REVIEW OF LITERATURE

In this chapter an attempt has been made to call out the essentials of important observations and studies conducted in relation to different aspects of care-giving and related problems. For the purpose of understanding, the chapter is divided into five sections such as (1) Dementia and family Care givers, (2) Studies on basic issues in family care giving, (3) Emotional and social reactions of Care givers, (4) Carers intervention and (5) Therapeutic approaches to care.

2.1 DEMENTIA AND FAMILY CARE GIVERS

2.1.1 The Dementias

Dementia is not a normal part of ageing but refers to a group of diseases which are associated with progressive and chronic disruption of intellectual functioning (Gurland et al., 1983; Malamud, 1972). Changes in intellectual functioning include disturbances in memory, reasoning, judgement, problem solving, learning, abstract thinking, language, and perception. People with dementia can also manifest non-cognitive symptoms including personality changes, emotional difficulties, and challenging behaviour (Absher & Cummings, 1994; Katzman, 1976). Typically the person with dementia has difficulty maintaining occupational and social roles and their everyday living skills are compromised.

The most common kinds of dementing illness are Alzheimer’s disease and cerebro-vascular dementia. Alzheimer’s disease (AD), characterised by an insidious onset (Miller & Morris, 1993), is the commonest form of dementia and accounts for 50-60% of all cases (Blessed et al., 1991; Burns et al., 1996; Roses et al., 1989). A diagnosis of Alzheimer’s
disease is made by excluding all possible competing causes of dementia and can only be confirmed at autopsy. Despite a great deal of basic research having been conducted, the cause of Alzheimer's disease is still unknown (Zarit et al., 1985). Evidence of there being a genetic predisposition for Alzheimer's disease is most convincing in people whose dementing illness begins before the age of 65 (Haupt et al., 1992; McGonigal et al., 1992; Rossor et al., 1984; Whalley et al., 1982).

The second most common form of dementia is cerebro-vascular dementia also known as multi-infarct dementia (MID), which accounts for about 20% of cases. In this kind of dementia a failure in cerebral circulation (e.g., haemorrhage, thrombosis, embolism) causes infarcts (or areas of dead tissue) in the brain (Miller & Morris, 1993). The onset of this kind of dementia is usually abrupt and the loss of functioning occurs in step-wise pattern corresponding to the insults to the brain (Miller & Morris, 1993). While the causes of Multi infarct dementia is not clear, diet, smoking and genetic factors most probably pay a role (Jacques, 1992) and as such, some argue it is “potentially preventable” (Rocca et al., 1991). Mixed dementias, which account for a further 20% refers to dementia which is caused by both Alzheimer's disease and Multi infarct dementia.

2.1.2 Who is the informal care giver?

There are many definitions of a carer. It may be defined by the relationship spouse, child, professional; primacy - primary or secondary carer; living arrangement with the patient or separately; style of care routine, regular, occasional; by job description unpaid or paid; or as formal or informal (Barer & Johnson, 1990). Pearlin et al (1990) differentiate between caring the affective part of a relationship and care giving the behavioural component. Both are intrinsic to any close relationship but with impairment, there is increasing dependency and the restricting of the relationship so that care giving becomes dominant and overrides other aspects of the relationship, resulting in a loss of reciprocity.
A definition of a caregiver proffered by Zarit & Edwards (1996) is a family member (or friend) helping someone on a regular (usually daily) basis with tasks necessary for independent living. The care recipients or patients are dependent, disabled and mentally impaired persons with dementia, most commonly Alzheimer's disease.

The majority of carers, from 33% to over 60% are spouses (U.S.) Congress Office Of Technology Assessment, 1987; Wells et al, 1990; Brodaty & Hadzi - Pavlovic, 1990) of whom about 75% are women (Tsien & Cheng, 1999; Coen, Swanwick, O'Boyle & Coakley, 1997; Stone, Cafferata & Sangl 1987; Brodaty & Hadzi Pavlovic, 1990; Dwyer & Secombe, 1991; Dwyer & Coward, 1992), although the proportion does vary according to both the sampling techniques and the country surveyed, Adult children and their partners, make up about a third of informal carers, although in Asian countries such as China and Hong Kong, adult children are more often the carers than spouses (Tsien & Cheng, 1999; Patterson, Semple, Shaw et al, 1998). Moreover, daughters are far more likely to be primary carers than sons (Horowitz, 1985; Coward & Dwyer, 1990; Dwyer & Coward, 1991; Lee, Dwyer & Coward, 1993), outnumbering them in a ratio of about 4:1 (Brody, 1990). Likewise, daughters-in-law often inherit the burden of care, particularly in certain cultures such as in Korea and Hong-Kong (Lee & Sung, 1997; Lee & Sung, 1998; Choi, 1993; Tsien & Cheng, 1999; Patterson, Semple, Shaw et al, 1998).

About 4% of persons with dementia live alone (U.S. Congress Office Technology Assessment, 1987). Persons living alone are less likely to have a carer and likely to be institutionalised earlier (Brody, 1981; Mace & Rabins, 1982). There is an enormous difference between living with a person and caring from a distance. Spouses almost always live with the person with dementia, whereas adult children who are carers often live separately.
2.1.3 Why does family Care givers care?

Eisdorfer (1991) pointed that family carers are motivated to provide care for several reasons. It may be out of a sense of love or reciprocity: the bonds of fifty years, the credit points accumulated over a lifetime together, and the recognition that the other partner would provide care were the situation reversed. Care-giving may be seen as spiritually fulfilling. Other carers do it out of a sense of duty because they feel guilt or in response to social pressure or cultural mores. These latter carers are more likely to resent their role and suffer greater psychological distress than the former carers in the first two groups. The motivation is greed: the prospect of financial gain as a result of caring.

While the negative aspects of caring have received most attention, caring has been associated with benefits and positive feelings, such as a feeling of satisfaction, a feeling that they have helped the patient and a sense of meaning (Archhold, 1983; Miller, 1988; Sheehan & Nuthall, 1988; Walker, Jones & Martin, 1989).

2.1.4 Family structure and care-giving

Care giving grows out of the normative patterns of inter generational exchange and interaction. Strong social norms govern who is most likely to become a caregiver. By any estimation, gender is the single strongest predictor of who will become a caregiver, with women comprising approximately 70% of all caregivers. (Aneshensel et al., 1995; Stone, Cafferata, & Sangal, 1987). Most research has suggested that caregivers assume their role hierarchically within the family structure. Married individuals will turn first to a spouse for assistance in times of need. In the absence of a spouse, adult children are the next choice followed by siblings, more distant relatives and finally neighbours and friends (e.g., Penning, 1990). Wives, daughters, and daughters-in-law are the most common female caregivers and husbands the most common male caregivers, followed distantly by sons.
(Aneshensel et al., 1995; Sotone et al., 1987), who are only likely to assume the care giving role in the absence of a female sibling (Horowitz, 1985).

