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Dementia: Coping with the Caregiving Role

by

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Abstract

As the proportion of the aged population continues to grow, a corresponding increase in dementing illness has resulted. A subsequent increase in the need for adequate long-term care for these dementing individuals has also occured and will continue to increase over the next few decades. Family care for the elderly is providing a pivotal role in health care and is often a link between community living and institutionalization of the elderly. Indeed, both the relatives of the elderly and health care systems share the expense of caring for dementing individuals.

The debilitating and chronic course of most dementing illnesses is reviewed. Dementia not only affects the diseased individual, but their family members as well. This impact on the family has been met by a growing concern about the effects of caring for a dementing individual; a wealth of literature on caregiving has emerged. Caregiver distress, caregiver burden, and caregiver well-being are some of the terms used to refer to the psychological, social, and economical ramifications of caregiving.

Coping with the long-term stresses of a dementing disease is affected by many variables and can largely influence perceptions of distress, burden and/or well-being. Many investigators have reported that the caregiver's general coping skills are essential features to be considered. Few caregiving studies, however, have investigated specific coping strategies used by dementia caregivers. A better understanding of the relationship between different coping methods and caregiver perceptions of stress may help caregivers, health care professionals, and social intervention programmes employ more effective coping strategies and lessen the burden of caregiving.

The present study is a preliminary exploration into the relationship between caregiver stress and coping methods. Thirty-three caregivers of dementing individuals living in the Victoria area participated in a personal interview and completed two self-report questionnaires. Psychological symptom patterns of the Brief Symptom Inventory (BSI) as well as active cognitive, active behavioural, and avoidance coping styles were measured. Results indicate a positive correlation among avoidance coping and stress manifestations. The caregivers who reported using more avoidance coping strategies also reported more stress symptoms in all dimensions measured except depression.

The complexity and individuality of the caregiving situation as well as the multidimensional interaction among various aspects of the caregiver, the care recipient, coping methods, and social support are discussed. A new approach to the concept of caregiver distress models is presented.

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Dedication

...to my Grandfather, and my
wonderful memories of him.

...to my Grandmother, Mother, and
family, and all others who
provided him with care.

Dementia

In the past few decades, the elderly population has steadily increased both in actual numbers and in percent within the over-all population. In 1950 eight percent of the United State's population was over the age of sixty-five, accounting for 12.3 million individuals; by 1978, the portion had risen to 11%, equalling 22 million seniors (Plum, 1979). It is estimated that by the year 2020 those over the age of 65 in the United States alone will equal 52 million persons and escalate to 68 million by 2040 (Schneider, & Guralnik, 1990). Thus, by 2020, there may be almost twice as many elderly individuals living in the United States as there are persons living in Canada today. Canada is experiencing a similar "age boom." In 1983, the population of Canadians 65 years of age and older was 2.5 million. By 2015, it will have doubled to about five million and by 2031, the number of elderly probably will exceed seven million (27% of the population), triple its present level (Statistics Canada, 1985).

The frequency of intellectual impairment increases sharply with age. Schneider, & Guralnik (1989) calculated median prevalence rates for severe to moderate dementia and found the prevalence of dementia increased from 2.8% at ages 65 to 74 years to 9% at ages 75 to 84 years and 28% at age 85 years and older. An accurate figure of the prevalence of dementia, however, is difficult to determine from the literature. One study indicates that 15 percent of individuals over 65 years of age are affected by some type of dementia (Crook, 1987).

Different definitions of dementia with varying ages of individuals sampled and differences in methodology have contributed to the inconsistencies in reported rates. Even with these discrepancies, all studies do agree that dementia is a major health concern among the elderly. Dementing syndromes account for more admissions and for more hospital in-patient days than any other psychiatric condition in the geriatric-age group (Christie, 1982).

The purpose of this chapter is to provide a definition, diagnostic criteria, and some general characteristics and etiologies of dementia. In order to understand fully the various stresses of individuals caring for a person with dementia, a broad base of knowledge about the syndromes they face is necessary.

Definition of Dementia

Dementia is not a single disease but rather an acquired syndrome of intellectual impairment. It is characterized by persistent dysfunction in at least three of the following spheres of mental activity: language, memory, visuo-spatial skills, emotions or personality, and cognition (abstraction, calculation, judgment) (Cummings, Benson & LoVerme, 1980). Some defining and distinguishing characteristics of dementia are that it is acquired, persistent, and involves global impairments. Being acquired in nature, primarily distinguishes dementia from congenital mental retardation syndromes and thus entails a loss of previously obtained abilities. Persistence is included as a criterion to exclude acute confusional states or delirium. These conditions usually include cognitive impairments, lasting hours to days, that typically result from acute traumatic, toxic and metabolic conditions (Cummings and Benson, 1983). Disorders lasting weeks to months are properly considered dementias. The required global deficits distinguish dementia from focal neuropsychological disorders such as aphasia or amnesia.

The American Psychiatric Association's (3rd edition-revised) Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R) (1987) specifies criteria for the diagnosis of dementia. The essential features are listed in Appendix A. The severity of impairment differs with etiology, stage of the disease, and the individual affected. The DSM-III-R criteria for severity of dementia are:

Mild: Although work or social activities are significantly impaired, the capacity for independent living remains, with adequate personal hygiene and relatively intact judgement.

Moderate: Independent living is hazardous, and some degree of supervision is necessary.

Severe: Activities of daily living are so impaired that continual supervision is required, e.g., unable to maintain minimal personal hygiene; largely incoherent or mute.

Differential Diagnosis of Dementia

Dementia has many etiologies and can be reversible, irreversible, progressive or non-progressive. An accurate diagnosis of etiology is extremely important because some dementing syndromes arise from potentially treatable disorders. Different patterns of neuropsychological deficits may be indicative of specific subtypes of dementing syndromes (Orsini, Van Gorp, and Boone, 1988). Cortical versus subcortical dementia is one classification system used in distinguishing these different deficit patterns.

Cortical dementia refers to a pattern of deficits primarily affecting higher cortical functions including: agnosia, apraxia, aphasia, and acalculia (inability to do mathematical calculations) (Orsini et al., 1988). Alzheimer's and Pick's diseases usually are categorized as cortical dementias. The primary neuropathological changes occur within cortical regions and the deficits are of functions mediated by cortical structures (Cummings & Benson, 1983).

Subcortical dementia refers to the patterns of intellectual deficits produced by diseases affecting subcortical structures and disrupting functions they mediate (Cummings, 1985). Fundamental functions of attention, motivation, arousal, and alertness are mediated by subcortical structures and are disrupted by dementing such as Parkinson's and Huntington's diseases (Slaby & Wyatt, 1974). A mixed cortical/subcortical dementia distinction is made for those dementias presenting a combination of deficits reflecting both cortical and subcortical dysfunction.

Even though this classification system can be helpful with regard to etiology, the definition of dementia requires global deterioration of a wide range of abilities, and observed syndromes rarely present strictly cortical or subcortical dysfunction. The brain is a highly integrated, complex structure, and the deterioration of cortical or subcortical regions often disrupts proper functioning of more than a single area. A current approach to classification of dementing syndromes is by etiology, although descriptions refer to primarily cortical or subcortical deficit patterns. Table 1 outlines the differential diagnosis of dementia. A brief description of the etiology of each major disorder is presented.

Alzheimer's disease

Alzheimer's disease (AD) was first described in 1907 by Alois Alzheimer. He documented the clinical features and the presence of neurofibrillary tangles and senile plaques in the brain of a fifty-one year old female who had died with a progressive dementia. It was first believed that the onset of

Table 1 Differential Diagnosis of Dementia

Alzheimer's disease

Pick's disease

Extrapyramidal Syndromes

- Parkinson's disease
- Huntington's disease

Multi-infarct dementia

Infectious dementias

Toxic and metabolic dementias

Hydrocephalic, traumatic, and neoplastic dementias

Dementia with Psychiatric disorders

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dementia of the Alzheimer's type occurred before the age of 65, but now the diagnosis of Alzheimer's dementia is made within a wider range of age of onset.

Of all the types of dementia, Alzheimer's disease is consistently reported the most prevalent. Cummings & Benson (1983) reviewed studies of the relative prevalence of different types of dementia and found Alzheimer's disease accounting for 22% to 57% (mean=39%) of the reported dementing syndromes. In older patients, Alzheimer's disease has been reported to account for 50-70% of the dementia cases seen in psychiatric practice (Kaszniak, 1986). There is a higher overall prevalence ratio of Alzheimer's disease in females, and a steep increase with age is found for both males and females (Rocca, Amaducci, & Schoenber, 1986). Familial studies of Alzheimer's disease reveal that risk to relatives of demented individuals increases with both closeness of genetic relationship and with more severe forms of the illness (Heston & Morris, 1986). Although there are many theories and etiological studies underway, the cause of AD is largely unknown.

The DSM-III-R criteria for the diagnosis of primary degenerative dementia of the Alzheimer's type include:

A. Dementia

B. Insidious onset with a generally progressive deteriorating course.

C. Exclusion of all other specific causes of dementia by history, physical examination, and laboratory tests.

More specific guidelines for a clinical diagnosis of Alzheimer's disease are offered by the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association (NINCDS\ADRDA) (McKhann, Drachman, Folstein, Katzman, Price, & Stadlam, 1984).

The clinical manifestation of Alzheimer's disease is an insidious progressive deterioration of cognitive, behavioural and emotional functions. It leads to years of disability and ultimately to total dependence for self-care activities.

Neuropathology of AD

A premorbid diagnosis of AD is made typically after all other etiologies of intellectual impairment have been excluded and usually includes the terms 'possible', 'probable', or 'clinically' diagnosed Alzheimer's disease. A definite diagnosis of Alzheimer's disease requires histopathological evidence from direct examination of brain tissue, usually obtained at autopsy.

Many neuroanatomical and biochemical research findings have been published about the macroscopic and microscopic changes seen in the brains of individuals with AD. Unfortunately, these findings have yet to lead to a cure or successful treatments for AD. In general, diffuse cortical atrophy, neurofibrillary tangles and senile plaques focal degeneration of a region in the basal forebrain (the nucleus basalis of Meynert), reductions in acetylcholine, choline acetyltransferase, and acetylcholine esterase all have been documented in the brains of diseased individuals. (Davies, 1979; Richter, Perry, & Tomlinson, 1980; Tomlinson, Blessed, & Roth, 1970).

Pick's disease

Pick's disease and Alzheimer's disease are clinically similar and can be hard to distinguish. Like AD, Pick's disease affects primarily cortical structures and progresses through a series of stages (Cummings, 1982). Onset is usually between the ages of 40-60 years of age and patients typically survive 4-6 years after onset (Slaby & Wyatt, 1974). Pick's disease is a relatively rare disorder, at least 10-15 times less common than AD, and affects more women than men (Cummings & Benson, 1983).

Less memory, calculation and visuospatial impairment and more extravagant personality changes occur with Pick's disease than with AD. In the early stages, patients are often disinhibited and features of Kluver-Bucy Syndrome (hyperorality, dietary changes, hypermetamorphosis, placidity, hypersexuality, and sensory agnosia) also may appear (Cummings & Duchen, 1981). Pathologically, focal atrophy of the frontal and anterior temporal lobes as well as histopathic alterations characterized by Pick bodies and inflated neurons are seen in brains of patients with Pick's disease (Cummings & Duchen, 1981).

Extrapyramidal Syndromes with Dementia

Extrapyramidal syndromes with dementia almost exclusively manifest features of subcortical dysfunction (Cummings & Benson, 1983) with the most common etiologies being Parkinson's and Huntington's diseases.

Parkinson's disease (PD) is associated with degeneration of basal ganglia structures, primarily the substantia nigra, and is usually considered a movement disorder. PD's most common symptoms are muscular rigidity, motor slowing and tremor (Lezak, 1983). A dementing syndrome is present in approximately 60% of patients with Parkinson's disease (Cummings & Benson, 1983).

Huntington's disease is a rare degenerative disorder of the nervous system with characteristic clinical features of dementia, chorea, and history of familial occurrence. The disease is transmitted by a single dominant gene and characterized by progressive degeneration of subcortical structures (Caine, 1978; Sarason & Sarason, 1989). The onset of the disease is usually in the fourth or fifth decade of life.

Multi-Infarct Dementia

The intellectual impairment of vascular dementias results from multiple vessel occlusions with infarctions in the corresponding areas of cerebral tissue (Cummings & Benson, 1983). Depending on the location of infarction, the intellectual deterioration associated with MID may present primarily cortical or subcortical dysfunctions or manifest a mixed cortical/subcortical dementia.

MID onset usually is abrupt and progresses in a stepwise manner. Hypertension and previous strokes are key historical features and the patient may have focal neurological signs and symptoms. Psychomotor retardation and emotional lability are present in most cases and can be accompanied by primarily cortical features (aphasia, amnesia, agnosia) or primarily subcortical features (psychomotor slowing, forgetfulness, inattention) (Cummings and Benson, 1983).

Infectious dementias

Infectious illnesses can involve the central nervous system and result in a dementing syndrome. For example, the Treponema pallidum organism associated with syphilis can invade the central nervous system and produce syndromes ranging from simple dementias to paranoid, schizoprehenic-like dementias (Schmidt & Gonyea, 1980). Slow, progressive intellectual deterioration also can be produced by viral infection (e.g., Jakob-Creutzfield's disease).

Toxic and metabolic dementias

Awareness of dementing syndromes resulting from toxic or metabolic means is especially important since most are treatable with partial or complete reversal of neuropsychological dysfunction (Cummings & Benson, 1983). Sudden and overwhelming metabolic or toxic conditions may result in an acute confusional state characterized by slowness and sluggishness, disorientation in time and space, fluctuating arousal, changes in mood, hallucinations, and reduced or erratic shifting of attention (Chedru and Geschwind, 1972). Metabolic disturbances or slow, insidious toxic exposures may yield cognitive changes of a slowly progressive dementia, conforming most closely to subcortical dementia characteristics (Cummings & Benson, 1983).

Hydrocephalic, traumatic, neoplastic dementias

Hydrocephalus refers to the presence of excessive cerebrospinal fluid (CSF) within the skull. It is either a congenital or acquired condition marked by dilation of the cerebral ventricles, occurring secondarily to tissue loss or more commonly, obstruction of CSF pathways. Dementia, gait disturbance and incontinence are often seen with hydrocephalic conditions (Cummings & Benson, 1983). Dementing syndromes also can occur following cerebral trauma or secondarily to brain neoplasms.

Myelin disease with dementia

Multiple sclerosis is a progressive and degenerative disease of the central nervous system that is marked by tremors, muscular weakness, speech disturbances, and visual complaints. Multiple sclerosis has been reported as an unexpected cause of dementia (Fox, Bernard, Gilley, & Stebbins, 1989) with some patients developing a dementing syndrome while others have little intellectual deterioration.

Dementia with Psychiatric disorders

Differentiating between dementia and depression is a necessary but often difficult distinction to make (Lezak, 1983). Some psychiatrically depressed patients can display a pattern of symptoms that so closely resembles the early stages of dementia it has been often called 'psuedodementia' (Wells, 1979). A study of patients diagnosed with presenile dementia and reexamined 5 to 7 years later showed 31% of the patients were misdiagnosed (Ron, Toone, Garralda, & Lishman, 1979). Functional psychiatric illnesses, chiefly affective disorders, were the principal disorders that went unrecognized as the cause for intellectual deterioration. Dementia can be produced by other psychiatric disorders as well, including schizoprehenia, mania, or hysteria.

