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Coping Strategies Employed by In-Home Family Caregivers of Alzheimer's Patients

Steven E. Reisler
Department of Educational & Counselling Psychology
McGill University, Montreal

A Thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements of the degree of
M.A. in Educational Psychology

Running Head: COPING STRATEGIES

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Coping Strategies Employed by In-Home Family Caregivers of Alzheimer's Patients

Steven E. Reisler

Abstract

Most demented individuals are now cared for at home by family members. The present study examined the coping strategies employed by family caregivers, their perception of burden, and the internal dialogues employed by caregivers to stressful events. Sixteen (13 females, 3 males) participants with an average age of 67.4 years were interviewed. Results indicate that caregivers who spend less hours per week caring for their care receiver perceived less overall burden and caregivers who subjectively felt that they were coping with their role tended to use more coping strategies. Caregivers' internal dialogues and comments concerning problems coping with Alzheimer's patients are included.

Key words: Alzheimer's disease; In-home Caregivers; Coping Strategies

Méthodes de traitement de situation utilisées par les membres de la famille prodiguant les soins aux patients atteints de la maladie d'Alzheimer

Steven E. Reisler

Abrégé

La plupart des individus en démence sont maintenant soignés à la maison, par des membres de la famille. La présente étude fait l'analyse des méthodes de traitement de situation utilisées par ceux qui prodiguent les soins, de la façon dont ces gens concoivent leur tâche, ainsi que des dialogues internes qui ont lieu chez ces personnes lors de situations difficiles. Seize participants (13 femmes et 3 hommes) âgés en moyenne de 67.4 ans ont été interrogés. Les résultats démontrent que les personnes qui passent moins d'heures par semaine à soigner les patients se sentent en général moins accablés par cette tâche, tandis que les personnes qui croient assumer adéquatement leur rôle ont tendance à utiliser davantage les méthodes de traitement de situation. Les dialogues et les commentaires formulés par les personnes qui prodiguent les soins concernant les problèmes aux quels ils ont à faire face avec les personnes atteintes de la maladie d'Alzheimer sont reproduits plus loin.

Mots-clés: Maladie d'Alzheimer; Personnes prodiguant les soins à la maison; Méthodes de traitment de situation

Chapter 1

Review of the Literature

> Alzheimer's disease (AD) is the most common form of dementia.... Affected individuals undergo a gradual but relentless loss of memory and other cognitive abilities. Social independence is lost. Survival is shortened. The impact on close relatives is devastating. (Hyman, Damasio, Damasio, & Van Hoesen, 1989)

Alzheimer's disease is now recognized as the most common cause of adult-onset dementia (Price, Whitehouse, & Struble, 1985). Dementia is defined "as a syndrome of global loss of cognitive function, especially memory, sufficient to impair social or occupational function" (Larson, Kukull, Katzman 1992, p. 431). It consists of impairment in short- and long-term memory, as well as disturbances of other cognitive functions and/or personality changes. This disturbance must be sufficient enough to disrupt work, usual social activities, or relationships with others.

The increasing and widespread interest in age-associated dementia is a result of the rapid aging of the world population. As Rocca and Amaducci (1991, p. 56) state, "The increasing number of elderly people implies a larger number of subjects at risk for age-associated neurological disorders such as dementia...." This dictates that we take the appropriate action in the provision of health, social, and other services (Grundy, 1987).

An increase in the incidence of Alzheimer's disease and other types of dementias will undoubtedly result in an expansion of both the formal and informal caregiving networks. Matras (1990) defines formal caregiving as (a) care provided in closed or institutional settings such as acute care hospitals or nursing homes; or (b) care provided in open or community settings such as health services, adult day care centers, private homes, or residential groups. In contrast, he defines informal caregiving as care provided by the family. For the purposes of this paper, informal caregiving includes care provided by family, friends, and all other informal networks and settings.

Several studies have alluded to the demands, risks, and costs associated with caregiving (see Clark & Rakowski, 1983). Even with the high emotional cost of caring for someone with Alzheimer's disease, family members and other caregivers go to great lengths to avoid institutionalization of an ill spouse, parent, relative, or friend. Thus, the informal support system is the primary resource for the aged (Clark & Rakowski, 1983; Hooyman, Gonyea, & Montgomery, 1985).

This will result in an increase in the emotional and financial costs associated with caregiving. Already, the costs of formal care are high. Estimates of the financial cost of Alzheimer's disease in the United States range between $24 and $48 billion each year (Martin, 1989). Partially due to the escalating costs of long-term formal care, the emphasis has shifted from institutional to community-based care for individuals, with the informal support system as the primary providers of emotional help and instrumental services to elderly individuals with Alzheimer's disease (Robinson, 1983). It has been estimated that family caregivers of the frail elderly save the United States federal government from $9 to $17 billion each year (Vitaliano, 1990).

Until recently, research on coping typically excluded individuals over 65 years of age. But, since the 1980s, there has been a growing interest in coping and the elderly (see Barusch, 1988; Cattanach & Tebes, 1991; Haley, Levine, Brown, & Bartolucci, 1987; Karuza, Zevon, Gleason, Karuza & Nash, 1990; Killeen, 1990; Lazarus & DeLongis, 1983; Stephens, Norris, Kinney, Ritchie, & Grotz, 1989) and social support for elderly caregivers (see Gallo, 1990; Greene & Monahan, 1989; Haley, Brown, & Levine, 1987; Haley, Levine, Brown, & Bartolucci, 1987; Jacob, 1991; Thoits, 1986; Vitaliano, 1990). The research has primarily examined the relationship between caregiver stress, health effects, and coping.

North American society is an aging society. Since the turn of the century, life expectancy has increased from 47 to 74.5 years. Since 1900, there has been an eightfold increase in the number of people 65 and older. Presently, in the United States, 11% of the population is over the age of 65. People over the age of 65 are now the fastest-growing segment of our population. With growing medical expertise, approximately half of the population should survive until age 85. Women are already approaching that optimum, with about half of all females living until 80 years of age (Plum, 1986).

By 2050, the ratio of Americans over the age of 65 is expected to be 1 in 5. This represents a four-fold increase in less than a century (Plum, 1986). Heckler (1985) affirms that the over-65 population in the United States will more than double from 26 million in 1980 to 67 million by the middle of the next century, representing over 17% of the total population (Davenport, 1980). Currently, one in nine Americans is over the age of 65. Martin (1989) further points out that 2.2 million Americans are over the age of 85, and that by the year 2040, more than 12.9 million Americans will be 85 or older. Moreover, in each decade since 1940, the over-85 age group has increased by more than 50%, reaching 8.8% of the total population in 1980 (Rosenwaike & Dolinsky, 1987).

One area that has recently gained attention is the effects of an aging population on in-home family caregivers of patients with Alzheimer's disease. The dominant institution of long-term care is the family. Increased life-expectancy has led to an expansion in the demand for families to assume the caregiver role (Long, 1990). Jutras and Veilleux (1991) report that 70-80 per cent of all caring for the elderly is shouldered by the family network. Further, most caregivers are women, primarily wives and daughters (Malonebeach & Zarit, 1991; Steinmetz, 1980). Brody (1985) estimates that well over 5 million people are involved in parent care at any given time.

In order to fully understand all the implications and demands of the caregiving role, we must examine the nature and background of Alzheimer's disease; the nature of family caregiving; and coping with the caregiving role.

Nature and Background of Alzheimer's Disease

Alzheimer's disease is a degenerative disorder which usually affects people over the age of 65, but is also known to strike individuals in their late forties (known as presenile dementia) (DSM-III-R, 1987). The basic feature of Alzheimer's is that it develops so slowly that family members and medical professionals do not recognize the deterioration for some time. It involves a "multifaceted loss of intellectual abilities, such as memory, judgment, abstract thought, and other higher cortical functions, and changes in personality and behavior" (DSM-III-R, 1987, pp. 119-120).

Origin of Disease

The term 'dementia' was used at the end of the nineteenth century to designate any state of psychological deterioration associated with chronic brain disease. In the elderly, such states were referred to as 'senile dementia' (Berrios, 1990). In 1907, Alois Alzheimer reported the case of a 51-year-old woman who had progressive cognitive impairment, focal symptoms relating to higher cortical functions, hallucinations, delusions and marked psychosocial incompetence. An autopsy later showed brain atrophy, *arteriosclerotic* changes, senile plaques and neurofibrillary tangles (Berrios, 1990).

Characteristics of Alzheimer's disease

From the time the disease was first reported in 1907 by Dr. Alzheimer, research has focused on its etiology. As Weiner (1991) reports, we stand very close to where Dr. Alzheimer stood 85 years ago. That is, we know little about the causes of the disease. Presently, suspected cases of Alzheimer's are diagnosed by a process of elimination. Tests are performed for other forms of dementia. If all the tests come back negative, we refer to the disorder as Primary Degenerative Dementia of the Alzheimer type. Thus, more than 85 years after Dr. Alzheimer reported the disease, we still do not know how such changes occur (Hyman et al., 1989).

The criteria for diagnosis of Alzheimer's disease are threefold: (a) the presence of dementia; (b) an insidious onset, followed by progressive deterioration; (c) the exclusion of all other specific causes of dementia and dementia-like symptoms by history, physical examination, laboratory tests, and psychometric and other special studies (Heckler, 1985). That is, a diagnosis of Alzheimer's can only be made after all other causes have been ruled out (Martin, 1989). An accurate diagnosis of Alzheimer's disease can be made only at autopsy (Perlmutter & Hall, 1985; Price, Whitehouse, & Struble, 1985). Without an autopsy, all other diagnoses are based on informed inference.

Alzheimer's disease is verified with an autopsy, which shows brain degeneration consisting of large numbers of neurofibrillary tangles (NFTs) and neuritic plaques (NPs) (Hyman et al., 1989) as well as intraneuronal granulovacuolar degeneration in the cerebral cortex (Davenport, 1980). Neurofibrillary tangles and senile plaques are the characteristic features of Alzheimer's disease (Schmidt, 1983).

Alzheimer's disease is a brain disorder of unknown etiology which is characterized by a progressive loss of memory and intellectual function (Heckler, 1985). In addition to progressive loss of memory individuals afflicted with dementia show signs of impaired ability to calculate; disorientation to time, place, and person; defective judgment; and a labile affect (Davenport, 1980). Earlier stages of the disease are marked by memory impairments and subtle personality changes such as signs of apathy, withdrawal, etc. Although later stages of dementia are easily recognizable, earlier symptoms are often poorly defined and missed. Changes are often so subtle that even close relatives or friends may be unaware of the beginning stages of dementia. Early symptoms of dementia are characterized by disturbances in the patient's capacity to solve simple problems, or by a deterioration of the patient's thought processes (Davenport, 1980). Weiner (1991) reports that Alzheimer's disease differs from normal age-associated cognitive deficits. Although all aspects of cognitive function are impaired in the later stages, the processes damaged earliest are: attention, concentration, short-term memory, naming objects, and the ability to copy simple geometric figures. In the early stages, an individual inflicted with Alzheimer's disease experiences functional difficulties in instrumental skills (e.g., shopping, handling money). As the disease progresses, the individual has problems with such self-care activities as toileting and dressing (Gauthier & Gauthier, 1990). By the middle stages of the disease, behavioral problems become more apparent, while the intellectual and personality disturbances become more severe. Individuals with Alzheimer's disease eventually show profound cognitive changes, including marked disorientation to time, place, and person. The individual may become inattentive, incontinent, and totally incapable of self-care (Heckler, 1985). As Alzheimer's disease progresses, recognition of familiar surroundings and faces becomes impaired (Hymen et al., 1989).

Although "normal" aging brings a decline in performance on the nonverbal subtests of the Wechsler Adult Intelligence Scale (WAIS), performance on verbal subtests is retained. In contrast, similar tests of individuals with Alzheimer's disease show a marked decrement on tests that assess such cognitive processes as memory, temporal orientation, visual perception, and language. In particular, factual memory of the episodic type, especially the acquisition of new episodic memories and the retrieval of previously acquired memories becomes progressively impaired (Hyman et al., 1989). In addition to profound changes in episodic and generic verbal and nonverbal memory processes, deficits can be seen in decision making, problem solving, sensory integration, and attention. However, motor and elementary perceptual processes, and both phonemic and syntactical aspects of language, remain relatively intact until very advanced stages of the disease (Hyman et al., 1989).