In studies of how siblings take responsibility for care tasks, Mathews (1987) (Mathews & Rosner, 1988) found that family structure (birth order, number of siblings, gender composition), history of parent - child affectionalities and extrafamilial roles (employment status, marital status and geographic proximity) all influence which sibling provides parent care (see also Brody, 1990). In families with two or more adult daughters, shared care was the norm, whereas sons consistently appeared to play less central roles.

Another important distinction in the care giving situation is whether or not the caregiver and care recipient share the same household (Chappell, 1990; Tenstedt, Crawford, & McKinley, 1993; Townsend, Noelker, Deimling, & Bass, 1989). Spouse caregivers usually live in the same household, but children may or may not live with a parent. An important source of cross-cultural differences is the extent to which aged parents and their adult children share a household (Sundstrom, 1992; Davery et al., 1996). In some countries such as the USA, rates of shared households have been relatively high, with children frequently taking in a disabled parent. In other countries, such as Sweden, two-generation households have been quite rare.

2.1.5 Caregiver - care recipient relationship

Providing care to an elderly relative with dementia presents stressors, which differ in fundamentally important ways from situations in which cognition is spread, or recovery is possible. In a comparison of caregivers of relatives with dementia and of relatives with cancer, Clipp and George (1993) found that dementia caregivers reported poorer self-rated health, greater substance use, poorer emotional health, reduced social functioning and poorer financial status, even when the effects of employment status, age, and duration of illness were controlled.
In spousal relationships, relationship quality between the Caregivers and care recipient may also play a role in the decision to institutionalise. Pruchno, Michaels, and Potashnik (1990b) found that spouses reporting a better quality of relationship with the care recipient reported less desire to institutionalise, but this finding did not extend to actual decisions regarding institutionalisation. By the same token, however, desire to institutionalisation, suggesting that an indirect link may exist.

2.1.6 Severity of dementia and Caregivers

The association between disease severity and carer health is complex (Baumgarten, 1989). Carers may respond quite differently to three manifestations of dementia: cognitive, functional and behavioural decline. Most studies have found no significant correlation between cognitive status and carer's psychological health. Functional decline is significantly correlated with restriction in carer activity (Deimling & Bass, 1986) but not with depressive symptoms. Deimling & Bass, 1986; Haley et al (1987) found that the patient's ability to perform instrumental activities of daily living (ADLs) was highly correlated with carer's depression score, but not with life satisfaction or self-rated health, which in any case is not strong, is that patients who have declined functionally are more likely to exhibit behavioural disturbances. Analyses have not allowed for the strong effect of behavioural disturbances on carer health.

The most consistent finding is the strong association between behavioural disturbances and carer distress. Despite differences in outcome measures, methods of assessing behavioural disturbances, populations and countries from which studies are reported, a robust and consistent finding emerges: behavioural disturbances account for about 25% of the variance in carer psychological distress (Brodaty, 1996; Mangone et al, 1993; Cohen et al, 1997; Bound & Buck, 1998). Certain types of behaviour are particularly likely to be associated with distress - incontinence, immobility, nocturnal
wandering, proneness to fall, inability to engage in meaningful activities, difficulties with communication, sleep disturbance, loss of companionship, disruptiveness, constant demands and aggression (Gilleard et al, 1982; Greene et al, 1982; Morris et al, 1988; Brodaty & Hadzi-Pavlovic, 1990).

Effective coping strategies can mitigate carer distress (Pruchno & Resch, 1989) and possibly enhance the quality of life for the dementing person. Problem-focused strategies - reframing, problem-solving, developing more social support or a greater social network - are associated with positive effects such as greater satisfaction with life, decreased feelings of burden and lower depression levels (Pruchno & Resch, 1989). Emotion-based responses (Lazarus & Folkman, 1984) - wishfulness, acceptance and fantasy (e.g. “Wish I was stronger person to deal with better”, “Accept the situation”, “fantasies about how things might end out”) are associated with more distress. The more immature the coping strategy, the greater the likelihood of increased burden, decreased satisfaction with life, and increased depression. Of course it may be possible that depression in carers leads to regression and to the adoption of less effective types of coping, which then perpetuates the depression.

2.1.7 Relationship factors

Premorbid unsatisfactory relationships are more likely to be associated with carer distress (Brodaty & Hadzi-Pavlovic, 1990). This may accompany the fragmentation of communication between couples, the increase in tension, the loss of companionship, the loss of a confidence, the increase in economic and household responsibilities and warning of sexual intimacy (Chenoweth & Spencer, 1986; Fitting et al, 1986; Wright, 1991). An association has been found between Expressed Emotion (EE) and distress in the daughters of people with dementia (Bledin et al, 1990) and carers in general (Fearon et al, 1998).
2.2. BASIC ISSUES IN FAMILY CARE-GIVING

In this section the emergence of family care giving as a major social issue is reviewed and four issues are presented which guide understanding of this phenomenon: (a) care giving as a career; (b) stress proliferation and containment; (c) the family context of care giving; and (d) the care recipient’s perspective.

Care giving has become an important concern because of the convergence of several social trends. The developed countries of the world are ageing societies, that is, increasing proportions of their populations are 65 years of age and older. In fact, the fastest growing segment of the population is the “oldest old”, people aged 80 years or over (Kinsella & Taeuber, 1993). Most of the older people live independently with few or no physical limitations, but the likelihood of disability increases with advancing age. By age 85 years, 60% of the population has at least some degree of disability, which requires regular, ongoing assistance (Zarit, Johansson, & Berg, 1995). Among 85 years old with no disabilities, approximately 30% develop problems over the next two years, and another 30% do so in the following two years. Clearly, there is a growing risk of disability at very advanced ages.

How the ageing of the population leads to increased risk of disability can be illustrated by the example of Alzheimer’s disease. Although this disease can occur in people as young as 40 years of age, the greatest risk of incidence is after 75 (Johansson & Zarit, 1995; Jorm, Kortem, Henderson, 1987; Kokman, Chandra & Scheonberg 1988). When most people in a society did not survive to 65, let alone 75 or 85, a disease such as Alzheimer’s had a trivial impact. The dementia syndrome has been described since antiquity, but it has only assumed importance since the 1950s as large numbers of people have survived to the ages of greatest risk. For people surviving to their mid 80s, the cumulative risk of developing dementia due to any cause before death may be as high as
47% (Johansson & Zarit, 1995). The result is that many older people require considerable assistance for a period of time before their death.

Extension of the average life span has meant that people have, on average, a longer period of active life. They are able to live independently into their 70s, 80s and even in some cases 90s. But the factors, which have led to improved life expectancy, better medical care and improved public health, may also be contributing to a prolonging of the period of disability at the end of life. The Expansion of Morbidity Hypothesis (Cassel, Rudberg & Olshansky, 1992) posits that people now survive longer with chronic diseases and with greater amounts of disability. While unequivocal data to support this hypothesis are not available, it is widely apparent that people with severe disabilities can survive for long periods of time. To cite one example, 50% of a sample of dementia patients (with varying diagnoses) were alive 11 years after the first set of symptoms, and just under 40% survived more than 14 years (Aneshensel, Pearlin, Mullan, Zarit & Whitlatch, 1995). This long duration of morbidity is an important factor in the heavy caregiver burden placed on families and society.

