Chapter II

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REVIEW OF LITERATURE

A review of related research on a topic has become a standard and virtually essential activity of scientific research projects. A literature review involves the systematic identification, location, scrutiny, and summery of written materials that contain information on a research problem.

Scientific research cannot add to human knowledge, if it is conducted in isolation from other scientific efforts. Studies need to be given a context if they are to be meaningful. Two mechanisms for providing such a context are the development of linkages with earlier relevant research via a literature review and the integration of the research problem into a theoretical framework.

This chapter is divided into two sections. Section one deals with the theoretical overview related to developing a structured teaching module & counselling and the care of a person with dementia. Section two deals with the important studies related to dementia caring and the effectiveness of structured teaching and counselling in reducing the burden of primary caregivers of persons with dementia.
2.1 THEORETICAL OVERVIEW

A theory is an abstract generalization that presents a systematic explanation about the relationships among phenomena. The overall purpose of theory is to make scientific findings meaningful and generalizable. Theories allow scientists to knit together observations and facts into an orderly system (Polit, 2007). These theories embody principles for explaining, predicting and controlling phenomena related to dementia care.

Dementia is a disease that affects mainly the old age people above 60 years. So a few important theories related to ageing process which help in developing a teaching module related to dementia care was considered by the investigator.

2.1.1 THEORIES RELATED TO AGEING

Ageing is a natural phenomenon. But the questions like – what is aging? Why do people age? What factors contribute or influence aging? Can a rapid change in these factors cause dementia? - initiated much curiosity in researchers. Many theories about aging are being reported in the current literature

I. Biological theories of ageing

Theories of cellular ageing have been classified as genetic & non genetic by Brookbank (1990). Genetic theories include those involving DNA,
error and fidelity theory, somatic mutation, and glycation theory. Non genetic theories include those involving wear and tear, nutrient deprivation and ageing pigment accumulation.

A. Genetic theories.
   a. Error and fidelity theory
      Ageing occurs as a result of an error that has occurred in the molecular development of a cell. The error may have occurred at the level of DNA or at the level of transcription, translation or post translation.

   b. Somatic-mutation theory
      Mutations are those inheritable changes that occur in the cellular DNA. If there is extensive damage to DNA, and it is not repaired, then there will probably be an alteration in a genetic sequence. The suggestion is that random genetic mutations caused by background radiation of various types, as well as other factors gradually produce failure in various body systems that eventually causes death (Yurick, 1984). The frequency of spontaneous somatic mutation is low, and the possibility of attributing the ageing process to these genetic changes is not very likely. Although x-rays do increase the rate of mutation, the lesions of ageing and of radiation damage differ.
c. Glycation theory

This theory suggests that glucose acts as a mediator of ageing. Glycation is the non-enzymatic reaction between glucose and tissue protein. Cellular studies of the effect of glycation suggest that glycated proteins show less enzyme activity, less degradation of abnormal proteins, and inappropriate cross linking (i.e., they do not form appropriate parallel connections with other proteins).

d. Programmed cellular ageing

This theory suggests that ageing may be due to an impairment of the cell in translating necessary RNA, as a result of increased turn-off of DNA. Some scientists speculate that the essential messages may be restricted in older persons (Brookbank, 1990). They suggest that the cell may stop exchanging genetic information, and without genetic guidance, the cell may undergo senescence (Hay, 1968).

e. Ageing pacemaker

This theory proposes that one cell or one type of tissue interferes with cell proliferation, hence initiating the process of senescence throughout the body.
f. Autoimmune theory

The immune system is less able to deal with foreign organisms as the body ages; and the immune system also increasingly makes mistakes, by erroneously identifying autologous tissues as being foreign.

g. Neuroendocrine control theory

The neurological and endocrine systems are major controllers of body activity. The loss of cells from both these systems is documented by scientists who study brain. A 10% decrease in the weight of the brain occurs during the human life span, which includes both a loss of cells and a loss of fluids in the cerebrum. The documented age-related changes in response to hormones, may be due to changes in the receptors for hormones, rather than changes in the activity of the endocrines themselves.

B. Non genetic biological theories

a. Effects of temperature.

The life span of warm blooded species is inversely proportional to their metabolic rate; observations confirm that mammals with high metabolic rates tend to be smaller, shorter-lived species. Ageing among those species with a higher metabolic rate is usually explained in terms of the cells wearing out. The rationale for this is that chemical reactions in living systems are slower at lower temperature and are accelerated at higher temperatures.
b. Nutrient deprivation

Nutrient deprivation is responsible for ageing. Scientists do not know whether deprivation of cellular nutrients causes ageing or is caused by ageing, or even whether both may be caused by some other factor.

II PSYCHOSOCIAL THEORIES OF AGEING

The Psychological aspects of ageing have centered on a variety of problems encountered with the ageing phenomena. Explanations for psychosocial ageing are complex, but helpful for developing a structured teaching module for education. The important theories are:

a. Disengagement theory.