With this brief review of the major characteristics of dementing syndromes, the vast array of etiologies, the variety of cognitive, behavioural, and functional dysfunctions, as well as the emotional or personality changes that may occur with a demented individual is evident. The severity of the clinical manifestations of dementia will vary not only with etiology but also among individuals with the same diagnosis. The families responsible for the care of affected individuals surely face a multitude of chronic and unpredictable stressors that may strain their abilities to live well and to continue providing care.

Caregiving

One misconception held by many individuals in our society is that the elderly are abandoned or alienated from their families. This myth has been largely discounted (Shanas, 1979). Providing care for older family members is an important part of today's family life and health care systems. Home care is often a link between healthy elders living in the community and infirm elders living in nursing homes. As the elderly population grows and the prevalence of dementing illnesses increases, so will family caregiving. Most families assume caregiving duties in order to keep infirm relatives in the home rather than in the hospital or in nursing homes. In-home care is generally viewed as more humane and cost effective than institutionalization (Lichtenstein, Ferderspiel, & Schaffer, 1985). The physical and mental health costs to the caregiver, however, also need consideration.

Many families have difficulties handling the increased stress incurred with the caregiving role. The structure, psychological and physical status, social functioning and financial resources of most families are strained when caring for an impaired family member. These strains can lead families to view caregiving as an insurmountable task and may lead to premature institutionalization of the care-recipient. Indeed, the burden experienced by families providing care for a cognitively impaired elder is a major factor in considering institutionalization (Knopman, Kitto, Deinard, & Heiring, 1988).

The intent of caregiver research is not to accumulate descriptions of multitudes of unmanageable stresses and possibly promote institutionalization of the elderly. But rather, the goals include both the identification of the effects of caregiving and the utilization of this information to develop services to help caregivers provide care in the most healthful way. The possible savings of health care dollars gained by not institutionalizing our elderly will not be truly economical if those health care dollars are spent treating the physical and emotional problems of the care-providers. A brief history of the effects that caregiving has on families and a review of the common terms used in the caregiving literature will lay the historical groundwork for interpreting much of the dementia caregiver literature.

Historical Review of Caregiving

Early studies on the effects of mental illness on families were done by Grad and Sainsbury (1963; 1965). In these studies of families providing care for psychiatrically impaired relatives, the patient's age, diagnosis, and duration of the illness were highly related to the severity of problems experienced by the family. Later research supports that these same three factors (age, diagnosis, and length of illness) affect the stress experienced by most care-providers.

Sainsbury and Grad (1970) found that the age of the care-recipient affected family functioning. In this study, 75% of families providing home care for older psychiatric patients had significantly more problems than those caring for younger persons. Though the burden was rated severe in 40% of the families, one third of the families tolerated the situation for more than two years before seeking psychiatric help.

Different mental disorders are associated with varying levels of caregiver distress. Hoening and Hamilton (1968) reported caring for a relative with an organic brain syndrome caused significantly more problems than other disorders.

The duration of illness is also a factor found to affect caregiver well-being. In a sample of 280 cases accepted for admission into a geriatric unit, Isaacs (1971) found the condition reported to be most unbearable was the long-continued presence of a mental disorder. Two-thirds of the cases were admitted because of inadequacy of basic care (usually because of lack of relatives) or because their relatives experienced 'undue' strain in caring for the elders.

Most dementing syndromes affect the aged, cause mental dysfunction, and have a chronic and debilitating nature. Caring for a demented individual, therefore, may make families more vulnerable to distress as a result of caregiving than those who care for non-dementing individuals. The recent increase in caregiving literature is a reflection of the growing awareness of this health care problem. Even with this increased concern, specific factors contributing to the absence or presence of caregiver burden have not been consistently identified within the caregiving literature. The lack of consistent terminology and definitions of burden or distress, as well as different methodological considerations (e.g., different sampling characteristics, different scales of measurement, cross-sectional versus longitudinal designs) have contributed to discrepant findings and make cross study comparisons difficult.

Terminology and definition of terms

Caregiver burden and caregiver distress are terms widely used in the caregiving literature and are often used interchangeably. Burden can be defined as: anything one has to bear or put up with, heavy load, as of work, duty, or responsibility (Webster, 1986). Caregiver burden can be ① conceptualized as the physical, emotional, and economic hardships, as well as the altered lifestyle incurred by caregiving. This concept of burden is a byproduct of concern about the extent of family caregiving and the costs of providing long term care in our society. Burden can be defined as an important factor leading to institutionalization of the care-recipient.

Caregiver distress is another term often used in the caregiving literature. Distress can be defined as: to cause ② sorrow, misery, or suffering to, pain, trouble; to exhaust or weaken with strain of any sort (Webster, 1986). Therefore, a distressed person would be one who is full of distress, anxious, suffering, or troubled.

Even though 'caregiver burden' and 'caregiver distress' initially seem quite similar, their definitions are not the same and using the terms interchangeably can lead to confusion when interpreting the caregiving literature. These two general terms are used to indicate the presence of absence of several psychological, physical, and emotional concepts including: depression, anxiety, morale, and life satisfaction. Clearly, the presence or absence of one or all of these factors could be different among individuals and within the individual depending on the situation. Many caregiving studies do not contain a specific definition of caregiver burden or distress and different interpretations of 'burden' and 'distress' have lead to difficulties in comparing studies. One estimate of how the terms were interpreted can be made by the way in which they were measured.

For the purposes of this study, caregiver distress will be used to denote the negative effects of caregiving, as characterized by the psychological manifestations of stress. These include situational feelings of depression, anxiety, and insecurity, along with possible exacerbations of preexisting susceptibilities to personality traits such as paranoia or psychosis. The term caregiver impact will be used to denote the global effects of caregiving. The terms caregiver burden or caregiver distress when used to refer to the entire caregiving process require negative connotations. Caring for an impaired family member or friend, however, can impact one's life with positive as well as negative feelings. Therefore, lumping all involved emotions into burden or distress terms invites caregivers as well as professionals to view the caregiving situation negatively. The factors of caregiving examined in this study focus solely on the negative consequences of caregiving (i.e., caregiver distress) and by no means capture the total caregiving experience.

Measurement of Caregiver Burden or Distress

Specific scales assessing the effects of caregiving have been developed. Zarit, Reever, & Bach-Peterson (1980) developed a burden interview designed to assess specific caregiver concerns. This scale consists of 29 items measuring the perceived impact of caregiving on the caregiver's financial status, physical, emotional, and social health.

Though scales such as this can provide useful information about specific stresses experienced by caregivers, one limitation of these scales is their specificity to caregivers alone. This limitation does not allow for the proper comparison with "normal" non-caregiving reference groups. To help alleviate this problem, many researchers are now using common non-specific psychological measures to assess the well being of caregivers. These are usually self-report questionnaires. The Brief Symptom Inventory (BSI) (Derogatis & Spencer, 1982) is one such self-report inventory that has been used to evaluate caregiver distress (Anthony-Bergstone, Gatz, & Zarit, 1988; Stebbins, Gilley, Willson, Bernard, & Fox, 1989). The BSI reflects psychological symptom patterns of individuals for the two weeks prior to administration.

Literature Review: Caregiver burden and dementia

Studies of caregiver burden and dementia reveal that caring for a demented individual can impact almost every area of life. Several manifestations of stress in dementia caregivers have been documented including emotional, physical, economic, and mental difficulties. Different types of dementing syndromes manifest various deficits that require many different types of care. Dysfunction also will vary within individuals having the same diagnosis. It is logical to assume that some caregiving tasks will be more difficult than others, depending on the disease, the infirm individual, and the caregiver.

In combination with individual differences, the previously mentioned methodological problems (differences in defining and measuring distress or burden, different populations sampled, and different research designs) have contributed to a wide variety of caregiver outcomes. Even with the discrepancy in findings, researchers agree that caregiving can be quite stressful and affects caregivers' lives.

Chronic fatigue, anger, and depression have been reported by caregivers of dementia patients (Rabins, Mace, and Lucas, 1982). Eight-seven percent of caregivers sampled reported these problems with mood and energy level. Other difficulties reported by a majority of these caregivers were family conflicts, loss of friends, hobbies, and personal time, worries about becoming ill themselves, and feelings of guilt.

Emotional stress is reported to be a major component of caregiving. In a survey of 289 caregivers of Alzheimer's disease patients, it was found that twenty-three percent of 23 the caregivers rated emotional stress as the primary problem in caring for the patient (Chenoweth and Spencer, 1986). Seventy-two percent of the caregivers who institutionalized 72 their dependents reported emotional stress as the major cause of institutionalization.

As mentioned earlier, the fact that many care recipients have cognitive impairments may influence their caregiver's well being. Scharlach (1989) reported that caring for a cognitively impaired person had a greater impact on caregivers than did caring for a physically impaired individual. It was found that employed persons caring for a cognitively impaired individual experience greater difficulties with personal and social functioning and report higher levels of emotional, physical and financial strain than other caregivers. They also have more work disturbances than other caregivers including: leaving early, extending a break, taking a day off, being too tired to work, and considering quitting because of their caregiving duties.

The severity of the cognitive impairment also may affect caregivers. In one study, though the presence of psychiatric difficulties in the caregiver was not related to the severity of dementia of the care recipient, the caregivers stress scores did vary with level of dementia (Eagles, Craig, Rawlinson, Restall, Beattie, & Besson, 1987). The caregivers of individuals with moderate to severe dementia reported more stress but not more psychiatric problems.

Other researchers, however, have found no association between the level of cognitive impairment of the dependent and caregiver burden. Gilhooly (1984) reported that the mental health or morale of dementia caregivers was not related to the amount of cognitive decline in the care-recipient. In fact, it was found that the individuals who had been caregiving the longest, and therefore, most likely caring for people with more advance stages of the disease, reported higher morale. This finding can be partially explained by a "survival effect," in that the most successful caregivers may continue in the role the longest. Another explanation could be that caregivers learn to cope and adapt more effectively with time. Even here there are contradictory findings as other researchers found no correlation between duration of caregiving and level of depression in caregivers (Townsend, Noelker, Deimling, & Bass, 1989).

Although some caregivers report high morale, depression is often experienced by caregivers, though it may or may not be dependent on length of caregiving. Depression in family caregivers has been found to be much more common than in the general population. In a recent study, sixty-four percent of family caregivers experienced clinical depression (Gallagher, Rose, Rivera, Lovett, and Thompson, 1989). This prevalence rate is in sharp contrast to the depression rates of the general U.S. adult population. About six percent of the population is expected to experience depression as defined by DSM-III-R (1987) in any given six month period (Holden, 1986) with women being at least twice as likely as men to experience depression (Nolan-Hoeksema, 1989). In Gallagher et al.'s (1989) sample, there was no difference in the prevalence of depression with gender. Of the depressed caregivers, however, women were typically more depressed than men. No major differences in depression rates with the more impaired dependents were reported.

This brief review of the growing body of knowledge about family caregivers indicates many inconsistent findings. Some studies report depressed and emotionally distressed caregivers and some found good morale and mental health of long term caregivers. Certain characteristics of the caregiver and of the recipient may make the situation more or less bearable and thus, contribute to these discrepant findings. Distinguishing between caregiver and recipient characteristics as preconditions or precursors to caregiver distress may be helpful.

Care-recipient Characteristics. A wide range of impairments occur within the different stages of dementing syndromes, and the type and magnitude of care required will change accordingly. Caregivers, consequently, must adapt to new types of difficulties as they arise. One way to divide the types of impairments often seen with dementing individuals is into three domains: (1) behavioural impairments, (2) cognitive impairments, and (3) functional impairments. Behavioural impairments include wandering, verbal and physical abuse, hoarding or hiding things and other noxious behaviours. Memory disturbances and confusion are signs of cognitive impairment, and common functional impairments include difficulties in self care (i.e., dressing, bathing, grooming) and incontinence.

Even though several reports outline the increased difficulties of caring for a cognitively impaired individual, more severe cognitive deficits alone may not lead to greater caregiver distress. Wilder, Teresi and Bennett (1983) found that caring for a dependent with dementia does not insure families reporting greater inconvenience or deciding to institutionalize relatives. Rather, it was the behaviour of the dependent that was associated with greater caregiver burden. In this study, the functional incapacity of the care-recipient to perform self-care activities required for independent living and the presence of angry, aggressive, and demanding behaviour correlated with higher burden for caregivers and influenced their decision to institutionalize the dependent. This finding is supported by Stebbins et al. (1989). It was reported that functional and behavioural impairments, independent of cognitive dysfunction, are associated with increased caregiver distress. Additional support of specific behaviours of the patient being more noxious than other difficulties is provided by Poulshock and Deimling (1984). The disruptive behaviour of the patient was associated with higher feelings of burden and disturbances in family relations. Higher depression levels were reported in these caregivers as well.

These findings, however, do not hold across all studies. Zarit et al. (1980) found the severity of behavioural impairments of the dementia patient was not associated with a subsequent increase in caregiver burden; but rather, the frequency of family visits was an important factor of caregiver well being. The amount of burden reported by caregivers was less when more visits were paid to the dementia patient by other relatives despite the behavioural impairments of the patient. These conflicting findings may indicate an interaction between the caregiver and specific care-recipient behaviours that results in caregiver distress, at least for some caregivers.

Caregiver characteristics. The age and sex of the caregiver may affect feelings of burden. Generally, women tend to report more psychological symptoms and are more likely to seek help regarding those symptoms than men. This higher willingness to share personal information, however, does not explain the higher prevalence of depression in women. The biological, social, emotional factors of being female may contribute to a susceptibility to depression and possibly distress.

This gender related trend for depression is supported in some of the caregiving literature. In addition to gender, the age of the caregiver may influence reports of distress. With the majority of caregivers being spouses (usually elderly) or female adults (usually daughters), specific factors related to age and gender would seem to be important characteristics involved in caregiver distress.

Anthony-Bergstone, Gatz, and Zarit (1988) found that while all caregivers were significantly elevated on the hostility subscale of the Brief Symptom Inventory (Derogatis & Spenser, 1982), female caregivers were additionally elevated on the anxiety subscale, and older women were elevated on the obsessive-compulsive, depression, and psychotism subscales as well. Being female and/or elderly, however, does not automatically increase the caregivers' feeling of stress. Eagles, Beattie, Blackwood, Restall, & Ashcroft (1987) studied the effects of a cognitively impaired spouse on elderly couples and found as the wife's cognitive abilities declined, the husband's depression scores increased. The reverse was not true for this sample.

Studies have shown that the more distant in blood/role relationship the less the burden (Gilhooly, 1984; George & Gwyther, 1986). This factor, however, is often confounded with living arrangements (i.e., spouse caregivers are more likely to live with the dependent). Isaacs (1971) found an increased report of strain associated with the patient living with the caregiver.