2.2.1 Care giving as an ongoing process: careers of caregivers

To describe this process, Pearline (1993) has introduced the model of care giving careers, that is, that care giving is a role involving certain predictable expectations and transitions. Using findings from a longitudinal study of caregivers of dementia patients (Aneshensel et al., 1995; Pearlin, 1993), Pearlin and his colleagues suggest three distinct phases in a caregiver’s career. First is the period of role acquisition, during which caregivers recognize the growing disability in their relative and make the decision to take on the care giving role. The tendency in dementing illnesses for patients to deny their problems or disabilities, especially as the disease progresses (e.g., Kaszniak, 1996),
undoubtedly contributes to family's ambivalence in recognizing the disorder and taking on care responsibilities.

The second phase in the care giving career is role enactment, during which caregivers provide regular, ongoing assistance to their relative. Role enactment includes providing care to people in the home and also in institutional settings. As we will see below, care giving does not end at the institution's door. Families remain involved in care. While placement relieves some stresses, it introduces other problems and challengers for the family (Zarit & Whitlatch, 1992). The transition from home to institution may also be one of the most stressful times for families. Most of the available research addresses the period of role enactment, especially concerning caregivers providing care in the home.

The third phase in care giving is disengagement, which is marked by the patient's death. Although psychological disengagement sometimes occurs sooner, death of the patient is a critical turning point that has complex effects on caregivers. Death of the patient is frequently welcomed when it brings release from a long, painful or deteriorated condition. Yet it also forces caregivers to re-examine and reorient their lives. Grief follows a predictable course, with symptoms greatest following the patient's death, and then gradually diminishing, although some caregivers remain distressed for a sustained period of time (Aneshensel et al., 1995).

2.2.2 Care giving stress: processes of proliferation and containment

Care giving has generally been viewed from the perspective of stress theory. Stressors represent all of the conditions, experiences, and activities that are problematic for people by thwarting their efforts, threatening their well being, and disrupting otherwise stable systems (Aneshensel et al., 1995; Pearline, Mullan, Semple & Skaff, 1990). Chronic stress creates a state of perpetual arousa that taxes the individual's usual ability to adapt to
the environment, and so compromises their ability to reach sought-after goals (Lazarus & Folkman, 1984).

A specific model is used to guide exploration of care giving. The stress process model, developed by Pearlin and his colleagues (Aneshensel et al., 1995; Pearlin et al., 1990) has been used to guide a major longitudinal investigation of caregivers of dementia patients. This model identifies three major components in caregiver's experiences: primary stressors, secondary stressors and outcomes. Primary stressors evolve directly from the needs of patient and represent the actual tasks of care giving. These stressors are called primary because they are intimately associated with the root of the stress namely, the chronic disabilities of the care recipient (Pearlin et al., 1990). Examples of primary stressors are behavioural problems, memory problems and difficulties carrying out activities of daily living (ADLs).

Coupled with the objective conditions of care giving are the caregiver's subjective appraisals of the memory problems, behavioural disturbances, and ADL deficits. Some primary stressors are more problematic or challenging than others and so can effect coping skills and erode caregiver's self-efficacy (Kinney & Stephens, 1989). Pearlin et al. (1990) specifically identify feelings of overload and role captivity, that is, a sense of being trapped in the care giving role, as primary subjective stressors. They also propose that the caregiver's sense of loss of the relationship with the care recipients should be considered a primary stressor.

Evolving out of the primary stressors are the secondary stressors. Although termed secondary, these stressors are of no less importance. They represent the way in which primary stressors encroach upon and disrupt other areas of the caregiver's life and thus are more variable and individual in their manifestation. Secondary stressors include family conflict, financial strain (e.g., reduced financial resources as a result of care giving) and
work conflict. They also involve psychological dimensions, such as diminished self-esteem and a feeling of loss of self, that the caregiver's identity has been absorbed totally in the care giving role (Skaff & Pearlin, 1992).

Stressors, however, do not have a fixed or constant effect on outcomes. The care giving literature has documented considerable variability in how caregivers adapt to similar circumstances (e.g., Aneshensel et al., 1995, Haley, Levine, Brown, & Bartolucci, 1987; Wright, Clipp & George, 1993; Zarit, Todd, & Zarit, 1986). The relation of stressors and outcomes is described in the stress process model in terms of two mechanisms; stress proliferation and stress containment (Aneshensel et al., 1995). Stress proliferation describes how the stressor involved in care giving infiltrate and disrupt other areas of the caregiver's life. Primary stressors lead in varying degrees to secondary stressors, which in combination lead to negative outcomes. Stress proliferation is greatest when caregivers are assisting someone with higher levels of behaviour problems and when there is a greater subjective effect of these stressors, for example, when caregivers feel overwhelmed or trapped in their role (Aneshensel et al., 1987; Zarit et al., 1986). Stress containment, in turn, describes how the caregiver's use of resources may limit or circumscribe the effects of stressors. How caregivers cope with specific problems as well as the amount of social and financial resources available to them can protect them from some of the adverse effects of stress.

The outcome of a particular configuration of care giving stressors is variable. The amount of variance in caregiver outcomes, such as expression that is accounted for by any particular stressor for example, the patient's behaviour problems or the amount of family conflict is statistically significant but relatively modest (Aneshensel et al., 1995). Instead, outcomes depend on the extent of proliferation or containment.
2.2.3 Care giving in a family context

Stress theory is useful for characterizing the problems and challenges faced by caregivers, but it does not take into account the specific family context in which care giving occurs. The relationship between caregiver and care recipient and their relationships with other family systems perspective focuses on what roles and functions a person performed within the family as well as the quality of these relationships (Zarit, Orr, & Zarit, 1985). Because of illness and disability, the care recipient can no longer perform certain activities and functions for the family. A spouse caregiver, for example, may experience the loss of a confident and sexual partner, and may have to take over activities that his/her spouse previously performed in the household. Besides these specific losses, care recipients and caregivers have varying amounts of prestige and influence in the family, which affects how much help and assistance other people will provide. Children who view a care giving mother as extremely competent may not view her as needing help. Conversely, a mother who is viewed as a needy or lacking competency may get too much help or a mixture of criticism and assistance. Care giving can also reawaken or intensify long-standing conflicts in the family.

2.2.4 The perspective of the care recipient

Lost in much of the care giving literature is the perspective of the person receiving care. In part, this omission is due to the extensive focus on providing care to people with dementia, who lose the ability to report their experience reliably as the disease progresses. This exclusion, however, means that the care recipient’s perspective is often overlooked. Care recipients can continue to provide some types of help, assistance, or comfort to the caregiver even in cases of moderate to severe dementia. The care recipient’s well being
and needs should be considered along with the caregiver's in decisions about living arrangements and care. It is important to consider whose interests are being represented when making a clinical intervention. What is good for the family may, not have been in the patient's best interest in some circumstances? The clearest example is nursing home placement, which relieves strain on families but puts the dementia patient at risk for a variety of adverse outcomes, including an increased risk of mortality (Aneshense et al., 1995). Though often omitted from research, the patient's perspective needs to be incorporated consistently into clinical intervention.