Causes of Alzheimer's disease

One of the most disturbing consequences of Alzheimer's disease to family members and caregivers, is that we are uncertain as to what causes the disease. Although we are uncertain of the etiology of the disease, several hypotheses have been put forward.

These include (a) neurotransmitter or other neurochemical deficits or imbalance, particularly acetycholine and neuropeptides; (b) selective brain cell death or injury induced by a slow virus or other atypical transmissible agents; (c) excessive accumulation in the brain of environmental toxins (e.g., exposure to aluminum); (d) genetic factors such as a defect to the trisomy 21 gene; (e) an autoimmune process; (f) vascular phenomena; and (g) head trauma (Davenport, 1980; Heckler, 1985; Larson et al., 1992; Price et al., 1985; Rocca & Amaducci, 1991; Schmidt, 1983; Schneck et al., 1982; Wilcock, 1988).

Prevalence of Alzheimer's Disease and Other Dementias

Approximately 4.4% of all persons over the age of 65 have some degree of severe intellectual impairment. Sixty-five percent of these elderly individuals suffer from Alzheimer-type dementia (Brill, 1984). It is estimated that over three million Americans are now affected by Alzheimer's disease, while milder forms of dementia probably affect two to three times this number (Hyman et al., 1989). Of the 3 million Americans, approximately half suffer from severe dementia (Martin, 1989) and 11% of those over the age of 65 have mild forms of dementia (Davenport, 1980). No longer can we consider chronic dementia as a simple concomitant of "normal" aging.

Although Alzheimer's disease has been known to afflict patients under 50 years of age, the risk of developing the disease increases dramatically with age. For instance, although the prevalence of Alzheimer's disease among individuals 65 and older is approximately 6%, this number increases to 10% at age 75 and mushrooms to 20% for persons 85 and older (Heckler, 1985). If one considers future demographics, the number of cases of Alzheimer's disease will double by the year 2000, and quintuple by the year 2040 (Martin, 1989). Plum (1986) reports that the annual incidence rate of new cases of Alzheimer's disease is about 3.5%. In addition to age-related factors, Rocca and Amaducci (1991) point out that the risk for Alzheimer's disease is higher for females than for males since women live longer than men.

Alzheimer's disease is a significant cause of morbidity in the elderly population. Alzheimer's disease and related disorders is now the fourth leading cause of death in the United States, with an expected 100,000 dying from the illness (Brill, 1984). Martin (1989) reports that patients with dementia are expected to survive one-third as long after onset as unaffected persons of the same age. Kay and associates (1962: cited in Schneck, Reisberg, & Ferris, 1982) found that the average survival period was 2.6 years for demented men and 2.3 years for demented women. This compares to 8.7 years and 10.9 years for an age-matched sample of nondemented men and women, respectively. One of the devastating apects of Alzheimer's disease is that no treatment has yet been shown to be effective in preventing, reversing, or even arresting its biological ravages (Blass, 1984).

Problems Associated with Alzheimer's Disease

Deutsch and Rovner (1991) have indicated that individuals afflicted with Alzheimer's disease are known to have certain behavioral symptoms. For instance, agitation, psychotic symptoms, wandering, and sleep disturbance are common behavioral problems associated with the disease. The authors go on to indicate that at least 50% of patients attending outpatient dementia clinics and 75% of demented nursing home patients have behavioral disorders. Rabins (1989) reports that 60-75% of demented individuals suffer from at least one significant behavioral problem.

Agitation is defined as "inappropriate verbal, vocal, or motor activity that is not explained by needs or confusion per se." Deutsch and Rovner (1991) have identified three syndromes of agitation: physical aggression, verbal aggression, and nonaggressive behaviors. Examples of the most common form of agitation, nonaggressive behaviors, include pacing, motor restlessness, and constant requests for attention. Dysphoric patients may seem lethargic during the day, while the evening brings insomnia and the "sundowning" phenomenon (increased confusion and disorientation during the evening). Other manifestations of agitation may include incessant purposeless activity (abulia), screaming, episodes of unprovoked or exaggerated rage (Martin, 1989), distressing pleas, apparent psychic torment (McLean, 1987), and irritability (Rabins, 1989).

In 1907, when Alzheimer first described the disease, one of the prerequisites for diagnosis was the presence of psychotic symptoms. Although this is no longer a prerequisite for diagnosis (DSM-III-R, 1987), a number of patients with dementia of the Alzheimer's type (DAT) suffer from psychosis. The most common forms of psychosis are persecutory delusions, suspiciousness, and the belief that people are stealing from them (Deutsch & Rovner, 1991). Accusations that things are being taken are especially common (Rabins, 1989).

Another serious problem for families of individuals with Alzheimer's is wandering behavior that occurs in 3% to 26% of outpatients attending a dementia clinic. Four types of wandering patterns have been identified: exit-seekers, self-stimulators, akathesiacs, and modelers. Exit-seekers attempt to leave, whereas self-stimulators manipulate the door, more as an activity that for the purpose of leaving. Akathesiacs are characterized in much the same way as those individuals who exhibit nonaggresive behaviors. That is, they manifest restlessness, pacing, and fidgeting behaviors. Individuals who follow people around are considered modelers (Deutsch & Rovner, 1991).

Sleep disturbance, as evidenced by multiple nighttime awakenings is another behavioral symptom that is commonly found in patients with DAT. Reebok (1990: cited in Deutsch & Rovner, 1991) found that 23% of subjects had two to five nighttime awakenings, and another 11% had early morning awakenings.

Another feature of Alzheimer's disease is that an individual's ability to express himself/herself or to comprehend what is being said is affected. For instance, the patient may say the opposite of what is meant to be said (no for yes), use an incorrect word (spoon for pen), or use words that are either combinations of other words (write downer for pen), or totally made up. These *paraphasic errors* are an important indicator of aphasic language disorder (Rabins, 1989).

Although not commonly reported, sexual problems in the demented are among the most distressing problems reported by caregivers. Examples of sexual problems include: hypersexuality, hyposexuality, and public displays of sexuality. Patients with an increased appetite for sexual activity frequently forget about their recent sexual activity (Rabins, 1989).

Early stages of Alzheimer's disease are characterized by passive changes in personality. Examples of passive behaviors include: coarsening of affect, decreased spontaneity, inactivity, passive changes of insecurity, and less cheerfulness (Deutsch & Rovner, 1991). Frequently, these passive personality changes are interpreted as depression. Family members and other caregivers report that the most commonly occurring problems are memory impairment, emotional disorders manifested by outbursts of anger and/or crying, demanding critical behavior, physical violence, night walking, daytime wandering, hiding things, suspiciousness, hallucinations, delusions, difficulties with meals and bathing, and incontinence (Baumgarten, Becker, & Gauthier, 1990; Brill, 1984).

Family caregivers report that obtaining assistance with providing recreational and diversional activities was their greatest need. Caregivers further indicated the need for assistance with elimination, nutrition, sleep needs of the demented, physical care, transportation, safety, and dental hygiene (Baines, 1984). In contrast, the greatest concern of family caregivers was not being able to leave the house. Other concerns centered around feeling worn out and tired and not knowing the best way to care for an individual with Alzheimer's disease. Of lesser concern to caregivers were sexual relationships and the responsibility of caregiving (Baines, 1984).

Chapter 2

Nature and Importance of Research

Several studies (e.g., Price, Cowen, Lorion, & Ramos-McKay, 1989; Haley, Brown, & Levine, 1987; Brown, 1983; Barrow, 1982) have examined coping-skills training. Although previous research has identified the nature of stress associated with caring for a family member with Alzheimer's disease, some findings seem contradictory to others.

Nature of Family Caregiving

One of the cruelest ironies of Alzheimer's disease is that while the mind slowly deteriorates, much of the individual's physical vigor retains intact. Thus, the primary caregiver, most often a spouse or a child, is forced to see their loved one transformed into a confused and helpless stranger. Heckler (1985) points out that caregivers are often the "hidden victims" of Alzheimer's disease. The caregiver is compelled to meet the patient's needs while attempting to preserve his/her own well-being. More often than not, the spouse caregiver spends exhausting days and nights in limbo between roles: neither wife nor widow, husband nor widower, deprived not only of a companion but also the opportunity to mourn. The caregiver suffers further emotional strain as the dementia worsens and patients are no longer able to recognize who helps them with their daily living (Heckler, 1985).

Characteristics of Family Caregivers

Most demented individuals are now cared for at home by family members. Those patients who were previously admitted to hospitals for long-term treatment planning are now denied this help due to more stringent utilization criteria and a move towards deinstitutionalization (Brill, 1984). As well as being necessitated by health care costs, home care is usually preferred by the older adult. At least half of the home care is provided by spouses, many of whom are themselves old and vulnerable to disease

(Baines 1984). In fact one-third of caregivers are over the age of 65, thus, the informal care system is partially composed of the young-old caring for the old-old (Stone et al., 1987). Further, it has been shown that men who assume the caregiver role are usually older than women (Zarit, 1982: cited in Barusch & Spaid, 1989).

Eventually, the disabled person becomes increasingly dependent on their children and relatives. This dependence is not without cost to families caring for their aged adults. The caregiving role may become an overwhelming burden, causing excessive stress, of which may result personal health problems. For instance, Baines (1984) found that only 10% of a sample of caregivers reported their health status as excellent. The majority of caregivers believed their health to be poor to good. Surprisingly, 70% of caregivers still reported being satisfied with their role as carer. Brody (1985) speculates that family caregivers report feeling satisfied with the caregiver role because of the normative nature of caring for a parent. She acknowledges that although normative, it is a stressful experience, and one of which we still know relatively little.

One would assume that due to their more advanced age, men would report greater difficulty in managing certain caregiver roles. In fact, the opposite is true. Barusch and Spaid (1989) report that female caregivers typically report greater burden than do male caregivers. They found that women's subjective reaction to caregiving tends to be more negative than those of men. Several theories have been put forth to explain why female caregivers report greater distress: (a) they experience greater "role overload," as they are typically younger than male caregivers; (b) elderly men are more difficult to take care of, partially because they rely more heavily on the primary caregiver; and (c) male caregivers receive more informal and formal sources of support to ease the burden of care.

Feminization of Caregiver Role

In data collected from the 1982 Informal Caregivers Survey (Stone, Cafferata, & Sangl, 1987), it was revealed that over 35% of all informal caregivers were spouses, with wives accounting for nearly 70% of this figure. Not only do wives make up the majority of spouse caregivers, but women in general assume the brunt of the caregiving duties (Brody, 1985; Finley, 1989; Kaye & Applegate, 1991; Malonebeach & Zarit, 1991; Stoller, 1990; Stone et al., 1987). For instance, women spend an average of 16 hours a week performing tasks associated with this role. They are generally closer to their elderly relatives than men are: they live closer to, interact more frequently with, and they tend to provide more "hands on" personal care than do men (Kay & Applegate, 1991). Some authors (e.g., Finley, 1989; Kaye & Applegate, 1991; Stoller, 1990) have labeled it the feminization of elder caregiving, thus making it a "women's issue in the truest sense." They have explained this gender difference in terms of a family division of labor, not unsimilar to the division seen in housekeeping and child care. England and Farkas (1986: cited in Finley, 1989, p. 85) state that "it seems that women's housework has been institutionalized to the point that it has virtually taken on a life of its own, unresponsive to household variations in potential efficiency, male power, and ideology." Finley argues that gender differences in caregiving appear to have been similarly institutionalized.

Women's traditional primary role as homemaker has carried over into caring for their sick elderly relatives. For many women, this results in doing triple duty: working outside the home, caring for growing children, and providing elder care. For many women, this combination produces chronic role overload accompanied by high levels of stress and probable burnout (Kay & Applegate, 1991). Brody (1985) reports that over one quarter of the women in her sample population had to quit their jobs because of their elderly mothers' needs for care. Caregiver role demands take on a greater significance when it is understood that caregivers rarely relinquish a previous role, even after they add caregiving to their repertoire (Killeen, 1990). Thus, two important sources of caregiver stress for female caregivers are: competing familial obligations and work conflict (Stone et al., 1987).

