophrenic patients C.jayakumar et al (2002) reported impairment in routines such as time to look after one's health, sleep and time for relaxation of caregivers of these patients. And for the patients with Dementia several factors have been identified to have a negative effect on caregivers. Shaji KS, et al. (2009) found certain, other than cognitive, factors to have this negative effect, such as behavioral disturbances, hallucinations and sleep disturbances of the persons with dementia. Problems in performance of Activities of daily living (ADLs), hours of informal care giving and level of social support Gender issues have also been shown to influence the situation. Female caregivers of persons with dementia seem more likely to report being burned out. Female caregivers have also been shown to experience lower levels of health related quality of life as compared with peers in the general population.

It has been acknowledged that care giving also has positive elements. In all two studies have total worked on positive element of care giving and seven of them have covered both the positive as well as negative aspects of care giving. However, satisfaction of giving care is "the neglected dimension", the caregiver satisfaction did not emerge as a strong factor either with income or with the age of the caregiver. (B. Devi Prasad et al, 2007). It has been pointed out that caregivers may experience both negative aspects, such as burden, and positive aspects, such as satisfaction from care giving. However, not all caregivers perceive the same burden of illness because personal characteristics of the caregiver have been thought to contribute the impact of family care giving. (Robinson K.M, et.al 2001)

It can be observed that in view of the economic and cultural conditions of a developing country being vastly different from those of the western world, the areas of burden, satisfaction and the pattern of accepting or rejecting patients in India may be entirely different. Not many studies have examined the ways in which family caregivers make care arrangements, cope with the stress while caring for a patient with dementia and the relationship of challenges (burden) and Satisfaction with Age, gender relationship with patient, support network and Health status. It has also emerged that caregiver feel depressed, frustrated and overwhelmed while caring for the elderly and mentally ill patients, in spite of the acknowledgement of the efforts by the care receiver. But in the case of caregivers of patient with dementia these feelings are much more because the patients do not recognize the caregiver and there are negligible chances of cure of the disease.

Thus, it is more relevant to study the management of dementia patients by the family caregivers. Further the Social work Intervention model (training module) would help develop community-specific programmes to target caregivers for psychosocial intervention which would make them more knowledgeable about dementia, enhance their management skills and teach them to focus on the positive feelings they experience in association with the care giving role and sustain this positive well-being. This could diminish the burden of illness felt by them, prevent 'role overload' and help them appreciate the ‘break from care giving’ that make care giving worthwhile.

Book Review: An Insight into Dementia Care in India Leena Mary Emmatty, 2009, Sage Publications, New Delhi Pages 132 pages, Rs. 240, Paperback.

Dementia has been described in this book as a ‘brain disorder’/ neurological disorder that affects multiple cognitive functions including memory, judgment, language and even insight. As the disease progresses, the abilities required for normal everyday living deteriorate. The increase in the population of the elderly is accompanied by a proportionate increase in their number with health problems such as dementia. As dementia is related to the issue of ageing, it has been a cause of concern for gerontologist in India too. Apart from the patient, the disease also has a significant impact on the caregivers and families. Care giving is broadly defined as an act of providing assistance and care to a family member or friend in order to enable the care-recipient maintain independence. Thus, with the speedily increasing population of the elderly in the country, dementia is progressively more a cause for primary concern.

This book is the outcome of the original research conducted by the author at the pre doctoral and doctoral level in India and the author’s interactions with several caregivers during her research on the subject. Through a carefully carried out review of literature available in this area, the author describes the impact of dementia on care givers, services available and psychosocial interventions used to deal with related issues, keeping the focus on India throughout. Hence the book outlines the existing research studies on dementia and focuses on providing information on issues related to dementia care and the care giving scenario in the country.

The book is divided into five parts and each is a focused input into dementia research. It also includes a list of abbreviations ad further readings. Part I deals with dementia as a “silent epidemic” where the pattern of disease development, the various forms of the disease, symptoms, magnitude of the problem, causes of the disease, medical examination of the symptoms and causes including the understanding of dementia in the Indian society are discussed. This is indeed a very brief introduction and the author herself calls it a “bird’s eye view” The chapter ends with a focus on India’s increasingly greying population and the need to develop strategies to deal with the demands of the disease. The inputs in the chapter are indeed contemporary and will help the reader to understand the various domains of the disorder.

Part II is a detailed focus on care giving in relation to dementia. In fact three separate chapters have been dedicated to this theme. The focus here is on care giving in general and the consequences of giving care to people with dementia. The author discusses recent trends in care giving in traditional societies like India, China and Japan. This part sketches the profiles of the caregivers who were part of the authors research and analysis of day-to-day activities of care givers. The focus is on the breakdown of traditional patterns of joint families due to socio-economic changes, migration, women entering the workforce resulting in dearth of manpower for care giving. Thus apart from giving details about changes, she focuses on the role of “feminisation of caring” in India where the burden of care giving falls solely on the women. The A-B-C analysis of communication patterns between the caregiver and the patient highlights that meaningful communication is important to maintain the personhood and identity of dementia sufferers. The section also gives an insight into the kind of factors that affect the care giving practices in India.

Part III of the book discusses the three major concepts in the transactional model of stress and coping: psychological distress, coping and social support, which is an integral part of care giving in dementia. Focusing on earlier research the author explains the extent of psychological distress experienced and the role of care giving characteristics in this experience. According to the author, it is crucial to understand now psychological distress of the caregiver affects care giving. The author’s study concludes with the findings that younger caregivers are high on well-being as compared to older ones. Further she found that care giving spouses reported lower well being than other adult caregivers. This has strong implications for developing stronger institutions for care giving in case of dementia. The role of coping has also been studied by the author and her findings suggest that Social support is the most used strategy followed by Problem focused strategy. Further her findings suggest that psychological distress was lower for caregivers using emotion focused rather than problem focused strategies because the former helps in the regulation of emotions. Another significant finding was that those using problem focused strategy had larger networks hence were more satisfied with the social support available.

The role of social support has been discussed in details by the author in this section as next chapter. Here she outlines the role of “social networks”, that is, its buffering role in alleviating the stress experienced by the caregiver. “Implication and Treatment” is the fourth section of the book. The areas for assessment and the need for planning person-centered assessment in dementia care is examined. A ten-point holistic assessment checklist has been discussed here. The chapter also deals with the skills required to identify the feelings of the caregivers and dementia patients. This focus on feelings is an important part of providing emotional support to the caregiver and is well documented by the author. Psychosocial Interventions has been given a great deal of thought as the author’s research indicates that the negative impact of the relatives’ impairment should be the target of intervention hence the interventions should be individualized and planned along with the caregivers. Concrete suggestions have been given by the author to make the interventions successful. For example, she focuses on providing communications training to the caregiver for improving the interaction between the patient and the caregiver. The author also emphasizes the need to train Indian families to develop dense supportive networks. While focusing on Psychosocial Interventions for persons with dementia the author emphasizes the role of behavior - oriented approaches, reality orientation, training in daily living skills, supportive psychotherapy, reminiscence therapy and stimulation oriented approaches. This provides a comprehensive review of interventions found in today’s contemporary dementia care.

An important focus of this book is the resources available in India and this is a very important contribution that the book attempts to make. The author has outlined the role of specialist clinics called “memory clinics” in different hospitals of India. The lack of programmes to cater to the problems of the elderly suffering from dementia is discussed with a concrete suggestion that offers NGOs a greater role in dementia care. Further the chapter highlights the services offered by Alzheimer’s and Related Disorders Society of India (ARSDI) in various cities of India. A great input from this is the Appendix that provides with the addresses of these chapters. This is definitely an important resource for any caregiver or researcher based in India.

The final section deals with training that needs to be provided to professionals who are already working in the field. Suggestions have been made regarding the integration of gerontological content, knowledge of culture, communication skills and techniques of intervention into the curricula of both graduate and post graduate students training in this field. Serious suggestions for future research have also been listed which provide a researcher interesting areas for future studies.

The author firmly belives that a person with dementia should be seen as a human being with the right to be treated with dignity and worth. The focus should be on the person and not the symptoms. According to her, “we”, as professionals, should take the first step to make a difference in the lives of people who come in contact with us. The language of the book is simple, so can be easily understood by any reader. The aim of the book as stated by the author is that it will serve as a reference book for students and research scholars studying Psychology, Psychiatric Nursing, Social Work, and Rehabilitation. Professionals like Psychiatrists, Psychologists, Social Workers, Nurses, and Paramedics and caregivers working with the elderly. To a large extent these aims are fulfilled by the contents of the book. This book can also be used in teaching related subjects such as Disability, Social Problems, Health Problems and Services and Therapeutic Intervention.

The role of comparative studies across cultures is not addressed. Hence a reader looking for a critical understanding of theoretical framework, concepts of social work practice and may not gain much from the book. However, book is valuable for both professionals and caregivers alike.

CHAPTER - 3

RESEARCH METHODOLOGY

> Age does not matter if the matter does not age
>
> - Carlos Romulo

STATEMENT OF THE RESEARCH PROBLEM

The number of people with dementia is rising quickly in the world. At present there are 35.6 million people affected with dementia across the world. It is estimated that by 2030, there will be four times the number of people with dementia in the developing world. Low or middle income countries like India will show a proportionately higher rate of increase of dementia cases over the next 40 years than developed countries. (Who report 2012)

Currently, One out of every 50 families in India has a person suffering from dementia. Dementia afflicts over 3.7 million Indians. This number is expected to increase manifold in the coming years. (Source: ARDSI) And as a result, informal caregivers will play an increasingly vital role in India.

Between 2006 and 2026, the number of people suffering from dementia in Jharkhand, Bihar and Delhi is expected to rise by 200 per cent or more. In Jammu and Kashmir, Uttar Pradesh, Rajasthan, Madhya Pradesh, West Bengal, Assam, Chhattisgarh, Gujarat, Andhra Pradesh, Haryana, Uttarakhand, Tamil Nadu, Karnataka and Maharashtra, the number may rise by 100 per cent. By 2026, Uttar Pradesh and Maharashtra are estimated to have over 5 lakhs people with dementia. Gujarat, Andhra Pradesh, Bihar, Rajasthan, West Bengal, Madhya Pradesh, Orissa, Karnataka, Kerala and Tamil Nadu will have between 20,000 to 40,000 afflicted persons. Of the 36 lakh Indians who suffer from dementia, 21 lakh are women and the rest are men. (Source: Indian Dementia Report 2010)

Most cases go undiagnosed as people assume that it is just a normal ageing problem. In cases where the diagnosis is made, it is likely to be in moderately advanced stage. The prevalence estimates in India suggest that 3 to 7% over 60 years have dementia and about half of them are Alzheimer's type (Rajkumar S, 1997). Shaji et al (2002) gives the prevalence rate of dementia as 34 per 1000 in the urban study.

Lack of reliable data at the national level makes the awareness and working on dementia a difficult exercise. Hence, there is a rising concern to look into the caring of dementia patients, have systematic data on the impact of caregiving on informal caregivers (family context) and gauge the impact of caregiving to facilitate the planning of social and health support services and government policies.

How do caregivers manage when the patient is an elderly member and caregiver is person of the opposite sex? Does the nature of relationship affect caregiving? (Patient is mother-in-law or father-in-law and daughter- in-law is the caregiver, or mother is patient and daughter is caregiver) Does coping mechanism vary from family to family in terms of availability of social support, health of a caregiver, work and social demands (crucial years in children education or marriages)? What happens when the head of the family develops Dementia? – are some questions that the present research study intends to answer.

RELEVANCE OF THE STUDY

"The elderly population will increase to 12% of the total population by 2025, 10% of which would be bedridden, requiring utmost care. India will soon become home to the second largest number of older people in the world. The challenges are unique with this population. A majority (80%) of them is in the rural areas thus making service delivery a challenge" (Union Ministry of Health, GOI 2012)

According to the 2006 World Population Prospects, the number of Indians aged above 80 will increase more than six times from existing 78 lakh to about 5.14 crore by 2059. At present, 20% of this category in India suffers from Alzheimer's disease. (The Registrar General of India, SRS, 2010). The Union Ministry of Health have revised the National Programme for the Health care of the Elderly (NPHCE) expects to have

20 institutions with capacity to produce 40 post graduates in MD in geriatric medicine per year, additional 6,400 beds in district hospitals and 1,000 beds in medical colleges for the elderly by 2017. It also envisages setting up of geriatric clinics in OPD and Physiotherapy units in 640 district hospitals and more that 2,000 Geriatric clinics in community and primary health centers. (The Economic Times 3rd April 2013)

Further, the emerging literature on families of dementia patients contains important findings for social work practice. First, life events are not independent: When one family member is confronted with adversity, others are affected (Cohler, 1983; Prunchno, Blow, & Smyer, 1984). Second, families often have the capacity to effect changes in their relatives that professionals can only guide (Gwyther, 1990). Third, dementia makes arduous demands on families as managers and advocates for the patient: Patients with dementia are typically involved in prolonged and complex relations with hospitals, nursing homes, and other community institutions (Cohler, Groves, Borden, & Lazarus, 1989). Moreover, the significance of family involvement in this illness is of particular interest to social workers who are seeking information about the relationship of the family to other institutions across the life cycle. Cohler et al. (1989) suggested that understanding these relationships may lead to a better understanding of the demands of caregiving and processes of adult socialization to grief; others have compared the impact on the family to that of grieving and loss often associated with the death of a family member (Cohen & Eisdorfer, 1988).

Caring for the elderly, care recipients in India has traditionally been family based. Indian families tend to view caring for the older family members as their obligation and sending them to long-term care institution is regarded as a violation of cultural norms, but care giving is increasingly more demanding in contemporary India with the fast-changing social system. Urbanization, changing role and status of women, decrease in family size, and small living space are all factors that may influence the care pattern of the elderly people and coping ability of informal caregivers. Data on the impact of caregiving on caregivers' and their burden or satisfaction in India is limited. Moreover, existing published studies have mostly been based on small samples in some pockets of India or on different disease categories.

This study would give much needed insights into care arrangements, challenges and satisfaction faced by the caregivers in caring of dementia patients. This study would also explore and understand various dimensions of care giving and coping strategies adapted by the caregivers of dementia patients in Indian context. No governmental effort has been seen to update data on the number of dementia cases in the country though the threat has been widening. Despite the prevalence, there is gross ignorance, and is often neglected in our country.

SIGNIFICANCE FOR SOCIAL WORK PROFESSION

An aging population has ramifications throughout society; one of particular concern is the impact it will have on the social work profession. The Council of Social Work Education (2001) estimates that between 60,000 and 70,000 gerontological social workers will be needed by 2030 to meet the needs of the elderly. These professionals will require specific knowledge, competency, and skills, particularly the ability to work with those coping with non -communicable diseases.

Since, Dementia is an all-encompassing illness that affects many spheres of the affected individual, his or her family and society. Social workers ability to understand individuals and to develop trusting relationships can be vital in helping clients cope with the challenges that dementia entails right from the time of initial diagnosis to the final stages of dementia.

The current Research study shall highlight the challenges to the profession that must be met if social work is to be truly effective in meeting the myriad needs faced by persons with dementia and their caregivers. It will encourage and stimulate social workers to not only increase their involvement with persons with dementia and their families but also educate and train those currently working with this population. As the number of persons with dementia multiplies in the coming decades, there is an urgent and immediate need for the profession’s commitment to strengthen and improve the quality of the systems affecting these persons.

The effects of dementia on individuals and communities demand a collaborative interdisciplinary approach and hence the social work leadership and communication strengths requisite to this approach. The needs of persons with the dementia and their families have direct implications for the social work profession because social work knowledge, skills, and roles can be critical throughout the course of the illness.

Broad Objective:

To explore and examine current care giving arrangements and management of dementia patients.

Specific Objectives:

1. To understand care giving activities and processes of care giving in the select families of Vadodara taluka having Pateint with Dementia (PWD).
2. To find out the stress associated domains of caregivers and its management
3. To explore association if any, between various aspects of care giving and background characteristics of family caregivers.
4. To understand health care professionals perspective on family caregiving and scope for services.
5. To suggest and prepare guidelines for a training module which focuses on
    - Awareness and Knowledge about Dementia
    - Management of Dementia Patients
    - Coping strategies for caregivers

RESEARCH QUESTIONS:

1. Is caregivers' responsibility shared in the family or there is only one caregiver who takes entire burden in informal caregiving.
2. Which aspects of care giving cause distress to the caregiver in informal setting.
3. What are different coping strategies used?
4. Does the management of dementia patient at home require special training?

OPERATIONAL DEFINITIONS /EXPLANATION OF RELEVANT TERMS

1. 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, judgment, impairment of cognitive functions accompanied and occasionally preceded by deterioration in emotional control, social behavior or motivation**.(International classification of disease.ICD 10).**

2. Person with Dementia(PWD):

In the present study person with Dementia are those who are of the age 60 and above**,** clinically diagnosed with Dementia by Neuro-physician or Psychiatrist, which is severe enough to impair the social and occupational functioning of the individuals.

3. Care giving Arrangements:

Care giving arrangements include conditions of care giving, arising due to Functional disability, Problem behavior, physical help with extent of dependence in activities of daily living & Instrumental daily living (ADL/ IADL), duration of care giving, hours of care giving, Number of care giving tasks, financial help, and emotional help.

ADLs and IADLs are activities that allow a person to live independently, are common classifications used in relation to assistance provided to individuals with functional limitations. Examples of ADLs include bathing, dressing, toileting and eating. Examples of IADLs include cooking, housecleaning, and shopping, managing money.

4. Family caregiver:

In this study, the term family caregiver refers to persons 18 years of age or older who satisfy a number of eligibility criteria for selection. To be eligible for inclusion in this study, the caregiver should be the spouse, daughter-in-law, daughter, son or a close relative staying with the family for at least six months. In joint households, if more than one member of the family share care giving tasks and reside in the same household, then among these caregivers, the primary caregiver is one who provides at least 4 hours of care per day and assists the patient with dementia on at least one activity of daily living (ADL) or two instrumental activities of daily living (IADL).

5. Caregiver Background / Contextual factors:

For this study it refers to the socio-demographic factors of the caregiver. This includes age, gender, culture, education, occupation, family income, work status, socio-economic status, relationship with the patient and relationship with the other members of the family.

6. Care giving Management Strategies :

This includes strategies or means used by the caregivers to deal with the care giving demands. It may include seeking help from other family members, relatives, friends neighbors to carry out unmet needs, employing additional domestic help, resort to alternative healing- unani, ayurvedic and homeopathy medicines, engagement in religious activities and associations, charity, fatalism (blaming it on past life, karma), yoga, meditation taking up part time jobs, working from home, taking loans and mortgage as financial help.

7. Health Status:

Health status involves health of caregivers physical as well psychological well being. Physical symptoms of health like fatigue, poor diet, lack of sleep and Psychological symptoms like depression, anxiety, fear of losing the loved one, social isolation and stress.

8. Support Networks:

This includes all those whom caregivers look up for support. Informal support derived from the social relationships of the caregiver with extended family, relatives, friends and neighbors. Use of formal services.

9. Caregivers perception towards care giving:

This will include the outcome of the care giving – challenges or satisfaction felt by caregivers.

Challenges: Caregiver challenges include physical, psychological, social, and financial problems; embarrassment; Role overload and captivity (feeling of entrapment); and resentment. The extent to which caregivers feel that their emotional or physical health, social life, and financial status have suffered as a result of caring for their relatives.

Satisfaction: For this study satisfaction means positive feeling of caregivers, rewarding consequences of caring, Enjoyable aspects of caregiving, enhanced caregiver–care recipient relationship, personal growth, caring self-competence and self-esteem, satisfaction with social involvement, ability to provide good care. Caregivers may feel; that caring for an afflicted loved one, while an unexpected task is seen more as an accepted responsibility that they wish to be an integral part of, rather than an unwelcome burden.

RESEARCH SETTING

The Gujarat State

According to Census 2011, the total population of Gujarat is 60,383,628 comprising of 31,482,282 men and 28,901,346 women. The percent decadal growth rate of population during 2001-2011 is 19.17. The female sex ratio for the state of Gujarat is 918. The literacy rate is 87.23 for men and 70.73 for women. Out of the total population of the state, 42.58 percent population stays in urban areas. The population in rural areas comprises of 17,802,975 (9.10%) men and 16,867,842 (9.37 %) women and 13,679,307 (35.87 %) men and 12,033,504 (35.78%) women reside in the urban areas (census 2011). The state has an elderly population of 3,489,009 which is 6.9 of the total population of Gujarat. Of these, men and women comprise 46.5 % and 53.5 % respectively (Govt of India (Census), 2001).

Vadodara District

According to Census 2011, the total population of Vadodara District is 4,157,568 of which men are 57.1 % and women are 42.9%. The population of Vadodara district is 6.89% of the total population of the state of Gujarat and it ranks 3rd by population size. The percent decadal growth rate of population of the district during 2001-2011 is 14.16. The female sex ratio is 934. In the Vadodara district the male and female literacy rates are 87.59 and 74.40 respectively. The district ranks 10 among the 25 districts of Gujarat for the literacy rate of the population (Census, 2011).

The length of the Vadodara district from north to south is about 109.3km and from east to west is 148.1 km. It is bounded in the North and West by Kheda and Anand districts, in east by Panchmahals and Dohad districts and in the south by Bharuch and Narmada districts. Also the boundaries of the district touch the boundaries of States Madhya Pradesh and Maharashtra. The area covered by the district is 7,550 Sq.km. Vishwamitri and Mahi are principal rivers of the district. The climate is characterized by a hot summer and dryness in the non-rainy seasons. Economic resources are an important means of subsistence of the working people of the district. The economic resources are from the important sectors such as forestry, minerals and mining, soil and cropping pattern, land and land use pattern.

The Vadodara City

The ancient town of Vadodara was once called Chandanvati after the name of Raja chandan of the Dor tribe of Rajputs who wrested it from the Jains. The name of Chandanvati that meant the ‘City of Sandalwood’ was afterwards changed to Viravati meaning the ‘Abode of Warriors ‘ and then again to ‘Vatpatra’ which means the ‘Leaf of the banyan tree’. One belief is that the flourishing Ankottaka (Modern Akota) developed one of its suburbs on the bank of the Vishvamitri where Banyan (Vad) trees were in predominance. The suburb near the ‘Banyan Tree’ means Vadapatraka. Much of the old walled city area was developed during the successive Muslim rule.

The Moghal rule over the city came to an end in 1732, when Pilaji brought the Maratha activities in Southern Gujarat to an end and captured it.

Except for a short break, Vadodara continued to be in the hands of the Gaekwads as their capital town from 1734 to 1949. Maharaja Sayajirao III (1875-1939) who did not come from the direct line of the ruling Gaekwad dynasty was the architect of modern Vadodara. It was the dream of this visionary ruler who was educated under English tutors and local teachers, to make Vadodara an educational, industrial and commercial centre. Under his rule Baroda showed tremendous progress and constructive achievements in all fields.

Sayajirao initiated a series of bold socio-economic reforms. He attached great importance to economic development and started a number of model industries to encourage initiative, and then handed over the industries to private enterprise. He started model textile and tile factories. It is as a result of his policy of industrial development that Vadodara is today one of the most important centers for textile, chemical and petroleum industries. He introduced compulsory primary education and library movement (the first of its kind in India) to augment his adult education scheme. He also visualized a general scheme of development in all branches of knowledge at different stages, with the Maharaja Sayajirao University of Vadodara at the apex. Modern Vadodara owes its beauty, its educational institutions, cultural uniqueness and architectural masterpieces to the insight and vision of Maharaja Sayajirao Gaekwad III. Vadodara is also popularly called as ‘Sanskar Nagari,’ that is, a ‘city of culture.’ It is also referred to as ‘the cultural capital’ of Gujarat. The city has rich traditions of composite culture and is cosmopolitan in nature.

Unique Features of the Vadodara City

Cosmopolitan and cultural diversity:

Vadodara is considered as one of the intellectual hubs in the state of Gujarat and is considered a cultural center. The city has welcomed a wide variety of people from all over India and also from all over the world. The city upkeeps rich cultural traditions and people have quite a full and hectic cultural life throughout the year. Thus, the culture of the city is not just history or heritage; it is dynamic, ever-changing and alive.

Prominence of Education:

Vadodara is synonymous with education. The patronage of education started with Maharaja Sayajirao and the city has built further on the academic infrastructure established by him. Maharaja Sayajirao University is the only university in Gujarat with English as medium of instruction. It has 13 faculties and 17 residential hostels, 4 of them for women students. The university caters to over 30,000 students.

Industry & commerce:

Vadodara enjoys a special place in the state of Gujarat. Till the early 1960's Vadodara was mainly considered to be a cultural and educational centre. Now the industrialization of Vadodara has attracted entrepreneurs not only from Baroda but also from all over Gujarat and India. The first modern factory (Alembic Pharamaceuticals) was established in Baroda in 1907 and subsequently companies such as Sarabhai Chemicals, Jyoti, etc., came up in the 1940s. By 1962 there were 288 factories employing 27510 workers. In 1962, Baroda witnessed a sudden spurt in industrial activity with the establishment of Gujarat Refinery. The discovery of oil and gas in Ankleshwar and North Gujarat led to the industrial development of Gujarat in a big way. Vadodara is no exception and the city and the surrounding areas are today humming with industrial activity.

Health and Medical Facilities

Vadodara is known as a Hub of Industries-academic-cultural and medical facilities. Apart from medical colleges both public and private, there are super specialty hospitals with state-of-art infrastructure. Unfortunately, in spite of large network of Government and Primary Health centers and hospitals in the city, there is lack of services and facilities required for addressing needs of patients with Dementia and their caregivers. One or two extensive private health care and not for profit providers do exists against Government systems with staff shortages and poor infrastructure. Therefore, though the Government services are free, many people choose to seek care under costly private systems. These private systems are fragmented in nature as these doctors work independently and in isolation. Though, people with dementia have registered and Diagnosed by Physicians, Neurologists and Psychiatrists in General and Private Hospitals in urban area of the city, follow up care is difficult in the absence of outreach services in the city.

RESEARCH DESIGN:

This is both exploratory and descriptive study and it attempts to answer questions about the current situation of caregiving of dementia patients in Vadodara city.

Both qualitative and quantitative approaches are taken to study the problem. Qualitative methods can capture the richness of everyday behavior by attempting to understand the reality on its own terms and describes people and their interactions in natural settings. The quantitative approach is helpful in assessing the relationships between the demographic variables of the patients and caregivers with the different dimensions of caregiving. Therefore, in the present study keeping in view the requirements of the objectives, the in-depth interview schedule was used for the purpose of data collection. The study had three distinct phases including pre-interview assessment (baseline data), in-depth interview with the caregivers, Case studies and Interview Guide for taking perspective of Health care professionals and providers.

SAMPLING

Universe of the Study:

The Universe of the study comprised of all dementia cases registered, diagnosed and attending the Psychiatry OPD at Government General Hospital and Private Clinics of Psychiatrist and Neuro-physicians in Vadodara city.

Being clinical study 103 patients who were clinically diagnosed (and available) as dementia patients constituted the target population.

The above sample is supported with substantial number of case studies and Interviews with Health care professionals and providers (Key informants).

Criteria for Sampling:

Following criteria were kept in mind while selecting the participants.

Inclusion Criteria

- Family caregivers of the clinically diagnosed dementia Patients residing in vadodara city.
- Family caregivers who were looking after the patient at least for past six months from the date of interview.
- Family caregivers who consented to give interview
- The family member who identified himself/herself to be caregiver was interviewed

Exclusion Criteria

- Family caregivers of patients who have wandered and passed away.
- The professional caregivers
- The family caregivers with pre-existing illness.

Sampling Procedure:

A non- probability, purposive sampling method was used to select the sample for the study. It was purposive because being clinical study; those family caregivers who were available and looking after patient with dementia were approached. Only those patients who were diagnosed as Dementia patients were taken, thus an expert judgment was sort, making the selection of sample purposive.

The researcher obtained the list of Neuro physicians and psychiatrist and details of the department of neurology and psychiatry from the data bank of Medical Association of Baroda city. After telephonic talk and prior appointments, these doctors were contacted and their permission was sought for data collection. Due to time constraint on the part of the family caregivers, due to the care giving and other priorities, the researcher had to visit them twice. Five respondents gave only half interview and then refused to answer and thus these schedules were discarded as they were incomplete.

While selecting the family caregivers for the case studies, care was taken to include respondents on basis of relationship and care arrangements and coping and care giving experience. The respondents were selected from among those who were already interviewed for the study.

TOOLS FOR DATA COLLECTION

Informed Consent

The informed consent form was developed based on the WHO guidelines of informed consent. The form has two parts. Ist part is the Information sheet which covers basic details like title of the research, academic institution, name of the researcher and research guide. Further it covers Introduction of the researcher and the purpose of study, type of research intervention, participant selection, voluntary participation, and procedure of interview, confidentiality, right to refuse or withdraw and contact information of the researcher. This part is to be retained by the respondent. II nd part consists of **Certificate of Consent** which covers statement of the respondent duly signed and in case of illiterate respondent thumb print in presence of a witness and also a statement of the researcher.

The Interview Schedule

The interview schedule used for the purpose of data collection consisted two major parts. First part consists of clinical data sheet of the patients and the Second part is constituted of seven parts 1.Caregiver context- socio demographic details; 2. Current care giving arrangements; 3. Dementia symptoms, associated issues in patient and its management strategies; 4. Overall health and well being of the family caregiver; 5. Support network; 6. Satisfaction (Rewards) / enjoyable aspects of care giving; 7. Caregivers skill abilities, awareness and knowledge.

FIRST PART: CLINICAL DATA SHEET.

This part included information about patient details, informant's relationship with the patient, and clinical details. Patient details included age, sex, diagnosis, onset and duration of the disease, and contact information.

SECOND PART: INTERVIEW SCHEDULE

1. Socio-Demographic data

Information about respondents sex, age, marital status, relationship to the patient, educational qualification, duration of caregiving, type of family size, total earning members, monthly income of the family, domicile, type of house, religion and details of other family members was obtained.

2. Current care giving arrangements

This part of the schedule included questions regarding time spent with the patient, what time of the day care is given, i.e. day, night, morning etc, what type of care is provided and difficulties faced and Whether the care provided is adequate or not.

3. Dementia symptoms, associated issues in patient and its management strategies

This part of the schedule included question on medications given to patient. Distress caused by Cognitive, behavioral, Psychological and Physical changes in the patient and if felt by the caregivers, was measured on the four point scale along with the brief description about its management.

Questions related possible stress domains and how effectively they are managed including whether they have dropped any activities due to caregiving.

4. Overall Health and wellbeing of the caregiver

This part covered five domains of overall health–Social, Personal, Social, Physical and Mental. Each domain has specific statements to be answered on 3 points scale. Disagree = 1 Neutral =2 Agree =3

5. **Support Network**

This part includes questions on what type of support is received, who gives the support, difference felt between informal and formal support, discontinuance of support and reasons for the same, what type of support is desired and to whom the caregivers resort to for support.

6. **Satisfaction (Rewards) / enjoyable aspects of care giving**

This includes question on what are the enjoyable aspects felt by the caregivers.

7. **Caregivers skills, abilities, awareness and knowledge**

This part has statements on skills and abilities on caregivers to be measured on five point scale. It also covers questions on which sources caregivers use for gaining knowledge on dementia, what efforts they put in, specific skills they are currently using to give care, awareness on services provided by the institutions in the city and what services are desired at the state level.

Adaptations for preparing various scales and questions in above mentioned parts of the Interview Schedule were done from:

1. Modified Caregiver Strain Index by Thornton, M., & Travis. S. S. (2003).

The Modified Caregiver Strain Index (CSI) is a tool The Modified Caregiver Strain Index is a version of the Caregiver Strain Index developed in 1983. The tool was modified and developed in 2003. It is a 13-question tool that measures strain related to care provision. There is at least one item for each of major domains: Employment, Financial, Physical, Social, and Time. This instrument can be used to assess individuals of any age who have assumed the role of caregiver for an older adult. Scoring is 2 points for each ‘yes’, and 1 point for each ‘sometimes’ response. The higher the score, the higher the level of caregiver strain.

Validity and Reliability: Internal reliability coefficient is slightly higher (=.90) than the coefficient originally reported for the CSI in 1983 (=.86). Two-week retest data for one-third of the care giving sample (n=53) were available and resulted in a test-retest reliability coefficient of .88.

2. Burden Assessment Schedule (BAS) by H.Sell, R.Thara, R. Padmavati and S. Kumar (1998), BAS is a most frequently used tool to assess the burden of care of psychiatric patients in India. It measures burden in nine areas: (a) Spouse related (b) Physical and mental health (c) external support (d) caregiver's routine (e) support of patient (f) taking responsibility (g) other relations (h) patients' behavior (i) caregivers' strategy. There are 40 items rated on three point scale. The reliability is .80. The validity ranges from .71-.80.

3. The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments by Given, C.W., Given, B., Stommel, M., Collins, C., King, S., & Franklin, S. (1992). Was used on 161 caregivers of people with a solid tumor who were older than 59, hospitalized for surgical treatment of the cancer, and who had a prognosis of six months or greater (Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999) * 187 caregivers of people receiving home care from a family member for a diagnosis of cancer (Pasacreta, Barg, Nuamah, & McCorkle, 2000) Validity: Factor structure was confirmed with caregivers of people with cancer and those with cognitive deficits. Construct validity was established comparing the CRA with measures of dependency and depression. Reliability: Internal consistency coefficients range from 0.80 to 0.90.

The tool was sent to experts from the fields of Social Work, Research and Mental Health and Aging. The changes suggested by them were incorporated and repetitive questions were appropriately reframed. The tool was translated in the local language (Gujarati) by the professional translator and was pretested. Examples were written in the schedule for better understanding of the question by the respondents.

Interview guide was prepared for taking perspectives of Health care professionals and for preparing case studies.

DATA COLLECTION:

The data collection took six months i.e. from May 2011 to November 2011. On an average it took one to one and half hour to administer the interview schedule. However, the interviews for case study were done after all the data was collected with prior appointment. The interview took almost two to three hours and at times the researcher had to take more than one visit.

Health care professionals were interviewed with prior appointments.

ETHICAL CONSIDERATION:

The researcher carried a formal letter signed by the research guide and the Dean, Faculty of Social Work. The informed consent developed by the researcher was translated in Gujarati and was either read out by the researcher or was given to the respondent. One part of the consent was to be retained by the respondents. (see informed consent in Annexure).

However, in case where respondents refuse to sign the informed consent verbal consent was taken before starting the interview.

DATA ANALYSIS:

The quantitative data is presented in bivariate and multivariate with percentage analysis. Association between some select variables has been worked out by using chi square through SPSS software. The qualitative data is presented describing the content of in- depth interviews with health care professionals and case studies with special feelings and verbatim captions.

CHAPTERISATION:

The report is divided into following chapters

- Chapter 1 - Introduction
- Chapter 2 - Review of Literature
- Chapter 3 - Research Methodology

- Chapter 4 - Data Analysis and Interpretation
- Chapter 5- Major Findings, Discussion and Conclusion
- Chapter 6 - Suggestions and Future Directions
- Reference
- Annexure

EXPERIENCES OF THE RESEARCHER:

The experiences which the researcher gathered during the data collection have given deep insight and sensitized her towards issues of management of dementia patients. There is much more to look into than just routine care giving of the dementia patient. There were experiences where few people completely refused to talk and were annoyed as how can a researcher approach them and ask them about the patient who has absconded or passed away. In one of the interviews, the respondent was so upset that she bluntly told the researcher that “If you are so concerned, why don’t you take him with you”. Researcher found that caregivers were emotionally charged. Researcher had vivid experiences as there was outburst of emotions to the extent of crying, anger and temper.

At times, the researcher found it difficult to stop the respondent from talking in spite of getting late. Many questions were raised by them related to the course of the disease, possible cure and how long the patient will live. During Interview, the family dynamics were observed, in some families everyone wanted to talk and share their views, at times proving the caregiver wrong.

Thus, respondents had many questions and clarifications. The researcher allowed the respondents to ventilate by remaining unbiased and answer their queries tactfully and objectively.

The researcher gained further insights that after all family caregivers are human beings and they also have multiple reactions and it cannot be expected from them to remain calm always while giving care to a person over the years. They do deserve the break and their emotional reactions such as anger, embarrassment, getting trapped needs to be looked into more judiciously.

STRENGTHS AND LIMITATIONS OF THE STUDY:

1. The sample is purposive and hence findings cannot be generalized to other caregivers groups.
2. The study is limited only to the family care givers perspective; Patients' and professional caregivers' perspective is not covered which could have given holistic picture.
3. Moreover, the impact on family members other than caregivers is not captured
4. The study is limited only to the urban area i.e. Baroda City.

However, in the absence of any study on family care giving of dementia patients in Gujarat, the findings of the study may be useful in developing insights in to the problems of family care giving of patients with dementia.

The case studies and health care professional perspectives added rich information about the family caregivers, the anxieties they face and how the dreaded disease of dementia can be treated. This has supported and enriched the quantitative data.

CHAPTER - 4

STATISTICAL ANALYSES AND DATA INTERPRETATION

> **The Family is a Heaven in a Heartless World**
>
> **~ Christopher Lasch**

This chapter attempts to analyze the data collected by applying appropriate statistics and interpret the same keeping in mind the objectives of the current study of family caregivers managing dementia patient. An attempt is made to highlight some of the typical cases in the form of Case Studies and views of Health care providers on dementia care giving . The chapter is divided into ten sections. This is done to present data in details and to maintain the flow of the information asked. Following are the sections:

1. Background details of the respondents
2. Current Care giving Arrangements
3. Issues related to Dementia and Management Strategies
4. Overall Health and well being of the respondents
5. Informal support to the respondents
6. Enjoyable Aspects of care giving
7. Care giving skills, abilities, awareness and knowledge
8. Association of variables
9. Case Studies
10. Views of health care professionals

A sample of 103 family caregivers has been indentified and interviewed. The interviews were conducted with the primary family caregivers who identified themselves as primary caregivers, however at times two family caregivers have also responded during the interview. These caregivers are of those Dementia patients who were diagnosed by clinicians. These family caregivers throughout the chapter have been referred as "respondents".

Information on several parameters of caregiving was gathered from the family caregivers of the patient with dementia. Statistics like chi-square has been applied to understand the association between variables.

SECTION-I

BACKGROUND DETAILS OF THE RESPONDENTS (CAREGIVERS & PATIENTS)

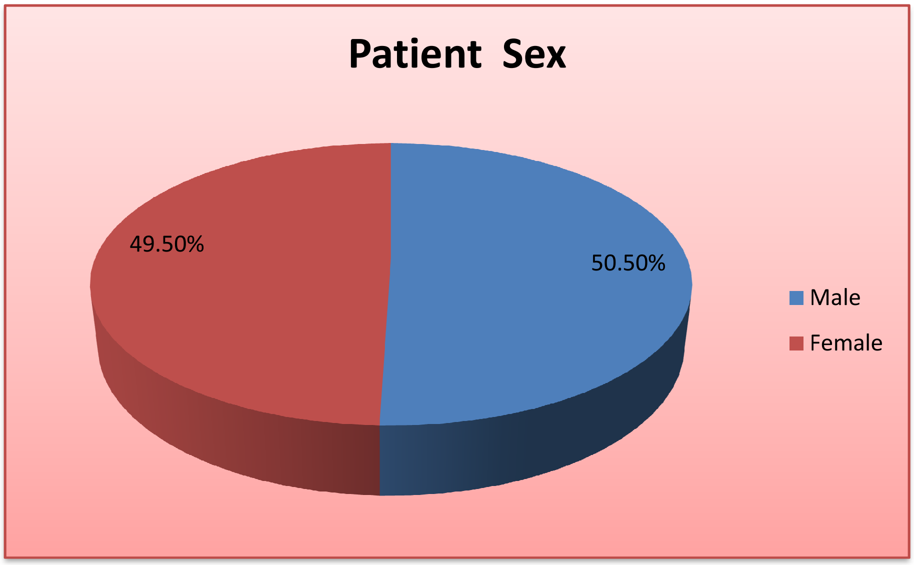
The current section presents data related to background information and economic status related to respondents and patients. The tables present simple frequency distribution and percentages are calculated from the total responses received. For the open ended question and questions with multiple responses, the categories were formed from the responses received.

The following table presents the frequency and percentage distribution of the data related to the patients' sex, age and severity of the disease.

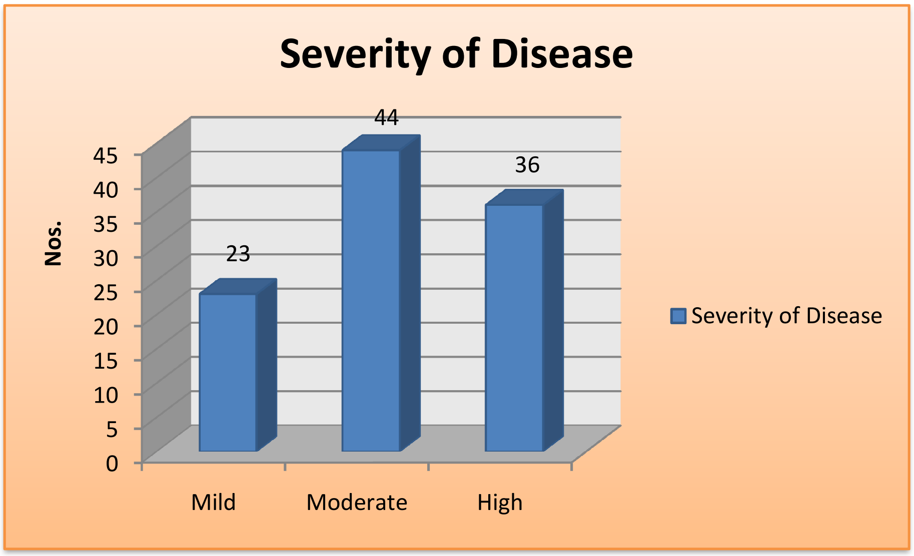
Table 1 Primary Details of Patients

Primary Details	**Frequency**	**Percentage**
Patient Sex		
Male	52	50.5
Female	51	49.5
Severity of Disease		
Mild	23	22.3
Moderate	44	42.7
High	36	35.0
Age		
60-70 years	40	38.8
71-80years	53	51.4
80 years and above	10	9.8
Total	**103**	**100**

Graph No. 1. 1



Graph No. 1. 2



The above table reflects that out of total 103 patients with dementia, 52(50.5%) are male and 51(49.5%) are female patients. When further seen within the severity of the disease maximum 44 (42.7%) patients have moderate, followed by 36(35.0%) High and 23 (22.3%) with mild stage of severity of disease. Maximum number of patients 53 (51.4%) are in the age group of 71to 80 years, 40(38.8%) patients are in the age group of 60-70 years followed by 10(9.8%) in the age group of 80 years and above.

It appears that the elderly in the age group of 71-80 years may be more prone the moderate stage of dementia, indicating onset or mild stage of dementia in the age group 60-70 years.

The following table gives demographic profile of family caregivers (respondents) which includes sex, religion, caste, marital status, education and relationship with the patient.

Table 2 Background Details of Family Caregivers

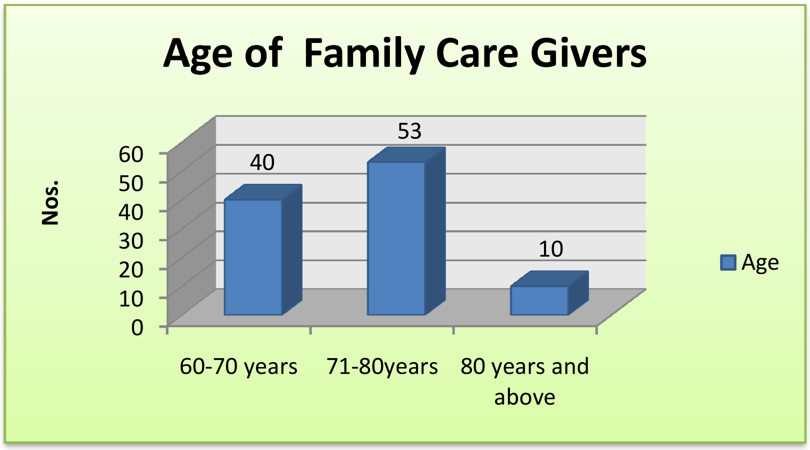
Primary Details	**Frequency**	**Percentage**
Sex		
Male	65	63.1
Female	38	36.9
Religion		
Hindu	78	75.7
Non-Hindu	25	24.3
Caste		
General	73	70.9
*Other	30	29.1
Marital Status		
Currently married	93	90.3
* *Other	10	9.7
Education		
Read and Write	15	14.6
Up to HSC	21	20.4
Graduate	27	26.2
Graduate &above	40	38.8
Relationship		
Spouse	36	35.0
Children	46	44.7
***Other family members	21	20.4
Total	**103**	**100**

* Other category includes: Schedule caste, SEBC, Schedule Tribe.

