Chapter V

Discussion
DISCUSSION

There is ample evidence that taking care of dependent elderly people comes at a very high cost to caregivers’ health; more specifically, caregiving affects their physical and psychological health both directly and indirectly. Caring for an elderly person with dementia is a major life challenge and it entails emotional, physical, social and financial burden. It also has been described as one of the most difficult situations encountered by caregivers.

Caregivers of dementia patients can experience various emotional problems during the course of the illness. One such disorder, that is frequently overlooked and not treated, is carers’ depression. It is well documented that family caregivers of persons with dementia have significantly more depressive symptoms than age and gender-matched non caregivers. According to one of the studies conducted by Schulz et al, (1995) caregivers of persons with dementia report more emotional strain and depressive symptoms than caregivers of persons who are not demented. Prevalence rates for depressive symptoms among caregivers of persons with dementia are reported to range from 28% to 55%.

Zarit and colleagues were among the first researchers who highlighted the burden of providing care to a relative with dementia. Following this study, there has been an explosive growth of care-giving research, focusing on the negative effects of providing care on carers and on interventions to reduce or prevent these effects. The stress of carers is an important issue for public health care, because of their central role in the care of persons with dementia and the negative health consequences they may experience. Its importance gains prominence, due to the expected increase in numbers of elderly persons with dementia and their family carers.

High levels of depression are found in individuals providing care to persons with dementia or Alzheimer's disease. Caring for an individual with Alzheimer's disease or a related dementia can be challenging and, at times, overwhelming. Such
stress and frustration with its impact on carers’ physical and mental health can set a scene for potential abuse.

This chapter presents discussion on this mental health issue, mainly focusing on the factors responsible for caregiver's burden, strain, burnout, depression, cultural and gender differences, enhancing caregiver health strategies used for coping and their social network.

The living arrangements for the aged persons are often considered as the basic indicator of the care and support provided by the family. However, it must be noted that this practice is more culturally based rather than development dependent. For example, in USA only about 15% of the aged persons lived with their children, whereas in India about 75% lived with their children (Martin 1989; Bose, 1982). In Singapore a survey conducted in 1982 found that 80% of the aged persons (defined as 60 years and over) were living with their children, while in Korea and in Jilin Province of China this percentage was found to be 79%. Similarly, the WHO surveys have indicated that among the aged persons, 72% in Malaysia and 79% in the Philippines were living with their children. In the study villages, 80% of the aged persons were living with their children.

The number of people with Alzheimer's disease (AD) and therefore, of their family caregivers is increasing worldwide. While caregiving is often rewarding, caring for someone with dementia can be stressful, and caregivers experience high levels of psychological morbidity. Several risk factors for carers developing psychological distress and morbidity have been reported. These relate to the caregiver's demographic profile, additional pressures in their lives or the care-recipient's (CR) symptoms. Commonly identified carer risk factors are: being a female carer, being a spouse of the CR, living with the CR, looking after a CR who lives in the community, having a poor relationship with the CR, having dependent children, having a job and having physical health problems. While being a spouse has been commonly found to be a risk factor for caregivers’ mental health, it has been speculated that it is not the relationship itself which increases vulnerability, but the fact that spouse caregivers
are likely to be older and in less good physical health. Factors in the CR include having neuropsychiatric symptoms, especially depression. Several studies have examined the effect of dependency in the CR and although the results have been equivocal, generally, no direct relationship has been found. The results from the statistical analysis of the data using different statistical methods clearly demonstrate the association of demographic and psychosocial variables.

In this discussion efforts are made to substantiate the discussion by comparing and contrasting with the findings of earlier studies and observations made.

The present chapter is logical step of continuing from the previous chapters on the results. The discussion is designed along with the direction of the aim and objectives of the present study. However, it is also found necessary to discuss the socio demographic variables, family related variables etc., as a prelude to the discussion of the data in line with the aim and objective of the study, so as to facilitate a clear understanding of the profiles and various issues and factors in the study.

Therefore to elucidate the results of the present study for the convenience, it is discussed in 2 sections: Section 1 and Section 2

**Section 1**

1. Discussion on the findings of the socio demographic profile of persons with dementia and their informal care givers
2. Discussion on the health condition of care givers and their perception on care giving
3. Discussion on commonly seen distressing/disturbing behaviors and distress experienced by the care givers
4. Discussion about coping strategies adapted by the care givers and its correlation with stress, burden, burnout and depression
5. Discussion on Social network & social support
Section 2
1. Discussion on designing and developing of an accurate and sustainable “Decision Support System for the informal care givers of persons with dementia” that will comprehend the health care professionals, researchers and community workers in taking decisions, prediction and interventional research.

Section 1
Discussion on the findings of the socio demographic profile of persons with dementia and their informal care givers

The 10/66 Dementia Research Group, 2000, Studies indicate the strength of cultural traditions over other factors in providing care and support to the aged by the families. It also cautions against concluding that the residential models adopted in many developed countries could be used in the developing countries in tackling this problem in the future. Indian culture emphasizes the reverential treatment of the aged persons. The social system puts pressure on the children, especially the male children to take care of the aged parents, apart from the legal requirements. The cultural practices also assign certain duties for the aged in the household chores. Taking care of the young children, looking after the societal responsibilities, settling inter-personal or inter-household or even inter-group conflicts, helping in the matrimonial match-making, are among the duties that the society expects the aged persons to take interest in and attend to. Thus, the aged are made to play useful roles in the household and in the society so as to make them feel reassured that they are an important part of the society. They also become the essential media for the transmission of the cultural values from generation to generation through the process of storytelling for entertaining the children.

To rule out the bias in determining the persons with dementia, diagnosed cases of dementia by a psychiatrist in the selected centers were considered for this study. There were no formal interviews with the persons with dementia. As investigators study of interest was the behaviors of the informal care givers, face-to-face interview was conducted with the care givers most of which was done in their home environments.
Previous studies have underlined that some characteristics of both patients affected by Alzheimer’s disease (AD) or other forms of dementia and of their caregivers; the most distinctive features are:

**Gender of the patient**

It has been highlighted in the global burden of disease by Colin Mathers & Matilde Leonardi (2002), that women have high incidence, prevalence and mortality rate of dementia. Two of the studies conducted by Chandra V (1994) and Ganguli M (1995) indicated that, in developing countries, low levels of education, literacy, and numeracy can result in cognitively unimpaired people screening positive for dementia.

The current study shows that 68 of the persons with dementia were males and 57 were females. This can be due to different reasons: Firstly, familism may be one of the strong reasons in Indian society. Familism is a cultural value that refers to strong identification and solidarity of individuals with their family as well as strong normative feelings of allegiance, dedication, reciprocity, and attachment to their family members, both nuclear and extended. In the Indian household, lines of hierarchy and authority are clearly drawn, shaping structurally and psychologically complex family relationships. Secondly, most of the family if father, who is head of the family shows any symptoms of aggression and memory loss the dependent family is likely to panic and they go for immediate access to health care. In the current study it clearly shows, in most of the families, male patient himself is reported (92.6%) as head of the family and correlation test show high signification association with the gender. The distressing symptoms and change of behaviors as its frequency is seen more in males make them seek the health care services.
Education

Ballard et al have demonstrated that a higher level of carer education regarding dementia increase carer's feelings of competency. This was more likely to have reduced their expectations of their dependents abilities. Previous studies which have looked at these coping strategies and feeling of competence have shown that unrealistic expectations of a dependant with dementia increase a carer's risk of depression, and conversely a reduction of carer's expectations is associated with lower rates of depression. Caregivers who maintain positive feelings towards their relative have a greater level of commitment to caring and a lower level of perceived strain; furthermore carers who experience feelings of powerlessness, lack of control and unpreparedness have higher levels of depression. The most effective treatments in depression of carers appear to be a combination of education and emotional support.