The theory postulates that with ageing, there is an inevitable mutual withdrawal of the individual from the society, and the society from the individual, resulting in decreased interactions between the ageing person and others in the social system he belongs to. The process may be initiated by the individual or by others in the situation (Brookbank, 1990).

b. Activity Theory

Activity theory emphasizes the importance of ongoing social interactions: as result of this activity, the elderly develop a positive concept of self (Cavan, 1962). A person’s self concept is related to the roles held by that person. As one age, it is expected that roles will change, but in
order to maintain a positive sense of self, the activity theory assumes that new roles must be substituted for those roles that one loses due to age; hence, well-being in later life depends on activity in newly acquired roles.

c. **Continuity Theory**

The central premise of continuity theory is that older adults try to preserve and maintain internal and external structures by using strategies that maintain continuity; that is, the older persons may seek to use familiar strategies in familiar arenas of life. Continuity is a subjective perception, and each person must uniquely adjust to changes by forming personal links to tie the new experiences to the previous experiences in life (Cobler, 1982).

d. **Exchange theory**

Exchange theory views elderly persons in the context of a collection of persons involved in ongoing exchange. Interaction between these individuals and the elderly person is based on the elders’ perceptions of what they find to be rewarding or costly to them. They usually choose to continue in those interactions they perceive as beneficial and withdraw from those perceived to be of no benefit to them.

e. **Social competency/breakdown theory.**

This theory tries to explain the positive and the problematic aspects of ageing, suggesting that the elderly get negative feedback from their
environment, thus initiating a continually downward spiral of the elders’ self concepts. As the elderly person see themselves in a more negative light, their self concept is diminished, they perceive themselves in an ever deepening negative view.(Kuyders and Bengtson, 1973).

f. Subculture theory

The elderly population is creating or developing its own subculture. They create their own norms and their own values, and they develop a group identity irrelevant of gender, race or socio economic class.

2.1.2. THEORIES RELATED TO DEMENTIA

Theories suggesting the causation of dementia in the elderly are:

A. Neurofibrillary Tangles & Plaques

Plaques, or more precisely amyloid load, might correlate with the degree of cognitive impairment, although a significant amyloid deposition is also found in normal unimpaired, aged individuals. There is a high degree of correlation between dementia severity and neurofibrillary tangle formation (Ronald, 1990).

B. The Cholinergic hypothesis

The cognitive impairment in Alzheimer’s disease (A.D.) is due to disorder predominantly affecting the cholinergic neurons.
C. The amyloid cascade hypothesis

The protein deposited in blood vessels (Congophilic angiopathy) in Alzheimer’s disease was shown to be a 4 KDa peptide known as B-amyloid. This peptide, which is identical to the amyloid in plaques, is derived from a larger peptide, APP, the gene for which is coded on chromosome 21. The formation of B amyloid is the initiating, or at least an early event, leading to all the other changes observed, including tangle aggregation & phosphorylation, neuronal loss, cholinergic deficits, and clinical symptoms. (Paul, 1991).

D. The presenilin genes

Mutations in presenilin-1(PS-1) and presenilin-2 (PS-2), two very similar genes on chromosome 14 and chromosome 1 respectively, also cause early onset autosomal dominant Alzheimer’s disease. The functions of these genes are not fully understood, but they have been postulated to participate in NOTCH signaling - a complex signal - transduction cascade, critical, among other things, in determining neuronal cell fate. Mutations in the presenilins result in an increase in the production of B amyloid.(Mike,1993; Wright,1984).

E. Tangle formation and tau phosphorylation.

Tangles are composed of paired helical filaments, themselves composed of hyper-phosphorylated tau. Neuropathological evidence suggest that highly phosphorylated tau does begin to accumulate in the brain before the
formation of tangles and before the clinical manifestations of A.D. (Lovestone, 1994; Whalley, 1992).

F. Molecular genetics

Mutations in three genes have been found to cause early onset familial A.D. which is inherited in an autosomal dominant fashion. Mutation in the APP gene (on chromosome 21) is the least common. Mutations in PS-1 (on chromosome 14) are somewhat more frequent, although are still a rare cause of A.D. Mutations of PS-2 (on chromosome) appear to be a major cause of A.D., especially in some ethnic groups. (Heyman, 1983; Deary, 1988).

2.1.3. THEORIES RELATED TO BURDEN OF CARING

Caring is as old as the human race. Proper knowledge about the disease, time, dedication, love and many other factors are needed for a successful caregiver. Caring is the only alternative treatment in dementia as there is no cure for the disease.

Care of patients with dementia and their caregivers can be organized using many theories. Theories related to caring virtually give direction for caregivers and make caring more meaningful and qualitative.

Mature adults deliberately learn and perform actions to direct their survival, quality of life, and well being. Nursing is required because of the inability to perform self-care as the result of limitations. The goal of nursing is
to help individuals meet their self-care requisites and build their self-care or dependent-care capabilities.

When a person has self-care abilities and is able to do self-care activities as per self-care demand, there is a balance. When a person progresses from mild to severe dementia, demand increases. But their abilities & activities decrease. So inorder to compensate the deficits, nursing capabilities should be used, like support & education for patients with mild dementia, partially compensatory care for patients with moderate dementia and fully compensatory care for patients with severe dementia.

Newens (1972) depicted the client system as a person or persons constantly bombarded by environmental stressors. The client system is exposed to stressors from within and outside the system. The client system is also protected by a series of concentric buffers that serve to minimize the impact of stressors and act as safely zones between environments and the central core.