The quality of the previous relationship between the caregiver and the recipient also plays a role in the feelings of the caregiver. Morris, Morris, & Britton (1988) reported that caregivers who experienced lower levels of marital intimacy both at the time of the study and before the onset of dementia reported higher levels of perceived strain and depression. Perhaps, the higher the past intimacy of the relationship the more likely the caregiving role is assumed with a desire to care for their partner rather than out of a sense of obligation.

In addition to the individual characteristics of the caregiver and those of the care recipient, some additional factors may influence the level of caregiver distress. Social support can be viewed as a factor that influences perceptions of caregiver burden. A wide variety of intervention programmes have been developed for caregivers in efforts to help them cope more effectively. Social intervention programmes have the potential of moderating a person's situation and stress level, and the efficacy of these programmes is now being systemically researched. Caregiver support groups, educational seminars, respite care, and in-home health care, are just a few of the programmes that have been developed. Isolation is a common consequence of caregiving and support groups offer a caregiver the chance to meet and talk with people in similar situations. Support groups provide an opportunity to expand one's informal support network, express feelings, share common experiences, worries, and frustrations.

Unfortunately, much of the current research does not show strong correlations between participation in intervention programmes and a decrease in caregiver burden or distress. Support groups that focus more on the emotional difficulties of the caregiver rather than problem solving strategies result in somewhat greater reductions in burden (Gonyea, 1989). Again, depending on the personal characteristics of the caregiver, different programmes will have different effects. For example, in one study the participation in intervention programmes resulted in a delay of institutionalization of the patient by adult children caregivers, but encouraged nursing home placement with spousal caregivers (Montgomery & Borgatta, 1989).

Types of social support can be broken down into two areas: formal support and informal support. Formal support (counselling, caregiver support groups, education) is usually provided by health care professionals such as social workers, home health aides, home care nursing, occupational therapists, psychologists, and physicians. Informal support is typically given by friends and family members.

The complexity of the caregiving process increases rapidly the more one investigates the situation. Not only does caregiver distress vary with the caregiver's personal characteristics, but also with characteristics of the care-recipient, deficit patterns of different disease syndromes, and familial and societal factors. In consideration of these multiple factors, many researchers have adopted multidimensional models of caregiving. One such model of studying the relationships between family burden and dementing illnesses is provided by Wilder et al. (1983). Their model includes five main groups of factors: (1) environmental factors (community, sociocultural, and family attributes), (2) characteristics of the dementing illness (type, severity, and duration), (3) symptoms of the impaired person (functional or behavioural problems), (4) caregiver burden (depression, health problems, and altered life style), and (5) outcome (institutionalization). Here, burden is conceptualized as inconvenience of the caregiver and the willingness to continue providing care.

Another multidimensional perspective is offered by

Poulshock & Deimling (1984). This model conceptualizes burden as a mediating force between the dependent's impairments and the impact of caregiving. The elder's disruptive behaviours and functional impairments along with the burden associated with them as well as the level of depression interact to impact family relationships. Here, a distinction between the impact of caregiving and the burden experienced by caregivers is made. Burden is used to refer to the subjective perceptions of the caregivers. These perceptions are related to the degree of problems experienced in relation to elders' specific impairments. The inclusion or exclusion of certain variables in models such as these will inevitably make cross study comparisons difficult. Multidimensional models, however, can provide a more complete picture of the caregiving process. In many unidimensional studies, factors associated with an increase of caregiver burden in one study are not associated with caregiver burden in another. With a broader outlook on the impact of caregiving, interactions between and among factors could explain many differences among studies.

The main emphasis, concept, or theme underlying the impact of caregiving should be interactive. These interactions include the perceptions of the caregiver, the factors influencing these perceptions, and how well caregivers accept or adapt to these perceptions. If the impact of caregiving is truly subjective, the perceptions of the caregiver will surely be coloured by the efficacy of the caregiver's abilities to cope with stress. Ironically, coping is one variable that is not often specifically measured or analyzed in many of the caregiver models. Before trying to incorporate coping into a multidimensional model, however, a review of the literature that does discuss its influence on caregiving is needed.

Caregiver Distress and Coping Methods

The large amount of contradictory findings within the caregiving literature leads to a frustrating and clouded picture of the caregiving situation. The individuality of responses to the various stresses of caregiving is evident from the many discrepant findings in the caregiving literature. Many investigators allude to the essential role of coping with the various aspects of caregiving. Few researchers, however, actually systematically study the specific strategies used or their impact upon caregivers. In a paper on psychological stress and coping in the aging, Lazarus & DeLongis (1983) commented,

> "...coping is a crucial variable influencing the adaptational outcomes of a person's struggle to get along or live well; research on psychological stress and functioning that does not account for its influence is limited or distorted."

Perhaps some of the individual differences in response to caring for a dementing elder can be understood better as components within the larger domains of stress and coping theories.

The chronic and unpredictable difficulties that arise in dementing illnesses require individuals to deal with a multitude of stresses over a long period of time. Indeed, the ways in which we cope with the unique as well as the common experiences in our lives are both contributors to and products of our individuality and influence our perceptions of ourselves and situations.

The fact that the prevalence of dementia is increasing with no known cure for many of it's etiologies, highlights the realm of coping with this debilitating illness as an important issue in our society. Researchers and clinicians involved with the aging are faced with the difficult task of measuring and understanding coping processes, as well as other subcomponents of caregiving such as normal aging, pathological or abnormal aging disorders, stress, stress reactions, and distress.

The numerous and diverse reactions and feelings to caregiving situations that pose demands or constraints on caregivers were outlined in the previous chapter. The purpose of this chapter is to provide some definitions of coping and review the relevant literature on caregiver adaptation.

Definitions of Coping

Coping is a simple and frequently used word, but understanding what is actually meant by "coping" involves the integration of numerous concepts. Coping is a process that is never completed; it continues and changes with time and experience. Like most processes, coping encompasses many different factors. It can be conceptualized as a shell around a myriad of emotions, thoughts, feelings, experiences and abilities.

Direct observation of how well an individual functions in society can be one index of coping ability. Generally, a person who is conforming to societal standards and not showing obvious psychological difficulties is viewed as "coping well," while an individual who is off the beaten path and shows signs of turmoil is often viewed as "not coping well." A person, however, can be within the normal boundaries of behaviour as far as society is concerned and still be quite distressed or maladjusted. These armchair observations do not offer specific guidelines for the definition of coping. A more precise index of an individual's coping abilities can be obtained by defining and measuring the various concepts, feelings, and skills involved in the coping process.

Sarason and Sarason (1989b) refer to coping as how people deal with difficulties and their attempts to overcome them. They outline a number of general skills or techniques that are useful in handling stressful situations that include thinking constructively, dealing with problems as they arise, behaving flexibly, and providing feedback to oneself about which tactics work in a given situation and which ones do not. The concept of vulnerability is one that Sarason and Sarason also refer to as involved in the relationship between stressful situations and successful adaptation. Vulnerability can be defined as how likely one is to respond maladaptively to certain situations. An individual's vulnerability may be increased by a number of factors including heredity, personality characteristics, lack of decision making skills, or a build-up of recent stressful events.

A global definition of coping was offered by Lieberman (1975). He defines coping as an adaptive process and states that definitions of coping often contain the concepts of competence, effectiveness, mastery, subjective experience of well-being, and maintenance of homeostasis. Using these concepts, two major themes of coping emerge: (1) mastery and competence and (2) absence of breakdown or crisis. Mastery and competence are usually measured by obtaining subjective statements by individuals, while a crisis or breakdown can be shown by the presence of psychological distress. The direct observation of an individual or the administration of various self-report inventories can provide measurements of psychological distress.

Another definition of coping can be obtained from the work of Folkman & Lazarus. They define coping as constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of an individual (Lazarus & Folkman, 1984). Much of their research concentrates on two foci in coping: (1) problem-focused coping and (2) emotion-focused coping. Problem-focused coping entails efforts aimed at managing or altering the problem or problems causing distress. Emotion-focused coping involves efforts directed toward regulating the individual's emotional response to problems (Folkman & Lazarus, 1980).

Coping can be defined, measured, as well as performed, in many different ways. Pearlin & Schooler (1978) offer several ways coping is exercised: eliminating or modifying problematic conditions, perceptually controlling the meaning of experience, or modifying the emotional consequences of problems. Even though coping is protective in nature and many of the listed techniques generally elicit positive connotations, its results are not necessarily benefical. The range of coping behaviours is quite broad and can be positive, negative, effective or ineffective. It is difficult to determine what is "effective coping," as beneficial coping modes change within and among individuals, as well as with the nature and duration of the problem, and various societal influences.

Certain dysfunctional or "avoidance" coping mechanisms have been explored. Attempts to deny or minimize the stressful situation, conceal feelings or take anger or depression out on others are examples of avoidance coping and have been related to psychological distress (Holahan & Moos, 1985). Typically, these behaviours do not deal with the problem specifically and do not help alleviate the distress associated with the problem.

The caregiving literature is increasing exponentially and the studies concentrating on the specific coping strategies used by caregivers are also increasing. Few studies, however, have focused on the specific coping techniques used by caregivers of dementing individuals and how they impact perceptions of distress. Coping with this caregiving role has not been fully examined and, given its pivotal role in elderly health care, requires much further research. Certainly, some life conditions in and of themselves increase one's vulnerability and the risk of maladaptive behaviour. Caregiving, at least for some individuals, may be one of those life conditions. Indeed, the aged population is often viewed as being at high-risk for experiencing the negative effects of stress, and many caregivers lie within that population.

Caregiver and Coping Literature Review

The relationship between coping strategies and psychological well-being of caregivers of individuals who were recently discharged from a rehabilitation hospital was investigated by Stephens, Norris, Kinney, Ritchie, and Grotz (1988). In this study, caregivers were asked to recall a recent situation in caregiving that they appraised as stressful and report how they coped with that situation. It was found that the caregivers who engaged in more escape-avoidance behaviours reported greater depression and more conflicts in their personal relationships. Younger caregivers, many of whom were women, used more avoidance behaviours.

Another study of coping and caregiving examines the subjective feelings of burden reported by caregivers. Pratt, Schmall, Wright, and Cleland (1985) investigated several coping strategies used by caregivers of Alzheimer's disease patients and their relationship to caregiver burden. Eight coping strategies that individuals or families may have used in response to problems or difficulties of caregiving were assessed. Significant correlations were found between specific measures of coping and caregiver burden scores. Confidence in problem-solving, ability to reframe the problem, spiritual support and help from extended family members were associated with lower levels of burden, while passivity of the caregiver was related to higher levels of perceived burden. Here, again, passive or avoidant-type behaviours are associated with reports of psychological difficulties.

The concepts of well-being and coping were addressed by Quayhagen and Quayhagen's (1988) investigation of families caring for an Alzheimer's disease patient. Fifty-eight caregivers were separated into three groups (female spouses, male spouses, and adult children) and analyzed on six coping styles, care management strategies, support factors, well-being, and reports of stresses associated with specific memory and behaviour problems. The coping dimensions measured were defined as (1) modifying the situation (problem-solving and help-seeking behaviours), (2) controlling the meaning of the situation (minimization of threat, and existential growth), and (3) altering the stress of the situation (fantasy and blame). The three groups did not differ in reported well-being. Differences, however, were found in how the measures of coping, care-management, and support correlated with the reports of well-being. In the total sample, fantasizing behaviours were inversely associated with well-being and self-blaming was associated with higher stress scores for all caregiver groups. Though they did not report significantly different well-being or stress scores, daughters were more likely to partake in self-blame or fantasy coping behaviours.

Problem-solving approaches, help-seeking behaviours, and low self-blame were all positively associated with well-being for both the female and male spouse caregivers. Interestingly, this relationship did not hold for the daughters. The authors defined fantasy and self-blaming behaviours as attempts to alter the stress of the situation. No specific examples of these types of coping behaviours, however, were provided. Intuitively both seem to be an indirect way of dealing with problems, and thus could be viewed as "avoidant behaviours."

Both problematic situations and ratings of effective coping techniques were investigated by Barusch (1988). Individuals caring for impaired spouses were asked to complete an inventory containing thirty-four problems that may arise during caregiving. The caregivers were to identify the problems that applied to them, report the way that they coped with the problems, and rate the effectiveness of that coping behaviour. The caregivers' coping responses were classified on a six dimension scale (not coping at all, inhibition of action, information seeking, partial action, cognitive restructuring, seeking help, and personal action). When dealing with problematic situations, the coping strategy most likely to be used by these caregivers was seeking help from family members or professionals and this coping behaviour was rated as effective. Interestingly, the second most common response to stressful situations was a failure to cope. In 24% of their responses, caregivers reported that they simply did not cope with the situation but rated this behaviour as not very effective. One difficulty in interpreting this finding is that no definition of the rating "not coping at all" was given. Whether this lack of coping consisted of attitudes of indifference, emotional outbursts, or withdrawal is uncertain.

Consistent with the definition of coping offered by Folkman and Lazarus (1980), Pruchno & Resch (1989c) assessed problem-focused and emotion-focused coping in spouse caregivers of Alzheimer's patients. In this study, emotion-focused coping was defined as using wishfulness, intrapsychic, and acceptance strategies, while problem-solving coping was defined in terms of instrumental activities (such as: 'made a plan of action and followed it'). It was reported that a greater use of wishfulness and intrapsychic coping ('wished you could change the way you felt', 'hoped a miracle would happen') was associated with greater depression and anxiety as well as more memory and thinking disturbances, physical complaints and being sensitive. Behaviours leading to acceptance of the situation ('refused to let it get to you', 'made the best of it') were associated with lower depression scores and increased positive affect. Problem-focused coping was associated with increased positive affect but did not affect reports of negative symptomology (i.e., anxiety, somatization, interpersonal sensitivity). This study indicates that greater use of wishfulness and intrapsychic coping strategies (i.e., emotion-focused) yield a poorer mental health outcome for the caregiver while problem-focused coping may affect the caregiver's perceptions of good mental health. One interesting finding was that problem-focused coping was not associated with a decrease in negative symptomology. Thus, problem-focused coping behaviours may influence one's perceptions of health without necessarily helping to alleviate stress manifestations.

One study focusing on the individual differences in response to caregiving investigated the utility of a stress and coping model to predict differences in caregiver adaptation. Haley, Levine, Brown, & Bartolucci (1987) reported consistent relationships between the ways caregivers appraised stresses, the coping styles used, the amount of social support/activity, and the adaptation outcome of caregivers (as measured by depression, life satisfaction, and self-rated health indices). Even though each outcome measure was able to be predicted through regression analysis, depression, life satisfaction, and self-rated health were predicted by different patterns of stressors, appraisals, coping, and social support. The severity of impairments in the dependent accounted for significant variance only on the measure of depression. The ways that the caregivers appraised stressors accounted for significant variance on the outcomes of depression and life satisfaction. The pattern of coping responses and the amount of social support and activities significantly predicted all three outcome measures.

Specifically, the caregivers who used logical analysis (i.e., 'tried to step back from the situation') and problem-solving coping strategies (i.e., 'tried to find out more about the situation') reported lower depression scores, higher satisfaction with life, and rated their health as better than those who did not use these strategies. Information seeking coping was related to better health outcome, and affective regulation was related to greater satisfaction with life and better health. The caregivers who engaged in more emotional discharge coping also reported higher levels of depression than other caregivers. It was reported that the caregiver's coping responses accounted for 24% of the variance in depression scores, 15% of the variance of life satisfaction scores, and 22% of the variance in self-rated health problems.