According to one of the cross cultural validation study conducted by 10/66 Dementia Research Group, despite the lack of fixed criteria, the distribution of education in low and high education groups was similar across regions. Thus, in low education groups, the proportions receiving no, or minimal education were 91% in India, 89% for China and Southeast Asia, and 80% for Latin America and the Caribbean. In the high education groups, the proportions completing secondary education were 81%, 99%, and 80% respectively. As per the current study, 21.6% of the patients had low or no education, and others were literates. This is in contrast to the previous studies, as most of the people in the current study catchment area were aware of the importance of education, which is indicated in the Udupi District Human Development Report of 2008, which states that in case of education, the annual growth achieved since 2001 was found to be 0.09 percent as against the average growth 0.15 percent during the last decade. The figures show almost equal distribution of sample in each group. Caregivers with no formal education and low income group reported of fewer burdens than caregivers belonging to other educational levels.
Caregivers relationship

Living with the patient is highlighted by most studies as a risk factor for caregiver suffering (Zanetti O, Frisoni GB, Bianchetti A et al (1998), though not all reach the same conclusion (Dura et al 1991; Russo J, Vitaliano PP 1995).

The Indian joint family structure is an ancient phenomenon, but has undergone some change in the late 20th century. Living arrangements vary widely depending on region, social status and economic circumstances. With the passing time, nuclear families have evolved that is a couple living with their unmarried children. There are often strong networks of kinship ties through which economic assistance and other benefits are obtained. Often clusters of relative live near each other, who are easily available and respond to the give and take of kinship obligations. Even when relatives cannot actually live in close proximity, they typically maintain other economic help, emotional support and other required benefits.

Several studies suggest that spouses and sons/daughters are more likely to undertake the role of caregivers and that this inevitably leads to a higher risk for stress. Rinaldi et al. (2005) showed that female spouses complain more about their role as caregivers and, together with sons/daughters, are most exposed to distress and suffering. Sons and daughters, because of their young age, are likely to be involved in their own social and working activities and can consequently rely on wider social networks; on the contrary, spouses, especially if elderly, have less recreational activities and are consequently almost completely devoted to caregiving. Other studies support these results (Collins C, Jones R (1997), suggesting that “wife” caregivers experience more strain than “husbands”. “Wife” caregivers seem to be pushed by a stronger sense of duty and are inclined to care more conscientiously for their husband, but at the same time, they would like to desert this role; all this contributes to a growing sense of guilt and uneasiness. González-Salvador et al. (1999) and Waite et al. (2004) found no impact whatsoever of familial relationship on caregivers’ stress levels.
Filial responsibility encompasses attitudes that endorse certain responsibilities or obligations that adult children should assume in addressing their parents’ needs and in maintaining their well-being. Researchers examining filial responsibility attitudes have employed a variety of different measures with varying sample populations (e.g., grandchildren, college students, elder parents, multigenerational families). Most have also measured filial responsibility expectations in a universal way ("What should children do for parents?"), rather than asking individuals what they expect from themselves or from their own children ("What should my children do for me?") Some inquire about a few select areas (e.g., shared living arrangements, financial assistance) of filial responsibility, whereas others are more comprehensive in their coverage, including items on instrumental, emotional, and contact norms.

Some cultural differences in expectations emerge. Expectations of shared living arrangements may be greater in Indian culture,

Current findings consistently reveal strong and persistent endorsement of filial norms by both adult sons and daughters as 54.4% of the caregivers are children. Greatest support is given to the notion that children should offer emotional support to their parents, with much emphasis placed upon physical assistance and financial support.

Although parents want to maintain their independence and typically do not expect as much from their adult children as children expect from themselves, parents also hope that children will be there for them when called upon to do so. Most of the children were of the opinion that the ways in which adult children express filial responsibility for parents includes maintaining personal contact, providing affection and emotional support, sharing living arrangements, and helping their parents meet daily needs. In addition, parents may alter their expectations of their children depending upon the characteristics of their children rather than on their own personal circumstances. For instance, in India, parents place greatest expectations on eldest sons rather than daughters or daughters-in-law as it was evident from the current study. Test for significance shows the significant association of caregiver's
relationship with the severity of depression experienced by them. In 68 children who take care of their parents, 30.9% of them reported severe depression.

**Household size**

Distribution of household sizes for people with dementia in developing countries was reported as household size of three family members as the highest followed by four members in a family. This study was done by 10/66 dementia research group (1991) under Alzheimer’s and related disorders society of India. In contrast to these studies, higher frequencies of the disease belonged to the family sizes of four to seven. Highest number of 28 households was with the household size of five was reported, followed by household size of six members (24 families), and 20 families with four members family and 12 families with household size of seven were reported. Overall 106 households were from nuclear family and 19 from extended family type. Largest household size was reported as 25 members in a family and two families with 22 family members.

In the Indian household, lines of hierarchy and authority are clearly drawn, shaping structurally and psychologically complex family relationships. All family members are socialized to accept the authority of those ranked above them in the hierarchy. In general, elders rank above juniors, and among people of similar age, males outrank females. Daughters of a family command the formal respect of their brothers' wives, and the mother of a household is in charge of her daughters-in-law. Among adults in a joint family, a newly arrived daughter-in-law has the least authority. Males learn to command others within the household but expect to accept the direction of senior males. Ideally, even a mature adult man living in his father's household acknowledges his father's authority on both minor and major matters. Women are especially strongly socialized to accept a position subservient to males, and to subordinate their personal preferences to the needs of the family and kin group. Reciprocally, those in authority accept responsibility for meeting the needs of others in the family group.
There are sizable studies in social and health sciences exploring the intricacies of informal care. Research has examined the perspectives of ‘carers’ as well as of those who are ‘cared for’. It has been shown that carers experience disruption when they adopt the role of carer, but this takes place alongside a sense that caring for a family member during an episode of ill health is a ‘normal’ state of affairs (Adamson J, 2004 & Pound P 1998). Women are more likely to be carers than men, and formal care services model themselves on traditional female domestic roles within the home (Twigg J 1992). The emphasis on caregiving as a female pursuit has provoked exploration of men’s roles as caregivers. It has been suggested that men caring for their wives adjusted to their new roles by orientating themselves according to one of four types: ‘worker’; ‘labour of love’; ‘sense of duty’ or ‘at the crossroads’ (Harris P 1993). In the context of palliative care, older people prefer to receive care from family members rather than from outsiders.

Out of 125 care givers 106 care givers are from nuclear family and 18 from extended family type. In this 18 of the care givers of extended family stay with their wards and one of the daughters who has moved out of extended family visit on daily basis for taking care of her father. The size of the family was correlated with the burden and caregivers depression but did not result in any significant association. Two of the caregivers from the extended families reported of lesser burden and distress as the work load of caregiving is distributed among other family members.

**Age of the caregivers**

In the UK, the greater part of caring responsibilities falls upon people in the 45–64 age groups, with 24% of people reporting that they are carers. The proportion of people aged 65 and over who are carers is also high at 16%. The heaviest load of informal caring responsibilities falls on partners or children (Maher & Green 2000).

The current study shows that the proportion of people aged between 36 to 50 years is high. And 20.8% of the care giver falls into the age group of 20 to 35 years and less care givers fall into the age group of 71 to 80 years as in some cases children or other family members play the role of primary care giver. The current
study shows that the age of the caregivers is significantly associated with the depression, burden and burnout experienced by them. Profiles of caregivers have been relatively consistent in the literature. One family member typically serves as the “primary caregiver,” and others serve as “secondary caregivers”. Spouses are most likely to be primary caregivers (29.6 %) and the majority is women. Spousal caregivers also provide the most extensive and comprehensive care. As per the load of care giving is concerned the study agrees with Maher J (2002), that the heaviest load of informal care giving responsibility falls on children and the partners. The study shows 33 (26.4%) daughters, 35 (28%) sons and 37 (29.6%) spouses are loaded with the responsibility of care giving in which severe depression is reported more by children.