2.1.4. THEORIES RELATED TO STRUCTURED TEACHING

A person, who is constantly subjected to stressors from within his own system and from environment, can loose equilibrium, get diseased or die. Interventions like structured teaching and counselling are purposeful actions to help the caregiver to retain or maintain system stability.
Teaching is an interaction process for achieving desired objectives (Flanders, 1982). Teaching is the means whereby society trains a person in a specific or selected environment, to adjust themselves to the world in which they live as quickly as possible (Yoakam & Simpson, 1989). A positive change, in the cognitive, affective and psychomotor domain, is expected in all teaching (Heidgerken, 1992). This structured teaching was prepared to effect changes in all domains of human learning.

According to Gestalt theorists, the structure and organization of teaching is important for effective learning (Kohler, 1925). Thorndike (1970) suggested that the objectives must be clearly defined for teaching. So the teaching module was prepared in advance with general and specific objectives. Thorndike also recommended that the objectives should be within the learner’s response capabilities and should be arranged from simple to complex.

According to the theory of insightful learning, learning occurs all at once, rather than a little bit at a time. Thorndike mentioned that incorrect responses are to be corrected rapidly, so that they are not practiced. The whole teaching (intervention) was given to all caregivers in the initial time itself and emphasized the correction of mistakes and maladaptive behaviour in the continuing visits. Reinforcement changes the stimulating conditions and thereby prevents unlearning (Guthrie, 1984).
Each caregiver might have learned some concepts and misconcepts about caring old persons with dementia by trial and error method. Thorndike has mentioned that every person is unique. The readiness of learners and their ability to exercise may vary. An orderly, arranged, familiar place is needed for better learning. So, individual teaching in their home setting was considered. According to Gestalt theorists, the individual variation needs to be considered because of the difference in intelligence. They also suggested that learning situations be arranged properly for getting more insight.

Audio visual aids like pictures are important for teaching. It makes teaching more effective and meaningful because of conditioning (Pavlov). The work of Skinner highlights that some stimulus in our environment can act as inherent reinforces. Bandura mentioned that anything that can be learned by direct experience can also be learned from observation. Guthrie described that a learner should learn to attach response to a stimuli. A structured teaching in the real situation will help for this.

Demonstration of care in the actual situation is useful based on the learning by insight by Gestalt theorists.

Effective teaching can reduce the burden of care giving. The primary caregivers are usually motivated learners as they are anxious about the problem they face. According to Hull, learning primarily takes place to reduce
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a drive. Janet and Taylor remarks that anxiety is a good drive in human learning. The cognitive theorists suggest that the thoughts, expectations and understanding of the world around direct motivation.

The caregivers are experiencing general health problems secondary to burden in care giving. They experience many emotional problems too. Lange concluded that the perception of a situation gave rise to a subjective feeling that in turn follows a series of bodily changes. He urged that the bodily changes result from the perception of the situation; and that recognition of bodily changes subsequently produces the subjective feeling.

According to the activation theorists, there is some optimal level of emotional arousal. Too little produces apathy, too much produces aimless activity and emotional disturbance. Strong emotions will be there when the homeostasis is broken. The role of a counsellor is to bring back this lost homeostasis.

Instincts are the inborn capacity for purposive action. Emotions occur along with some goal directed activities. Help of a counsellor is needed to establish the goal directed activities.
2.2 STUDIES RELATED TO DEMENTIA AND CAREGIVING.

An attempt is made in this section to review the different aspects of dementia studies from the available literature. Dementia is a disease that was detected very early. The Alzheimer Disease (AD) constitutes the major type of dementia. The first documented case of Alzheimer’s disease was a woman aged 41 who had died after suffering from dementia. The German neuropathologist Alois Alzheimer examined her brain in 1907 and found that it was highly abnormal compared with those of non-demented patients of the same age.

Numerous studies have been done throughout the world regarding various aspects of dementia and dementia care. A great share of studies was done in U.S.A., U.K. and in other developed countries. Number of studies from the developing countries is less. So a comparative data from Indian scenario in all aspects of dementia is not available.

This section is subdivided into the following areas.

1. Dementia
2. Burden of care giving
3. Effectiveness of structured teaching and counselling.
2.2.1 Studies related to Dementia

The prevalence of dementia has been researched extensively all over the world especially in developed countries. Many studies (Jorm et al, 1994; Zhenchao, 1996; Morgan, 1993) showed that the prevalence of dementia rises steeply with age, following approximately an exponential form up to the age of 90 years. Some authors (Jonghan, 1994) argued that the prevalence of dementia would eventually reach 100% after that.

In one cross national study by Jonghan(1994), it was found that the age-adjusted prevalence of dementia was only 2% in Koreans compared with 8% in African-Americans, and the prevalence of AD was also lower (1% versus 6%)

Mortimer (1985) reported that AD afflicts between two & four million persons in the United States and accounts for 40% to 59% of nursing home admissions.

Review of 47 prevalence studies conducted between 1980 and 1985 were done by Jorm, et al (1987). A constant finding the researcher reported was the increasing prevalence of AD with the prevalence doubling every 5.1 years, up to at least age 95. This trend was noticed in most of the recent populations studied in the review. Evans, et al (1987), studied the
prevalence of Alzheimer’s disease in a southern California community using strict diagnostic criteria and found that 15.3% of persons above 65 years of age and 36% of those 80 years and above met the criteria for AD.