2.3. SOCIAL AND EMOTIONAL REACTIONS OF CARE GIVERS

Dementia is an "unremitting burden" on the family (Anderson, 1987). Caring for a person with chronic mental condition is more stressful than caring for a person with a physical disorder or disability (Lezak, 1978; Gillears, 1984; Mohide, Torrance & Streiner et al., 1988; Poulshock & Deimling, 1984). The effects on family carers are diverse and complex and there are many other factors which may exacerbate or ameliorate how carers react and feel as a result of their role.

2.3.1 Emotional problems of Care givers

Care giving is a uniquely stressful event. Being a long-term caregiver has been found to be associated with a variety of negative outcomes. The consensus among studies examining physical and mental health outcomes is that a majority of caregivers report feeling physically and emotionally distressed (Anthony-Bergstone, Zarit & Gatz, 1988; Brodaty & Hadzi Pavlovic, 1990; Clipp & George, 1990b; George & Gwyther, 1986; Haley, Levine, Brown, Berry, & Hughes, 1987; Kinney & Stephens, 1987). Several studies report higher levels of psychological morbidity among caregivers compared to no care giving samples of the population. Anthony-Bergstone and her colleagues (1988) noted the
increased feelings of hostility, anger, and anxiety among caregivers as compared to the general population. An Australian study showed that mean scores on the General Health Questionnaire (GHQ), a measure of psychological morbidity, was higher in the care giving sample and among care giving spouses than the general population or other sub samples of caregivers (Brodaty & Hadzi-Pavolovic, 1990). Women caregivers' generally report higher levels of psychological distress than men (Anthony-Bergstone et al., 1988; Zarit & Whitlatch, 1992).

Schulz, Visintainer, and Williamson (1990) reviewed several studies showing the psychiatric morbidity effects of care giving. In studies using self-report measures such as the Beck Depression Inventory (BDI) or the Centre for Epidemiological Studies Depression Scale (CES-D), three general conclusions emerged. First, greater severity of the care recipient's problems is linked to more depressive symptomatology. Second, women have higher rates of depression than men. Third, the more representative the care giving population, the lower the rate of depression. Thus, caregivers drawn from specific sub samples such as daughters taking care of severely demented relatives or those seeking help from a service program show higher rates of depression symptoms.

A second group of studies has used clinical assessment tools (e.g., the Schizophrenia Interview), which yield rates of clinical diagnosis of depression and other problems. These studies have found that caregivers frequently meet diagnostic criteria for depression or other diagnoses (e.g., Cohen & Eis dorfer, 1988; Drinka, Smith, & Drinka, 1987: Goldman & Luchins, 1984). In one of the most comprehensive studies of this kind, Gallagher and colleagues (Gallagher, Rose, Rivera, Lovett, & Thompson, 1989) found prevalence rates for depression ranging from 31% for men to 46% for women. These studies provide strong evidence that caregivers are at the risk of increased psychiatric symptoms and clinical disorders.
The model of the stress process illustrates how primary and secondary stressors can have a cumulative effect on caregiver’s mental well-being and physical health. Among the primary stressors, behaviour problems are most likely to lead to adverse outcomes for family caregivers. The common behaviour problems identified by caregivers as difficult or stressful for them are incontinence of the bowel and/or bladder, crying easily, hiding things, acting restlessly or agitated, and becoming irritable, angry, or accusatory (Haley & Pardo, 1989). These behavioural problems require vigilance, surveillance, and control on the parts of the caregiver. Pruchno and Resch (1989) found that asocial and disoriented behaviours on the part of the care recipient are associated with greater burden, decreased social participation, and less satisfaction with care giving. For forgetful behaviours, the consequences for caregiver’s mental health increase at first, and then diminish as the severity of behaviour problems increases, suggesting a curvilinear relationship between the two.

In a study of depression in dementia caregivers, Redinbaugh, MacCallum, and Kiecolt-Glaser (1995) found that caregivers who experienced chronic depression over a three-year period reported their relative’s behaviour as more problematic and had higher levels of upsetting social support than non depressed caregivers or caregivers who had experienced a transient depressive episode during the course of the study.

Vitaliano and colleagues (Vitaliano, Young, Russo, Romano, & Magana-Amato, 1993) were interested in examining the possibility that caregiver’s behaviour, specifically in the form of expressed emotions, were predictive of subsequent care recipient behaviours one and a half years later. Controlling for initial levels of problem behaviours, dementia patients who were cared for by an individual with high levels of expressed emotion displayed significantly more negative behaviours at follow-up. These findings are significant because caregiver’s expressed emotion is correlated with higher levels of
depression, suppressed anger, and lower life satisfaction (Bledin, McCarthy, Kiupers, & Woods, 1990; Vitaliano et al., 1993).

2.3.2 Psychological morbidity

Carers, who are women, and those who are spouses, have higher rates of psychological morbidity than their counterparts (Fitting et al, 1986, 1992; Baumgarten et al. 1992). The spouses of younger patients may have higher rates of psychological morbidity, perhaps because of the increased stresses inherent in being married to a younger person with dementia and the increased likelihood of having younger children at home (Luscombe et al, 1998).

Carers who cohabit are more likely to be depressed or psychologically stressed than those living apart (Broadly & Hadzi - Pavlovic, 1990; Harper & Lund, 1990; Gilhooley, 1984; Wels & Jorm, 1987; George & Gwyther, 1986). The gender of the patient does not appear to affect carer well being once allowance is made for the increased likelihood for behavioural disturbances in men (Brodaty & Hadzi-Pavlovic, 1990).

There have been no consistent association found between carer age and psychological distress, with higher levels having been reported in older carers (Fiore, Coppel, Becker et al, 1986) and in younger supporters (Gilleard et al, 1984). However, such comparisons need to control for the effects of relationship in looking at age.

In five studies, scores on the General Health Questionnaire (GHQ; Goldberg, 1978) were used to provide a measure of psychological distress in caregivers. Three of these papers noted an independent association between aspects of non-cognitive disturbance and GHQ morbidity (Brodaty & Hadzi - Pavlovic, 1991; Draper et al, 1992; LoGiudice et al, 1995). In Eagles et al’s (1987) comunity study, scores on a combined measure of disturbed and dependent behaviours (night time wandering, incontinence, immobility) were found to be highly correlated with GHQ scores. Separate assessments of dependent
behaviours in patients were made by Brodaty & Hadzi-Pavlovic (1990), Draper et al (1992) and LoGiudice et al (1995), but these authors did not report a relationship with psychiatric distress. Eagles et al (1987a), Reis et al (1994) and LoGiudice et al (1995) looked at the impact on carers of cognitive deficits in patients, but no associations with GHQ scores were noted.

These investigations suggest that GHQ morbidity in carers is closely associated with patient psychopathology. These findings are consistent with the literature on care giving in other disorders (e.g. cancer), which report a strong correspondence between psychiatric distress in patients and relatives (Baider & Kaplan D-Noir, 1988).