** Other category includes: Widow, Divorcee, Separated, and Unmarried

*** Other Family members includes: Daughter- in- law, Siblings Son in law, brother-in-law

Graph No. 2.1



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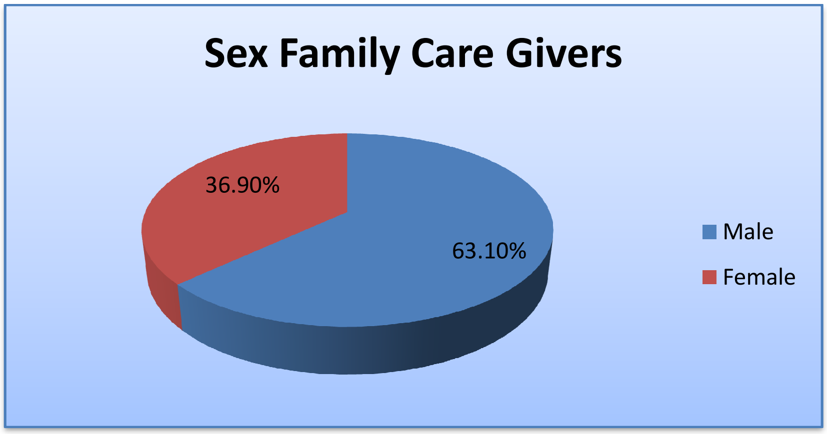

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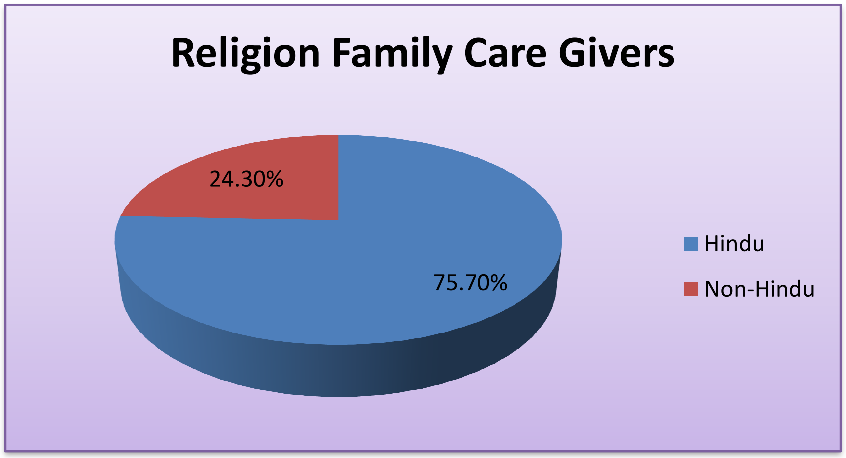

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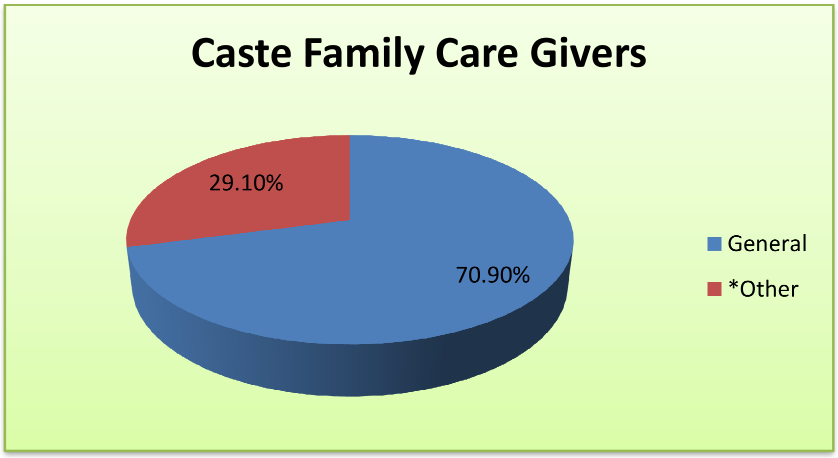

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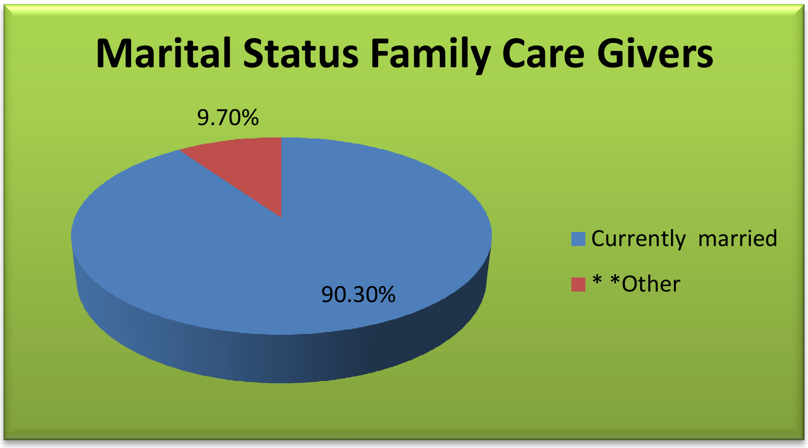

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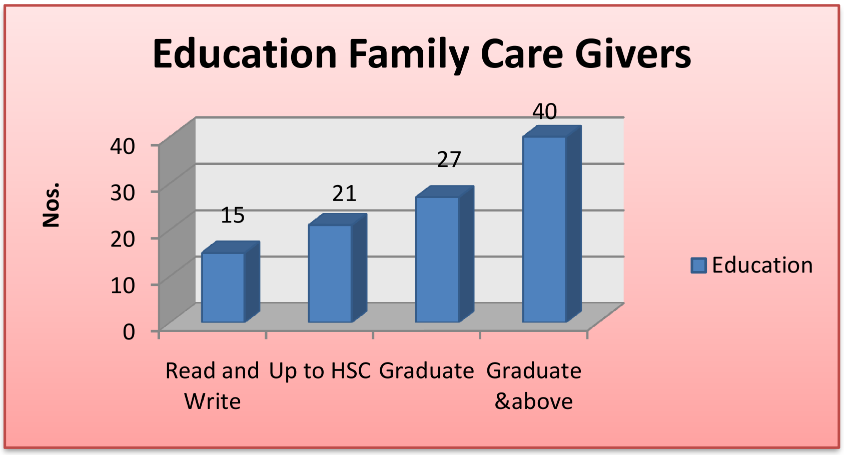

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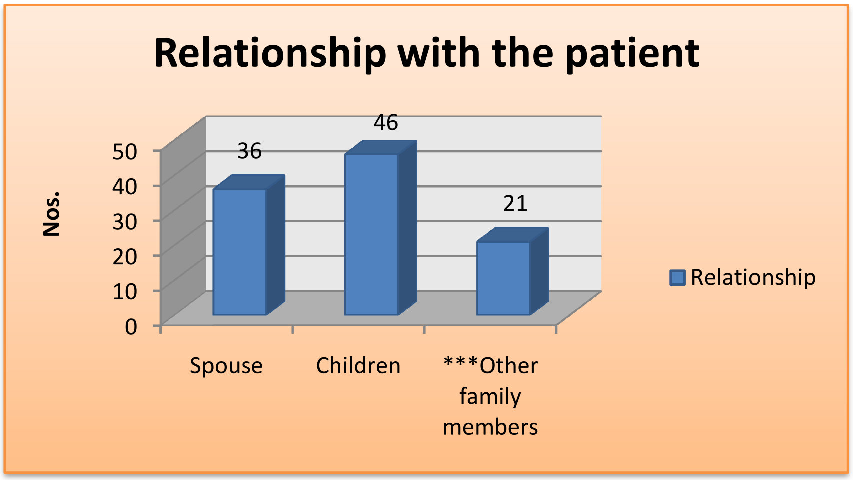


Out of total 103 family caregivers, 65 (63.1%) are male family caregivers and 38 (36.9 %) are female family caregivers. Most of them 78 (76%) approximately, are Hindus and 73 (71%) of them belong to general caste. Educational level of the family caregivers shows that 27 (38.8%) are graduate and above. The relationship of the family caregivers when seen with the patients, it is evident that majority 46 (44.7%) are children, 36 (35%) are spouse of the patient and 21 (20.4%) are other family members.

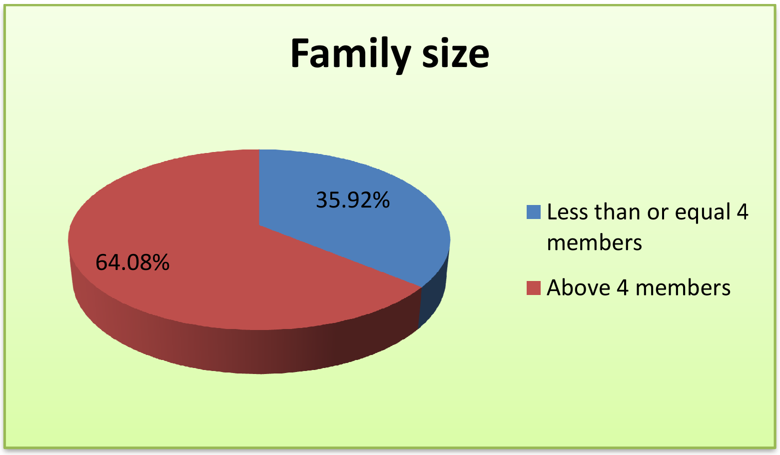
It appears that the sex of the family caregivers can be an indicator to understand that who is primary family caregiver in the Indian setting. Also, children being majority of family caregivers indicate Indian tradition of taking care of older people in the families which is obligatory by Son and daughter.

The following table presents frequency and percentage distribution of the background details of the caregivers which includes family size, family type, domicile, care required for a family member other than the patient, monthly income, employment status, type of job, source of household income and source of income for care giving.

Table 2.1 Background Details of Caregivers contd.

Details	Frequency	Percentage
Family size		
Less than or equal 4 members	37	35.9
Above 4 members	66	64.1
Family type		
Nuclear	47	45.6
Joint	56	54.4
Domicile		
Urban	72	69.9
Semi-Urban	12	11.8
Rural	19	18.6
Care of family member other than patient		
Yes	17	16.5
No	86	83.5
Total	**103**	**100**

Graph No. 2.1.1



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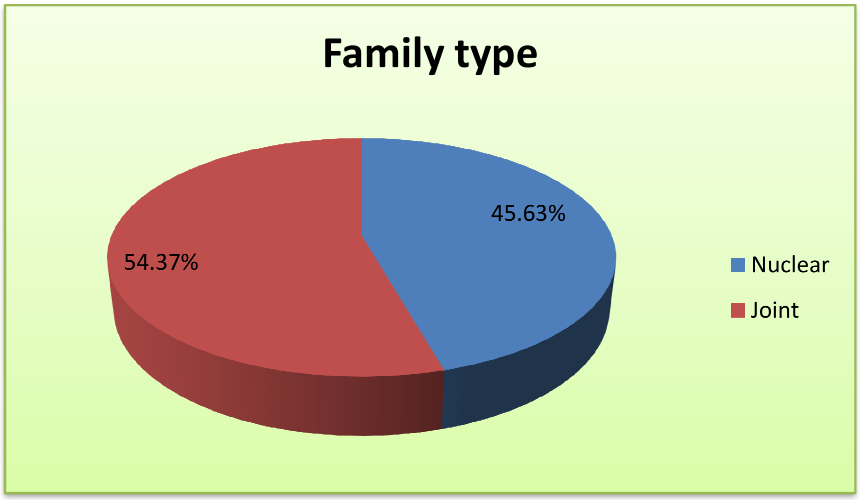

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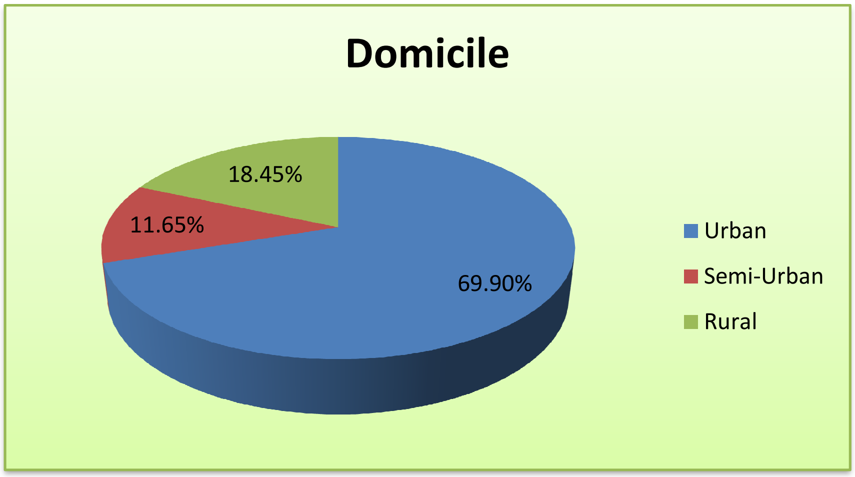

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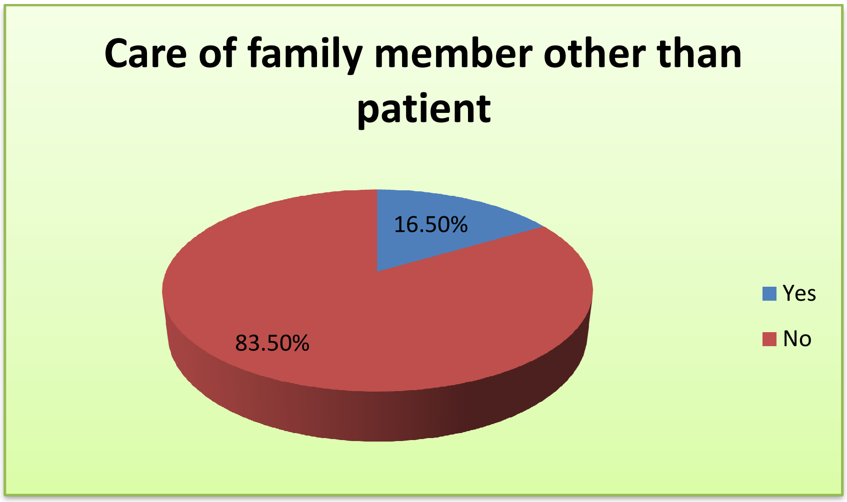


The above table reflects majority 66 (64.1%) family caregivers have family with more than four members and 56 (54.4%) of them live in joint families. 72 (70%) family caregivers have urban domicile while 19 (18.6%) have rural domicile and 12 (11.8%) have semi urban domicile. Further, it is evident that 86 (83.5%) family caregivers do not have additional responsibility of care giving to anyone else in the family other than the patient with dementia.

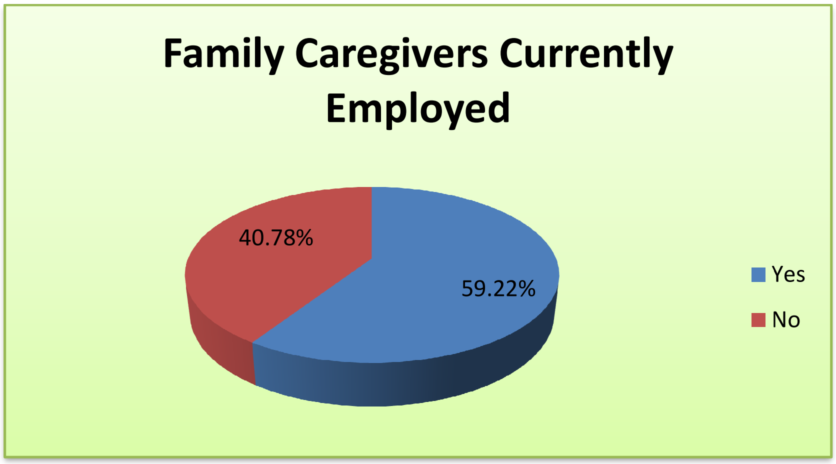
It emerges that as majority of family caregivers do not have additional responsibility of looking after other person than the patient with dementia in the family, they may possibly have less care giving burden.

The following table presents the frequency and percentage distribution of the data related to Employment status of the family caregivers. This will help to understand the financial arrangements done by the caregiver in the management of the dementia Patient.

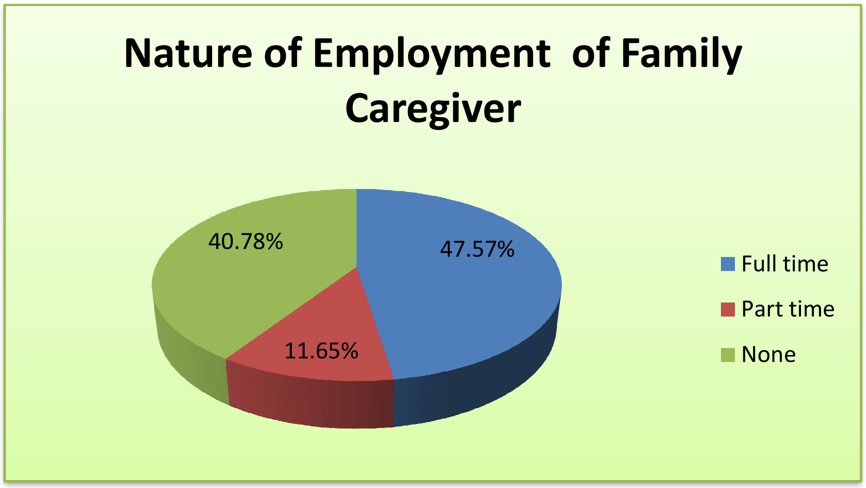
Table 3 Employment Status of Family Caregivers

Details	Frequency	Percentage
Currently Employed		
Yes	61	59.2
No	42	40.8
Current Employment Status /Nature of Employment		
Full time	49	47.6
Part time	12	11.6
None	42	40.8
Type of Job		
Non-Government	23	22.3
Government	12	11.6
Self Employed	26	25.24
No job	42	40.8
Total	**103**	**100**

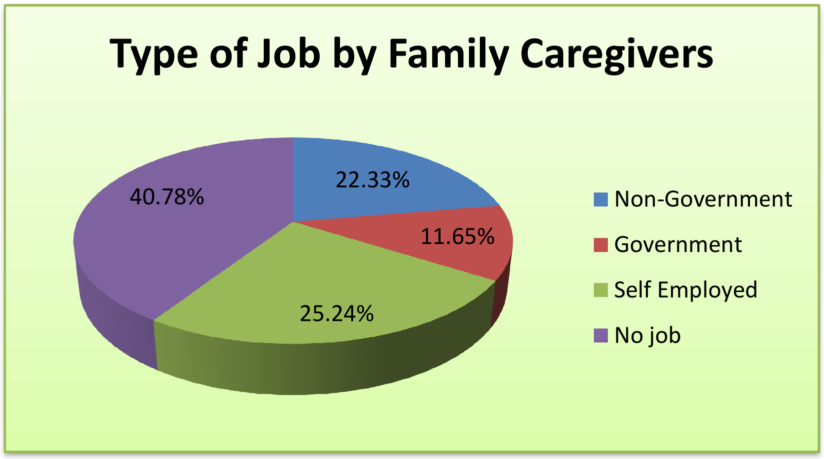
Graph No. 3.1



Graph No. 3.2



Graph No. 3.3



As it can be seen, majority of caregivers. 61 (59.2%) are currently employed out of which 49 (47.6%) are having full time jobs and 12 (11.6%) are having part time jobs. Majority of the caregivers 26(25.2%) are self employed (in to jobs like daily laborer in nearby industries, contract worker and farm labour and small shops) followed by 23(22.3%) caregivers into non-Government jobs.

Further, 40.8% are not having any job and 11.6% have part time jobs which are note worthy as caregiving to dementia patient without financial support is a challenge.

The following table presents the frequency and percentage distribution of the data related to monthly Income, source of income and household budget of the family. This will help to understand the financial arrangements done by the caregiver in the management of the dementia patient.

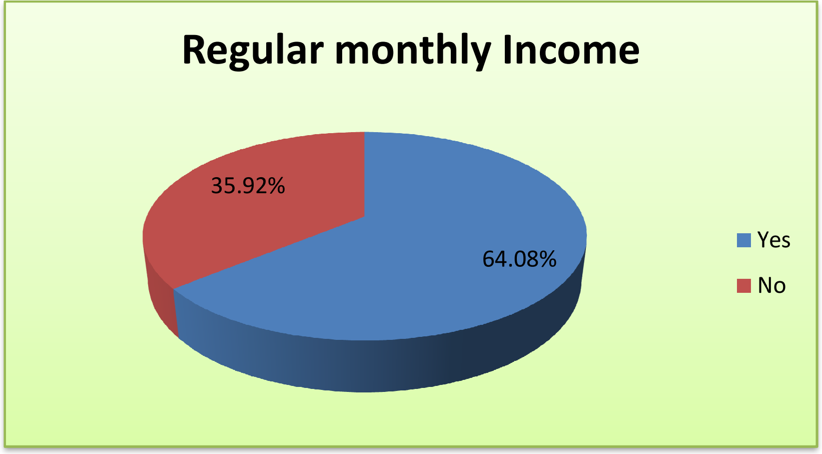
Table 3.1 Economic Status of Caregivers

Details	Frequency	Percentage
Regular monthly Income		
Yes	66	64.1
No	37	35.9
Monthly Household Income		
Less or equal to Rs.5000	15	14.6
Rs. 5001-10,000	25	24.3
Above Rs.10,000	63	61.2
Source of Household income		
Earnings of Family members	95	92.2
*Other	8	7.8
Financial Independence		
Yes	88	85.4
No	15	14.6
Total	**103**	**100**
Source of income for care giving expenses Multiple Response N= 103		
Household Budget	23	**22.3
From workplace	15	14.6
Pension	21	20.4
Other sources	19	18.4
Savings	61	59.2

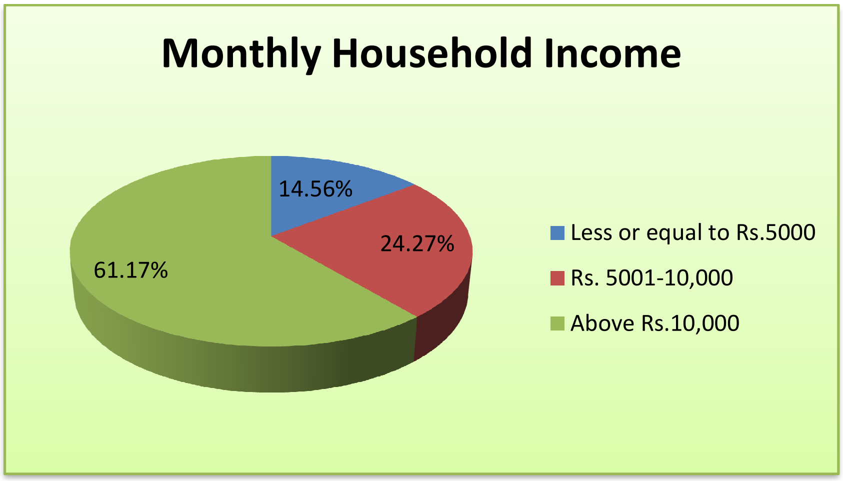
*other category includes earnings from both family members and relatives of the patient like married daughter, son-in-law, elder brother etc.

** Multiple response and hence the percentages do not add to 100. N=103

Graph No. 3.1.1



Graph No. 3.1.2.



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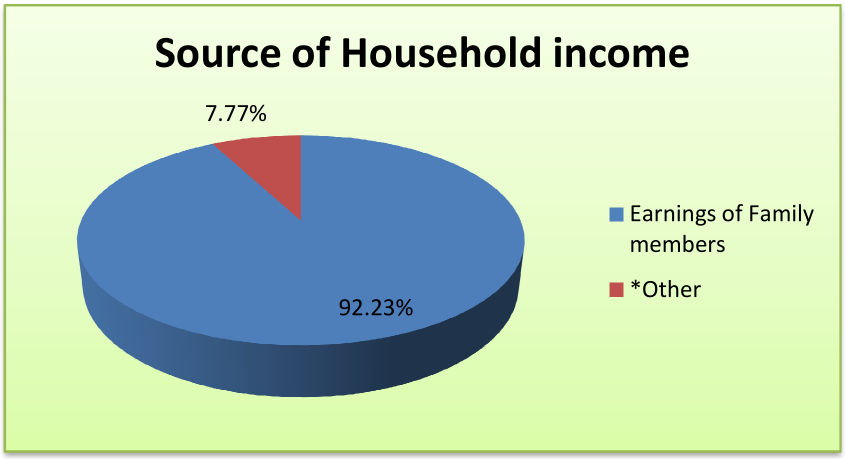
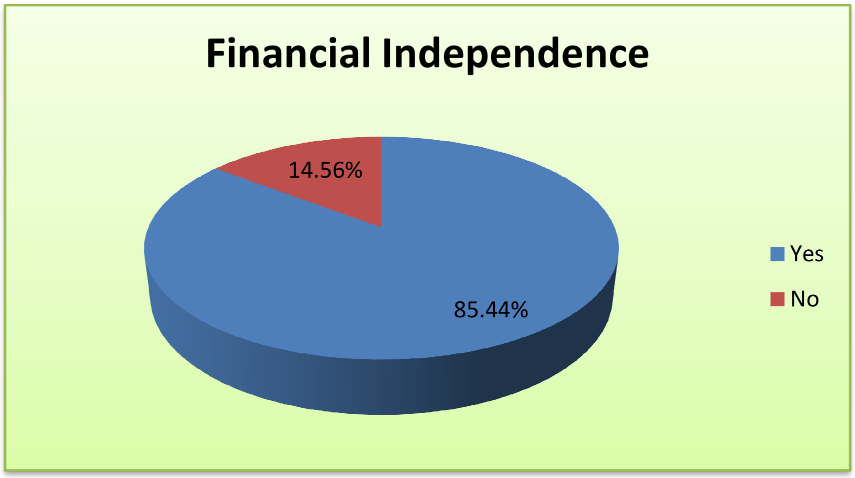
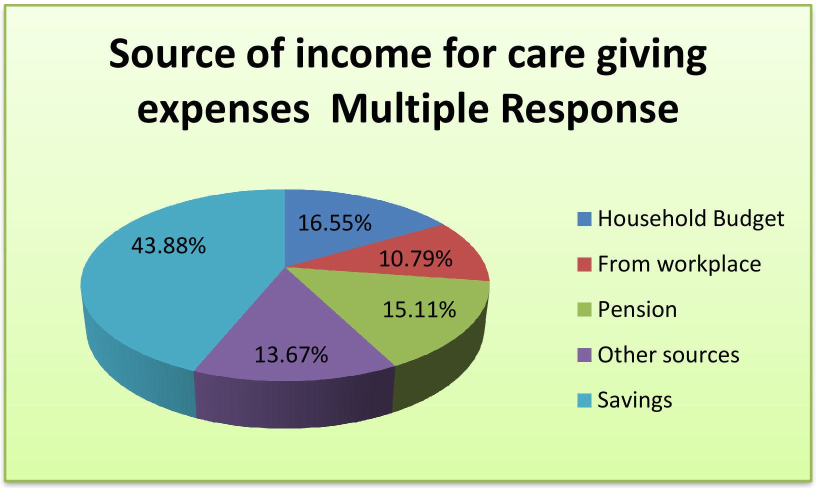


Graph No. 3.1.4



Graph No. 3.1.5



The above table reflects that out 103, 66 (64.1%) family caregivers have regular monthly income, 63(61.2%) family caregivers have monthly income above Rs. 10,000/- The main source of income for household is from the family members earning for 95(92.2%) caregivers. 88 (85.4%) caregivers are financially independent and for 61(59.2%) caregivers the major source of care giving expenses is from the savings while for 42(40.77%) caregivers is household budget.

It appears that the source of income for care giving expense is through savings and household budget and there is no financial support to the caregivers from outside.

SECTION-II CURRENT CARE GIVING ARRANGEMENTS

In the current section on care giving arrangements, data related to aspects like taking up caregivers role, care giving hours, sharing of the care giving responsibility by the family members, type of care provided, difficulties faced while providing care and who would take the role of caregiver in absence of the person who is currently looking after the patient is captured and presented with frequency and percentage distribution.

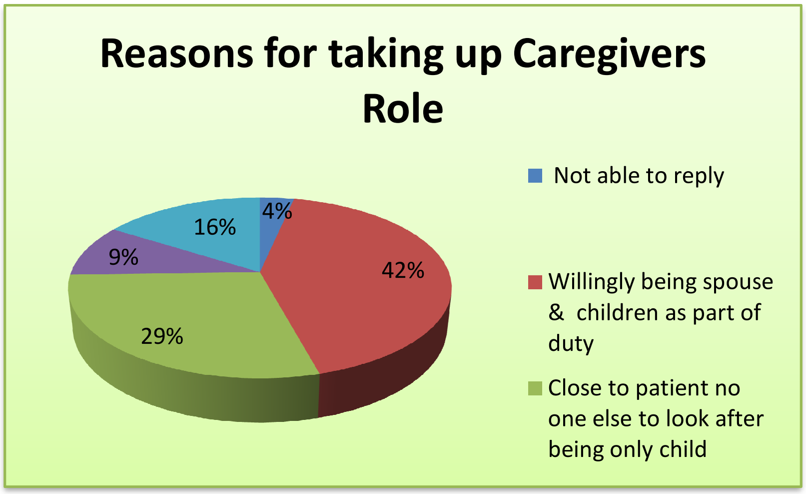
Following table represent multiple responses of the family caregivers as to how did they get in to the caregivers role. Being the open ended question, multiple responses were received; categories of the responses were made for better understanding.

Table 4 Reasons for taking up Caregivers Role

Responses	Frequency	*Percentage
Not able to reply	4	3.9
Willingly being spouse & children as part of duty	50	48.5
Close to patient no one else to look after being only child	34	33.0
By compulsion, no other choice	11	10.7
Sins of last birth, time to repay	19	18.4

*Multiple response and hence the percentages do not add to 100. N=103

Graph No. 4.1



Above table reflects that 50(48.5%) family caregivers got into the care giving role willingly, being spouse of the patient and children of the patient, giving care is the part of their duty, while 34(33%) caregivers got into the care giving role being the only child they felt close to the patient and there is no one else who can take care of the patient. 11(10.7) caregivers got into caregiver role due to compulsion and felt that there was no other choice while 19(18.4%) of them thought they are repaying the sins of last birth.

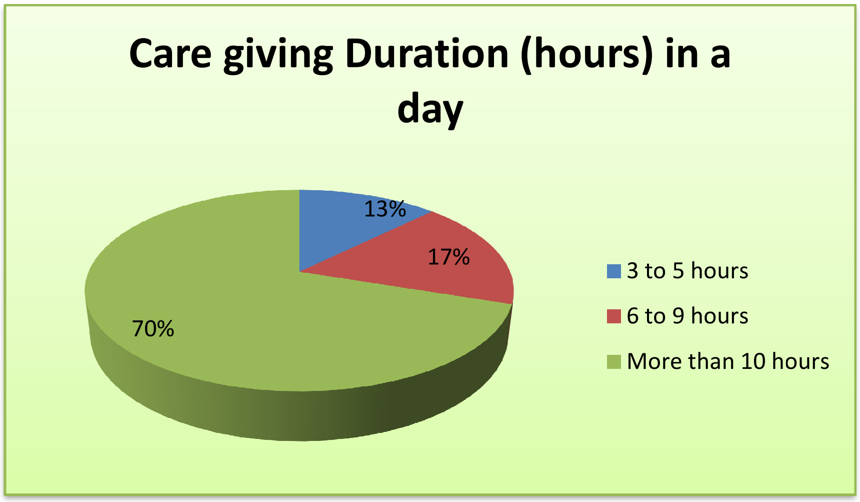
It appears that understanding reasons for how caregivers get into the caregiving role, will affect the care giving process.

The following table presents the frequency and percentage distribution of the data related to care giving duration in a day by the caregivers. This will help to understand how many hours caregivers have to give for management of dementia patient along with management of daily chores.

Table 5 Care giving Duration (hours) in a day

Care giving Duration	Frequency	Percentage
3 to 5 hours	13	12.6
6 to 9 hours	18	17.4
More than 10 hours	72	69.9
Total	**103**	**100**

Graph No. 5.1



From the above table it is evident that maximum 72(69.9 %) family caregivers give care for more than ten hours, followed by 18(17.4%) family caregivers giving care for 6 to 9 hours give while only 13(12.6%) give care for 3 to 5 hours.

It clearly appears that care giving duration is exceeding 10 hours in a day, which means that family caregivers may hardly get any time for any extra work as they stay engaged in care giving activities almost whole day.

The following table presents the frequency and percentage distribution of the data related as to who shares the responsibilities of care giving. This will help to understand people who share the responsibilities of care giving with the primary caregiver.

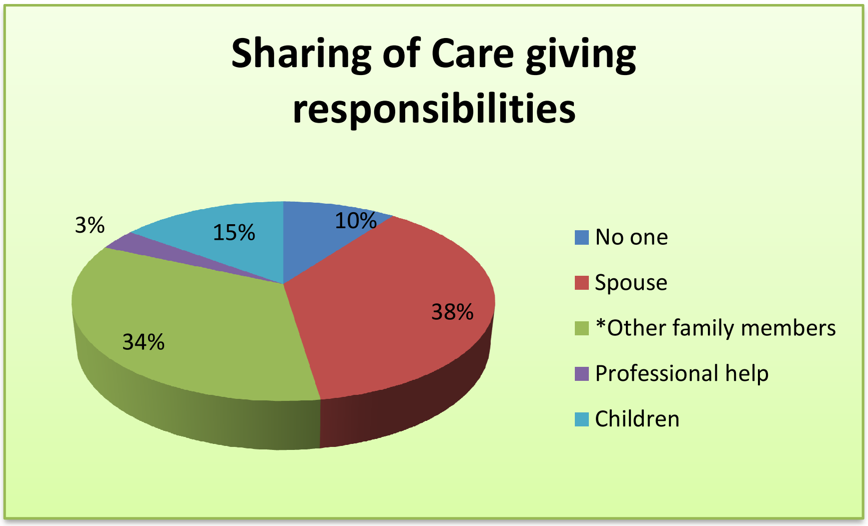
Table 6 Sharing of Care giving responsibilities

Response	Frequency	** Percentage
No one	15	14.6
Spouse	55	53.4
*Other family members	50	48.5
Professional help (part time for house hold work)	5	4.9
Children	22	21.4

*Other family members include spouse of the patient, daughter- in- law, son-in-law and siblings

**Multiple response and hence the percentages do not add to 100. N=103

Graph No. 6.1



From the above table it is obvious that sharing of care giving in majority is done by the spouse of the 55 family caregiver followed 50 caregivers who get the support from the other family members (daughter –in-law, spouse of the patient and siblings). Interestingly, 15 family caregivers have no one who can share their responsibility of care giving and 5 of them have professional help to share the responsibility.

It is clear that majority of care giving responsibility is shared by the primary caregiver, which means it is daughter-in –law if son has identified himself as primary caregiver and son-in-law incase of married daughter who is taking care.

Following table presents frequency and distribution of type of care provided by the family caregivers. To gain clarity, care types were categorized viz; Activities of daily living (ADL) such as help with bathing, dressing, using the toilet, shaving, doing hair, getting in and out of the bath and feeding. Instrumental activities of daily living (IADL) such as help with meal preparation, cleaning and laundry, use of telephone and money management, Entertainment; taking patient to place of worship, for a stroll, operating TV, being with the patient during socializing and celebrations, playing music and Transportation, shopping, supervision for safety and Medicine administration.

Table 7 Type of Care provided by the family caregivers

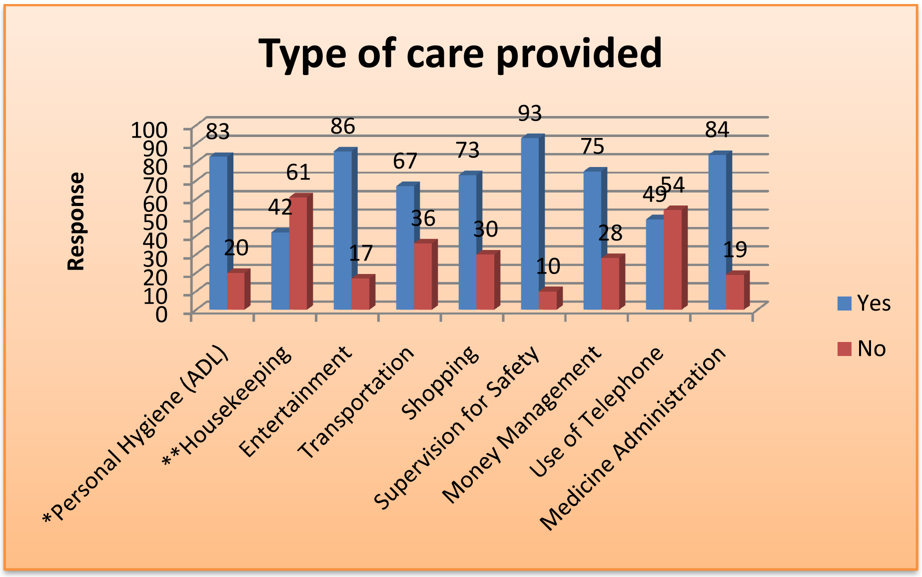
Type of care provided	**Yes**		**No**		**Total**	
	N	**%**	**N**	**%**	**N**	**%**
*Personal Hygiene (ADL)	83	80.6	20	19.4	103	100
**Housekeeping	42	40.8	61	59.2	103	100
Entertainment	86	83.5	17	16.5	103	100
Transportation	67	65.0	36	35.0	103	100
Shopping	73	70.9	30	29.1	103	100
Supervision for Safety	93	90.3	10	9.7	103	100
Money Management	75	72.8	28	27.2	103	100
Use of Telephone	49	47.6	54	52.4	103	100
Medicine Administration	84	81.6	19	18.4	103	100

Personal hygiene reflects help with bathing, dressing, using the toilet, shaving, getting in and out of the bath, and feeding

**Housekeeping reflects help with meal preparation, cleaning and laundry

Adapted from Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living.

Graph No. 7.1



From the above table it is evident that maximum 93(90.3%) caregivers supervise for safety of the patient followed by 86(83.5%) caregivers look after care related to entertainment ; which includes activities like operating TV for the patient, talking them for a walk, taking patient to the place of worship, social gatherings etc. and 83(80.6%) of caregivers provide care related to personal hygiene which includes activities like bathing, dressing, using the toilet, shaving, getting in and out of the bath, and feeding. It is also evident that 61 (59.2%) caregivers do not provide care related to housekeeping which includes activities like meal preparation, cleaning and laundry.

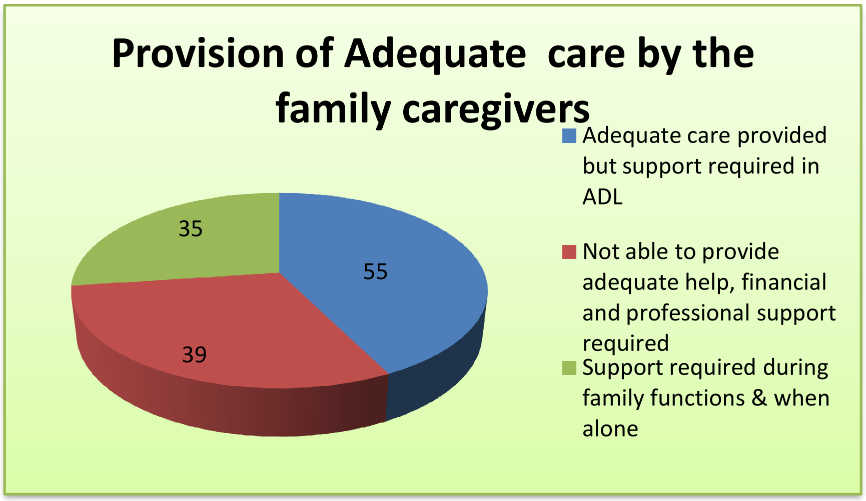
Thus supervision for safety; entertainment and activities of daily living have emerged as significant in this study which is very typical to the patient of dementia.

Following table presents responses of the family caregivers to understand whether they are able to provide adequate care and which other type of care / specific support is needed by them in the management of Patient with Dementia (PWD).

Table 8 Provision of Adequate care by the family caregivers

Responses	Frequency	*Percentage
Adequate care provided but support required in ADL	55	53.3
Not able to provide adequate help, financial and professional support required	39	37.86
Support required during family functions & when alone	35	33. 98
*Multiple response and hence the frequency and percentages do not add to 100. N=103		

Graph No. 8.1



The above table reflects that majority 55(53.3%) of family caregivers are able to give adequate care but support is required in performing Activities of Daily Living (ADL), for the patient. While 39 37.86%) family caregivers feel that they are not able to provide adequate care and need financial and professional support. 35(33.98) Caregivers feel that support is required for looking after the patient during family functions and when no one is at home.

It is very clear that Three things – 1) support in Activities of daily living, 2) financial and professional support and 3) management/ handling of the patient during family functions, when no one is at home makes care givers feel that the care they provide is inadequate.

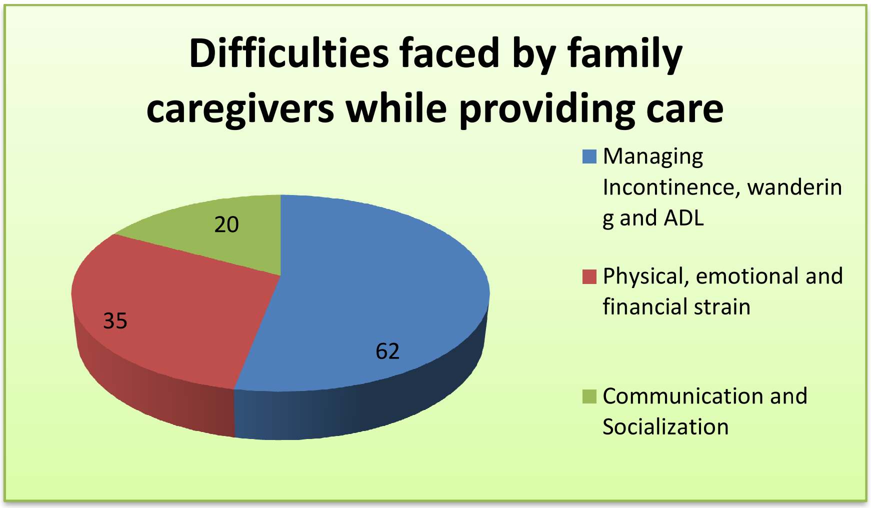
Following table presents responses of the family caregivers to understand difficulties faced by them while providing care to the Patient with Dementia (PWD).

Table 9 Difficulties faced by family caregivers while providing care

Difficulties faced	Frequency	*Percentage
Managing Incontinence, wandering and ADL	62	60.19
Physical, emotional and financial strain	35	33.98
Communication and Socialization	20	19.41

*Multiple response and hence the frequency and percentages do not add to 100. N=103

Graph No. 9.1



The above table reflects that the majority 62(60.19%) of family caregivers have faced difficulties in managing incontinence, wandering and Activities of daily living. 35(33.98%) caregivers had difficulty in providing care due to physical, emotional and financial strain while 20(19.41%) caregivers faced difficulty in communication with the patient and socialization with friends, relatives and society.

Clearly three most typical behaviours seen in the patient with dementia i.e. Managing of incontinence, wandering and ADL have emerged as three most difficult behaviours the caregivers have to manage.

Following table presents responses of the family caregivers to know that who will replace them for giving care to the patient.

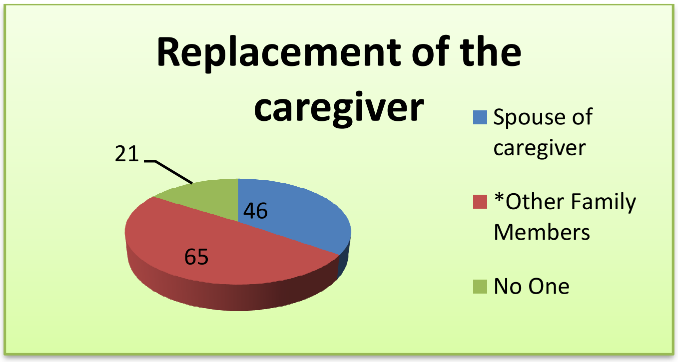
Table10 Replacement of the caregiver

Persons likely to replace	Frequency	**Percentage
Spouse of caregiver	46	44.66
*Other Family Members	65	63.10
No One	21	20.38

*Other family members include daughter- in- law, son-in-law and siblings.

***Multiple response and hence the percentages do not add to 100**.** N=103

Graph No. 10.1



The above table reflects that 65(63.10%) family caregivers responded that other family members like daughter- in- law, son-in-law and siblings will replace them i.e. take up care giving activities in their absence. 46(44.66%) Family caregivers feel that their spouse will replace them and interestingly 21(20.38) family caregivers have no one who can look after the patient in their absence.

It Appears that Family members (daughter- in- law, son-in-law and siblings) have emerged as significant aspect of informal support as well as important indicator of replacing the current primary caregiver.

SECTION-III DEMENTIA SYMPOTMS, ASSOCIATED ISSUES AND ITS MANAGEMENT

The current section captures the data about dementia symptoms present in the patient. The major parameters covered in this section are cognitive, behavioral, psychological and physical changes / symptoms in the patients, severity of these symptoms and distress caused by it. Further, impact due to these changes and symptoms on the behavior of the patient, problems experienced by the caregivers in management of the patient, domains in which stress is felt by the caregivers, strategies adopted by them to overcome the felt stress and if they have dropped any activities due to their care giving responsibilities are covered.

It was also felt necessary to understand if along with dementia symptoms there exist other medical conditions, which needs caregivers attention. This data is presented in the following table along with the frequency and percentage distribution.

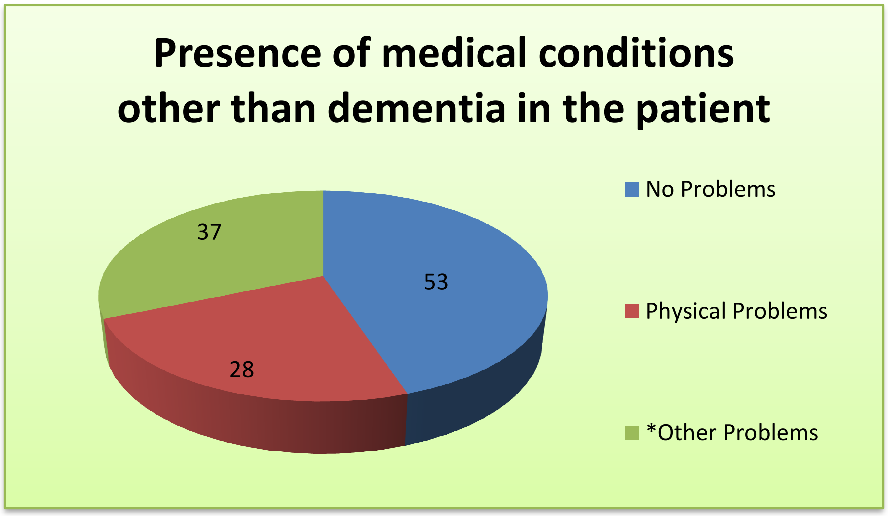
Table 11 Presence of medical conditions other than dementia in the patient

Medical problems other than dementia	Frequency	**Percentage
No Problems	53	51.5
Physical Problems	28	27.2
*Other Problems	37	35.9
**Total		

* other problems include: hyper acidity ,hypertension ,diabetes

** Multiple response and hence the percentages do not add to 100. N=103

Graph No. 11.1



The above table reflects that the majority 53(51.5%) of family caregivers have reported that no other medical problems are faced by the patients and they need no medication, While 28(27.2%) family caregivers reported that patients are facing problems of hyperacidity, hypertension and diabetes.