Incidence of dementia of 21.8 per 1,000 population per year in the age group 80 years and above was reported by Bachman and colleagues (1989) in a study in Bronx, New York. The elderly population who were free of dementia in the period from 1976 to 1978 was followed up with periodic mental status testing for five years in an ongoing prospective study of a large group of individuals in Massachusetts (Framingham study, 1990). The incidence of dementia had increased markedly with age. Doubling in the incidence of dementia from 7.0 per 1,000 in those persons aged 65 to 69 to 11.8 per 1000 in those aged 85 to 89 in the successive five years was noticed. Again there was a significant increase in the incidence of AD with advancing age, ranging from 3.5 per 1000 in those people aged 65 to 69 to 72.8 per 1000 in those ages 85 to 89 (Bachman, et al, 1993).

Higher incidence rate than this was reported by few other researchers. Newens (1995) reported the prevalence rate of AD to be 34.4 per 1000 population aged between 45 & 64 with an annual incidence rate in this age group of 7.2/1000.
In the study done by Ballard, et al (1996), 76.5% of the study subjects were women with the mean age of dementia occurrence of 79.36 years.

A four year follow up study in Britain, to find the relation between the incidence of dementia and age group by Morgan, et al(1993), revealed a high incidence of dementia in the age group 80-84 years(Average annual incidence 2.25%) and then in 85-89 years(2.18%). This study also revealed that the highest 4 year incidence occurred among men from 70-79 years. The highest incidence in women was found in the age group 80-89 years.

The comparative studies from Kerala and India were few in number. The total number of persons affected with dementia in India was estimated to be 5 million. There will be an increase in the number of cases in the coming years, the study says. (Roy, 2005).

A study to find out the prevalence of dementia in the population of Kerala was found to be around 5% in people over the age of 65 (Shaji, 1996). This finding is similar to that of developing countries.

The ability to identify individual in the earliest stages of dementia would be particularly valuable to enable definitive diagnosis and early intervention. O’connr et al (1988) had demonstrated the failure of physicians and community nurses to recognize cognitive impairment
among their patients. Handerson (1986), reported that despite recent investigation techniques, the prevalence of Alzheimer's disease is not known with any precision and even less is known about the incidence.

Alzheimer’s disease is the fourth leading cause of death in adults, preceded only by heart disease, cancer and stroke in the U.S.A. It is estimated that, one in ten families has a member who has A.D. in U.S.; and that may reach to 14 million (Mortimer, 1990). People with A.D. occupy more than half the beds in skilled nursing facilities in U.S.(Morgan & Stewart, 1998).

Alzheimer disease is becoming a major health care problem as increasing number of persons are diagnosed.

Studies conducted in different parts of the world, regarding the relationship between heredity and incidence of dementia, have brought out several interesting facts. Increased frequency of dementia among first degree relatives were reported by Breitnet et al in 1988. Deary (1988) performed a clinicopathological investigation to find family risk factors by studying 407 patients with definite AD & 100 dementia patients without AD as healthy control subjects. Among several risk factors analysed, the most consistent association with AD was found to be advancing age and
family history of dementia. Zarit et al (1998) studied 421 first degree relatives of 43 AD patients and found a 45% risk of AD.

Breitner, et al (1998) found a cumulative incidence of Alzheimer’s disease in 49% of the relatives of AD patients. These authors also noted that the age of onset tends to be consistent within families and suggested that there may be genetically distinct, early and late onset forms of AD.

Alzheimer’s disease (AD) and other dementias incur huge costs to society, to the families of those affected and the individuals themselves. Costs to society include both direct costs to health & social services and indirect economic costs in terms of lost productivity, as carers are taken out of the work places. (Lovestone, 2000).

As the prevalence of dementia in elderly population continues to increase, this disorder will impose an expanding economic burden on patients, their family and on the nation. In a study, it was calculated that the overall annual cost of caring all types of dementia in the US was between $20 billion and $38 billion. (Hu, 1986)

Terry and Katz man (1983) reported that the cost for nursing home care alone was projected to increase to $75 billion in 1990 from $21 billion in 1981 for caring aged with AD.
These articles reviewed revealed a high expenditure for caring the demented. The exact picture of actual expenditure in developing countries, especially in the Indian community, is not deducible from the available literature.

The life expectancy of women is more than men all over the world. So the number of women affected with dementia is more. This logical fact is accepted in the literature reviewed here.

In a study by Jorm and co-workers (1990), it was found that although the prevalence of dementia in general was similar among men and women, the prevalence of AD specifically was higher among women, possibly affecting a longer survival after developing Alzheimer’s disease.

Women were found to have a higher incidence of A.D. in very old age, and men tended to have a higher incidence of vascular dementia at younger ages in the study by Jorm. (1998).

A somewhat higher prevalence of AD among women has been confirmed by some investigators (Breitner et al, 1988). Higher prevalence of dementia among women- that is 66% of cases in comparison to men were women- was reported by Emerson (1998). Newen, et al (1995) conducted a study on AD patients who were taken care of at home &
institutions and found that 56% of the affected were women & only 44% were men. Mortimer (1990) also reported higher incidence of AD among females in his studies.