Although women continue to provide to the substantial portion of the caregiving load, increasing numbers of men are now assuming caregiving responsibilities for their aging relatives. Stone et al. (1987) report that 28% of caregivers are now men, with 45% of these being husbands. However, nonspousal male caregivers are more likely than their female counterparts to be secondary caregivers. It appears that men provide care from a greater emotional distance, focusing more on such concrete, instrumental tasks as legal and financial assistance. Adjustment to the caregiver role was found to be associated with being in functional health, being male, and being a spouse caregiver. One explanation for why men seem to adjust to the caregiving role easier than women is that they tend to be more emotionally detached (Hinrichsen, 1991). Subsequently, women suffer more stress and burden than do men (Kaye & Applegate, 1991).

Stoller (1990) reports that male helpers provide intermittent care, and less frequently undertake routine household chores. Male caregiving tasks are associated with day-to-day elder care. Male caregivers report the highest feeling of competence for such tasks as: cooking, cleaning, home repairs, and case management. They report lower feelings of competence for such tasks as: bathing, grooming, toileting, and other functional tasks. It is in these tasks that men report the highest levels of stress and burden (Kaye & Applegate, 1991).

Malonebeach and Zarit (1991) report that daughters tend to care for parents who are more severely impaired in both instrumental activities of daily living (IADL) and activities of daily living (ADL). Further, they are more likely to perform personal and hygienic tasks such as feeding, bathing, and toileting. Also, daughters provide a fuller range of assistance compared to other helpers (Stoller, 1990).

Caregiver Roles/Tasks

Caregiving is a complex, time-consuming role. Some of the tasks involved in caring for an elderly individual with Alzheimer's disease are: instrumental activities of daily living (IADL), such as communication (dialing the telephone, finding a phone number, writing a simple message, writing a legible signature) money management, food preparation, home maintenance, and medication management; and activities of daily living (ADL), which include personal hygiene, mobility, dressing, and eating (Barusch & Spaid, 1989; Noelker & Bass, 1989). Other tasks include: "normalizing" care-receiver's routine, satisfying need for creativity, gaining knowledge about the disease/condition (Clark & Rakowski, 1983), heavy household chores, laundry (Stoller, 1990), shopping, and assistance (Stone et al., 1987).

Although men report performing more tasks than women (27 tasks in a month as compared to 23), women reported experiencing more problems than men (an average of 17 problems in a month as compared to 12). More specifically, women were more likely to report greater cognitive and emotional difficulties. However, men were more likely to have experienced health problems, to have been hospitalized, and to have been unable to care for themselves (Barusch & Spaid, 1989).

Problems Associated with the Caregiving Role

Smith, Smith, and Toseland (1991) have identified seven pressing problem categories of caregiving. They are: (a) improving coping skills, including time management and dealing with stress; (b) family issues, including those regarding spouse, siblings, and children; (c) responding to elder's care needs, including emotional/behavioral, physical/safety, and legal/financial; (d) quality of the relationship with elder; (e) eliciting formal and informal support; (f) Guilt and feelings of inadequacy; and (g) long-term planning. Barusch and Spaid (1989) divided problem situations into six major areas: care management (e.g., physically difficult, little time/energy), personal and psychological (e.g., lonely, depressed, guilty, resentful, angry), interpersonal with spouse (e.g., arguments, no appreciation, spouse overly dependent), interpersonal with others (e.g., hard to ask for help, others don't understand), financial (e.g., loss of income, lack of money, worried about future), and personal health related (e.g., problems with health, hospitalization, unable to care for self).

Caregivers of individuals with Alzheimer's disease report that the most serious and difficult problems to deal with are physical violence, impaired memory, urinary and fecal incontinence, and suspiciousness (Brill, 1984). Other problems associated with caregiver stress include: level of disability, caregiver's health, finances, and safety problems (Baines, 1984). Several studies (e.g., Barusch, 1988; Brill, 1984; Jutras & Veilleux, 1991; McLean, 1987) have identified common problems experienced by families in giving care to individuals with Alzheimer's disease. These problems include relatives not being helpful, loss of friends, no time for oneself, conflicting family demands, criticism from relatives, worries of carer becoming ill, various feelings like frustration, sadness, resignation, impatience, anxiety, and exhaustion. Barusch (1988) found that the most common problems identified were missing the way the spouse was, worrying over what would happen if the caregiver became ill, feeling depressed, and finding it physically difficult to perform care-related tasks. In fact 30% to 50% of caregivers in one study (Hooyman, Gonyea, & Montgomery, 1985) felt that their personal lives had changed for the worse as a result of their role as caregiver. Although, 27% of the respondents in the same study reported an increase in life satisfaction as a result of caring for their older relative.

There are common emotional reactions that are associated with caring for a progressively deteriorating relative or spouse. These include: anger, fatigue, depression, grief, embarrassment, guilt (McLean, 1987), anxiety, psychosomatic disorders, and self-blame (Toseland & Rossiter, 1989). Brody (1985) reports a long litany of mental health symptoms, such as: depression, anxiety, frustration, helplessness, sleeplessness, lowered morale, and emotional exhaustion. In addition to the emotional strains, the physical demands of caregiving (e.g., loss of sleep) can also negatively affect physical health (Toseland & Rossiter, 1989).

Emotional distress in caregivers is intensified when the care-receiver is someone whom the caregiver feels a deep affection for, or an obligation to. Caregiving situations are especially difficult when the caregiver role represents a regression from a past relationship that was more satisfying. This often leads to repressed fear and anger, which cause depression and feelings of guilt and hopelessness (Greene & Monahan ,1989).

Pollack (1987) conceptualized five stages of emotional reactions that family members dealing with chronically ill patients go through. *Stage 1: Frustration*. In the earliest stage, often beginning before diagnosis, well family members feel a sense of disbelief, puzzlement, and discomfort. In this stage, the family feels a sense of frustration, loneliness, guilt, anger, and embarrassment; denial alternates with fear and resentment builds. *Stage 2: Isolation*. As the physical and behavioral manifestations of the illness become more pronounced, the caregiver senses more isolation with friends and relatives phoning less frequently, socializing less, etc. The physical and emotional burdens of caring for the patient increase. *Stage 3: Resentment*. As the care receiver becomes partially or totally dependent on the caregiver for all the activities of daily living, the caregiver's loneliness, exhaustion, guilt, anger, and sadness manifest themselves in resentment. "Why me?" asks the caregiver, who is feeling the burden even more strongly. *Stage 4: Letting Go*. As the patient's illness continues and dependency heightens, the caregiver must raise the question as to whether the patient needs to be institutionalized. This stage usually results with the caregiver experiencing an incredible sense of sadness and guilt. *Stage 5: Relief Versus Despair*. The feelings of guilt, anger, the sadness for the loss, and the relief that sometimes comes from the end of caregiving must be confronted.

Even with all the problems associated with caring for a relative with Alzheimer's disease, families remain reluctant to accept formal services, are fiercely independent, and are hard to find or serve until they reach a crisis point (Montgomery & Borgatta, 1989). In their study on formal and informal caregivers, Noelker and Bass (1989) found that a large portion of households (42%) did not use formal services to meet personal care and home health needs of elderly relatives.

Stress and Burden in the Caregiving Role

Jutras and Veilleux (1991, p. 41) define caregiver burden as the "overall difficulties experienced by caregivers as a result of the assistance they provide." Miller and McFall (1991) break caregiver burden into two parts: personal and interpersonal burden. Personal burden represents the caregiver's appraisal of his/her limitations in personal actions and activities caused by providing care. Interpersonal burden echos the caregiver's perceptions of the older person's problematic behaviors. Ory et al. (1985: cited in Novak & Guest, 1989, p. 798) define burden as "the impact of changes in cognition and behavior of the Alzheimer patient on the family, and the patient's subsequent need for care and supervision." Novak and Guest go on to describe burden as being made up of five factors: time-dependence burden, development burden, physical burden, social burden, and emotional burden.

McLean (1987) indicates that the assessment of caregiver burden includes: time devoted to caring for the demented person, time spent away from the sufferer, changes to personal and social life resulting from caring, and frequency of behavioral symptoms and stress caused by them. Heckler (1985) states that taking care of an Alzheimer's patient is physically grueling as well as emotionally exhausting. She points out that patients are in constant need of attention and affection.

Lazarus and Folkman (1984) assert that providing care is stressful for caregivers because the demands of the caregiving situation threaten to overwhelm the caregivers' coping resources. They have defined stress "as any event in which environmental or internal demands (or both) tax or exceed the adaptive resources of the individual, social system, or tissue system." Lazarus and associates (e.g., Folkman & Lazarus, 1980; Folkman, Lazarus, Gruen, & DeLongis, 1986; Lazarus & DeLongis, 1983; and Lazarus & Folkman, 1984) have conceptualized one aspect of stress as hassles of daily living. Kinney and Stephens (1989, p. 330) have defined hassles as "irritants - things that annoy or bother you; they can make you upset or angry. Some hassles occur on a fairly regular basis and others are relatively rare. Some have only a slight effect, whereas others have a strong effect." Non-normative events are likely to be more stressful than normative events (Schulz & Rau, 1985).

Baillie, Norbeck, and Barnes (1988) found that two conditions of caregiving were significant predictors of psychological distress: the mental condition of the elder and the years of caregiving. It appears that caregivers who have been providing care to mentally impaired elders for extended periods of time, and who have low social support are more prone to psychological distress and depression. Barusch and Spaid (1989) concluded that the most important predictor of caregiver burden was the number of memory or behavior problems exhibited by the patient. The second most important factor was caregiver age, with younger caregivers reporting greater subjective burden. Other causes of psychological distress and burden that have been identified in the literature include: level of assistance provided, participation in personal care activities of daily living, interaction with professionals on behalf of the elderly, level of functional independence and health status of the demented elderly, level of responsibility assumed by the caregiver, shared living arrangements, social supports, subjective perceptions of caregiving, and the relationship between the caregiver and the care receiver (Jutras & Veilleux, 1991; Malonebeach & Zarit, 1991; Novak & Guest, 1989).

What one must keep in mind is that although caregiving for an impaired elder has been termed stressful, "...the primary stressor in caregiving is not necessarily an isolated event, but rather the extended situation of deterioration and dependency" (Cattanach & Tebes, 1991. p. 247). However, when the impairment is chronic (as in the case of Alzheimer's disease), caregiving may be conceptualized as a chronic stressor.

Effects of Caregiving on Physical and Emotional Well-Being

As already mentioned, there is a heavy emotional strain associated with providing care to a demented elder. In fact, studies (Gallo, 1990; Greene & Monahan, 1989; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991) have shown that depression in caregivers is above population norms or comparative groups. Yaffe (1988) lists several emotional and medical problems that may besiege the adult child caregiver, for instance, (a) unpreparedness for suddenly assuming the role of caregiver may result in a sense of helplessness and ambivalence; (b) feelings of parental overdependence, in terms of both time and emotion, countered by a sense of guilt for not doing enough; (c) resentment that expected middle-age freedoms may be lost; (d) anger at siblings for not assuming equal responsibility in parental care; (e) frustration and demoralization arising from difficult and tiresome communication with a complex network of professional; and (f) heightened fear of one's own aging, mortality, personal illness or disability. Yaffe concludes that these feelings may result in depression and emotional collapse, lower life satisfaction, poorer perception of one's own health, greater use of prescription medication, and greater use of health care services. This constitutes evidence that it is appropriate to view psychological well-being as an outcome of caregiving.

A number of studies (Cattanach & Tebes, 1991; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Long, 1991; Preston & Mansfield, 1984; Richman & Flaherty, 1985) have shown that caregiving may have negative effects on health. Caregivers of functionally impaired elders are more likely to report poorer health than are caregivers of functionally intact elders. Haley, Levine, Brown, and Bartolucci (1987) report that caregivers' subjective appraisals of care-recipient problems were better predictors of depression than were objective measures. In addition, greater use of such problem-focused coping strategies as logical analysis, information seeking, problem solving, and affective regulation were related to higher self-reports of health.