Mean age of the patients is found to be 69.87 (SD 10.278) and Mean age of the care givers was found to be 48.90 (SD13.787). Minimum age of the patient is 24 years as it was a case of dementia due to trauma and brain damage. In most of the cases patients were the earning member of the family. It was found out that 59 (47.2%) patients themselves were the bread winner of the family. This has led to sudden change in the home environment as reported by the caregivers. Most of the care givers especially children reported that they were not prepared for their role as care givers or as primary source of support for the family.

2. Discussion on the health condition of care givers and their perception on care giving

Result showed that most caregivers are ill-prepared for their role and provide care with little or no support, yet more than one-third of caregivers continue to provide intense care to others while suffering from poor health themselves. Studies have shown that an influential factor in a caregiver’s decision to place an impaired relative in a long-term care facility is the family caregiver’s own physical health.

A substantial body of research shows that family members who provide care to individuals with chronic or disabling conditions are themselves at risk. Emotional,
mental, and physical health problems arise from complex caregiving situations and the strains of caring for frail or disabled relatives.

Risks for carer depression are related to gender, age, health status, ethnic and cultural affiliation, lack of social support, as well as certain other characteristics related to the caregiver.

**Gender of the caregiver**

It has been highlighted that women who take care of demented patients are at higher risk for stress than men carrying out the same assistance role.

Women have higher rates of depression than men in the care giving role (McGrath et al., 1992). These gender differences in levels of depressive symptoms and depression may be due to variations in stress exposure, coping responses used, the role of social support and biological factors. The literature on gender differences in the psychological well being of caregivers points to the increased risk for females in terms of depressive symptomatology.

Schulz and Williamson (1991) found that 39% of female caregivers, compared to 16% of male caregivers, qualified as being at risk for clinical depression on The Center for Epidemiologic Studies-Depression Scale (CES-D). AD caregivers reporting symptoms of depression have ranged from 28% to 55% and female caregivers were more likely to experience depressive symptoms than male caregivers.

In this systematic review of gender differences and caregiving, showed that women caregivers reported more psychiatric symptoms than men caregivers, including greater depression burden and strain. However, few studies have examined the relationship between gender and intervention effects. In a randomized controlled trial by Gitlin et al., (1999) found that women were more likely than men to comply with a home environmental modification intervention, implement recommended strategies, and derive greater benefits.
Thus, in general, female carers seem to suffer higher levels of distress than male carers. Certainly, women in societies are more likely to be thrust into the caregiving role than men. Female carers are also more likely to be ‘hands-on’, that is, they tend to do everything themselves rather than delegate to others. Male carers tend to have more of a ‘managerial’ style that allows them to distance themselves from the stressful situation to some degree by delegating tasks.

In the current study, most of the caregivers were females. This can be due to different reasons: social and gender issues make them more likely to assume a fuller role as a caregiver; moreover, women tend to spend more time with the patient, which leads them to feel more burdened. The gravity of distress experienced by the female carers is reported more than their male counterparts. Most of the spouses reported of being abused physically and orally by their husbands. Higher levels of strain is also reported more by the female carers.

Donaldson et al (1998) found that non-cognitive features of AD, such as psychotic symptoms, depressive features and behavioural disturbances were the most stressful manifestations for carers, resulting in feeling of burden. Yet Zarit et al. (1980) reported that the severity of behavioural problems was not associated with high levels of burden.

Interestingly as the current study, both male and female caregivers reported of severe burden in equal numbers. This may be because of the years of caring which is positively associated with the burden. But in all the other categories of burden female carers reported more of burden than male carers. This may explained in relation to the condition of the patient. As cognitive function deteriorates, and behavioral problems increase, the extent of burden increases that cannot be handled by the female carers if their ward is male. As more of the carer role is shifted to the male members of the family, usually son. So it can be said that the burden experienced with reference to carer gender is directly proportional to the years of caregiving or progression of the disease.
As per the gender-wise distribution of depression is concerned the current study agrees with the previous study conducted by Beach, Schulz, Yee (2000) prevalence of depression is reported more in females than males.

**Caregiver’s physical and mental health status**

Caregiver health has also been identified as a significant predictor of caregiver depression (Lawton et al 1992). This association with depression suggests that caregivers with lower levels of physical health are more vulnerable to the psychological consequences of caregiving. Studies have reported poorer physical health among caregivers than age-matched peers, and such health problems are linked to an increased risk of depression.

In recent years, significant attention has been directed towards understanding the impact of caregiving on caregivers’ personal and social well-being, and their health. Specific factors that have been looked at include the physical and emotional health indicators associated with stress, which include depression, sick days and health care utilization. Although early studies focused on all caregivers, regardless of the disabilities of the patients they cared for, more recent studies have distinguished between the experiences of persons caring for elders with dementing illnesses and elders with other types of disability.

More female caregivers (69) reported of current illness than male caregivers (41). Most of them were spouses. Sleep distress apart from other symptoms is the common symptom experienced by most of the carers. Two of the female caregivers reported of previous mental disorder.

Reports of caregivers’ physical health show a wide range (Stone; Cafferata; Sangle 1987). Based on United States (US) national data, 44% of spouse caregivers above age 65 perceived their health as poor in contrast to 30% of same-aged peers in US population (Stone et al 1987). In several studies, caregivers attributed a decline in health to caregiving responsibilities. Black Asian caregivers and older women were more likely to report health problems as a result of caregiving than white caregivers.
and men (Silliman et al 1986; Young & Kahana 1989; Anderson et al 1995). The progression from depression to declining physical health was documented by Stone et al (1987). The researchers tested a causal structural model with 200 Alzheimer's disease spouse caregivers and found that for female spouse caregivers, baseline depression predicted physical health decline at 6 months follow-up, depression at 6 months predicted decreased physical health at 12 months, but no time was physical health a predictor of depression.

This study agrees with this argument, the result of the correlation tests show significant association of care giver relationship with the patient with the depression experienced by them and also with the gender of the carers. As previously discussed, females reported of experiencing more depression than males.

The study reveals that the care givers who had past illness, reported of experiencing more depression. Result shows that 69 (55.2%) of the caregivers are suffering from current illness and in this 66 (52.8%) have taken treatment but 21 (16.8%) reported that their condition worsened in spite of the treatment. The various illnesses reported by the caregivers (diabetes, hypertension, cardiac problems, asthma, arthritis and other major illness and symptoms). Mental illness was reported by three of the caregivers. When the outcome of the treatment taken was correlated with the depression experienced by them it showed significant association.

Common physical complaints reported by caregivers include lack of sleep and inadequate exercise and nutrition; back ache; constant head ache etc., these problems are attributed to patients’ disturbed sleep patterns, distressing symptoms or their need for constant supervision.

“I do not have time to take care of myself, my hand pains and children are bothered about the health of their mother and my health is of least importance to them” says a spouse carer who had a broken wrist in a road traffic accident few years back.
A major challenge for future health care is the care for dementia patients and their informal care givers. In usual care, the problems of caregivers often remain invisible until a crisis occurs. This inhibition is partly the result of informal caregivers paying scant attention to their own problems. Another reason is that other family members may not know how to support informal or understand the magnitude of stress and depression experienced by the care givers.