The relationship between non-cognitive disturbances in patients and caregiver depression was examined in six studies. Haley et al (1987) and Brodaty & Hadzi Pavlovic’s (1990) investigations used bivariate correlations to examine these data, but did not report a significant relationship between these variables. Gilleard et al (1982), however, revealed a significant correlation between depressive mood ratings in carers and demand behaviour in patients, although disturbance problems (accusations, temper outbursts, bad language, and aggression) showed no association. The three remaining studies Deimling & Bass, 1986; Pruchno & Resch, 1989; Baumgarten et al, 1992) employed large numbers of subjects and used multivariate procedures to analyse this relationship. All of these papers reported a strong positive relationship between caregiver depression and aspects of non-cognitive disturbance in patients.

The balance of evidence is marginally in favour of an association between non-cognitive features (NCFs) and caregiver depression. Although the contradictory findings reported by Haley et al (1987) and Brodaty & Hadzi-Palvovic (1990) could be explained in terms of the limitations of correlation tests or lack of statistical power in smaller scale
investigations, further research is required to enable the nature of this relationship to be
determined conclusively.

A large body of evidence suggests that family caregivers for patients with Alzheimer’s disease experience substantial risk for depression. Recent reports suggest that 30 to 55% of Alzheimer's dementia caregivers report clinically significant depression on self-report instruments. Another study of caregivers of all patients with coexisting depression found that more than 70% of these caregivers had depressive disorders. Mental health effects of care giving have been found to persist even after nursing home placement or the death of the patient. (William & Healey et al)

Numerous studies have demonstrated increased psychological morbidity in carers (e.g. Grafstrom & Winblad, 1995; Gilleard et al, 1982, 1984; Brodaty & Hadzi - Pavlovic, 1990; Poulshock & Deimling, 1984; Morris et al, 1988; George & Gwyther, 1986). Depression levels and rates are also high (Rosenthal et al, 1993; Gallagher et al, 1989; Pearson et al, 1993; Mittelman et al, 1995; Morris et al, 1988, Naley et al, 1987; Schulz & Williamson, 1991; Baumgarten et al, 1992). For example, Gallagher et al found that amongst carers seeking help, 26% met Research Digenetic Criteria (RDC) for major depression and 8% for minor depression. Rates among non-help-seekers were 10% and 8% respectively. In a study by Coope et al (1995) of 100 carers of research subjects, 29.4% met GMS-AGECAT criteria for major depression, and 11.9% met criteria for minor depression. Mittelman et al (1995) reported that over 41.7% of carers had a Geriatric Depression Scale score of 11 or greater, the rate being higher amongst women (50%) than men (30%).

2.3.3 Behavioural problems of the Care givers

Research confirms this varying impact of behaviour problems on caregivers (e.g., S.Zarit et al., 1986). Measures of primary stressors, such as the extent of disability or
number of behaviour problems, account for a surprisingly small portion of variance of subjective strain and well-being. Even when the constellations of stressors are similar, the outcomes can be quite different. Perhaps the best test to date of the impact of disabilities and behaviour problems is a study that followed caregiver's longitudinally over a 4-year period (Aneshensel et al., 1995). Using a longitudinal perspective, it was possible to evaluate how increases or decreases in stressors affected caregivers' emotional well-being. Stressors such as behaviour problems accounted for a significant but surprisingly small proportion of changes in well-being over time.

We see a similar pattern with secondary stressors. Some employed caregivers find the added demands and pressures of caring for a spouse or parent overwhelming. Other caregivers, however, report that their employment gives them a break from care giving. Research generally indicates that working care givers are not worse off than comparable people who are not employed (e.g., Scharlach, 1994; Brody, Kleban, Johnsen, Hoffman & Schoonover, 1987), though the amount of strain may depend partly on the ability of working caregivers to find paid help to supplement their efforts.

2.3.4 Problems with activities of daily living

Seven studies examined the relationship between activities of daily living (ADL) limitations (self-care problems and difficulty carrying out everyday instrumental activities, e.g., using transport, managing finances) and caregiver burden. Six papers did not report a significant independent relationship between these variables (Zarit et al, 1980; Gilleard et al, 19982; Greene et al, 1982; Farran et al, 1993; Weiler et al, 1994; Lo Giudice et al, 1995), but Harper & Lund (1990) found that ADL limitations predicted burden in female carers but not in males.

Qualitative features of the patient-carer relationship may influence the degree of commitment relatives have towards care for the dementia sufferer (Morris et al, 1988).
Two studies (Greene et al, 1982), Deimling & Bass, 1986) examined the advances changed in the patient - carer relationship as an outcome variable. Both reported the aspects of disturbed behaviour in patients such as aggression, mood changes and withdrawal were closely related to negative changes in caregiver's feelings towards the dependant. These behaviours may exert the influence on carer - patient affiliation disrupting the bonds of affection and reciprocity that are vital in maintaining interpersonal relationship (Horowitz shindelman, 1983).

2.3.5 Burden in care-giving

Two models of the effects of care giving adapted from the work of Poulshock & Deimling (1984) dementia lead to dependency and problem behaviours, which impose an objective burden on the carer. The results of this on carers vary. Strain may manifest itself psychologically, physically, financially, socially or through increased use of health services. Carer strain may be influenced by patient, carer, protective and exacerbating variables.

In the second model from Pearlin et al (1990), which overlaps with the first, there is a background and context, which leads to primary stresses, secondary role strains and secondary intra-psychic strains. Several variables can mediate the results of these leading to different outcomes.

*Objective and Subjective burden*

Objective burden reflects the dependency of the patient, as evidenced by the loss of activities of daily living, instrumental activities, cognition, other abilities, companionship and communication. Problem behaviours and psychiatric disorders that commonly accompany dementia are further types of objective burden.
Subjective burden is the appraisal by the carer herself. It includes feelings of entrapment, resentment, stress, overload, inability to cope and exhaustion. Activities become restricted and outside relationships diminish.

2.3.6 Coping

Gilhooly (1987) looked at coping strategies used by supporters of the dementing elderly. Adapting the work of Pearlin and Schooler (1978) she differentiated between 'behavioural' coping and 'psychological' coping. Behavioural coping referred to finding out and make use of health and social services and the organisation of help from family and friends. Psychological coping referred to efforts to modify and control the meaning of the stressful experience. Gilhooly found that those supporters who used behavioural strategies had higher morale than those who used only psychological ones. Those who were coping least would be tended not to use any of the techniques and had the lowest morale. Male supporters were greater users of behavioural coping than were the female supporters. Whithik (1993) conducted a study to determine the native and range of the coping techniques used by 100 supporters of the dementing elderly. Qualitative and quantitative measures were used. The qualitative part of this study provided good descriptive detail about the ways in which the supporters were coping with the daily stresses of caring for someone with dementia and revealed main categories of coping: verbal action, practical action and withdrawal.