Table 12 to Table 15 presents data pertaining to symptoms possibly present in the patient with Dementia, in terms of association between severity of these symptoms and distress level of the family caregivers. To understand these symptoms Neuro Psychiatry Inventory (NPI) has been used. Wherein, three point scales from mild to severe has been used to understand the severity of symptoms among the patient and five point scales from No-distress to extreme-distress has been used to understand the distress level among the family caregivers.

Following table gives the frequency and percentage distribution of presence of cognitive impairment symptoms in patients, its severity level (mild, moderate and high) along with the kind of distress experienced by the caregivers due to these symptoms (no distress, minimal, mild, moderate, severe and extreme).

Table 12 Cognitive impairment in patients

Cognitive Impairment in patients	Delusion		Hallucinations		Irritability		Motor Disturbance	
	N	%	N	%	N	%	N	%
Presence of Symptoms								
Yes	84	81.6	74	71.8	91	88.3	58	56.3
No	19	18.4	29	28.2	12	11.7	45	43.7
Total	**103**	**100**	**103**	**100**	**103**	**100**	**103**	**100**
Severity level of the symptom								
Mild	36	42.9	14	18.9	34	37.4	23	39.7
Moderate	40	47.6	34	45.9	39	42.9	17	29.3
High	8	9.5	26	35.1	18	19.8	18	31.0
***Total**	**84**		**74**		**91**		**58**	
Distress faced by caregivers								
No	6	7.1	5	6.8	4	4.4	7	12.1
Minimal	5	6.0	7	9.5	9	9.9	7	12.1
Mild	37	44.0	17	23.0	54	59.3	20	34.5
Moderate	32	38.1	20	27.0	10	11.0	14	24.1
Severe	4	4.8	25	33.8	11	12.1	10	17.2
Extreme	0	.0	0	.0	3	3.3	0	.0
***Total**	**84**		**74**		**91**		**58**	

* Multiple response and hence the frequency and percentages do not add to 100. N=103

From the above table it is evident that out of total 103, maximum family caregivers 91 (88.3%) have confirmed presence of irritability symptom as a cognitive impairment followed by 84 (81.6%) delusions and 74 (71.8%) hallucinations in the patients, further when this is seen with the severity of the symptom 39(42.9%) patients have moderate irritability symptom and mild distress is felt by 54(59.3%) caregivers. Severity of delusion is moderate in 40 (47.6%) patients and mild distress is felt by 37 (44%) caregivers. Severity of hallucination is moderate in 34 (45.9%) and severe distress is felt by 25 (33.8%) caregivers.

Clearly symptom of hallucination as a part of cognitive impairment in the patient with dementia has emerged as a factor creating severe distress among the caregivers as compared to other symptoms of delusion and irritability.

The following table presents multiple responses of the family caregivers related to management of patient's behavior due to cognitive impairment. Management of behavioral aspects like suspicion, accusation, talking with unseen people, shouting-yelling and repetitive actions are covered.

Table 12.1 Management of the patient by family caregivers due to cognitive impairment

Responses	Frequency	*Percentage
Make Patient understand no one is stealing things		
Become Strict with Patient	**24**	**41.3**
Calm the patient and show patience	**34**	**58.62**
Total	***58**	
Accusations by the patients in front of others		
Feeling Sad, Ashamed & embarrassed	**27**	**50.9**
Do nothing as it is not patients fault	**26**	**49.05**
Total	***53**	
Patient talks to unseen people/ hear voices		
Do nothing let patient talk	**16**	**34.7**
Give sleeping medicine, distract patient, do prayers	**30**	**65.2**
Total	***46**	
Patient shouts and yells		
Calm the patient, distract & do as per patients wish	**32**	**42.1**
Get angry, leave patient alone, sleeping medicine	**44**	**57.8**
Total	***76**	
Patients does repetitive actions		
Make patient sleep or watch TV, distract or Leave patient alone	**26**	**60.4**
Constant Supervision, allow to do activities as far as they are safe	**17**	**39.5**
Total	***43**	

* Multiple response and hence the frequency and percentages do not add to 100. N=103

From the above table it is evident that managing behavior of the patient due to cognitive impairment, out of total 76, 44(57.8%) family caregivers have reported to manage shouting and yelling of the patient by giving them sleeping medicine, leaving the patient alone and honestly submitted that they also get angry on the patient. While 32 (42.1%) of them try to calm, distract or do as the patient say. Out of 58 family caregivers 34(58.6%) have reported that they calm the patient and make them understand that no one is stealing things while 24(41.3%) of them reported of becoming strict with patient and scold them. 53 family caregivers reported that they feel sad, ashamed & embarrassed ashamed and do nothing as it is not the patients fault when the patient is accusing the family members in front of others.

It is clearly seen that behavior due to cognitive impairment is difficult to manage by the caregiver and mostly they have applied negatives of dealing with the patient.

Following table gives the frequency and percentage distribution of presence of possible behavioral changes occurring in the patients with dementia, its severity level viz mild, moderate and high along with the kind of distress experienced by the caregivers due to these changes viz no distress, minimal, mild, moderate, severe and extreme

Table 13 Behavioral Changes in patients

Behavioral Changes in Patients	**Night time behavior**		**Appetite & Eating**		**Incontinence**		**Wandering**		**Communication**	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Presence of Symptoms										
Yes	69	67.0	48	46.6	77	74.8	73	70.9	90	87.4
No	34	33.0	55	53.4	26	25.2	30	29.1	13	12.6
Total	**103**	**100**	**103** **100**		**103**	**100**	**103**	**100**	**103**	**100**
Severity level of the Symptoms										
Mild	12	17.4	17	35.4	17	22.1	29	39.7	26	28.9
Moderate	43	62.3	10	20.8	18	23.4	25	34.2	29	32.2
High	14	20.3	21	43.8	42	54.5	19	26.0	35	38.9
***Total**	**69**		**48**		**77**		**73**		**90**	
Distress experienced by caregivers										
No	1	1.4	3	6.3	1	1.3	4	5.5	5	5.6
Minimal	7	10.1	2	4.2	14	18.2	9	12.3	12	13.3
Mild	16	23.2	13	27.1	15	19.5	29	39.7	21	23.3
Moderate	34	49.3	7	14.6	9	11.7	10	13.7	17	18.9
Severe	11	15.9	13	27.1	23	29.9	19	26.0	28	31.1
Extreme	0	.0	10	20.8	15	19.5	2	2.7	7	7.8
***Total**	**69**		**48**		**77**		**73**		**90**	

* Multiple response and hence the frequency and percentages do not add to 100. N=103

From the above table it is evident that out of total 103, maximum 90(87.4%) family caregivers have confirmed communication problem followed by 77(74.8%) respondents have confirmed problem of incontinence and 73(70.9%) respondents have confirmed problem of wandering. Further when this is seen with the severity of the symptom and distress caused by it, 35(38.9%) and 42(54.4%) caregivers reported high level of severity for communication and Incontinence behavior respectively while 29(39.7%) reported mild level of severity for wandering behavior. 35(38.9%) Caregivers reported sever to extreme distress for the communication behavior while 38(49.4%) caregivers reported severe to extreme distress for incontinence behavior. Inspite of severity of wandering behavior is mild, 58(79.4%) caregivers reported mild to severe distress.

Symptoms/ behaviours very typical of patient with dementia i.e Communication, Incontinence and Wandering have emerged as behavioral problems which cause distress among caregivers.

The following table presents multiple responses of the family caregivers related to management of possible behavioral changes occurring in the patients with dementia, Aspects like managing nighttime behaviours and wandering, understanding eating and toilet needs of the patient and talking habits of the patient.

Table 13.1 Management of the patient by family caregivers due to Behavioral changes

Responses	**Frequency**	***Percentage**
Precautions to prevent patient from wandering & waking up in night		
Not able to manage, if patient sleeps during day time does not wander in night	49	49.49
Someone sleeps with the patient, door is locked, railing on all sides of the bed, constant supervision	50	50.50
Total*	**99**	
Understand if patient had taken enough food		
Food intake is from Less to normal, food is given as much patient can finish	52	61.2
Food given on regular intervals with specific portion, liquid diet if bedridden	33	38.8
Total*	**85**	
Patient either talks a lot or is extremely quiet		
Not able to communicate, leave patient alone	39	48.41
Try to change the topic, distraction, explain things repeatedly, with actions	42	51.8
Total*	**81**	
Realize that patient wants to eat or go to toilet		
Paces in the room , observing patients behavior, take to bathroom at regular interval	35	38.46
Not able to understand, feaces anywhere, feaces in bed	56	61.53
Total*	**91**	
* Multiple response and hence the frequency and percentages do not add to 100. N=103		

From the above table it is evident 99 family caregivers have reported taking precautions for managing nighttime behaviours and wandering. Out of which 50(50.5%) caregivers said that someone sleeps with the patient, door is locked, railing is there on all sides of the bed and constant supervision is done to manage the patient. While 49(49.4%) of them said that they are not able to manage wandering and night time behaviours however, if patient sleeps during day time do not wander in night. 85 family caregivers have reported food related behavior of the patient. 52 (62.2%) of them say that they give the patient as much as the patient can eat. While 33(38.8%) of them give food on regular intervals with specific portion and liquid diet if the patient is bedridden. Further out of 91, 56 (61.53%) family caregivers reported that they are not able to understand whether patient wants to eat or go to toilet, the patient faces anywhere.

It appears that constant vigilance and management of incontinence is what family caregivers do while managing typical behavior of the patient with Dementia.

Following table gives the frequency and percentage distribution of possible psychological changes occurring in the patients with dementia, its severity level viz mild, moderate and high along with the kind of distress experienced by the caregivers due to these changes viz no distress, minimal, mild, moderate, severe and extreme.

Table 14 Psychological Changes in patients

Psychological Changes in the patient	**Agitation**		**Depression**		**Disinhibition**		**Disorientation**	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Presence of Symptoms								
Yes	41	39.8	73	70.9	72	69.9	84	81.6
No	62	60.2	30	29.1	31	30.1	19	18.4
Total	**103**	**100**	**103**	**100**	**100**	**103**	**100**	**103**
Severity level of symptom								
Mild	11	26.8	22	30.1	15	20.8	35	41.7
Moderate	21	51.2	45	61.6	43	59.7	23	27.4
High	9	22.0	6	8.2	14	19.4	26	31.0
***Total**	**41**		**73**		**72**		**84**	
Distress experienced by caregivers								
No	2	4.9	4	5.5	2	2.8	7	8.3
Minimal	2	4.9	6	8.2	4	5.6	16	19.0
Mild	18	43.9	29	39.7	36	50.0	23	27.4
Moderate	15	36.6	33	45.2	27	37.5	15	17.9
Severe	4	9.8	1	1.4	3	4.2	13	15.5
Extreme	0	.0	0	.0	0	.0	10	11.9
***Total**	**41**		**73**		**72**		**84**	

* Multiple response and hence the frequency and percentages do not add to 100. N=103

From the above table it is evident that out of total 103, maximum (84) family caregivers have confirmed disorientation followed by (73) family caregivers confirming depression as a result of psychological changes in the patient. Further when seen with the severity of the symptom and distress caused by it, 58(69.1%) family caregivers have reported mild to moderate level of severity due to disorientation and distress caused by it ranges from mild to extreme. Moderate severity of depression is reported by 45(61.6%) caregivers and distress felt is also moderate. (31) Caregivers have experienced severity in all the psychological areas but more in disorientation.

Very clearly Disorientation and depression have emerged as psychological change in the patient as witnessed by the caregivers. The severity and distress levels are moderate.

The following table presents multiple responses of the family caregivers related to management of possible psychological changes occurring in the patients with dementia. Aspects like agitation, aggression, making patient participate in family discussion, orientation to the patient about time, place and people and bizarre behavior in front of others are covered.

Table 14.1 Management of the patient by family caregivers due to psychological changes

Responses	**Frequency**	***Percentage**
Patient showing agitation /aggression		
Talk to patient politely as well as strictly, make them sit in one place or give sleeping medicine	38	61.3
Not able to control situation	24	38.7
***Total**	**62**	
Help patient participate in family discussion		
Keep patient involve in talks held in the family, call relatives to talk with the patient	16	30.8
Patient not able to participate because of forgetfulness and is bedridden	36	69.3
***Total**	**52**	
Bizarre behavior of the patient in front of others		
Feeling of embarrassment, feeling sad, Angry ashamed	29	49.1
Pity the patient, understand that patient is not doing it purposely, avoid situation , leave the place	30	50.84
* **Total**	**59**	
Orient patient about time , place and people around		
Child like behavior, difficult to understand don't know what to do	22	37.9
Reminder for past incidence reintroduce persons	36	62.0
***Total**	**58**	
* Multiple response and hence the frequency and percentages do not add to 100. N=103		

From the above table it is evident that managing the patient due to behavioral changes, (62) family caregivers have reported managing patient showing agitation and aggression, out of which 38(61.3%) of them have reported that they are both Strict & polite with the patient, make the patient sit in one place or give sleeping medicine followed to manage aggressive behavior. (59) Family caregivers reported of managing bizarre behavior by the patient in front of others, out of which 30(50.84%) caregivers manage the situation by leaving the place of incidence, try to avoid such situation, pity the patient and understand that patient is not behaving purposely.

Aggression, Agitation and bizarre behavior of the patient have emerged as a concern due to psychological changes in the patient.

Following table gives the frequency and percentage distribution of physical pain and safety issues related to the patients with dementia, its severity level viz mild, moderate and high along with the kind of distress experienced by the caregivers due to these changes viz no distress, minimal, mild, moderate, severe and extreme.

Table 15 Physical Pain & Safety Issues in patients

Physical Pain & Safety Issues	Mobility		Self Hygiene		Eating Habits		Confined to bed	
	N	%	N	%	N	%	N	%
Presence of Symptoms								
Yes	82	79.6	85	82.5	63	61.2	41	39.8
No	21	20.4	18	17.5	40	38.8	62	60.2
Total	**103**	**100**	**103**	**100**	**103**	**100**	**103**	**100**
Severity level of Symptoms								
Mild	25	30.5	21	24.7	12	19.0	10	24.4
Moderate	25	30.5	34	40.0	12	19.0	02	4.9
High	32	39.0	30	35.3	39	61.9	29	70.7
***Total**	**82**		**85**		**63**		**41**	
Distress experienced by caregivers								
No	07	8.5	02	2.4	03	4.8	07	17.1
Minimal	02	2.4	08	9.4	03	4.8	03	7.3
Mild	24	29.3	32	37.6	11	17.5	01	2.4
Moderate	22	26.8	16	18.8	03	4.8	01	2.4
Severe	20	24.4	19	22.4	28	44.4	10	24.4
Extreme	07	8.5	08	9.4	15	23.8	19	46.3
***Total**	**82**		**85**		**63**		**41**	

* Multiple response and hence the frequency and percentages do not add to 100. N=103

From the above table it is evident that out of total 103, (85) family caregivers have confirmed self hygiene, followed by (82) caregivers confirming issue of mobility and (63) caregivers confirming eating habits as physical and safety related issues they face with the patient. Further, when this is seen with the severity of the symptom and distress caused by it, 34(40%) caregivers have felt issue of maintaining self hygiene of the patient as moderate and the distress felt due to it, is mild. While, 32(37.6%) caregivers felt the issue of patient mobility as highly severe and distress cause by it as mild. 39(61.9%) caregivers felt the issue of eating habits as high and distress felt by them is severe.

It appears maintaining self hygiene for the patient, mobility issue and eating habits of the patient have emerged as three major issues related to physical pain and safety of the patient. Distress caused by self hygiene and mobility issue is mild while that of eating habits is high.

The following table presents multiple responses of the family caregivers related to management of physical and safety issues related to the patients with dementia. Special structural changes to avoid patient from falling /getting hurt, precautions during bathing, feeding, shifting from the bed of the patient, are the aspects covered.

Table 15.1 Management of the patient by family caregivers with Physical pain & Safety issues

Responses	**Frequency**	**Percentage**
Special structural changes to avoid patient from falling /getting hurt		
Not possible due to space constrain	34	46.5
Constant supervision, railing on bedside, bed is on floor, remove unsafe things	39	53.4
*Total	**73**	
Managing patient with food, bath and dressing		
Help by the family members and nurse	40	40
Bedridden but persuasion in eating food & Support in sponging and dressing required	60	60
*Total	**100**	
Ensure safety of the patient while feeding, bathing and dressing		
Keep floor clean, constant supervision	21	45.6
Careful during shifting, moving around, lock the patient in the room at times with someone to watch	25	54.3
***Total**	**46**	
Shift the patient from the bed		
Hold hands, wheel chair, support of nurse	31	59.6
Not possible bedridden	21	40.4
***Total**	**52**	
* Multiple response and hence the frequency and percentages do not add to 100. N=103		

From the above table it is evident that (100) family caregivers have reported managing feeding, bathing and dressing the patient as an important issues related to physical pain and safety. Out of which (60) have reported that support in bathing and dressing is required and lot of persuasion is required for making patient eat. (73) family caregivers have reported special structural changes to avoid patient from falling /getting hurt in which (39) of them manage the same by constant supervision, putting railing on bedside or putting bed is on floor and by removing unsafe things from the patients' room / nearby place.

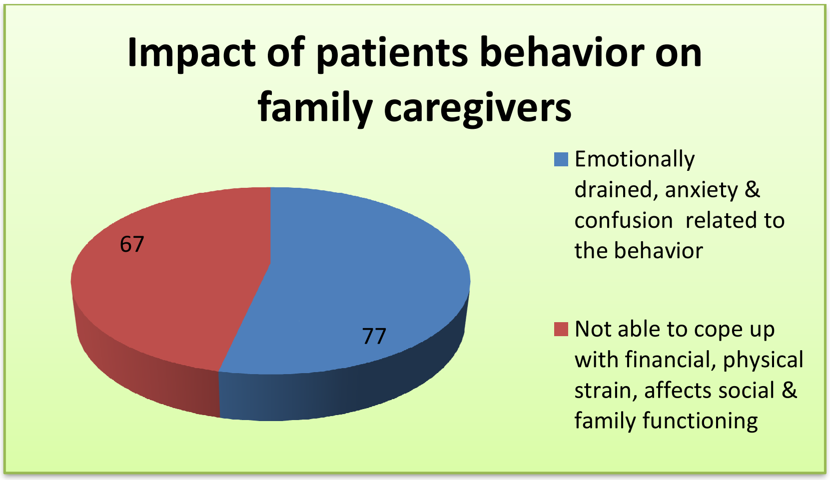
Bathing, dressing and feeding the patient has emerged as important issue related Safety and physical pain of the patient.

Following two tables 16 & 17 show response related to the impact of patients behavior on the family caregivers and if there are any other problems faced by them, as each patient of dementia may show typical symptoms and behavior.

Table 16 Impact of patients behavior on family caregivers

Response	**Frequency**	**Percentage**
Emotionally drained, anxiety & confusion related to the behavior	77	78.6
Not able to cope up with financial, physical strain, affects social & family functioning	67	68.4
Total	**98**	
* Multiple response and hence the frequency and percentages do not add to 100. N=103		

Graph No. 16.1



From the above table it is evident that out of total 103, (98) family caregivers have agreed that patient's behavior impacts them negatively, out of total (98), 77(78.6%) caregivers responded behavior of the patients due to psychological symptoms makes them emotionally drained and creates lot of anxiety and confusion related to the behavior. While 67(68.4%) of them are not able to cope up with the financial and physical strain and they feel that their family functioning and social life is affected due to the patients behavior.

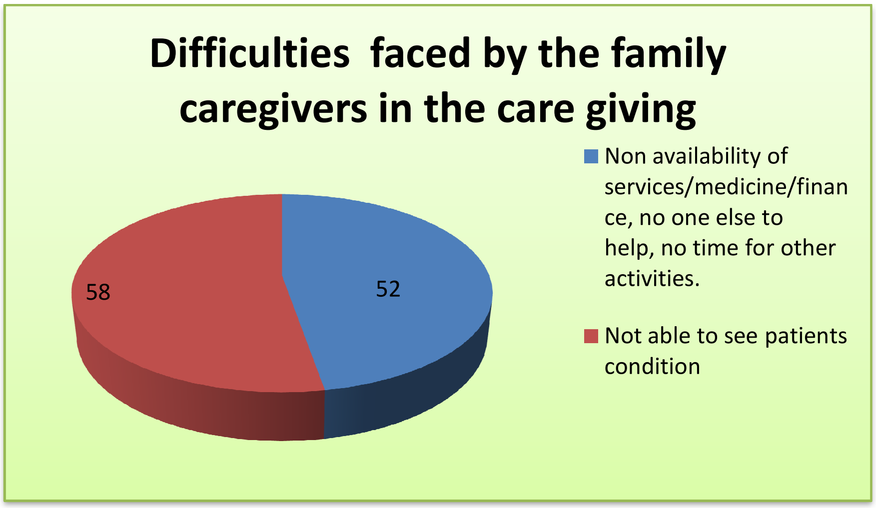
It appears that the behavior of the patient due to various cognitive impairment and psychological symptoms has negatively affected the caregivers.

Table 17 Difficulties faced by the family caregivers in the care giving

Response	Frequency	*Percentage
Non availability of services/medicine/finance, no one else to help, no time for other activities.	52	55.9
Not able to see patients condition	58	62.4
Total	**93**	

* Multiple response and hence the frequency and percentages do not add to 100. N=103

Graph No. 17.1



From the above table it is evident that out of total 103, 93 family caregivers have agreed of facing the difficulties while giving care and looking after the patient. Out of which, 58(62.4%) are not able to see patients' condition. While 52(55.9%) face the difficulties due to non availability of services /medicine/finance and lack of support.

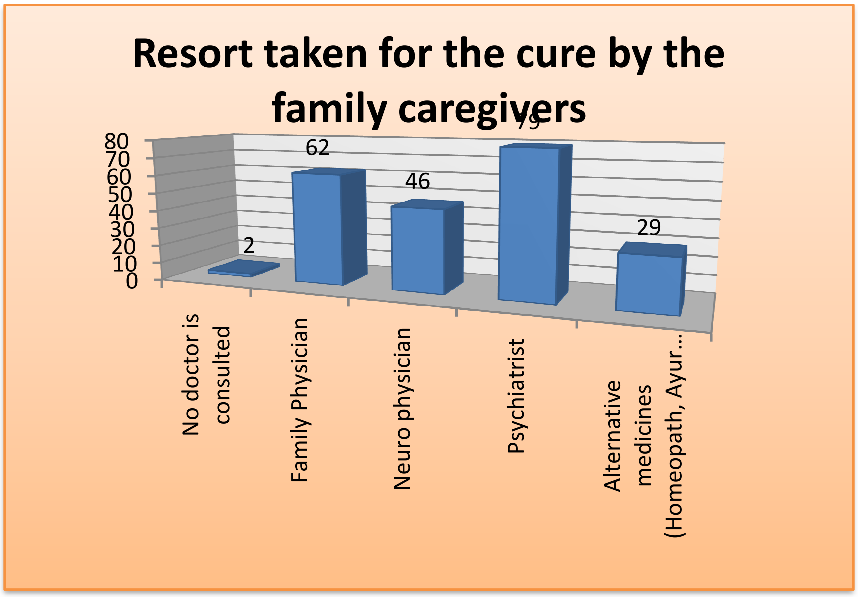
It appears that difficulties faced by the caregivers while looking after the patient are not able to see the patient's condition, lack of support, non availability of services, medicines and finance.

To further understand the possible areas of care giving which may require caregivers time and availability were probed. The following two tables highlight the frequency of visit to the doctors or alternative ways of healing on regular basis.

Table 18 Resort taken for the cure by the family caregivers

Response	**Frequency**	**Percentage**
No doctor is consulted	2	1.9
Family Physician	62	60.2
Neuro physician	46	44.7
Psychiatrist	79	76.7
Alternative medicines (Homeopath, Ayurved, religious /spiritual place)	29	28.2
Total	**103**	**100**

Graph No. 18.1



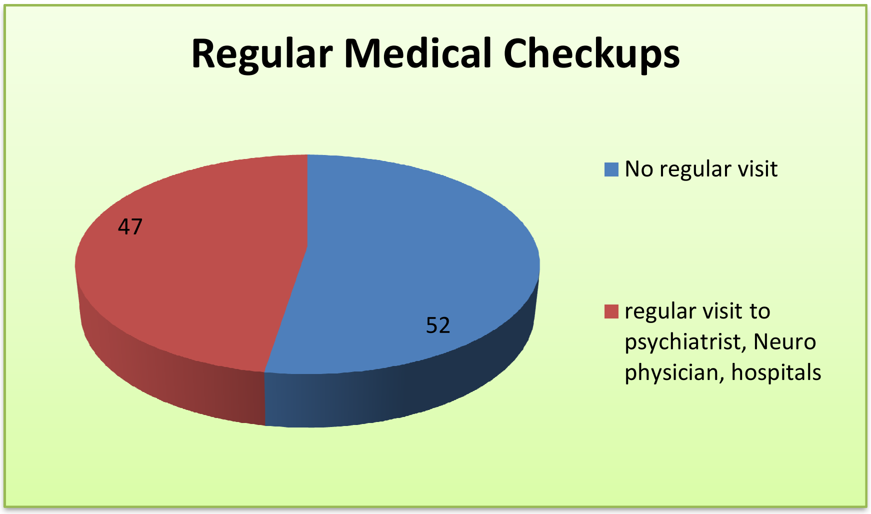
From the above table it is evident that out of total 103, 79(76.7%) family caregivers consult the psychiatrist on regular basis followed by 62(60.2%) caregivers visiting family physician and (46) neuro physician. Very few family caregivers 2(1.9%) do not consult any doctor on regular basis.

It appears that very few take resort to alternative source of medicines like Homeopath, Ayurved, and visit religious /spiritual places.

Table 19 Regular Medical Checkups

Response	**Frequency**	**Percentage**
No regular visit	52	52.5
regular visit to psychiatrist, Neuro physician, hospitals	47	47.5
Total	**99**	**100**

Graph No. 19.1



From the above table it is evident that out of total 103, 52(52.5%) family caregivers do not have to take the patient for regular medical tests and checkups. While 47(47.5%) of them require regular visits to doctors and experts.

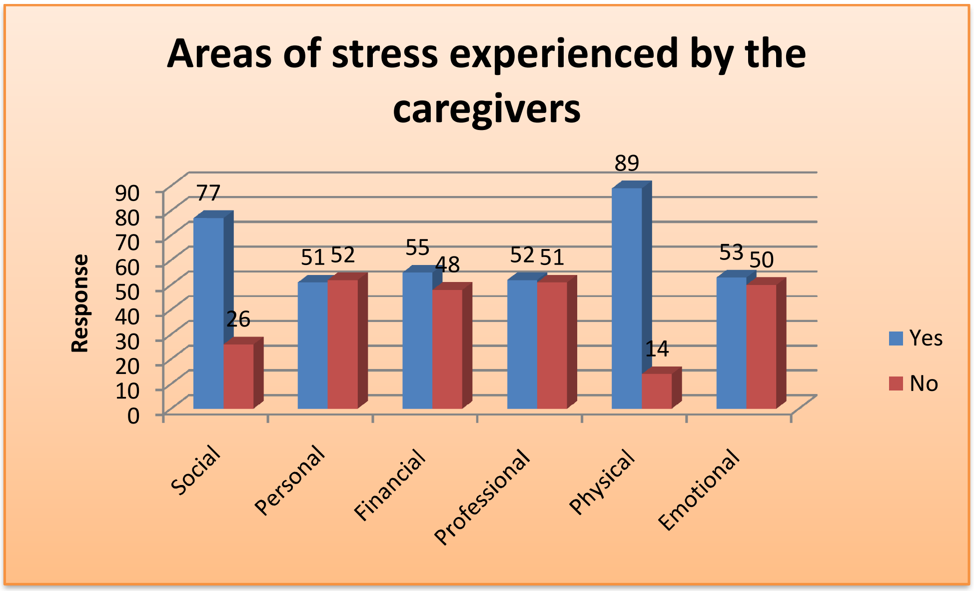
It is seen that caregivers are saved from the huge responsibility of taking the patient to the doctors on regular basis which requires time and energy, more so in the case of patient with dementia.

Following table gives data related to the specific stress areas which, caregivers may possibly feel while managing the patient with dementia. For this study, the specific stress areas are Social - stress may arise due to absurd behavior in front of others, Personal - stress may arise as relationships are affected negatively, Financial - stress may arise due to inability to meet the expense, Professional –Job role stress may arise & inability to handle pressure both at home and at work, Physical - stress may arise due to fatigue and difficulty in time management. Emotional – stress may arise due to inability to meet the demands of spouse and children.

Table 20 Areas of stress experienced by the caregivers

Stress Area	Yes		No		Total	
	N	%	N	%	N	%
Social	77	74.7	26	25.2	103	100
Personal	51	49.5	52	50.5	103	100
Financial	55	53.4	48	46.6	103	100
Professional	52	50.5	51	49.5	103	100
Physical	89	86.4	14	13.6	103	100
Emotional	53	51.5	50	48.5	103	100

Graph No. 20.1



From the above table it is evident the 89 (86.4%) caregivers perceived/ felt stress in the physical area while 77 (74.7%) perceived/felt stress in social 55(53.4%) have felt stress related to finance.

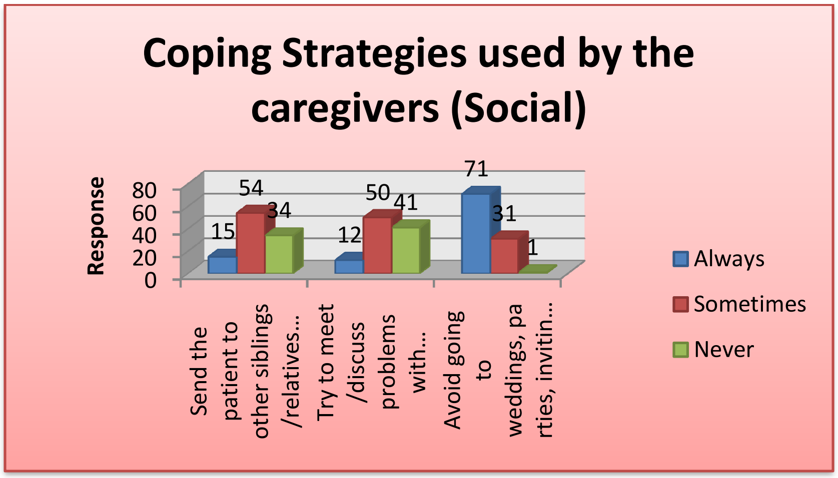
Physical, social and financial domains have emerged as stressful areas felt/perceived by the caregivers in that order.

Once the stress area if any, is known it was felt appropriate and important to know the coping strategies used by the caregivers to overcome the stress in these domains. The domains of stress are divided into social, physical, personal/ emotional and professional. Possible strategies which the caregivers may use are ;sending the patient to other siblings /relatives place for some time, Try to meet /discuss problems with relatives of similar patient, Avoid going to weddings, parties, inviting friends, employ paid nursing/ maid for 24 hours, employ part time help in meal preparation, house maintenance etc, practice yoga, meditation, any other spiritual activity or alternate healing, resort to other branches of medicines –unani, homeopathy, ayurvedic, listen to music, gardening, reading (hobbies), take holidays, break from care giving, take up part time job/financial activities, take help from doctors (counseling, advise etc). Barring one or two, all other coping strategies are positive.

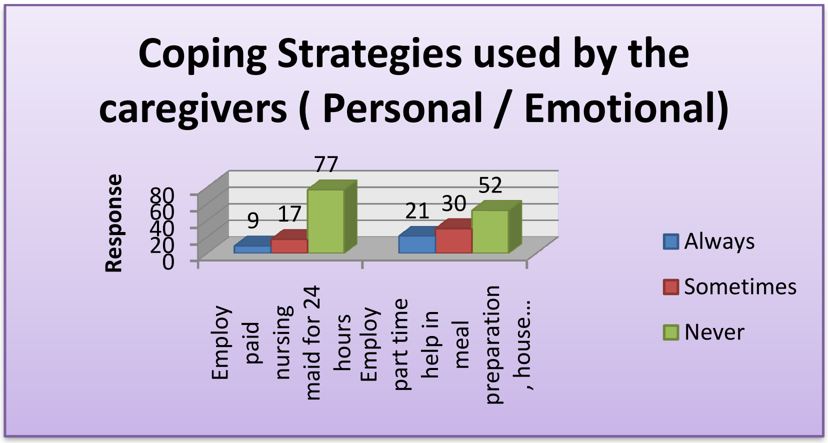
Table 21 Coping Strategies used by the caregivers

Responses	Always		Sometimes		Never		Total	
	N	%	N	%	N	%	N	%
Social								
Send the patient to other siblings /relatives place for some time	15	14.6	54	52.4	34	33.0	103	100
Try to meet /discuss problems with relatives of similar patient	12	11.6	50	48.5	41	39.8	103	100
Avoid going to weddings, parties, inviting friends	71	68.9	31	30.1	1	1.0	103	100
Physical								
Employ paid nursing maid for 24 hours	9	8.7	17	16.5	77	74.8	103	100
Employ part time help in meal preparation, house maintenance etc	21	20.4	30	29.1	52	50.5	103	100
Personal / Emotional								
Practice yoga, meditation, any other spiritual activity or alternate healing	10	9.7	36	35.0	57	55.3	103	100
Resort to other branches of medicines –unani, homeopathy, ayurvedic	11	10.7	28	27.2	64	62.1	103	100
Listen to music, gardening, reading (hobbies)	4	3.9	58	56.3	41	39.8	103	100
Professional								
Take holidays, break from care giving	4	3.9	45	43.7	54	52.4	103	100
Take up part time job/financial activities	5	4.9	18	17.5	80	77.7	103	100
Take help from doctors (counseling, advise etc)	83	80.6	17	16.5	3	2.9	103	100

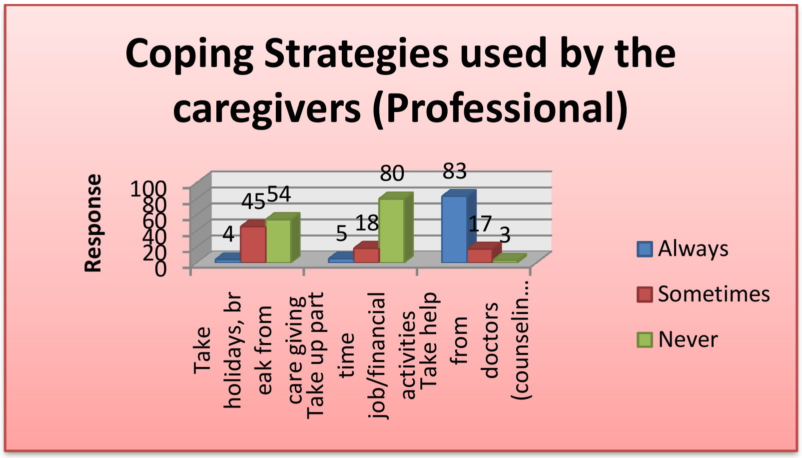
Graph No. 21.1



Graph No. 21.2



Graph No. 21.3



The above table reflects the coping strategies by the family caregivers in the different domains. Looking to the social domain 71 (68.9%) family caregivers always avoid going to weddings, parties and inviting friends. 54 (2.4%) family caregivers sometime send the patient to other siblings /relatives place while 41 (39.8%) family caregivers never try to meet /discuss problems with relatives of similar patient.

In physical domain 21(20.4%) of the family caregivers always employ part time help in meal preparation and house maintenance, while 77 (74.8%) never employ paid nursing maid for 24 hours.

In personal and emotional domain 64 (62.1%) family caregivers have never taken resort to other branches of medicines like unani, homeopathy or ayurvedic. 58 (56.3%) caregivers sometimes take out time for their hobbies like listening to music, gardening and reading.

In professional domain 83(80.6%) family caregivers always take help from the doctors in the form of advice and counseling, while 80(77.7%) family caregivers have never taken up part time job /financial activities while 45(43.7%) family caregivers sometimes have taken break from care giving and holidays.

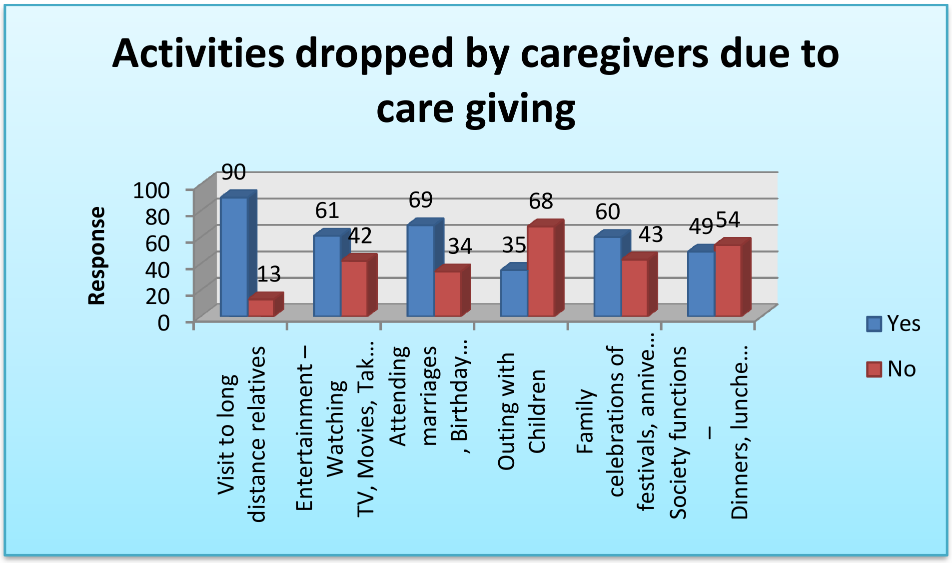
It appears that family caregivers are using both positive and negative coping strategies.

Further, it is important to know if there are activities which caregivers give up or drop due to management of the patient with dementia. Few possible activities that were dropped are mentioned in the following table.

TABLE 22 Activities dropped by caregivers due to care giving

Response	Yes		No		Total	
	N	%	N	%	N	%
Visit to long distance relatives	90	87.4	13	12.6	103	100
Entertainment – Watching TV, Movies, Taking Holidays	61	59.2	42	40.8	103	100
Attending marriages , Birthday parties etc	69	67.0	34	33.0	103	100
Outing with Children	35	34.0	68	66.0	103	100
Family celebrations of festivals, anniversary etc	60	58.3	43	41.7	103	100
Society functions – Dinners, lunches, get-together etc	49	47.6	54	52.4	103	100

Graph No. 22.1



From the above table it is evident that majority of 90 (87.4%) of family caregivers have dropped visiting long distance relatives, followed by 69(67%) caregivers who have stopped attending marriages and birthday parties, 60 (58.3%) have dropped celebrations of festivals and anniversaries in the family, while, 68 (66%) caregivers have reported that they have not dropped the activity of going out with children.

SECTION-IV OVERALL HEALTH & WELL BEING OF THE FAMILY CAREGIVERS

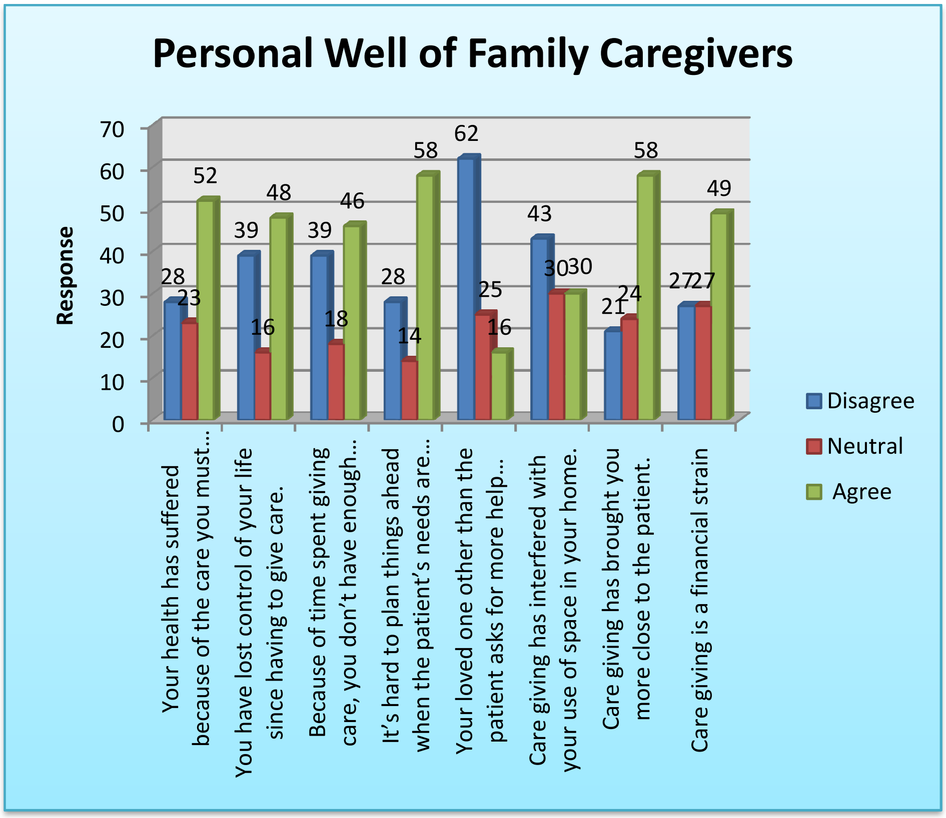
This section attempts to cover overall health aspects of the caregivers and thus understanding impact of care giving on their overall well being. The scale has been adapted and modified from Lawton, M.P., Kleban, M.H., Moss, M., Glicksman, A. (1989) Measuring caregiver appraisal. To keep the uniformity in understanding the holistic caregiving aspects, the health and wellbeing was differentiated into personal, social, physical and psychological domains. Following table covers these aspects of health and wellbeing.

The Following table presents data related to personal well being of family care givers.

TABLE 23 Personal Well being of Family Caregivers

Category	**Disagree**		**Neutral**		**Agree**		**Total**	
Health Domains	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Personal								
Your health has suffered because of the care you must give.	28	27.1	23	22.3	52	50.5	103	100
You have lost control of your life since having to give care.	39	37.9	16	15.5	48	46.6	103	100
Because of time spent giving care, you don't have enough time for yourself.	39	37.9	18	17.5	46	44.7	103	100
It's hard to plan things ahead when the patient's needs are so unpredictable.	28	27.1	14	13.6	58	56.4	103	100
Your loved one other than the patient asks for more help than is necessary.	62	60.2	25	24.3	16	15.5	103	100
Care giving has interfered with your use of space in your home.	43	41.7	30	29.1	30	29.1	103	100
Care giving has brought you more close to the patient.	21	20.4	24	23.3	58	56.4	103	100
Care giving is a financial strain	27	26.2	27	26.2	49	47.5	103	100

Graph No. 23.1



As seen from the above table 52(50.5 %) of family caregivers agree to the fact that their health has suffered because of the care they give 28(27.1%) of them disagree and 23(22.3%) are neutral about it.

48(46.6%) the family caregivers agree that they have lost control over their life while 39(37.9%) disagree to this fact and 16(15.5%) are neutral about it.

46(44.7%) family caregivers agree to the fact that because of the time spent in care giving they do not have time for themselves while 39(37.9%) disagree to this fact and 18(17.5%) of them are neutral about it.

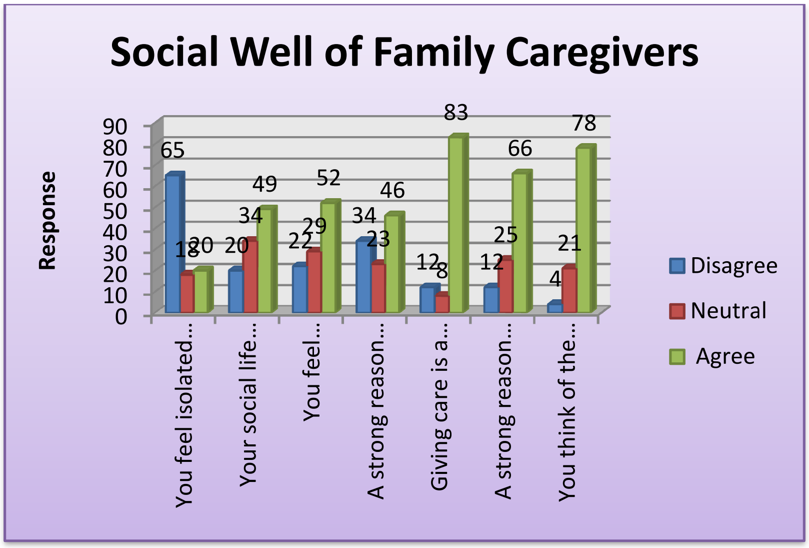
58(56.4%) family caregivers agree to the fact that it is hard to plan things ahead as the patients needs are so unpredictable and that care giving has bought them more close to the patient while 28(27.1%) and 21(20.4%) disagree to these facts respectively.

The following table presents date related to social well being of family care givers.

TABLE 24 Social Well being of Family Caregivers

Category	**Disagree**		**Neutral**		**Agree**		**Total**	
Health Domains	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Social								
You feel isolated and alone as the result of giving care.	65	63.1	18	17.5	20	19.4	103	100
Your social life has suffered because you are care giving.	20	19.4	34	33.0	49	46.9	103	100
You feel uncomfortable having friends over because of him/her.	22	19.3	29	28.2	52	50.5	103	100
A strong reason for taking care of him/her is to be true to family traditions.	34	33.1	23	22.3	46	44.7	103	100
Giving care is a way for you to live up to religious and/or moral principles.	12	11.7	8	7.8	83	80.6	103	100
A strong reason for care giving is to provide a good role-model for your children.	12	11.7	25	24.3	66	64.0	103	100
You think of the help you give as an opportunity to repay him/her.	4	3.8	21	20.4	78	75.7	103	100

Graph No. 24.1



62(60.2%) family caregivers disagree with the fact that family members other than the patient asks for their help more than necessary, while, 16(15.5%) of them agree to it.