As with the caregiving and stress literatures, the ambiguities of defining coping undoubtedly have resulted in additional difficulties in making meaningful research comparisons. Even so, with this brief literature review, it is clear that the perception of stress and the well-being of caregivers are associated to some degree with coping methods. Even though the semantics varied, avoidance-type behaviours were associated with psychological difficulties in each of the reports. The results from both Quayhagen & Quayhagen (1988) and Stephens et al. (1989) indicate that women, especially younger ones, may be more likely to use these behaviours when caring for a dementing individual.

Of the few studies that studied coping abilities of dementia caregivers, the major focus was usually on coping with specific problem areas of caregiving and not on the general feelings involved with caregiving. Mastery of behaviour modification techniques or problem solving strategies typically provided a definition of coping in these studies. Although, these techniques can be quite beneficial to caregivers, they are not the only ways in which to cope and should not be used to measure global coping behaviours.

An additional difficulty in assessing the impact of coping on caregivers is related to the methods used to elicit descriptions of coping behaviour. When caregivers are asked to report how they coped with a recent stressful situation, the request itself actually may have produced elevated reports of avoidance coping since the situation has already been appraised as stressful and an avoidance response, therefore, may be more likely. How caregivers deal with problematic situations may not necessarily be the way that they deal with the more global stresses of caregiving.

Additionally, some coping studies do not provide a measurement of caregiver well-being or distress. Obviously then, the relationship between coping techniques and the psychological health of the caregivers cannot be determined. The following study was designed to address some concerns arising from reviewing the literatures of caregiver distress and caregiver coping.

Introduction of Caregiver Impact Model

The present study introduces a model of the impact of providing care for a dementing individual and offers exploratory data for one part of the model (see Figure 1). The model is a three dimensional sphere reflecting an individual's ability to move in multiple directions within the framework of the model. In the generic form, the factors listed have equal influence upon the impact of caregiving. Each caregiver, of course, will have different portions of the factors represented in the model. The components included as factors influencing the impact of caregiving are: caregiver characteristics or factors, recipient characteristics, coping strategies, social support, and stress vulnerabilities.

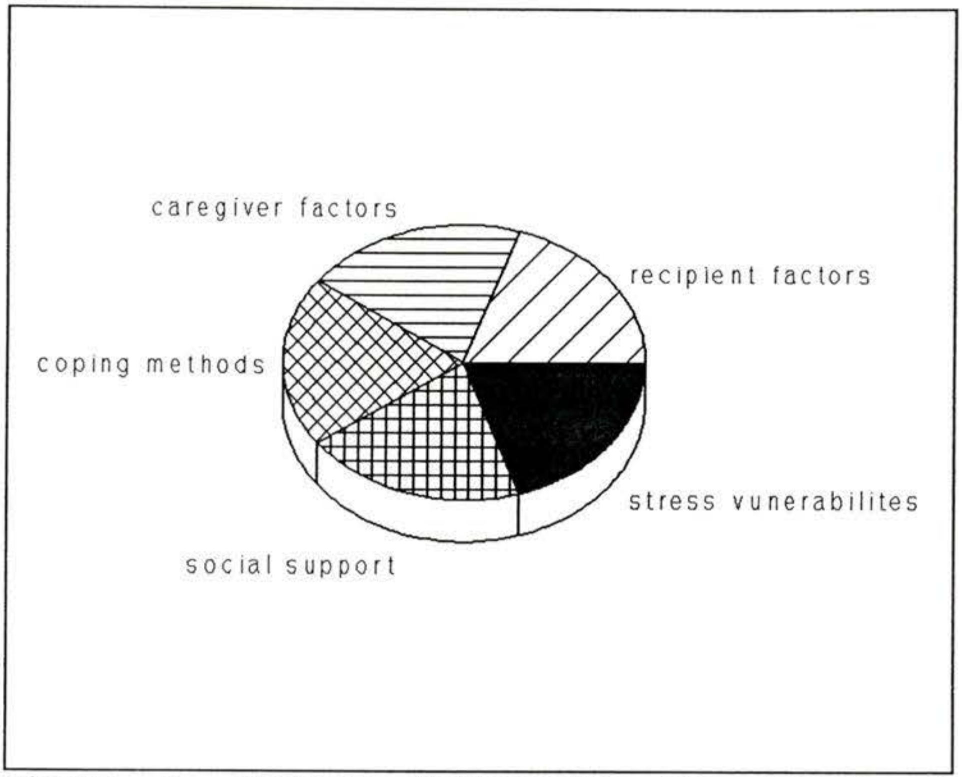

Figure 1. Factors Influencing the Impact of Caregiving

Although not specifically outlined in the model, factors associated with strains for the caregiver could include: hours of caregiving, length of caregiving, gender, relationship to dementia patient, and financial status. Patient associated strains may consist of the functional, behavioural, and cognitive impairments of the dementing individual. The types of coping strategies employed by the caregivers, as well as the knowledge, use, and satisfaction with social support, are also important factors. Reports of psychological symptoms can provide a measurement of the manifestation of stress, or more commonly termed, caregiver distress. The presence of these symptom patterns can represent an individual's vulnerabilities to stress. Perhaps having a schematic diagram can help conceptualize some key components of the entire caregiving process. Even being just a piece of the "pie," coping behaviours can and do play an important role in caregiver well-being.

The objective of this study was to assess the relationship between caregiver distress and coping style. Many factors could potentially influence one or both of these factors, as well as the caregiver's ability or willingness to report their presence. The types of coping methods used, the personal characteristics of the caregiver, and the particulars to the caregiving situation are hypothesized to influence caregiver distress. Specific hypotheses are:

(1) caregivers obtaining higher stress scores would report poorer and fewer effective coping strategies (i.e., avoidance)

(2) caregivers reporting fewer stress symptoms also would report using more effective coping strategies (i.e., active behavioural and/or active cognitive)

Additional exploratory hypotheses include:

(3) the sex of the caregiver will influence reported stress levels and use of coping strategy: female caregivers may be more likely to use more avoidant coping strategies and also report higher stress levels

(4) the relationship between the caregiver and care-

recipient will affect caregiver burden as well as coping style: spouse caregivers may report more stress and use more avoidant coping strategies

(5) the location of the recipient (in-home or facility placed) will affect the caregiver's perception of burden and method of coping: in-home caregiving may elicit more stress and avoidant coping styles

(6) the individuality of experienced stress of the caregivers can be largely explained by coping strategies, gender, residence of the recipient, and the relationship between the caregiver and care-recipient.The current study is by no means attempting to explain all the relationships and interactions involved in the caregiving process.

The relationship between coping strategies and perceptions of distress in dementia caregivers has not been fully examined and needs much clarification. Determining whether specific coping skills are more or less adaptive for caring for a dementing individual would be quite beneficial to numerous individuals including clinicians, researchers, various other health care professionals, and especially, to family caregivers.

Methods

Data were gathered in collaboration with the Victoria Health Project, the Greater Victoria Support Network, and the Elderly Outreach Service. A survey assessing the needs of caregivers in the Victoria area is underway and this study was part of the pilot data collection. A large amount of information was gathered about the caregiver, the care recipient, and about the knowledge and use of the services available to caregivers in this community. Measures used include: a demographic questionnaire, Instrument of Daily Living Form (Lawton & Brody, 1969), Patient Behavioural Checklist (Gilley, Wilson, Bennett, Bernard, & Fox, 1990), Geriatric Depression Scale (Yesavage & Brink, 1983), Life Satisfaction Z Index (Wood, Wylie, & Sheafor, 1969), a services questionnaire, the coping section of the Health and Daily Living Form (HDLF) (Moos, Cronkite, Billings, & Finney, 1984), the Brief Symptom Inventory (BSI) (Derogatis & Spencer, 1982), an assistance questionnaire, and the Mini-Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975). Appendix B contains a sample of the extra measurements used at the time of interview that were not analyzed in this study.

For purposes of this study, descriptive demographic information, the coping index of the HDLF, indices of the BSI, and the MMSE scores were examined. A medical information release form was signed by each recipient or caregiver and a brief letter was sent to the recipient's physician to confirm their diagnosis. See Appendix C for all measures used for this study alone.

Thirty-three caregiver/recipient dyads were recruited from caregiver support group meetings (n=11), the Dialogue on Care Conference (n=6), and the Elderly Outreach Service (n=16). Contact with support group leaders was made by the coordinator of the Caregiver Support Group Network. If interest in the study was shown, the phone number of the group leader was given to the primary researcher. After telephone contact was made, either a brief letter (see Appendix C) was sent to group leaders to be read at their next meeting or the researcher attended the caregiver support group meeting, gave a brief talk on stress and coping and announced the study to group members. Volunteers were also recruited from a conference held in the Victoria area for professional and non-professional caregivers where the primary researcher gave a brief talk at the conference, introduced the study, and asked for volunteers. Other caregivers were recruited from the Elderly Outreach Service (EOS). A research assistant and employee of EOS contacted caregivers by phone and made them aware of the study, and again, if interest was shown, their names and telephone numbers were given to the primary researcher. All volunteers were then contacted to set up an interview time. Most interviews were done at the caregiver's home.

Basic demographic information about the recipient and the caregiver was gathered from the caregiver. A brief (5-10 minutes) evaluation of the recipient and a longer (60-90 minutes) semi-structured interview with the caregiver was completed. The caregiver was asked to complete two self-report inventories following the interview and mail them in a provided self-addressed stamped envelope to the Psychology Department of the University of Victoria.

Two research assistants were involved with data collection and scoring. One assistant was an Occupational Therapist in the Victoria area (female, age 27) and the other a post University graduate (male, age 26); both had prior experience working with the elderly. Each assistant was briefed on the purpose of the study and proper administration of measures used. Observation of their interviewing skills was completed by the primary researcher before their participation in the interviews began.

A majority of the interviews were completed by the primary researcher alone (n=17), the female research assistant observed two interviews with the primary researcher and then completed 6 interviews alone. The male assistant observed three interviews and then completed the remaining 5 alone. No differences of scores on any of the measures used for this study were found among the researchers.

Caregiver Assessment

Caregivers were assessed in two domains: psychological symptom patterns and coping style. The psychological symptoms reported on the BSI are used here to indicate caregiver distress. Indices derived from responses to the coping section of the HDLF are used as measures of the caregiver's coping style.

The Brief Symptom Inventory (BSI) (Derogatis & Spenser, 1982). The BSI is a self-report inventory of 53 items designed to measure psychological symptom patterns. It is often used as a measure of current psychological distress, reflecting symptom patterns experienced over the two weeks prior to administration. The BSI can be administered in 7-10 minutes to psychiatric and medical patients as well as non-patient individuals. It is an abbreviated form of the Symptom Check List-90-R (Derogatis, 1977), a longer self report inventory measuring the same symptom dimensions. Normative data for the BSI were gathered on non-patient normals (n=719), psychiatric outpatients (n=1002), psychiatric inpatients (n=310), and adolescent non-patients (n=2408). The internal consistency of the BSI is good, ranging from an alpha of .71 on the psychoticism dimension to .85 for the depression subscale. Test-retest reliabilities are also high (.68 for somatization to .90 for Global Symptom Index) Each normative sample was divided into male and female groups. Normative data for the elderly on the BSI are also available (Hale, Cochran, & Hedgepeth, 1984).

After the personal interview, caregivers were instructed to report how much they were distressed by the problems and complaints listed on the BSI form. Each item is rated on a 5-point scale of distress (0-4), ranging from 'not at all' (0) to 'extremely' (4). Nine primary symptom dimensions including somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism are assessed. A Global Symptom Index (GSI) also can be calculated, providing a measurement of overall psychological distress.

The Health and Daily Living Form (HDLF) (Moos, Cronkite, Billings, & Finney, 1984). The HDLF is a structured assessment procedure that can be administered either as an interview or as a questionnaire. There is the initial Adult version A, a revised Adult version B, and a Youth Form of the HDLF. The HDLF was developed to investigate the process of psychosocial adaptation among psychiatric, medical, and community populations.

The HDLF is used to examine the influence of treatment interventions as well as to explore the social resources and coping processes people use to prevent and adapt to stressful life circumstances. The revised Adult Form B is recommended by the authors and measures a variety of areas including: sociodemographic and employment-related factors, individual health-related and social functioning, family functioning, stressful life events, coping responses to stressful life events, and both quantitative and qualitative aspects of an individual's family and social resources. Each composite index can be used separately and, for the purposes of this study, only the coping index was used.

The coping scale of the HDLF is a 33 question self-report inventory assessing strategies used in response to a major life event. Normative data on the Coping Response Index is classified according to the method of coping, the focus of coping, and help-seeking coping of depressed patients (n=424) and community adults (n=424). The reliability reported by Moos et al. (1984) for the three methods of coping, using the community adult data, are acceptable (active cognitive=.62, active behavioural=.74, and avoidance=.60).

All caregivers were instructed to rate, in connection with caring for a dementing individual, their frequency of use of the listed coping methods. Responses ranged on a 4-point scale from 'no'(0) to 'yes, fairly often (3).' Three methods of coping were measured: (1) active behavioural (e.g., 'tried to find out more about the situation', 'made a plan of action and followed it'), active cognitive (e.g., 'tried to step back from the situation', 'went over the situation in my mind'), and avoidance (e.g., 'kept feelings to myself', 'drinking more'). Active behavioural coping methods comprised 13 out of 33 questions with a range from 0 to 39. Active cognitive coping was made up of 11 questions with a range of 0 to 33. Avoidance coping was measured with 8 questions, allowing a maximum score of 24.

Recipient Assessment

Before caregivers volunteered to participate in the study, they were informed that a 5-10 minute evaluation of the care recipient would be required. If the caregiver/recipient dyad was a client of the Elderly Outreach Service, a release of medical information form was signed by the caregiver so that MMSE scores could be taken from the recipient's file. The recipients were re-examined if the most current documentation of their cognitive functioning was done 4 months prior to the caregiver's interview or if a drastic change in the recipient's functioning had been noted. Consent to test the recipient's cognitive status was obtained from the primary caregiver if the recipient was unable to give consent due to cognitive difficulties. The cognitive abilities of the recipients were evaluated to document the presence or absence of cognitive impairment. Most MMSEs were done either directly before or after the interview with the caregiver if the recipient was at home. Arrangements were made to evaluate the patients at their place of residence (i.e., long term care facility) if the recipient did not reside at home. Sixteen of the recipients were assessed by the primary researcher, 6 by either one of the research assistants, and the remaining 11 MMSE scores were obtained from Elderly Outreach Service files.

The Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975). The MMSE is a frequently used screening device of cognitive functioning. Administration takes approximately 5-10 minutes and can be performed at the bedside. All questions are asked orally. Areas of orientation, attention/concentration, memory, praxis, and language functioning are assessed. Scores range from 0-30, with higher scores indicating less cognitive impairment.

Description of Sample

Caregivers. A total of thirty-three caregivers participated in the study, twenty-three females and ten males. Demographic information about the caregivers is included in Table 2.