The number of women with dementia is 2 times more than the number of men with dementia. Increased life expectancy of women and the earlier death of men are the most important reasons for this difference. (Jorm et al, 1990).

Demographic variables of caregivers were widely studied throughout the globe. Data related to the demographic variables of caregivers is important, as it has predicted relationship with the burden of caregiver.

The association between low educational level and lower scores on mental status examination amongst patients with dementia has been observed in studies of Brayne (1990).

In the scientific articles written by Dey (2002), it was reported that dementia occurs mostly in less educated persons with less intelligence. The
person who does less complex jobs, without the involvement of thinking or domains of brain, is more prone to develop dementia. The exact scientific reason for the associations between these variables could not be found in the literature reviewed.

In a study about caregivers, Sweeting (1994) found that 56% of total caregivers were children, 10% were spouses and 32% were others.

Newens, et al (1995) found that the principal caregiver was a spouse in 81% patients. Among the total persons with dementia, 3% were cared by their sisters, 12% by their daughters and 4% of them by their sons. Significantly, more of the relatives who were not a spouse were women.

Variations in the demographic variables were observed in other studies.

In one of the recent studies by Karlikaya et al (2005) in Turkish population found that, 51.9% of total patients were males and 48.1% were only females. But among the caregivers most of them were women (84.6%). The age of the caregiver ranged between 31-84 years, with a mean age of 53.6 years. Among the caregivers, 4.2% were spouses, 40.4% were adult child, 13.4% were daughter-in-laws and 1.9% a niece.
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The important findings about demographic variable of caregivers in a study by Taub et al (1999) in Brazil were, 82% of them were women, ranging from 23-81 years of age (average age 56 years) with 3-19 years of schooling (average 11 years), 78% were married, 70% were housewives and 56% were patient’s daughters. The relation of burden to demographic variables like age, gender, education and relationship of caregivers with patient was studied by Karlikaya, et al (2005). The researchers found that there were no significant differences for most of the analyzed factors.

A few studies were conducted about the total time of caring by the caregivers.

In their study, Taub et al (1999), in Brazil, found that a weekly average of 111 hours was dedicated to caring for the patients, with the minimum time of caring of 1 hour and the maximum of 168 hours. 64% of caregivers received help from other family members, whereas 78% had the assistance of a hired professional.

Time spent with the demented by the caregivers that is Primary & Secondary caregiver, is another aspect of a few studies. In a study conducted by Emerson (1998), among 28 primary caregivers, the subjects reported that they spent 7 days/week with the patients. The average time
spent with the patients by caregivers, was found to be 11 hours/day (range 3-24 hours).

### 2.2.2 Studies related to burden of caregiving

Caring for the persons with dementia is one of the important psychosocial problems as it is associated with a number of burdens. The intensity of burden may vary in studies. Sara (2009) reported severe stress and burden in caring among all caregivers.

Family care-givers play a vital role in the support of the people with dementia. Donaldson et al (1997) reported that in addition to opportunity costs, care-giving has been linked to a wide range of negative outcomes, including psychological disturbances, physical health problems, relationship changes and social activity restrictions.

The demands placed on the caregivers by several impairments in the demented are heavy and their consequences diverse. George & Gwyther (1986), reported the association of many negative outcomes on dementia caregivers, including psychological disturbances.

Michon et al (2005) reported multiple determinants for the caregiver burden. Volicer (2005) reported primary stressors (related to patients) and
secondary stressors (related to family and caring) are equally responsible for burden.

Many other researchers reported the association of other physical symptoms with dementia care like physical health problems (Golodetz et al, 1969), relationship changes (Morris et al, 1988) and social activity restrictions (Sainsbury & Alarcon, 1970). An accumulation of these pressures can threaten the caregivers’ ability to continue supporting the dementia sufferer at home.

Burns et al, 1990, reported the common non-cognitive features in persons with dementia which include psychotic symptoms like hallucinations and delusions, depressive features like sadness and lack of interest and behavioural disturbances like aggression and wandering. According to the report of many researchers (Gillear, et al 1982, Harper & Lund, 1990; Reis et al 1994; LoGiudice, et al, 1995), caregivers’ burden is closely associated with the presence of these non-cognitive features of the demented. Ninety percentage of caregivers in the study done by Jennifer et al (2007) reported behavioural problems in demented patients as the major factor for their burden.

Finding from Greene et al (1982) and Lo Giudice et al (1995) studies suggest that deficits of behaviours like withdrawal, apathy etc. are
more closely related to caregiver’s burden, than excesses of behaviour like hoarding, sleep disturbances etc.

Several studies were done to see the relationship between the burden of caregiver and the cognitive deficits like memory loss, visuospatial disturbances, language abnormalities etc. in patients. Zarit et al (1980), Greene et al (1982) and Farran et al (1993) failed to find a significant correlation between these variables. Whilst, Eagles et al (1987), O’connor et al (1990) and Lo giudice et al (1995) reported significant positive correlations between cognitive disability and burden in mixed gender samples of carers. However, Harper (1990) found that carer rated memory loss and wandering were predicted burden in male caregivers, but not in females. Weiler et al (1994) reported a negative relationship between clinician rated cognitive impairment and burden in their study of adult caregivers.