43(41.7%) family caregivers disagree with fact that care giving has interfered with their space in the home, while, 30(29.1%) are neutral about it .and agree that care giving has interfered with their space in the home.

49(47.5%) family caregivers have felt that at personal level, they have experienced the financial strain.

It appears that majority of family caregivers have agreed that their personal well being is negatively affected because of the process of the care giving, however they also agree that it has brought them close to the patient

As it s seen from the above table that 65(63.1%) the family caregivers disagree to the fact that they do not feel socially isolated and alone because of the care giving while 20(19.4%) of them agree to this fact and 18(17.5%) are neutral towards it.

49(46.9%) the family caregivers have agreed to the fact that their social life has suffered due to care giving while 20(19.4%) of them disagree to it and 34(33%) of them are neutral towards it.

52(50.5%) family caregivers agree to the fact that they feel uncomfortable having friends because of the patient while 22(19.3%) disagree to it and 29(28.2%) are neutral about it.

49(44.7%) family caregivers agree to the fact that the strong reason is taking care of the tradition, 34(33%) of them disagree to it and 23(22.3%) of them are neutral about it.

83(80.6%) family caregivers agree to the fact that care giving is the way to live up to moral and religious principles while only 12(11.7%) of them disagree with this fact and only 8(7.8%) are neutral about it.

66(64%) family caregivers agree to the fact that they do the care giving to provide a good role-model for their children while 12(11.7%) of them disagree to the fact and 25(24.3%) are neutral about it.

78(75.75) family caregivers disagree with the fact that help they provide to the patient is an opportunity to repay back, 21(20.4%) are neutral about it and only 4(3.8%) disagree to it.

It appears that social well being of the family caregivers has suffered , though they don't feel isolated they do feel uncomfortable calling their friends home, take it as time to repay back and set a role model for their children.

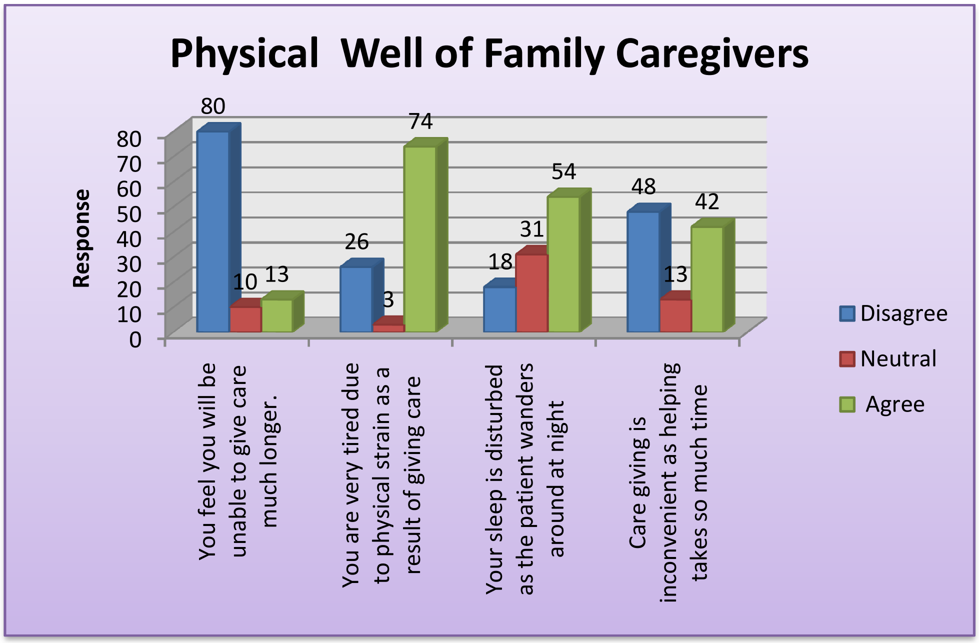
80(77.6%) family caregivers disagree to the fact that they will be unable to give care much longer while 13(12.7%) agree to it and 10 (9.7%) are neutral about it.

The following table present date related Physical well being of family caregivers.

TABLE 25 Physical Well being of Family Caregivers

Category	**Disagree**		**Neutral**		**Agree**		**Total**	
Health Domains	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Physical								
You feel you will be unable to give care much longer.	80	77.6	10	9.7	13	12.7	103	100
You are very tired due to physical strain as a result of giving care	26	25.2	3	2.9	74	71.8	103	100
Your sleep is disturbed as the patient wanders around at night	18	17.4	31	30.1	54	52.4	103	100
Care giving is inconvenient as helping takes so much time	48	46.6	13	12.6	42	40.7	103	100

Graph No. 25.1



74(71.8%) family caregivers agree to the fact that they feel very tired due to the physical strain as a result of care giving while 26(25.2%) disagree to it and only 3(2.9%) are neutral about it.

54(52.4%) family caregivers agree to the fact that their sleep is disturbed as the patient wander around at night. while 31(30.1%) are neutral about it and 18(17.4%) disagree with it.

48(46.6%) family caregivers disagree with the fact that care giving is inconvenient as it takes so much of time while 42(40.7%) agree to it and 13(12.6%) are neutral about it.

It appears that physical wellbeing is affected due to caregiving and their sleep at night is disturbed however it has not deterred them from not giving care for longer duration if need be

The following table presents data related to Emotional well being of family caregivers.

TABLE 26 Emotional Well being of Family Caregivers

Category	**Disagree**		**Neutral**		**Agree**		**Total**	
Health Domains	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Emotional / Psychological								
You feel nervous or depressed when giving care.	58	56.3	16	15.5	29	28.1	103	100
You feel trapped when giving care.	52	50.4	6	5.8	45	43.6	103	100
You feel resentful of other relatives who could help, but do not.	29	28.1	25	24.3	49	47.5	103	100
You wish you could just leave care giving to someone else.	76	73.8	12	11.7	15	14.5	103	100
Patients behavior upsets you because of trouble in remembering things; or because patient accuses people of taking things	22	21.3	34	33.0	47	45.6	103	100
You worry about the patient and have concerns about how you will manage (overwhelmed)	14	13.6	38	36.9	51	49.5	103	100
Do you feel there is no solution to your problems?	12	11.7	19	18.4	72	69.9	103	100
Your family stability has been disrupted by the patients illness (frequent quarrels, arguments, breakups)	20	19.4	38	36.9	45	43.6	103	100
You feel often frustrated that the improvement is slow or no improvement at all or deterioration in patients condition.	5	4.9	10	9.7	88	85.4	103	100
You have started to feel lonely and isolated since patient's illness.	27	26.2	20	19.4	56	54.3	103	100
You really enjoy being the patient.	19	18.4	25	24.3	59	57.2	103	100
The patient shows real appreciation of what you do for him/her.	16	15.5	17	16.5	70	67.9	103	100
The patient's pleasure over little things gives you happiness.	12	11.6	21	20.4	70	67.9	103	100
It makes you happy to know that the family is caring for him/her.	11	10.7	18	17.5	74	71.8	103	100
You take care of the patient because you are willing to and as a part of your duty	12	11.6	11	10.7	80	77.6	103	100
The patient affects your relationship with other family members	4	3.9	29	28.2	70	67.9	103	100

It can be seen from the above table 58(56.3%) family caregivers disagree with the fact that they feel nervous or depressed when giving care, while 29(28.1%) of them agree to it and 16(15.5%) of them are neutral about it.

52(50.4%) family caregivers disagree with the fact that they are trapped when giving care, while 45(43.6%) of them agree to it and only 6(5.8%) of them are neutral about it.

49(47.5%) family caregivers agree that they resent that relatives who could help but are not doing so, while 29(28.1%) of them disagree with and 25(24.3%) of them are neutral about it.

47(45.6%) family caregivers agree that patients behavior of forgetting thing and accusing in front of others upsets them, while 34(33%)of them are neutral about it and 22(21.3%) of them disagree with it.

51(49.5%) family caregivers agree that they are overwhelmed and are concerned about how to manage, while 38(36.9%) are neutral about it and 14(13.6%) of them disagree with it

72(69.9%) family caregivers agree that there is no solution to their problems while 12(11.7%) of them disagree with it and 19(18.4%) of them are neutral about it.

45(43.6%) family caregivers agree that the family stability has disrupted by the patients illness and that there are frequent quarrels and argument, while 38(36.9%) are neutral about it and 20(19.4%) of them disagree with it

88(85.4%) family caregivers agree that they feel frustrated that the improvement is slow and that the patient's condition is deteriorating, while only 10(9.7%) of them are neutral about it and only 5(4.9%) of them disagree to it.

80(77.6%) family caregivers agree that they take care of the patient willingly and as a part of their duty, while 11(10.7%) of them are neutral about it and 12(11.6%) of them disagree to it.

70(67.9%) family caregivers agree that they their relationship with other family members has affected due to the caregiving, while 29(28.2%) of them are neutral about it and only 4(3.9%) of them disagree to it.

SECTION-V SUPPORT NETWORK /INFORMAL SUPPORT

This section covers the aspects related to informal support and the support network available to the family caregivers. This section includes aspects like whether the caregiver is the only person responsible for taking care of the patient, who else helps the caregiver on the regular basis, kind of support /help received and if anyone has discontinued help/support to the caregiver and if yes then what were the reasons. The section also covers difference perceived by the caregivers on formal and informal support, to whom they take resort to for the cure and guidance and what kind of service or informal support is desired by them.

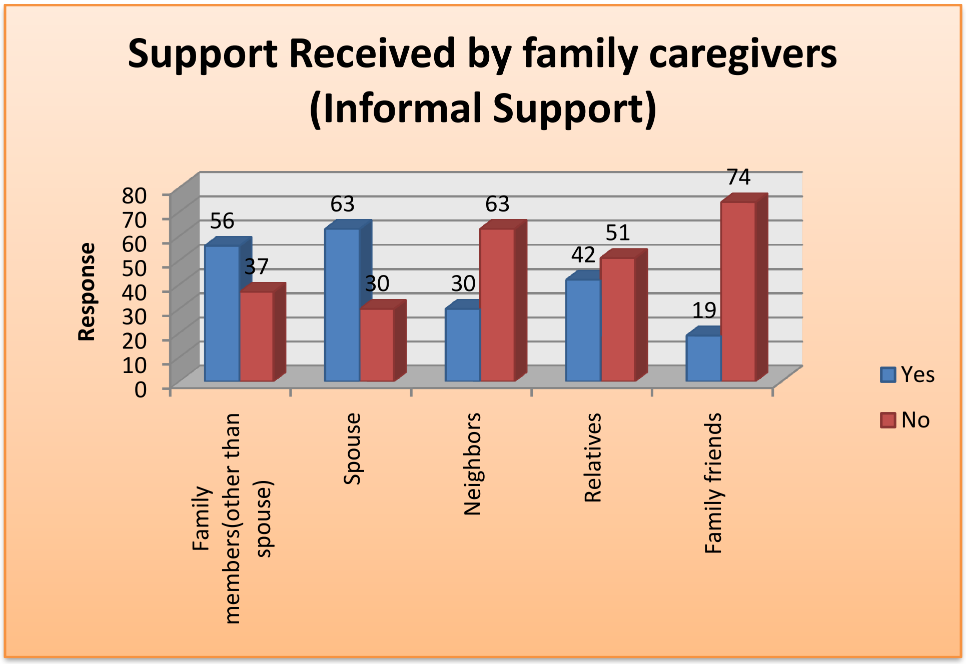
The data revealed that (93) i.e. (90.7%) of the family caregivers are not alone in giving care to the patient and do receive support from others. However, it was felt important to know the people extending support.

Following table shows people who give help and extend support to family caregivers in managing the patient with dementia

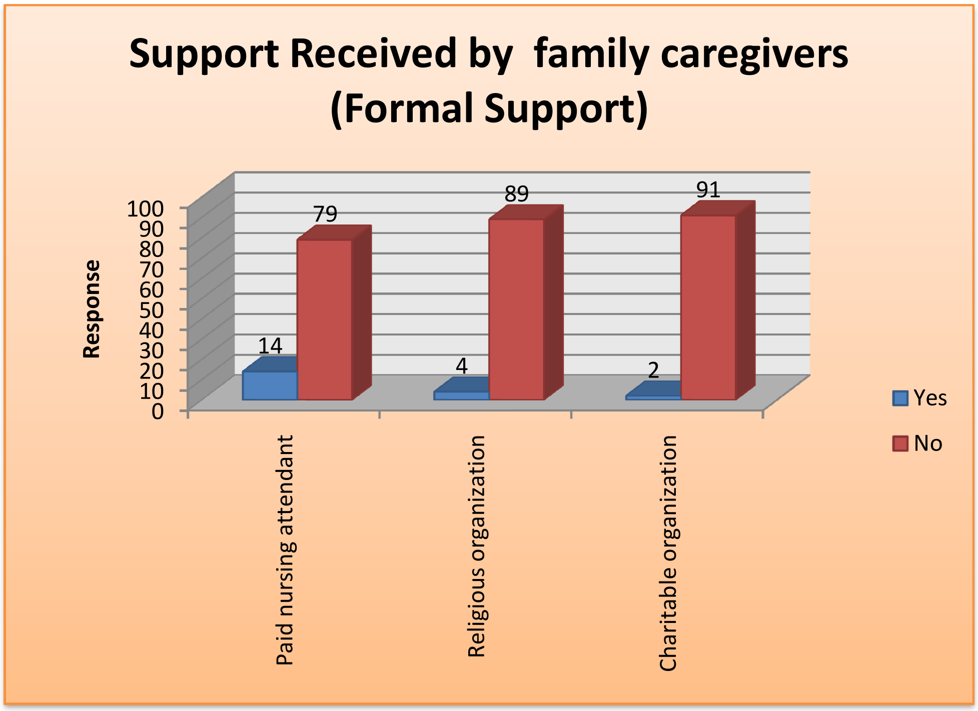
Table 27 Support Received by family caregivers

People Extending support	Yes		No		Total	
	N	%	N	%	N	%
Informal Support						
Family members(other than spouse)	56	60.2	37	39.8	93	100
Spouse	63	67.7	30	32.3	93	100
Neighbors	30	32.3	63	67.7	93	100
Relatives	42	45.2	51	54.8	93	100
Family friends	19	20.4	74	79.6	93	100
Formal Support						
Paid nursing attendant	14	15.1	79	84.9	93	100
Religious organization	4	4.3	89	95.7	93	100
Charitable organization	2	2.2	91	97.8	93	100

Graph No. 27.1



Graph No. 27.2



From the above table it is evident that 63 (67.7%) family caregivers said help is given by the spouse followed by 56 (60.2%) caregivers receive support from other family members and least help is received from religious and charitable organization as reported by 6(6.5%) family caregivers.

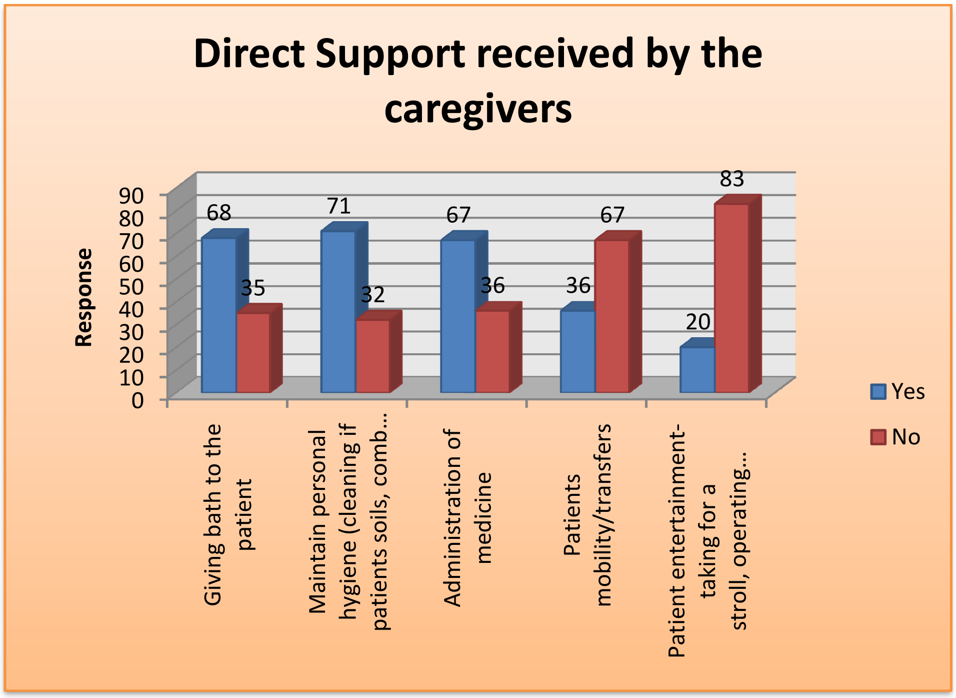
It appears that family caregivers get more of informal support than the formal support.

Following tables covers the nature of support /help received by the caregivers. The help is categorized into direct and indirect help. Direct help covers support in activities related to the patient like; giving bath to the patient, Maintain personal hygiene (cleaning if patients soils, comb hair, wear clothes, nails trim, brush shaving etc), Patients mobility/transfers, giving medicine, and taking patient for stroll, putting on TV etc. While indirect help covers support in day to day activities done by the caregiver like; meals preparations, Taking kids to school (if applicable), Taking care for few hours or for a day or two enabling to attend social functions, keeping clothes, vessels, dusting and routine arrangements in the house. Help in shopping buying routine commodities groceries, vegetables, milk and other work related to banks, paying of bills, etc

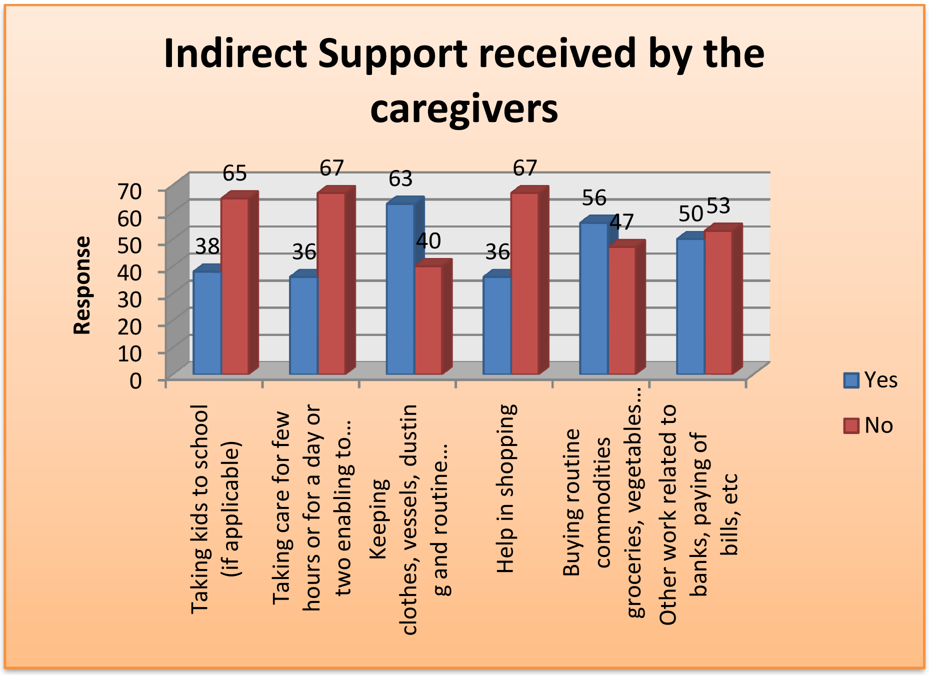
Table 28 Direct and Indirect Support received by the caregivers

Response	**Yes**		**No**		**Total**	
	N	**%**	**N**	**%**	**N**	**%**
Direct Help						
Giving bath to the patient	68	66.0	35	34.0	103	100
Maintain personal hygiene (cleaning if patients soils, comb hair, wear clothes, nails trim, brush shaving etc)	71	68.9	32	31.1	103	100
Administration of medicine	67	65.0	36	35.0	103	100
Patients mobility/transfers	36	35.0	67	65.0	103	100
Patient entertainment- taking for a stroll, operating TV, Music, talking etc	20	19.4	83	80.6	103	100
Indirect Help						
Meals preparation	76	73.8	27	26.2	103	100
Taking kids to school (if applicable)	38	36.9	65	63.1	103	100
Taking care for few hours or for a day or two enabling to attend social functions	36	35.0	67	65.0	103	100
Keeping clothes, vessels, dusting and routine arrangements in the house.	63	61.2	40	38.8	103	100
Help in shopping	36	35.0	67	65.0	103	100
Buying routine commodities groceries, vegetables, milk etc	56	54.4	47	45.6	103	100
Other work related to banks, paying of bills, etc	50	48.5	53	51.5	103	100

Graph No. 28.1



Graph No. 28.2



From the above table it is evident that maximum (71) (68.9%) caregivers receive direct help in maintaining personal hygiene (cleaning if patients soils, comb hair, wear clothes, nails trim, brush shaving etc) followed by (68) (66%) caregivers receive direct help in giving bath to the patient, while only (20) (19.4%) caregivers received help for entertainment of the patient like taking for a stroll, operating TV, Music, talking etc.

76 (73.8%) receive maximum Indirect help in meals preparation, followed by 63 (61.2%) caregivers receive help in Keeping clothes, vessels, dusting and routine arrangements in the house and 56 (54.4%) caregivers receive indirect help in buying routine commodities groceries, vegetables, milk etc.

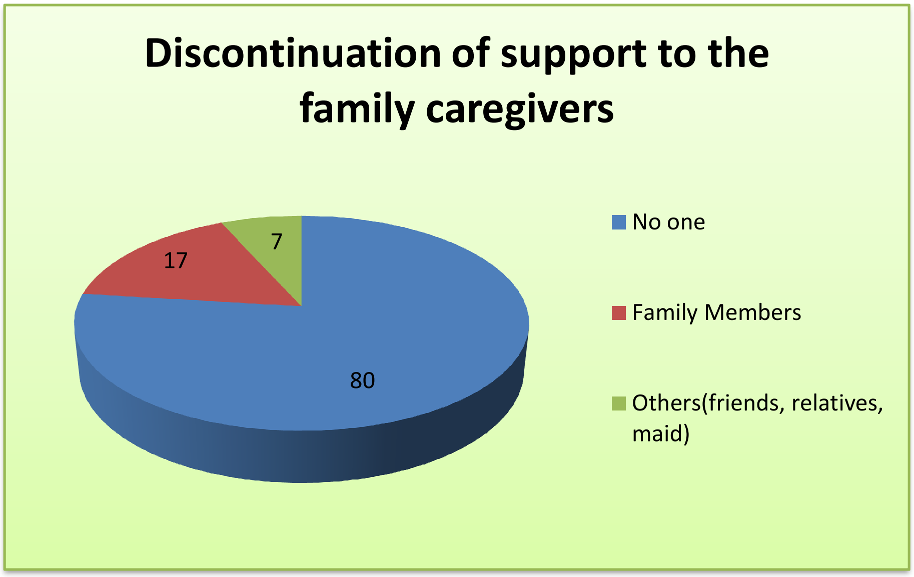
It is clear that direct help is received in activities of daily living and least direct help is received in Instrumental activities of daily living.

Following table shows people who have discontinued giving support to the family caregivers, covering categories like family members, friends, relatives and maid servants.

Table 29. Discontinuation of support to the family caregivers

Response	Frequency	Percentage
No one	80	77.7
Family Members	17	16.5
Others(friends, relatives, maid)	7	6.8
Total	**103**	**100**

Graph No. 29.1



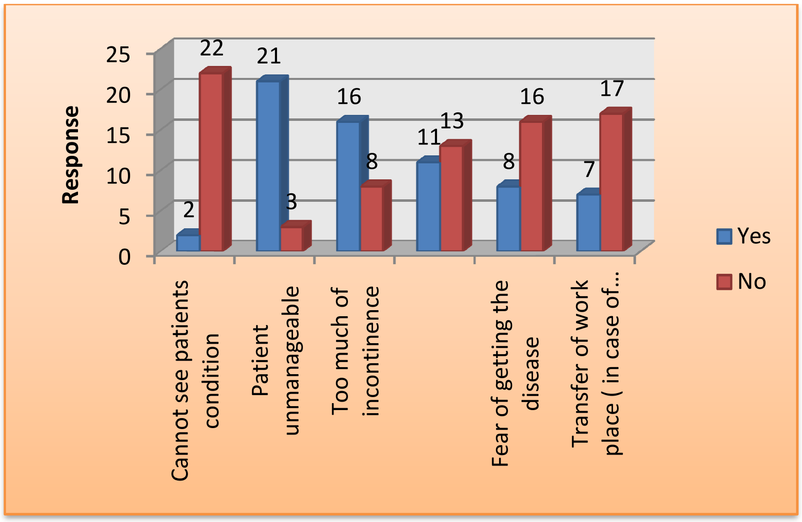
From the above table it is evident that 80 (77.7%) caregivers reported that no one has discontinued support to the family caregivers while 17(16.5%) caregivers reported that family members had discontinued support and 7 (6.8%) caregivers have reported that friends, relatives and maids have stopped giving support.

Following table shows reasons due to which the support was discontinued. The possible reasons seem to be that a person providing support is not able to see the patient's condition, patient is unmanageable, too much of incontinence by the patient, inappropriate behavior on the part of the patient, fear of getting the disease, transfer of work place in case of the paid nurse and other priorities.

Table 30 Reasons to discontinue the support

Response	Yes		No		Total	
	N	%	N	%	N	%
Cannot see patients condition	2	8.3	22	95.7	24	100
Patient unmanageable	21	87.5	3	13.0	24	100
Too much of incontinence	16	66.6	8	34.8	24	100
Wrong/ /inappropriate behavior on the part of patient	11	45.8	13	56.5	24	100
Fear of getting the disease	8	33.3	16	69.6	24	100
Transfer of work place (in case of paid nursing attendant)	7	29.1	17	73.9	24	100

Graph No. 30.1 Reasons t o discontinue the support



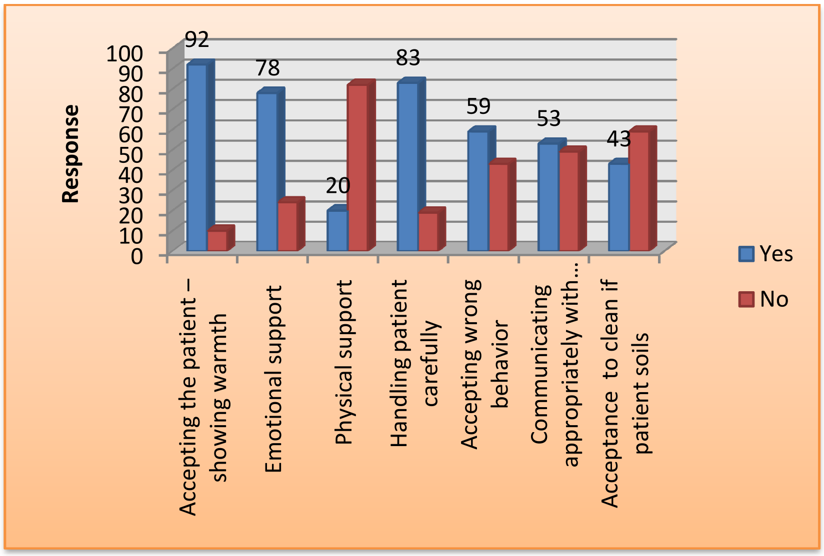
The above table explains reasons for discontinuation of support. Major reason for discontinuation of support was patient is unmanageable, which was reported by 21(87.5%) followed by too much of incontinence reported by 16(66.6%) caregivers, while 11(45.8%) caregivers reported that wrong or inappropriate behavior on the part of the patient was one of the reason. Only 2 caregivers report that help was discontinued due to the fact that patient's condition could not be seen.

The perception of family caregivers towards formal and informal care will highlight availability and quality of formal care and their views related to informal care will bring out how they manage with the care giving of the patient with dementia at home. The following table shows perceived difference by the caregivers between formal and informal care.

Table 31 Difference between informal & formal care as perceived by the family caregivers

Response	**Yes**		**No**		**Total**	
	N	**%**	**N**	**%**	**N**	**%**
Accepting the patient – showing warmth	92	90.2	10	9.8	102	100
Emotional support	78	76.5	24	23.5	102	100
Physical support	20	19.6	82	80.4	102	100
Handling patient carefully	83	81.4	19	18.6	102	100
Accepting wrong behavior	59	57.8	43	42.2	102	100
Communicating appropriately with patient	53	52.0	49	48.0	102	100
Acceptance to clean if patient soils	43	42.2	59	57.8	102	100

Graph No. 31.1 Difference between informal & formal care as perceived by the family caregivers



It is clearly seen form the above table that accepting the patient and showing warmth is better seen during informal support than in formal support, as reported by 92 (90.2%). 83 (81.4%) caregivers reported that patients are handled more carefully in informal care as compared to formal care. 78(76.5%) family caregivers feel that informal care gives emotional support to the patient while it lacks in the formal support.

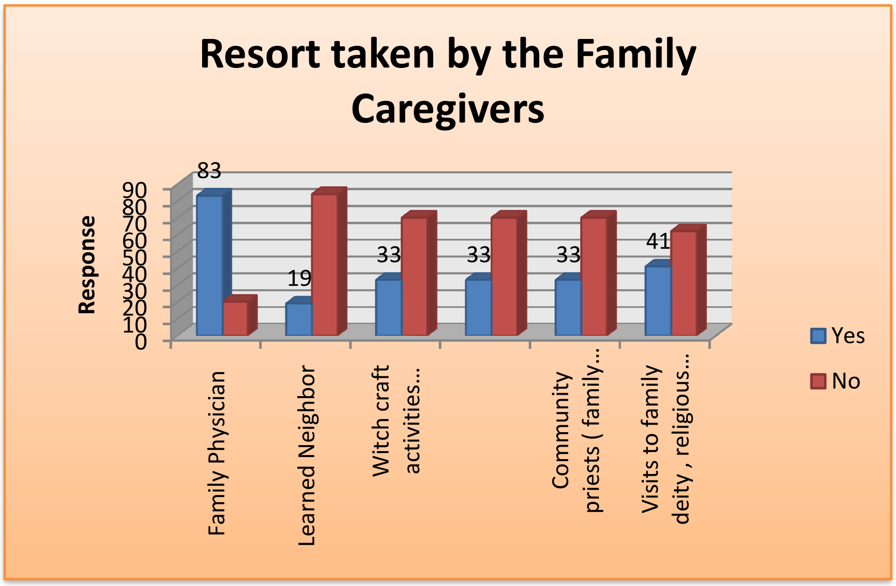
It is seen that handling patient carefully, emotional support and accepting patient are three major differences that have emerged between formal and informal care.

Following table shows the place where caregivers take resort to, for curing the disease. Keeping in mind the Indian culture possible places of resorts are mentioned in the table.

Table 32 Resort taken by the Family Caregivers

Response	Yes		No		Total	
	N	%	N	%	N	%
Family Physician	83	80.6	20	19.4	103	100
Learned Neighbor	19	18.4	84	81.6	103	100
Witch craft activities (bhuva), ceremonies suggested by astrologer	33	32.0	70	68.0	103	100
Psychologist / professional counselors/ Physiotherapist, occupational therapist	33	32.0	70	68.0	103	100
Community priests (family guru)	33	32.0	70	68.0	103	100
Visits to family deity , religious ceremonies etc	41	39.8	62	60.2	103	100

Graph No. 32.1 Resort taken by the Family Caregivers

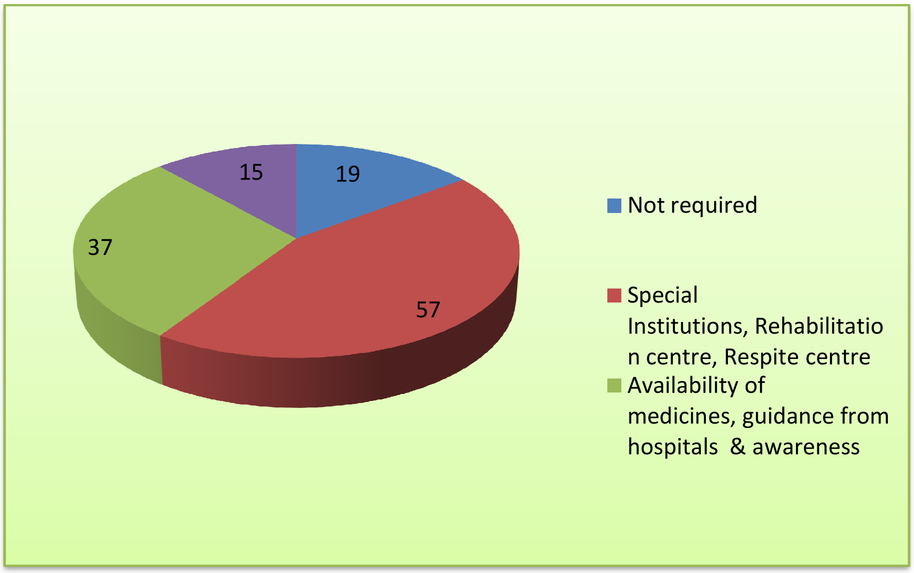


The above table explains to whom the family caregivers resort to, for the treatment of the patient. Majority of caregivers 83(80.6%) approach the family physician while 33(32%) of them visit other medical professionals like psychologist, physiotherapist while more than 90% take resort to ceremonies suggested by astrologer, religious ceremonies, community priest and visit the family deity.

Above data reveals the fact that most of the caregivers go to the family physician and then probably are directed to psychiatrist or neurophysicians. Interestingly, most of them have also responded that they do visit astrologers, community priests and family deity and undertake religious ceremonies.

Following table gives the idea what kind professional support is desired by the family caregivers like; special institutions, respite care, guidance and awareness about the disease, financial help etc.

Graph No. 33.1 Professional support desired by the family caregivers



From the above table it is evident that majority of the family caregivers 57(55.3%) desire to have professional support in the form of special institutions, Rehabilitation centre and Respite centre, followed by 37(35.9%) need support in the form of availability of medicines, guidance from hospitals and awareness or more information about the disease. Few caregivers have reported to get a financial support or help form government organizations and NGOs.

It has clearly emerged that professional help and support is required by the caregivers in many ways.

SECTION-VI ENJOYABLE ASPECTS OF CAREGIVING

Though maximum studies have shown burden/burnout as a major outcome of the care giving, it was felt important to know the enjoyable aspects of care giving. Following table captures what according to the caregiver is the enjoyable aspect of the care giving.

Table 34 Enjoyable aspects of care giving

Response	Yes		No		Total	
	N	%	N	%	N	%
Being with the patient	73	70.9	30	29.1	103	100
Feeling relaxed	24	11.7	91	88.3	103	100
Sense of accomplishment	75	72.8	28	27.2	103	100
Care giving is moral obligation	89	86.4	14	13.6	103	100

From the above table it is evident that most important enjoyable aspect of care giving felt by 89 (86.4%) caregivers is that they are able to fulfill their moral obligation towards the patient. While, for 75 (72.8%) care givers sense of accomplishment was enjoyable aspect and 73 (72.8%) caregivers felt that being with patient as an enjoyable aspect. 91 (88.3%) caregivers were very clear that it does not relax them form stress.

It is important to note that 88.3% caregivers do not feel relaxed and out of stress. These caregivers are daughter –in-laws of the patient.

SECTION-VII PERCEPTION OF CAREGIVERS RELATED TO CARE GIVING PROCESS, AWARENESS ABOUT THE DISEASE, KNOWLEDGE AND SERVICES AVAILABLE

This section tries to capture the details about the care giving process as perceived by the caregivers, their knowledge, source of getting knowledge/information about the disease, skills required for managing dementia patient, awareness about the services available in the city and their views regarding the services required for the betterment of the dementia patient.

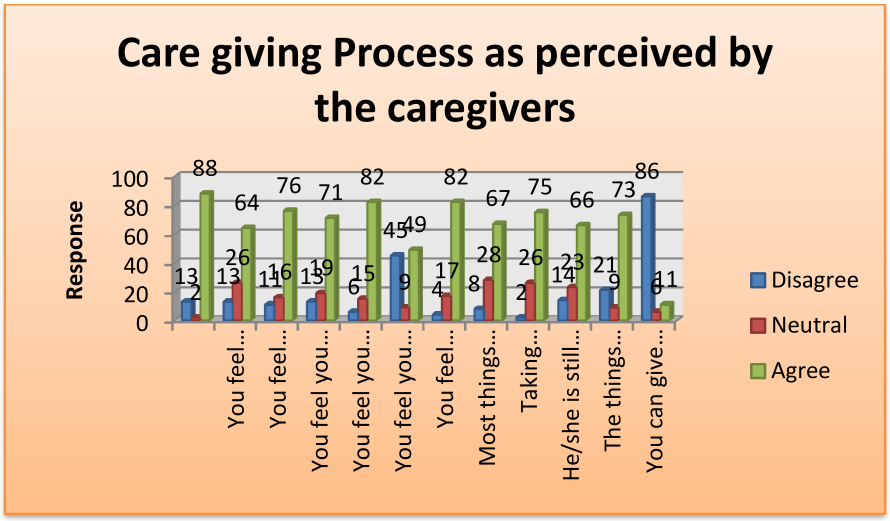
Following table captures the feelings of the caregivers i.e. how they perceive the care giving process. This will help to understand how they manage the patient with dementia and their preparedness to take up the caregiver role.

Table 35 Care giving Process as perceived by the caregivers

Care giving Process as perceived by the caregivers	Disagree		Neutral		Agree		Total	
	N	%	N	%	N	%	N	%
You feel that you are able to adapt to the caregiving	13	12.6	2	1.9	88	85.4	103	100
You feel certain about what to do with your loved one, the patient.	13	12.6	26	25.2	64	62.2	103	100
You feel reassured knowing that as long as you are giving care, your loved one is getting proper care.	11	10.6	16	15.5	76	73.8	103	100
You feel you are doing more for him/her now.	13	12.6	19	18.4	71	69	103	100
You feel you are doing a better job caring for him/her now.	6	5.8	15	14.6	82	79.6	103	100
You feel you are able to handle most caregiving problems that arise.	45	43.7	9	8.7	49	47.6	103	100
You feel pretty good about figuring out what he/she needs.	4	3.9	17	16.5	82	79.6	103	100

Most things you do for him/her seem to please your loved one.	8	7.8	28	27.2	67	65.1	103	100
Taking responsibility for him/her gives your self-esteem a boost.	2	2	26	25.2	75	72.9	103	100
He/she is still being helped by most of the things you do for him/her.	14	13.6	23	22.3	66	64	103	100
The things you do keep him/her away from getting worse.	21	20.4	9	8.7	73	70.8	103	100
You can give care with no help, or could if need be.	86	83.5	6	5.8	11	10.6	103	100

Graph No. 35.1



From the above table it is evident that 45(43.7%) of the family caregivers disagree to the fact that they are able to handle most caregiving problems that arise. While, 49 (47.6%) of family caregivers agree with this fact. 21(20.4%) of them disagree with the fact that whatever efforts they are putting is keeping the patient away from getting worse while 73(70.8%) agree with this fact. 86(83.5%) of family caregivers disagree with the fact that they can give care with no help or could give if need arises. While 11(10.6%) of them agree to it.

88(85.4%) agree to the fact that they are able to adapt to the caregiving. 82(79.6%) of family caregivers feel that they are feeling pretty good about when they are able to figure out what patients want.

It appears that caregivers perceive their role of caregiving positively and feel assured that they are able to take care of their beloved family member.

Data also reveals that 57 (55.3%) caregivers make efforts to know more about Dementia. This reflects the need for creating avenues for generating more information and disseminates it to the general public at large.

Table 36 Sources of gaining knowledge about Dementia

Response	Yes		No		Total	
	N	%	N	%	N	%
Browsing Internet	43	75.4	14	24.6	57	100
Social Networking sites	7	12.3	50	87.7	57	100
Books on care giving, dementia	15	26.3	42	73.7	57	100
Through Media – Advertisements, posters, public interest advertisement, TV	11	19.3	46	80.7	57	100
Doctors , Psychiatrist	52	91.2	5	8.8	57	100
Professional social worker	13	22.8	44	77.2	57	100
Counselors	2	3.5	55	96.5	57	100
Other caregivers experience	22	38.6	35	61.4	57	100
Non-government organizations, service providers	19	33.3	38	66.7	57	100
Government hospitals, PHCs etc.	38	66.7	19	33.3	57	100

From the above table it is evident that the most widely used source for gaining knowledge is doctors and psychiatrists as reported by 52 (91.2%) caregivers, followed by browsing Internet as reported by 43 (75.4%) caregivers and getting information from Government hospitals as reported by 38 (66.7%) caregivers.

Following table covers those aspects if a caregiver will educate other caregivers of dementia patient. This will help indirectly to understand what were the most difficult condition / situation they might have face during managing the patient in their family.

Table 37 Readiness to educate other caregivers with similar conditions

Response	Frequency	Percentage
No response	2	1.9
Will share experience & extend possible help	52	50.5
Will tell symptoms and causes of typical behavior	49	47.6
Don’t know what to say	34	33.0
Total	**103**	**100**

From the above table it is evident that out of 103 family caregivers, 53 (50.5%) caregivers reported that they will share their experiences of managing the patient and extend possible help to the caregivers of other patients with similar conditions followed by other 49 (47.6%) caregivers who were ready to tell symptoms and cause of typical behavior.

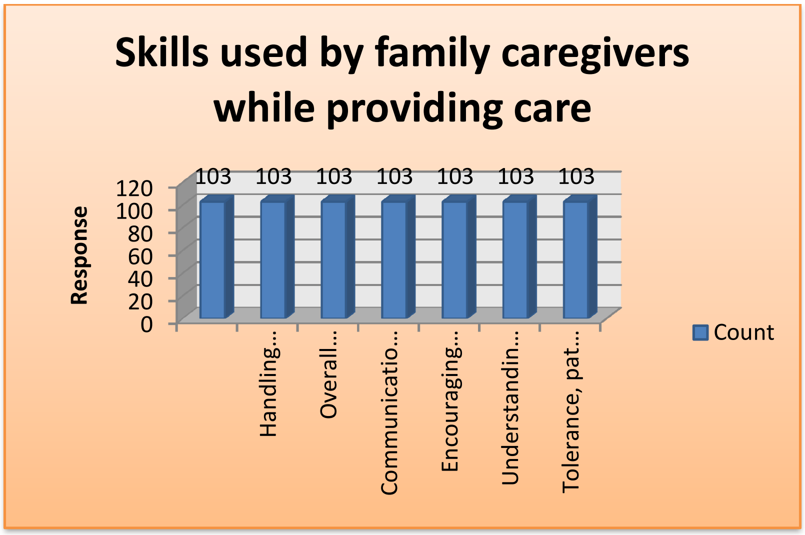
The data indicates the willingness of the caregivers to share their experiences with other caregivers.

Following table reflects the skill most important in managing the patient with dementia.

Table 38 Skills used by family caregivers while providing care in rank order

Response	Count	Mean
Cooking special food and feeding	103	5.0
Handling embarrassing situation	103	3.9
Overall handling of the patient(ADL, mobility, sickness, administering medicine,etc)	103	1.8
Communication & understanding through observation	103	3.1
Encouraging socialization	103	5.0
Understanding of / dealing with hostile behavior	103	4.5
Tolerance, patience	103	4.4

Graph No. 38.1 Skills used by family caregivers while providing care in rank order



Family caregivers have ranked the skills used while providing care to the patient with dementia form 1(most important) to 7 (least important). From the above table it is evident that the lowest mean 1.8 is scored for the overall handling of the patient followed by 3.1 communications and understanding through observation and 3.9 handling embarrassing situation, while the highest is cooking special food and feeding and encouraging socialization.

It has emerged from the data that the most important skill in management of dementia patient is handling of the patient during ADLs, communication and handling of embarrassing situations.

Following three tables reflect the need for training in managing the patient with dementia, awareness regarding the availability of the dementia related services in city and legal aid provided by the Government.

Table 39 Need for Training as felt by family caregivers

Response	**Frequency**	**Percentage**
Yes	80	77.7
No	23	22.3
Total	**103**	**100**

From the above table it is evident that 80 (77.7%) caregivers have felt the need for training to increase skills and knowledge regarding management of the dementia patient. The need for the training in management of patient with dementia and awareness is already established earlier through the data presented in this study.

Table 40 Awareness regarding Services in the City & legal provisions by the Government		
Categories	**Frequency**	**Percentage**
Yes	2	1.9
No	101	98.1
Total	**103**	**100**

Almost all the caregivers except two of them are not aware about services related to dementia specifically. 98.1% of the family caregivers were not aware regarding any services available in the city & legal provision by the Government for dementia cases. Two people who have said that they are aware about the services referred to all purpose care centre for elderly and some information available at General Hospital, but nothing in specific and are not aware about legal provision by the Government, if any. This clearly calls for the services related to dementia and caregivers to be made available in the city.

Following table covers the perception of caregiver related to the dementia services, its availability, need and preference. This will help to understand what further course of action should be taken to make the services available to the caregivers and make the existing services reachable to them.

Table 41 Perception of caregivers regarding services related to Dementia

Responses	Disagree		Not Sure		Agree		Total	
	N	%	N	%	N	%	N	%
I would rather ask my family or friends for help than use Government /Hospital /Institutional services	76	73.8	12	11.7	15	14.5	103	100
I believe the government should support the care for people of dementia at home	3	2.9	13	12.6	87	84.5	103	100
I believe that disability arising due to dementia should be made part of disability Act	4	3.8	57	55.3	42	40.7	103	100
I believe that insurance companies should cover dementia in the policies	1	1	38	36.9	64	62.1	103	100
I believe in the idea that families should give care on their own and not ask for outside help	81	78.6	7	6.8	15	14.5	103	100
I am not aware of what services are available for the patient	9	8.8	29	28.2	65	63.1	103	100
There is need for the Government and NGOs to create awareness regarding dementia	1	1	12	11.7	90	87.4	103	100
Dementia services like respite care, day care homes, medicines at subsidized rates should be provided by the government	2	2	13	12.6	88	85.4	103	100
I wish there were someone who could tell me more about services for the patient	3	3	24	23.3	76	73.8	103	100
I believe Specialized services like separate Geriatric wards at government hospitals, ID cards for patients, Help lines, 24 hrs. medical shop should be available for dementia patient	0	.0	6	5.8	97	94.2	103	100

From the above table it is evident that out total 103 family caregivers 76 (73.8%) of them have disagreed that they would rather ask family or friends for help than use Government /Hospital /Institutional services. 81 (78.6%) caregivers disagree to believe in the idea that families should give care on their own and not ask for outside help.