In general, female caregivers were younger than the males, though the age difference was not statistically significant (t=1.61 (31), p=.119). The mean age for the entire sample was 67 years of age, and both the female and the male caregivers had roughly the same educational background. Most caregivers were spouses of the recipient, while the remainder consisted primarily of adult daughters and other relatives. All of the caregivers were either living with the care-recipient or the dependent was in a facility (i.e., none of the dependents were living alone). Caregivers providing in-home care had been caregiving about the same length of time as the facility based caregivers. They, however, provided significantly more hours per week of care (t=6.68 (31), p<.001) (see Table 2).

Table 2 Characteristics of the Caregivers

Age: mean (sd)		
Female	65.1 (10.7)	range: 44.4-80.3
Male	70.9 (6.20)	range: 57.2-77.8
Relationship to recipient:		
spouse	25	
daughter	5	
niece	2	
friend	1	
Education:		
Female	13.7 years	
Male	13.6 years	
Type of care provided:		
in-home	17	
facility	16	
Duration of care:		
in-home	57.5	
facility	58.3	
Hours/week caregiving:		
in-home	91.9 (23.1)**	
facility	20.1 (26.9)	

<u>note</u>: n=33 **$p<.001$

<u>Care-recipients</u>. There was an approximately equal number of female and male care-recipients (17 women, 16 men). Demographic information about the care-recipients is found in Table 3. Diagnosis of the recipient was confirmed in 16 of the 22 letters that were returned by physicians. Six of the 22 diagnoses did not agree with the caregivers' reports of the type of cognitive impairment of the recipients. Five of the

Table 3 Characteristics of the Care-recipients

Age:	
women	76.1 (9.8) range (55-93)
men	76.2 (8.3) range (61-89)
Education:	
women	10.94 years (3.8)
men	12.00 years (3.3)
Length of illness:	
female	65.0 months (43.9) range (20-180)
male	77.8 months (47.4) range (36-228)
Diagnosis (as provided by caregiver)	
AD	13
MID	6
Mixed	3
non-dx	9
unknown	2
Mini-Mental State Exam	
women	11.13 (7.6) range (0-22)
men	10.54 (6.9) range (0-22)
in-home	12.30 (6.6) range (0-22)
facility	9.07 (7.7) range (0-22)

note: AD=Alzheimer's disease, MID=multi-infarct dementia, mixed=mixed etiology dementia, non-dx=non diagnosed cognitive impairment.

discrepancies were changing of diagnostic category (i.e., from AD reported by the caregiver to MID reported by the physician); one physician reported that the recipient was not demented, while the caregiver reported an unknown diagnosis of cognitive impairment. This recipient's MMSE score was 15, which would suggest significant cognitive impairment.

The MMSE was not completed on four of the 33 care-recipients (3 males, 1 female) due to agitation of the recipient or consent to test was not given. The range of the

MMSE for all recipients tested was 0 to 22; thus, all scored below the commonly used 23/24 cut-off score for cognitive impairment (Folstein, Folstein, & McHugh, 1975). The MMSE scores between female and male dependents and in-home versus community residents were not significantly different (t=-.21 (27) p=.83; t=1.22 (27) p=.24, respectively). These data indicate that all of the care-recipients, regardless of gender or place of residence, had significant and approximately equal cognitive impairment.

Results

Caregiver distress

The amount of distress experienced by each caregiver was calculated from responses on the Brief Symptom Inventory (Derogatis & Spencer, 1982). The reliability of the BSI was assessed through the reliability procedure of Statistical Package for the Social Sciences (SPSS-X) (1986). This procedure performs an item analysis on the components of additive scales by computing reliability coefficients (e.g., Cronbach's alpha). The BSI, as a whole, showed good reliability with a coefficient of .94, and the subscale alphas ranged from .39 on the phobic anxiety index to .82 on the anxiety index. Alpha coefficients, as well as the mean scores for both female and male caregivers, on the BSI are found in Table 4.

As a whole, the caregivers in this study did not report elevated levels of stress as compared to the normal population. Normative data for the elderly on the BSI were used in comparison with caregivers who were 60 years of age or older (n=22, 14 females, 9 males). These norms were used since it has been reported that elders tend to report higher levels of distress on most symptom dimensions of the BSI than younger individuals (Hale et al., 1984). Normative data published by Derogatis and Spenser (1982) were used with the younger caregiver group (n=11). No significant differences were found between any of the nine subscales of the BSI and

Table 4 Nine Primary Symptom Dimensions and the Global Symptom Index of the Brief Symptom Inventory of Female and Male Caregivers

BSI subscale	females mean (sd)	males mean (sd)	alpha coefficient
Somatization	.44 (.49)	.38 (.27)	.68
Obs. Compulsive	1.00 (.75)	.82 (.54)	.80
Intp. sensitivity	.48 (.64)	.18 (.21)	.77
Depression	.90 (.76)	.64 (.63)	.75
Anxiety	.78 (.72)	.49 (.39)	.82
Hostility	.42 (.45)	.38 (.31)	.68
Phobic Anxiety	.18 (.27)	.02 (.06)	.39
Paranoid Ideation	.34 (.54)	.39 (.42)	.67
Psychoticism	.32 (.44)	.34 (.35)	.57
Global Symp. Index	.57 (.42)	.43 (.24)	.94

Note: n=33.

age appropriate norms. This sample of caregivers, regardless of age, did not report extreme amounts of distress.

As shown in Table 4, the females' BSI scores were generally higher than the males, except the paranoid ideation and psychoticisim subscales, where the males averaged slightly higher scores. Though typically higher, the female caregivers' scores did not differ significantly from the males on any of the nine BSI dimensions or the Global Symptom Index.

Of the 53 symptoms listed on the BSI, the caregivers were moderately to extremely distressed most frequently by the following symptoms: (1) 'feeling tense or keyed up'(n=16) (48%), (2) 'feeling lonely' (n=15) (45%), (3) 'feeling blocked in getting things done' (n=14) (42%) (4) 'feeling blue (n=13) (39%), and (5) 'feeling easily annoyed or irritated (n=13) (39%). An additional 25-30% of the caregivers reported feeling a little bit of distress by these symptoms. Therefore, even though the caregiver's stress scores were not significantly elevated when compared to age matched peers, a large majority of them did report some feelings of anxiousness, depression, hostility, and difficulties with memory and thinking.

Coping Responses

Measures of active cognitive, active behavioural, and avoidance coping strategies were calculated for each caregiver. The mean scores for each coping index are provided in Table 5. The same reliability procedure that was used with the BSI was completed on all coping indices of the Health and Daily Living Form (Moos et al., 1984). The total coping scale and two of the indices were fairly reliable: total scale alpha=.78, active behavioural index alpha=.73, active cognitive index alpha=.63. The avoidance index, however, showed poor reliability with an alpha of .36.

Four questions from the avoidance index were identified contributing to the low reliability: (1) 'kept feelings to

Table 5 Coping Methods from the Health and Daily Living Form for Female and Male Caregivers

Coping Method mean (sd)	Female	Male
Active Behavioural	25.6 (5.7)	27.3 (5.4)
Active Cognitive	15.0 (4.4)	16.9 (3.3)
Avoidance	1.6 (2.1)	1.4 (1.8)

n=33.

myself,' (2) 'refused to believe it was happening' (3) 'eating more,' and (4) 'smoking more'. The removal of these four questions dramatically improved the reliability of the avoidance scale (alpha=.65); therefore, this revised version of the avoidance coping index was used for all further analyses. The correlation between the Global Stress Index and avoidance coping index rose from .56 (original scale) to .65 (revised scale).

There were no significant differences between men and women on any of the coping styles. Further analyses of the BSI and coping scores do not separate the sample by gender since neither the BSI or coping responses showed any significant gender effects. Even though the differences were not significant, it is interesting to note that on average the women used fewer coping responses than did men, except for the avoidance scale, which they used more (see Table 5). By counting the frequency that caregivers reported using a particular coping method either 'sometimes' or 'fairly often' the most commonly reported responses were calculated. These methods included: (1) from the active cognitive index: 'went over the situation in my mind to try to understand it' (n=23)(70%), and 'took things one day at a time, one step at a time (n=22) (67%), and (2) from the active behavioural index: 'tried to find out more about the situation'(n=26) (79%). In general, the caregivers tended to take a more active approach to dealing with the caregiving situation as reflected by their higher use of the methods on the active behavioural scale.

Stress and Coping

Correlational analyses between the BSI scores and coping methods of the HDLF were completed (see Table 6). Significant correlations were found between avoidance coping and eight out of the nine stress dimensions of BSI as well as the Global Symptom Index. No significant relationships between the active behavioural or active cognitive coping methods and the BSI scores were found. Depression was the only subscale of the BSI that did not significantly correlate with the avoidance coping index.

These data indicate that there is a relationship between the use of avoidance coping strategies and reported stress symptoms. This finding would support the first hypothesis that caregivers reporting higher stress symptoms also would

Table 6 Pearson Correlation Coefficients between the Brief Symptom Inventory and Coping Method

Coping Method	Active Cognitive	Active Behavioural	Avoidance
BSI Dimensions			
Somatization	.27	.07	.65**
Obs. Compulsive	.20	.00	.60**
Intp.Sensitivity	.02	.07	.54*
Depression	.00	.21	.24
Anxiety	-.07	.04	.55**
Hostility	.09	.10	.43*
Phobic Anxiety	.09	-.03	.56**
Paranoid Ideation	-.03	.00	.34*
Psychoticism	.14	.15	.54*
Global Symp. Index	.08	.11	.65**

Note: *p<.05. **p<.001.

report higher use of avoidance coping methods.

The second hypothesis that caregivers with lower reports of stress also would report more active behavioural and active cognitive coping is not supported by these data. Expected negative correlations between the active behavioural index and the active cognitive index with the BSI were not found.

As mentioned earlier, no significant differences between female and male caregivers were found on any of the BSI dimensions, the Global Symptom Index, or the coping scales. Therefore, the third hypothesis that the sex of the caregiver would influence the reported stress score did not hold. The hypothesis that the place of residence of the recipient would affect the caregivers' reported stress was not supported by these data. Even though in-home caregivers were providing significantly more hours per week of care than the caregivers of facility-placed recipients, they did not report more stress symptoms. Additionally, no significant differences were found between stress or coping scores and the relationship between the care-provider and the care-recipient (i.e., spouse vs. other relative or friend).

It was further hypothesized that some of the variability in reported stress scores could be accounted for by differences in the use of avoidance coping, the sex of the caregiver, the residence of the recipient, and the relationship between the caregiver and the care recipient. Hierarchial multiple regression analysis was performed on the data.

In the first model, the Global Stress Index of the BSI was predicted by (1) avoidance coping, (2) sex of caregiver and (3) relationship to recipient. Forty one percent of the variance in the GSI score could be accounted for by avoidance coping alone. The addition of the other two variables (caregiver sex or relationship) did not add a significant amount of additional variance explained. The second model used

(1) avoidance coping, (2) sex of caregiver, and (3) location of recipient (in-home vs. facility residence) as predictor variables. Again, caregiver sex and location of recipient did not add significant amounts of variance explained. These findings suggest that the use of avoidance coping strategies can be used to explain a large proportion of the variance of stress scores. The sex of the caregiver, residence of recipient, and the relationship between the care-provider and care-recipient do not play significant roles in predicting caregiver distress.

Outliers

By plotting the Global Stress Index with avoidance coping scores, data points that fell outside the general pattern of the sample were identified as outliers. From this plot, three individuals were identified as outliers. Two of three outliers were female, all were spouses, and two were providing in-home care for the recipient. There were a wide range in the length of providing care (24-96 mo, mean=72) and hours per week of caregiving (range 25-112, mean=77). The MMSE score of the recipients average 12.5 (with one recipient not tested because the caregiver refused to give consent). These individuals reported relatively high distress levels (>.75) along with low avoidance coping scores (<1.4). There were no significant differences between these individuals and the rest of the sample on relationship to patient, residence of patient, GSI scores, or any of the coping responses. Therefore, it was the pattern of the responses that made these persons unique rather than the actual responses themselves. The correlation between GSI score and avoidance coping rose from .65 to .73 after these three individuals were excluded from the analysis.

High Stress Group

Individuals were identified as having relatively high stress scores than the rest of the sample by viewing a histogram of the Global Stress Index. Two of the caregivers reported stress symptoms that were greater than two standard deviations above the mean (one female, one male), and another two women reported scores one standard deviation above the mean. It is interesting to note the wide range of caregiving situations that resulted in high reports of caregiver burden. Two of the dyads were spousal caregivers (one wife caregiver and one husband caregiver) and the other two were daughters caring for their mothers. There were a wide range of both the hours per week of provided care (3 to 102 hours), and the length or duration of caregiving (24 to 124 months). The MMSE was discontinued on two of the recipients due to agitation and the other two scored quite low (0 and 4). Thus, the "high stress" caregivers were providing care for agitated or severely demented individuals, within a wide range of caregiving situations.

Discussion

As a whole, this sample of dementia caregivers did not report higher stress scores than the normal population. An initial explanation might be that the caregivers were simply not distressed and their lack of variation from the normative data is an accurate representation of their state of being. Clinical impression of these caregivers, however, would not support this conclusion. A majority of these caregivers seemed quite distressed and were tearful, anxious, irritable, and commented that 'they just couldn't take it anymore.' Their responses on the BSI did not reflect these psychological difficulties.

The normative data (both the original and subsequent elderly norms) for the Brief Symptom Inventory were gathered in the United States. Perhaps the use of these norms for a Canadian sample is not appropriate. The geography, life style, customs, and certainly health care systems of these two countries are quite different and may affect stress levels. Comparison between this sample and non-caregiving Canadian elders possibly could cast this sample's stress reports in a more relative and accurate light.

Additionally, several factors involved in sampling bias surely contributed to the low stress scores reported. As with all caregiving research, a self-selection sample bias is present. The individuals who would become the most distressed by caregiving will choose other options for care of a dementing elder and never become caregivers in the first place. Therefore, there is an inherent self-selection bias of caregivers themselves and consequently, the range of stress and coping scores is automatically curtailed.

Other factors that may have lead to lower stress scores are exclusionary criteria. Most of the individuals enrolled in the Elderly Outreach Service were contacted and asked to volunteer. Certain exclusionary criteria, however, were considered before contact was made. The reasons for not contacting caregivers were (1) clinical impression was that they were experiencing too much turmoil at the time and it would have seemed unfair to approach them, (2) active spouse abuse was present, (3) extreme alcohol consumption was present, (4) the care-recipient had recently died, (5) the caregiver was too physically frail, or (6) the caregiver lived too far away. In consideration of these exclusionary criteria, many seemingly quite stressed individuals were excluded. Though these criteria were ethically and clinically necessary, they certainly contributed to sample bias and possibly low stress scores.

Additionally, one must consider the various motivations that elicit participation. The caregivers were asked to participate in a study investigating stress and coping methods of caregivers. The focus was strictly educational and no specific supportive interventions were offered. Other researchers have reported that volunteers who sought help rather than simply volunteered to participate in a study about Alzheimer's disease reported more depression than those who strictly participated for "research" purposes (Gallagher et al., 1989). Many caregivers in this sample, when being thanked for participating, mentioned that they were just trying to help others. Perhaps these caregivers viewed participation as a contribution to research and not a way to learn about and develop their own coping styles. These volunteers might have been better able to cope with the caregiving situation and wanted to share their experiences with individuals having more difficulty.