Gallagher et al. (1989) report that female caregivers were more distressed than the normative sample, or than male caregivers, and that wives were the most distressed of all. They also found that 46% of individuals who sought help suffered from depression, but among non-help-seekers, only 18% were clinically depressed. In addition, another 22% of help-seekers had evidence of depressive features. Thus, only 32% of help-seekers were clearly not depressed. Vitaliano, Maiuro, Russo, and Becker (1987) found that wishful thinking was positively related and problem-focused coping was negatively related to depression in Alzheimer's disease spouses. Contrary to their expectations, the relationship between coping and depression did not vary with appraisal or source of stress.

Lazarus and Folkman (1984) have identified three pathways through which coping might adversely affect somatic health: (a) coping can influence the frequency, intensity, duration, and patterning of neurochemical responses; (b) health is negatively affected when coping involves excessive use of alcohol, drugs, or tobacco, or when it involves the individual in activities of high risk to life and limb; and (c) certain forms of coping (e.g., denial) can impair health by impeding adaptive health/illness-related behavior.

Coping with the Caregiving Role

Diagnosis of Alzheimer's is a difficult event for a family to cope with. For one thing, society has attached a certain stigma to the term Alzheimer's disease. It is very stressful on both the patient and the caregiver(s). One reason why it is so stressful is because we have so many uncertainties regarding the disease (e.g., etiology, diagnosis, treatment).

Folkman and Lazarus (1980) identified five factors involved in coping: situational factors, including what the event was about, who was involved, how the event was appraised, as well as two demographic variables, age and gender. What Lazarus and his colleagues (e.g., Folkman & Lazarus, 1980; Folkman et al., 1986; Lazarus & DeLongis, 1983; and Lazarus & Folkman, 1984) have conceptualized is a cognitive phenomenological theory of psychological stress. The overall theoretical framework involves a transactional reciprocal relationship between the person and the environment. They have identified two processes which mediate this relationship: appraisal and coping.

Appraisal is a cognitive process. Primary appraisal involves the process through which an event is evaluated. Secondary appraisal involves what coping resources and options are available, as well as which will have the best effect (Folkman & Lazarus, 1980). Three types of stressful appraisals have been hypothesized: harm-loss (refers to damage that has already occurred), threat (refers to harm or loss that has yet to occur but is anticipated), and challenge (refers to an anticipated opportunity for mastery or gain).

Folkman and Lazarus (1980, p. 223) define coping as "the cognitive and behavioral efforts made to master, tolerate, or reduce external and internal demands and conflict." There are three key features to this definition. First, it is *process oriented,* that is it focuses on what the person actually thinks and does in a specific stressful encounter. Second, coping is viewed as *contextual,* that is, influenced by the person's appraisal of the actual demands and the resources for managing them. Third, no a priori assumptions are made about what constitutes good or bad coping. Therefore, coping is simply defined as a person's efforts to manage demands, whether or not the efforts are successful (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Folkman & Lazarus, 1984). There are two main functions of coping, which are referred to as problem-focused coping and emotion-focused coping. Problem-focused coping involves the management or alteration of the source of stress for the relationship between the person and the environment. Emotion-focused coping, on the other hand, refers to the regulation of stressful emotions.

According to appraisal theory, emotion-focused modes of coping will be employed when the situation is viewed as threatening or harmful, and is appraised as holding few possibilities for beneficial change. On the other hand, problem-focused techniques are used when a situation is appraised as having the potential for amelioration by action. However, Folkman and Lazarus (1980) report that 98% of stressful episodes were handled with both problem-focused and emotion-focused strategies. What one must keep in mind is that appraisal and coping continuously influence each other. Lazarus and Folkman (1984) report that men are more likely to use problem-focused strategies, whereas women are more likely to employ emotion-focused strategies. (For examples of problem-focused and emotion-focused strategies, see Killeen, 1990.)

Coping Strategies

Caregivers of elderly individuals with Alzheimer's disease report using several different forms of coping strategies. These include: prayer, busying self, crying, talking, hiding feelings, getting away, yelling, ignoring/forgetting, asking for help, taking drugs or alcohol, exercise, smoking (Baines, 1984), avoidance, active mastery, failure to cope, seeking information, manage but not change situation, use reframing or other cognitive restructuring, seek help to change situation (Barusch & Spaid, 1989), social support (Berkman & Syme, 1979; Gottlieb, 1991; Kaye & Applegate, 1991; Montgomery & Borgatta, 1989; Toseland & Rossiter, 1989), group intervention (Clark & Rakowski, 1983), formal intervention (Hooyman et al., 1985; Miller & McFall, 1991), environmental self-management, relaxation (Barrow, 1982), passivity, extended family (Barusch, 1988), self-reinforcement, assertiveness (Brown, 1983), deliberate effort, criticism (Hinrichsen, 1991), biofeedback, meditation (Porter, 1981), use of imagery, deep breathing exercises (Smith, Smith, & Toseland, 1991), passive forbearance (Strong, 1984), mutual role-playing, relabeling, situational reinterpretations (Thoits, 1986), and engaging and disengaging strategies (Cattanach & Tebes, 1991). Moos (1993) divides coping strategies into two categories - approach coping strategies and avoidance coping strategies. He states:

> In general, approach coping is problem-focused; it reflects cognitive and behavioral efforts to master or resolve life stressors. In contrast, avoidance coping tends to be emotion-focused; it reflects cognitive and behavioral attempts to avoid thinking about a stressor and its implications, or to manage the affect associated with it. (p. 1)

Vitaliano, Russo, Carr, Maiuro, and Becker (1985) report that certain coping strategies may be maladaptive. They found that coping strategies whose aim is to regulate emotional reactions are associated with increased anxiety in family caregivers.

In addition, those strategies which attempt to alter or manage the stressful environment have been found to be negatively related to depression and anxiety. Neundorfer (1991) concludes that examples of positive coping strategies are: problem-solving, reframing, spiritual support, and reliance on extended family. Examples of negative coping strategies include: passive avoidance, wishful thinking, confrontive coping, seeking social support, accepting responsibility, and escape-avoidance.

Pearlin and Schooler (1978) report that women tend to use less effective coping strategies than men. Perhaps one explanation for this is that men describe themselves as more active copers, with greater internal locus of control (Barusch & Spaid, 1989; Folkman & Lazarus, 1980), whereas women tend to view coping as outside of their control.

Locus of Control

Rotter (1966) first coined the term internal locus of control. Since then, an effective coping style has been characterized as one in which the stressed individual assumes some control and believes that his/her own behaviors make a difference in the outcome of a stressful situation (Preston & Mansfield, 1984).

Brown (1983) reports that internal attributions of blame for failure may be associated with depression. Simply stated, feelings of control over one's life are important determinates of psychological well-being in caregivers of Alzheimer's patients (Cattanach & Tebes, 1991) and help buffer the effects of stress (Richman & Flaherty, 1985). In a study on adult children's filial anxiety regarding the caregiver role, Cicirelli (1988) found that those participants who had an internal locus of control reported less anxiety than those with an external locus of control. Folkman et al. (1986) found that the more mastery an individual felt, the better their health was. In contrast, Rodin et al. (1980: cited in Karuza et al., 1990) found the opposite.

Social Support

Cohen and McKay (1984, p. 253) define the term social support as "the mechanisms by which interpersonal relationships presumably buffer one against a stressful environment." The buffering hypothesis thus states that psychosocial stress will have deleterious effects and both health and well-being of individuals with few or no social supports, while these effects will be lessened for those individuals who have strong social networks. A more simplistic definition of social support has been presented by House, Kahn, McLeod, and Williams (1985, p. 85). They write:

> The term social support (like the terms social network and social integration) refers to a number of different aspects of social relationships. Social support is sometimes defined...in terms of the existence or quantity of social relationships in general, or of a particular type such as marriage, friendship, or organizational membership.

Social support has the potential of preventing illness to the caregiver by lessening the effects of certain stressors. Social support could provide needed respite from caregiving as well as reduce feelings of isolation and loneliness (Toseland & Rossiter, 1989). Berkman and Syme (1979) hold that people with few connections (small social network) are more likely to be sick or physically unable to maintain ties. They found that people who lacked social and community ties were more likely to have died during the nine-year follow-up period, than those with more extensive contacts.

Barusch and Spaid (1989) reported an interesting finding concerning social support for caregivers. It seems that the primary source of social support for spouse caregivers was not family members, but friends and neighbors. When spouse caregivers did turn to family members for support, it was usually to the adult child of the same sex. Thus, wife caregivers would look to their daughters for support, whereas husband caregivers would look to their sons. Toseland and Smith (1990) report that individual counseling, whether by a professional or by a peer, was effective in reducing the amount of stress involved in caring for a frail elderly parent.

Chapter 3

Purpose and Methodology of the Study

The major purpose of this study is to determine the different kinds of coping strategies employed, and in which situations, by family caregivers of Alzheimer's patients. More specifically, the objectives of this study are: (1) to determine how family members of individuals with Alzheimer's disease cope with their role as caregiver; (2) to determine what types of behaviors/problems caregivers are confronted with; (3) to assess how well caregivers feel they cope; (4) to assess differential reactions of the caregivers to their role; (5) to uncover the internal dialogues employed by caregivers in dealing with stressful events; (6) to examine the effects of the caregiver's role on women.

Research Questions

1) What coping strategies do in-home caregivers of Alzheimer's patients employ?

2) When do in-home caregivers employ coping strategies?

3) Where (what situations) do in-home caregivers employ coping strategies?

4) What are the most typical behaviors that in-home caregivers have to cope with in in-home situations?

5) When faced with a stressful situation, what are some of the internal dialogues and/or self-instructional statements in-home caregivers use to deal with the problem situation?

6) What are the short-term effects of the in-home caregiving role on the family unit and on women in particular?

Method

Subjects

A total of 16 individuals (13 females, 3 males) ranging in age from 29 to 77 years ($\bar{x}$ = 67.4 years; s = 13.15 years) participated in the present study. Participants were predominantly primary caregivers (15 primary, 1 secondary) and were predominantly the care receiver's spouse (13 wives, 3 husbands, 1 daughter, 1 granddaughter). On average, they had 11.5 years of school (range: 8 to 15 years; s = 2.4 years), and had a family income that ranged from \$14,400 to \$75,000 ($\bar{x}$ = \$34,462.50; s =\$18,571.91). In terms of religious affiliation, participants were grouped into three categories: Jewish (n = 9), Catholic (n = 4), and other Christians (n = 3).

The caregivers provide between 10 to 158 hours of care per week ($\bar{x}$ = 106.9 hours; s = 44.5 hours) and have been providing care for 8 to 84 months ($\bar{x}$ = 42.5 months; s = 26.25 months). Caregivers reported that care provided constituted both active (bathing, dressing, etc.) as well as inactive care (type of care where the caregiver is present but there is no requirement for active care). They reported to have between 0 to 12 people ($\bar{x}$ = 3.94 people; s = 3.8 people) that they could turn to for assistance (emotional and/or physical) and utilized between 0 to 4 ($\bar{x}$ = 2.25 services; s = 1.125 services) support services (e.g., support groups, day centers, home health care, social/activity groups, physical therapy, and psychiatric therapy) on a weekly basis.

The care receivers (12 females, 4 males) ranged in age from 53 to 89 years ($\bar{x}$ = 77.4 years; s = 8.2 years). Care receivers in the study were predominantly diagnosed with Alzheimer's disease (13 Alzheimer's disease, 1 Alzheimer's disease & Parkinson's disease, 1 multi-infarct dementia, and 1 dementia, unspecified & Parkinson's disease). The care receivers also had other health problems ($\bar{x}$ = 2.2 ; s = 1.4) which included seizures, ulcers, coronary problems.