57 (55.3%) family caregivers are not sure regarding disability arising due to dementia should be made part of disability Act. Out of 103, 38 (36.9%) caregivers are not sure whether insurance companies should cover dementia as a disease in their policies.

87 (84.5%) family caregivers agree that the government should support to help care for people of dementia at home and 88 (85.4%) agree to have services like respite care, day care homes, medicines at subsidized rates to be provided by the Government.

90 (87.4%) family caregivers agree that there is need for the Government organizations and NGOs to create awareness regarding dementia and 97(94.2%) believe that specialized services like separate Geriatric wards at government hospitals, ID cards for patients, Help lines, 24 hrs. Medical shop should be available for patient with Dementia.

It has emerged from the above data that there is a lot of scope for interventions in the city as far as services related to Dementia patients and their caregivers is concerned. Along with specific social work interventions, it also requires integrated approach to intervention. Special Geriatric wards at government hospitals, ID cards for patients, Help lines, 24 hrs. Medical shop can be taken up at the policy level immediately.

SECTION-VIII ASSOCIATION OF VARIABLES

This section explores relationship in terms of the association of variables in the study by applying Chi-Square statistics. The association between select background characteristics of the caregivers and patients is explored with:

1) Stress areas felt by the caregivers in various domains 2) Activities dropped by the Caregivers due to care giving and 3) Overall Wellbeing of the Caregivers.

1) Stress areas felt by the caregivers in various domains:

The following table presents Frequency and Percentage distribution of the stress domain among family caregivers with select background characteristics like Age, Gender, and Relationship with the patient, Family type, responsibility of care giving shared by the family member and severity of disease.

Table No. 42. Stress area & select background characteristics

Stress Area	Age						Gender				Relationship						Family type				Resp shared by family member				severity of disease							
	<=35		36-50		>50		Male		Female		Spouse		Children		Family member		Nuclear		Joint		No		Yes		Mild		Moderate		High		Total	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Social	28	73.7	23	74.2	25	75.8	46	71.9	30	78.9	28	77.8	30	66.7	18	85.7	35	76.1	41	73.2	68	73.9	8	80	36	81.8	17	73.9	23	65.7	76	74.5
Personal	24	63.2	10	31.3	17	51.5	34	52.3	17	44.7	18	50	23	50	10	47.6	26	55.3	25	44.6	49	52.7	2	20	26	59.1	8	34.8	17	47.2	51	49.5
Financial	22	57.9	15	46.9	18	54.5	33	50.8	22	57.9	19	52.8	28	60.9	8	38.1	24	51.1	31	55.4	45	48.4	10	100	20	45.5	12	52.2	23	63.9	55	53.4
Professional	19	50	26	81.3	7	21.2	38	58.5	14	36.8	14	38.9	25	54.3	13	61.9	20	42.6	32	57.1	51	54.8	1	10.0	22	50	13	56.5	17	47.2	52	50.5
Physical	28	73.7	30	93.8	31	93.9	56	86.2	33	86.8	33	91.7	38	82.6	18	85.7	43	91.5	46	82.1	80	86.0	9	90.0	36	81.8	20	87.0	33	91.7	89	86.4
Emotional	19	50	22	68.8	12	36.4	34	52.3	19	50	16	44.4	22	47.8	15	71.4	21	44.7	32	57.1	52	55.9	1	10.0	19	43.2	16	69.6	18	50	53	51.5
Total	38	100	32	100	33	100	65	100	38	100	36	100	46	100	21	100	47	100	56	100	93	100	10	100	44	100	23	100	36	100	103	100

Table No. 42.1 Chi-square statistics association

Variables		Age	Sex	Relationship	Family type	Resp shared by family member	severity of disease
Social	Chi-square	.042	.628	3.048	.110	.176	2.667
	df	2	1	2	1	1	2
	Sig.	.979	.428	.218	.740	.675	.264
Personal	Chi-square	7.153	.550	.038	1.165	3.859	3.687
	df	2	1	2	1	1	2
	Sig.	*.028	.458	.981	.280	*.049	.158
Financial	Chi-square	.873	.489	3.014	.189	9.666	2.722
	df	2	1	2	1	1	2
	Sig.	.646	.484	.222	.664	.002	.256
Professional	Chi-square	23.432	4.484	3.307	2.176	7.262	.493
	df	2	1	2	1	1	2
	Sig.	*.000	*.034	.191	.140	*.007	.782
Physical	Chi-square	8.301	.010	1.422	1.901	.122	1.643
	df	2	1	2	1	1	2
	Sig.	*.016	.922	.491	.168	.727	.440
Emotional	Chi-square	6.873	.051	4.305	1.589	7.620	4.256
	df	2	1	2	1	1	2
	Sig.	*.032	.821	.116	.208	*.006	.119

P Value $\leq$ 0.05, significant at 5% level of significant

From the above table, the overall picture of stress among family caregivers in various domains reflects that out of total 103, majority of family caregivers (86.4%) have reported the physical domain to be the most stressful, followed by social domain (74.5%) and (53.4%) in financial domain.

When looked with background characteristic of age of the family caregivers, it is observed that family caregivers in the age group below 35 years, 73.7.% of them have equally felt stress in Social and Physical domain. Those between the age group of 36-50 years, 93.8% of have reported physical domain as the most stressful, and 81.3% felt stress in professional domain. While in the age group above 50 years, 93.9% have felt stress in physical domain followed by 75.8% of them feeling stress in social domain.

Looking to the sex of the family caregivers, Almost 86% both male and female family caregivers have reported physical domain as most stressful. 71.9% male caregivers have felt stress in social domain while 78.9% of females have felt stress in social domain. After physical and social stress, 58.5% of male caregivers have felt stress in professional area while 57.9% have felt stress in financial domain.

When seen with the relationship of the caregivers with the patient, it can be seen that 91.7% of spouse, 85.7% of other family members (Daughter-in-law, siblings & brother in law) and 82.6% of children have felt physical domain as most stressful. This is followed by social domain as the most stressful, felt by 85.7% family members, 77.8% spouse and 66.7% children

Family caregivers with both 91.5% in nuclear and 82.1% in joint families have felt most stress in physical domain followed by 76.1% of nuclear family and 73.2% of joint family in social domain. Both the family caregivers whose responsibility is shared by the family member and those whose responsibility is not shared have reported physical domain to be most stressful 90% & 86% respectively. Family caregivers of the patients with mild, moderate and high severity have reported physical domain as most stressful (81.8%, 87% & 91.7%) respectively followed by social (81.8%, 73.9% and 65.7%) respectively.

Chi-square statistics is applied between Stress areas felt by the family caregivers and the background characteristics like Age, Gender, relationship, Family type, responsibility of care giving shared by the family member and severity of disease of the patient, to explore association if any. The results of association shows that Out of all the categories Age of the family caregivers is having association with Personal domain (chi-square:7.153, P value: 0.028), Professional Domain (chi-square:23.432, P value: 0.00), Physical Domain (chi-square:8.301, P value: 0.016), and Emotional Domain (chi-square:6.873, P value: 0.032). Sharing of responsibility is also having association with Personal domain (chi-square:3.859, P value: 0.049), Financial Domain (chi-square:9.666, P value: 0.02), Professional Domain (chi-square:7.262, P value: 0.007), and Emotional Domain (chi-square:7.620, P value: 0.006).

2) Activities dropped by the Caregivers due to care giving:

Table 43 Activities dropped due to carrying & select background characters

Variables	Age						Gender				Relationship						Family type				Resp shared by family member				Severity of disease							
	<=35		36-50		>50		Male		Female		Spouse		Children		Family member		Nuclear		Joint		No		Yes		Mild		Moderate		High		Total	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Visiting long distance relative	31	81.6	29	90.6	30	90.9	55	84.6	35	92.1	33	91.7	38	82.6	19	90.5	42	89.4	48	85.7	80	86.0	10	100	36	81.8	21	91.3	33	91.7	90	87.4
Entertainment	26	68.4	23	71.9	12	36.4	40	61.5	21	55.3	18	50	28	60.9	15	71.4	34	72.3	27	48.2	58	62.4	3	30.0	32	72.7	12	52.2	17	47.2	61	59.2
Attending Marriages	29	76.3	24	75	16	48.5	43	66.2	26	68.4	21	58.3	32	69.6	16	76.2	23	48.9	46	82.1	63	67.7	6	60.0	26	59.1	19	82.6	24	66.7	69	67.0
Outing with Children	15	39.5	13	40.6	7	21.2	23	35.4	12	31.6	9	25	18	39.1	8	38.1	16	34.0	19	33.9	35	37.6	0	.0	15	34.1	9	39.1	11	30.6	35	34.0
Family celebrations	18	47.4	26	81.3	16	48.5	38	58.5	22	57.9	20	55.6	24	52.2	16	76.2	26	55.3	34	60.7	57	61.3	3	30.0	26	59.1	14	60.9	20	55.6	60	58.3
Social Functions	18	47.4	13	40.6	18	54.5	32	49.2	17	44.7	15	41.7	27	58.7	7	33.3	20	42.6	29	51.8	41	44.1	8	80	17	38.6	12	52.2	20	55.6	49	47.6
Others	3	7.9	5	15.6	2	6.1	6	9.2	4	10.5	3	8.3	5	10.9	2	9.5	4	8.5	6	10.7	8	8.6	2	20	5	11.4	3	13.0	2	5.6	10	9.7
Total	38	100	32	100	33	100	65	100	38	100	36	100	46	100	21	100	47	100	56	100	93	100	10	100	44	100	23	100	36	100	103	100

Activities Dropped		Age	Gender	Relationship	Family type	Resp shared by family member	Severity of disease
Visiting long distance Relative	Chi-square	1.838	1.220	1.732	.308	1.600	2.155
	df	2	1	2	1	1	2
	Sig.	.399	.269	.421	.579	.206	.340
Entertainment	Chi-square	10.593	.391	2.615	6.159	3.917	5.943
	df	2	1	2	1	1	2
	Sig.	*.005	.532	.270	*.013	*.048	.051
Attending Marriages	Chi-square	7.533	.056	2.162	12.742	.245	3.780
	df	2	1	2	1	1	2
	Sig.	*.023	.813	.339	*.000	.621	.151
Outing with Children	Chi-square	3.539	.155	1.997	.000	5.701	.460
	df	2	1	2	1	1	2
	Sig.	.170	.694	.369	.990	*.017	.794
Family celebrations	Chi-square	10.105	.003	3.585	.306	3.635	.185
	df	2	1	2	1	1	2
	Sig.	*.006	.955	.167	.580	.057	.912
Social Functions	Chi-square	1.263	.194	4.493	.873	4.669	2.524
	df	2	1	2	1	1	2
	Sig.	.532	.659	.106	.350	.031a	.283
P Value ≤ 0.05, significant at 5% level of significant							

The following table presents Frequency and Percentage distribution of the Activities dropped by the family caregivers with select background characteristics like Age, Gender, and Relationship with the patient, Family type, responsibility of care giving shared by the family member and severity of disease.

Table 43.1 Chi-square statistic for association

Activities Dropped		**Age**	**Gender**	**Relationship**	**Family type**	**Resp shared by family member**	**Severity of disease**
Visiting long distance Relative	Chi-square	1.838	1.220	1.732	.308	1.600	2.155
	df	2	1	2	1	1	2
	Sig.	.399	.269	.421	.579	.206	.340
Entertainment	Chi-square	10.593	.391	2.615	6.159	3.917	5.943
	df	2	1	2	1	1	2
	Sig.	*.005	.532	.270	*.013	*.048	.051
Attending Marriages	Chi-square	7.533	.056	2.162	12.742	.245	3.780
	df	2	1	2	1	1	2
	Sig.	*.023	.813	.339	*.000	.621	.151
Outing with Children	Chi-square	3.539	.155	1.997	.000	5.701	.460
	df	2	1	2	1	1	2
	Sig.	.170	.694	.369	.990	*.017	.794
Family celebrations	Chi-square	10.105	.003	3.585	.306	3.635	.185
	df	2	1	2	1	1	2
	Sig.	*.006	.955	.167	.580	.057	.912
Social Functions	Chi-square	1.263	.194	4.493	.873	4.669	2.524
	df	2	1	2	1	1	2
	Sig.	.532	.659	.106	.350	.031a	.283
P Value $\leq$ 0.05, significant at 5% level of significant							

It can be seen from the above table that out of total 103 family caregivers majority of family caregivers 87.4% have stopped visiting relatives staying at a long distance 67% of them are not able to attend marriages while 59.2% are not able to have any entertainment activities.

When looked with the background characteristics of Age of the caregivers, it is observed that across the age groups i.e. below 35 to above 50 yrs 80% to 90% of family caregivers have dropped the activity of visiting long distance relatives. While in the age group of 36-50 years, 81.3% of family caregivers have stopped family celebrations. While in the age group of 35 years and below, 76.3% of family members have stopped attending marriages and 54.5% in the age group of 50 years and above have stopped attending social functions.

Both male and female family caregivers have reported same activities being dropped: visiting long distance relatives (84.6% & 92.1%), not able to attend marriages (66.2% &68.4%) and not able to do family celebration (58.5%,&57.9%) respectively.

Spouse, children and other family members have reported of inability to visit the long distance relatives (91.7%, 82.6% & 90.5%) respectively followed by unable to attend marriages (58.3%, 69.6% and 76.2%) respectively.

Looking to the family type both nuclear and joint families have dropped the activity of visiting to long distance relative (89.4%, 85.7%) respectively. However, those with nuclear family type, 72.3% have dropped entertainment activity followed by 55.3% family celebrations. While those with joint family type, 82.1% have stopped attending marriages and 60.7% have stopped family celebrations

It is evident that 86% family caregivers who do not have sharing of the responsibility by the family members have dropped visiting long distance relatives followed by 67.7% of them not attending marriage. 81.8% family caregivers of the patients with mild, 91.3% family caregivers of the patients moderate and 91.7% family caregivers of the patient with high severity have reported to have dropped visiting long distance relatives.

Chi-square statistics is applied between activities dropped by the family caregivers and the background characteristics like Age, Gender, relationship, Family type, responsibility of care giving shared by the family member and severity of disease of the patient to explore association if any.

The results of association showed that Out of all the categories Age of the family caregivers is having association with dropped activities of Entertainment (chi-square:10.59, P value: 0.005), Attending marriages (chi-square:7.533, P value: 0.02), Family celebrations (chi-square:10.105, P value: 0.006).

Family Type is also having association with Entertainment (chi-square:6.15, P value: 0.013), Attending marriages (chi-square:12.74, P value: 0.00). Sharing of responsibility is also having association with Entertainment (chi-square:3.917, P value: 0.048), outing with children (chi-square:5.701, P value: 0.017) and social functions (chi-square:4.669, P value: 0.031).

3) Overall Wellbeing of the Caregivers:

A Frequency and percentage distribution of overall health and wellbeing of the caregivers with respect to Patients age, Patients Sex, Severity of the disease and background characteristics of the family caregivers like Age, Sex, Relationship, Income and responsibility of care giving shared by the family member

Table 44 Overall well being & data background characteristics

Category	Personal Well being						Social Well being						Physical Well being						Emotional Well being						Total	
	LOW		MOD		HIGH		LOW		MOD		HIGH		LOW		MOD		HIGH		LOW		MOD		HIGH			
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Patients Age																										
<=60 yr	8	40.0	7	35.0	5	25.0	5	29.4	5	29.4	7	41.2	7	35.0	7	35.0	6	30.0	9	45.0	3	15.0	8	40.0	20	100
61-70 yr	16	37.2	17	39.5	10	23.3	13	41.9	11	35.5	7	22.6	18	41.9	12	27.9	13	30.2	17	39.5	11	25.6	15	34.9	43	100
>70 yr	12	30.0	11	27.5	17	42.5	9	28.1	13	40.6	10	31.3	12	30.0	21	52.5	7	17.5	10	25.0	19	47.5	11	27.5	40	100
Patient Sex																										
Male	20	38.5	17	32.7	15	28.8	16	35.6	15	33.3	14	31.1	21	40.4	21	40.4	10	19.2	19	36.5	15	28.8	18	34.6	52	100
Female	16	31.4	18	35.3	17	33.3	11	31.4	14	40.0	10	28.6	16	31.4	19	37.3	16	31.4	17	33.3	18	35.3	16	31.4	51	100
Severity of disease																										
Mild	19	43.2	15	34.1	10	22.7	14	42.4	11	33.3	8	24.2	18	40.9	13	29.5	13	29.5	22	50.0	9	20.5	13	29.5	44	100
Moderate	7	30.4	6	26.1	10	43.5	9	45.0	6	30.0	5	25.0	7	30.4	10	43.5	6	26.1	3	13.0	11	47.8	9	39.1	23	100
High	10	27.8	14	38.9	12	33.3	4	14.8	12	44.4	11	40.7	12	33.3	17	47.2	7	19.4	11	30.6	13	36.1	12	33.3	36	100
Age																										
<=35	15	39.5	12	31.6	11	28.9	11	34.4	12	37.5	9	28.1	15	39.5	15	39.5	8	21.1	16	42.1	10	26.3	12	31.6	38	100
36-50	15	46.9	5	15.6	12	37.5	9	30.0	11	36.7	10	33.3	14	43.8	13	40.6	5	15.6	5	15.6	9	28.1	18	56.3	32	100
>50	6	18.2	18	54.5	9	27.3	7	38.9	6	33.3	5	27.8	8	24.2	12	36.4	13	39.4	15	45.5	14	42.4	4	12.1	33	100
Sex																										
Male	24	36.9	22	33.8	19	29.2	17	32.7	20	38.5	15	28.8	23	35.4	25	38.5	17	26.2	23	35.4	20	30.8	22	33.8	65	100
Female	12	31.6	13	34.2	13	34.2	10	35.7	9	32.1	9	32.1	14	36.8	15	39.5	9	23.7	13	34.2	13	34.2	12	31.6	38	100
Relationship																										
Spouse	9	25.0	16	44.4	11	30.6	7	31.8	10	45.5	5	22.7	8	22.2	14	38.9	14	38.9	13	36.1	15	41.7	8	22.2	36	100
F.mem	14	30.4	15	32.6	17	37.0	20	44.4	11	24.4	14	31.1	17	37.0	22	47.8	7	15.2	18	39.1	14	30.4	14	30.4	46	100
Children	13	61.9	4	19.0	4	19.0	0	.0	8	61.5	5	38.5	12	57.1	4	19.0	5	23.8	5	23.8	4	19.0	12	57.1	21	100
Responsibility shared by family members	1	10	3	30	6	60	2	33.3	1	16.7	3	50	0	0	8	80	2	20	2	20	7	70	1	10	10	100

Table 44.1 Chi-square statistics for association

Category	Personal Well being	Social Well being	Physical Well being	Emotional Well being
Patient Age				
Chi-square	4.144	2.697	5.692	8.036
Sig.	.387	.610	.223	.090
Patient Sex				
Chi-square	.588	.383	2.151	.492
Sig.	.745	.826	.341	.782
Severity of disease				
Chi-square	4.379	6.717	3.131	10.449
Sig.	.357	.152	.536	.034
Age				
Chi-square	12.158	.505	6.070	16.292
Sig.	.016	.973	.194	.003
Sex				
Chi-square	.388	.316	.078	.135
Sig.	.824	.854	.962	.935
Relationship				
Chi-square	9.710	11.191	12.106	8.241
Sig.	.046	.024	.017	.083
Resp shared by family member				
Chi-square	5.008	1.551	8.932	7.466
Sig.	.082	.460	.011	.024
P Value $\leq$ 0.05, significant at 5% level of significant				

As it is seen from the above table that out of total 103 family caregivers 52 family caregivers who look after male patients and 51 family caregivers looking after female patients. When the same looked into context of; personal well being it is seen that 38.5% of caregivers looking after male patients are on the lower level, as compared 31.4% of caregivers looking after female patients. 35.3% caregivers looking after female patients are at the moderate level of personal well being against 32.7% of caregivers looking after male patients. In the context of social well being, 40% of caregivers looking after female patients are having moderate level against 33.3% of those looking after male patients of social well being. However, 35.6% of caregivers looking after male patients are low level of social well being against 31.4% of caregivers looking after female patients. In the context of physical well being, 31.4% of caregivers looking after female patients are on high level against only 19.2% of caregivers looking after male patients. 36.5% of caregivers looking after male patients are low on emotional wellbeing against 33.3% on of caregivers looking after female patients.

43.2% of family caregivers looking after patients with mild level of dementia are on the low level of personal wellbeing, while those looking after patients with high level of dementia are on the moderate level of personal well being. More than 80% of family caregivers looking after mild and moderate level of dementia patients are low on social wellbeing. 40.9% of family caregivers looking after mild dementia patients are low on physical well being, while 43.5% of family caregivers looking after moderate dementia patients are on moderate level of physical well being. Almost 80% of family caregivers looking after mild, moderate and high level of dementia patients are low on emotional wellbeing.

Looking to the age of the caregivers it is seen that 46.9% of caregivers in the age group of 36-50 years have low personal well being, while those above 50 years of age have moderate level of wellbeing. 38.9% caregivers above 50 years of age are on the low level of social wellbeing against 30% of those in the age group of 36-50 years. 43.8% of caregivers in the age group of 36-50 are low on physical wellbeing as against 39.5% in the age group below 35 years. 4.5% of caregivers in the age group of above 50 years are low on emotional wellbeing against 15.6% in the age group of 36-50 years.

Well being when seen in the context of sex of the caregivers, 36.9% of male caregivers are on the low personal wellbeing against 31.6% of female caregivers while 34.2% of female caregivers are on moderate as well as high level of personal wellbeing. 38.5% male caregivers are on moderate level of social well being against 32.1% of female caregivers. 39.5% female caregivers are on moderate level of physical well being against 38.5% of male caregivers. 35.4% of male caregivers are on low level of emotional wellbeing against 34.2% of female caregivers.

Wellbeing when seen in the context of relationship of the caregiver with the patient it is seen that 61.9% of children are on low personal wellbeing as compared 25% spouse and 30.4% other family members. 45.5% of spouse are on the moderate social well being as compared to 61.5% of children and 24.4% of other family members. 57.1% of children are low on physical wellbeing as compared to 22.2% of spouse. 38.9% of spouses are on moderate and high level of physical wellbeing. 41.7% of spouses are on the moderate level of emotional wellbeing as compared to only 19% of children and 30.4% of family members.

60% of family caregivers show high level of personal wellbeing as their responsibility of caregiving is shared by the family members. Similarly, 50% of them show high level of social wellbeing. However 80% of them show moderate level of Physical wellbeing and none of them are on the low level of physical wellbeing. 70% of them are on the moderate level of emotional wellbeing and only 10% are on high of emotional wellbeing.

Chi-square statistics is applied between Overall wellbeing of the family caregivers and the background characteristics like Age and sex of the patient, Severity of the disease ,Age, sex, relationship, responsibility of care giving shared by the family member to explore association if any.

The results of association shows that ; Out of all the categories Severity of disease is having association with Emotional well being (chi-square:10.44, P value: 0.034). Age of the family caregivers is having association with personal wellbeing (chi-square:12.15, P value: 0.016) and Emotional wellbeing (chi-square:16.292, P value: 0.003).

Relationship of the family caregivers with the patient is having association with personal wellbeing (chi-square:9.710, P value: 0.046), Social well being (chi-square:11.191, P value: 0.024) and physical wellbeing (chi-square:12.106, P value: 0.017).

Responsibility of caregiving shared by the family members is having association with physical wellbeing (chi-square:8.932, P value: 0.011) and Emotional wellbeing (chi-square:7.46, P value: 0.024).

Table 45 B Frequency and percentage distribution of overall health and wellbeing of the caregivers with respect to Stress Areas

Category	**Personal Well being**						**Social Well being**						**Physical Well being**						**Emotional Well being**							
	LOW		**MOD**		**HIGH**		**LOW**		**MOD**		**HIGH**		**LOW**		**MOD**		**HIGH**		**LOW**		**MOD**		**HIGH**		**Total**	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Social stress	31	40.8	25	32.9	20	26.3	23	41.8	20	36.4	12	21.8	31	40.8	30	39.5	15	19.7	31	40.8	21	27.6	24	31.6	76	100
Personal Stress	14	27.5	23	45.1	14	27.5	12	31.6	12	31.6	14	36.8	15	29.4	20	39.2	16	31.4	26	51.0	16	31.4	9	17.6	51	100
Financial Stress	15	27.3	18	32.7	22	40.0	14	31.1	11	24.4	20	44.4	13	23.6	29	52.7	13	23.6	19	34.5	22	40.0	14	25.5	55	100
Professional Stress	23	44.2	14	26.9	15	28.8	8	17.4	23	50.0	15	32.6	20	38.5	22	42.3	10	19.2	13	25.0	11	21.2	28	53.8	52	100
Physical Stress	29	32.6	32	36.0	28	31.5	23	33.8	25	36.8	20	29.4	31	34.8	34	38.2	24	27.0	29	32.6	27	30.3	33	37.1	89	100
Emotional Stress	24	45.3	12	22.6	17	32.1	13	28.3	21	45.7	12	26.1	21	39.6	19	35.8	13	24.5	11	20.8	16	30.2	26	49.1	53	100
Total	36	35.0	35	34.0	32	31.1	27	33.8	29	36.3	24	30	37	35.9	40	38.8	26	25.2	36	35	33	32.0	34	33	103	100

Table 45.1 Chi-Square statistics for association

Categories	**Personal Well being**	**Social Well being**	**Physical Well being**	**Emotional Well being**
Social stress				
Chi-square	4.356	6.408	5.667	4.156
Sig.	.113	*.041	.059	.125
Personal Stress				
Chi-square	5.726	1.666	2.699	14.662
Sig.	.057	.435	.259	*.001
Financial Stress				
Chi-square	5.076	11.320	10.945	4.381
Sig.	.079	*.003	*.004	.112
Professional Stress				
Chi-square	4.293	14.473	2.018	20.672
Sig.	.117	*.001	.365	*.000
Physical Stress				
Chi-square	1.834	.086	1.055	4.926
Sig.	.400	.958	.590	.085
Emotional Stress				
Chi-square	7.501	4.158	.689	14.929
Sig.	.024	.125	.709	*.001
P Value $\leq$ 0.05, significant at 5% level of significant				

It can be seen from the above table 40.8% of family caregivers feeling stress in social areas have low personal, social, physical and emotional wellbeing. Those family caregivers feeling stress in personal areas; 45.1% of them are on moderate level of personal wellbeing, 39.2% of them are on moderate level of physical well being and 51% of them are on level of emotional wellbeing. 52.7% of family caregivers with financial stress are on moderate level of physical wellbeing and 40% of them are high on personal wellbeing. 44.2% of family caregivers with professional stress are low on personal wellbeing and 50% of them are on social wellbeing. 36% of family caregivers with physical stress are on the moderate level of personal wellbeing and 45.3% those with emotional stress are on the low of personal well being, 45.7% are on moderate level of social well being.

Chi-square statistics is applied between Overall wellbeing of the family caregivers stress areas as experienced by them, to explore associations if any. The results of association shows that; Out of all the categories Social stress is having association with social well being (chi-square:6.408 P value: 0.041). Personal stress is having association with emotional wellbeing (chi-square:14.662, P value: 0.001). Financial stress is having association with social well being (chi-square:11.320 P value: 0.003) and physical well being (chi-square:10.945 P value: 0.001). Professional stress is having association with social wellbeing (chi-square:14.473 P value: 0.001) and Emotional well being (chi-square:20.672 P value: 0.00). Emotional stress is having association with emotional well being (chi-square:14.929 P value: 0.001)

SECTION-IX CASE STUDIES

In this section case studies of 6 primary caregivers are presented, the case studies illustrate care giving arrangements, behaviour present, management of the patient with dementia, difficulties faced if any and their overall response to the care giving role that they have taken up. **The cases given do not include real names to protect the confidentiality of the individuals.**

6 cases were selected for the presentation on the basis of relationship and Care arrangements and Coping and Care giving experience.

CASE STUDY 1 – End of life care, Emotional moments, and decisions: Daughter narrates

Primary Caregiver	**Patient**
Name : Ms Vijaya	**Name :Mr. Rao**
Age: 43 years	**Age: 73 years**
Sex: Female	**Sex: Male**
Relationship with Patient: Daughter	**Relationship with Caregiver: Father**

Ms. Vijaya, a qualified accountant had to set it aside her career to take care of her father. This is a typical case, where the patient had passed away after the first interview.

Medical Condition: Ms. Vijaya's father Mr. Rao has developed dementia caused by multi infarct (vascular dementia) for over 4 years. He also had suffered from other medical conditions Of age related arthritis.

Family Members: Vijaya, her sister and mother.

Care Arrangements: Vijaya's father was bed ridden, very weak physically and used to be awake for many hours during the day as well as night. After his initial diagnosis he displayed laughing, crying and hallucinations. He increasingly needed more help with his daily activities. Everything had to be done for him, like brushing teeth, cleaning after toilet, giving him bath, dressing him, spoon–feeding etc. He did not even know he had to ask for water if he was thirsty. Family members had to remember to give him water from time to time and make him sip from a glass we held. He was not even aware that he needed to hold the glass they take it to his lips. At times would not sleep at all for days together and at times would be sleeping all the time and had to be woken up for bath time, mealtimes etc. Usually when he was awake, vijaya's sister and she would walk him around the house twice a day with the support of the walker. At times make him seat near the window to get the view of the road and the garden. Vijaya left her career so that she could stay at home to take care of the housework and the day time activities of care giving. Her sister would spend some time in the evening with the father after returning from the work, feed him dinner, administer medicine and put him to bed. Both the sister shared the caregiving but Vijaya's care giving hours were more as compared to her sister. They kept a close supervision on him, inspite of that he fell down a few times either by sitting position or in the toilet. However, he did not suffer any fractures but was frightened. Mr. Rao's decline very gradual and the family did not realize when he actually reached the late stage. During this time he was not able to have small conversation which he used to earlier, he was not able to respond and speak, he never initiated conversation. One day the family realized that he could not speak any more. With this swallowing difficulties also started, he was kept on semi liquid diet as he would not chew. Mr. Rao had stated fearing strangers and would not respond to untrained maids hired for help. During his visits to hospitals, Mr. Rao would try to fight off nurses and would get agitated unless one of the daughters held his hand and told him what was going to be done and that they are watching.

"My father whom I had seen as a strong man, holding me on his shoulders and playing with me and now was so fragile and dependent. He could do nothing on his own. He would just let go of the glass if we let him hold it."

"One common problem I faced was that the nursing staff had no idea how to deal with someone who could not understand and would not co-operate, they would not allow me to be present alongside during treatment"

After various experiences Vijaya and her family had over the years, they decided to provide care at home for as long as possible and not move their father to a hospital unless unavoidable, because it was easier to handle all the work at home than to supervise the hospital staff.

Coping & Emotional Moments:

As Mr. Rao was not able to speak he was good at non-verbal communication. He would blink his replies so slightly that Vijaya and her sister had to be very careful about noting his response. He would never answer the same question twice. But in the last couple of months, even such replies were rare. M. Rao, though incontinent, would sometimes not pass urine for an entire day. Before, bedtime, however, he had as his catheter and urine bag needed change every night.

In last few days before his death, Mr. Rao was unable to stand up, one day after picking him up and putting him in the chair, Vijaya was out of breath and stood up straight to take a deep breath. Mr. Rao just started crying out loudly. He had earlier done this only on the day when he realized his wife had died. Vijaya instinctively felt he was crying out of fear of what was to come, she consoled him saying, that they are doing the massage with the oil so he would be able to walk again. He understood that Vijaya was trying to console him and stopped crying.

"I had no more caregiving to do, I missed it terribly. I missed the routine. I missed his company. I missed having someone to speak to during the daytime, even if it was as superfluous as telling my father, "Look at that tree" or "There is so much traffic today".

"We always told him he was the best ***appa*** *in the world and on the days he could comprehend, he would smile back. Singing his favourite songs always brought tears to his eyes".*

Vijaya always told him that he was the best appa in the world and on the days he would comprehend he would smile back. Singing or playing his favorite songs always brought tears to his eyes. Vijaya was not able to take her father's death, it seemed unreal to her. In the days following her death, even as she went out shopping for items required for the death rituals, mentally she would tell herself that she needs to return home as Mr. Rao was alone and would need her help. Then another thought would remind her that he was no more and there was no need to rush back.

Vijaya had chosen to suspend her career and stay at home to be a caregiver and now she has nothing to do.

Vijaya feels guilty that she did not know about many things, she feels that having oxygen cylinder handy, whenever her father faced respiratory problems would have been better. She never really considered dementia as an illness but only as an altered state, because of which she did not look or help. Now that she is trying to remember all that has happened, Vijaya feels she should have done much more and sooner.

Care giving Experience:

In the early stages of her father's illness Vijaya was an impatient person. She had fights and arguments with him, which she now realizes were totally unnecessary. Only over the time did she realized that her father was trying his best to co-operate and could not help his condition. Vijaya reported that as her father's condition worsened care giving was a circumstance which she had to accept. At first she was not particularly happy being home all day but this was necessity and also her duty towards family. She used to get upset about some things that caregiving involved.

> *"Before I became a caregiver, I was responsible only for myself. I was career oriented and need to fulfill my wants and desires. Then father's condition worsened and I had to accept care giving. At first I was not particularly happy being home all day but this was a necessity and also my duty to my family.*"

Vijaya strongly said that there is no reason why the people living in our country should lack the social infrastructure that exists in the developed world today. Death has touched her twice, both times when it was least expected. “When life is so unpredictable, the least one can do is try to make it a comfortable one”. Vijaya said that her outlook to life has changed because of past few years. She is no longer interested in 10 hours workdays and mad rush that leads nowhere.

CASE STUDY 2 – Diagnosis, Medication, Side Effects and Elderly Spouse: A daughter talks of her mother's Dementia.

Primary Caregiver	**Patient**
Name : Mr. Gupta	**Name :Mrs. Gupta**
Age: 80 years	**Age: 78years**
Sex: Male	**Sex: Female**
Relationship with Patient: Husband	**Relationship with Caregiver: Wife**

In this case though the husband is the primary caregiver, it was the second interview where the researcher met the daughter (Sheila, name changed) and got more details about the care giving and experiences of the family.

Medical Condition: Sheila has a mother suffering from Alzheimer's disease, from last five years. Currently was in the last stage of Dementia.

Family Members: Sheila, her two elder brothers and her 80 years old father. Sheila is now married and stay in the same city with her in laws. Her two brothers are also married and settled in Ahmedabad.

Care Arrangements: Sheila's father is her mother's caregiver and she along with her brothers try to support him in various ways. Though her father insists he does not need more help right now and will ask if needed.

Mrs. Gupta was an ideal home maker. After working for few years, she was happy to leave her job and switch to full time home making. Mr. Gupta a quiet man worked at a private firm. Mrs. Gupta loved to cook, was very social and actively participated in community activities. Mrs. Gupta loved oil painting, helped with society club and volunteered in many activities and also helped with managing the society club administration. Sheila, first notice her mother's forgetfulness around the time her marriage was fixed. The family had recently moved in a new house and Mrs. Gupta would often keep things at strange places and the kitchen arrangement was all mixed up, very much unlike what she used to arrange earlier. Though it felt bit odd Sheila thought it was just because of a new house.

During the six months between Sheila's engagement and marriage, she saw her mother behave in many strange ways. Mrs. Gupta seemed very disinterested in all the hustle and bustle of the wedding arrangements. Her disinterest in all these activities and interaction with relatives was very odd as she and socially very active earlier. Everyone in the family noticed this behavior of Mrs. Gupta and felt sad because the only child left at home would also be leaving. (two brothers had already left home for their jobs). During the ceremony, Mrs. Gupta walked off in a disoriented way when the kanyadaan was taking place.

"Everyone in the family noticed my mother's behavior and felt sad because the only child left at home would also be leaving. She walked off in a disoriented way when the kanyadaan was taking place."

After marriage, Sheila would visit her parents; she saw that her mother had lost all interest in cooking. She was quiet and inattentive. However, Sheila did not think that anything was seriously wrong and was preoccupied with her new life and in-laws and career.

Sheila began registering that something was wrong when she came to her parent's home for the delivery of her first child. Mrs. Gupta seemed very scared of holding child and would not just pick him seasoning up. She continued cooking only to serve undercooked rice and daal without. When her father pointed out her mistake, her mother would calmly say she forgot and corrected, but she always looked preoccupied and distant. Sheila's father would sometimes get irritated, thinking she was being careless or doing things wrong purposely. Mrs. Gupta could not follow even simple instructions neither got upset upon scolding by the family members. Gradually her forgetfulness got worse; Sheila's father tried to cover it up and never let her or his sons knew what he was undergoing.

"My mother seemed very scared of holding child and would not just pick him up. She continued cooking only to serve undercooked rice and daal without seasoning and my father thought she was doing it purposely"

Coping & Emotional Moments:

Sheila came to know about dementia at a workshop she attended at her office in Mumbai. She realized that her mother had many symptoms as described by the doctors. She started suspecting that her mother could be a dementia patient. Sheila's emotional reaction was one of guilt, for not having realized this earlier. She had a hope that maybe her mother's problem was of reversible type of dementia. The challenge however was to convince her father and her brothers that Mrs.Gupta had a psychiatric problem and it was not just forgetfulness. The idea of consulting the psychiatrist was frightening for the family.

More discussion brought more incidences that convinced Sheila that her mother may have dementia. Mrs. Gupta on some days would say she had no children, and on some days claimed she had only one child, while sometimes she would correctly state that she had three children. On numerous occasions she seemed to be much disoriented, wandering around the apartment not at all sure what she was doing. After a long discussion, the family decided to finally see the doctor.

> *"The doctors did not give any explanation for the disease neither did explain the side-effects. My mother's nature changed- irritable agitated and violent. She behaved like a college girl, and would be distressed to she her gray hair. She introduced me as her sister and called my father an old man – I was shattered"*

The doctors did not give any explanation neither did explain the side-effects. Doctors behaved as if the family does not understand anything. Gradually, Mrs. Gupta's nature changed, she become irritable and agitated and violent. She behaved like a college girl, and would be distressed to she her gray hair. Her ability to recognize people went down and started calling her husband as "old man". Once during the visit to the doctor for neuro-assessment, she recognized Sheila as her sister which shook Sheila. Later Shelia's father told that often mother is not able to understand who is who. She had hallucinations; she would seem to see things that weren't there. She would talk to herself in the mirror, walk out of the apartment, insisting that she wanted to return to her father's place. Mr. Gupta's health was also deteriorating, he was less mobile and was finding difficult to handle Mrs. Gupta's Behavior. He became upset and irritated more often. He suggested stopping the medication or placing her in an old age home as he could not handle her any more. He also refused to keep full time maid, as he thought someone hanging around whole day would only add to this worries. He however, agreed to employ someone for cooking.

It was difficult time for the whole family. The eldest son was supporting financially, second son was always available for emergencies. While, Sheila was providing emotional support. Sheila's father though tired and frustrated, refused to take help.

Care giving Experience:

Sheila reported: There were lots of small problems, most unexpected things were happening. Once her mother wandered off in the morning. She was nowhere to be found. After informing police; the family members started searching her in various small side –roads. After several hours she was found sitting in a park watching children play. When she saw Sheila, she smiled and said "Oh, you have come, let us go home," After that day Sheila's father was very careful to keep the apartment locked from inside so that she did not wander. Sheila feels very bad that her mother suffered so much and so did her father. She feels highly ignorant as was not able to tell doctors that medicines are not suiting her mother and not able to find out herself the side effects of medication.

Currently, Sheila's father is taking care of her mother cheerfully. He cajoles her, jokes with her and accepts that deterioration will happen. He calls his sons or daughter and at times neighbors to be with Mrs. Gupta to get few hours of respite or to do his bank or other work. He seems to have found his rhythm in looking after his wife.

As of now the family members have been managing to share the work and everything is going smoothly. All of them are concerned about the future. Mr. Gupta has not shared with any of his children about the financial arrangements for the future. The family is very sensitive and no one wants to talk about unpleasant things like death, Will and money.

Sheila feels very confused, guilty and angry. Her major concern is what will happen if father dies? Who will manage? She strongly feels that only if they knew those early symptoms, dementia could have been detected earlier. Anger is due to not receiving good guidance from the doctors and on self for not doing enough of reading and getting information from other sources.

> *"I am very confused, guilty and angry. What will happen if my father dies? Who will manage? I feel angry for not receiving good guidance from the doctors not doing enough for my mother. How helpless will be those who are uneducated and ignorant"*

She thinks that if an educated person like her was not able to do the right thing at the right time, how helpless will be those who are uneducated and completely ignorant of all aspects of the disease. She thinks if her father's health was better he would have reconciled to her mother's problem and coped with it without much suffering.

CASE STUDY 3 – Denial of the disease, hopelessness and Guilt: The Son's agony

Primary Caregiver	**Patient**
Name : Mr. Naidu	**Name :Mrs. Raju**
Age: 37 years	**Age: 74years**
Sex: Male	**Sex: Female**
Relationship with Patient: Son	**Relationship with Caregiver: Mother**

Medical Condition: Mr. Naidu's mother has developed dementia for over 3 years. She has no history of any other medical condition, except for that which happened during the course of the disease.

Family Members: Two married daughters and three married sons. Mrs. Raju lives with the youngest son.

Care Arrangements:

A separate room, with decent bed, a maid to help for assistance and looking after Mrs. Raju till the evening. The daughter-in-law, a housewife had two small kids of 3 and 1and half year old and the son was working in a MNC. Mrs. Raju's elder son with his family would occasionally drop in to see her, feed her a little bit and go. Mr. Naidu had difficulty in managing things because the maid would leave in the evening, his wife would be busy looking after the kids, so ultimately after evening hours he had to take the charge of care giving. Mrs. Raju in the early stage was very aggressive and agitatited, she would not allow the maid to make her bath or touch her or make her wear clothes. She would get these things done only from her son, Mr. Naidu narrates with tears in his eyes that initially he felt ashamed and sad that why his mother was behaving like this. When the maid left because Mrs. Raju was unmanageable and used to hit her, Mr. Naidu however, did not believe it and said that it just because that she has become weak and feeling lonely she showing change in behavior.

"In the early stage, when the maid and my wife complained about my mothers behavior I denied of her having any psychiatric problem, later when doctors diagnosed her as patient with Dementia that I had no choice but accept the reality"

Once when no one was at home, Mrs. Raju wandered away and after much difficulty Naidu could find her near the airport in an Auto. She had gone to church and while coming back she was not able guide the auto driver way back home neither was able to tell her address and name of the society. Mrs. Raju would endlessly keep on talking about her parents waiting for her near the auto and are calling her to go to Chennai with them.

Coping & Emotional Moments:

The trouble increased at home when Mr. Naidu was transferred to Mumbai for his job. She would not eat and complained to Mr. Naidu that his wife has not served her food and that she is hungry since last two days. In early stage Mr. Naidu took it seriously and had arguments with his wife for the same. Mr. Naidu was not able to control his anger and helplessness when his elder brother who took Mrs. Naidu at his place and complained that he and his kids are getting disturbed because of strange behavior of Mrs. Raju. The elder son asked Mr. Naidu to immediately come and take the mother as he could not keep her any more. Mr. Naidu had no option but to leave his job in two months.

"I felt helpless, angry, and lonely and worried for my mother and my family. I was looking for answers to so many questions related to the disease and its cure and progression but did not find any answers"

Mr. Naidu felt emotionally drained out but could not share his feelings, he decided to take his mother to her village as she was remembering it off and on. To his surprise, Mrs. Naidu eat curd rice and groundnut chutney sumptuously, while she was not able to eat much at home. Whenever, the daughter-in-law played old hindi songs for Mrs.

Raju there would be glitter in her eyes, as her late husband used to listen to those songs.

> *"I felt helpless, angry, and lonely and worried for my mother and my family. I was looking for answers to so many questions related to the disease and its cure and progression but did not find any answers"*

Care giving Experience:

Mr. Naidu strongly feels that had he known what dementia is all about and how it progresses, he would have done better for his mother. There was no guidance from the doctors, medicines were not available nor did he know that these patients need to be handled differently. It was very traumatic to see his beloved mother withering away in front of his eyes. The home care for the patient with dementia needs very specific skills related to communication, food, managing behavior etc. Knowledge and awareness related to change in behavior is must for a caregiver, as it can be an indicator for early detection of the disease.

CASE STUDY 4 – Is there any cure? How long does it go on: A 72-year-old wife taking care of her 75-year-old husband

Primary Caregiver	**Patient**
Name : Mrs. Purandare	**Name :Mr. Purandare**
Age: 72 years	**Age: 75 years**
Sex: Female	**Sex: Male**
Relationship with Patient: Wife	**Relationship with Caregiver: Husband**

Mrs. Purandare stays alone with her husband; is primarily responsible for her husband's care and has to cope with it alone. She shares the progression of her husband's condition, her ways of handling care and her feeling of exhaustion and overwhelming emotions.

Medical Condition: Mr. Purandare diagnosed with dementia 3. 5 years back.

Family Members: One son married and settled in Mumbai with two children and wife.

Care Arrangements: The first indication that something was wrong with Mrs. Purandare's husband came around 3.5 years ago, when he fell down couple of times. She took him to the family physician and he suggested various tests and brain scans and pointed out some areas and gaps caused due to ageing.