**Knowledge and awareness about the disease**

Care givers and their family members had a very good understanding of the illness and its causation. Eighty six i.e., 68.8% care givers were explained about the disease and its prognosis by the psychiatrist / psychiatric social worker. Most of them are familiar with the terms like dementia or Alzheimer Disease. Though most of the care givers perceived this as a disease some of them i.e., 35 (28%) of the care givers were unable to differentiate it from ageing. They knew little about its likely course and prognosis. There was a marked tendency for care givers attribute symptoms or dementia as deliberate misbehavior. As this was the perception of four (3.2%) of the care giver who thinks that it is deliberate behavior.

Though all of the people with dementia had received medical help, some of them were in regular continuing contact with health care facilities and others perceived this as neither feasible nor useful. Most of the care givers i.e., 100 (80%) had been given information or advice about good caring practices and 91 (72.8%) received advice regarding management of behavioral problems, which for many was the focus of their concerns. Thirty six (28.8%) expressed their wish to know more about the disease and its management that will help them in better management of disease.

The family constitutes the major caregiving response to the needs of the elderly who are no longer self-sufficient. These caregivers are often wives or daughters who have chosen to keep the patient at home with them. On an average, three-quarters of the caregiver’s day is devoted to the patient, a proportion that tends to increase linearly as the disease progresses. Caring for a person with disabilities
can be physically demanding, especially for older caregivers, who make up half of all caregivers. Caring for a person with dementia at home can be overwhelming. The caregiver must cope with declining abilities and difficult behaviors. Basic activities of daily living often become hard to manage for both the care receiver and the caregiver. As the disease worsens, the care receiver usually needs 24-hour care.

This study shows 48(38.4%) of the carers say that it is their responsibility to take care of their wards. Most of them were sons looking after their parents. Most of the daughters say that they do not have other options but were made to look after their parents or in-laws. In total 29 (23.2%) said that they did not have any other option. Seventeen (13.6%) of the caregivers perceived this as their fate in this most of them were spouses. Five of the care givers said it is miserable experience of which four cases are discussed in detail. This was again correlated with the depression experienced by the caregivers. The depression experienced by them is significantly associated with the attitude they are showing towards care giving. Some of the cases are discussed below:

**Case 1**

The caregiver, a 50-year-old daughter (Mrs. A), with financial constraints is made to look after her father aged 85 for the last 7 years. The caregiver complains of physical abuse by the patient like hitting on the head with whatever he lays his hands on whenever agitated. She also complains of his suspicious nature due to which indulges in verbal abuse (using obscene words) in front of other family members, which embarrassed her, her relatives and neighbors. For this, she would argue with other family members, which is very disturbing and finds herself emotionally upset. She also vent out of her financial problems as her husband works in a small hotel in Mumbai and has to look after 4 children, 2 daughters and 2 sons and that she cannot make both the ends meet.

She complains of being trapped by the family members who promised to support her and her family financially. She becomes touchy whenever spoken to and easily moved to tears and expressed helplessness.
Women in the lower economic class, homemakers faced a different problem of being victimized by other family member, who is financially sound. They are being burdened to look after the older people who are difficult to handle. In the current case, the daughter was summoned to look after her ill father and was manipulated into taking up the responsibility forever. Her old father who is a victim of dementia subjected her to verbal and physical abuse. Financial support, which they promised, was denied and ‘the maid –like’ attitude towards her disturbed her mind.

Woman in the present day Indian scenario has traditional role entrusted on her as a caregiver in a largely patriarchal society, with no financial independence and if she happens to be a financially unsound then the world may not be a very nice place to live.

**Case 2**

The 53-year-old wife (Mrs. B) is the informal caregiver of the patient. She narrates about how the patient is becoming a burden on the family members by his disturbing behaviors like getting up at night, wandering etc. She also tells about how their son can only control him by scolding and sometimes beating him. “He doesn’t listen to any one in the house and we females cannot control him and only my son can control him by scolding and sometimes he requires some hitting to put him to sleep”.

In this case, his well-educated son who is in medical profession abuses patient who is a victim of Alzheimer’s disease. Verbal and physical abuse has become a part of caregiving whenever patient shows non-cooperation.

**Case 3**

In this case, narrator is 34-year-old daughter- in-law (Mrs C) who is looking after her 80 years old mother-in-law. The caregiver says she is not much strained looking after her mother-in-law. The narrator showed her hostility towards other family members who did not share the responsibility of care giving. The patient is having four children, two sons and two daughters who at present are not staying with
their mother except the elder son - narrator’s husband. She expressed that. “*Her other children are enjoying life without any responsibility. I am trapped here in this house looking after her and cannot leave her and go anywhere. I am mentally tortured and I sometimes show my frustration towards the patient by abusing her verbally.*”

Here the caregiver looked very frustrated by the burden of caregiving. The attitude towards her mother-in-law is a result of such frustration. Here, patient, depending on her family for care, is emotionally abused and humiliated, but remains powerless to stop it, due to her dependent situation.

**Case 4**

Caregiver is patients youngest daughter (Miss D). She is unmarried and she lives with her mother taking care of her who is being exposed to high level of stress looking after her mother who is suffering from dementia since the last three years and who is exhibiting disturbing behaviors like wandering, depression and incontinence. The other family members after their marriage left her with their mother and living separately with their own families. She could not find any servants or social support as she is resided in a rural area. She looks after her mother without complaining as she thinks that it is her fate. She has a suicidal tendency as she says, “*I feel like ending my life sometimes. My mother doesn’t show any emotions and she is like a child herself. I live because of her and I am afraid what lies ahead for us*”. She does not want to disclose about any kind of abuse towards the patient during the interview.

Among caregivers of dementia, there is a gender-biased pattern of familial transmission of responsibility for care of relatives suffering from dementia and such responsibility becomes an important source of burden if the patient shows problematic behavior as is evidenced from this case vignette.

Informal supporters provide the majority of long-term care to chronically disabled elders. Care giving has been recognized as an activity with perceived benefits and burdens. Caregivers may be prone to depression, grief, fatigue and
changes in social relationships (Nelis et al, 2007). They may also experience physical health problems and fatigue.

The largest area of unidentified elder abuse and neglect is in the elderly population that remains in their own homes. Included in this area of abuse is also self-neglect (Tumosa, 1999). Unfortunately, signs that may be interpreted as abuse by a caregiver or family member may also be a sign of self-neglect by the elder. Failure for health care personnel to report suspected cases of elder abuse may cause loss of license and or fines (Marshall, et al, 2000).

In fact, there was a general uneasiness among the carers and a genuine attempt was made to evade the issue. On being forceful about the specific issues of physical abuse, verbal abuse and financial abuse, the carers agreed the existence of such happenings in the community, at least within their own.

Taking advantage of financial situation (case 1), family members are victimized by their own siblings or parents. This is a very uneasy situation for any outsider/researcher/social worker to intervene and come up with the solutions even though the ‘abused’ implied for some kind of support or relief. Financial abuse was linked with people of the low-income group especially women in the family who were dependent. Daughter was made to look after the sick father, who abused her both physically and verbally and her own close family relatives abused her.

One example at this point would be of Miss. D (case 4) who never disclosed about any kind of abuse towards her mother. The avoidance of the issue is very evident which also points to the fact that whatever exists she was not willing to discuss.

Even physical abuse was sighted in one of the cases (case 2). The symptoms such as restlessness, wandering and agitation exhibited by these patients led to verbal and the physical abuse by the caregiver which is an alarming trend of ignorance about the disease pattern which has to be taken up as a serious issue for discussion in all levels of the society.
Another major factor was the fact that the older parents themselves were unaware of the abuse, which they are facing and were inhibited, to discuss this matter with the investigators to justify “neglect” in the existing circumstances. Whatever be the cause, carers were sympathetic towards their parents. The reason could either be emotional bonding with the parents.