An interesting observation is that both professionals involved with caregivers and many of the caregivers themselves commented that they were 'just too stressed out' to participate in a study. Some caregivers commented that they were not 'good' examples of coping caregivers and as a result should not participate, while others were at the initial stages of caregiving and did not think their situation applied. By these few examples, it is evident that there are numerous and diverse reasons for participating and not participating in caregiving research. Therefore, the small number of caregivers who actually did volunteer is surely a subsample, and somewhat unknown one, of the entire caregiving population.

Another consideration of sample bias is that, besides being volunteers, most of the caregivers were involved with caregiver support groups. The motivations of the caregivers to participate in support groups may distinguish them from non-support group members. Even though not specifically assessed in this study, how often the caregivers attended caregiver meetings and if they were satisfied with the support groups are variables that might have affected feelings of distress. Indeed, it has been reported that the satisfaction with support, rather than quantity of support, influences caregiver burden (Gilhooly, 1984).

As mentioned earlier, a majority of this sample was obtained through the Elderly Outreach Service, a division of Victoria's mental health services. Perhaps the benefits of being involved with this service organization lessened the caregiver's feelings of stress. Even though previous studies indicate that caregiving samples obtained from psychiatric-based referrals may show higher levels of distress than caregivers obtained from non-psychiatric resources (Eagles et al., 1987a & 1987b), this finding was not supported by these data. It seems that a mere connection with psychiatric services does not guarantee high levels of distress. In fact, these individuals may show no greater levels of stress than non-psychiatric referrals. Further research addressing this specific issue would offer important interpretive information.

Despite these numerous methodological considerations, a relationship between higher levels of caregiver distress and more frequent use of avoidance coping strategies was found in this study. It seems that the caregivers using more avoidant behaviours as a means of coping with providing care for a dementing relative are also more likely to report higher levels of distress. In fact, the use of avoidance behaviours explained a large proportion of the variability in stress scores.

Interpretation of this association should be made cautiously for several reasons. The small sample size and correlational design of the data are large limiting factors. Obviously causality cannot be determined, and it is still unclear whether (a) higher stressed caregivers used avoidant coping methods because they were highly stressed and had difficulty choosing more effective coping styles, or that (b) individuals who used avoidance coping methods coped ineffectively because of these behaviours and consequently experienced more stress or, in fact, (c) an unstudied variable or variables created higher levels of stress in conjunction with a higher use of avoidant strategies. Even though this study cannot tease apart these relationships, it should be noted that in each of these scenarios, a cycle of higher stress with poorer coping is set into action.

The fact that active cognitive and active behavioural coping indices did not correlate with caregiver distress does not indicate that these coping strategies are unimportant to caregivers. The results reflect that the use of these coping strategies, as measured by the HDLF, was not associated with caregiver distress, as measured by stress symptoms reported on the BSI. Other studies have found that reports of behavioural coping strategies are more associated with measurements of well-being rather than reports of negative symptomology (Pruchno & Resch, 1989c). Perhaps, since these caregivers did not report high levels of negative symptomology (e.g., elevated BSI scores), a measurement of well-being might have more accurately represented their true psychological state and may have shown more of an association with these types of coping methods. Surely there is some overlap in measurements of well being and stress symptomology, and the difficulty of defining an individual's psychological state by the way in which it was measured is a common problem in the stress and caregiving literature.

The specific characteristics of the caregiver and the care-recipient chosen for analysis in this study did not significantly correlate with caregiver distress or coping methods. There were no significant relationships among gender, relationship, or care-recipient residence and the caregivers' stress and coping scores.

The lack of sex differences is in contrast to the hypothesized finding that women caregivers may experience and report more distress than men caregivers and may use more avoidant coping methods. It also is in contrast with other researchers who found that female and spousal caregivers experience greater burden (Barusch, & Spaid, 1989; Gallagher et al., 1989; Pruchno & Resch, 1989b) and use more avoidant coping methods (Quayhagen & Quayhagen, 1989; Stephens et al., 1989).

Many factors need to be considered when assessing sex differences between caregivers. Both Stephen's et al. (1988) and Quayhagen & Quayhagen's (1988) studies reported a greater use of avoidance strategies used by younger women, usually daughters of the demented individual. Daughters may have to juggle the demands of their own children, spouse, and job to care for an infirm parent. The fact that the majority of the women in this study were spouses, in their sixties, and probably not balancing a job and children's demands to the same degree as younger women often do, may have contributed to the lack of gender differences.

Additionally, the traditional roles that men and women hold in our society and how closely the caregiver and care-recipient adhered to those roles prior to the onset of dementia are important factors. Traditionally, women have taken a nurturing role, and this gender role is still quite evident especially in the elderly population. Women, therefore, may assume the caregiving role more naturally than males. The self-care duties (bathing, grooming, feeding), that become necessary when caring for a dementing individual, may be easier, or more natural, for women to perform than males. Male caregivers may have to cook, do the laundry, clean the house, and other in-home tasks, all of which they may have never or seldom participated in prior to the illness. Indeed, it has been reported than men caregivers tend to receive more home-delivered meals, more home nursing services, and more home aid services than females (Barusch & Spaid, 1989). On the other hand, women may be more susceptible to feelings of failure if caregiving becomes too much to handle alone; they may feel that they are failing in their nurturing abilities. Another consideration of gender differences, as pointed out by Pruchno & Resch (1989b), is that women may feel resentment by having to continue caring for family members as they may have done most of their lives.

The fact that some studies (such as this one) do not show gender differences, leads to the viewpoint that gender related burden is influenced by a multitude of factors and not just a chromosomal difference. By the results of this study, just being female does not ensure higher stress or more avoidance coping and in fact, the stresses of caregiving seemed to have affected female and male caregivers uniformly. The lack of gender differences in coping methods may be a factor involved in the low stress scores. It is unclear, however, if this similarity in coping may lead to or be a result of the lack of gender related stress scores.

These data indicate that strictly one's gender does not specify the perception of stress or the types of coping methods used. The individual factors of age, relationship to the care-recipient, economic, familial situations, and viewpoints on traditional roles, therefore, may play important roles in gender stress and coping differences. Investigating the ways in which men and women view the caregiving role, in light of their historical backgrounds, could add important dimensions to interpreting gender differences or lack thereof, as shown in this study. Again, larger and more proportional samples need to be obtained to examine fully the interactions involved.

The hypothesized finding that those individuals closest in the blood/role relationship would report higher stress scores and possibly higher avoidance coping patterns was not supported by these data. Again, the stress of caregiving seemed to have affected spousal and non-spousal caregivers equally. The perceptions of closeness in a relationship may be more involved in caregiver distress than strict blood/role distinction. As mentioned earlier, the level of marital intimacy may affect caregiver distress (Morris et al., 1988). This important perception of closeness of relationship was not measured in this study. Future research should focus on the feelings of closeness, or level of intimacy, between the caregiver/care-recipient dyad. Here, again, the individual characteristics of the caregiver and the care-recipient and their interactions seem to be the most important factors involved in assessing caregiver distress and coping methods.

The residence of the care-recipient did not seem to influence the level of distress or coping methods reported by the caregiver. This finding was somewhat unexpected since intuitively, it seems that with the recipient living in the home (and subsequently more hours spent caregiving) more stress would be experienced by the caregiver and this could influence choice of coping method.

The hours per week of caregiving were substantially higher in the in-home care group versus the facility based group. No difference, however, was found between their stress or coping scores. Many facility-based caregivers had just recently placed their recipient in nursing home care. These caregivers were openly concerned as to whether they had made the "right choice."

Feelings of failing in the caregiving role (or relational role), worries that the care provided would not be adequate, finally accepting the gravity of the situation, having feelings of loneliness or depression, and grieving may have been experienced by these caregivers. Perhaps the feelings of guilt and the additional worries of placing a loved one in a nursing home result in different but still present stresses upon the caregiver and could help explain the lack of stress and coping differences between in-home versus facility-based caregivers.

An interesting note is that even though the stresses and certainly the situations of caregiving had changed between these two groups, their choice of coping methods did not. This finding could have important implications for intervention programmes. Perhaps facility-based caregivers would have more time to examine their own feelings and possibly focus on accepting the situation. Recognizing and dealing with feelings of guilt and failure also could be addressed. Indeed, the affectiveness of this type of intervention programme would be quite interesting and useful to investigate empirically.

The utility of the BSI to assess distress in the caregiving population is another factor needing consideration. Despite overt symptoms of distress, the caregivers in this sample did not report BSI scores that were strikingly different from the normal population. A self-report format might not provide the best assessment of caregiver distress, and this could help explain the low level of reported stress symptoms. The caregivers may have been able to pull themselves together while filling out the BSI form to answer questions non-pathologically. They may not have wanted to admit their difficulties on paper, and therefore, acknowledge these difficulties, to themselves and others. Many of the caregivers seemed quite hesitant to express too many negative feelings. Whether this behaviour was avoiding acknowledging distress and thus, actually another example of avoidant tendencies, or an attempt to see the bright side of things is unclear. Many caregivers seemed to be hanging on to the edge, and though many were tearful, they also were quite guarded and conservative in expressing their feelings. This observation might be indicative of self-survival or self-protective behaviours. These behaviours might have influenced their reports on the BSI.

The caregivers may have viewed admitting stresses as a failure in their caregiving abilities or perhaps they thought that people would judge them as "unfit" caregivers if they reported too many stress symptoms. More open ended questions focusing on these issues may add to the accuracy of self-reported distress scores within this population.

Another explanation for the low distress scores is that the BSI simply does not contain the proper questions to capture the experienced stresses. In support of this notion, one caregiver did indeed mention that the BSI 'did not adequately reflect what he was experiencing'. The BSI is a quick and easy way to assess stress symptomology; in the self-report format, however, it may not offer an accurate measurement of caregiver distress.

The large standard deviations found with the BSI dimensions are indicative of large amounts of variability in perceived stress. The high variability in stress scores might have masked the individual's experience of stress. Surely an involved factor is that "people are people" and there is quite an individual nature in stress reactions.

The poor reliability of the avoidance coping index also should be addressed. The revised scale consisted of only four questions. Is answering positively to those four questions really indicative of a general pattern of avoidance coping? Stress and coping are processes (i.e., changing, non-static, fluctuating), and a one time measurement cannot capture the intricacies of these processes. Longitudinal studies using more reliable and comprehensive measurements of stress manifestations and coping methods are needed. Understanding how caregivers adapt to the stresses involved, and how their coping strategies change accordingly, is an important part of understanding the entire caregiving process.

Again, even with the numerous methodological problems, exploratory studies such as these can help professionals as well as caregivers more fully understand the caregiving situation. The fact that the use of avoidance coping strategies explained almost half the variability of stress scores should not be discounted. Surely, many caregivers would benefit from being aware of their typical coping patterns and the possible interaction of these patterns with their experience of stress. Initial studies such as these may help in the formulation of new theoretical models and research designs that can analyze more accurately the complex interactions involved in the caregiver role.

Some of the complex interactions that can occur in the caregiving process are exemplified by the three individuals identified as outliers in this study. Possible explanations for their unique responses propose some interesting hypotheses and include: (1) that these individuals truly experience high distress without using avoidance coping styles, or (2) the HDLF coping scale did not capture their ineffective coping styles, or (3) they 'avoided' or denied their use of avoidance behaviours (which, of course, is another form of avoidant behaviour). More in-depth research of coping behaviour will be needed to explain such seemingly paradoxical patterns of behaviour.

Studying such debilitating diseases as the dementias, as well as working with the individuals who chose to provide care for such persons, has its inherent difficulties. To find an answer, to help caregivers, in fact, to care for the caregivers, seems quite a natural reaction. Attempts to tease apart the problems of caregivers and then categorize caregivers by these difficulties in hopes to devise successful intervention programmes are automatic responses. The boxes, however, that caregivers must fit into to agree with current research models are getting more and more numerous as well as smaller and smaller. Thus, a role that is so naturally assumed by many is becoming quite complex and difficult for even the caregivers themselves to understand; such an exercise in intellectualization seems fruitless. The large individual variation of this population makes categorizing them quite difficult and, in the clinical perspective, seemingly unnecessary.

This is not to say that the efforts of researchers are trivial. Familiarity with the various etiologies of dementing syndromes, along with the typical characteristics, treatments, and prognoses of these syndromes, form an important base of knowledge to acquire. Knowing which behaviours of the patient tend to be more noxious than others, which caregivers tend to be more distressed than others, and which intervention programmes tend to be successful are very non-trivial issues. In addition, however, individual variation needs to be considered and perhaps even emphasized, as it is quite an evident factor involved given the large amount of discrepant findings within the literature.

Nonetheless, professionals and caregivers alike can benefit from the findings already within the caregiving literature. Appropriate intervention programmes can be developed using such detailed and categorical information. The advantages of behavioural management programmes and the irreplaceable services offered by occupational therapists, social workers, respite care facilities and workers, home health aides, in-home nurses, psychologists and other health professionals can alleviate many difficulties of caregiving. Additionally, offering a variety of services to caregivers gives them the opportunity to design their own individualized support programmes, something that seems necessary given the wide range of individualized responses to caregiving. Awareness of the services available can provide caregivers the information they need to make the most healthy choices for their personal care as well as for their recipient's care.

When first faced with the task of caring for another person, caregivers may revert to their usual coping patterns. These would include both productive and self-defeating strategies. The simultaneous process of evaluating and possibly restructuring one's stress management techniques in conjunction with caring for a dementing individual, is seemingly an insurmountable task. The old cliche that 'education is the key' seems to have important implications here. This notion is supported by the framework for health promotion published by Health and Welfare Canada (Epp, 1986). One of the three recognized challenges for a national healthy Canada is to enhance peoples' capacity to cope with chronic conditions, disabilities, and mental health problems.

Part of this enhancement of coping skills could be reached by having individuals aware of the likelihood that they themselves or one of their relatives could need extensive care in later life. Educating families about the illnesses of the aged and the possibilities of becoming a caregiver or care recipient before they are faced with these situations enables them the time and energy to think about their options and to discuss them with other family members. RO

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All family members, regardless of age, should be sensitive to the issues involved. Families should discuss their views on the proper times and situations where institutionalization may be necessary and is the 'right' thing to do. Even so, it should be realized that the stresses experienced by caregivers may not automatically decline with institutionalization. The results of this study, as well as others (e.g., Pratt et al., 1985), lend support to this belief. Perhaps much of the grief and guilt of institutionalizing a family member could be avoided if families had previously discussed personal views on health care.

With the growing elderly population, thought and foresight into the gifts and grievances of aging is necessary. Even though chronic illness may not be a topic discussed with happiness, the growing number of families faced with dementing illnesses makes this a reality that cannot be easily ignored. The security and comfort of knowing that one will receive proper care with respect for needs, for some levels of independence and self-determination, as well as knowing that these discussions provide potential caregivers help in decision making, are likely beneficial results.