Mrs. Purandare has only one son and he lives in Mumbai with his wife and two kids. He visits as and when he gets time, mostly once every fortnight. Currently Mrs. Purndare looks after her husband all alone. She is looking out for the option to have an nursing attendant but not aware whom to contact. Mrs. Purandare looks after him all alone. She finds it extremely difficult to handle the incontinence and bathing her husband and gets physically tired.

> *"This is extremely difficult because I cannot physically do anything for my husband I am very scared of risking anything, because if I get injured, who will take care of me and my husband?"*

In addition to this, she has to make bill payments, bank work etc. She goes for evening walks & on the way buy vegetables. Earlier, her husband used to do all this work. She also manages the house, which means doing the shopping and cooking and other house work. She cannot sit back and relax, because she is responsible for everything. She cannot go and stay with her son in Mumbai because the house has two bedrooms, which are used by his kids and himself, there is no place, plus Mr. Purandare is incontinent and kids are small, both son and daughter-in-law go on their jobs so it is just not possible to adjust with them.

Coping & Emotional Moments:

Mrs. purandare tried to be strong enough to do what was needed, but when told that there was no cure, she felt mentally and physically exhausted . The doctors gave her information about care for her husband, but did not fully explain what to expect and what not to expect. Mrs. Purandare is worried about her own health, being old and is tensed about amount of work that she has to do.

Her husband has become very weak and lost weight. His ability to understand and do things has deteriorated a lot. He keeps pissing in the whole house. His ability to understand and do things has deteriorated a lot. He is usually on a wheel chair and needs help to be moved from and to the bed. He needs to be helped for everything. He does not seem to know his wife or any of the things in the apartment. He does not really know who she is.

Care giving Experience:

Mrs. Purandare describes her husband to be very quiet person fond of reading but very particular and stingy about having things according to his wish and way. Even at his job in the bank where he was manager, his expectations from people under him were very high and would normally shout at them for not doing the perfect job.

> “Uptill now I have heard of many diseases like hypertension, diabetes, and stroke but have never heard of Dementia. What happens further?, how long will it go on? ”

She further describes the behavior shown by her husband:

- Loosing balance while walking or climbing stairs
- Hoarding things
- Anger and Shouting
- Insisting on going for work though he had retired long ago
- Insisted on getting updated bank statements, paying of bills
- Going away, out of the house without informing her.

Though she felt that the behavior is odd, she thought it to be because of emptiness, getting old and not mixing with people around. Mrs. Purandare shares that uptill now she had heard of many diseases like hypertension, diabetes, and stroke but has never heard of Dementia. Mrs. Purandare feels that it is like her husband is not there for her. He is like a toy, she is constantly worried, and how long will it go on? What if she dies before him?

CASE STUDY 5 – Care giving Challenges, trained maid and depression: A daughter-in-law's story

Primary Caregiver	**Patient**
Name : Mrs. Neena Shah	**Name :Mrs. Shah**
Age: 42 years	**Age: 86 years**
Sex: Female	**Sex: Female**
Relationship with Patient: Daughter-in-law	**Relationship with Caregiver: Mother-in-law**

Ms. Neena shah a chartered accountant quit her work to manage care for her mother-in-law. She describes the care giving situation and its challenges.

Medical Condition: Mrs. Shah diagnosed as a patient of Vascular Dementia in 2009.

Family Members: Two sons aged 57 and 50, two daughters-in-law, four granddaughters and a grandson. Mrs. Shah's husband passed away in 2005.

Care Arrangements:

Ms. Neena's mother-in-law remembers old memories like they happened yesterday, but does not remember what happened today or yesterday. Since, neena and her husband could not find any long term care for such people, she had to leave her job and employ a full time maid for assistance. Care giving is not shared between two sons of Mrs. Shah. Neena's son who is the younger son has taken the full responsibility. Ms. Neena is the primary caregiver with a lot of support physically and emotionally from her husband in assisting wherever he can.

Neena finds her mother-in-law to be very rude both with her and her maid. She feels that neena and the maid force her to go through daily chores like walking, eating, bathing etc. Mrs. Shah also goes through phases of aggressions and hallucinations. At times keeps on crying endlessly, keeps on repeating things and doubts neena for taking away her jewellery. Neena is used to such allegations now, but earlier used to get embarrassed and angry.

> *“Ealier I used to think why should I care for her? She doubts me for things I have not done, she is rude and still I am expected to all the care giving”*

The biggest challenge neena feels is to keep her mother-in-law engaged and to get things done from her. E.g/ eating, going to bathroom, going to toilet, walking, listening to music or watching television.

Coping & Emotional Moments:

Mrs. Shah’s agitated behavior upsets the whole family, including her kids who are often studying. She does not let the maid go out of her eyesight even if the maid wants to take a lunch break or go for bath. She is dependent for every activity. Neena very specifically mentioned that initially everybody sympathizes, but then in the end it is only the primary caregiver who has his/her hands full.

> *“I have two teenage kids and my husband travels a lot, and my family depends on me for running the house and managing her care. I could have continued working, but the stress got on me so I* simply QUIT.”

Neena reported that due of caregiver role, she and her husband has self inflicted social isolation in early phase when both were afraid to stay for longer than required. Gradually they got used to the stress and learnt to recognize the way out of it.

Care giving Experience:

Neena personally feels that it is very essential need for patient with dementia and the family caregiver to have an old age facility/ respite home where the patients can be cared for in hygienic and clean conditions.

Neena feels that if one son is taking care the other siblings should support the primary caregiver in whatever way they can. This will help primary caregiver to cope with the stress.

> *"To everybody whose aged parent is being looked after by another sibling / spouse, I would say, please give your support to the primary caregiver, because caregiving is one of the most difficult and emotionally draining phase in their lives and every bit of emotional support helps the caregivers cope with the stress."*

Neena reported that looking after a parent who is very old and suffers from dementia; the biggest challenge is to keep the primary away from form getting into acute depression. If the caregiver is son and has siblings, the parent with dementia will complain to these siblings about how she/he is uncared for etc, Often siblings who are not responsible for the care and are living far away, tend to believe the parents perspective. This often leads to misunderstanding amongst siblings and in the end leaves the care giving family feeling very let down.

CASE STUDY 6 – Enjoying the Care giving: A doting daughter care for her mother

Primary Caregiver	Patient
Name : Mrs. Padma	**Name : Maniben**
Age: 60 years	**Age: 81 years**
Sex: Female	**Sex: Female**
Relationship with Patient: Daughter	**Relationship with Caregiver: Mother**

Ms. Padma is a housewife looking after a large family of eight family members. Graduated from NID, gave up her aspiration to support her husband and looking after the family.

Medical Condition: Maniben was diagnosed as patient of dementia in 2005. Her medical condition is extremely fit and fine, since last eight years she is bedridden without a single bed sore.

Family Members: Three daughters all married, one stays in Baroda, one at Rajkot and the third one is at London.

Care Arrangements:

Maniben stays with the youngest daughter in Baroda. The family is well to do. Mrs. Padma's husband is very supportive and from the day he has insisted on keeping maniben with him. Padma is aware of this fact and appreciates it as this kind of support is difficult to find in India context.

Padma has a special room for her mother, with a typical hospital bed with ralling from all the side and which can be folded so that maniben can sit and have her food on the bed. Other support systems like diapers, oxygen bottels, wheel chair and so on. She shares that as a duaghter it is her duty to give her the best possible comfort.

"As a daughter I think what else can be my priority but to give her best possible comfort, which I am afford to give"

There is special nurse to take care of maniben throughout the day, however padma has to assist while sponging, lifting while changing her clothes and diapers. This is needed because maniben is more than 80 kgs and it's not possible for one person to manage her. Maniben is given the feed, time to time, her surrounding are very hygienic and clean.

Coping & Emotional Moments:

Maniben likes to talk to people though she does not comprehend most of the time, her response is not very appropriate. Padma makes a point that at the end of the day when everyone returns back home from their work, each of the family members goes and talks to maniben, during family functions and marriages, padma also ensures that maniben is also dressed with ornaments and heavy sari, all set in wheel chair and taken to the place of marriage.

Every one treats maniben as a very normal family member, they also take turns to look after her if need be, especially padma's spouse and her daughter. They joke with her and cajole her too; every new person or visitor or friend is introduced to her.

"I am such a luck daughter that I can take care of my mother but this is not the case with my elder sister in Rajkot she feels guilty looking at my care. Her in laws are not that supportive and therefore she is not able to take mummy at her place even if she wants to"

Care giving Experience:

Padma feels that care giving experience has been enjoyable to her so far. The only troubling times are, when the maid and nurse is not available and don't come without informing her. This puts the whole load of sponging; changing clothes on padma and at times she has to request her daughter for help. As the family is financially well of, the expense is not an issue but padma realizes that what happens to those who are not so well off? How can they take care? Padma feel what would have happened if her in-laws and husband had not cooperated or permitted to let live her mother with her? Padma with this thought was tearful and thanks god for beautiful family and informal support she gets.

> *"I think I can afford all this because I have money. I cannot think what would happen to her in my absence. We badly need long term care facilities and respite care for such patients and needy families."*

SECTION-X VIEWS OF HEALTH CARE PROFESSIONALS

This section deals with views presented by various clinicians / specialists from whom the sample was taken after having been diagnosed as dementia cases, interviews with them brought deeper insights into needs and problems of not only dementia patients but also the care givers. The presented their prospective and gave certain concrete suggestion. A total of 10 psychiatrist and neurophysician were interviewed with the help of an interview guide.

Stage at which Patients come to Clinic

Health care professionals (Drs.) opined that they get dementia patients at all the three stages that is mild, moderate and severe. Generally at the clinic patients are brought by their caregivers. Patients are in a stage of Mild to Moderate Dementia, when they come for the first time. They are brought after 2-3 years of onset of illness on an average. They come during this stage as interference is seen with the activities of daily living.

Description by relatives in terms of complaints

Most common complaints described by relatives who accompany the patient at the clinic are as follows:

- Forgetfulness- forgetting things like names/focus/tasks/going to bathroom etc, not recognizing people they met recently, not completing tasks which they could do earlier.
- Aggressive behavior, abnormal behavior, crying spells, sleep disturbance, inappropriate dressing and toilet behavior.
- Depressed mood, familial conflicts, sleep disturbances, thought disturbances, anger outburst

Above are some of the most common complaints that relatives describe during first consultation.

Assessment of patient with Dementia by the clinicians.

Various methods of assessment are used; the most common are MMSE, Brain scans and patient observations. Following are the more specific assessment methods:

- Detailed psychiatric history, Mental Status Examination (MSE), Mini Mental Scale Examination (MMSE), Dementia Rating Scale, Addenbrooker Scale, Neurological examination, blood workup, routine investigations (esp. focusing on reversible causes of dementia & finding aetiology of dementia) & brain scans (MRI). Patient interview & examination informant interview and regular follow up observation aid in further diagnosis/ monitoring.
- 5 plan things memory plan is easier and takes less time for assessment.

Line of treatment as suggested by the clinicians

Along with pharmacology and medical treatment, psycho education and supportive care is also suggested. Few of them have clearly recommended the following:

- First and foremost Psycho education which is very important both to the patient and caregivers and then Psychopharmacology
- Medical, supportive care, Counseling for caregivers
- Treatment depends on type of Dementia, Vascular/ other causes may be drug treatment/ supportive therapy
- Psychopharmacology treatment -: Antidementia drugs & neurotrophic factors treatment of reversible causes/aetiological factors; symptomatic treatment of sleep/mood/behaviour/thought disturbances
- Neurological treatment from neurophysician/neurosurgeon if required
- Medical management from a physician if required
- Family intervention, family therapy, psycho education, behavioral interventions life style modifications – for the patients and caregivers ,Providing constant support and guidance to patient and family - at every stage of care (mild to mod. to severe to disabling) – by the treating team (psychiatrist psychologist, social worker)

Advice to family members as caregivers

Clinicians advice family members to treat the patient like a baby, usually not to ask complex questions to the patient, to make life as simple as possible, not to humiliate patient in front of others by asking questions and to take care of patient – in terms of managing patient daily, routine, when to seek doctor, helping patient with limited cognitive capacity. Holistic care – personal nutrition and hygiene and help in activities of daily living.

Few of them give psycho education to the patients; try to address their concerns and queries, support them in coping with the patient/disease at every stage, explain them the role of medications, behavioral interventions and different methods to cope with various problems that emerge. They also explain them the expected course and outcome of illness, showing readiness to support / help them to cope / share burden of care with the treating team. Few of them suggested that family members should be given printed booklet on how to interact with patients, what to expect from patient, in severe cases keep a track of patients so he/she doesn't get lost.

Clarifications sought by the family members/ Expectations of family members

Family members usually don't know much about the illness. They primarily presume it to be a simple psychological problem / personality change / stressful period for which they seek psychiatric consultation. Even after explaining them about the illness and its course, they usually tend to expect some sort of cure / complete recovery after treatment and usually tend to underestimate the seriousness / severity of the problem or poor prognosis. As the problems worsen, they tend to become more realistically orientated to the problem, feel more incapacitated and incapable of handling the affairs and seek more help from the doctor

Further, they also want to know whether the medical care have side effects, whether the medicines will cure this illness, how will the medicines act and how fast patient will recover. They also expect to revert/ halt the disease process. They seek at least minimum improvement so that person can take care of himself and that the condition should be improved.

Specific training required for handling dementia patient by family and professional caregivers

Health professionals have opined that family members and professional caregivers should be trained in General nursing care, patience and sympathetic handling of agitation and restless patient. They should be further trained in early identification, supportive & palliative care.

Family members should be told to communicate repeatedly about patients interest, spend time with them, understanding of illness, what progressive illness means and basic training of how to help the patient. As the disease is progressive, more care and supervision is required.

Education about various aspects and training of all special needs of the patient is necessary methods to cope with the patient/disease, education about medical treatment and related decisions at the right time as the situation demands, work in groups, how to integrate / coordinate with doctor-counselor-social services-friends to work as a team rather than managing the patient/illness on their own

Dealing of Dementia and related issues with Family, Community and Hospital /clinic level

To fight this dreaded disease, following was suggested:

- **At family level:** close monitoring of patient and keeping him oriented to present as much as possible, caregiver education, Keep medication boxes, write chits about daily chores. Awareness/education, early detection, prompt treatment, good care of medical illnesses, restructuring lifestyle of patient/caregiver according to the stage of illness, providing support/care/aid to the patient/caregivers at every stage in all forms should be focused.
- **At Community Level:** Old age homes, social ward, doctors and paraprofessionals training in handling dementia patients. awareness, education, alternative lifestyle advocacy, availability of healthcare / psychosocial care to everyone, accessible/available/cost effective treatments, specialized professional centres / homes for managed care / respite care of patients, specialized professional centers for support of caregivers, support groups for caregivers, government/policy makers taking more initiatives to support caregivers and shoulder responsibility with them in the care of patients, provisions for medical care at home by the treating team if required.

- **Hospital / Clinic level –** at hospital level, send the patient reminders of their appointments; tell caregivers the need to handle psycho-social problems, starting specialized treatment facility / specialty for geriatric care / medicine, providing emergency care along with routine care, developing all investigative/therapeutic facilities for management of dementia under one roof, availability of doctors/counselors/social workers exclusively working in the area of dementia/geriatric care, provisions for early doctor contact / no waiting time / all support for patients/caregivers, training all physicians to identify dementia in their routine old age patients and refer them to appropriate doctor, special dementia wards, mass media education to recognize easily the symptoms of disease, Long term indoor facility for dementia patients.

CHAPTER - 5

MAJOR FINDINGS AND DISCUSSION

> *They said I was mad, I said they were mad, Damn them they outnumbered me!*
>
> ***Nathaniel Lee***

This chapter is divided into three sections. In Section I deal with the major findings of the study based on the quantitative data, Section II deals with the findings from Interviews with health care professionals and case studies and In Section III the major findings of the study are discussed under broad themes and conclusions of the study are arrived at. Implications of the study findings for social work practice and suggestions for future research and action are given in next chapter.

SECTION I MAJOR FINDINGS BASED ON THE QUANTITAVE DATA AND INTERVIEWS WITH HEALTH CAREPROFESSIONALS

I. Background details of the respondents (caregivers & patients)

1. Out of the total 103 patients with dementia, 50.5% are male and 49.5% are female patients.

2. Out of total 103 patients with dementia, 42.7% patients have mild, 35% have high and 22.3% have moderate level of severity of disease.

3. 49.5% patients are in the age group of 60 to 69 years, 32% are in the age group of 70-79 years and 18.5% in the age group of 80 years and above.

4. Out of total 103 family caregivers, 63.1%are male and 36.9 % are female

5. 76% approximately, are Hindus and 71% of them belong to general caste.

6. Educational level of the family caregivers shows that 38.8% are graduate and above.

7. Out of total 103 family caregivers, 44.7% are children of patients, 35% are spouse of the patient and 20.4% are other family members (daughter-n-law, son-in-law, grandson, brother-in-law and siblings).

8. 64.1% family caregivers have family with more than four members

9. 54.4% of family caregivers live in joint families.

10. 70% family caregivers have urban domicile while 18.6% have rural domicile and 11.8% have semi urban domicile.

11. 83.5% family caregivers do not have additional responsibility of care giving to anyone else in the family other than the patient with dementia.

12. 59.2% are currently employed out of which 47.6% are having full time jobs and 11.6% are having part time jobs. Majority of the caregivers 25.2% are self employed followed by 22.3% caregivers into non-Government jobs.

13. 40.8% are not having any job which is note worthy as caregiving to dementia patient without financial support is a challenge.

14. Out of 103, 64.1% family caregivers have regular monthly income, 61.2% family caregivers have monthly income above Rs. 10,000/-

15. For 92.2% caregivers, the main source of income for household is from earnings of family members.

16. 85.4% family caregivers are financially independent

17. For 59.2% family caregivers the major source of care giving expenses is from the savings while for 40.77% caregivers there is household budget.

II Current Care Giving Arrangements

18. 50 family caregivers got into the care giving role willingly, by virtue of being spouse of the patient and children of the patient

19. 34 family caregivers got into the care giving role being as they are the only child and are close to the patient, there is no one else who can take care of the patient.

20. 11 family caregivers got into caregiver role due to compulsion and not willingly.

21. 69.9 % family caregivers give care for more than ten hours a day.

22. Sharing of care giving in majority of cases is done by the spouse and from the other family members (daughter –in-law, spouse of the patient and siblings)

23. 15 family caregivers have no one who can share their responsibility of care giving and 5 of them have professional help to share the responsibility.

24. 90.3% caregivers supervise the patient for their safety as patient require this otherwise they may endanger themselves

25. 83.5% caregivers have to take care of the patient in entertaining them ; which includes activities like operating TV for the patient, taking them for a walk, taking patient to the place of worship, social gatherings etc. In short they have to accompany them and assist them.

26. 80.6% of caregivers provide care, related to personal hygiene which includes activities like bathing, dressing, using the toilet, and shaving, getting in and out of the bath, and feeding.

27. 59.2% caregivers do not provide care related to housekeeping which includes activities meal preparation, cleaning and laundry as they have housemaids to do the housekeeping work.

28. 87.2% of family caregivers are able to give adequate care but support is required in helping patients in the Activities of Daily Living (ADL) and for looking after the patient during family functions and when no one is at home.

29. Lack of financial and professional support has lead to inadequacy of providing help as felt by the 37.8% of family caregivers.

30. 60.19% Family caregivers have faced difficulties in managing incontinence, wandering and Activities of daily living.

31. 20% of family caregivers had difficulty in communication with the patient and socialization with friends, relatives and society.

32. 33.9% family caregivers had difficulty in providing care due to physical, emotional and financial strain

33. 63.10% of family members like daughter- in- law, son-in-law and siblings will replace family caregivers in taking up care giving activities in their absence.

34. 44.6% of Family caregivers feel that their spouse will replace them.

35. 20.3% Family caregivers have no one who can look after the patient in their absence.

III Dementia symptoms, associated issues and its Management

36. 35.9% Family caregivers reported that patients are facing problems of hyperacidity, hypertension and diabetes.

A) Cognitive Impairment:

37. Symptom of hallucination as a part of cognitive impairment in the patient with dementia has emerged as a factor creating severe distress among the caregivers as compared to other symptoms of delusion and irritability.

38. Shouting and yelling, being suspicious about getting things stolen and accusing family members in front of others has emerged as the most disturbing behavior of the patient

39. Family caregivers make use of sleeping medicine, get angry, leave the patient alone, become strict and scold them while managing patients behavior of shouting and yelling, being suspicious about getting things stolen and accusing family members in front of others.

B) Behavioral Changes:

40. Communication, Incontinence and Wandering have emerged as behavioral problems which cause distress among Family caregivers. Severe to extreme distress was felt due to these problems.

41. Wandering and Night time behaviours are managed by constant supervision and locking of the door. Communication related to the food and going to toilet is managed by giving food and taking patient to toilet at regular intervals.

42. Family caregivers are not able to manage the incontinence as the patients are not able to communicate about it.

C) Psychological Changes:

43. Disorientation and depression have emerged as psychological change in the patient as witnessed by the caregivers.

44. Family Caregivers have experienced severity in all the psychological areas but more in disorientation and distress caused by them are from mild to moderate.

45. Aggression, Agitation and bizarre behavior of the patient have emerged as a concern due to psychological changes in the patient.

46. Aggressive and Agitative behaviors are managed by being strict with the patient and giving sleeping pills. Bizarre behavior by the patient in front of others is managed by leaving the place of incidence and by avoiding such situations.

D) Physical Pain & Safety Issues in patients

47. Maintaining self hygiene for the patient, Mobility issue and eating habits of the patient have emerged as three major issues related to physical pain and safety of the patient.

48. Severity of patient's mobility is high but distress caused by it is mild while the severity of issues related to eating habits is high and distress caused by it is severe.

49. Bathing, dressing and feeding the patient has emerged as important issue related to safety and physical pain of the patient. To manage with these issues caregivers have made structural changes to avoid patient from falling and getting hurt and take help for shifting patient a from the bed and while giving bath.
50. Behavior of the patient due to various cognitive impairment and psychological symptoms has negatively affected the caregivers as feelings of Emotional, Financial and Physical strain are evident among caregivers. The impact is also seen on overall family functioning and social life of the caregivers.

51. Not able to see the patient’s condition, lack of support, non availability of services, medicines and finance makes care giving difficult for the family caregivers.

52. It is heartening to note that maximum caregivers take patient to psychiatrist, family physician and neuro physician for treatment. Few take resort to alternative source of medicines like Homeopath, Ayurved, and visit religious /spiritual places.

53. Physical, social and financial domains have emerged as stressful areas felt/perceived by the caregivers in that order.

54. **Finding related to Coping Strategies used by the family caregivers:**

- 68.9% of family caregivers always avoid going to weddings, parties and inviting friends.
- 52.4% of family caregivers sometime send the patient to other siblings /relatives place
- 39.8% of family caregivers never try to meet /discuss problems with relatives of similar patient.
- 20.4% of family caregivers always employ part time help in meal preparation and house maintenance
- 74.8% of family caregivers never employ paid nursing maid for 24 hours.
- 62.1% of family caregivers have never taken resort to other branches of medicines like unani, homeopathy or ayurvedic.
- It is found that caregivers are using negative coping strategies like 68.9% avoid social functions always, 74.8% never employed paid worker for assistance, 55% and 39.8% have never used positive strategies like yoga, meditation .listening to music, taking up part time jobs and taking break from caregiving holidays. etc.

55. 87.4% of family caregivers have dropped visiting long distance relatives due to care giving activities.

56. 67% of family caregivers have stopped attending marriages and birthday parties.

57. 58.3% of family celebrations of festivals and anniversaries are few activities that caregivers have dropped.

58. 66% of family caregivers have not stopped going out with their children on holidays and outings.

IV Overall Health & Well Being of the Family caregivers

59. 50.5 % of family caregivers agree to the fact that their health has suffered because of the care they give

60. 46.6% the family caregivers agree that they have lost control over their life because o f care giving

61. 44.7% family caregivers agree to the fact that because of the time spent in care giving they do not have time for themselves

62. 56.4%family caregivers agree to the fact that it is hard to plan things ahead as the patients needs are so unpredictable

63. 60.2% family caregivers disagree with the fact that family members other than the patient asks for their help more than necessary.

64. 41.7% family caregivers disagree with fact that care giving has interfered with their space in the home

It appears that majority of family caregivers have agreed that their personal well being is negatively affected because of the process of the care giving, however they also agree that it has brought them close to the patient

65. 63.1% the family caregivers disagree to the fact that they do not feel socially isolated and alone because of the care giving

66. 46.9% the family caregivers have agreed to the fact that their social life has suffered due to care giving

67. 50.5% family caregivers agree to the fact that they feel uncomfortable having friends because of the patient

It appears that social well being of the family caregivers has suffered , though they don’t feel isolated they do feel uncomfortable calling their friends home, take it as time to repay back and set a role model for their children.

68. 77.6% family caregivers disagree to the fact that they will be unable to give care much longer

69. 71.8% family caregivers agree to the fact that they feel very tired due to the physical strain as a result of care giving

70. 52.4% family caregivers agree to the fact that their sleep is disturbed as the patient wander around at night.

It appears that physical wellbeing is affected due to caregiving and their sleep at night is disturbed however it has not deterred them from not giving care for longer duration if need be.

71. 56.3% family caregivers disagree with the fact that they feel nervous or depressed when giving care

72. 50.4% family caregivers disagree with the fact that they are trapped when giving care while

73. 47.5% family caregivers agree that they resent that relatives who could help but are not doing

74. 45.6% family caregivers agree that patients behavior of forgetting thing and accusing in front of others upsets them

75. 49.5% family caregivers agree that they are overwhelmed and are concernedabout how to manage

76. 69.9% family caregivers agree that there is no solution to their problems

77. 43.6% family caregivers agree that the family stability has disrupted by the patients illness

78. 85.4% family caregivers agree that they feel frustrated that the improvement is slow and that the patient’s condition is deteriorating

79. 77.6% of family caregivers agree that they take care of the patient willingly and as a part of their duty

80. 67.9% family caregivers agree that they their relationship with other family members has affected due to the caregiving while 29(28.2%) of them are neutral about it and only 4(3.9%) of them disagree to it.

V Support Network /Informal support

81. Support from the spouse of the family caregivers has emerged as the major source of support. Caregivers receive support from other family members and least help is received from religious and charitable organizations.

82. Direct help in activities of daily living, (cleaning if patient soils, comb hair, wear clothes, nails trim, brush shaving and giving bath to the patient) is received by maximum caregivers who are male.

83. The least direct help is received in Instrumental Activities of Daily Living (entertainment of the patient like taking for a stroll, operating TV, Music, talking etc. activities)

84. Indirect help is received in meals preparation, Keeping clothes, vessels, dusting and routine arrangements in the house and buying routine commodities groceries, vegetables, milk etc.

85. In case of 16.5% family caregivers, family members have discontinued support and in case of 6.8% family caregiver’s friends, relatives and maids have stopped giving support.

86. Patient is unmanageable, too much of incontinence and wrong or inappropriate behavior on the part of the patient, are reasons for discontinuation of the support.

87. Handling patient carefully, emotional support and accepting patient are three major differences that have emerged between formal and informal care.

88. It is found that most of the caregivers go to the family physician and then probably are directed to psychiatrist or neurophysicians. Interestingly, they also visit astrologers, community priests and family deity and undertake religious ceremonies. This can be justified in the context of cultural context.

89. It is found that majority 55.3% of the family caregivers desire to have professional support in the form of special institutions, Rehabilitation centre and Respite centre.

90. 35.9% of family caregivers need support in the form of availability of medicines, guidance from hospitals and awareness or more information about the disease. Few caregivers have reported to get a financial support or help from government organizations and NGOs.

VI Enjoyable Aspects of Care giving

91. This is a very specific aspect of care giving which gives joy to caregivers but few 11.7% said that feeling relaxed and out of stress is not experienced by the caregivers as a part of enjoyable aspect.

92. More than 80% of family caregivers feel that being with the patient is enjoyable as they think that they perceive care giving as moral obligation and feel as sense of accomplishment.

VII Perception of Caregivers related o Care Giving Process, Awareness about the Disease, Knowledge and Services Available

93. 43.7% of the family caregivers are not able to handle most caregiving problems that arise.

94. 83.5% of family caregivers disagree with the fact that they can give care with no help or could give if need arises.

95. 55.3% caregivers make efforts to know more about Dementia as it is less known and less publicized health problem

96. It has emerged that most widely used source for gaining knowledge is doctors and psychiatrists, browsing Internet and getting information from Government hospitals in that order.

97. It has been found that caregivers are willing to share their experiences of managing the patient, tell symptoms and cause of typical behavior and extend possible help to the caregivers of other patients with similar conditions.

98. It has emerged from the data that most important skill in management of dementia patient is handling of the patient during ADLs, communication and handling of embarrassing situations.

99. 77.7% have felt the need for training to increase skills and knowledge regarding management of the dementia patient.

100. Almost all the caregivers except two of them are not aware about services related to dementia specifically. 98.1% of the family caregivers were not aware regarding any services available in the city for dementia cases.

101. It has emerged that caregivers trust and feel confident about getting more information about dementia through doctors, then by internet and government hospitals.

102. Almost all the caregivers except two of them are not aware about legal provision by the Government, if any.

103. Family caregivers said that they would use Government /Hospital /Institutional services rather than ask family or friends for help and believe in the idea that families should ask for outside help and not only care on their own.

104. 55.3% family caregivers are not sure regarding disability arising due to dementia and it should be made part of disability Act.

105. 77.7% family caregivers agree that the government should support to help care for people of dementia at home and agree to have services like respite care, day care homes, medicines at subsidized rates to be provided by the Government.

106. 57.3% family caregivers agree that there is need for the Government organizations and NGOs to create awareness regarding dementia and believe that specialized services like separate Geriatric wards at government hospitals, ID cards for patients, Help lines and 24 hrs. Medical shop should be available for patient with Dementia.

VIII Association of Variables

1. Stress Domains & Background Characteristics

107. Age of the family caregivers is having association with Personal domain (chi-square:7.153, P value: 0.028), 63.2% of caregivers in the age group below 35 years and 51.5% of caregivers in the age group have felt stress in personal domain. Stress in personal domain refers to negative effect on relationships in the family, friends and relatives not able to take care of children, spouse, other family members and relatives.

108. Age of the family caregivers is having association with Professional domain (chi-square:23.432, P value: 0.00), 81.3% of caregivers in the age group of 36 to 50 years have felt the most stress in professional domain. Stress in professional domain refers to job role stress, not able to handle both at work and home. The caregivers in the above age group must be in the peak years of their jobs.

109. Age of the family caregivers is having association with Physical Domain (chi-square:8.301, P value: 0.016), 93.9% of the family caregivers in the age group above 50 years have shown stress in physical domain. Stress in physical domain refers to fatigue and tiredness due to care giving and thus, higher the age high are the chances of caregivers becoming prone to physical stress.

110. Age of the family caregivers is having association with Emotional Domain (chi-square:6.873, P value: 0.032)., 68.8% of the family caregivers in the age group of 36-50 years have shown stress in emotional domain. Stress in emotional domain refers to feeling of sadness, depression and hopelessness. Again, as majority of the caregivers are children, they are young and is natural for them to feel stress in emotional domain.

111. Sharing of responsibility by the family members is also having association with Personal domain (chi-square:3.859, P value: 0.049), where in 52.7% of family caregivers say that their responsibility is not shared by family members other than spouse and hence they feel the stress.

112. Sharing of responsibility by the family members is also having association with Financial Domain (chi-square:9.666, P value: 0.02), where in 48.4% of family caregivers say that their responsibility is not shared by family members other than spouse and hence they feel the stress.

113. Sharing of responsibility by the family members is also having association with Professional Domain (chi-square:7.262, P value: 0.007), and Emotional Domain (chi-square:7.620, P value: 0.006). 54.8% and 55.9% of family caregivers say that their responsibility is not shared by family members other than spouse and hence they feel the stress in professional and emotional domain respectively.

Thus, it has emerged that Age of the family caregiver and sharing of their responsibility affects the stress felt by them in various domains.

2. Activities dropped & Background Characteristics

114. Age of the family caregivers is having association with dropped activities of Entertainment (chi-square:10.59, P value: 0.005), 71.9% of the family caregivers in the age group of 36-50 years, have stopped their entertainment activities. These caregivers are young and entertainment is important aspect of their life.

115. Age of the family caregivers is having association with dropped activities of Attending marriages (chi-square:7.533, P value: 0.02), and Family celebrations (chi-square:10.105, P value: 0.006). Again 75% and 81.3% of family caregivers form the same age group mentioned above have stopped attending marriages and family celebrations respectively.

116. Family Type is also having association with Entertainment (chi-square:6.15, P value: 0.013), Attending marriages (chi-square:12.74, P value: 0.00). 72.3% of family caregivers with nuclear family type and 82.1% of family caregivers with

joint family type have stopped entertainment activities and attending marriages respectively.

117. Sharing of responsibility is also having association with Entertainment (chi-square:3.917, P value: 0.048), outing with children (chi-square:5.701, P value: 0.017) and social functions (chi-square:4.669, P value: 0.031). 62.4%, and 37.6% of family caregivers have stopped entertainment activities as well as stopped outing with children respectively as their responsibility of sharing is not done by the other family members

Thus, it has emerged that Age of the family caregiver, Family type and sharing of their responsibility have affected activities taken up by the family caregiver, wherein entertainment has emerged to be the most affected one across all the three variables.

3. Overall Well being & Background Characteristics

118. Severity of disease is having association with Emotional well being (chi-square:10.44, P value: 0.034). 50% of Family caregivers looking after the patient with dementia with mild severity are low on emotional well being and 47.8% of family caregivers looking after patient with dementia with moderate severity are moderate on emotional well being.

119. Age of the family caregivers is having association with personal wellbeing (chi-square:12.15, P value: 0.016) and Emotional wellbeing (chi-square:16.292, P value: 0.003). 54.5% and 45.5% of family caregivers above 50 years of age are on moderate level of personal well being and low level of emotional well being respectively.

120. Relationship of the family caregivers with the patient is having association with personal wellbeing (chi-square:9.710, P value: 0.046), Social well being (chi-square:11.191, P value: 0.024) and physical wellbeing (chi-square:12.106, P value: 0.017). 61.9% of family caregivers who are children of the patient are on low level of personal well being, 61.5% are on the moderate level of social well being and 57.1% are again on low level of physical wellbeing.

121. Responsibility of caregiving shared by the family members is having association with physical wellbeing (chi-square:8.932, P value: 0.011) and Emotional wellbeing (chi-square:7.46, P value: 0.024). 80% of the caregivers whose responsibility is share by the family caregivers are on moderate level of physical well being and 20% of them are on the low level of emotional well being. Thus, it has emerged that they get help in activities where physical work is involved, but their emotions are still not taken care of.

SECTION II MAJOR FINDINGS BASED ON THE INTERVIEWS WITH HEALTH CARE PROFESSIONALS AND CASE STUDIES

1. Findings from perspectives of Health Care Professionals

- It was found that generally at the clinic patients are brought by their caregivers.

- Patients are in a stage of Mild to Moderate Dementia, when they come for the first time.

- They are brought after 2-3 years of onset of illness on an average.

- They come during this stage as interference is seen with the activities of daily living.

- Most common complaints described by relatives who accompany the patient at the clinic are as follows:

    - Forgetfulness- forgetting things like names/focus/tasks/going to bathroom etc, not recognizing people they met recently, not completing tasks which they could do earlier.
    - Aggressive behavior, abnormal behavior, crying spells, sleep disturbance, inappropriate dressing and toilet behavior.
    - Depressed mood, familial conflicts, sleep disturbances, thought disturbances, anger outburst
- Various methods of assessment are used; the most common are MMSE, Brain scans and patient observations and 5 plan things memory plan is easier and takes less time for assessment.

- Along with pharmacology and medical treatment, psycho education and supportive care is also suggested. Psycho education is considered more important than the psychopharmacology.

- Family intervention, family therapy, psycho education, behavioral interventions life style modifications – for the patients and caregivers ,Providing constant support and guidance to patient and family - at every stage of care (mild to mod. to severe to disabling) – by the treating team (psychiatrist psychologist, social worker)

- Clinicians advice family members to treat the patient like a baby, usually not to ask complex questions to the patient, to make life as simple as possible, not to humiliate patient in front of others by asking questions.

- It was opined to give Holistic care – personal nutritional and hygiene and help in activities of daily living

- It was found that Family members usually don't know much about the illness.

- They primarily presume it to be a simple psychological problem / personality change / stressful period for which they seek psychiatric consultation.

- Further, they also want to know whether the medical care have side effects, whether the medicines will cure this illness, how will the medicines act and how fast patient will recover.

- Education about various aspects and training of all and special needs of the patient behavior was explained by all health care professionals.

- Caregivers should be trained in handling patients, Disease education, and awareness about the problem in society.

- Empowering them with methods to cope with the patient/disease, education about medical treatment, make treatment related decisions at the right time as the situation demands.

- Work in groups, how to integrate / coordinate with doctor-counselor-social services-friends to work as a team rather than managing the patient/illness on the own.

- **Family level:** Awareness/education, preventive lifestyle, early detection, prompt treatment, good care of medical illnesses, restructuring lifestyle of patient/caregiver according to the stage of illness.

- **Community Level:**
    - Old age homes, doctors and special training in handling dementia patients.
    - Preventive lifestyle advocacy, availability of healthcare / psychosocial care to everyone, accessible/available/cost effective treatments, specialized professional centres
    - Homes for managed care / respite care of patients, specialized professional centers for support of caregivers,
    - support groups for caregivers, government/policy makers taking more initiatives to support caregivers and shoulder responsibility with them in the care of patients provisions for medical care at home by the treating team if required

- **Hospital / Clinic level** –
    - Starting specialized treatment facility / specialty for geriatric care / medicine.
    - Providing emergency care along with routine care developing all investigative/therapeutic facilities for management of dementia under one roof
    - Availability of doctors/counselors/social workers exclusively working in the area of dementia/geriatric care, provisions for early doctor contact / no waiting time.

2. Findings derived from Case Studies

- Misinterpretation of the symptoms and taking it as a part of normal gaining

- Patients behaviors related to incontinent, agitation, aggression and hallucinations are difficult to manage
- Communication with the patient is difficult.
- Activities of daily living cannot be handled by only caregiver, support is needed
- Lack of proper guidance from health care professionals and respite care
- Caregivers have feeling of guilt; they feel they could have done better if they had awareness regarding the disease.
- Family dynamics and disruption in the functioning due to siblings do not share the responsibilities
- Care giving as difficult and emotionally draining process except in one case.
- Relationship of the caregiver with the patient before the disease may impact the care giving process.

SECTION II DISCUSSION - MAJOR FINDINGS OF THE STUDY DISCUSSED UNDER

BROAD THEMES AND CONCLUSIONS

The discussion is done under broad headings for better understanding. 1) Current care giving arrangements, activities and processes in the families; 2) Behavioral and Psychological symptoms and its management 3) Stress Areas and coping strategies by the family caregivers 4) Current awareness and knowledge, need for special skills and training and views of health care professionals.

The questions posed for the discussion what are the care giving arrangements done by the family caregivers? How do they manage the patient with dementia with behavioral and psychological problems that the disease poses? Which are the stress areas, what difficulties they face while giving care arrangement? What is the source of their support – both formal and informal? And how much are they aware about the disease, do they feel need for special training, facilities and professional support for managing the patient with dementia.

1. Current care giving arrangements, activities and processes in the families

Usually Dementia is not identified as a health condition. Even if it is identified, caregivers do not receive practical advice or long term support (Shaji *et al*, 2003). Most of the care for people with dementia is done at home by their families. A reason for this could be many, but most apparent ones are non-availability of institutional care in most of the parts of our country and most of the families may not afford institutional care. In Indian context, not to look after ill, elderly or putting them in an institution, is generally not acceptable culturally and therefore, family members hesitate in thinking about such alternative arrangements.

In the current study, out of total 103 patients with dementia, 52(50.5%) are male and 51(49.5%) are female patients. Numbers of male and female patients are almost equal, however according to India Dementia Report 2010, higher prevalence of dementia is seen among older women than in men because of the fact that women live longer in India. But the report also states that studies of age-specific incidence of dementia among elderly show no significant difference for women and men. Thus, supporting the finding for this study that gender is not a risk factor for Dementia among elderly.

Out of total 103 family caregivers, 65 (63.1%) are male family caregivers and 38 (36.9 %) are female family caregivers Gender of family caregivers has emerged as an indicator for understanding who is the primary family caregiver in Indian setting. As data reflects that majority of the caregivers are male, and children of the patient. It highlights the socio-cultural fact, typical of Indian setting in which elderly are cared by the son in the family. Second, conclusion possibly drawn is that actually daughter –in-law is doing most of the care giving, however son claims to be the primary caregiver reflecting male dominating society and subordination of women's role in the family.

It is clearly evident from the data that religion and caste do not emerge as risk factor for dementia further it can be supported with the fact that population concentration in vadodara city is more of Hindu families belonging to general caste.

Data reflects majority 66 (64.1%) family caregivers have family with more than four members and 56 (54.4%) of them live in joint families. 72 (70%) family caregivers have urban domicile while 19 (18.6%) have rural domicile and 12 (11.8%) have semi urban domicile. It is clearly evident from the data family size is large and joint type which is emerging as a indicator of possible support network that may impact care giving. As most of the caregivers have urban domicile, it clearly states that registration of cases and awareness about the disease is low in rural and semi rural areas.

Majority of family members do not have to look after anyone else in the family, which will reduce their stress /lessen the burden of care giving.

64.1% family caregivers have regular monthly income, 61.2% family caregivers have monthly income above Rs. 10,000/-. 40.8% family caregivers are not having any job which is note worthy as caregiving to dementia patient without financial support is a challenge. Source of income for care giving expense is through savings and household budget, also it is emerging that the source of family income is only through the members of the family. Thus, there is no financial support to the caregivers from outside. Further, inspite of financial independence, caregivers may possibly feel the financial strain due to care giving.

In the current study, family caregivers got into the care giving role willingly, by virtue of being spouse of the patient and children of the patient, being close to the patient and at times due to absence of any one else to take care of the patient. While few got into the care giving role due to compulsion. Thus, willingness and being the spouse/children of the patient is emerging as an important factor in understanding how caregivers get into this role. This ensures that caregivers getting into the caregivers role willingly and as a part of their duty may feel less burdened. Interestingly, those who are giving care forcibly and see it as a result of past life sins may feel over burdened and will also affect the care giving process.

69.9% of family caregivers give care for more than ten hours a day. Provision of care 24 hours a day all year round constituted one of the major sources of burden. (WC Chan, et al.2004). As data reveals, maximum caregiving duration of more than ten hours, it is emerging clearly that care giving for dementia patient is different and more taxing in terms of time than care giving to patient with other diseases. A 2003 survey of 227 US dementia caregivers found that nearly one quarter provided 40 hours of care or more per week (compared with 16% for non dementia caregivers)

(Alzheimer's Association Chicago 2007). Another study by the 10/66 Dementia Research Group on Care arrangements for people with dementia in developing countries state that Caregivers in developing countries spend a median of 3 to 6 hours a day with the person with dementia, and 3 to 9 hours assisting with activities of daily living. Eleven to 25% of caregivers spend more than 11 hours per week providing informal additional support. (Int J Geriatr Psychiatry 2004; 19:170-177Pub Med)

As evident from the data that majority of care giving responsibility is shared by the spouse of the primary caregiver, (i.e. wives of the caregivers, daughter-in-law, spouse of the patient and siblings.) In few cases there is no on to share the care giving responsibilities and hence are forced to take help from professional caregivers. It supports the finding of this study that most of the primary caregivers are male. This can be supported with the fact that in context of Indian setting it is the female who does most of the work related to household and looking after the family members. Further the sharing is also done by other family members who includes daughter- in-law, son-in-law and siblings, possibly as these caregivers are living in large families again revealed in this study.

The above finding is similar to the study by 10/66 Dementia Research Group on Care arrangements for people with dementia in developing countries, which states that - As people are more likely to live in large households, care is distributed among a greater number of individuals, and there is some evidence that the main caregiver experiences less strain. However, the effect is small and applies only for cohabitating primary caregivers. (Int J Geriatr Psychiatry 2004; 19:170-177Pub Med).

When looked into the specific care arrangements 90.3% of family caregivers supervise for safety of the patient and 83.5% family caregivers have to look into care, related to entertainment ; which includes activities like operating TV for the patient, talking them for a walk, taking patient to the place of worship, social gatherings etc. Here, it needs to be highlighted that these responsibilities are usually done by male members in the families, who have identified themselves as primary caregivers in this current study. Research on male caregivers shows more instrumental approach to the role than women have i.e. their role is seen in context of providing help in the Instrumental activities of daily living e.g. Providing financial support, taking care of shopping of necessary items etc.(Jamuna 1997)

80.6% of family caregivers with the help of their spouse provide care related to personal hygiene which includes activities like bathing, dressing, using the toilet, and shaving, getting in and out of the bath, and feeding. Again, confirming the fact that these household chores are done by women in Indian families. 61 (59.2%) caregivers do not provide care related to housekeeping which includes activities meal preparation, cleaning and laundry. Thus, It has emerged that the type of help required by the patient of dementia is completely different than no-demented patients as they require assistance /are dependent for the performance of each activity. Though the functional capabilities of the patient with dementia may deteriorate according the stage of dementia, the types of care provided i.e. Supervision for safety; entertainment and activities of daily living have emerged as significant in this study which is very typical to the patient of dementia.

Type of care related to Safety is must as wandering is a typical symptom shown by the patient with dementia. Next type of care is related to entertainment (operating TV for the patient, talking them for a walk, taking patient to the place of worship, social gatherings) of the patient must be provided as the patient is at a loss of functional capabilities and losses sense of direction, communication etc. The most important type of care is that of personal hygiene of the patient (bathing, dressing, using the toilet, shaving, getting in and out of the bath, and feeding) which is again typical for the patient with dementia as they forget how to perform these activities of daily living. Work related to housekeeping (meal preparation, cleaning and laundry) is not done by the caregivers, as they live in large household and are able to get help for this work either from family members or have employed maid servant for this work.