In case of Mrs. C, daughter-in-law, who was frustrated in the family situation did not mention about any evidence of abuse towards her mother-in-law other than verbal abuse, for which she was blaming other family members. This incident depicts the negative side of the Indian tradition where the daughters in laws are still the weaker part of the family.

Woman in the present day Indian scenario has traditional role entrusted on her as a caregiver in a largely patriarchal society, with no financial independence and if she happens to be a financially unsound (case 1 & 4) then the world may not be a very nice place to live.

There is substantial support for the idea that abuse is associated with personality problems of the caregiver, rather than characteristics of the elderly victim (Pillemer and Finkelhor 1989). The present study also indicated that females make up a greater proportion of caregivers than do adult males.

Informal supporters provide the majority of long-term care to chronically disabled elders. Care giving has been recognized as an activity with perceived benefits and burdens. Caregivers may be prone to depression, grief, fatigue and changes in social relationships (Nelis et al, 2007). They may also experience physical health problems and fatigue. Perceived caregiver burden has been associated with premature institutionalization and patient reports of unmet needs. Screening tools are useful to identify families who would benefit from a more comprehensive assessment of the care giving experience.
Mona Baumgarten et al (1994) in their study of health of family members caring for elderly persons with dementia, suggest that the economic impact of dementia is a particular issue for families living in developing countries and the combination of reduced family incomes and increased family expenditure on care is particularly stressful.

The reluctance to intervene in family affairs, difficulty in knowing how to cope with the problem when it is identified, and defining the problem are reasons given for why elder abuse has been ignored.

3. Discussion on commonly seen distressing/disturbing behaviors and distress experienced by the care givers

Behavioral and psychological symptoms of dementia were relatively common and poorly tolerated by the care givers. However, 101 (80.8%) of the care givers said that they had a good relationship with their ward in the past. More than 50% of the care givers agree that they get angry with their wards because of their distressing behaviors. Care givers also agree that their relationship in the past affect their attitude towards care, or the current relationship. Some of care givers are adamant that the relationship problems in the past did not affect their attitude towards care giving situations. Most of the care givers felt that their physical and psychological well-being was adversely affected by the stress and strain of caregiving. Their social life had suffered, as most of them were unable to go out, even to attend important functions like marriages. The correlation test shows a significant association of depression and the attitude of caregivers towards caregiving.

Severity of cognitive impairment

This issue remains controversial. While some studies report a positive correlation between the patient’s cognitive status and the caregiver’s burden of distress (Eagles et al 1987; Pearson et at 1988; O’Connor et al 1990; LoGiudice et al 1995) others did not find any association between the two variables (Burns & Rabins 2000; Rossi et al 2003; Zarit et at 1980; et at 1982; Farran et at 1993).
The physical and emotional health of the primary caregiver is critical to optimal care of the patient with Alzheimer’s disease. Caregivers suffer from increased rates of depression and physical illness and are prescribed medications at a higher rate than persons not required being in a care-giving role. (Schulz et al 1995), the investigator was guided by the Neuropsychiatric Inventory Questionnaire. This tool provides a reliable assessment of behaviors commonly observed in patients with dementia and caregivers distress for each distressing symptoms.

One of the studies was conducted by Robinson (2001). They measured the frequency of problem behavior and caregiver reaction using two separate measuring tools; The Revised Memory and Behaviour Problem Check list (Teri et al.1992) and the impact from the care giving was operationalized using the Cost of Care Index developed by Kosberg and Cairl (1986). The result of their study showed significant associations for 11 of the 20 subscales that measured the association between the frequency of problem behavior in the client and the impact from caregiving was even more significant in value with 15 subscales of 20 being significant. Female caregivers experienced greater reaction to disruptive and depressive behavior when compared with male caregivers even though both genders reported similar frequencies of problem behaviors. In regard to finding about impact from caregiving four of six indicators were higher for women than for men.

The Neuropsychiatric Inventory Questionnaire (NPI-Q) was used for current study. NPI-Q is a rapidly administered instrument that provides a reliable assessment of behaviors commonly observed in patients with dementia and distress experienced by the caregivers (Kaufer et al 2000). NPI lists out 12 distressing symptoms seen in persons with dementia Delusions, Hallucinations, Agitation, Depression, Anxiety, Elation, Apathy, Disinhibition, Irritability, Motor disturbance, Night time behaviors, Appetite and eating.

The current study shows the overall score of severity of symptoms shown by the patient with overall score of distress experienced by the caregivers for each symptom. Highest frequency of irritability was seen with 272 score and the distress
experienced by the caregivers for the same symptom was highest with score of 419. Agitation was reported second highest with the score of 257 and the distress experienced was 409. The less seen symptoms were elation with total frequency score 92 and the distress experienced by the caregivers was 102. And it interesting to note that the score for frequency of appetite and eating problems were reported by the caregivers with the score of 123 and the distress experienced by the caregivers is found less than the symptom score. The total distress experienced by the caregivers was 116. They reported that they felt relieved if their ward is keeping quiet and do not talk to anybody. Some of the caregivers discussed about changed eating habits of their wards. Some of them said usually their wards complained to the people about their caregivers of not providing them food. This behavioral problem did not result in more distress. With reference to gender, female caregivers showed greater reaction to problem behaviors when compared to male caregivers; even though both genders reported experience of distress. The total distress score for females is more compared to males. But the correlative analysis of symptoms shown by the persons with dementia with the distress associated with distress experienced by male and female caregivers is not significantly associated.

Female caregivers experienced greater reaction to two problem behaviors i.e., depression and disinhibition when compared with male caregivers even though both genders reported similar frequencies of these behaviors. Examples of depression behaviors included: appearing sad or depressed, crying, making comments about hopelessness, loneliness, and death, being a burden, a failure, or threatening suicide. The other type of behavior that was most upsetting was disinhibition. The examples of disinhibition related behaviors include: arguing, talking loudly or rapidly, waking the caregiver up, arguing with the neighbors, accusing the guests/visitors of theft, verbal aggression, embarrassing behavior, and dangerous behavior to self or others and destroying property. These types of behaviors were associated with the most upset reaction in female caregivers. It is not surprising that these types of behaviors may be the most threatening. The female caregiver probably is concerned about their safety or that of others and ability to control this kind of behavior. Thus
caregiver knowledge and understanding about anger and frustration management may be important interventions for women.

Overall cross tabulation analysis for the impact from caregiving experience and the relationship between the caregiver’s reaction to the problem behavior shows ten of the variables as significantly associated with each other. Two variables elation and eating habits were not significant.

Certain personal characteristics of the caregiver have been thought to contribute to the impact of family caregiving. The current findings are supportive of other research that suggests female caregivers experience a greater impact from caregiving. Females also had higher impact from caregiving in most of the indicators compared with males. The finding that women report a higher level of impact from caregiving than male caregivers do was interpreted in many ways, including the possibility that women assist in more personal aspects of caregiving such as toileting and bathing. Another interpretation was that females have more stress from multiple social roles than male caregivers do. Our findings add still another interpretation for increased impact: women may react more to depressed and disinhibition care recipient behaviors than experiencing more negative consequences. Women's reaction to depressed and disinhibitive behaviors is an additional variable to be added to the study of gender differences that determine caregiving outcomes. Future interventions are also needed that promote a positive attitude toward use of respite and other community resources to decrease personal and social restrictions experienced by women caregivers.