Procedure

Participants were recruited from three centers: (a) Alzheimer Groupe (A.G.I.) Inc., in Montreal, Quebec; (b)The N.E. Focal Point Alzheimer's Day Care Services Center (ADCSC), in Deerfield Beach, Florida, and (c) the research division of the Douglas Hospital, in Verdun, Quebec. The criteria for inclusion in the study were that care receivers had to be diagnosed by a multi-disciplinary geriatric team, the caregivers had to be fluent in English, and that the care receivers had to be living within the community (home) and not an institution. An exception that was made with regard to the last criteria was that one caregiver had recently placed her care receiver in an institution a few weeks prior to the interview. Three potential participants were eliminated from the study because two did not speak any English and the third's care receiver had been institutionalized during the prior six months.

After initial contact over the phone, interviews were arranged. Participants were informed as to the demands of the interview (See Appendix A) and were given the choice to withdraw. No participants withdrew.

The interviews were semi-structured and ranged from 35 to 180 minutes ($\bar{x}$ = 106.25 minutes ; s = 42.7 minutes). Participants were encouraged to speak openly and freely and to make whatever comments they felt were appropriate. Responses were transcribed word for word.

Measures

Caregiver background characteristics. In addition to the aforementioned demographic descriptors, the caregivers' functions, as well caregivers' and care receivers' medical histories were ascertained by means of an in-take interview.

Coping strategies. Coping was measured by using part II of the Coping Responses Inventory - Adult Form (CRI-Adult), a general measure of eight different types of coping responses to stressful life circumstances (Moos, 1993). (Part I of the CRI-Adult was not used because the 10 appraisal items it purports to measure are not suitable to this population.) Participants were asked how often they used each of 48 different coping strategies (*0 = No, not at all* , to *3 Yes, fairly often*) to grapple with caregiving-related circumstances (See Appendix B). According to Moos (1993), the inventory assesses coping responses which reflect *focus-* and *method*-of-coping domains. The focus-of-coping framework includes the eight scales of: Logical Analysis (LA), Positive Reappraisal (PR), Seeking Guidance and Support (SG), Problem Solving (PS), Cognitive Avoidance (CA), Acceptance or Resignation (AR), Seeking Alternative Rewards (SR), and Emotional Discharge (ED). The items can also be grouped according to a method-of-coping framework which divides coping responses into approach and avoidance responses (See Table 1). Each of these two sets can be divided into two categories that reflect cognitive or behavioral coping methods (Moos, 1993). Scores on the CRI-Adult are recorded on the reverse side of the answer sheet, which allows the examiner to convert the respondent's raw scores to *T* scores (*M* = 50; *SD* = 10) and to plot the respondent's coping responses profile (See Appendix C).

Table 1. CRI-Adult Scales and Descriptions

Scale	Description
Approach Coping Responses	
1. Logical Analysis	Cognitive attempts to understand and prepare mentally for a stressor and its consequences.
2. Positive Reappraisal	Cognitive attempts to construe and restructure a problem in a positive way while still accepting the reality of the situation
3. Seeking Guidance & Support	Behavioral attempts to seek information, guidance, or support
4. Problem Solving	Behavioral attempts to take action to deal directly with the problem
Avoidance Coping Responses	
5. Cognitive Avoidance	Cognitive attempts to avoid thinking realistically about a problem
6. Acceptance or Resignation	Cognitive attempts to react to the problem by accepting it
7. Seeking Alternative Rewards	Behavioral attempts to get involved in substitute activities and create new sources of satisfaction
8. Emotional Discharge	Behavioral attempts to reduce tension by expressing negative feelings

Source: Moos (1993)

In addition to the CRI-Adult, participants were asked to give a self-assessment of how they perceive themselves to be coping with their role as caregiver. They were then asked to justify their responses.

Measure of burden. Caregiver burden was measured using the Caregiver Burden Inventory (CBI), a 24-item measure that evaluates feelings of burden specific to an individual's role as caregiver (Novak & Guest, 1989). Respondents were asked to respond how descriptive (*1 = Not at all descriptive* to *5 = Very descriptive*) a given statement is to their situation (See Appendix D). The inventory is divided into five factors: Time-Dependence Burden; Developmental Burden; Physical Burden; Social Burden; and Emotional Burden. Respondents' scores on each factor could range from 0 to 25, except for Factor 3 (with only four items), where scores could range from 0 to 20. Factor 3 scores were adjusted by multiplying the obtained score out of 20 by 1.25 to give an equivalent score out of 25.

Measure of behavior disturbance in care receivers. The degree of behavior disturbance of the care receivers was determined through the administration of a revised version of the Dementia Behavior Disturbance (DBD) Scale (Baumgarten, Becker, & Gauthier, 1990) to the caregivers. The DBD is a 26-item instrument which asks caregivers whether their care receiver displayed a given behavior, and if so, how often (See Appendix E). In addition to the standard instrument, participants were asked how they cope or would cope with a given behavior disturbance.

Chapter 4

Results

As an initial step to identifying the coping strategies utilized by caregivers, participants were asked which function(s) were most difficult. Sixty-two percent of the caregivers reported that having to look after the greater part of their care receiver's activities of daily living (ADLs) was the most difficult aspect of caregiving. Fifty-six per cent reported that their own loss of activities and the fact that they have no time for themselves (37%) were most difficult to cope with. In addition, 19% of caregivers also stated that not being recognized by their care receivers and lack of communication between them and their care receivers are difficult to contend with.

There appears to be a relationship between age of caregiver and number of hours of caregiving performed. The older the caregiver, the more hours of caregiving performed in a week ($\chi^2 = 18.51$, $p < .005$). Caregivers over the age of 75 appear to have a higher likelihood of caring for their care receiver for over 100 hours per week, possibly due to the fact that they tend to care for older care receivers who require more care and attention. In addition, caregivers who utilize fewer support services (e.g., day centers, home health care, etc.) tend to have more hours of caregiving per week ($\chi^2 = 16.45$, $p < .01$). Caregivers who make use of more support services tend to have care receivers with more secondary health problems ($\chi^2 = 10.48$, $p < .03$).

Prevalence of Specific Behavior Disturbances

The prevalence of a problem was measured by finding the percentage of caregivers who reported a given behavior disturbance on the DBD scale. The most prevalent behavior disturbances identified (See Table 2) were: loses, misplaces, and hides things (93.75%), shows lack of interest in daily activities (81.25%), and asks the same question over and over (81.25%). Other behavior disturbances identified were: empties drawers or closets (62.5%), is verbally abusive (43.75%), wanders in the house at night (25%), and makes physical attacks (18.75%).

Table 2. Percentage of Care Receivers who Exhibited Behavioral Symptoms

DBD Items	Percentage (n= 16)
Loses, misplaces, or hides things	93.75
Shows lack of interest in daily activities	81.25
Asks the same question over and over again	81.25
Overeats	68.75
Empties drawers or closets	62.5
Dresses inappropriately	62.5
Wakes up at night for no obvious reason	62.5
Wanders aimlessly outside or in the house during the day	62.5
Repeats the same action over and over	62.5
Makes unwarranted accusations	56.25
Paces up and down	56.25
Hoards things for no obvious reason	56.25
Refuses to eat	50.0
Is verbally abusive, curses	43.75
Sleeps excessively during the day	43.75
Cries or laughs inappropriately	43.75
Gets lost outside	37.5
Refuses to be helped with personal care tasks	31.25
Makes inappropriate sexual advances	25.0
Moves arms or legs in a restless or agitated way	25.0
Wanders in the house at night	25.0
Screams for no reason	18.75
Makes physical attacks (hits, bites, scratches, kicks, spits)	18.75
Destroys property or clothing, breaks things	18.75
Exposes himself/herself indecently	0
Throws food	0

Participants were asked how they cope or would cope with the various behavior disturbances displayed by their care receiver. Responses were coded according to comments and through factor analysis seven themes were identified (See Table 3). The most common approaches caregivers reported in their attempts to cope with or handle a given behavior were: to try reasoning with the care receiver (81% of items), to ignore the behavior (77% of items), and to try and distract or involve the care receiver in new activities (69% of items). Caregivers also reported that sometimes they handle a given behavior by yelling, arguing, or fighting back (50% of items).

Table 3. Ways of Coping With Behavior Disturbances

Response Categories	Sample Responses	Percentage of Items (N = 26)	Average # of Responses/Items
Try Reasoning With	"What again? Why are you doing this." "You shouldn't say that, you know it isn't very nice." "Try to explain to him that it's an inappropriate way to act."	81	4.76
Ignore/Let	"Used to it now, just leave it." "Nothing, I go about my business as best as I can." "Wouldn't pay attention to it because he doesn't know what he's saying."	77	4.75
Distract/Get Interested in Something Else	"Try to coax him, but nothing I can do." "Try to make a difference. Try to interest him in other activities." "She knows about her illness so I try to distract her with activities."	69	1.7
Argue, Yell, Fight Back	"Be mad, yell back at him." "Became a little violent. Pulled her hair, grabbed hold of her and threw her on the couch. I admit that it was a thing to do."	50	5.0
Pacify, Soothe, Talk Calmly	"Be caring, cuddle, give him a hug. It changes his temperament." "Look at him and quiet him down. If I stay quiet, he quiets down." "Talk to him and calm him down."	35	2.6
Treat as a Joke/Don't make an Issue	"Try to treat it as a joke. If you don't laugh you're going to cry." "Same way as with a child. Make him get dressed and pretend I don't notice what he's doing."	27	4.3
Insist, Force/Correct Behavior	"Force him. Threaten to get somebody in to help him. Get angry." "Force him, be strict with him." "Correct it. Tell him to change."	23	5.0

Perception of Burden

Table 4 shows the average score for perception of burden on each question of the CBI. From the table, we see that on average caregivers perceived themselves to have more burden on Factor 2 (Developmental Burden - $\bar{x}$ = 20.25, s = 4.82) items. One can also see from Table 4 that care receiver dependence (Factor 1: question #2 - $\bar{x}$ = 4.81, s = 0.54) was viewed as one of the major causes of caregiver burden. Caregivers who did not make common use of behavioral types of coping reported more perceived burden (F = 4.49, $p < .02$).

Sociodemographic Factors and Perceived Burden.

Caregivers with a higher family income (over $30,000 per year) appear to have a lower perception of emotional burden ($\chi^2 = 12.61$, $p < .05$). Caregivers whose care receivers are old-old elderly have a higher perception of physical burden ($\chi^2 = 7.27$, $p < .03$).

Hours of Care and Perceived Burden.

In general, caregivers reported a higher perception of overall burden as hours of care increased ($F = 4.33$, $p < .03$). More specifically, as hours of care provided on a weekly basis increases, caregivers reported a higher perception of developmental burden ($\chi^2 = 8.89$, $p < .03$). Caregivers who had more free time and had less hours occupied caring for their care receiver reported a lower perception of emotional burden ($\chi^2 = 12.25$, $p < .04$)..

Support and Perceived Burden.

Caregivers who have larger social networks and more people that they can turn to for assistance (emotional or physical) with their caregiving role, reported a lower perception of social burden ($\chi^2 = 13.70$, $p < .03$). Analysis of variance revealed that caregivers who make use of more support services have a higher overall perception of burden ($F = 4.65$, $p < .03$).