2.3.7 Physical morbidity

Carers have poorer physical health than non-carer controls (Schulz et al, 1990), higher levels of chronic conditions, prescription medications and doctor visits (Haley et al, 1987) and more physical symptoms and poorer self-rated health (Baungarten et al, 1992). Those with poor psychological health are even more likely to have physical morbidity (Brodaty & Hadzi - Pavlovic, 1990). The findings of decreased immunological
competence in carers of Alzheimer's disease patients (Kiecolt-Glaser et al, 1987) have been supported recently. Vehara et al (1999) reported that elderly carers of spouses with dementia have increased activation of the hypothalamic-pituitary axis and a poor antibody response to the influenza vaccine. They concluded that carers may be vulnerable to infectious diseases.

Other indicators of poorer physical health are increased such as service use - hospitalisation, physician visits, drug use, aggregate use of health service; and less healthy behaviours as reflected by use of alcohol, smoking, sleep patterns, eating behaviour and nutrition (Schulz & Williamson, 1997). Further, pre-existing conditions such as hypertension are more likely to be exacerbated by the care giving role (Schulz & Williamson, 1997).

Four research groups investigated the impact of patient variables on caregivers' physical health. Small-scale correlations studies by Haley et al (1987) and Brodaty & Harzi-Pavlovic (1990) did not reveal any significant relationships between patient impairments and caregiver health, and no patient variables made an adequate independent prediction of physical well-being of caregivers in Baumgartern et al's (1992) study. Deimling & Bass (1986) used a path analytic approach to examine the effects of behavioural deficits on caregivers in their large-scale study of elderly, mentally impaired patients. They reported that while ADL limitations had the strongest direct effect on caregivers' physical health, disruptive behaviour and social functioning deficits (e.g. level of co-operation, withdrawal) also had significant effects.

2.3.8 Social Isolation

Dementia is a very isolating condition. At the very time that families need more support, their friends feel unsure about what to say on the taboo topic of dementia, they are disconcerted by the patient’s lack of communicativeness and feel embarrassed by the
patient's displays of disinhibition (Brodaty, 1998). They may feel uncomfortable about the
carers' distress and tend to avoid paying visits. Simultaneously, carers abandon their
leisure pursuits and hobbies, stop seeing friends and discontinue employment. Their lives
become focused on the caregiving role, which takes up most of their time (Brodaty,
1998a). In a survey of Australian carers, it was found that half the carers had seen a person
from outside their home only once a week or less often (Brodaty & Hadzi-Pavlovic 1990).
The multiple demand of caregiving is known to put supporters at risk of social isolation
(Gilhooly, 1987). Two larger studies have investigated the influence that patient
impairments have on carer's participation in social activities. Deimling & Bass (1986)
noted that ADL limitations and disruptive behaviour had adverse effects on caregiver's
social participation and Pruchno & Resch (1989) reported disoriented and disruptive
behaviours linked to reductions in caregiver's social activities. ADL impairments were
assessed in this study. Greene et al examined the relationship between patient's behaviour
and a variable they called upset', which assessed caregiver's social household routine and
holidays.

2.3.9 Financial Problem

There are considerable financial costs to families looking after persons with
dementia. The direct costs are those of medical consultations, investigations,
pharmaceuticals, provision of personal and nursing care and later, residential care. Indirect
costs comprise loss of earnings by the patient and by family carers if they have to
relinquish employment.

Most of the care for patients at home is provided informally by family members
and friends (Max, 1999). While the cost of caring for an institutionalised patient is twice
the cost of caring for a patient at home (Hu et al, 1986), the total social cost of care per
person was nearly the same in two settings when both paid and unpaid informal care were
included (Rice et al, 1993). However, most of the expenses for patients living at home are borne by their families (Rice et al, 1993; Gray & Fenn, 1993; Stommel et al, 1994). As the disease progresses, the cost of care increases. Hu et al (1986) found that severely demented patients required more than twice as many hours of informal care as mildly demented ones. Others have found rates of 1.28-1.63 times greater costs for severely demented patients compared to mildly dementing ones living at home (Rice et al, 1993; Souetre et al, 1995). Max (1999) went on to conclude that “Alzheimer’s disease is extremely costly, no matter how it is measured and what cost is included for patients cared for at home, most of the care is provided informally by family members and friends and most of the burden of care for patients at home is borne by their families, in the form of out-of-pocket payments for services or in the form of hours of time spent caring for the patients without reimbursement”.

2.4. CARE GIVER’S INTERVENTIONS

Education, support groups and provision of information have limited efficacy in reducing carer distress, although they have been demonstrated to result in carer satisfaction with the training and increase in knowledge (Brodaty, 1992). Several studies have demonstrated that carer interventions can reduce carer stress or burden (Kahan et al 1985, Zarit et al, 1987; Lovett & Gallagher, 1988; Mittelman, 1993; Mittelman et al 1995; Brodaty & Gresham, 1989; Brodaty & Peters 1991; Hinchcliffe et al, 1995).

Two studies are particularly noteworthy because, in addition to reducing carer psychological morbidity, they demonstrated that nursing home admission could be delayed by almost a year. The first was a ten-day intensive, comprehensive and extensive training programme for groups of up to four carers and their charges in a residential setting (Brodaty & Gresham, 1989). The programme consisted of counselling, provision of information, practical advice, role plays and skills training. For the following year the
groups of carers were linked by telephone conference calls second weekly, then fourth weekly and sixth weekly. The program was part of a randomised controlled trial with one group of carers receiving training immediately, a second group after six months delay and a third group no training at all. For the third or control group, patients were admitted for ten days and participated in a memory re-training program while their carers had ten days respite. All groups of carers had similar telephone conference links over twelve months (Brodaty & Gresham, 1989). At the end of the twelve months, patients declined uniformly on tests of cognition and function regardless of which group they were in. However, the carers in the immediate training program had a significant decline in their General Health Questionnaire (GHQ) scores, a commonly used measure of psychological morbidity, while the GHQ scores of control carers rose. The GHQ score of the delayed training carers remained steady. Rates of institutionalisation were significantly lower for both carer training groups over 8 years follow-up. For example, at four years 55% of patients in the immediate dementia care giving training programme, and 40% of those in the delayed program, were still at home, whereas, only 8% of patients whose carers were in the control group were still at home (Brodaty, Gresham & Luscombe, 1997). Although the program was more costly than necessary, as it was residential and conducted within a hospital setting, it still resulted in savings of about USD $ 6000 per couple over 39 months, because of the delay in nursing home admission (Brodaty & Peters 1991).

Mittelman and colleagues demonstrated almost identical findings using a different modality of intervention (Mittelman et al, 1993; 1995; 1996). Carers were randomly assigned to receive counselling or standard management. The counselling condition consisted of four family sessions and two individual sessions but ad libitum contact and the availability of weekly support group meetings. The counselling program was effective in reducing depression scores (Mittelman et al, 1995) and delaying nursing home
admission (Mittelman et al, 1996). Over eight years, there was a delay in nursing home admission in the counselling condition by a median 327 days (Mittelman et al, 1996).