4. Discussion about coping strategies adapted by the caregivers and its correlation with stress, burden, burnout and depression

Majority of people with dementia reside in the community and most have at least one caregiver, usually a family member or possibly a friend or neighbor. There is some suggestion that daughters and wives make up the majority of caregivers (Stone 1987). It is estimated that family caregivers spend between 5-20 hours per day caring for the dependent family member and that the average primary caregiver
spends 60 hours per week fulfilling caregiving activities dependent on the severity and course of dementia (Marziali 2006). The nature of dementia progression means that the level of dependency, care and burden on caregivers tends to increase over time. Interest in the experiences of caregivers of persons with dementia who reside in the community has increased since the 1980s (Droes 2006) with a growing recognition of the social, financial, health and psychological consequences of caregiving (Lorensini 1997). Caregiving for people with dementia is now regarded as an important health issue. In examining caregiving much research has focused on the demands and difficulties experienced by caregivers, but it is also acknowledged that there can be more positive aspects to caregiving and to the experiences of caregivers.

Research has suggested that caregivers experience greater levels of emotional distress than the general population, such as higher levels of depression, with studies reporting the rate of depression in caregivers at 22% compared with 11% for older people generally (Vitaliano 2003). Caregivers are also relatively high users of psychotropic medications. Some of the physical effects of caregiving include poorer immune functioning, poorer physical health and increased mortality rates. On a practical level, caregivers may experience financial difficulties, for example if they have to give up paid employment in order to care for their relative. The requirements and demands of caregiving can mean that caregivers feel both burdened and socially isolated. In the current study only two primary caregivers said they had to quit their job because they could not balance between the caregiving burden and their job.

“I could not concentrate on my work, the effects of my caregiving was so strong that other employees (colleagues) could make out the change of my personality. They say I have turned into a different person altogether so I thought of quitting the job”, says a spouse who is now taking care of her husband full time at home.
Caregiver burden and their coping strategies

The term caregiver burden is frequently used to describe the “physical, emotional, and financial toll of providing care”. (Parks & Novielli, 2000). Caregiver burden can be the reason for physical, emotional, and psychological problems such as depression, lowered immunity, anxiety, reduced marital satisfaction, and a negative social impact (Bee & Boyd, 2003).

Studies of caregivers of dementia patients show that the level of perceived burden shows no correlation to the length of the caregiving relationship, nor does the amount of impairment of the care receiver; however it appears that the level of behavioral issues of the care receiver has the most impact on the burden felt by the caregiver (Montgomery 2007). Additionally, according to Dr. Montgomery, it is the problem behavior of the care receiver, not the care load that is the main determining factor in placement.

Perceived burden by caregivers can be measured in several ways. However, the most commonly referenced tool is the Zarit Burden Interview. Caregiving can also take a toll financially upon a caregiver. A study done by the National Alliance of Caregiving (1997) found that from 10 - 13% of caregivers either retire prematurely or leave their jobs in order to attend to their caregiving demands. This presents a dilemma for the caregiver-either they can stay at their jobs and hire someone to care for an aging parent or spouse or they can retire or quit their job and provide the care themselves. Either way the situation impacts the caregiver financially.

The current study shows the frequency of burden experienced by the caregivers as 43.2% suffer from severe burden; 28% suffer from moderate burden and 24% experience mild to moderate burden. Of these caregivers most of them are burdened with their dual roles of caregiving and earning for the family. Caregiving demands and financial demands make them cling on to their current jobs.

Researchers in this area increasingly have turned to applied settings to conduct their studies (Carver et al 1989). Such settings permit examination of coping
with respect of psychologically impactful and highly meaningful stresses. Increasingly the studies also are prospective in design, with multiple measures of both coping and outcome variables.

In this study reports on brief measure of coping reactions, based on the COPE inventory. 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. For the current study 14 dimensions were categorized into three coping strategies: problem focused coping, emotion focused and avoidant coping strategies.

Caregivers experiences of burden are molded by their involvement of their care giving situation. From the caregivers point of view, burden in caring for a demented elderly relative emanates from a number of interrelated factors.

The shifting of women as caregivers of their elderly relatives, place these people into a vulnerable position for developing burden and distress. It is interesting to note that the age of the patient is not significant with caregiver factors such as distress, and burden. More the years of care giving, more will be the experience of burden. One of the spouse caregiver said “I myself am weak, and need somebody to look after me, I cannot take this burden any more, I am waiting for the day of relief”. One of the unmarried daughter said “I feel like running away from the responsibility, it looks like never ending burden and my brothers want to escape from the responsibility of care giving”. Similar kinds of situation were experienced by many of the caregivers.

Of the three categories of coping strategies emotional focused coping methods are used more frequently by the carers followed by problem focused and least coping strategy used by the caregivers is found to be avoidant.
From the study it was evident that the caregivers were craving for support and guidance from other family members. Characteristics of the caregivers’ coping methods are directly related to caregiver burden. For example, positive reframing methods and using instrumental support strategies are associated with lower levels of caregiver burden. Active strategies include “constructing a larger sense of the illness” and being firm in directing a relative’s behavior. In the current study, most of the caregivers showed behavioral disengagement and religion as their coping methods to divert themselves from the emotional stress. Some of the caregivers opined that they have always tried to “cope up” with the care giving burden and rest of them said that they are “giving up the attempt to cope with the situation”.

Gender is important since the sexes differ in the kind of care giving and care giving burden; males displayed fewer adverse effects.

Most of the caregivers had higher level of education. One of the important findings is that the burden experienced the different groups (educational level) were significant when correlated with depression experienced. The language of distress and burden is same for every individual despite of education levels. Care giving was associated with more psychological complaints and a poor quality of life both physical and mental. Although it may be tempting to classify people according to their style of coping, the current study found considerable change and overlaps between types of strategies. Categorizing caregivers according to personal orientations may be questionable. Instead, people’s relationships alter both subtly and significantly alongside fluctuations in health and mobility. This indicates that classifying couples or individuals according to one or other type may not reflect their experiences over time or the nature of changes in relationships at times of mobility change. Although the circumstances of each individual were unique, instead of depicting their relationships as ‘care’, what mattered most was the change in their relationships with each other. While constructs such as ‘care’ have an important role in claims about rights and responsibilities, it seems sensible to remember that such language does not necessarily echo that of the everyday life of older people with dementia.
It was found out that the care givers emotions and feelings are wide-ranging and individualistic. They used different care giving strategies to help their situation and sometimes they used more than one strategy.

These findings are important implications for the theories about coping with burden. Results indicate that developing or experiencing burden either has a direct effect on coping strategy or influences the relationship between burden and coping strategy. In fact this study shows that mixed strategies of positive reframing, emotional support, venting, behavioral disengagement, self blame to be effective strategies.

5. Discussion on Social network & social support

Support in patient's care and availability of help

Several studies (Redinbaugh et al 1995; Coen et al 1997) underlined that poor social support is frequently associated with higher caregiver's stress levels.

Social support has profound effects on caregiver outcomes. Reports invariably indicate that more social support corresponds to less depressive symptomatology (Baumgarten et al 1992; Schulz & Williamson, 1991) and lower perceived burden (Gallant & Connell, 1997). Social support and caregiver burden have been found to mediate depression in caregivers (Clyburn et al 2000).

Social support has other important functions in that, carers may find out about services from people who have used them before and form a network with others in similar situations. (Gruetzner, 2001).

Role of respite

Respite care is seen by many carers as a very important service in caring for patients with dementia. Information about various respite options, and the availability of affordable, reliable and flexible programs which can manage behavioural problems, appear to be high priorities in enhancing carer well-being (Bloch, 1998). Burdz et al. (1988) examined the effect of respite care and defined it as temporary
institutionalization (in both cases for a period of two weeks) of the person with dementia in a nursing home and in a hospital.