Table 4. CBI: Descriptive Data of Perceived Caregiver Burden

Perception of Burden Items	M	SD	Range
Factor 1: Time-Dependence Burden (Total of all Factor 1 scores)	20.0	4.80	7-24
1. My care receiver needs my help to perform many daily tasks.	4.38	1.15	1-5
2. My care receiver is dependent on me.	4.81	0.54	3-5
3. I have to watch my care receiver constantly.	3.75	1.53	1-5
4. I have to help my care receiver with many basic functions.	3.88	1.20	1-5
5. I don't have a minute's break from my caregiving chores.	3.19	1.33	1-5
Factor 2: Developmental Burden (Total of all Factor 2 scores)	20.25	4.82	9-25
1. I feel that I am missing out on life.	3.56	1.59	1-5
2. I wish I could escape from this situation.	4.0	1.37	1-5
3. My social life has suffered.	3.81	1.42	1-5
4. I feel emotionally drained due to caring for my care receiver.	4.19	1.17	2-5
5. I expected that things would be different at this point in my life.	4.69	0.87	2-5
Factor 3: Physical Burden (Total of all Factor 3 scores)	16.17	6.23	5-25
1. I'm not getting enough sleep.	3.81	1.52	1-5
2. My health has suffered.	3.13	1.63	1-5
3. Caregiving has made me physically sick.	2.31	1.62	1-5
4. I'm physically tired.	3.69	1.66	1-5
Factor 4: Social Burden (Total of all Factor 4 scores)	11.06	5.16	5-25
1. I don't get along with other family members as well as I used to.	1.38	1.34	1-5
2. My caregiving efforts aren't appreciated by others in my family.	2.44	2.44	1-5
3. I've had problems with my marriage.	1.69	1.69	1-5
4. I don't do as good a job at work as I used to.	2.56	2.56	1-5
5. I feel resentful of other relatives who could but do not help.	3.0	3.00	1-5
Factor 5: Emotional Burden (Total of all Factor 5 scores)	9.19	4.86	5-23
1. I feel embarrassed over my care receiver's behavior.	1.69	1.69	1-5
2. I feel ashamed of my care receiver.	1.31	1.31	1-5
3. I resent my care receiver.	1.88	1.88	1-5
4. I feel uncomfortable when I have friends over.	1.75	1.75	1-5
5. I feel angry about my interactions with my care receiver.	2.56	2.56	1-5
Total Burden Score (Sum of all individual items)	76.67	17.17	43-109

Note: Factor 3 (Physical Burden) is based on adjusted scores

Self-Assessment of Coping

Participants were asked to subjectively rate how they felt they were coping with their role as caregiver. Twenty percent of the caregivers felt that they were not coping at all, while 18.75% felt that they were just barely coping, but at a great cost to their well-being. Another 37.5% felt that they were adequately coping, but that they could be coping better . The final 18.75% felt that they were coping well. Those caregivers who perceived themselves not to be coping well with their role attributed part of the problem to feelings of isolation. In contrast, the caregivers who reported that they are well attributed their ability to cope on being able to talk with someone, having strong religious beliefs, and keeping active or interested in a hobby.

One interesting finding was that caregivers whose care receivers had more secondary health problems appear to have a higher subjective rating of coping (12.73, $p < .05$). One possible explanation is that caregivers who care for individuals with more health problems may be more resigned to their role as caregiver and therefore internalize more personal satisfaction of knowing that they are doing their best. Caregivers who felt that they were having trouble coping with their role, tended to have a higher perception of overall burden ($F = 3.68$, $p < .04$).

Types of Coping

Table 5 summarizes the frequency that caregivers reported using a given coping strategy. Caregivers were most likely to accept their role and the problems associated with it (Acceptance and Resignation), reduce tension by expressing negative feelings (Emotional Discharge), and attempt to construe and restructure their problem (Positive Reappraisal). Caregivers were least likely to seek information, guidance, or support (Seeking Guidance and Support), attempt to understand and prepare mentally for a stressor and its consequences (Logical Analysis), and attempt to deal directly with the problem (Problem Solving). On average, caregivers utilized more avoidance ($\bar{x}$ = 222.19, s = 20.29) and behavioral ($\bar{x}$ = 216.19, s = 28.06) types of coping strategies.

Sociodemographic Factors and Coping Strategies.

There appears to be a relationship between types of coping strategies used and age of caregiver. Older caregivers appear to use less cognitive avoidance ($\chi^2 = 13.81$, $p < .03$) as well as less cognitive types of coping strategies ($\chi^2 = 13.44$, $p < .04$). Caregivers who have been caring for longer periods of time (over three years) tended to use more approach coping strategies ($\chi^2 = 20.23$, $p < .02$). Healthier caregivers seem to use more approach styles of coping ($\chi^2 = 12.58$, $p < .05$).

Table 5. **CRI-Adult Descriptive Data of Measures of Coping**

Type of Coping Strategy	M	SD	Range
Logical Analysis	42.94	7.36	29-55
Positive Reappraisal	58.88	8.58	44-69
Seeking Guidance & Support	42.81	7.74	31-58
Problem Solving	48.38	9.63	34-64
Cognitive Avoidance	50.56	8.69	34-65
Acceptance or Resignation	62.69	6.39	49-74
Seeking Alternative Rewards	49.63	11.12	37-78
Emotional Discharge	59.31	8.81	48-79
Approach Coping	193.00	22.96	155-237
Avoidance Coping	222.19	20.29	180-262
Cognitive Coping	199.00	17.51	161-222
Behavioral Coping	216.188	28.06	173-277
Approach Cognitive Coping	85.75	11.53	70-108
Approach Behavioral Coping	107.25	14.07	81-129
Avoidance Cognitive Coping	113.25	10.28	88-131
Avoidance Behavioral Coping	108.94	16.87	85-148
Total Composite	415.19	38.72	354-499

Note: Scores converted to *T* scores (M = 50; SD = 10)

Social Networks and Coping Strategies.

Analysis of variance revealed that the larger a caregiver's social network and the more individuals he/she could turn to for assistance, the greater the number of coping strategies practiced ($F = 7.37$, $p < .005$). However, caregivers who have smaller social networks and less people that they can turn to for assistance, have a higher likelihood of practicing avoidance coping strategies ($\chi^2 = 18.33$, $p < .03$) in general, and specifically tend to use more cognitive avoidance coping strategies ($\chi^2 = 19.36$, $p < .02$) while using less behavioral avoidance coping strategies ($\chi^2 = 19.00$, $p < .03$).

Self-Assessment of Coping and Utilization of Coping Strategies.

In general, people who rated/perceived themselves as coping tended to utilize more coping strategies ($F = 4.72, p < .02$). More specifically, caregivers who subjectively rated themselves as coping with their role as caregiver tend to use more behavioral coping strategies ($F = 5.06, p < .02$), especially approach behavioral coping strategies ($F = 3.89, p < .04$).

Internal Dialogues and Comments Made by Caregivers

CRI-Adult.

On average, 7.1 ($s = 3.01$) comments per item on the CRI-Adult were made. These comments ranged from general observations about the inventory to realizations about their role as a family caregiver of an individual with Alzheimer's disease and how to cope with that role.

Strategies for Coping With Alzheimer's Patients. Many of the caregivers advocated the use of support groups, day centers, and care assistance programs like home health care. As one caregiver stated, "One way to cope is to participate in a group. Only a person in a similar position knows." Another stated, "It helps both sides." However, not all the caregivers were advocates of support groups, as one caregiver commented, "How am I going to help others, when I can barely help myself? And I have no time." Another caregiver made this observation, "I've got enough with my own, I don't need to hear other peoples' problems."

For the most part the caregivers in the study seemed to accept that little or nothing can be done to help their care receiver. This resignation was best summed up by one caregiver who commented: "It's an illness and I have no control and I must deal with it one way or another." Still, the majority of the caregivers in the study appeared to remain hopeful that their situation would get better. One caregiver finds comfort and inspiration in a card which states, "Look for tomorrow, it's going to be a brighter day."

When asked if they had made a plan of action, all 16 caregivers stated that it was impossible to make any long term plans, and the general consensus was that you just have to take it one step at a time. One caregiver commented, "Just do daily plans, can't go beyond that. Do try to make little plans for the week." Another stated, "Can't, have tried, but because she is so erratic, I don't know what to do next." On going over in one's mind what one would say or do, one caregiver remarked, "No, because they don't work. That's planning and you can't plan with Alzheimer's because mood changes too much." Another stated, "I just do. Whatever you think of, it will turn out the other way."

The caregivers interviewed in this study were not interested in trying to anticipate any new demands that are going to be placed on them. As one caregiver plainly put it, "I'm fearful of new demands, don't want to think about them." Another remarked, "I don't believe in borrowing trouble." One caregiver expressed the following attitude, "Taking things one step at a time. No sense driving yourself crazy until the time comes. Going to worry about something that may never happen?"

Although caregivers try to forget their dilemma, the majority of caregivers in the study reported that it is impossible to forget. One caregiver commented, "It's always in the back of your mind. But have to say, if I'm going to live, this is what I have to do. I had to block to survive." Another stated, "Can't. You forget momentarily as a way of self protection, but then you're right back where you were." One caregiver proposes that the only way someone can momentarily forget about caring for an individual with Alzheimer's disease is to do other things, to involve oneself in other activities.

Caregiving for a loved one with Alzheimer's disease can be a very frustrating experience, and sometimes caregivers feel the need to take out their frustrations. Some stated that they take their frustrations out on themselves, while others admitted to yelling at their care receiver. As one caregiver commented, "I'm trying not to (in reference to yelling and taking his frustrations out on his care receiver). I hate to have to repeat things. I don't really accept her illness. I don't like the idea of not being able to help her."

Another remarked, "Yes, then I'm sorry because he doesn't understand." As one caregiver observed, "Need patience and understanding. Have to be very giving of yourself."

One way to try to cope with the perils of caring for an individual with Alzheimer's disease is to try to take a step back and be more objective. However, the majority of the caregivers reported that it is impossible to be objective because they are too involved. For instance, one caregiver remarked, "How can you be objective about a situation like this, you would have to be a whiz." Another simply stated, "It's right there, you can't." One caregiver had this to say: "You sorta try, but it doesn't work. Tomorrow will be better because I'll just ignore it." While another caregiver declared, "Oh I do, that's the way I'm coping. I'm involved physically, but in terms of my survival, I'm doing what I have to do to survive."

Some caregivers in the study advocated talking with a friend as a measure of coping. For instance, one caregiver explained, "You can't be reluctant to talk about it." But another caregiver stated, "Something I have to face myself, but how do you do it, when you can't win."

For the most part, the caregivers in the study commented that there was no good side to the illness. However, one caregiver expressed, "At least I have someone to live with. Have a companion, it's not all bad."

General Comments on Coping and Being a Caregiver

Apart from responding to the various questionnaires in the study, caregivers were encouraged to speak freely and to make any comments or observations that they felt would be appropriate. Caregivers' internal dialogues showed that they are aware of the reality of their situation and have accepted or are resigned to the fact that their care receiver's condition is not going to improve. Caregivers repeatedly commented on the importance of self-survival and protection, the need for support, and the difficulties in caring for a loved-one with Alzheimer's disease.

The comments and observations represent an example of and some insight into the dialogues that take place when caring for an individual with Alzheimer's disease. The comments were grouped into 17 themes, of which sample comments are supplied.

Theme 1: Things that help you cope

- "Religion has been important in my time of need. I pray every day."
- "You learn to ignore a lot of things."
- "In the beginning, I had very little patience, but now I do. I used to take everything personally, like he was trying to get my goat."
- "Having an activity makes you less uptight towards the person. It makes you forget the problems and lets you face it a little better. It makes me feel better."
- "Enjoy the peace of being alone. That's restful to me."

Theme 2: Ways of dealing with one's care receiver

- "The low key approach is best. In terms of tone and reaction, don't give statements and/or actions any importance."
- "They go by the tone of voice, more than by what they understand."
- "You cannot argue with people like that."
- "Can't get angry with them. It is the worst thing you can do."
- "Can't try and make them understand, because they don't."
- "Can't reason with her because she has Alzheimer's."
- "Patience, that's the most important thing."
- "No use going against their ideas because they don't understand. Can't go against what they have in their minds because it's not usually bad."
- "Now I recognize that I should have ignored a lot of things that he did and said."
- "I can see where a caregiver can agitate a problem. Certain times you have to stop. If you see you're not getting through, you get back to it an hour later."

Theme 3: Rewards of caregiving/Why caregivers care

- "I get a lot of hugs and kisses, he sometimes smiles and says I love you."

- "My only ambition right now is to help her. Helping her, helps me, it gives me peace of mind."
- " Even with all the thoughts I had, I did everything possible. I didn't neglect him. This helps me get through the day. I felt it was my duty."
- "I'm doing things like this because he was a good guy and we had good years together."
- "One thing I do know is that if anything happens, I have done the best for him and that will help me deal with it."
- "A happy day for her is a happy day for me."
- "Caregiving by a sense of love, duty, and responsibility."