Further the current study reveals that Family caregivers are able to give adequate care but support is required mainly in performing Activities of Daily Living (ADL) and for looking after the patient during family functions and when no one is at home in that order. In a study at Hong Kong, most caregivers found it very demanding to help their family members with their activities of daily living (WC Chan, et al. 2004). In fact activities of daily living like bathing, dressing, Toilet etc require more physical energy and time, which becomes burdensome and strenuous to caregivers. Lack of financial and professional support has led to inadequacy of seeking help. Family caregivers have faced difficulties in managing incontinence, wandering and

Activities of daily living, in communication with the patient and socialization with friends, relatives and society. Thus, Managing of incontinence, wandering and ADL have emerged as three most difficult behaviours the caregivers have to manage. These three are the most typical behaviours seen in the patient with dementia.

(46) Family caregivers feel that their spouse will replace them and interestingly (21) Family caregivers have no one who can look after the patient in their absence. Family members (daughter- in- law, son-in-law and siblings) have emerged as significant aspect of informal support as well as important indicator of replacing the current primary caregiver. Second important person who may replace the current primary caregiver is the spouse of the caregiver, for the purpose of this study majority of primary caregivers are male and hence the finding is supported with the fact that wives of the caregivers will surely replace their husbands in caregiving in pretext of moral duty which is typical of Indian society. Schulz Ft and Martire LM in their study on Family caregiving of persons with dementia: prevalence, health effects, and support strategies stated that while there may be a number of care managers involved, most of the hands-on day to-day caring is still likely to be left to an individual, who is a primary caregiver. (J Geriatr Psychiatry 2004; 12:240-249 Pub Med)

Physical , emotional and financial strain are the second important factors which caregivers are finding difficult to manage and overcome them, meaning there by that they can directly affect the care giving process**.** The third important factor is communication and socialization; unlike non demented patients, dementia patients lose their ability to communicate and hence they cannot ask what they actually need or want, this creates a barrier between the patient and the caregiver and hence caregiver find it difficult to communicate with the patient.. Thus it can be concluded from the current study that the care giving arrangements in the families typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting which makes care giving a difficult task.

Further, there is not much of an option for the caregivers to get into the care giving roles as they get into it either by virtue of being spouse, children or being daughter-in-law. This can be attributed to the typical Indian culture that prevails in spite of changing family pattern due to fast changing society. The challenges and pressures of family care giving are a reality of daily life. Today, family caregivers monitor chronic and sometimes acute medical conditions as well as provide long-term care at home. Hence it is important to recognize, respect, assess and address family caregivers' needs. Studies shows that family members who provide care to persons with chronic or disabling conditions are themselves at risk. Emotional, physical and financial problems arise from the complexities and strains of caring of frail or disabled relatives, especially when the care is for a person with dementia. These burdens and health risks can impede the caregiver's ability to provide care, lead to higher health care costs, and affect their quality of life and those for whom they care.

2. Behavioral and Psychological symptoms and its management (BPSD)

Behavioral and Psychological Symptoms of Dementia (BPSD) is a term used to describe a range of heterogeneous psychiatric symptoms, psychological reactions, and behaviors occurring in people with dementia of any aetiology. They are common and cause significant distress to patients and caregivers. These symptoms could be misinterpreted by the family caregivers as deliberate misbehavior. Others could even misinterpret BPS as evidence of the poor quality of care provided by the family. Allegations of this kind only add to the misery of the caregiver.

It represents an important clinical dimension of dementia that has not been much considered and discussed, and been ignored from both research and therapeutic points of view until recently. Due to their frequency and their adverse effects on patients and their caregivers, these disturbances should be ascertained and treated in all cases of dementia. In India, Prevalence of Behavioral and Psychological Symptoms of Dementia (BPSD) is very high and more common in patients with Dementia (Shaji KS, George RK, et al 2009).

In the current study 71.8% hallucinations is observed in the patients, Severity of hallucination is moderate and distress is felt by family caregivers which is severe as compared to that of delusions and irritability. To manage these behaviours the caregivers make use of sleeping medicine, get angry, leave the patient alone, become strict and scold them and feel ashamed and sad. However on the other hand very few have reported of managing patient calmly, distracting them and understanding their behavior. Symptom of hallucination as a part of cognitive impairment in the patient with dementia has emerged as a factor creating severe distress among the caregivers as compared to other symptoms of delusion and irritability. Thus, presence of hallucination symptoms may make management of the patient troublesome

Majority of family caregivers have ranked communication, incontinence and wandering in that order as a problem. High level of severity for communication and Incontinence behavior is observed and severe to extreme distress is felt by family caregivers. Wandering can be both puzzling and stressful for the caregivers. Morris et al 1988, Brodaty Hadzi-1990 reported that Night time wandering of dementia patients cause great distress on the caregivers. Haley and Pardo in 1989 reported that the common behavioral problems found as difficult or stressful for the caregivers as the management of incontinence of the bowel and bladder. Further, family caregivers have expressed their inability to understand and communicate with patient. These concerns are managed by constant supervision, locking of the door and giving food at regular intervals. To prevent patient from wandering, night time behaviours followed by inability to understand if the patient have had enough food, wants to go to toilet have emerged as major concerns by the family caregivers. These concerns are managed by constant supervision, locking of the door and giving food at regular intervals. However, the family caregivers are not able to manage the incontinence as the patients are not able to communicate the same

These, concerns are typical of dementia patients which distinguishes their care giving from patients with other patients.

Further, Disorientation and depression have emerged as psychological change in the patient. Family caregivers have witnessed severity of these symptoms and felt moderate distress. Aggression, Agitation and bizarre behavior of the patient have emerged as a concern due to psychological changes in the patient. These behaviors are managed by being strict with the patient, giving sleeping pills etc which reflects the possible tiredness on the part of the caregivers. Bizarre behavior by the patient in front of others is managed by leaving the place of incidence; try to avoid such situations which reflect feeling of embarrassment as well as understanding of patient's condition.

Maintaining self hygiene for the patient, Mobility issue and eating habits of the patient have emerged as three major issues related to physical pain and safety of the patient. Distress caused by self hygiene and mobility issue are mild while that of eating habits is high, this confirms that special food for patient with dementia should be looked into. Caregivers must be made aware about changes in the food patterns that may possibly occur in the patient with dementia To manage with these issues caregivers have made structural changes to avoid patient from falling and getting hurt and take help for shifting of patient a from the bed and giving bath. Once again activity of daily living has emerged as a difficult area. Pearlin et al 1990 reported that difficulties in carrying out activities of daily living (ADL) are the best example of primary stress to the care givers since it is a chronic disability of the patients.

98 family caregivers have agreed that patient's behavior impacts them negatively, psychological symptoms makes them emotionally drained and creates lot of anxiety and confusion related to the behavior of the patient. 68.4% of them are not able to cope up with the financial and physical strain and they feel that their family functioning and social life is affected due to the patient's behavior. Further, majority of family caregivers have agreed that they find it difficult to look after the patient as they are not able to see patients condition and non availability of services /medicine/finance, lack of support and guidance. The data reveals that maximum family caregivers take patient to psychiatrist, family physician and neuro physician for treatment. Few take resort to alternative source of medicines like Homeopath, Ayurved, and visit religious /spiritual places. However, need for medical help and specialized treatment for the patient with dementia has emerged out clearly.

Thus, Making family caregivers aware about BPSD and educating them may prove to be important and effective in management of patient with Dementia. In a study by Shaji KS, George RK, et al 2009 BPSD were rated as troubling to most caregivers and Caregiver burden was associated with adverse effects on the mental health of the caregivers. Problem behavior has been reported to be the most stressful aspect of care giving and contribute to the increased burden of caregivers (Coen te al 1997, Payne and Caro 1997). It can be thus concluded that these symptoms are stressful for the co-resident family caregivers due to existing low levels of public awareness about dementia in India and lack of support and guidance from the health care delivery system. Social Work Interventions leading to reduction or of BPSD will be of immense help in the management of patients with Dementia. There is every reason to believe that BPSD is present across the cultures in both developed and developing regions of the world. (Shaji KS, George RK, et al 2009). Hence, to be effective, dementia care services in country like India need to focus on management of BPSD at home. This calls for development of a low cost, effective and sustainable dementia care service by the policy makers / Government.

3. Stress Areas and Coping Strategies by the family caregivers

Caregivers are important to the management of patient with Dementia. Earlier in this chapter we have seen that patient symptoms and behavior have an effect on the caregiver. Therefore, it is imperative that caregivers are recognized as being part of the illness process and do not remain hidden patients.

Unlike in the West, the traditional joint family system in India acts as a buffer against various kinds of stresses. However, due to rapid urbanization and industrialization, the joint family is breaking. The nuclear families are more vulnerable to stresses and are less equipped to handle mentally ill members (Kapoor, 1992; Sethi & Manchanda, 1978). Moreover, chronic illness of a family member is an objective stressor that results into strain for the caregiver or relative because of the difficult tasks of care of patient (Schene, 1990). This is likely to affect both physical and mental health of the caregiver, which depends upon the characteristics of the patient, the relative, their relationship and their environment (Brown & Birstwistle, 1998). In order to understand caregivers plight, it is necessary to comprehend certain key components essential in maintenance of social interaction and inter personal operation among caregivers and the patient with dementia. Caregivers need to “cope” with burden of objective and subjective stress. Coping is a process by which the care giver eases out the hardship of care giving.

It is seen that caregivers are saved from the huge responsibility of taking the patient to the doctors on regular basis which requires time and energy, more so in the case of patient with dementia. Further, it is heartening to note that maximum caregivers take patient to psychiatrist, family physician and neuro physician for treatment. Few take resort to alternative source of medicines like Homeopath, Ayurved, and visit religious

/spiritual places. However, need for medical help and specialized treatment for the patient with dementia as emerged out clearly.

In the current study 86.4% perceived/ felt stress in the physical area while 74.7% perceived/felt stress in social and 53.4% have felt stress related to finance. Physical, social and financial domains have emerged as stressful areas felt/perceived by the caregivers in that order. This implies that care giving causes lot of physical strain on the caregivers, affects their social life and takes toll on the finance also.

Barring one or two, all other coping strategies are positive adopted by the family caregivers in the current study. Looking to the social domain 68.9% family caregivers always avoid going to weddings, parties and inviting friends. 52.4% family caregivers sometime send the patient to other siblings /relatives place while 39.8% family caregivers never try to meet /discuss problems with relatives of similar patient. In physical domain 20.4% of the family caregivers always employ part time help in meal preparation and house maintenance 74.8% never employ paid nursing maid for 24 hours. In personal and emotional domain 56.3%caregivers sometimes take out time for their hobbies like listening to music, gardening and reading. In professional domain 77.7% family caregivers have never taken up part time job /financial activities while 43.7% family caregivers sometimes have taken break from care giving and holidays. (Nolan et a 1998) states that the individual selects a coping response or resource to deal with the threat, harm or challenge. If no appropriate response can be made, stress is likely to occur. If the threat, harm or challenge is met successful coping has taken place.

However, few caregivers have never met relatives of similar patient to discuss problems faced during care giving, never employed maid for 24 hours, taken resort to other branches of medicines like unani, homeopathy or ayurvedic or taken up part time job /financial activities. It is found that caregivers are using negative coping strategies like 68.9% avoid social functions always, 74.8% never employed paid worker for assistance, 55% and 39.8% have never used positive strategies like yoga, meditation .listening to music etc.

It can be concluded that caregivers need a platform to come together and discuss out the issues of care giving which can minimize their stress level. Scope in other branches of medicine for the treatment of dementia needs to be looked into, which can give a ray of hope to the caregivers and possibly have less financial burden on the caregivers.

Further looking to the activities dropped by the caregivers, it is found Visiting long distance relatives, attending marriages and birthday parties, celebrations of festivals and anniversaries are few activities that caregivers have dropped. However, they still continue to go out with their children on holidays and outings. Thus, it has emerged that care giving has affected the socialization pattern of caregivers as all the activities that they have dropped are social in nature. Not dropping the activity of going out with children implies that children's need is important to the caregivers being parents and therefore responsibility towards children cannot be ignored.

Looking to the informal support, it is revealed that 67.7% family caregivers said, help is given by the spouse and 60.2% family caregivers receive support from other family members. Support from the spouse of the family caregivers has emerged as the major source of support, which confirms the finding of this study, where majority of caregiver are males. This can be further justified, as in Indian setting wife inspite of doing the majority of the work in the household is not treated as the main caregiver. Support from other family members means those who are residing with the patient and caregivers and are grown up children, siblings of the caregivers at times spouse of the patient. This indicates scope to widen the informal or the support network for the family caregivers.

68.9% caregivers receive direct help in maintaining personal hygiene (cleaning if patients soils, comb hair, wear clothes, nails trim, brush shaving etc) , 66% caregivers receive direct help in giving bath to the patient and 19.4% caregivers received help for entertainment of the patient like taking for a stroll, operating TV, Music, talking etc. Thus, Direct help in activities of daily living, (cleaning if patient soils, comb hair, wear clothes, nails trim, brush shaving and giving bath to the patient) is received by maximum caregivers who are male. Most of the time of caregivers is spent in communicating, supervising and helping with eating and toileting. Caregiver strain is notably higher among caregivers of people with dementia (Amit Dias, Ravi Samuel et al 2004)

Once again it confirms the finding of this study, where majority of caregiver are males. This can be further justified, that Indian setting wives of caregivers take up these direct help. The least direct help is received in Instrumental Activities of Daily Living (entertainment of the patient like taking for a stroll, operating TV, Music, talking etc. activities) which is typically done by the male members of the family in Indian setting. On similar lines, indirect help is received in meals preparation, Keeping clothes, vessels, dusting and routine arrangements in the house and buying routine commodities groceries, vegetables, milk etc.

Now, on one hand if these family caregivers are getting direct and indirect help there are also cases wherein the support was discontinued.16.5% caregivers reported that family members had discontinued support and 6.8% caregivers have reported that friends, relatives and maids have stopped giving support. Studies have shown that strong support system has impact on to the overall wellbeing of the caregivers. It may be further interpreted that there is possibility of facing increased stress and difficulties in care giving process by those caregivers whose family members and relatives have discontinued their support in care giving. Thus, it is imperative to know the reasons of discontinued support.

87.5% family caregivers reported that the major reason for discontinuation of support was that patient is unmanageable, 66.6% said that the support was discontinued because of too much of incontinence while 45.8% caregivers reported that wrong or inappropriate behavior on the part of the patient was one of the reason. This implies how stressful it is to manage the patient with dementia. One of the factors for such reason could be lack of awareness and skills on the part of caregivers required for looking after the patient with dementia. Too much of incontinence and inappropriate behavior on the part of the patient are two typical symptoms of patient with dementia which are not seen in any other patient and hence the caregivers find it difficult to cope with such situations.

The perception of family caregivers related to informal care brought out how they manage with the care giving of the patient with dementia at home. Accepting the patient and showing warmth is better seen during informal support than in formal support, as reported by 90.2% family caregivers. 81.4% family caregivers reported that, patients are handled more carefully in informal care as compared to formal care.

And 76.5% family caregivers feel that informal care gives emotional support to the patient while it lacks in the formal support. Thus, Handling patient carefully, emotional support and accepting patient are three major differences that have emerged between formal and informal care. This reflects very clearly that family caregivers being part of informal care give prime importance to these three aspects of care giving. Moreover, the patient with dementia needs more warmth, acceptance and emotional connect as communication becomes difficult with them. This can be further interpreted that caregivers give their best in taking care of the patient and may have faced difficulties in formal care setup.

When looked into the professional support required by the family caregivers, 55.3% desire to have professional support in the form of special institutions, Rehabilitation centre and Respite centre, 35.9% need support in the form of availability of medicines, guidance from hospitals and awareness or more information about the disease. Few caregivers have reported to get financial support or help form government organizations and NGOs. It has clearly emerged that professional help and support is required by the caregivers in many ways. Further, there is dire need for special institutions, rehabilitation and respite centers, chemists, special hospitals financial support. The data has clearly paved the way for many interventions required not only by social worker but an integrated intervention with other disciplines and professions like medicine and Para medicine.

Data reveals the fact that most of the caregivers go to the family physician and then probably are directed to psychiatrist or neurophysicians. Interestingly, most of them have also responded that they do visit astrologers, community priests and family deity and undertake religious ceremonies. This can be justified in the context of cultural context. Most of the caregivers during interview revealed that it is painful for them to see the family member suffering and hence they take up religious ceremonies for faster recovery of the patient. This also confirms the nature of the disease which continually increases and the patient deteriorates till the death

4. Current awareness and knowledge need for special skills and training and views of health care professionals

55.3% caregivers make efforts to know more about Dementia. This reflects the need for creating avenues for generating more information and disseminates it to the general public at large. It has emerged that caregivers trust and feel confident about getting more information about dementia through doctors, then by internet and government hospitals. The data clearly indicates that these are the sources readily available and are trustworthy. Also development of more sources like caregivers associations, support groups, through media and advertisement and literature in local language is required as indicated from the data of both caregivers and Health care providers.

50.5% caregivers reported that they will share their experiences of managing the patient and extend possible help to the caregivers of other patients with similar conditions and tell symptoms and cause of typical behavior. The data indicates the willingness of the caregivers to share their experiences with other caregivers and this call for providing them a platform for coming together and share their experiences and help each other. As mentioned earlier in this study, the data is indicative of setting up of support group or self-help groups for caregivers of patient with dementia.

Family caregivers have ranked the skills used while providing care to the patient with dementia from 1(most important) to 7 (least important). The lowest mean 1.8 is scored for the overall handling of the patient followed by 3.1 communications and understanding through observation and 3.9 handling embarrassing situation, while the highest mean score is for cooking special food and feeding and encouraging socialization.

It has emerged from the data that the most important skill in management of dementia patient is handling the patient during ADLs, communication and handling embarrassing situations. The study by Gillerad et al 1982, Morris et al, 1988 found that difficulties in communicating with the patient are one of the major issues of caregivers of patient with dementia. As the disease progresses it can be very difficult for them to understand and communicate with dementia patients. All these three skills are directly related to the typical symptoms and difficulties faced by the patient with dementia. The patient gradually forgets how to brush, eat, dress and incontinence which is part of ADL, they also forget how to communicate due to severe loss of ability to use vocabulary, repetitive talking of one single thing and their behavior of being suspicious about the caregivers, putting false accusations and allegation on the caregivers leading to embarrassing situation. Thus, it requires a special skill of managing the patient and understanding of the disease. Further, it can be interpreted that the training to caregivers on such skills to manage the patient as well the difficult situation is the need of an hour.

77.7% have felt the need for training to increase skills and knowledge regarding management of the dementia patient. 98.1% of the family caregivers were not aware regarding any services available in the city for dementia cases. Almost all the caregivers except two of them are not aware about legal provision by the Government, if any. , there is a dire need to create awareness regarding legal provision by the government if any and advocate the same at the policy level.

It has emerged from the data that there is a lot of scope for interventions in the city as far as services related to Dementia patients and their caregivers is concerned. Along with specific social work interventions, it also requires integrated approach to intervention. Special Geriatric wards at government hospitals, ID cards for patients, Help lines, 24 hrs. Medical shop can be taken up at the policy level immediately.

Looking to the overall picture coping of the family caregivers, majority of them are positive barring one or two. Caregivers, for most of the time are providing person-centered care without professional guidance. Many have use certain therapeutic techniques, such as reassuring the patient that no one is stealing things and everything is alright, being patient, walking away from the patient when angry, or leaving the place of incidence when patient put allegation on them in front of others. Further, the caregivers also try to get more information about the disease and care giving from the internet and doctors, could be termed as cognitive strategies. Taking personal time to pursue hobbies, listening to music and reading, highlights the importance of caregivers ‘taking time out’ from the stressful care giving environment for themselves. These findings are similar to those in the study by Dr. Simon T O’Donovan on Dementia care giving burden and breakdown.

Thus, it can be concluded that In India, unlike West, family is the key resource in the care and management of patients with mental illness and also person with disability and dementia. The role of primary caregivers is assumed by the families for two reasons. First, it is because of the Indian tradition of interdependence and concern for near and dear ones in adversities. Due to this, most Indian families prefer to be meaningfully involved in all aspects of care of their relatives despite it being time-consuming. Second, there is a paucity of trained mental health professionals required to cater to the vast majority of the population; hence, the clinicians depend on the family. Thus, having an adequate family support is the need of the patient, clinician and the healthcare administrators.

Looking at the Health care Professionals perspectives, it could be gathered that patients are not capable of doing anything on their own and are brought to clinic by their caregivers during middle to moderate stage of dementia and when there is interference with activities of daily living. This supports finding of many studies reviewed in the current study.

Most common complaints described by relatives who accompany the patient at the clinic are as follows: Forgetfulness- forgetting things like names/focus/tasks/going to bathroom etc, not recognizing people they met recently, and not completing tasks which they could do earlier. Aggressive behavior, abnormal behavior, crying spells, sleep disturbance, inappropriate dressing and toilet behavior, depressed mood, familial conflicts, sleep disturbances, thought disturbances and anger outburst. This matches with the responses of the family caregivers in the current study wherein they have reported to find it difficult to manage these BPSD symptoms

The data related to lack of awareness about the disease and its course, confusion related to the patients behavior by the family caregivers is confirmed by the health care professionals. Along with this they also confirm the need of training and education related to special needs of the patient behavior.

Further, health care professionals have suggested that along with pharmacology and medical treatment, psycho education and supportive care is also suggested. They have also suggested intervention at following three levels:

Family Level: Awareness/education, preventive lifestyle, early detection, prompt treatment, good care of medical illnesses, restructuring lifestyle of patient/caregiver according to the stage of illness. Family members to treat the patient like a baby, usually not to ask complex questions to the patient, to make life as simple as possible, not to humiliate patient in front of others by asking questions.

Community Level: Old age homes, doctors and special training in handling dementia patients, accessible/available/cost effective treatments, specialized professional centres, Homes for managed care / respite care of patients, specialized professional centers for support of caregivers, support groups for caregivers.

Clinical Level: Starting specialized treatment facility / specialty for geriatric care / medicine. Providing emergency care along with routine care developing all investigative/therapeutic facilities for management of dementia under one roof. Availability of doctors/counselors/social workers exclusively working in the area of dementia/geriatric care, provisions for early doctor contact / no waiting time.

Thus, highlighting Holistic care – personal nutritional and hygiene and help in activities of daily living may reduce the burden of caregivers and will support the families which not only lessens the burden of state level but also maintain contact with the patient who needs emotional support.

The Way Ahead:

Family caregivers along with the professional caregivers are important and critical to the management of patient with Dementia (PWD). One of the important findings of the current study has shown that Behavioral and psychological symptoms, which are present in dementia, are a major source of distress to caregivers and its management takes most of the time of the caregivers.

Further, the study reveals the need for informal and formal support and intervention at various levels which will make the care giving process easier and equip caregivers to cope with the stress caused and manage with the distressing behaviours. Most importantly, the caregiver is uniquely placed to understand the context in which the behavior is occurring; it's meaning, the person behind the behavior and the world of the person with dementia making them crucial in the overall management of the patient with Dementia.

Hence coming to understand that patient's condition is influenced, naturally by the illness itself, but also by the care they receive. It is imperative that caregivers are recognized as being important part of illness process and do not remain hidden patients. The current study brings out the fact that many of them need high-quality, reliable and responsive support from Government or voluntary services to continue their role and maintain their own health and well-being. To date, however, there are few efforts across the country and almost no efforts in the city to put into effect these emerging concerns. The answer however, does not all lie at the door of increased resources for public services, but also in a thorough understanding of the illness situation at the family level. In the next chapter an attempt is made to give specific suggestions and interventions for social work practice.

CHAPTER - 6

SUGGESTIONS AND FUTURE DIRECTIONS

> **“The important thing….. is not to be cured, but to live with one’s ailment”**
>
> **-- Albert Camus**

This chapter discusses implication, of the study findings for social work practice, suggestions and future direction. In this section suggestions are classified into two broad categories which are aimed at improving family caregivers in the management of patient with Dementia.

1) Social Work Implications

2) Guidelines for Family caregivers Training Module

First part talks of social work implications, which have two sub sections**:**

1) Social Work Intervention Model for family caregivers of PWD and

2) Integration with the Social Work Profession, highlighting the intervention services that can be carried out by the social worker and Second part gives guidelines for the family caregivers in the management of Dementia patient.

Towards betterment of the Caregivers: What needs to be done

The current study has revealed that Family caregivers typically grapple with more than one caregiving concern. A review of literature demonstrates that an integrated approach and Interventions would benefit caregivers effectively. Access to better treatment for patients, including medications, psychosocial interventions and rehabilitation services is to be ensured. Our mental health policy ought to have the necessary flexibility rather than being rigid. Moreover, caregivers need to be supported through active programs of support and guidance rather than being left on their own. Family insurance of mentally ill could be a positive step in that direction.

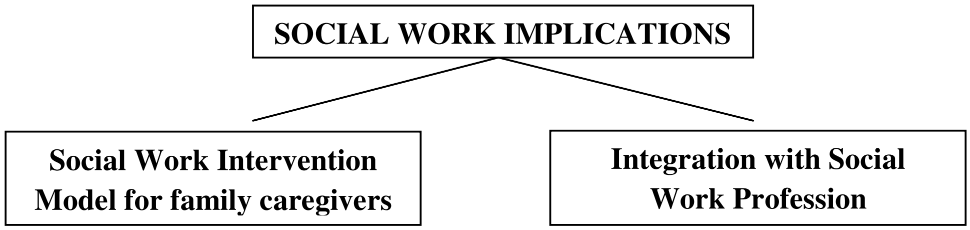
In a number of Western countries, there exists legislation to provide incentives for families to take care of their patients with long-term disabilities. The mental health social work professionals need to take up this issue with the policy makers.

Family interventions are neither widely used nor appropriately integrated in care plans, and are frequently underfunded, they should focus on skills in handling patient and task sharing of household chores, adequate information and support. Research Studies recommend that in addition to focusing on the symptoms of patients, more attention needs to be given to mental health and wellbeing of family caregivers. Given the basic differences in health care systems and services between India and the West, there has been a rapid propagation of support, self-help, or mutual support groups for family members of persons with severe psychiatric disabilities in the West and to some extent in our country. Caregivers must be encouraged to join such groups so that they can seek mutual help, learn from experience of others, can share their problems etc Psychosocial treatments often used so successfully in the West, cannot be directly transposed to the countries like India. Hence, there is need to develop a locally applicable / indigenous ways of rehabilitation and models of intervention which can be tested.

Because of lack of mental health infrastructure in India, the ultimate sufferer is the institution of family. Thus, Time has come to take a positive step towards full integration of family in the care of the patient with Dementia to combat the ill effects of this changing world and make this world a happier place to live in!

1) Social Work Implications:

Caring for a disabled family member can be challenging, potentially impacting caregivers’ health, mental health, work, social relationships, and quality of life. To alleviate caregiver stress, enable caregivers to better cope with the demands of caring for a loved one, and improve caregiver and care recipient outcomes, many interventions have been developed. However, although programs supporting caregivers have proliferated, there exists limited research regarding their effectiveness. The researcher in the current study has made an attempt to propose Social Work Implications in broad Domains:



1.1 Social Work Intervention Model for family caregivers of patient with Dementia (PWD):

In this section, an attempt has been made to develop an Intervention Model for Social Work Practice. The proposed model is adapted from the study by Richard Schulz and Lynn M. Martire on Family care giving of persons with Dementia (Am J Geriatric Psychiatry 2004 12:240–249)

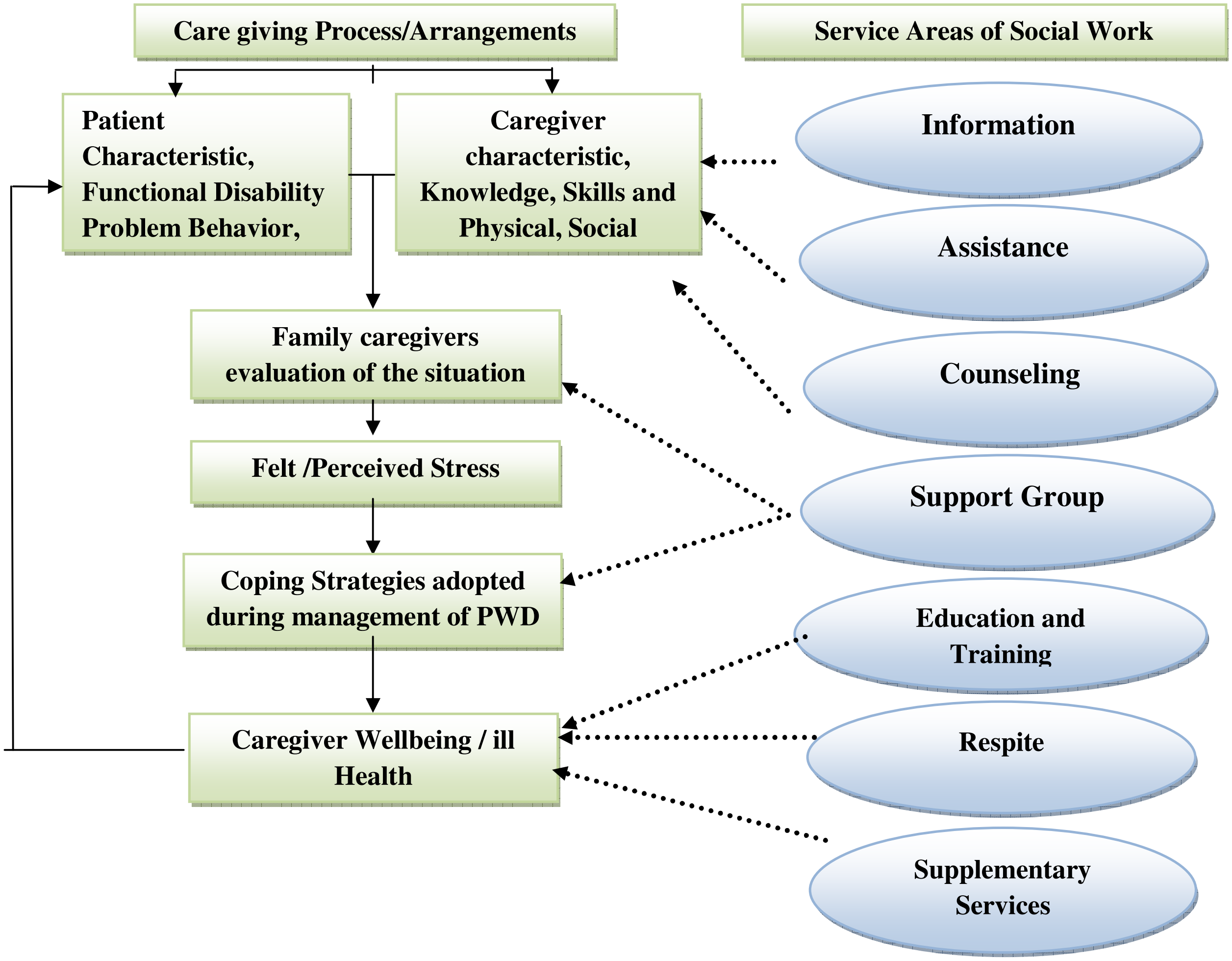
From the findings of the current study and intervention studies reviewed, it is evident to decrease the burden and stress and impact of care giving on personal, social and health of caregivers. The model (fig. no. 1) proposed has two parts: on the left side is illustrated the Care giving Process and arrangements by the caregiver, adapted from theoretical model of stress /health, widely used to understand stress process in care giving. On the right side is illustrated the seven areas of social work intervention. This can be a full- fledged family caregiver support program. It is assumed that these services as a part of social work Intervention will alleviate strain felt by caregivers if any and help them in management of patient with dementia. However, these services will be impacted by variety of factors: the caregiver's background characteristics, their psychosocial strengths and vulnerabilities; and the care recipient's type and level of impairment.

Looking to the figure no. 1, the left column describes the care giving process and arrangement by the family caregivers. The possible stressors that may emerge out of care giving are divided into two broad categories: (1) the primary stressors which include patients' characteristic, cognitive impairment, problem behaviors, care giving duration, managing with Activities of daily living and Instrumental Activities of daily living (ADL/IADL) - example bathing, dressing, shopping, and housework. (2) Secondary stressors which include caregivers characteristics like gender, age, financial condition etc, change in relationship due to physical and emotional dependency, family conflicts, sharing and division of responsibilities, job roles etc.

Family caregivers evaluate and appraise their situation of care giving. They try to understand and perceive whether they will be able to cope and use sufficient coping strategies. If they perceive the care giving to be more demanding and have inadequate coping resources they will experience stress. Thus, the experience of strain and stress possibly contributes to negative emotional response by the caregivers. However, if they perceive care giving less demanding with adequate coping resources they may possibly have positive experience of care giving. Subsequently it may either lead to caregiver's wellbeing or ill health. Again, the wellbeing or ill health will impact the care giving process and ultimately the patient.

The right column of the model illustrates how the various social work interventions might affect the care giving process and related stress if any. Interventions targeting caregiving knowledge about caregiving and availability of the social support should have impact on caregivers evaluation and coping strategies.

Figure no. 1 the Social Work Intervention Model for family caregivers of PWD



The seven areas a social worker can take up are:

1. **Information about available services to the family caregivers:**

   Information, advice, and referral are considered to be the most needed caregiver services (Friss, 1990), when services are available, many caregivers remain unaware of them (Maslow & Selstad, 2001). It is not possible to make meaningful decisions about the caregiving situation unless adequate and complete information is available. Sharing information, advice and referral are the roles done by the social workers. Information regarding health conditions and their implications, care needs, costs of care, and how to plan for future care needs also is important for caregivers (Feinberg, 1997). Therefore, it is important to note that the need for information goes beyond how and where to get help. As a result, most caregiving interventions strive to increase the caregiver's knowledge of available services, the recipient's disease, and caregiver challenges and solutions (Kennet, Burgio, & Schulz, 2000). This has come out as an important finding of this study.

2. **Assistance in gaining access to these services to the family caregivers:**

   Availability of Information about services does not necessarily ensure utilization of caregiver services. A social worker should keep in mind five key elements in analyzing the barriers in accessing the services by the caregivers and assist accordingly. These five elements are Availability, Accessibility, Appropriateness, Acceptability, and Affordability. First of all the needed services must be **available** in their community, Second these must be **accessible** to them. Support groups or counseling services must be located conveniently enough for the caregiver to arrange for a respite worker and make the appointment within a reasonable amount of time. Service accessibility applies not only to physical location of services, but to the mode of service delivery as well. For example working hours of such support networks should be such that the caregivers are able to utilize them reasonably. Thirdly, services offered must be **appropriate** to the caregiver's needs. Fourth, services must be culturally **acceptable** to the caregivers, as requesting help from those outside family can be different from culture to culture. For example, if the patient is female, an orthodox family may prefer female caregiver or a counselor. Caste issues also cannot be ruled out particularly in Indian context. Most important, the services must be linguistically accessible in terms of native language, as well as in terms of level of education within that native language. Fifth, services must be **affordable** to the caregivers. Affordability of services does not include financial costs, but also costs in terms of time and efforts.

3. Counseling:

In 1996, Bourgeois, Schulz, Burgio did a comprehensive review of over 100 AD caregivers and found that Individual counseling intervention have shown positive results on family caregivers as compared to group counseling. Counseling services vary greatly form caregivers to caregivers. This is not limited to traditional psychotherapy, but may include individual problem-solving, couples counseling, group counseling and family treatment. Counseling strives to relieve caregiver depression and / or anxiety, resolve pre-existing personal problems which may complicate care giving. Thus, aims at improvement in family functioning.

4. Organization of support groups:

In western countries, Support groups are among the most popular and most prevalent interventions available to the caregivers. In general, they are designed to provide informal peer support, information about diseases and disability and referrals for caregiver support services. They are often affiliated with nonprofit organizations and work towards help of elderly. In addition there is some evidence that they provide knowledge and enhance informal support networks (Bourgeois, Schulz, and Burgio, 1996).

5. Education and Training Programs:

Education and training programs strive to help caregivers by educating them about resources and teaching specific problem solving and coping techniques (Toseland & Smith, 2001). Studies have found that teaching specific care giving skills used to resolve real-life problems have been found to produce significant changes (Bourgeois, et al., 1996). Galagher-Thompson,Lovett, et al (2000) found that psycho-educational interventions teaching either mood management skills or problem solving skills were effective in reducing depression, reducing burden and increasing coping.

Social workers can develop indigenous education programs for the caregivers and also train the health care professionals who are working in the communities. They can train the interested caregivers and develop manpower and capacity building through skill development programs.

6. Respite Care:

Respite care programs are designed to offer temporary or periodic relief from demands of care giving by providing care for the patients who are unable to remain alone due to mental or physical impairment. Respite is a secondary benefit received by caregivers. The services like shopping, running errands, visiting doctors and extend opportunity to the caregivers to do other tasks. Respite care services are in three main forms: In-home care, adult day care and overnight respite. Respite services have shown to contribute to decreases in caregivers' perceived stress burden, anxiety and somatic complaints and increase morale, although respite use does not necessarily relieve caregiver depression. (Biegel & Scultz1998; Bourgeois e al 1996; Lyons & Zarit, 1999;Zarit, Stephens, Townsend and Green,199 Zarit et al.1999). Research indicates that regular, on-going use of respite services, in contrast to intermittent inconsistent use, can result in lower levels of care giving related stress, reduced feelings of overload and burden and better psychological wellbeing. (Bourgeis et al, 1996, Toseland et al, 2001;Zarit et al,1998)

7. Supplementary Services Care:

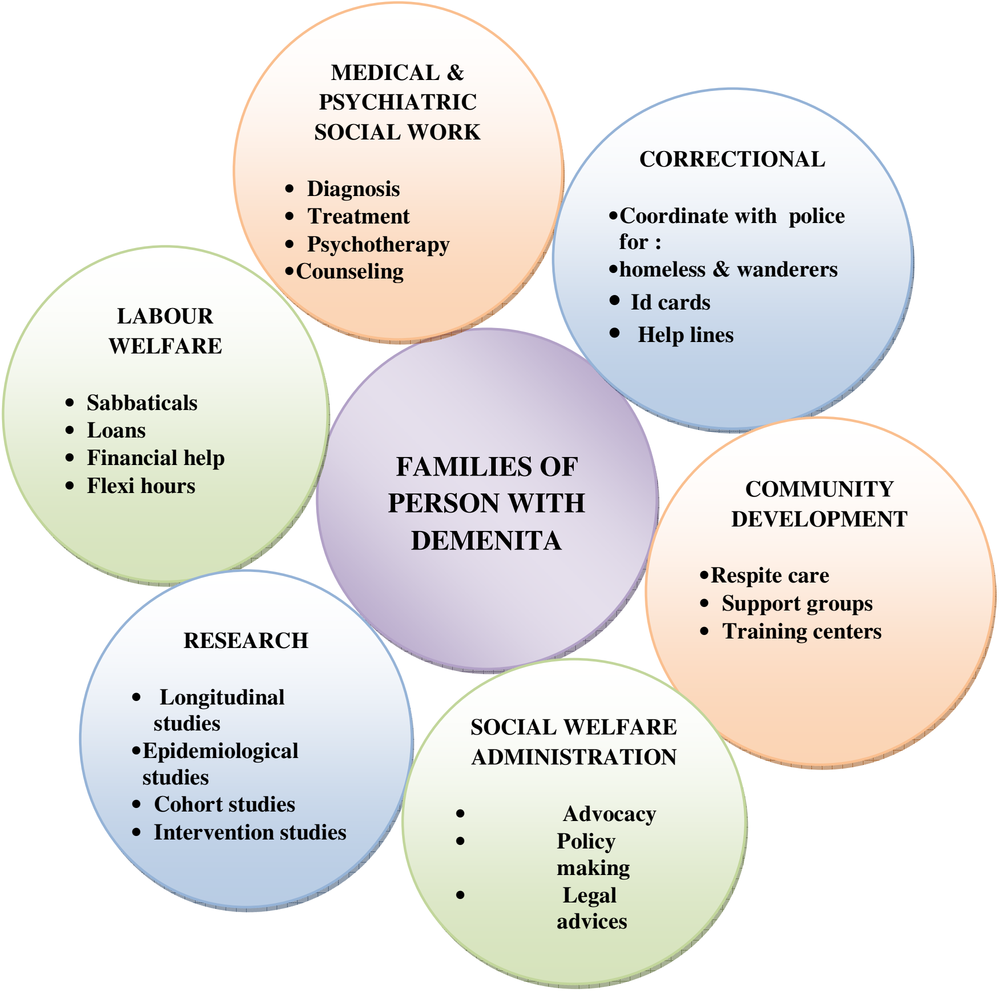
Services which complement the care provided by the caregivers are called supplementary services. The scope of supplementary services is loosely defined, for example assistive devices like wheel chairs from the Government for the patient with Dementia. Here it is expected from the social worker to make available of such assistive devices to the caregivers. Other supplementary services are legal assistance, home delivered meals, medicines etc.

To conclude, Interventions should be geared to the specific needs of family caregivers. This is important as the needs of caregivers of demented individuals differ substantially from the needs of other caregivers. The interventions should be sustaining. The ultimate aim should be improving caregiver well-being and moving beyond the individual caregiver to the organizational, community and policy level.

1.2 INTEGRATION WITH SOCIAL WORK PROFESSION:

In this section it is suggested that intervention to help the family caregivers of patient with Dementia needs an integrated approach. It requires integrating with the fields of Social Work – Medical and Psychiatry, Correctional, Community, Research and Social Welfare Administration. In part 1.1 earlier in this chapter, Applicability of Case work and Group work is already established.

FIGURE NO. 2 : INTEGRATION WITH SOCIAL WORK PROFESSION FOR FAMILIES OF PWD



1. Medical and Psychiatric Social Work:

This field is directly associated with the families of patient with Dementia. The social worker can help the families to understand the course of the disease right from getting the patient diagnosed at early stage, help in getting appropriate treatment, provide psychotherapy and counseling to the family caregivers if need be. Social worker can be a great help as Case managers and navigate the families though the available health care system for availing the facilities.

2. Correctional Field:

Social workers can help families of patient with Dementia to get assistance from police in cases where the patient wanders off. Also, the families can be assisted in getting benefits for elderly from the social defense offices. They can co-ordinate with appropriate government authorities for 24 hours help line and Identity cards for the dementia patients. This will help the families to locate the persons who wander off and help lines will give them proper guidance, specifically to those caregivers who are alone and have no support.

3. Community Development:

In this field, development of community resources should be the focus of the social worker. Advocacy for the community services and special facilities for the patient with dementia and their family caregivers should be taken up. Initiatives for starting support groups, training for caregivers can be taken up by the social workers. Special facilities like respite care, community care centers, special geriatric ward and OPD can be advocated for.

4. Social Welfare Administration:

The main role a social worker can be of advocacy at various levels. Create political interest for developing various policies related to dementia as a health concern and recognition of family caregivers. Create awareness related to legal needs and requirements of family caregivers of Dementia.

5. Research:

Social work researchers can take up intervention studies, longitudinal, Epidemiological studies and Cohort studies. Qualitative studies can bring insights in to greater needs of the family caregivers as well as the patient with dementia. This is important in Indian context as no data is available on dementia patients both at National as well as State level.

6. Labour Welfare:

In this field, a social worker working as a labour welfare officer can propose for sabbaticals for the family caregivers, make arrangements for financial help and loans if asked or required by the family caregivers of the dementia patients. Flexi hours or work at home when the patient needs them can also be suggested

2) GUIDELINES FOR FAMILY CAREGIVERS TRAINING MODULE

An Extensive training module for the family caregivers can be developed. The program can be developed with three focus areas, giving practical skills strategies for care giving situations.

The training prgoramme should have three modules: (3 hours each)

1. UNDERSTANDING MEMORY LOSS – THE DISEASE

- To know what is dementia, causes of dementia, Diagnosis and treatment and stages of dementia.
- To understand dementia in terms of how it impacts the patient's emotions

2. LIVING WITH DEMENTIA

- Understand the family caregiver's role
- Planning care across the years
- Creating safe environment for the dementia patient
- Learning essential care giving skills

    1. **Activities of daily living**
        - How to assist patient
        - Awareness on increase level of assistance as disease progresses
        - How to Establish a Daily Routine and a friendly environment
    2. **Tips for specific activities Bathing, Dental care, Grooming, Dressing, Toileting, Eating, Drinking water, cooking and Exercise.**
    3. **Handling challenging Behaviors**
        1. General understanding of reasons why people wander

    2. Making changes at home to reduce triggers
    3. Discussion on specific challenging behaviors with special tips on wandering, incontinence and repetitions

4. **Late stage Dementia Care**
    1. Setting up the home for care. - Support systems, infrastructure changes etc.
    2. Learning about end-of-life care, family decisions and legalities. Relating with the patient
    3. Understanding handling of Grief and taking counseling sessions

5. **Communication**
    1. Basic communication tips
    2. How to communicate without distractions and in a non-threatening environment
    3. Use of non-verbal clues
    4. How to simplify communication & instructions

The approach should be on the basis of CARES. Cares stands for

C – CONNECT WITH THE PERSON

A – ASSESS BEHAVIOUR

R – RESPOND APPROPRIATELY

E – EVALUATE WHAT WORKS

S – SHARE WITH OTHERS

Training Methodology:

The training with the caregivers should be participatory in nature, with workshops and practical exposures. Caregivers can be given self help booklets on handling burnouts and stress. This will help them cope the burden experienced by them. The program can be made rich with activities and video interviews with family caregivers, people with dementia, and dementia experts.

Directions for future Research:

Studies on caregivers have been done so far recently in 1990's, however most of them were on caregivers of mentally ill patients, more specifically on schizophrenia. There are very few studies on dementia and caregivers in India; these too are very recently done in 2000. The focus however was not much on family caregivers and care giving arrangements. More studies are needed in this area. Following areas are suggested for further research:

- Studies for caregivers in general with larger perspectives – Rural settings, Patient, Health care professionals and Service providers.
- Social work Intervention studies for caregivers.
- Studies to derive Subjective and Objective stress indicators in care giving process
- Emotional Reactions of caregivers to the care giving process
- Impact on overall quality of life and well being of caregivers
- Family Functioning studies from social work perspective – special reference to Ecological framework.