In the Burdz et al. study, respite care proved to have a positive effect on the burden experienced by the caregivers, and it also had a positive effect, against all expectations, on the cognitive and physical functioning of the persons with dementia. Sutcliffe and Larner (1988) studied the effect of individual support for the carers at home (information and emotional support combined with relaxation exercises). The group receiving emotional support improved significantly on mood, whereas the control group deteriorated significantly. Zarit et al. (1998) report the findings of an evaluation of the psychological benefits of the use of adult day care by family caregivers assisting a relative with dementia. It was concluded that use of day care results in lower levels of caregiver-related stress and better psychological well-being.

The current study shows most of the families have the family size more than three. Only one person was single and two-member families were three. Rest of the sample had three and more than three family members. The mean of family size was found to be more than six members in a family (mean 6.51).

In total, 112 (89.6%) of the caregivers had the relievers in the form of daughters, sons, spouses, other family members or neighbors. Severe depression is observed in six (46.2%) out of 13 caregivers who said they did not have any relievers. Two (15.4%) of them experienced moderate depression five (38.5%) caregivers said that they did not experience any depression as the patients were in the initial state of dementia.

The various stages of depression are almost evenly distributed in the carers who had one reliever to lessen their burden. Out of 71 caregivers, various stages of depression ranged from 21% to 29.6%. Severe depression is experienced by 21 (21.6%) of the caregivers. Study agrees with the previous studies (Baumgarten et al., 1992; Schulz & Williamson, 1991) the more the support lesser is the burden experienced.
Within the entire social network, the most important component to an individual is his primary network group. Primary network or group refers to kin (immediate family, in-laws and other relatives) and friends (for example, neighbors, peers, work associates) with whom the individual has regular contact.

In India, the family provides for an enduring pattern of continuous intermittent ties that play a significant part in maintaining the psychological and physical integrity of the individual over a period of time. An individual’s interaction with family members or in a wider context with his/her primary group provides the basis for the formation of social bonds. Social bonds refer to the range of relationships which connect an individual to those who make up the primary group. The bond may be primarily affection as with a spouse, a special friend or close kin.

Current study shows the frequency of personal availability of social support to the caregivers. Out of total caregivers, 88.8% of the caregivers have relative, daughter, son, friend or some neighbors to help them whenever they required. It was observed that most of the time neighbors help the caregivers to take the patient to the medical facility when needed. Only 2.4% (3) caregivers said they do not have any helping hand when required. One of the caregiver was in very much distress both her sons were staying in far off places and they are not aware of the home situation and she says she do not have hope for future and wants to die. But her only worry was "who will take care of my husband if I am not there?" This thought makes her to cling on to life. Even though the results are not significantly associated with the social support statistically we cannot ignore the clinical significance.

Most of the caregivers had support from the social group almost daily. As the result shows most of the caregivers were Hindus (81.6%), followed by Christians (12%) and Muslims (6.4%). Christians they have the membership of church congregation and they will be in touch with the pastors and elders of their church and also with other members of their community. Usually caregivers say frequently they make the home visits and help them when required. Hindus most of the time are in touch with their relatives, neighbor and also some of the families have local club
membership. As per the findings Muslims have large family members, and other community members who are willing to help them in time of need.

The result also shows that 17 of the caregivers indulged themselves in some group activities like clubs, church activities and other social group activities. In general most of the caregivers visit their place of worship for socializing especially women. Ninety eight caregivers have their group network with whom they often vent out their feeling or experiences of caregiving. As per the caregivers view personal availability is more relieving than the group availability.

A social bond is an evolved and valuable component of human behavioral repertoire. Social bonds are considered necessary for people to maintain a reasonable degree of affective comfort, and to operate effectively in the face of adversity. While social relationships almost certainly carry multiple functions as described by Weiss (1974), one category which is assumed to be of special significance to health is the provision of 'support'. The commodity called 'support' is mediated through the element which is referred to as social bonds. The strength, quality and value of social bonds gradually decrease as one move from the immediate family to the periphery of the social network.

As per the results, for some female as well as male caregivers for demented elderly people, it was shocking that they reported little or no support and a lack of positive outlook in their caregiving role. However, both the genders suffered the most strain and burden. Some of the caregivers reported of their suicidal instincts.

According to Schulz et al (1995), studies on caregiving usually focus on social support and satisfaction as key predictors of strain. Investigations have shown that caregivers who experienced no or less satisfaction with support provided and less positive outlook on caregiving felt more strained and depressed the availability and use of social support may be important in coping with strain in caregiving in that it may provide emotional sustenance, information and tangible assistance, Social
support might be a way of sharing the caring role and this may in turn act as a buffer against strain.

In the current study, however, female as well as male caregivers of demented elderly people received the social support but not the extent that they wished. Only thirty one (24.8%) care givers got the score point of nine for instrumental support availed by them. Ten (8%) care givers got the highest score of ten. And five (4%) of the care givers have zero instrumental support. For the emotional support 40 (32%) said their families are providing maximum emotional support (120) and nine (7.2%) are without any emotional support. For during their crisis time or bad times, 10 (8%) of the care givers said that they did not get support from anyone. It was striking that only three (2.4%) of the caregivers reported of getting the maximum social support. One explanation for the differences in social support experienced by caregivers for demented elderly people may be that the caregivers for demented elderly people demand and need much greater support both practically as well as emotionally.

A belief that you have poor personal control over the outcome of your situation may be stressful and discourage the feeling of positive outlook (Lazarus & Folkman 1984; Pines & Aronson 1988). In these study caregivers of demented elderly people found it difficult to get a positive outlook on their caregiving situation. In view of the fact that the dementia process develops gradually and the situation becomes more and more uncontrollable, it is not surprising that the caregivers possess little or positive outlook on their situation.

In this study, there more number of women (59.2%) which are common in caregiving studies. In India, as in most countries, women most of the care for all categories of elderly disabled people including those with dementia. When a spouse is not available to provide care, the responsibility typically falls to a daughter. In the absence of a daughter, a son may become the primary caregiver, although there is evidence to suggest that sons often pass along caregiving responsibilities to their wives. To be considered for respite care.
Types of social support

Instrumental support

Most of the caregivers said they availed maximum support in the form of finance and other forms of support like helping by taking the patients for follow up or getting the vehicle for conveyance, getting the ration for the household or as relievers.

Emotional support

Emotional support is most given by the family members. Especially when spouse is suffering from dementia, they rely on children for emotional support. Most of the wives reported that they got emotional support from their daughters whenever required. In one of the families the caregiver was of the opinion son is the best person to share your burden even though she had daughters. The result shows maximum caregivers avail the emotional support from their family members.

Crisis related support

Out of total sample, only 29 caregivers reported of maximum crisis related support in general by person or by group. As per the caregivers, whenever event of major difficult situations had to be faced the support provided by the group or person was not satisfactory. In most of the families the incidence of dementia occurred because of natural process. In some because of the death of their dear and near ones, in some cases it was family disputes (as reported by caregivers) over property, some due to accidents and falls. Most of them experienced these kind of crisis situations but for them as they say they had to handle the situation single handedly.

Positive appraisal

Positive appraisal was also one of the categories of social support. Current study shows a total of 43 caregivers were interested in supporting their group or social network whenever it was required. They reported that they found happiness in helping others may it be family members or others whenever there is an opportunity to help. This can be taken as one of the positive approaches used by the caregivers as their coping strategies.
However, it may not possibly heal the caregiver’s family conflicts or change caregiver’s role with respect to the family or others. Concerning social support, the caregivers may need less practical support but still need emotional support because they may have feelings of grief and guilt resulting from the anger and frustration they are showing towards their once dear and near ones. This may also in turn influence the caregivers feeling of poor health.