Theme 4: Need for support and help

- "If I had someone to stay with her, I wouldn't be so nervous and irritable."
- "When with people, I don't have time to feel sorry for myself. I try to surround myself as much as possible."

Theme 5: Hope

- "I do hope that some miracle would happen, some vaccine, for the betterment of mankind."
- "This is a sickness where there is no hope, it's a matter of time. I don't believe in miracles."

An example of false hope

- "Sometimes when he smiles I think he's getting better, he's getting better!"

Theme 6: On resenting one's care receiver

- "Can't resent my care receiver, because it's not his fault."

Theme 7: Reasons why it is hard to be a good caregiver

- "My husband was always selfish, it makes it hard to be a good caregiver."
- "I become frustrated and impatient when he has trouble expressing himself. I don't know if I'm angry at him or at myself."

Theme 8: Resignation and acceptance

- "You accept things the way they are, you have no choices in life."
- "Sometimes I get frustrated and agitated, but other times I'm resigned to it.

Theme 9: Planning

- "Have to learn to play games. There are no set standards and no one can tell you how to deal with something."
- "There's no cut and dry answers."
- " Can't plan and can't deal with things ahead of time. One day at a time. When you survive that day, you go on to the next. Have to be one step ahead of the game."

Theme 10: Placement

- "I wouldn't place him until the last straw. I had it all and I feel I owe it to him in care."
- "I consider placement like incarceration."

Theme 11: Caregiver sleep patterns

- "She sleeps better than I do."
- "Even when I sleep, I'm not sleeping. I have one ear out."
- "Sleep with one eye and one ear open, like when you have your first child."

Theme 12: Analogy to caring for a child

Sixty-two percent of the caregivers commented on how caring for an individual with Alzheimer's disease is comparable to caring for a child.

- "It just occurred to me that some of the answers are exactly what you would do with a child."
- "Such a responsibility. Worse than having children because children remember and you have hope for them."
- "Have to realize that she's like a child."

Theme 13: Wanting to give up

- "Sometimes wished he would die or that I would walk out. But never really meant it. Sometimes I hated him."

- "I know what it involves, and I'm going to fight to the end for sure."
- "Just want to give up, but you can't."

Theme 14: Trying to forget

- "While you're doing it, it's a different world. But once you put your coat back on, you know that you're going back to the problem."
- "There's something new every day, you can't get away from this. Can't forget."
- "You cannot get away from it, it is always there."

Theme 15: Factors which negatively affect coping

- "After I yell at him, I feel so guilty because I know he doesn't understand."
- "After I yell at him, I feel guilty. It lets off steam, but it just adds to the pressures.
- "Sometimes she doesn't know me visually."
- "Even though you're not giving physical care to the person, you are giving mental care."
- "Always have the stress of not knowing what's in store. What is going to happen next."

Theme 16: General comments on coping

- "Living from happiness to misery."
- "You see it, you feel it, you eat it. You feel that you can't make a mistake for her benefit."
- " The devil keeps fighting god, and it's going to get worse."
- " I do the best I can under the circumstances."
- "You never exactly know how you will react to something and it depends on how you feel at the moment. If you're not tired, you let him do it, if you're tired and/or nervous, you yell."
- "When it gets dark, I get nervous. I have sundowning too because I get nervous."
- "It's not easy and it's going to get worse. I know that the longer it is, the worse it's going to get me."
- "Nothing is rational in this sickness because you can't talk to the person, you can't reach out. You have no relationship. It's like speaking to a wall, table, or chair."

- "Don't like myself sometimes when I get angry."
- "You're the only one who can control what you're saying or doing." (with reference to caregiving).
- " It's not only sad. There's a lot of humor. If you sit and cry, there's a lot to be sad about. But we have to look at the humor of situation. It's the only way to survive."
- "Have to teach yourself not to feel guilty. No matter what decision you take, it's not good."
- "It comes to the point where you know the mistakes she's going to do and therefore can anticipate."
- "The worst thing is seeing him deteriorating right in front of you. It's like seeing someone around without a head."

Chapter 5

Discussion

A primary objective of this study was to determine how family members of individuals with Alzheimer's disease cope with their role as caregiver. The results confirm previous findings (e.g., Long, 1991; Barusch, 1988; Haley et al., 1987) that family caregivers experience stress, burden, and feelings of guilt associated with their caregiving role. Several factors were found to contribute to how well caregivers cope with their role and responsibilities as caregiver. In addition, it appears that different coping strategies elicit better caregiver coping.

Coping Strategies: What, When, and Where

The present study found that family caregivers tend to employ primarily avoidance or emotion-focused coping strategies. Caregivers who rarely employed behavioral coping strategies had a higher perception of overall burden. This supports Long (1991) who found that caregivers' use of emotion-focused coping increased as stress increased.

Caregivers reported using more acceptance or resignation and emotional discharge forms of avoidance coping and less positive reappraisal. This is particularly alarming since Stephens et al. (1988) reported that caregivers who engage mostly in escape-avoidance coping reported greater depression and more conflict in their personal relationships, while those engaging in positive reappraisal demonstrated greater positive affect.

The present study found that the greater the social network, the greater number of coping strategies employed by caregivers, regardless of type. In addition, those caregivers who utilized more than one coping strategy perceived themselves as coping with their role as caregiver. Caregivers in the present study who had reported having several people that they could turn to for assistance used less avoidance coping and had a lower perception of social burden than those who had few people to turn to. Similar findings were reported by Haley et al. (1987), who found that social support was a significant predictor of caregiver outcome. Gold, Cohen, Shulman, Zucchero, Andres, and Etezadi (in press) report that affect management techniques, such as finding some positive features in overwhelmingly negative situations, appears to be a useful coping strategy. Cohen, Gold, Shulman, and Zucchero (in press) report that some positive aspects of caregiving act as a buffer to reduce the intensity of the burden experienced. Two in particular, perceived adequacy of social support and quality of past relationship, appear to mitigate the negative effects of burden and stress in caregiving. Austrom and Hendrie (1992) report that health, economic security, social interaction, and peer and marital relationships are important overall predictors of well-being.

The findings show that as caregivers utilize more support services (e.g., day care, respite) their perception of burden increased; this may be explained by the fact that the caregiver's perception of burden is influenced by a subjective impression of care-receiver health based on the usage of support services as well as knowledge of the disease. Gold et al. (in press) report that their study failed to indicate the utility of social services in increasing the positive aspects of caregiving. Another possible reason why caregivers' perception of burden was higher when they utilized more support services is that the caregiver makes use of these services when they are close to or are considering placement for their care receiver, a time filled with feelings of guilt (Aronson, 1988). Gold, Andres, Dastoor, Grauer, and Bergman (1989-90) found that caregivers made very little use of support services, except for the period just prior to institutionalization, a finding which seems to support the hypothesis that caregiver burden is influenced by the usage of social services, and the realization of placement. Further research is needed to determine the extent of caregiver burden as a factor of social services usage and impending placement.

McGuire and Kinney (1993) found that the strongest predictor of caregiving hassles was caregivers' appraisals of care recipients' cognitive functioning. An objective assessment of the care recipients' actual level of cognitive impairment was not a predictor of caregiving stress. This implies that a caregiver's perception of his/her care receiver's cognitive deterioration is more stressful than the care receiver's actual level of decline. In audition, they found that caregivers with more knowledge of Alzheimer's disease reported fewer caregiving events as stressful. This suggests that experienced caregivers know what to expect, resulting in a less stressful caregiving experience, a finding that seems to contradict the results found in the present study. Nevertheless, by providing caregivers with more knowledge about the course of Alzheimer's disease and aspects of general caregiving, we might be able to reduce caregivers' appraisals of caregiving as stressful thereby reducing caregiver burnout (McGuire & Kinney, 1993).

Caregivers who reported being in better health tended to use more approach forms of coping and appeared to be coping better with their role as caregiver (based on internal dialogues). Gold et al. (in press) found that the ability to enjoy caregiving was more likely to occur for caregivers who were experiencing better health, which suggests that health is crucial for positive outcomes of caregiving.

Coping with Behavior Disturbances

The most common behavior disturbances of care receivers, reported by caregivers in the present study, were losing or hiding things, lack of interest in daily activities, and repetitive questions. The more severe and violent behaviors such as inappropriate sexual advances and physical aggression were less frequent. Similar findings were reported by Baumgarten, Becker, and Gauthier (1990) who found that increased behavioral disturbance was positively associated with disease duration and severity.

In the present study, caregivers reported that they were most likely to utilize a given coping strategy when their care receiver displayed a given behavior disturbance. The most common reactions of the caregivers to these problematic behaviors was to try reasoning with their care receiver and to ignore the behavior. Caregivers reported that attempts at reasoning with their care receiver were futile and led to stress and caregiver strain, whereas attempts at ignoring a given behavior met with more success and helped the caregiver to cope. However, caregivers did report that ignoring a given behavior was not always feasible due to frustration with their care receiver. This usually led to venting and verbal aggression by the caregiver, which added to their feelings of guilt and caregiver strain.

Short- and Long-Term Effects of Caregiving

Caregiving for an individual with Alzheimer's disease is a stressful and potentially physically and emotionally harmful role that many family members, usually wives and daughters, have to endure. Caregivers in the present study reported that although they had wanted to quit and stop caring for their loved-one, they continued with their role and caregiving responsibilities out of a sense of duty, even though it was harmful to their own well-being. With increased burden and stress, caregivers are likely to suffer more health problems, become a burden on society themselves due to the cost of medical and mental health care, and be forced to relinquish their caregiving responsibilities in favor of formal caregivers or institutionalization. Miller and McFall (1991) found that use of formal helpers was greater in situations combining high levels of need, burden, and insufficient support from the informal network.

Studies (e.g., Killeen, 1990; Stephens et al., 1988) have shown that one of the effects of caregiving is decreased health. Caregiver burden appears to be related to decreased caregiver health. Gold et al. (1989-90) found that length of caregiving was related to poorer caregiver psychological health. They also report that psychological and physical health of the caregiver are crucial in influencing caregiver burden. Caregivers whose health is poor report that caregiving is more distressing when the relationship with the care receiver has been difficult before the onset of dementia, when the patient has multiple behavioral and memory problems, and when caregivers have few pleasurable activities in which they engage. Gold et al. (in press) found that as caregiving situations become more stressful, social support was experienced as less satisfactory. Thus, caregivers may receive both less satisfactory and fewer amounts of social support as length of caregiving and care recipient's cognitive deterioration escalates. This occurs when the caregiver needs more social support to act as a buffer against health complaints and distress.

The emotional predisposition caregivers has been found to affect their health (Reis, Gold, Andres, Markiewicz & Gauthier, in press). Reis et al. (in press) found that feelings of burden and declining health were related and that caregivers who are neurotic are vulnerable to the negative effects of caregiving. Further, these caregivers may benefit from early interventions that provide functional help, emotional support, and medical care.

Austrom and Hendrie (1992) conclude that many variables interact to determine the effect of caregiving on one's well-being. They state, "The impact on quality of life is not simply a function of how one copes with each of the stressors described; rather, there appears to be a complex relationship between the caregiver, the perception of his/her caregiving burden, and the caregiver's relationship with the patient and others in the social network, which together mediate the stress and well-being relationship" (p. 59).

Suggestions for Caregivers

From comments and observations made by caregivers in the present study, it is concluded that a successful caregiver needs to be flexible and have the ability to adapt. The majority of the caregivers reported that taking things one day at a time was essential, and that planning should be undertaken on only a small scale. The majority of caregivers reported that due to lack of time, they were forced to cut down on activities. However, those caregivers who were able to maintain some of their leisure activities perceived themselves to be coping better than most caregivers they know. Thus staying active through sports (swimming, walking, golfing), engaging in a hobby, and meeting with friends and going to a restaurant are all possible ways to give a caregiver much needed personal time away from their care receiver. One caregiver in the study, who was unable to leave his care receiver, suggests that finding some activity that one can do alone in the house (e.g., listening to music) is important. The need to have time alone and rejuvenate was strongly advocated by the caregivers in the present study. Caregivers must remember that being a martyr is not a healthy response. They need to accept help from friends and family, and to make use of outside services throughout their caregiving career and not just in the final stages prior to institutionalization. There is a need for innovative programs and services that meet the changing needs of caregivers (Gold et al., 1989-90). Regular use of social services should be encouraged throughout the caregiving time-span, not just near the point of institutionalization. Agencies should increase their efforts to work with the entire family unit, not just the primary caregiver. Aronson (1988) suggests that goals established by the caregiver should be to maximize whatever function the care receiver has remaining.