With the current emphasis on preventive and holistic health, what can results from studies such as this actually offer to individuals already in the caregiving situation? The answer largely depends on their willingness to learn about and possibly change coping behaviours. Caregivers are often too tired to think about how they are dealing with the difficulties they face. They often want someone to talk to, but do not have the energy to change their behaviours. Many studies indicate that caregivers often work themselves until the point of "burn out" or crisis before seeking help (Barusch, 1988). Caregivers are faced with the additional job of providing care to themselves. There is often little time or energy, however, for this type of care to be given. Caregivers should be encouraged to realize, accept, and appreciate the limitations of providing care for a family member. Individuals working with caregivers should be able to identify avoidant coping strategies and teach more productive styles, while being sensitive to the individuality of the person.

The complexity of the caregiving process is highlighted by the fact that each of the factors involved is multidimensional. The sources of stress (i.e., caregiver and care-recipient characteristics), the coping mechanisms of caregivers, the distress experienced by caregivers, and the resultant effects of being a care provider are all quite complex. Future research should focus upon the interactions among all of these factors.

The educational importance of the multitude of issues involved in caregiving cannot be stressed enough. Successful adaptation to the caregiving role should include both cognitive and behavioural processes. The use of avoidant behaviours should be identified, discussed and discouraged. Caregiving is by no means an easy role. The satisfaction of helping provide a loved one with the care that they need during the final years of life, however, can be a rewarding experience. Research in this area should reflect some of these more positive factors. Indeed, caregivers can learn to admire their strengths as caregivers. They can come closer to knowing the true meaning and purpose of the word 'family.' Caregivers can grow by giving and receiving the ultimate gift of love, care.

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Appendix A

DSM-III-R Criteria for Dementia:

A. Demonstrable evidence of impairment in short-term and long-term memory. Impairment in short-term memory (inability to learn new information may be indicated by inability to remember three objects after five minutes). Long-term memory impairment (inability to remember information that was known in the past) may be indicated by inability to remember past personal information (e.g. what happened yesterday, birthplace, occupation) or facts of common knowledge (e.g., past Presidents, well-known dates).

B. At least one of the following:

(1) impairment of abstract thinking, as indicated by inability to find similarities and differences between related words, difficulty in defining words and concepts, and other similar tasks

(2) impaired judgement, as indicated by inability to make reasonable plans to deal with interpersonal, family, and job-related problems and issues

(3) other disturbance of higher cortical function, such as aphasia (disorder of language), apraxia (inability to carry out motor activities despite intact comprehension and motor function), agnosia, (failure to recognize or

identify objects despite intact sensory function), and "constructional difficulty" (e.g., inability to copy three-dimensional figures, assemble blocks, or arrange sticks in specific designs)

(4) personality change, i.e., alteration or accentuation of premorbid traits

C. The disturbance in A and B significantly interferes with work or usual social activities or relationships with others.

D. Not occurring exclusively during the course of delirium.

E. Either (1) or (2):

(1) there is evidence from the history, physical examination, or laboratory tests of a specific organic factor (or factors) judged to be etiologically related to the disturbance

(2) in the absence of such evidence, an etiologic organic factor can be presumed if the disturbance cannot be accounted for by any non-organic mental disorder, e.g., Major Depression accounting for cognitive impairment

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Note: From Diagnostic and Statistical Manual of Mental Disorders 3rd. ed., by the American Psychiatric Association, 1987, Washington, D.C.: American Psychiatric Association.

Appendix B

The complete set of instrumentation used in data collection, in the order of administration is:

1.) Thesis Questionnaire (demographic information)

2.) Instrumental Activities of Daily Living

3.) Patient Behaviourial Checklist

4.) Geriatric Depression Scale

5.) Life Satisfaction Index Z

6.) Services Questionnaire

7.) Assistance Questionnaire

8.) Brief Symptom Inventory*

9.) Coping Index of the Health and Daily Living Form

The following appendix contains only the set of additional instruments <u>not</u> used in the analyses of this study.

*<u>note</u>: Due to copyright restrictions, only nine items from the Brief Symptom Inventory will be provided.

INSTRUMENTAL ACITIVITIES OF DAILY LIVING SCALE

Data __________

Subject __________________ Informant __________________ Unit # ______________

A. Ability to use telephone

1. Operate telephone on own initiative - looks up and dials numbers, etc.
2. Dials a few well-known numbers.
3. Answers telephone, but does not dial.
4. Does not use telephone at all.

B. Shopping

1. Takes care of all shopping needs independently.
2. Shops independently for purchases.
3. Needs to be accompanied on any shopping trip.
4. Completely unable to shop

C. Food Preparation

1. Plans, prepares, and serves adequate meals independently.
2. Prepares adequate meals if supplied with ingredients.
3. Heats and serves prepared meals, but does not maintain adequate diet.
4. Needs to have meals prepared and served.

D. Housekeeping

1. Maintains house alone or with occasional assistance; e.g., "heavy work, domestic help."
2. Performs light daily tasks, but cannot maintain acceptable level of cleanliness.
3. Needs help with all home maintenance tasks.
4. Does not participate in any housekeeping tasks.

E. Laundry

1. Does personal laundry completely.
2. Laundry not done frequently enough makes mistakes like too much soap, not sorting.
3. Requires assistance; launders small items - rinses socks, stockings, etc.
4. All laundry must be done by others.

F. Mode of Transportation

1. Travels independently on public transportation or drives own car.
2. Arranges own travel via taxi; travels on public transportation when assisted or accompanited by another.
3. Travel limited to taxi or automobile with assistance of another.
4. Does not travel at all.

G. Responsibility for Own Medications

1. Anticipates prescription renewals and arranges for filling.
2. Is responsible for taking medication in correct dosages at correct time.
3. Takes responsibility if medication is prepared in advance in separate dosages.
4. Is not capable of dispensing own medication.

H. Ability to Handle Finances

1. Manages financial matters independently budgets; writes checks; pays rent and bills; goes to banks; collects and keeps track of income.
2. Manages monthly needs, but not long term planning. Some spending not compatible with resources.
3. Manages day-to-day purchases, but needs help with banking, major purchase, etc.
4. Incapable of handling money.

PATIENT BEHAVIOR CHECKLIST

NAME: ______________________________

DATE: ______________________________

INSTRUCTIONS: Each item on this scale will be evaluated for two distinct time periods. FIRST, the informant will be asked if the behavior has occurred since the patient began to have memory loss. SECOND, the informant will be asked to estimate the frequency of each behavior within the past month. For the frequency counts, it is important to clarify any uncertainty that you might have about the frequency. For example, if the informant states that a behavior occurs once or twice a week, then a rating of 2 or 3 might apply. In this instance, you might ask the informant if the behavior has occurred at least 8 times. Also, if the informant reports that a behavior has never occurred, then rate the frequency in the past month as 0.

KEY

0 never occurred this month
1 several times this month
(less than 4 times)
2 approximately once per week
(4 to 7 times)
3 several times per week
(8 to 20 times)
4 nearly every day
(more than 20 times)

	Ever been a problem	Frequency in past month
1. is irritable or in a bad mood	YES NO	____
2. refuses to comply with requests	YES NO	____
3. temper outbursts	YES NO	____
4. makes threats to harm you or others	YES NO	____
5. tried to hit or actually hit you or others	YES NO	____
6. destroys things	YES NO	____
7. yells or swears at people	YES NO	____

IRRITABLE ☐

KEY

0 never occurred this month
1 several times this month
(less than 4 times)
2 approximately once per week
(4 to 7 times)
3 several times per week
(8 to 20 times)
4 nearly every day
(more than 20 times)

		Ever happened	Frequency in past month
8.	says that others have cheated or slighted or stolen from him/her	YES NO	____
9.	says that others are plotting against him/her	YES NO	____
10.	questions your fidelity	YES NO	____
11.	questions motives of family members or friends	YES NO	____
12.	accuses others of misdeeds	YES NO	____
13.	acts as if he/she sees or hears things which are not there	YES NO	____
14.	claims to have spoken to or seen deceased relatives or friends	YES NO	____
15.	believes that his/her image in the mirror is another person	YES NO	____
16.	misperceives common objects (e.g., a nail as a bug, door slamming as a gunshot)	YES NO	____
17.	talks to or says that persons on the radio or television are actually present in the room	YES NO	____

DELUSION ☐

KEY

0 never occurred this month
1 several times this month (less than 4 times)
2 approximately once per week (4 to 7 times)
3 several times per week (8 to 20 times)
4 nearly every day (more than 20 times)

		Ever happened		Frequency in past month
18.	hoards things (newspapers, bits of paper)	YES	NO	______
19.	eats things that she/he shouldn't (e.g., dog food, cigarette butts)	YES	NO	______
20.	does things that embarrass or concern you	YES	NO	______
21.	inappropriate sexual behavior	YES	NO	______
22.	laughs aloud for no apparent reason	YES	NO	______
23.	gorges self at meals	YES	NO	______
24.	takes things that do not belong to him/her	YES	NO	______
25.	interrupts conversations	YES	NO	______

ODD ☐

KEY

0 never occurred this month
1 rarely occurs
(1 to 3 times)
2 occurs weekly to daily
3 occurs frequently each day
4 severe problem that occurs
the majority of the time

	Ever been a problem		Frequency in past month
26. has difficulty sitting still	YES	NO	____
27. paces or walks aimlessly around	YES	NO	____
28. fidgets (changes position in the chair, plays with things in sight, fingers clothing)	YES	NO	____
29. complains of being bored	YES	NO	____
30. follows you around when you leave the room	YES	NO	____

AGITATION ☐

KEY

0 never occurred this month
1 several times this month
(less than 4 times)
2 approximately once per week
(4 to 7 times)
3 several times per week
(8 to 20 times)
4 nearly every day
(more than 20 times)

	Since having memory problems, have you noticed?		Frequency in past month
1. lost control of their bladder (wet themselves) ONLY at day ____ ONLY at night ____ EITHER day/night ____	YES	NO	_____
2. lost control of their bowels (soiled themselves) ONLY at day ____ ONLY at night ____ EITHER day/night ____	YES	NO	_____
3. complains of not having much warning when he/she has to go to the bathroom	YES	NO	_____

INCONTINENCE ☐

MOOD ASSESSMENT SCALE

Name: ____________________ Date: __________

1. Are you basically satisfied with your life?.......... yes/*no*
2. Have you dropped many of your activities and interests?.... *yes*/no
3. Do you feel that your life is empty?.......... *yes*/no
4. Do you often get bored?.......... *yes*/no
5. Are you hopeful about the future?.......... yes/*no*
6. Are you bothered by thoughts you can't get out of your head?.......... *yes*/no
7. Are you in good spirits most of the time?.......... yes/*no*
8. Are you afraid that something bad is going to happen to you?.......... *yes*/no
9. Do you feel happy most of the time?.......... yes/*no*
10. Do you often feel helpless?.......... *yes*/no
11. Do you often get restless and fidgety?.......... *yes*/no
12. Do you prefer to stay at home, rather than going out and doing new things?.......... *yes*/no
13. Do you frequently worry about the future?.......... *yes*/no
14. Do you feel you have more problems with memory than most?.......... *yes*/no
15. Do you think it is wonderful to be alive now?.......... yes/*no*
16. Do you often feel downhearted and blue?.......... *yes*/no
17. Do you feel pretty worthless the way you are now?.......... *yes*/no
18. Do you worry a lot about the past?.......... *yes*/no
19. Do you find life very exciting?.......... yes/*no*
20. Is it hard for you to get started on new projects?.......... *yes*/no
21. Do you feel full of energy?.......... yes/*no*
22. Do you feel that your situation is hopeless?.......... *yes*/no
23. Do you think that most people are better off than you are?.......... *yes*/no
24. Do you frequently get upset over little things?.......... *yes*/no
25. Do you frequently feel like crying?.......... *yes*/no
26. Do you have trouble concentrating?.......... *yes*/no
27. Do you enjoy getting up in the morning?.......... yes/*no*
28. Do you prefer to avoid social gatherings?.......... *yes*/no
29. Is it easy for you to make decisions?.......... yes/*no*
30. Is your mind as clear as it used to be?.......... yes/*no*

Cutoff: normal = 0-9; mild depression = 10-19; severe depression -- 20-30.

Comments/Observations:

Examiner: ____________________

LIFE SATISFACTION INDEX Z

Here are some statements about life in general that people feel differently about. Would you read each statement on the list, and if you agree with it, put a check mark in the space under "AGREE." If you do not agree with a statement, put a check mark in the space under "Disagree." If you are not sure one way or the other, put a check mark in the space under "?." Please be sure to answer every question on the list.

	AGREE	DISAGREE	?
1. As I grow older, things seem better than I thought they would be.	A	D	?
2. I have gotten more of the breaks in life than most of the people I know.	A	D	?
3. This is the dreariest time of my life.	A	D	?
4. I am just as happy as when I was younger.	A	D	?
5. These are the best years of my life.	A	D	?
6. Most of the things I do are boring or montonous.	A	D	?
7. The things I do are as interesting to me as they ever were.	A	D	?
8. As I look back on my life, I am fairly well satisfied.	A	D	?
9. I have made plans for things I'll be doing a month or a year from now.	A	D	?
10. When I think back over my life, I didn't get most of the important things I wanted.	A	D	?
11. Compared to other people, I get down in the dumps too often.	A	D	?
12. I've gotten pretty much what I expected out of life.	A	D	?
13. In spite of what people say, the lot of the average man is getting worse, not better.	A	D	?

Services Questionnaire

There are many services available to help elderly people and their caregivers. I am going to ask you some questions about some types of services that may be available in your area. I want to know about your knowledge of, anticipated use of, current use of, satisfaction with, and whether or not the service is adequate for your needs.

	Knowledge	Anticipated Use	Use	Satisfaction	Adequate
11-15) Long Term Care:	Y N	Y N	Y N	Y N	Y N
16-20) Adult Day Care	Y N	Y N	Y N	Y N	Y N

21) if yes, which one:
1. Mt. Newton
2. AFCC
3. Beckley Farm Lodge
4. Western Communities
5. Cubbon
6. Oak Bay Lodge
7. Pathways
8. Other
9. NA

	Knowledge	Anticipated Use	Use	Satisfaction	Adequate
22-26) Home Support Worker	Y N	Y N	Y N	Y N	Y N
27-31) Home Care Nursing	Y N	Y N	Y N	Y N	Y N
32-36) Home Physio	Y N	Y N	Y N	Y N	Y N
37-41) Respite Services: Facility	Y N	Y N	Y N	Y N	Y N
42-46) Overnight in home	Y N	Y N	Y N	Y N	Y N
47-51) Meals on	Y N	Y N	Y N	Y N	Y N

Wheels

52-56) Medical Y N Y N Y N Y N Y N
Alert System (Alarm system)

57-61) LTC Facility Y N Y N Y N Y N Y N

62) if yes, what level of care is care recipient using?
1. personal _____
2. intermediate ____
3. extended ____ 9 NA

63-67) Mental Health
Services: Y N Y N Y N Y N Y N
(professional counselling, peer counselling, etc)

68-72) Caregiver
Support Y N Y N Y N Y N Y N
Group

73-77) Information Y N Y N Y N Y N Y N
& referral
(Seniors Serving Seniors, Caregiver network, Needs crisis hotline, voluntering agencies, Wellness centres, etc.)