A non-linear relationship was found between subjective ratings of forgetful behaviours & burden, with the caregiver of patients who were sometimes or often forgetful experiencing more burden, than the caregivers of patients who were rarely forgetful or not forgetful most of the time. Reis et al (1994) showed that the objective measurements of cognitive impairments were significantly related to caregiver burden.
Prunchno & Resch (1989) proposed that although caregivers may feel burden when memory problems initially reach a level that necessitates their assistance, this burden later abates as supporters adjust to these demands.


The burden related to activities of daily living (ADL) limitation was found to be more in female caregivers than in males (Harper & Lund, 1990).

Qualitative features of the patient-carer relationship may influence the degree of burden among the relatives (Morris et al, 1988). Greene et al (1982) and Deimling & Bass (1986) examined adverse changes in the patient-carer relationship as an outcome variable. Both reported that aspects of disturbed behaviour in patients such as aggression, mood changes and withdrawal were closely related to negative changes in caregivers’ feelings towards their dependant. These behaviours may exert their influence on carer-patient affiliation, by disrupting the bonds of affection and reciprocity.
that are vital in maintaining interpersonal relationship and general health of caregiver. (Horowitz & Shindelman, 1983).

Two large-scale studies have investigated the influence of patient impairments on caregiver participation in social activities. Deimling & Bass (1986) noted that ADL limitations and disruptive behaviour had adverse direct effects on caregivers’ social participation. Pruchno & Resch (1989) reported that disoriented and disruptive behaviours were linked to reductions in caregivers’ social activities.

Poor physical self-maintenance in patients significantly affects the caregivers' social life, household routine and holidays. Findings from the studies by Greene et al (1982) show that, the two major factors restricting the social and recreational activities of carers are the increased nursing care to patients to meet their activities of daily living and the supervisory activities as those in the disturbed behaviour.

General health and psychological health of caregiver may be affected because of the burden of care giving. Four important variables were considered by many researchers, namely psychological distress, anxiety/stress, depression and physical health. General Health questionnaire
(GHQ Golberg, 1978) was used by majority of researchers to measure the psychological distress in caregivers.

Independent association between aspects of non-cognitive disturbances and GHQ morbidity was noted by Bordaty (1990), Drapoer et al (1992), Lo Giudice et al (1995) and Bell (2001).

In a community study by Eagles et al (1987), the scores on a combined measure of disturbed and dependent behaviours like night time wandering, incontinence & immobility were found to be highly correlated with GHQ scores.

Bordaty (1990) did a separate assessment of dependent behaviours in patients and found that there was no relationship with psychiatric distress. Eagles et al (1987) & Reis et al (1994) looked at the impact on carers of cognitive deficits in patients, but no association with GHQ scores were noted. These findings suggest that GHQ morbidity in carers is closely associated with patient psychopathology.

The relationship between behavioural deficits and general anxiety/stress in caregivers was examined by a few studies. Weiler et al (1994) assessed cognitive and daily living deficits in patients, but did not
find any significant association between these symptoms and anxiety in caregivers.

In a longitudinal study, Gallagher et al (1992) measured cognitive deficits and night-time disruptive behaviour. He found that the level of night time disruptive behaviour makes predictions of perceived stress.

In the study conducted by Eagles et al (1987), it was found that the cognitive deficits were found to be unrelated to stress symptoms in caregivers.

A significant correlation between dependency and demand behaviour in patients and burden in caregivers was reported by Gilleard et al (1982). He revealed a significant correlation between depressive mood ratings in carer and demand behaviours in patients, although disturbance problems like accusations, temper outbursts, bad language, aggression etc. showed no association. Haley et al (1987) and Brodaty (1990) used bivariate correlations to examine these data later, but did not report any significant relationship between these variables.

A strong positive relationship between caregivers’ burden and aspects of non-cognitive disturbance in patients were reported in the studies of


The impact of patient variables on caregiver physical health was investigated by a few research groups. Small scale correlation studies by Annersted et al (2006), Haley et al (1987) and Brodaty (1990) did not reveal any significant relationships between patient impairments and caregiver health.

Deimling & Bass (1986) reported that ADL limitations had the strongest direct effect on caregiver’s physical health disruptive behaviours and social functioning deficits also had significant effects.

Newens et al (1995) reported that among the problems of ADL, the earliest need for assistance are bathing, dressing and using toilet. Moving in /out of a bed or chair is the last ADL to require assistance.
The clients’ behaviours on caregiver & others were studied by Catherine (1997). In this study, 85% caregivers informed that the behaviours were troublesome for them, and 58% reported that the behaviours of the client were troublesome for others. 43% of caregivers felt depressed or hopeless, 67% said that they were tired and had low energy, 33% reported trouble sleeping and 27% reported trouble in concentrating.

Bellard et al (1996) did a follow up study of depression in the caregivers of dementia patients. The author reports that among the primary caregivers 23.5% were showing signs of minor depression and 7.1% were having major depression. The researcher concludes that depression occurs in 30-50% of carers. Problem behaviours were significantly associated with the number of months or period of depression. Among the carers, the annual incidence of depression lasting 9 months or more was almost 50% and of that lasting 3 months or more was 25%.