SECTION 2
Discussion on designing and developing of an accurate and sustainable “Decision Support System for the informal caregivers of persons with dementia” that will comprehend/assist the health care professionals, researchers and community workers in taking decisions, making predictions and plan interventions.

Interventions for caregivers may be difficult to implement. Caregivers are conceived as the “hidden patient” because all the medical, social, and family attention is focused upon the care receiver (Parks & Novielli, 2000). It is important to bring intervention to the caregiver as early in the process as possible to prevent the negative impact of care giving that can lead to burnout. Burnout is one of the determining factors that lead to placement of the care receiver into an institutional facility (Parks & Novielli, 2000).

Variables
A prevailing theme across the studies of caregiving interventions explored by Parks & Novielli, 2000 was that interventional strategies should be tailored to the needs of a specific group of caregivers because of the many variables at play. For example, spouses or adult children who are giving care to someone who has dementia have different needs from a person caring for someone with cancer; and female caregivers have different needs than their male counterparts. Other variables include the degree of dependency on the part of the care receiver, family dynamics and history, and the length of time of the caregiving arrangement (Toseland & McCallion 1997).
Descriptive and Intervention Research

According to McMillan, there are two general types of studies that have comprised the body of information we have on caregivers: descriptive research and intervention research.

Descriptive research gives information on who the caregivers are and the results for the caregiver and care receiver. For example, it details the number of caregivers who are spouses, and how many are adult children; and the age and condition of the care receivers. Descriptive research also points out the aspects of the caregiver’s life that are affected – physical, emotional, or financial.

Intervention research are studies with caregivers taking into account the variables or aspects of their lives affected by the caregiving in order to find what interventions help in which situations.

A study by McMillan (2005), demonstrates why variables must be taken into consideration when considering interventions.

Sorenson’s (2002) group performed a meta-analysis composed of 78 different studies of caregiver interventions. The majority of the individuals studied were caregivers to dementia patients but also included people who were elderly and those who had cancer or strokes. The interventions included: psycho educational, supportive, educational, and multi-component interventions.

The psycho educational interventions revealed a significant effect on the entire group of caregiver outcome variables studied: burden, depression, perception of well-being, satisfaction with caregiving, and coping ability.
Supportive interventions were helpful in reducing caregiver burden and coping ability. Educational interventions increased the caregivers' perceived well-being but did not significantly reduce burden, depression or coping ability.

The multi-component interventions revealed significant results on burden, well-being, coping ability, but not on depression.

Taking into consideration all these dimensions of intervention, SNEHA was developed based on the caregiver protocols by REACH II program.

For the current software, multivariate measures were considered using questionnaires for care recipients symptoms and distress experienced by the caregivers, depression, strain/burden experienced by the caregiver. Questionnaires for measuring coping styles, social support, satisfaction with life and for caregivers own perception of burden.

The primary outcome is a multivariate measure comprised of indicators in major six domains: distress, depression, strain, coping, social support and satisfaction with life.

Demographic information collected provides basic descriptive data on caregivers and care recipients. Caregiver overall health included in caregiver related variable module helps the care manager to assess caregiver’s own view of one’s general health. Care recipients behavior is assessed with Neuro Psychiatric Inventory. Caregiver’s proxy report of problem behaviour of the patient and level of distress experienced by them, i.e. the caregiver is assessed. If the caregiver is experiencing distress in any listed distressing behaviors (NPI) shown by the patient, the software will assist the care managers with the intervention guidelines for the specified component.

CES-D is used to assess caregiver experience of depression. CES-D contains 20 questions that detail the frequency of depressive symptoms experienced by the
caregiver, which will assist the care managers in taking decision about the type of intervention depending on overall score.

The Center for Epidemiologic Studies Depression Scale (CES-D) is one of the most common screening tests for helping an individual to determine his or her depression quotient. The quick self-test measures depressive feelings and behaviours during the past week. It has been demonstrated to measure depressive symptoms and not merely general psychological distress. CES-D scale is widely used in medically ill populations because it does not over-emphasize physical symptoms such as fatigue, which could falsely elevate the symptom ratings. It is a short self-report scale designed to measure depressive symptomatology in the general population. The items of the scale are symptoms associated with depression which have been used in previously validated longer scales. It was found to have very high internal consistency and adequate test-retest repeatability.

Care giver strain index (CSI) contains the items about role strain and personal strain in caregiver. Brief COPE helps the care manager in assessing activities that help the caregiver in coping with stress or burden. Coping also depends on personal characteristics, and the interplay between social support and personality assets may be crucial for the health effect of stressors.

It is important for public health policy to collect information on social support in the population, to enable both risk assessment and the planning of preventive interventions at different levels. There are several valid instruments to collect such information. With respect to health, social support may have direct or indirect (buffer) effects (Cohen & Syme, 1985).

The direct effect implies that social support has a positive effect on health, irrespective of life situation. The buffering effect occurs only when the person is exposed to stressors, like negative life events and more lasting adversities. In this instance, social support is supposed to help the person to cope better with the
situation, and hence prevent stress. Poor social support is associated with mental health problems

A large number of studies suggest that poor social support is associated with mental health problems, such as depression (e.g. Brown & Harris, 1978; Dalgard et al., 1995a). In a survey of seventeen EU countries, a lower level of social support (measured by the OSS-3) was strongly associated with an enhanced prevalence of psychological distress (EORG, 2003a). Association between social support and psychological distress was observed for all three items of the OSS-3. In all countries the percentage of people reporting psychological distress decreased as the social support increased; the strength of the association was highly significant in 14 of the 17 countries. Countries with the highest level of social support (i.e. Sweden and Ireland) tend to report the lowest levels of psychological distress and vice versa (EORG, 2003a)

Considering the above studies OSS-3 is used in the current software ‘SNEHA’ to interview the caregivers about the frequency of three facets (confidants, concerns and neighbour) of social support availed by them.

Life satisfaction is one factor in the more general construct of subjective well being. Theory and research from fields outside of rehabilitation have suggested that subjective well being has at least three components, positive affective appraisal, negative affective appraisal, and life satisfaction. Life satisfaction is distinguished from affective appraisal in that it is more cognitively than emotionally driven. Life satisfaction can be assessed specific to a particular domain of life (e.g., work, family) or globally.

The SWLS was developed to assess satisfaction with the respondent’s life as a whole. The scale does not assess satisfaction with life domains such as health or finances but allows subjects to integrate and weigh these domains in whatever way they choose. Normative data are presented for the scale, which shows good convergent validity with other scales and with other types of assessments of
subjective well-being. Life satisfaction as assessed by the SWLS shows a degree of
temporal stability (William P & Ed Diener, 1993), yet the SWLS has shown sufficient
sensitivity to be potentially valuable to detect change in life satisfaction during the
course of clinical intervention. The SWLS is recommended as a complement to
scales that focus on psychopathology or emotional well-being because it assesses
an individuals' conscious evaluative judgment of his or her life by using the person's
own criteria. Hence SWLS is used in the current software ‘SNEHA’ as the existing
data (William P & Ed Diener, 1993) suggest that the SWLS has potential as a cross-
cultural index of life satisfaction.

All the fields of the soft ware are mandatory. After the completion of the
interview with the caregiver the soft ware displays “care plan” interface that displays
the mean values and Standard Deviations for five questionnaires and also prompts
the care managers for intervention in required areas. The “include” options of NPI
and CES-D is hyperlinked with respective intervention guidelines. Stages of
Alzheimer’s and related dementia are linked with the educational information about
the corresponding stages.

Follow up feature of software displays the Base line evaluation that can be
compared with the successive interventions this helps the care managers in self
assessment, care giver assessment and line of management and intervention.