78-82) Quick Y N Y N Y N Y N Y N
Response
Team

83-87) Palliative Y N Y N Y N Y N Y N
Care
(Hospice, Caring Friends, Juan de Fuca)

88-92) Transportation Y N Y N Y N Y N Y N
(Handi-dart, Road runner, Volunteer Drivers, Bus, taxi, friends)

Are there other services that you would like to see become available?

If not satisfied with or not receiving enough of some services. Please elaborate.

How much assistance do you provide the care recipient for each of the following activities?

	None	Partial	Total
1) Transferring from bed to chair	____	____	____
2) Bathing	____	____	____
3) Feeding	____	____	____
4) Dressing	____	____	____
5) Grooming	____	____	____
6) Bladder Problems	____	____	____
7) Muscle Exercises	____	____	____
8) Breathing Exercises	____	____	____
9) Scheduling doctor appointments	____	____	____
10) Transportation to doctor appts.	____	____	____
11) Handling financial matters	____	____	____
12) Providing leisure/ social activities	____	____	____
13) other:			
________________________	____	____	____
________________________	____	____	____

Appendix C

The following appendix contains the set of instruments used in the described study alone.

Caregiver Psychological Research

Kelly Thorstad is a graduate student at the University of Victoria working with Dr. Glenn Stebbins. She is conducting a research project on stress and coping styles of caregivers for dementing elders.

The study will investigate the different ways that caregivers cope with dementia and the amount of stress that they feel. This information will be gathered by an interview and questionnaires. Two of the questionnaires are psychological inventories designed to measure coping methods and stress levels.

If you are interested in volunteering, please call Kelly at 721-7546 or Laurie-Anne Keith with the Elderly Outreach Service at 356-8903.

THESIS QUESTIONNAIRE

<u>DEMOGRAPHIC INFORMATION</u>:

Date: caregiver's birthdate

Sex: caregiver's gender

Education: years of formal education of caregiver

A & B: subject number

C: page number of form

D: sex of recipient 1 male 2 female

E: Primary language spoken

for caregiver

- 1 English
- 2 French
- 3 Other 1=German, 2=Spanish, 3=other

F: for recipient (1-3: same as above)

G & H: age of recipient

I & J: years of formal education of recipient

K: What is your marital status?

<u>Caregiver</u>

- 1 never married
- 2 married
- 3 widowed
- 4 divorced
- 5 separated
- 6 living together (unmarried)
- 9 unknown

L: <u>Recipient</u> (1-9 same as above)

M & N: What type of residence do you and the recipient currently live in?

M: caregiver:	N: recipient:
1. house	1. house
2. condominium	2. condominium
3. apartment	3. apartment
4. rooming home	4. rooming home
5. long term care	5. long term care
6. nursing home	6. nursing home
7. residential care facility	7. residential
8. mental hospital	8.mental hospital
9. other	9. other

O: How many people live with the care recipient?

P: What is your relationship to the recipient?

1. spouse
2. daughter
3. son
4. sister/brother
5. other relative (specify)______________
6. friend
7. neighbour
8. paid caregiver
9. other (specify)________________

1: How many people live with you? ___ (include recipient if true)

2: Has there been a change in primary caregiver within the past six months? 1 no 2 yes

3: What diagnosis has the recipient received?

1. Alzheimer's disease
2. multi-infarct dementia
3. Parkinson's disease
4. mixed dementia
5. psychiatric impairment
6. physical/mobility impairment
7. medical impairment
8. non-diagnosed cognitive impairment
9. don't know

4-6: How long has the recipient had this/these condition(s)? (in months)

7-9: How long have you been partly or fully responsible for the recipient's care? (in months)

10-12: How many hours a week do you spend providing care for the recipient?

13-14: How many people are dependent on you other than the recipient?

15-19: Who (tick as many as apply)

1 spouse
2 child
3 other relative
4 friend
5 other, 9 NA

20. Do you work now? 1 no 2 yes

21-22: About how many hours per week are you employed? (9=NA)

23: Have you had to adjust your work schedule to care for the recipient in the past six months? 1 no 2 yes 9 NA

24-25: if yes, # of hours took off (9=NA)

26-27: if yes, # of hours cut back (9=NA)

28: Over the past six months have you had to modify your home for the sake of the recipient? 1 no 2 yes

29-32: If yes, how much did it cost? (9=NA)

33: Is there someone other than the recipient who relies on you for financial support?

1 no

2 yes, someone is partially dependent

3 yes, someone is fully dependent

34: Do you feel that you have sufficient income to meet your needs as a caregiver?

1 I do not have enough income

2 I have enough income

3 I have more than enough income

In the past year have you had any medical problems?

35: heart trouble (1=no,2=yes)

36: circulation problems/atherosclerosis

37: been paralysed in any way

38: arthritis, rheumatism

39: a tumor or growth/cancer

40: diabetes

41: other

42. Are you currently taking any kind of medication? 1=no2=yes

About how many times have you seen any kind of doctor during the past six months other than as a patient in hospital?

43-44: caregiver # of times

45-46: recipient # of times

How many days during the past six months were you or the recipient in the hospital for physical health problems?

47-48: caregiver # of days

49-50: recipient # of days

How would you rate your and the recipient's health at the present time?

51: caregiver	52: recipient
1 excellent	1 excellent
2 good	2 good
3 fair	3 fair
4 poor	4 poor

How much do health problems stand in the way of doing things you want to do?

53: caregiver	54: recipient
1 not at all	1 not at all
2 a little	2 a little
3 a great deal	3 a great deal

55: Was the recipient ever treated for an emotional problem before the current problem began?

1 no

2 any counselling/psychotherapy

3 medication (i.e. "nerve pills")

4 hospitalization

5 don't know

56: Were either of the recipients parents ever hospitalized for emotional problems? (1=no, 2=yes, 3=don't know)

57: brothers/sisters? 58: children?

59: Who including yourself are involved in caring for the recipient?

60: Does this person live with the patient? 1=no 2=yes

61: Do they live within a 30 min. drive? 1=no 2=yes

62: How many hours a week do they spend with the recipient?

63: Are they paid for the services? 1=no 2=yes

64: Do you consider them a primary caregiver? 1=no 2=yes

65-98: same questions as above for up to five helpers.

99: Is there a legally appointed person to handle the recipient's finances?

1 no

2 yes

3 don't know

100: If yes, what is their relationship to recipient? (1=spouse, 2=daughter, 3=son, 4=sister/brother, 5=other relative, 6=friend,7=other, 9=NA)

101: Can the recipient participate in any discussion and decision about their personal well-being, property, and other assets in meaningful way?

1 no

2 yes

3 don't know

Currently, who participates in decision making about formal services being used? Rank in order of responsibility. (i.e. day care, respite care, home worker, facility placement)

102: LTC

103: Physician

104: Caregiver

105: Care recipient

106: Family

In your opinion, who should have the most input into those decisions? (107-111: same choices as above)

112: Have you ever considered a nursing home or boarding home for the patient? 1 no 2 yes

Brief Symptom Inventory

Instructions: Below is a list of problems and complaints that people sometimes have. Read each one carefully, and select one of the numbered descriptors that best describes how much discomfort that problem has caused you during the past two weeks, including today. Circle that number in the space to the right of the problem. Please do no skip any items.

Descriptors

0 = not at all
1 = a little bit
2 = moderately
3 = quite a bit
4 = extremely

How much were you distressed by:	Descriptor
1.) Faintness or shakiness inside?	0 1 2 3 4
2.) Trouble remembering things?	0 1 2 3 4
3.) Your feelings being easily hurt?	0 1 2 3 4
4.) Thoughts of ending your life?	0 1 2 3 4
5.) Feeling tense or keyed up?	0 1 2 3 4
6.) Feeling easily annoyed or irritated?	0 1 2 3 4
7.) Feeling afraid in open spaces?	0 1 2 3 4
8.) Feeling others are to blame for most of your troubles?	0 1 2 3 4
9.) Feeling lonely even when you are with people?	0 1 2 3 4

For a complete copy of the BSI, write or call:

Clinical Psychometric Research, Inc.
P.O. Box 619
Riderwood, Maryland 22139
USA
1 (800) 245-0277

Instructions: Below is a list of ways that some people cope with difficult situations. Read each one carefully and select one of the numbered descriptors that best describes how much you have used that response in dealing with caring for someone with memory problems. Please answer each item.

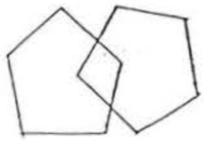
	NO 1	YES, once or twice 2	YES, some-times 3	YES, fairly often 4
Tried to find out more about the situation . .	☐	☐	☐	☐
Talked with spouse or other relative about the problem	☐	☐	☐	☐
Talked with friend about the problem	☐	☐	☐	☐
Talked with professional person (e.g., doctor, lawyer, clergy)	☐	☐	☐	☐
Prayed for guidance and/or strength	☐	☐	☐	☐
Prepared for the worst	☐	☐	☐	☐
Didn't worry about it. Figured everything would probably work out	☐	☐	☐	☐
Took it out on other people when I felt angry or depressed	☐	☐	☐	☐
Tried to see the positive side of the situation	☐	☐	☐	☐
Got busy with other things to keep my mind off the problem	☐	☐	☐	☐
Made a plan of action and followed it	☐	☐	☐	☐
Considered several alternatives for handling the problem	☐	☐	☐	☐
Drew on my past experiences; I was in a similar situation before	☐	☐	☐	☐
Kept my feelings to myself	☐	☐	☐	☐
Took things a day at a time, one step at a time	☐	☐	☐	☐

	NO 1	YES, once or twice 2	YES, some-times 3	YES, fairly often 4
Tried to step back from the situation and be more objective	☐	☐	☐	☐
Went over the situation in my mind to try to understand it	☐	☐	☐	☐
Tried not to act too hastily or follow my first hunch	☐	☐	☐	☐
Told myself things that helped me feel better	☐	☐	☐	☐
Got away from things for a while	☐	☐	☐	☐
I knew what had to be done and tried harder to make things work	☐	☐	☐	☐
Avoided being with people in general	☐	☐	☐	☐
Made a promise to myself that things would be different next time	☐	☐	☐	☐
Refused to believe that it happened	☐	☐	☐	☐
Accepted it; nothing could be done	☐	☐	☐	☐
Let my feelings out somehow	☐	☐	☐	☐
Sought help from persons or groups with similar experiences	☐	☐	☐	☐
Bargained or compromised to get something positive from the situation	☐	☐	☐	☐
Tried to reduce tension by:				
(a) drinking more	☐	☐	☐	☐
(b) eating more	☐	☐	☐	☐
(c) smoking more	☐	☐	☐	☐
(d) exercising more	☐	☐	☐	☐
(e) taking more tranquilizing drugs	☐	☐	☐	☐

Patient Number ____

Date of Birth ____ Date of Examination ____ Examined by ____

	ANSWER	SCORE	POINTS
ORIENTATION			
1. What is the Year?			1
Season?			1
Month?			1
Date?			1
Day of the Week?			1
2. What are we?			1
Country?			1
Province?			1
City? Building?			1
Floor?			1
REGISTRATION			
3. Name three objects, taking on second to say each. Then ask the patient all three after you have said them. Give one point for each correct answer. Repeat the answers until the patient learns all three. apple, elephant, chair			3
ATTENTION AND CALCULATION			
4. Serial sevens. Give one point for each correct answer. Stop after five answers. Alternate: Spell WORLD backwards.			5
RECALL			
5. Ask for names of three objects learned in Question 3. Give one point for each correct answer. 1.) fruit: orange/apple 2) animal: elephant / tiger 3) furniture: table/chair			3
LANGUAGE			
6. Point to a pencil and a watch. Have the patient name them as you point.			2
7. Have the patient repeat "No ifs, ands, or buts."			1
8. Have the patient follow a three-stage command: "Take the paper in your right hand. Fold the paper in half. Put the paper on the floor."			3
9. Have the patient read and obey the following: "CLOSE YOUR EYES."			1
10. Have the patient write a sentence of his or her own choice. (The sentence should contain a subject and an object and should make sense. Ignore spelling errors when scoring.)			1
11. Enlarge the design printed below to 1-5 cm per side and have the patient copy it. (Give one point if all sides and angles are preserved and if the intersecting sides form a quadrangle.			1
		____	= Total 30



COMMENTS

____

____

Province of
British Columbia

Ministry of
Health

ELDERLY OUTREACH SERVICE

Victoria Mental Health Centre
2328 Trent Street
Victoria
British Columbia
V8R 4Z3
Phone: (604) 356-8903
FAX: (604) ~~356-1872~~ X 356-9342

August 15, 1990.

Dear Dr.____________________________,

This is a brief letter to inform you that your patient, ____________________________, along with his/her primary caregiver, ____________________________, have volunteered to participate in a study investigating the types of coping methods used in caregiving. The Elderly Outreach Service has been assisting in this research project, which is under the direction of Ms. Kelly Thorstad, a Masters student in psychology at the University of Victoria.

Clarification of the patient's diagnosis is an important part of the validity of this study. Your cooperation in filling out the following questions would be greatly appreciated (consent form is enclosed). Please note that this is strictly voluntary information (ie. neither the patient nor the caregiver should be billed). Please circle your answers.

1. Is the above-named patient demented?
   yes no uncertain

2. If yes, what type of dementia?
   - (a) Alzheimer's disease
   - (b) Multi-infarct dementia
   - (c) Parkinsonian dementia
   - (d) Mixed dementia
   - (e) Cognitive Impairment secondary psychiatric illness
   - (f) Medical Impairment (eg. metabolic or toxic condition resulting in cognitive impairment)
   - (g) Non-diagnosed cognitive impairment
   - (h) Other:____________________________

3. Would you like a brief report of the results of this study?
   yes no

Please place the completed form in Dr. Anne LaBonté's or Dr. Derek Carroll's mail slot at the Royal Jubilee Hospital. If you have questions about this study, please call Kelly Thorstad at 721-7525 or Laurie-Anne Keith with the Elderly Outreach Service at 356-8903.

Sincerely,

Anne LaBonté, M.D., F.R.C.P. (C)
Clinical Director
Elderly Outreach Service

Laurie-Anne Keith, B.Sc.(O.T.)(C),
Reg. Occupational Therapist (B.C.),
Elderly Outreach Service

VITA

Surname: THORSTAD Given Names: KELLY GAYLE

Place of Birth: Topeka, Kansas

Date of Birth: August 22, 1965

Educational Institutions Attended

Kilgore College	1983 to 1985
University of Texas	1985 to 1988
University of Victoria	1988 to present

Degrees Awarded

B.A. in Psychology	1988	University of Texas (with honors)

HONORS AND AWARDS

Wesley Foundation Scholarship, 1984/1985

Wesley Foundation Scholarship, 1985/1986

Golden Key National Honor Society, 1987/1988

University of Victoria Fellowship, Jan. 1989/Aug. 1989

University of Victoria Fellowship, Sept. 1989/Aug. 1990

University of Victoria Fellowship, Sept. 1990/Jan. 1991

PRESENTATIONS

Stress and Coping Issues in Caregiving. Alzheimer's Support Group Meeting. May, 1990.

Workshop for Health Care Professionals: Dementia: Coping with the Caregiving Role. The Elderly Outreach Service. November, 1990.

Title of Thesis: Dementia: Coping with the Caregiving Role

Author [redacted]
Kelly Thorstad

19 Jan 91
(Date)