Jennifer et al (2007) reported that 50% of caregiver studied experience depression, anxiety, strain and stress. Vellore (2002) also reported the prevalence of high level stress and anxiety among 25% of total caregivers and is positively correlates with caring hours.
The caregivers’ role in family and caring process has greatest impact on the mental health of spouses, particularly older women, who usually provide the most intensive care.

Relationship of the demented person with spouse caregiver was studied by Zarit (1980). He found out, after interviewing 54 caregivers that 25% of the husbands reported having an improved relationship with their spouse with dementia since care giving began.

Caregiver who is other than spouse is also widely studied. Cohen et al (1990) and Stone et al (1987) showed from their studies that 63% of wives, 39% of husbands, 39% of both daughters and daughters-in-law, 28% of other family members and 25% of sons reported significant burden. Two thirds to half of husbands, daughters, daughters- in-law and other family members had sought counselling, but only 10% of sons had consulted with a Counsellor.

Cohen and Eisdorfer (1988) report that the caregivers who share a residence with the patient appear to be the most burdened. Even when the patients were send to nursing homes later, the use of psychotropic drug among caregivers suggests that caregiver’s burden was continued.
Karlikaya et al (2005) reported that, overall, 90% of the caregivers had some degree of burden. The researchers observed high burden on caregivers who are very close and emotionally attached to patient. The burden score of the spouses and adult-child caregiver in the Zarit burden scale with maximum 80 score was 42.96 and 41.00 respectively, whereas the daughters-in-law’s score was only 30.5.

In the same study, researchers observed the mean burden of male caregivers taking care of male and female patients as 44.2 and 35.9 and the female caregivers taking care of male and female patients as 40.36 and 39.63 respectively. They have reported that, even though it is not significant, the burden was higher in the younger caregiver and the level of burden did not correlate with the duration of time spent as a caregiver.

A study on caregiver’s health by Mockus & Novielli (2005) in Philadelphia revealed that elderly spouse caregivers, who experienced caregiving burden, had a mortality risk that was 63% higher than that in control subjects. The early identification of caregiver burden and appropriate intervention was found to be very important.

Few reviewed studies suggest that the burden of a caregiver largely depend on the personality of caregiver. Daire et al (2000) and Jennifer
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(2007) reported the perception of caregiver about care giving and coping skill during caring as important determinants of burden.

Extensive review of literature revealed that only a few studies were done to find out the increase in burden of caregivers according to the progress in severity of dementia.

A prospective study to find out the difference in burden of family members of patients with dementia, when the severity of disease progress from mild to moderate and moderate to severe in the same patient, for a period of five years, was conducted by Farran (1993). The researcher reported significant increase in burden of all caregivers in the family.

Burden of caregivers according to the severity of dementia was studied by few researchers.

Enid (1996) measured the burden of caregivers of patients with mild, moderate and severe dementia after a support programme which included education, counselling and sharing of experience by other caregivers. The difference in the scores was highly significant after support programme. Eagles (1987) found no significant relationship between severity of dementia and burden of caregiver.
Studies discussed above review the various types of burdens associated with dementia care. These burdens in care giving raise certain challenges to the caregivers.

2.2.3 Studies related to Effectiveness of structured teaching & counselling

Education and counselling are the essential elements in the care of caregivers of patients with dementia. Blackwell et al (1992) remarked that carers identify access to information and training as an essential requirement in their struggle to continue in the care giving role.

After reviewing many studies, Brodaty (1992) remarked that even though the carers find intervention programmes to be helpful, the results of controlled trials have not produced consistent evidence of benefit.

Studies to see the effectiveness of teaching and or counselling in reducing the burden of care giving are quite a few all over the world. Nancy et al in 1998 did one such study. She found that a reduction in the tired and low energy feeling of caregiver had occurred after educating the caregiver whereas troubled sleep of caregiver was not improved. A notable finding is that the suicide thought, that 10% of the caregivers had, was reduced to 0% after counselling sessions for 6 months.
Bellard et al (1996) found a reduction in symptoms of depression from 50% of caregivers to 25% after structured teaching and counselling programme for a period of 3 months. A similar result of significant reduction in distress and depression in the intervention group compared with control group at post treatment and follow up was given by Marriot et al (2000).

In the study findings of Elliot (2009) noted that after intervention caregiver reported better self rated health, sleep quality, physical health and less burden. Meredith (2009) also reported improved sleep and less anxiety after night time monitoring among caregivers.

Cohen, (1994) tested the effectiveness of a structured teaching plan in reducing the burden of all family members. It was found to be effective in reducing the burden of all caregivers. The tested module was later published as ‘seven steps to effective patient care’.

A stress reduction and teaching module to reduce the stress of caregiver who is a spouse of patient was developed by Zarit et al (1989). The result obtained after administration of the module indicated a significant reduction in stress.
Nilufer et al (2003) reported that 80% of caregivers reported increased tolerance towards burden of caregiving after treatment, education and counselling.

Champell & Blandford (1991) studied the effectiveness of formal and informal teaching for caregivers in Canada with a control group. The result showed that the general health of caregivers in the experimental group had improved significantly than control group.