To Conclude:

From the current study, the researcher is able to gather insights into the care giving arrangements by the family caregivers of patient with dementia. Caregivers are not able to recognize early symptoms and take it as a part of normal Aging. Recognition of illness i.e. "Something is wrong" happens only when psychiatric symptoms are evident in the patient. Further, Caregivers are not able to make proper arrangements due to lack of proper training, Trial & Error methods of handling/ managing patients was observed during the interview. Lack of information related to course of the disease impacts the care giving arrangements. Registration of cases is low in PHCs, Government and Private Hospitals. In spite of Baroda being a well developed city with multispecialty hospitals, medical colleges and private clinics, there is no facility and infrastructure specially for handling dementia Patients like memory clinics, geriatric wards, Special OPDs, respite care centre. There is dearth of trained manpower who can handle Dementia patients, as this care giving is different from care giving of other patients

On the other hand, looking to the broader picture at national level, the percentage of elderly is growing very fast, especially in India and in Southeast Asia. The projections are that India will have between 12-13 percent of elderly as part of entire population by the year 2025, and that it is going to reach some 17 percent of the population being elderly by 2050. This calls for drastic improvement in public service and spend more money to prepare for a surge in its elderly population in the coming decades. (Country Head WHO).

Thus, if every fifth Indian is being elderly, this is going to be a very different society as a whole which needs to be seriously taken into consideration. It is not a surprise for anyone that generally healthcare provision in India needs major improvement as there are obvious differences of health care provision / infrastructure in urban and rural areas. These may not be challenges specific to elderly, but are health care challenges in terms of providing good quality services to public in general, which includes elderly. Hence, with high and growing number of elderly this needs to be looked into carefully.

Further, Indian society puts various expectations on families and extended families to take care of elderly through their incomes as being in productive age, thus more burden will be put on the youth population as the group of elderly becomes bigger for India. It also poses a huge financial challenge on the nation to take care of elderly especially we are moving from the joint large family model towards nuclear family, which will make elderly less attended by those families in future. Obviously there will be more demand for all kinds of services for the elderly, more for those with disabilities. And as they will live longer, more investment shall be required for maintaining these institutions.

Also young Indians, want to live a life like westerners. Nuclear family with wife and kids and old traditional joint family system is almost fading to oblivion especially in the urban belts. Migration of population to urban and metro cities brings with it lack of housing and infrastructure making it impossible for them to keep the elders living with them even if they want to. Today, the nation has a huge population who wants to live a western life and with no trace of infrastructure compared to what the west has for its elders. Sooner we wake up the better it is…

REFERNCES

1. Alan Bryman: Social Research Methods, Oxford University Press third edition.

2. Alison M. Heru, Asma Iqbal Christine E. Ryan (2004) Family functioning in the caregivers of patients with dementia International Journal of Geriatric Psychiatry 19: 533–537. Published online in Wiley Inter Science (www.interscience.wiley.com). DOI: 10.1002/gps.1119

3. Allan v. Kaufman and jordan i. Kosberg (2010) Social Support, Caregiver Burden, and Life Satisfaction in a Sample of Rural African American and White Caregivers of Older Persons With Dementia Journal of Gerontological Social Work, 53:251–269,

4. Allen Rubin and Earl Babbie: Research Methods for Social Work, Wadsworth Publishing Company California.

5. Allen, J.E.: When Memory Fails: Helping the Alzheimer's and Dementia 1992 Patient, New York: John Wiley and Sons

6. Amit Dias, Ravi Samuel, Vikram Patel, Martin Prince, R. Parameshwaran, and E. S. Krishnamoorthy (2004) The impact associated with caring for a person with dementia: a report from the 10/66 Dementia Research Group's Indian network J Geriatric Psychiatry 19: 182–184.

7. Asia Pacific Journal of Public Health 2003, 15(1):23.

8. Avasthi A.: Preserve and strengthen family to promote mental health Indian J Psychiatry. (2010)

9. Bajaj MK, Sinha UK (2009) Relationship between cognitive functioning and caregiver burden in dementia. Indian J Psychiatry [serial online] 51:206-10. Available from: http://www.indianjpsychiatry.org

10. Beasley, C. (1999). What is feminism? An introduction to feminist theory. London: Sage.

11. Bhavna Mehta, Anandmala Desai, Hina Desai: Marital Violence: It's Impact on Health – A women's perspective.(2002) faculty of social work, M S university Baroda.

12. Black K, LoGiudice D, Ames D, Barber B and Smith R(2001) Diagnosing Dementia, Alzheimer's Association Australia, Canberra

13. C.jayakumar K.Jagadheesan & A.N.verma (2002) Caregiver's burden: a comparison between obsessive Compulsive disorder and schizophrenia Indian Journal of Psychiatry, 44(4), 337-342

14. Caregiver Stress: Womens Health (2006) National Women's Health Information Center.

15. Census of India. (2001, January). Census data 2001: Projected population for the year. retrieved from www.censusindia.gov.in/Census_Data_2001/Projected_population.aspx

16. Chakraborti, D. (2004). The graying of India: Population aging in the context of Asia. New Delhi, India: Sage.

17. Chan, A. (2005). Aging in Southeast and East Asia: Issues and policy directions. Journal of Cross-Cultural Gerontology, 20, 269-284.

18. Chandra, V., Ganguli, M., Pandav, R., Johnston, J., Belle, S., & DeKosky, S. T. (1998).

19. Channa, H., & Talwar, P. (1987). Aging in India: Its socioeconomic and health implications. Asia-Pacific Population Journal, 2(3), 23-39.

20. Corey-Bloom, J. and Folstein, C. : Diagnosis and Evaluation of Dementia, Neurology, 45(2), 211-218 2004

21. Creado DA, Parkar SR, Kamath RM.(2006) A comparison of the level of functioning in chronic schizophrenia with coping and burden in caregivers. Indian J Psychiatry 48:27-33

22. Dandekar, K. (1996). The elderly in India. New Delhi, India: Vedan Press.

23. Datta, P., Poortinga, Y. H., & Marcoen, A. (2003). Parent care by Indian and Belgian caregivers in their roles of daughter/daughter-in-law. Journal of Cross-Cultural Psychology, 34, 736-749.

24. Dayabati S, Bagga (2006) Ageing in Women- a study in North-East India,mittal publication, New Delhi

25. Deborah j Monahan (1993): "Assessment of dementia patients and their families: an ecological –family-centered approach". Deborah J. Monahan; Health and Social Work Approach Journal article by, Vol. 18

26. Deborah j Monahan: "Assessment of dementia patients and their families: an ecological –family-centered approach". Deborah J. Monahan; Health and Social Work Approach Journal article by, Vol. 18, 1993

27. Dementia care is the more stressful type of family caregiving. Family Caregiving of Persons With Dementia *Prevalence, Health Effects, and Support Strategies Richard Schulz, Ph.D. Lynn M. Martire, Ph.D.* Am J Geriatr Psychiatry 2004; 12:240–249)

28. Desai, M. and B.R. Siva Raju, S. (2000): Gerontological Social Work in India, New Delhi: Publishing Corporation.

29. Devi Prasad, B and Indira Rani, N (2007). Older persons, and care giver burden and satisfaction in rural family context, *Indian Journal of Gerontology,* 21 (2):216-32.

30. Dhooper, S.S.: Social Work in Health Care in the 21st Century, London: Sage Publications. 1987

31. Dias A, Dewey ME, D'Souza` J, Dhume R, Motghare DD, et al. (2008) The effectiveness of a Home Care Program for Supporting Caregivers of Persons with Dementia in Developing Countries: A Randomised Controlled Trial from Goa, India. PLoS ONE 3(6): e2333. oi:10.1371/journal.pone.

32. Dias A, Patel V.(2009) "Closing treatment gap in India". Indian Journal Psychiatry:51:S93-7.

33. Dr. Desai K G et al Problems of retired people in greater Bombay, Tata Institute of Social sciences Bombay

34. Directorate General of Health Service, Government of India: National Programme for the Health Care of the Elderly, Operational Guidelines.(2011)

35. Dr. Kaur.U: Geriatric Social Work: Pertinence in contemporary Scenario (2010), Helpage India Research and Development Journal Vol. 16(2010).

36. Emmatty M.L (2009) An Insight into Dementia Care in India,Sage Publications, New Delhi

37. Ferri, Cleusa P [et. al.] (2005) Global prevalence of dementia: a Delphi consensus study. Lancet 366: 2112-7

38. Florence M Hollis Casework: A psychosocial Therapy, Random House New York 2nd Edition.

39. Gale Encyclopedia of Medicine. Copyright 2008 The Gale Group, Inc

40. Ganguly KK, Chadda RK, & Singh TB. (2009). A Study of Socio Cultural Perspectives of Care Givers in burden Coping Behavior in Bipolar Disorder and Schizophrenia Cases. International Journal of Psychosocial Rehabilitation. Vol 13(2). 93-103

41. Geriatric Psychiatry- Clinical Practice Guidelines: Published by Indian Psychiatric Society.

42. Gerontology India. (2008). National policy on ageing. Retrieved from http://www.gerontologyindia.com/national policy.htm

43. Goldstein, M., & Griswold, K. (1998). Practical geriatrics: Cultural sensitivity and aging. Psychiatric Services, 49, 769-771.

44. Gorman, C.: The New Science of Alzheimer’s, Time, July. 2000

45. Government of Gujarat Mental Healthcare Policy, Published Govt of Gujarat April2004.

46. Government of India: National Policy for Older People (1999).

47. Gruetzher, H.(1992): Alzheimer's: A Caregiver's Guide and Sourcebook, New York: John Wiley and Sons.

48. Gupta, R. (2007). Perceived caregiver burden scale for caregivers of the elderly in India. Journal of Applied Gerontology, 26, 218-238.

49. Gupta, R., & Chaudhuri, A. (2008). Elder abuse in a cross-cultural context: Assessment, policy and practice. Indian Journal of Gerontology, 22, 148-171.

50. Gupta, R., & Pillai, V. (2002). Cultural influences on perceptions of caregiver burden among Asian Indians and Pakistanis. Southwest Journal on Aging, 17(1-2), 65-74.

51. Hanspal, S., & Chadha, N. K. (2006). Economic aspects of aging in India: The multi-generational issues. Journal of Intergenerational Relationships, 4(1), 81-92.

52. HelpAge India—Self-sufficience for disadvantaged senior citizens. Retrievedfrom http://www.copalpartners.com HelpAgeIndia_Final_Report. (2008).

53. Herd, P., & Meyer, M. H. (2002). Care work: Invisible civic engagement. Gender & Society, 16, 665-688.

54. Hilde Verbeek, Erik van Rossum et al,(2010), Small-scale, homelike facilities versus regular psychogeriatric nursing home wards: A cross-sectional study into residents' characteristics. BMC Verbeek et al. BMC Health Services Research 2010, this article is available at http://www.biomedcentral.com/1472-6963/10/30

55. Hill Collins, P. (1986). Learning from the outside within: The sociological significance of Black feminist thought. Social Problems, 33, 514-530.

56. Hill Collins, P. (1989). The social construction of Black feminist thought. Signs, 14, 745-773.

57. I. Sreeja, G. Sandhya, l. Rakesh & M. Singh(2009) : Comparison Of Burden Between Family Caregivers Of Patients Having Schizophrenia And Epilepsy . The Internet Journal of Epidemiology. Volume 6 Number 2

58. Indian Journal of Psychiatry Vol 51 Jan2009

59. Indian Journal of Gerontology (a quarterly journal devoted to research in ageing) Vol 21 No: 2, 2007

60. International Journal of Aging and Human Development, 62(1), 61-78.

61. International Journal of Geriatric Psychiatry Volume 19 Issue 6, Pages 533 – 537 Published Online: 17 May 2004 John Wiley & Sons, Ltd.

62. International Longevity Centre India: A study on ‘Comparative study of two developing and two developed nations in the field of ageing.’

63. J.S. Siegel and S.L. Hoover (2000), ‘Demographic Aspects of the Health of the Elderly to the Year 2000 and Beyond’, World Health Statistical Quarterly 35, 1982, pp. 132-202.

64. Jamuna, D. (2003). Issues of elder care and elder abuse in the India context. Journal of Aging and Social Policy, 15(2-3), 129-142.

65. Jathanna RPN, Latha KS, Bhandary PV. Burden and Coping in Informal Caregivers of Persons with Dementia: A Cross Sectional Study *Online Journal of Health and Allied Sciences* Peer Reviewed, Vol. 9, Issue 4; 2010, ISSN 0972-5997

66. Jorm A (2001) Dementia: a Major Health Problem for Australia, Alzheimer’s Australia, Canberra(1998)

67. Jenny Billings, Kai Leichsenning(Eds.): Integrating Health and Social Care Services for older persons, Ashgate Publishing limited ,England (2005)

68. K. Kinsella and C.M. Taeubar(1992), An Aging World II, US Government Printing Office, Washington D.C.

69. Kaplan, H.I., Sadock, B.J. and Grebb, J.A.(1994) : Dementia, Baltimore: Williams and Williams.

70. Kaplan.D.B, Berkman.B (2011) Dementia care: A global concern & social work challenge, International Social Work (2011) Vol. 54

71. Koenig, Terry L. (2006) female caregivers' reflections on ethical decision-making: the intersection of domestic violence and elder care. Clinical Social Work Journal 34(3)

72. Kuei-Ru Chou1*, Hsin Chu2, Chu-Li Tseng3, and Ru-Band Lu(2003) The Measurement of Caregiver Burden, Med Sci 23(2):73-82

73. Lazarus, R. (1974). Psychological stress and coping in adaptation and illness. International Journal of Psychiatry Medicine, 5(4), 321-333. Available on http://www.ncbi.nlm.nih.gov

74. Linda K. George, & Lisa P. Gwyther (1986), Caregiver Weil-Being: A Multidimensional Examination of Family Caregivers of Demented Adults, The Gerontological Society of America gerontologist Vol. 26, No. 3.

75. Lundberg, G. D.(1995): ' How to Approach Universal Access to Basic Medical Care Without Our Government Doing It, Journal of American M edical Association, 4(2), 23-29.

76. MacReady, Norra(2003). "Prompt Intervention May Help Slow Dementia." Clinical Psychiatry News, 38.

77. Mc Laughlin, L., & Braun, K. (1998). "Asian and Pacific Islander cultural values: Considerations for health care decision-making." Health and Social Work, 23 (2).

78. Mega, M. S., and Cummings, J. L(1996). : "The Spectrum of Behavioural Change in Alzheimer's Disease'; Neurology, 46(1), 130-135.

79. Mehta, K. (2005). Stress among family caregivers of older persons in Singapore. Journal of Cross Cultural Gerontology, 20, 319-334.

80. Marie. B, Oberg et al changing worlds of the ageing subject:Dimensions in the study of ageing and later life, Ashgate Publications Limited, England

81. Muttagi.P.K : Aging Issues and Old Age Care(A global Perspective), Classical Publishing Company ,New Delhi (1997)

82. Myonghwa Park, PhD, RN,(2002) Korean Family Caregivers' Perceptions of Care in Dementia Care Units Journal of Korean Academy of Nursing Vol. 32, No. 7

83. Patel, V., & Prince, M. (2001). Ageing and mental health in a developing country: Who cares? Qualitative studies from Goa, India. Psychological Medicine, 31, 29-38.

84. Philips, G(1995).: Assessment and Management of the Dementing Patients, Journal of Mental Health; 4(2), 165-175.

85. Pollen Young: Scientific Social Survey and Research, Prentice Hall England, 3rd Edition.

86. Prakash, I. J. (2003). Aging, disability and disable older people in India. Journal of Aging & Social Policy, 15(23), 85-100.

87. Prakash, L. J.(2009) : Functional Competence and Well-Being of Elderly-1: Indian 1997Data. Report Submitted to HelpAge India, New Delhi.

88. Prince MJ. The 10/66 dementia research group-10 years on. Indian Journal Psychiatry:51:S8-15.

89. Prevalence of Alzheimer's disease and other dementias in rural India: The Indo-US Study. Neurology, 51, 1000-1008.

90. Robinson K.M., Adki S Son P. & Weinrich S. (2001) Journal of Advanced Nursing 36(4), 573-582

91. Rosner, D. (1989). "Doing Well or Doing Good: The Ambivalent Focusof Hospital Administration." In The American General Hospital: Communities and Social Contexts, edited by D. Long and J. Golden, 157–169.

92. Rudnick, A. (2004). Burden of Caregivers of Mentally Ill Individuals in Israel: A Family Participatory Study. International Journal of Psychosocial Rehabilitation. 9 (1), 147-152.

93. Sathyanarayana Rao TS, Asha MR (2009). Dementia: Merging frontiers and demerging vistas. Indian Journal Psychiatry:51:S2-4.

94. Shaji KS (2009) Dementia care in developing countries: The road ahead. Indian Journal Psychiatry:51:S5-7.

95. Shaji KS, George RK, Prince MJ, Jacob KS.(2009) Behavioral symptoms and caregiver burden in dementia. Indian J Psychiatry;51:45-9

96. Shaji, K. S., Smitha, K., Lal, K. P. and Prince, M. J. (2003), Caregivers of people with Alzheimer's disease: a qualitative study from the Indian 10/66 Dementia Research Network. International Journal of Geriatric Psychiatry, 18: 1–6. doi: 10.1002/gps.649

97. Shaji, S., Bose, S., & Verghese, A. (2005). Prevalence of dementia in an urban population in Kerala, India. British Journal of Psychiatry, 186, 136-140.

98. Srivastav.R.C(1994) The problems of old age, classical publishing company New Delhi 110015

99. Stanley S. & Shwetha, S. (2006).Integrated Psychosocial Intervention in Schizophrenia: Implications for Patients and Caregivers. International Journal of Psychosocial Rehabilitation. 10 (2), 113-128.

100. Stevens, R. (1999) In Sickness and in Wealth: American Hospitals in the Twentieth Century. Baltimore: The Johns Hopkins University Press.

101. Thara R, Padmavati R, Kumar S, Srinivasan L. Burden Assessment Schedule: Instrument to assess burden on caregivers of chronic mentally ill. Indian Journal of Psychiatry1998; 940:21-29.

102. The American Heritage® Medical Dictionary Houghton Mifflin Company. Published by Houghton Mifflin Company.

103. UNDP, Human Development Report (1990) Oxford University Press, New York.

104. UN department of Economic and Social Affairs Seminar report on Social, Health and Economic consequence of Population ageing in context of changing families (2007).

105. Vyas J N (2011) Short textbook of Psychiatry New Central Book Agency Kolkata 2011 reveiwd in Indian Journal of Psychiatry (2011) Vol. 53 by Kangan Pathak

106. Volicer, L., and Hurby,(1995) A.: Protecting Self-determination of Dementia Patients, Journal of the American Geriatric Society, 43(8), 935-938. 1995

107. WC Chan, C Ng, CCM Mok, et al. (2004) Lived Experience of Caregivers of Persons with Dementia in Hong Kong: a Qualitative Study. East Asian Arch Psychiatry 2010, Vol 20, No.4

108. Zarit, S.H., and Orr, N.K.(2000): The Hidden Victims of Alzheimer’s disease: Families under Stress, New York: University Press.

Faculty of Social Work

The M.S University of Baroda
Vadodara -390 002 Gujarat India

Informed Consent Form for the Family Caregivers of the Patient with Dementia.

This informed consent form is for family caregivers providing care to the patient with dementia at home and who we are inviting to participate in PhD study titled **"Management of Dementia Patients by Family caregivers- A Social work perspective**

Name of Investigator: Ms. Sunita Jolly

Name of Organization: Faculty of Social Work, The M S university of Baroda, Vadodara-2

Name of the Research Guide: Prof. (Dr.) Aruna Khasgiwala

Please not that this Informed Consent Form has two parts:
- Information Sheet (to share information about the study with you)

- Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet

Introduction

I am Sunita Jolly, working at the Faculty of Social Work, M S University of Baroda. I am doing my PhD Research on Dementia an all-encompassing illness that affects many spheres of the affected individual, his or her family and society, common in elderly population. I am going to give you information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research.

This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them to me.

Purpose of the research

The main purpose of this study is to explore and examine current care giving arrangements of dementia patients. We believe you can help us by telling us what you know both about dementia and about care giving arrangements that you make in general. We want to learn about the different ways that people try to cope and manage, and how people know when someone has it. This knowledge might help us to learn how to ease the situation of the caregivers through a training module which focuses on Awareness and Knowledge about Dementia Management of Dementia Patients Coping strategies for caregivers

Type of Research Intervention

This research will involve your participation in an interview that will take about one and a half hour, and if required in a group discussion for half an hour.

Participant Selection

You are being invited to take part in this research because we feel that your experience as a Caregiver can contribute much to our understanding and knowledge of care giving practices for a patient with Dementia.

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not.

Procedures

During the interview, I will sit down with you in a comfortable place. If you do not wish to answer any of the questions during the interview, you may say so and I will move on to the next question. No one else but me will be present unless you would like someone else to be there. The information recorded is confidential, and no one else except me, my guide and examiners will access to the information documented during your interview. The entire interview if tape-recorded, is confidential and no-one will be identified by name on the tape.

Confidentiality

I will not be sharing information about you to anyone outside of the Academic research team (Myself, guide and the examiners) The information that we collect from this research project will be kept private. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is and we will lock that information up with a lock and key. It will not be shared with or given to anyone.

Right to Refuse or Withdraw

You may stop participating in the [discussion/interview] at any time that you wish. I will give you an opportunity at the end of the interview/discussion to review your remarks, and you can ask to modify or remove portions of those, if you do not agree with my notes or if I did not understand you correctly

Contact

If you wish to ask questions later, you may contact on the following number:

9824549212 – Sunita jolly

Part II: Certificate of Consent

I have been invited to participate in research about Management of Dementia patients by family caregivers.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Name of Participant

Signature of Participant

Date

If illiterate [1]

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness **Thumb print of participant**

Signature of witness

Date

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Name of Researcher taking the consent

Signature of Researcher taking the consent

Date

---

[1] A literate witness must sign (if possible, this person should be selected by the participant and should have no connection to the research team). Participants who are illiterate should include their thumb print as well.

Management of Dementia patients by Family Caregivers – A Social work perspective
Faculty of Social Work,
Maharaja Sayajirao University of Baroda,
Vadodara.

ID NO: __________

CLINICAL DATA SHEET

(This page is to be filled up at the clinic/referrals. Complete *before the interview)*

Dr./Clinic:____

1. PATIENT

Name: ____

Address: ____

____

Contact No:__________________________

Sex: 1 Male 2 Female **Age:** ____________

Dementia Diagnosis: __________________ **Date of Diagnosis:** ________________

Date for follow up: _____________**Any other co morbidity:**__________________

Agreed for Interview?: ________ 1 Yes 2 No

ID NO: __________

MANAGEMENT OF DEMENTIA PATIENTS BY FAMILY CAREGIVERS – A SOCIAL WORK PERSPECTIVE

INTERVIEW SCHEDULE

Complete ☐

Incomplete ☐

To be edited ☐

Consent Signed? Yes ☐ NO ☐

Date of Interview: ____________________

Time Interview started:_________________

Time Interview ended:__________________

Sign Interviewer:________________________

(Introduction of self to the caregiver, with name of referral or Dr.) Thank you for agreeing to talk to us. I would like to spend some time talking to you about the patient and his/her situation, and also about the help that you provide and care you give. I would like to begin by first asking you a few questions about yourself.

I) CAREGIVER CONTEXT/ SOCIO DEMOGRAPHIC DETAILS

1	Age	:	____________________ years				
2	Gender	:	Male -1		Female -2		
3	Religion	:	Hindu-1	Muslim-2	Christian-3	Sikh-4	Other -5
4	Caste	:	GEN-1	SC-1	SEBC-3	ST-4	
5	Marital Status	:	Married-1		Widow -2	Divorcee-3	
			Separated-4		Unmarried-5	Not Informed -6	
6	No. of years of marriage	:	________________years				
7	Children if any	:	________________total no.				
8	W/D/S Since	:	________________years				
9	Education	:	read & write-1	Up to HSC-2	Graduate -3	Graduate and Above-4	

10	Since when you are taking care of the patient(care giving duration	:	___________________ years / months
11	Caregivers relationship to patient	:	___________________________________
12	How did you get into caregiver role?	:	___________________________________
13	Family Status:		

13.1Size of the family:__________		(1) 4 & below (2) 5to 8 (3) 9& above
13.2 Type of Family:____________		(1) Nuclear , (2) Joint, (3) Extended
13.3Domicile:__________ ________		(1) Urban, (2) Semi-Urban, (3) Rural

14.1	Are you currently employed?	:	____________	(1)Yes	(2) No	
14.2	What is your current employment status?	:	Full time -1	Part time-2	None -3	
14.3	If yes what is the type of job	:	Non Govt-1	Govt-3	Self Emp-3	No job-4

13.4 Do you have to take care of any of the other family members other than the patient? _________ 1 YES 2 NO

15 Do you have regular monthly income? ___ YES-1 ____ NO-2

15.1 What is your monthly household income? _______

(1) Less than or equal to 5000 (2) 5001- 10,000 (3) 10,001 and above

15.2 What is the source of Household income?
(a) Earnining from family members _____________________
(b) Financial help from relatives______________ (specify relative)

15.3 Are you financially independent? __________ 1. YES 2. NO

15.4 What is the source of income for care giving?
(1) Household Budget (2) From Workplace (3) Pension (4) Savings (5) other sources (religious institutions, NGOs)

II) CURRENT CAREGIVING ARRANGEMENTS (Care needed & Provided, ADL/IADL)

16.1 How many hours of care you give to the patient?
(1) 3 to 5 hours (2) 6 to 9 hours (3) More than 10 hours

16.2 Does any other family member share care giving responsibility with you?
____

16.3 From the list given below what care you provide for the patient in the family?

No	care provided	1= Yes	2= No
1	Personal Hygiene (such as help with bathing, dressing, using the toilet, shaving, getting in and out of the bath, and feeding)		
2	Housekeeping (such as help with meal preparation, cleaning and laundry)		
3	Entertainment(visit to temple(place of worship), for a stroll, operating T V, being with the patient during socializing, playing music, celebrations)		
4	Transportation/Travel		
5	Shopping and Errands		
6	Supervision for safety		
7	Money management		
8	Use telephone		
9	Medicine administration		

16.4 Do you think you are able to provide adequate care/help mentioned above? (Specify if more is needed)

____

____

____

16.5 What difficulties are faced while providing care to the patient?

____

____

____

16.6 If you were not available/ unable to continue with care, who would take your role/place?

____

____

____

III <u>Dementia symptoms, associated issues in patient and its management strategies</u>

17. Does the patient have medical problem other than dementia? Specify?
    (1) No problems (2) Physical Problems (3) others (hyper acidity, hyper tension, diabetes)

18. Please answer the following questions based on Cognitive, behavioral, Psychological and Physical changes seen in the patient. Circle “yes” only if the symptom has been present in the past six months, otherwise, circle “no”. If the symptoms/changes are present, rate its severity on the given scale and briefly describe how you management the same. (* reverse score)

For each item marked “yes”:Rate the severity of the symptom {how it affects the patient}:	Rate the distress you experience because of that symptom {how it affects you}:
1 = Mild {noticeable, but not a significant change}	0 = Not distressing at all
2 = Moderate {significant, but not a dramatic change}	1 = Minimal {slightly distressing, not a problem to cope with}
3 = Severe {very marked or prominent; a dramatic change}	2 = Mild {not very distressing, generally easy to cope with}
	3 = Moderate {fairly distressing, not always easy to cope with}
	4 = Severe {very distressing, difficult to cope with}
	5 = Extreme or very severe {extremely distressing, unable to cope with}

Please answer each question honestly and carefully. Ask for assistance if you are not sure how to answer any question. Encircle the relevant item.

18.1 COGNITIVE IMPAIRMENT												
Delusions		Does the patient believe that others are stealing from him or her, or planning to harm him or her in some way? How many times does the patient hide things due to belief that others may steal them?										
Yes	No	Severity:	1	2	3	Distress:	0	1	2	3	4	5
Hallucinations		Does the patient act as if he or she hears voices? Does he or she talk to people who are not there? How frequently and when does patient talk to unseen people or hear voices										
Yes	No	Severity:	1	2	3	Distress:	0	1	2	3	4	5
Irritability		Is the patient impatient and cranky? Does he or she have difficulty coping with delays or waiting for planned activities? Does the patient shout, yell or is irritable if there is delay in serving food or more time in nursing, wearing clothes										
Yes	No	Severity:	1	2	3	Distress:	0	1	2	3	4	5
Motor disturbance		Does the patient engage in repetitive activities, such as pacing around the house, handling buttons, wrapping clothes, or doing other things repeatedly?										
Yes	No	Severity:	1	2	3	Distress:	0	1	2	3	4	5

Managing CI	**Description**
a) How do you make patient understand that no one is trying to harm him/her or steal things?	
b) How do you feel / what do you do when patient accuses you in front of other?	
c) What you tell patient when he/ she talk to unseen people/hear voices?	

d) How do manage the patient when he/she shouts and yells?	
e) What do you do when the patient does repetitive activities mentioned above?	

18.2 BHEVIOURAL SYMPTOMS/ CHANGES

Nighttime behaviours		Does the patient awaken you during the night, rise too early in the morning, or take excessive naps during the day? Does the patient wander during night time or early morning										
Yes	No	Severity:	1	2	3	Distress:	0	1	2	3	4	5
Appetite and eating		Has the patient lost or gained weight, or had a change in the food he or she likes? Is the patient able to eat the same food as before, does the patient eat enough? Any changes in frequency of taking food or quantity of food										
Yes	No	Severity:	1	2	3	Distress:	0	1	2	3	4	5
Incontinence / Lost control over Bowels		Does patient urinate and faces anywhere and anytime of the day? Does the patient understands about his/ her urge but not able to locate toilet?										
Yes	No	Severity:	1	2	3	Distress:	0	1	2	3	4	5
Wandering		Is the patient able to find the way back home if gone out? Is the patient able to find way back to his/her room in the house? Any incidence										
Yes	No	Severity:	1	2	3	Distress:	0	1	2	3	4	5
Communication		Is the patient able to understand what is said to him/her and respond sensibly? Repeat things over and over again? Able to ask for food or water? Able to say about going to toilet? Remain quiet most of the time? Able to take part in family conversations meaningfully? *										
Yes	No	Severity:	1	2	3	Distress:	0	1	2	3	4	5

Managing Bheviaoural Symptoms	**Description**
a) What precautions you take to stop the patient from wandering and get up at night?	
b) How do you understand that patient had enough food? (e.g changes in food serving pattern, preparation)	
c) How do you make the patient understand what you want to tell or inform him/her? What do you do when the patient repeat things over and over again or keep talking all the time or does not speak at all?	
d) How do you realize that patient wants to eat or go to toilet or wants something	

18.3 PSYCHOLOGICAL SYMPTOMS/ CHANGES

Agitation or aggression		Is the patient stubborn and resistive to help from others? Does patient resist/hits/agitated when others help to dress/undress and bathe him/her?										
Yes	No	Severity:	1	2	3	Distress:	0	1	2	3	4	5
Depression		Does the patient act as if he or she is sad or in low spirits? Does he or she cry? Does the patient have episodes of crying endlessly; do not talk at all for days together?										

Yes	No	Severity:	1	2	3	Distress:	0	1	2	3	4	5
Disinhibition		Does the patient seem to act impulsively? For example, does the patient talk to strangers as if he or she knows them, or does the patient say things that may hurt people's feelings? Does the patient start complaining about / blames you or family members in front of others?										
Yes	No	Severity:	1	2	3	Distress:	0	1	2	3	4	5
Disorientation/ Confusion		Does the patient get confused about place, day, date, year and time (day and night)? Is the patient able to recognize familiar people, e.g. family relatives, neighbors, you & friends? Does the patient seem lost in a world of his/her own? Does the patient try to get up and dressed out of context(woolens in summer, party wear)										
Yes	No	Severity:	1	2	3	Distress:	0	1	2	3	4	5

Managing Psychological Symptoms	**Description**
a) How do you manage when the patient shows aggression / agitation during situations mentioned above.	
b) How do you help patient talk or participate in the family discussion meaningfully?	
c) What do you do when the patient accuses /abuses you in front of others or to others	
d) How do you help patient understand about day and night? How do you help patient recognize familiar people and yourself?	

18.4 PHYSICAL PAIN & SAFETY ISSUES

Mobility		Problems in standing/walking/using stair case, lift and crossing the road										
Yes	No	Severity:	1	2	3	Distress:	0	1	2	3	4	5
Take care of self hygiene		Difficulty brushing/washing/bathing/dressing, undressing										
Yes	No	Severity:	1	2	3	Distress:	0	1	2	3	4	5
Eating habits		Feeding self properly, swallowing food										
Yes	No	Severity:	1	2	3	Distress:	0	1	2	3	4	5
Confined to bed		completely immobile and needs lifting, suffers with bed sores or any other pain										
Yes	No	Severity:	1	2	3	Distress:	0	1	2	3	4	5

Managing Physical pain & Safety issues	**Description**
a) What precautions you take to avoid patient from falling and getting hurt? (any sp. Structural arrangements)	
b) How do you feed, bath and dress the patient?	
c) How do you ensure the safety of the patient while doing the above activities mentioned in point (b)	
d) How do you shift the patient from the bed	

19. How does the above mentioned behavior and related effects impact (affect) you?

____
____
____

20. Is there any other problem you experience?

____
____
____

21. Do you consult doctor on regular basis? If yes which of the following.
(1) Family Physician (2) Neuro physician (3) Psychiatrist (4) Homeopath (5) Ayurved (6) religious/spiritual place (7) other _________

22. Does the patient have to undergo medical test or treatment on regular basis? Specify.

____
____
____

24. Following are the possible stress areas which a dementia caregiver may undergo? Please read carefully and answer whatever is applicable to you.

No	**Stress Giving Area**	**Yes/No**
1	Social – absurd behavior in front of others	
2	Personal- relationships are affected negatively, Not able to take care of children/spouse/other relatives	
3	Financial – Not able to meet the expense, mortgage	
4	Professional - Job Role stress, Not able to handle both at work and home	
5	Physical - Time Management, fatigue	
6	Emotional – Not able to meet demands of others	

24. Keeping in mind the domains in the above question which of the following management strategies do you use, and briefly describe how effective they are?

No	Domains	Strategies	1=Always 2= Sometimes 3= Never
1	Social:	Send the patient to other siblings /relatives place for some time	
		Try to meet /discuss problems with relatives of similar patient	
		Avoid going to weddings, parties, inviting friends	
2	Physical:	Employ paid nursing maid for 24 hours	
		Employ part time help in meal preparation, house maintenance etc	
3	Personal / Emotional:	Practice yoga, meditation, any other spiritual activity or alternate healing	
		Resort to other branches of medicines –unani, homeopathy, ayurvedic	
		Listen to music, gardening, reading (hobbies)	
4	Professional:	Take holidays, break from care giving	
		Take up part time job/financial activities	
		Take help from doctors (counseling, advise etc)	

25. Have you dropped any of the following activities due to care giving? Do you resent it?

		YES	NO
1	Visit to long distance relatives		
2	Entertainment – Watching TV, Movies, Taking Holidays		
3	Attending marriages , Birthday parties etc		
4	Outing with Children		
5	Family celebrations of festivals, anniversary etc		
6	Society functions – Dinners, lunches, get-together etc		

IV) OVERALL HEALTH AND WELL BEING OF THE FAMILY CAREGIVER

26. Following are the domains of overall health –Personal, Social, Physical and Psychological. Please indicate your degree of agreement with each statement by circling a number according to this scale: Disagree =1, Neutral = 2 Agree = 3

	Personal	**Disagree**	**Neutral**	**Agree**
1	Your health has suffered because of the care you must give.	1	2	3
2	You have lost control of your life since having to give care.	1	2	3
3	Because of time spent giving care, you don't have enough time for yourself.	1	2	3
4	It's hard to plan things ahead when the patient's needs are so unpredictable.	1	2	3
5	Your loved one other than the patient asks for more help than is necessary.	1	2	3
6	Care giving has interfered with your use of space in your home.	1	2	3
7	Care giving has brought you more close to the patient.	1	2	3
8	Care giving is a financial strain			
	Social			
9	You feel isolated and alone as the result of giving care.	1	2	3
10	Your social life has suffered because you are care giving.	1	2	3
11	You feel uncomfortable having friends over because of him/her.	1	2	3
12	A strong reason for taking care of him/her is to be true to family traditions.	1	2	3
13	Giving care is a way for you to live up to religious and/or moral principles.	1	2	3
14	A strong reason for care giving is to provide a good role-model for your children.	1	2	3
15	You think of the help you give as an opportunity to repay him/her.	1	2	3
	Physical			
16	You feel you will be unable to give care much longer.	1	2	3
17	You are very tired due to physical strain as a result of giving care.(lifting patient in or out of chair)	1	2	3
18	Your sleep is disturbed as the patient is in and out of bed or wanders around at night	1	2	3

19	Care giving is inconvenient as helping takes so much time	1	2	3
	Emotional /Psychological			
20	You feel nervous or depressed when giving care.	1	2	3
21	You feel trapped when giving care.	1	2	3
22	You feel resentful of other relatives who could help, but do not.	1	2	3
23	You wish you could just leave care giving to someone else.	1	2	3
24	Patients behavior is upsets you because of trouble in remembering things; or because patient accuses people of taking things	1	2	3
25	You worry about the patient and have concerns about how you will manage (overwhelmed)	1	2	3
26	Do you feel there is no solution to your problems?	1	2	3
27	Your family stability has been disrupted by the patients illness (frequent quarrels, arguments, breakups)	1	2	3
28	You feel often frustrated that the improvement is slow or no improvement at all or deterioration in patients condition.	1	2	3
29	You have started to feel lonely and isolated since patient's illness.	1	2	3
30	You really enjoy being the patient.	1	2	3
31	The patient shows real appreciation of what you do for him/her.	1	2	3
32	The patient's pleasure over little things gives you happiness.	1	2	3
33	It makes you happy to know that the family is caring for him/her.	1	2	3
34	You take care of the patient because you are willing to not because it is part of your duty	1	2	3
35	The patient affects your relationship with other family members negatively or this situation has brought you closer to someone else?	1	2	3

V) SUPPORT NETWORK / INFORMAL SUPPORT

27. Are you the only one responsible to take care of patient?

☐ No ☐ Yes

28. If No, who else from the following helps you on regular basis? Briefly explain the kind of help they provide.

Sr. No		Yes/No
1	Family members(other than spouse)	
2	Spouse	
3	Neighbors	
4	Relatives	
5	Family friends	
6	Paid nursing attendant	
7	Religious organization	
8	Charitable organization	

29. What kind of support is provided / you get?

Sr. No	Direct Help	Yes/No
1	Giving bath to the patient	
2	Maintain personal hygiene (cleaning if patients soils, comb hair, wear clothes, nails trim, brush shaving etc)	
3	Administration of medicine	
4	Patients mobility/transfers	
5	Patient entertainment- taking for a stroll, operating TV, Music, talking etc	
	In Direct Help	
6	Meals preparation	
7	Taking kids to school (if applicable)	
8	Taking care for few hours or for a day or two enabling to attend social functions	
9	Keeping clothes, vessels, dusting and routine arrangements in the house.	
10	Help in shopping	
11	Buying routine commodities groceries, vegetables, milk etc	
12	Other work related to banks, paying of bills, etc	

30. Is there anyone who has stopped giving help / support? If yes, Who?
1) Family members 2) Relatives 3) Friends 4) Other

31. Which of the following is/are the reasons for discontinued help / support?

Sr. No	**Reasons to discontinue**	**Yes/ No**
1	Cannot see patients condition	
2	Patient unmanageable	
3	Too much of incontinence (faces, urination)	
4	Wrong /inappropriate behavior on the part of patient (blame for stealing, sexual advances, hitting etc)	
5	Fear of getting the disease	
6	Transfer of work place (in case of paid nursing attendant)	
7	Other priorities (specify)	

32. What difference you perceive in Informal (family members) and formal (paid nurse /hospitals) support? / Are there conflicting views on care giving with other caregivers? Does this affect the patient? How?

Sr. No		**Yes/ No**
1	Accepting the patient – showing warmth	
2	Emotional support	
3	Physical support	
4	Handling of patient carefully	
5	Accepting wrong behavior	
6	Communicating appropriately with patient(slowly, in lower voice etc)	
7	Accepting to clean if patient soils	

33. From the following whom do you visit /take resort to? (There can be one than more answer)

Sr. No	**Source**	**Yes/ No**
1	Family Physician	
2	Learned Neighbor	
3	Witch craft activities (bhuva), ceremonies suggested by astrologer	
4	Psychologist / professional counselors/ Physiotherapist, occupational therapist	
5	Community priests (family guru)	
6	Visits to family deity , religious ceremonies etc	

34. Describe what kind of services or support is needed/ desired by you?

____

VI) REWARDS/ ENJOYABLE ASPECTS OF CAREGIVING

35. What are the enjoyable aspects of care giving, select from the following?

Sr. No	Enjoyable aspects	Yes/ No
1	Being with the patient	
2	Relaxes you of your stress	
3	Sense of accomplishment	
4	Care giving is a function of moral obligation	

VII). CARE GIVER PERCEPTION ABILITIES, AWARENESS AND KNOWLEDGE

36. Please indicate your degree of agreement with each statement by circling a number according to this scale: Disagree =1, Neutral = 2 Agree = 3

Sr No	CAREGIVING PERCEPTION	Disagree	Neutral	Agree
1.	You fit in most things you need to do in spite of the time taken by giving care.	1	2	3
2.	You feel certain about what to do with your loved one, the patient.	1	2	3
3.	You feel reassured knowing that as long as you are giving care, your loved one is getting proper care.	1	2	3
4.	You feel you are doing more for him/her now.	1	2	3
5.	You feel you are doing a better job caring for him/her now.	1	2	3
6.	You feel able to handle most caregiving problems that arise.	1	2	3
7.	You feel pretty good about figuring out what he/she needs.	1	2	3
8.	Most things you do for him/her seem to please your loved one.	1	2	3
9.	Taking responsibility for him/her gives your self-esteem a boost.	1	2	3
10.	He/she is still being helped by most of the things you do for him/her.	1	2	3
11.	The things you do keep him/her from getting worse.	1	2	3
12.	You can give care with no help, or could if need be.	1	2	3

37. Did you make efforts to know more about Dementia?

1. Yes__________ 2. No___________

38. If yes, which of the following were the sources of gaining knowledge?

Sr. No	**Source of information / gaining knowledge**	**Yes/ No**
1	Browsing Internet	
2	Social Networking sites	
3	Books on care giving, dementia	
4	Through Media – Advertisements, posters, public interest advertisement, TV, special clippings, newspaper etc.	
5.	Doctors , Psychiatrist	
6.	Professional social worker	
7.	Counselors	
8.	Other caregivers experience	
9.	Non-government organizations, service providers	
10.	Government hospitals, PHCs etc.	

39. How will you educate other caregivers of patient with similar condition on dementia?

____

____

40. What skills from the following list are consciously used by you while providing care to the patient? Assign Rank from 1 to 7 (1= Most Important, 7= Least Important)

Sr. No	**Skills required**	**Yes/ No**
1	Cooking special food and feeding	
2	Handling embarrassing situation	
3	Overall handling of the patient(ADL, mobility, sickness, administering medicine, changing of nappies)	
4	Communication & understanding through observation	
5.	Encouraging socialization	
6.	Understanding of / dealing with hostile behavior	
7.	Tolerance, patience	

41. Do you feel the need for taking training for above mentioned skills and increase knowledge?

1._________yes 2. _________No

42. Are you aware of services available for dementia in your city?

1. __________yes 2. ____________No

43. Are you aware of any legal provisions by the government for such conditions?

1. __________yes 2. ____________No

44. If yes mention those you know. (for Q 43,44)

____

45. In light of your current experience of care giving, Please give you views regarding the services for betterment of the dementia patient. Please indicate your degree of agreement with <u>each</u> statement by <u>circling a number</u> according to this scale: Disagree =1, Neutral = 2 Agree = 3

Sr No	**SERVICES**	**Disagree**	**Neutral**	**Agree**
1.	I would rather ask my family or friends for help than use Government /Hospital /Institutional services	1	2	3
2.	I believe the government should support to help care for people of dementia at home	1	2	3
3.	I believe that disability arising due to dementia should be made part of disability Act	1	2	3
4	I believe that insurance companies should cover dementia in the policies	1	2	3
5	I believe in the idea that families should give care for their own and not ask for outside help	1	2	3
6	I am not aware of what services are available for the patient	1	2	3
7	There is need for the Government and NGOs to create awareness regarding dementia	1	2	3
8.	Dementia services like respite care, day care homes, medicines at subsidized rates should be provided by the government	1	2	3
9	I wish there were someone who could tell me more about services for the patient	1	2	3
10.	I believe Specialized services like separate Geriatric wards at government hospitals, ID cards for patients, Help lines, 24 hrs. medical shop should be available for dementia patient	1	2	3

CONCLUDE: This is the end of the interview. Thank you very much for your help and your patience. This completes your participation in the Study of Management Dementia Patients. We are very grateful for your assistance.

INTERVIEW GUIDE

Sir/ Madam,

I am a PhD student from the faculty of Social Work The M S University of Baroda and my research topic is ***"Management of Dementia Patient by Family Caregivers – A Social Work Perspective".***

In order to complete my study, I need to include some information from health professionals working in this field. I would be very obliged to receive your valuable response.

Name: ____

Contact Details: ____

Following questions were developed for guiding the interview with health care professionals

- When / how early do the patients of dementia come to you? What stage of Dementia the patient is generally at when comes at clinic?
- What do relatives describe in the terms of complaints?
- How do you assess the patient with Dementia? What are the indicators?
- What line of treatment you suggest /give?
- What advise you give to family members as caregivers?
- What are the expectations / hopes /clarification family members seek?
- What type of specific training is required for handling dementia patients by family as well as professional caregivers?
- How shall dementia and related issues be dealt with at Family, Community and Hospital/ Clinic Level? *(Geriatric wards, In case of emergency where should be patient taken)*

***********THANK YOU FOR YOUR VALUABLE RESPONSE************