2.4.1 Support

The relationship between support and carer outcome is extremely complex. There are differences between actual and perceived support, formal (from professionals) and informal (from friends and relatives) support, between psychological and instrument support, and between how males and females use support (Brodaty, 1994). Enright (1991) reported that husbands were more likely to receive help than wives. There is also the potential for negative effects from so-called supportive figure (Fiore et al, 1986; Edwards & Cooper, 1988).

An association between the number of supports and carer distress might merely reflect an increased likelihood of distressed carers seeking help; while a negative correlation could suggest that support has an ameliorating effect (Brodaty, 1994). A lack of either a positive or negative correlation might result where both effects occur in the one population being sampled. Also carers who use more informal services may need less professional help and make fewer demands on community services (Fitting et al, 1986; Chesterman et al, 1987). Finally, gender and culture influence the use of informal support. For example, men, who are more likely than female carers to seek help, and African-American carers, who are more likely than Caucasian carers to engage with larger extended networks of family and friends, both have lower levels of psychological distress than their counterparts.

In summary, there is support for a relationship between informal supports and lower psychological distress, but it may be that happier people are more included to seek contact in the first place or that lack of happiness and social support are independently
related to disturbing behaviours. Carer satisfaction with social support is generally associated with better health (Gilhooley, 1984; Fiore et al, 1986). It may be that unhappy carers perceive the world negatively in general and so rate the satisfaction with their supports in the same way, thus contaminating the results. On the other hand, social support may provide a protective buffer against stress but have little effect on those who are not exposed to stress (Baumgarten, 1989).

2.5. THERAPEUTIC APPROACHES TO CARE

Gilhooly et al (1994) point out that the decline observed in dementing illnesses may be as much a function of the social care received as of the biological cause. This section will discuss a variety of therapeutic approaches to care: psychological care approaches and activities; therapeutic environments; supportive technologies and empowerment strategies. Ideally these approaches work in concert. However, for purposes of discussion these approaches are dealt with separately.

2.5.1 Psychological care strategies

There are an increasing number of psychological therapies and activities that challenge the therapeutic nihilism commonly found in the care of people with dementia. This review will focus on the most common programmes, which include: reality orientation, reminiscence therapy, validation therapy, therapeutic activities and expressive therapies.

Reality orientation and reminiscence work are the two most commonly used psychological approaches when working with people with dementia (Morton & Bleathman, 1991). Reality orientation (RO) is both an informal technique for one-on-one interactions and a kind of group work (Bleathman & Morton, 1994). The group sessions are intended to supplement visual and verbal cues in order to mitigate the disorientation,
which accompanies dementia (Morton & Bleathman, 1991). The basic tenet of RO is that inaccuracies made by the person with dementia should be confronted.

Evaluations of RO suggest that this approach does improve orientation. However, critics point out that the absence of any long-term effects or short-term changes in behaviour question the merit of this approach. Proponents of RO improve the quality of interactions between carers and people with dementia.

a) **Reminiscence work (RW)**, usually conducted in a group setting, is based on Butler's (1963) notion of life review whereby with age we review our lives to make sense of and resolve, past conflicts (Morton & Bleathman, 1991). Reminiscence work with people with dementia involves using a variety of aids to prompt memory and affirm the sense of self. Most recently, emphasis has been placed on personalising the aid such that they have relevance for a particular person or group. Evaluation studies, though rare, suggest that reminiscence work may improve mood (Goldwasser et al., 1987) and increase knowledge of the person with dementia (Baines et al., 1987) Gibson (1994) provides a useful guide for doing reminiscence work with people with dementia.

b) **Validation therapy (VT)** was developed by Naomi Feil (Feil, 1982) as an alternative to reality orientation (Morton & Bleathman, 1991) VT challenges the basic tenet of RO by focusing on the importance of affirming rather than confronting the sense of reality of the person with dementia. It assumes that the person's behaviour and speech has an underlying meaning. As such, the listener 'validates' what is said by attending to the emotional rather than the factual content (Bleathman & Morton, 1992). Like RO, VT can be conducted in group settings or during individual interactions. Most of the evidence about the effects of this therapy is provided by anecdotal reports. Bleathman and Morton (1992) suggest that people with dementia improve in functioning during the group sessions and conclude that this therapy holds great promise which awaits empirical verification.
The benefits of providing stimulating activities to people with dementia have been known of some time. Most of the literature on activities has centred on group activities conducted in residential and day centre settings (Mace, 1987; Zgola, 1987). However, activities can be used by carers in home settings (Teri & Logsdon, 1991). The aim of therapeutic activities for people with dementia is to maintain optimal functioning and improve quality of life (Zgola, 1990). Effective activities would also affect the carer’s stress and frustration level (Zgola, 1990).

Zgola (1990) stresses those activities for people with dementia should not be limited to traditional structured activity programmes, which focus on recreation and diversionary activities but be broadened to include a range of daily activities. Such activities provide the person with dementia an opportunity to experience a sense of mastery and success so severely compromised with dementia. It is important, therefore, to have a clear idea of a person’s values and previous life style when choosing an appropriate activity (Zgola, 1990). Teri and Logdon (1991) describe a tool, which can be used to identify events, and activities, which are pleasant for the person with dementia.

Archibald (1993) and Bowlby (1993) provide a useful guide to a variety of activities, which carers can use with people with dementia. The ranges of activities, which are possible, are being expanded with technological innovations (Maki, 1994).

Expressive therapies include the use of dance, movement, visual art, and music (Aldridge, 1993). In addition, aromatherapy (Henry, 1993) and other approaches have been described but little empirical investigation of their effect has been conducted (Bleathman & Morton, 1994).

2.5.2 Care in the community

The majority of people with dementia are cared for in the community by relatives. With some exceptions (e.g., Gilhooly, 1984), the stressful nature of caring for a relative
with dementia has been amply documented in the past 15 years (Anthony-Bergstone et al., 1988; Deimling & Bass, 1986; Gatz et al., 1990; George & Gwyther, 1986; Gilleard, 1987; Gilleard et al., 1984; Levin et al., 1989; Pruchno & Resch, 1989; Zarit, 1990a). Carers have been called the hidden victims' because caring costs families in terms of problems with physical health, emotional well-being, financial hardship, employment, social activities and relationships (Zarit et al., 1985).

Care giving families are well known for their determination to continue caring, often without any formal support (Levir et al., 1994), until they reach a crisis point which precipitates institutionalisation (Montgomery & Borgatta, 1989; O' Connor et al., 1988; Tyrrel, 1993; Zarit et al., 1985). The literature presents a confusing picture with respect to predictors of institutionalisation. Some studies suggest that characteristics of the person with dementia predict institutionalisation (Gilleard, 1984) whereas others emphasise the importance of carer characteristics and the nature of the caring relationship (Colerick & George, 1986; Levin et al., 1994; Morcysz, 1985). Nevertheless, most agree that providing support to carers is a critical component of effective community-based dementia care (Levin et al., 1994; Zarit et al., 1985).