Racial difference was noticed in the reduction of burden after intervention in few studies. Steven (2006) reported greater improvements in quality of life among Hispanic in U.S.A. than the control group. Ishan (2005) reported higher burden among caregivers who are black.

Caregivers’ health and their relation with patient was studied by Harper (1990). The results from the study indicated a significantly higher general health score for daughters than other caregivers. Daughters maintained this higher score in the second measurement after a counselling session.

In the study, 40% of the caregivers experienced nervousness and anxiety in the beginning, which was reduced to 20% after teaching. The reduction in worrying was from 53.3% to 50% and sadness from 20% to
0%. The researcher had observed improvements in emotional and mental health of caregiver (from 40% to 70%), (reduction in frustration from 60% to 50%) and improvement in caregiver’s health & self-care, social life and the preparedness to handle stress related to care giving situations. In this study, 70% of the total caregivers agreed that this educational programme was very useful for them.

A study by Duffy (2006) in Pittsburg, it was reported that after 6 months follow up of a structured teaching, the severity of burden to be significantly lower among the caregivers who received the intervention than those in the control group. Care givers also reported that the intervention helped them to feel more confident and be able to deal with caring for their loved one, to improve the care recipient’s quality of life and helped them to keep the recipient at home.

The impact of a highly structured and intensive 10-day residential programme and continued support, in the form of telephone conference calls, over a 12-month period, was assessed by Bordaty & Gresham (1989). They found that the carers and patients in the training programme had significantly lower psychological distress and lower rates of institutionalization respectively, compared with controls.
Gilhooly (1984) did a study on caregivers with occupation and without occupation after giving education about different aspects of caring. A significant reduction in burden and stress scores were reported in the caregivers who had no occupation in the post test measurement after one week and one month from the educational programme.

Although increasing carer knowledge has been reported to be beneficial, two recent studies have failed to demonstrate that educational programmes produce a positive impact on caregivers.

Brodaty et al (1994) designed a six session training programme focused on the provision of information on the disease process, stress management and the management of disruptive behaviour in a group setting. Carers who completed the programme showed no reduction in psychological burden compared with controls. Cohen et al (1999) assessed the impact of an eight-session carer education and support programme. Although carer’s knowledge of dementia increased, the programme had no significant impact on their quality of life or psychological burden.

Structured teaching was not found to be effective in another study reviewed. Ostwad et al (1999) also reported from his study that there was no significant decrease in disruptive behaviour of patients compared with
controls, whereas carers in the control group experienced a marked rise in burden score after a multi dimensional training programme.

The numerous problems throughout the course of the dementia create a pile up of distressing life events with complex social, economic and legal implications. Cohen et al (1983) says that the family members, however, can be taught skills to help them be effective caregivers for a relative with dementia.

Caregivers need frequent counselling to express their problems. Now there is much research to show that when spouses join support groups & receive counselling to help them to cope with the effects of their partner’s symptoms, their partner feels better (Collin, etal, 1994). Caregivers who participate in awareness training and problem solving programmes are better able to manage difficult behaviour such as wandering and inappropriate sexual behaviour. (Ghatak, 1994).

Effectiveness of counselling for caregivers in the group living centre was studied by few researchers. In a recent study conducted by Elstahl et al (1997) in Sweden, it was found that total burden of caregiver decreased after 12 months of starting group living care and counselling programme.
Mignor (2006) reported that caregivers who used the services of home health nurse were significantly less burdened and less depressed than caregivers who did not use these services.

The effectiveness of structured teaching in reducing the burden was studied by Thara (1998). It was found that there was a significant reduction of burden for caregivers in family set up in Chennai.

A pretest - post test comparison of burden of female and male caregivers was done by Adam (2001). The caregivers were followed up for a period of six months. The difference in burden was not found to be significant during all assessment.

Barusch (1989) found a significantly higher burden among female caregivers. As per the researcher, lack of support system and other opportunities to vent the feelings were the probable reasons for this higher burden.

Counselling and support are not available for many due to lack of resources. The lack of counselling resources is related to the lack of information about the disease. It is important to explain and to inform the relatives & family about the nature and progression of dementia. It is also important to explore individual’s emotional and psychological reactions to
the deterioration of their relatives (Nori, 1995). The personal aspect of care must go hand in hand with education, counselling and support.

The spiritual dimension of care is also to be addressed in the teaching and counselling programme.

This chapter dealt with the theoretical overview and the selected important literature review related to the disease dementia, burden of caregivers and the effectiveness of structured teaching and counselling. The major share of literature is from west. The researcher has not come across much studies from India related to the teaching and counselling of caregivers of patients with dementia. It is evident from the majority of literature reviewed that there is a direct relationship between age and incidence of dementia. Dementia is an important health problem in the present and will be so in the future, all over the world. As there is no treatment, caring is the only treatment available for the disease. The disease can affect anyone who is aged, irrespective of their caste, creed, religion, sex, social and economic status, even though slight variations were reported in studies. It is also evident from the literature that the burden on caregiver is immense and that can be reduced with a properly structured education and counselling programme. Sufficient theoretical back up for all the concepts studied could be cited from the literature reviewed.