Critics point out that community-based services should not be judged solely on their role in preventing or delaying institutional care (Gilhooly et al., 1994; Weissert et al., 1995). Their role in alleviating carer burden should be viewed as being an equally important outcome (Zarit & Teri, 1991). Furthermore, Gilhooly et al (1994) and Weissert et al (1985) argue that carers' preference for, and satisfaction with, community-based care is sufficient justification for promotion of these services. For example, while Lawton et al (1989) found no evidence for deceased stress or institutionalisation following respite, carers reported high levels of satisfaction with the service.
2.5.3 Effectiveness of community based services

The most common kinds of community-based care that are provided include: 1) support groups and training; 2) respite: day care services and residential respite; and 3) home support. It is important to recognise that both the development and research of these services are relatively recent phenomena (Zarit & Teri, 1991). Most of the literature is concerned with describing these services and the people who use them rather than with evaluating their effectiveness (Levin et al., 1994)

a) Support groups and training

Support groups are a popular, though poorly researched, approach to helping carers cope with the stress of caring. Support groups provide information and opportunities for mutual support.

Research evidence of the effect of support groups in alleviating carer burden presents a confusing picture (Toseland & Rossiter, 1989). While carers report decreased burden and improved well-being following support group attendance, this is not corroborated by more objective measures or when experimental designs are used (Haley et al., 1987; Zarit et al., 1987). As discussed earlier, this may be because the objective measures used do not assess relevant outcomes (Gatz et al., 1990; Haley et al., 1987). As mentioned earlier, knowledge about dementia or coping skills might be a more appropriate outcome than well-being or mood.

Studies, which examine the role of support groups in delaying or preventing institutionalisation, produce some unexpected findings. Haley (1989) suggests that attendance at support groups increases the likelihood of admitting one's relative to institutional care. This he attributes to their having been prepared for the transition by their attendance at group meetings.
There is some evidence that educating carers can affect both their sense of burden and the likelihood or their institutionalising their relative. Brodaty and Gresham (1989) have found that a ten-day residential training programme for cares was associated with decreased psychological distress for the carer and delays in institutionalisation for the person with dementia. These effects were particularly marked for carers who were provided with training early in their caring career and these effects lasted beyond the initial 12 month period to three years after training (Brodaty & Peters, 1991). Teri and Uomoto (1991) found carers' depression was alleviated after they had been trained to apply behavioural principles when caring for their relative with coexisting depression and dementia.

b) Respite

Respite is one of the most commonly requested services by carers (Gatz et al., 1990; Mace, 1986). Respite is offered for varying lengths of time from a few hours during the day to short-term placement, which is usually residential but can also be provided at home (Gatz et al., 1990). Respite services were developed to provide the carer with time off from the continual demands of caring (Levin et al., 1994) with a view to reducing carer stress and delaying institutional care. Consequently, research on their effectiveness tends to focus on the carer to the exclusion of the person with dementia.

As with the support group evaluations, carers report high degrees of satisfaction with respite care (Burdz et al., 1988; Lawton et al., 1989; Levin et al., 1994). However, predicted decreases in burden and stress have not been supported (Lawton et al., 1989) and some carers have been more likely to resort to long-term residential care for their relative following respite (Burdz et al., 1988). In the United States, Lawton et al (1989) found that while carers reported satisfaction with respite, these services had little effect on either carer burden or likelihood of institutionalisation. However, while some have concluded
that respite services are an ineffective approach to community-based care (Callahan, 1989), others have questioned the adequacy of the methodology employed (Zarit, 1990b).

c) Day Care Services.

Day time respite care is one of the cornerstones of community-based services for people with dementia in Europe and the United States (Moriarty & Levin, 1993). Despite its key role it has been a relatively neglected area of research. Levin et al's (1994) recent study of respite services in Britain suggests by its title alone that day care is a valuable service to people with dementia and their carers.

d) Residential Respite.

Residential respite programmes have been described by Burdz et al (1988), Miller et al (1986) and Scharlach Frenzel (1986). Evidence suggests that carers show decreased levels of return to baseline when the relative returns home (Adler et al., 1993). Both Miller et al (1986) and Sharlach and Frenzel (1986) found that experience with residential respite increased the chances of placing a relative in a long-term care setting. Burdz et al (1988) explain this finding by suggesting that the temporary relief provided by respite makes carers more aware of the difficulties they face and less willing to continue caring. Gatz et al. (1990) suggest that for some people respite may function as a trial nursing home placement.

e) In-Home Respite.

Levin et al (1994) recommend that in-home respite services be developed more fully. At this time in-home respite appears to be the most sought after, yet least well developed, form of respite for carers.
Home support schemes provide a variety of different services including help with daily living tasks; mental, physical and emotional support to the person with dementia; respite for the carer; support and information to the carer and care management.

Home support provision is a relatively new service for people with dementia and their carer's (Askham & Thompson, 1990). The limited research in this area presents a confusing picture. While several studies found no change in various measures of stress and depression following home support services (Askham & Thompson, 1990; Lundervold & Lewin, 1987; Mohide et al., 1990), others found improvements in carers' well-being and burden (Turvey & Toner, 1990; Quahagen & Quayhagen, 1989). These conflicting findings can in partly be explained by the different kinds of home support examined. Those, which were found to be effective, tended to offer a more comprehensive range of home-based services.

The evidence of the role of home support in delaying or preventing institutionalisation is equivocal. Studies found that institutionalisation was delayed (Ferguson & Hynd, 1993) provided more comprehensive services than those, which found no such evidence (Askham & Thompson, 1990; Mohide et al., 1990).

One conclusive finding regarding home support services is the differential rates of use between male and female carers. Interestingly, home support services appear to play a greater role in preventing institutionalisation of people with dementia cared for by male than female relatives (Colerick & George, 1986).

Studies, which have examined the effect of home support schemes on people with dementia, are rare. The limited research has yielded conflicting findings. Some studies have found that cognitive functioning and behavioural difficulties remain stable (Quayhagen & Quayhagen, 1989) and quality of life is improved (Ferguson & Hynd,
1993), while others found home support to have no such effects (Askham & Thompson, 1990). However, the potency of Askham and Thompson’s (1990) intervention and the adequacy of their control group have been questioned.

2.6 CONCLUSION

One of the major features of an ageing society is that families are caring for disabled elders more often and for longer periods of time than ever before. There is considerable individual variability in how care-giving is handled and experienced, but it is typically stressful for the primary family helper and sometimes for the extended family network. The phenomenon of care-giving cannot be captured within a single measure of burden or stress. Rather, the many dimensions involved in the family’s responses and the types of different stressors or problems care givers experience have been observed.

The challenge for the future is to find ways to support families so that they can provide high quality, personalized care without excessive strain on themselves. The responsibility for care cannot fall exclusively either on families, because the burden is too great, or on society, since the cost will be too high. There is a need; instead, to form partnerships that find creative ways of sharing care, and which address the needs of both care recipient and Care givers. A small, but growing, clinical literature suggests that timely and well conceived clinical interventions can be an important part of this partnership, helping families develop better strategies for managing a patient’s disabilities and regulating the stress on themselves.