Caregivers often become so involved in caring for their care receiver that they forget about caring for themselves. Aronson (1988) strongly recommends that caregivers include themselves in the caregiving plans. She suggests the following recommendations: (1) *Begin to let go.* Caregivers need to learn to put some emotional distance between themselves and their care receiver. Caregivers must recognize that as their care receiver's dependency increases, their need for independence will increase; (2) *Work on resolution.* Caregivers should try to work towards a sense of closure and should try to resolve conflicts rather than create new ones; (3) *Avoid martyrdom.* Martyrdom may lead to isolation, which can create more stress. Caring for an individual with Alzheimer's disease is a big job; seek and accept whatever help is available; (4) *Use a confidant.* Share your feelings and experiences with someone you trust. This can be a friend, family member, or mental-health professional; (5) *Look for the "silver lining in the black cloud."* No one goes unchanged from the impact of Alzheimer's disease.

Caregivers should consider how they have grown as an individual due to their experience (e.g., learning to do things on one's own); (6) *Listen to your own feelings.* Caregivers should consider how they feel and pay attention to possible symptoms (e.g., being tired, feeling ill, feeling sad), and discuss these symptoms with a doctor; (7) *Attend a support group.* Attendance at a support group may provide information, emotional support, caregiving tips, and a chance to think about rebuilding social supports and to plan for the future; (8) *Use respite services.* All caregivers need time away from their caregiving responsibilities, be it an hour at a time, an afternoon, a weekend, or a week. Caregivers must seek out opportunities to get relief whether from family, friends, paid workers, or community agencies; (9) *Ventilate.* It is important for caregivers to express their frustrations, although this should be away from the care receiver as much as possible since yelling at one's care receiver leads to feelings of guilt. The caregiver should try talking with a friend, attend a support group, or talk with a counselor. Physical exercise is also a great source of relief; (10) *Be good to yourself.* One of the things a caregiver may miss is the positive feedback, the thank-yous, holiday celebrations, and gifts. The caregiver should indulge in some of the things that make them happy (e.g., go to a restaurant, go to the barber or beauty shop, see a movie); and (11) *Take things in manageable chunks.* Although planning and decisions have to be made, not all decisions have to be made at one time. Take things in discrete portions - one day at a time.

Limitations and Future Directions

The small sample size of the study permits only guarded generalization of the results. However, the in-depth interviews and the internal dialogues obtained through these interviews provide important information about the dimensions used by caregivers to define their situations and the coping strategies used. Another limitation of the study is that all participants were volunteers. One cannot be certain of the representativeness of the sample since individuals who participate in such studies are not the norm. It may be that the findings reported here are inflated since participants may have been seeking help.

Another limitation of the present study was that the coping inventory used (Coping Response Inventory-Adult Form) is a general measure of coping that is not specific to caregivers of Alzheimer's patients. An inventory geared specifically towards assessing the coping strategies of caregivers should be undertaken.

In conclusion, programs should be implemented at the national, provincial, and municipal levels (at the federal, state, and county levels in the United States) to enable easier access to support services. Although these already exist in many regions, they need to be expanded. Caregivers reported that availability of day-care programs and respite was too low and cost was too high. Therefore, more funding is needed to help caregivers to continue caring for family members in the home, a far less expensive option than institutionalization.

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APPENDIX A

Coping Strategies Employed by In-Home Family Caregivers of Alzheimer's Patients

Informed Consent Form

I have been informed that the research in which I will participate is part of a Master's Thesis for the Department of Educational and Counselling Psychology and that the purpose of the research is to examine some of the ways caregiver's cope with stressful situations that they encounter in their role as caregiver. I have been informed that my participation requires me to answer 3 questionnaires, and that these questionnaires will be answered during an interview at a time and location convenient to me, and that the total time involved to complete the tasks should not exceed 90 minutes. I have been advised that all information I provide will be treated with complete confidentiality and anonymity, that I am free to withdraw from the project at my discretion at any time, and that no risks or deception are involved. I am aware that I may expect frank and sufficient answers to any questions I may have concerning the research and my participation.

I agree to participate in this research and allow any information I provide to be used in any way deemed appropriate by the researcher responsible for this project.

Name ______________________________(please print)

Signature ______________________________

Date ______________________________

APPENDIX B

Coping Response Inventory Part II

(Moos, 1993)

Circle the appropriate response on the answer sheet:
Circle "N" if your response is NO, Not at all.
Circle "O" if your response is YES, Once or Twice.
Circle "S" if your response is YES, Sometimes.
Circle "F" if your response is YES, Fairly often.

1. Did you think of different ways to deal with the problem?
2. Did you tell yourself things to make yourself feel better?
3. Did you talk with your spouse or other relative about the problem?
4. Did you make a plan of action and follow it?
5. Did you try to forget the whole thing?
6. Did you feel that time would make a difference - that the only thing to do was wait?
7. Did you try to help others deal with a similar problem?
8. Did you take it out on other people when you felt angry or depressed?
9. Did you try to take a step back from the situation and be more objective?
10. Did you remind yourself how much worse things could be?
11. Did you talk with a friend about the problem?
12. Did you know what had to be done and tried hard to make things work?
13. Did you try not to about the problem?
14. Did you realize you had no control over the problem?
15. Did you get involved in new activities?
16. Did you take a chance and do something risky?
17. Did you go over in your mind what you would say or do?
18. Did you try to see the good side of the situation?
19. Did you talk with a professional person (e.g., doctor, lawyer, clergy)?
20. Did you decide what you wanted and try hard to get it?
21. Did you daydream or imagine a better time or place than the one you were in?
22. Did you think that the outcome would be decided by fate?
23. Did you try to make new friends?
24. Did you keep away from people in general?
25. Did you try to anticipate how things would turn out?
26. Did you think about how you were much better of than other people with similar problems?

APPENDIX B (CON'T)

27. Did you seek help from persons or groups with the same type of problem?
28. Did you try at least two different ways to solve the problem?
29. Did you try to put off thinking about the situation, even though you knew you would have to at some point?
30. Did you accept it; that nothing could be done?
31. Did you read more as a source of enjoyment?
32. Did you yell or shout to let off steam?
33. Did you try to some personal meaning in the situation?
34. Did you try to tell yourself that things would get better?
35. Did you try to find out more about the situation?
36. Did you learn to do more things on your own?
37. Did you wish the problem would somehow be over with?
38. Did you expect the worst possible outcome?
39. Did you spend more time in recreational activities?
40. Did you cry to let your feelings out?
41. Did you try to anticipate the new demands that would be placed on you?
42. Did you think about how this event could change your life in a positive way?
43. Did you pray for guidance and/or strength?
44. Did you take things one day at a time, one step at a time?
45. Did you try to deny how serious the problem really was?
46. Did you lose hope that things would ever be the same?
47. Did you turn to work or other activities to help manage things?
48. Did you do something that you didn't think would work, but at least you were doing something?

APPENDIX C*

CRI-ADULT ANSWER SHEET

Form: Actual____ Ideal____

Name ______________________ Date ____ /____ /____ Sex ____ Age ____

Marital Status ____________ Ethnic Group ____________ Education ____________

Part 1

Describe the problem or situation ______________________________

____

____

____

DN = **Definitely No** **MN** = **Mainly No** **MY** = **Mainly Yes** **DY** = **Definitely Yes**

1. Have you ever faced a problem like this before? DN MN MY DY
2. Did you know this problem was going to occur? DN MN MY DY
3. Did you have enough time to get ready to handle this problem? DN MN MY DY
4. When this problem occurred, did you think of it as a threat? DN MN MY DY
5. When this problem occurred, did you think of it as a challenge? DN MN MY DY
6. Was this problem caused by something you did? DN MN MY DY
7. Was this problem caused by something someone else did? DN MN MY DY
8. Did anything good come out of dealing with this problem? DN MN MY DY
9. Has this problem or situation been resolved? DN MN MY DY
10. If the problem has been worked out, did it turn out all right for you? DN MN MY DY

Part 2

N = No, Not at all **O** = Yes, Once or twice **S** = Yes, Sometimes **F** = Yes, Fairly often

1 N O S F	2 N O S F	3 N O S F	4 N O S F	5 N O S F	6 N O S F	7 N O S F	8 N O S F
9 N O S F	10 N O S F	11 N O S F	12 N O S F	13 N O S F	14 N O S F	15 N O S F	16 N O S
17 N O S F	18 N O S F	19 N O S F	20 N O S F	21 N O S F	22 N O S F	23 N O S F	24 N O S
25 N O S F	26 N O S F	27 N O S F	28 N O S F	29 N O S F	30 N O S F	31 N O S F	32 N O S F
33 N O S F	34 N O S F	35 N O S F	36 N O S F	37 N O S F	38 N O S F	39 N O S F	40 N O S
41 N O S F	42 N O S F	43 N O S F	44 N O S F	45 N O S F	46 N O S F	47 N O S F	48 N O S

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APPENDIX C (CON'T)

CRI-ADULT PROFILE

T Score	Raw Score								T Score
80								14-18	80
79								13	79
78							18		78
77									77
76					18		17		76
75						18		12	75
74					17		16		74
73						17			73
72			18		16			11	72
71									71
70						16			70
69			17		15		14	10	69
68		18							68
67	18		16	18	14		13		67
66								9	66
65	17	17			13				65
64			15	17			12		64
63						13		8	63
62	16	16	14	16	12		11		62
61						12			61
60	15	15		15	11		10	7	60
59			13			11			59
58		14			10		9		58
57	14		12	14				6	57
56		13				10			56
55	13			13	9		8		55
54			11			9		5	54
53		12			8		7		53
52	12		10	12		8			52
51		11			7		6	4	51
50	11			11					50
49		10	9			7			49
48				10	6		5	3	48
47	10	9	8			6			47
46					5		4		46
45		8		9				2	45
44	9		7		4	5	3		44
43				8					43
42	8	7	6			4	2	1	42
41				7	3				41
40		6				3			40
39	7		5		2		1	0	39
38		5		6					38
37	6		4		1	2	0		37
36		4		5					36
35						1			35
34	5	3	3	4	0				34
33						0			33
32	4		2						32
31		2		3					31
30									30
29	3	1	1	2					29
28									28
27	2	0	0	1					27
26									26
25									25
24	1			0					24
23									23
22	0								22
21									21
20									20
Raw Score	LA	PR	SG	PS	CA	AR	SR	ES	

APPENDIX D

Caregiver Burden Inventory (Novak & Guest, 1989)

Now we would like to know how you see your experience as a caregiver and what your feelings are about giving care. Think of your experience as a family caregiver. How well does each of the following statements describe your experience in caring for your care receiver in the past month?

1	2	3	4	5
Not at all	Slightly	Moderately	Quite	Very

1. My care receiver needs my help to perform many daily tasks ________
2. My care receiver is dependent on me ________
3. I have to watch my care receiver constantly ________
4. I have to help my care receiver with many basic functions ________
5. I don't have a minute's break from my caregiving chores ________

Factor 1 Score ________

6. I feel that I am missing out on life ________
7. I wish I could escape from this situation ________
8. My social life has suffered ________
9. I feel emotionally drained due to caring for my care receiver ________
10. I expected that things would be different at this point in my life ________

Factor 2 Score ________

11. I'm not getting enough sleep ________
12. My health has suffered ________
13. Caregiving has made me physically sick ________
14. I'm physically tired ________

Factor 3 Score ________

15. I don't get along with other family members as well as I used to ________
16. My caregiving efforts aren't appreciated by others in my family ________
17. I've had problems with my marriage ________
18. I don't do as good a job at work as I used to ________
19. I feel resentful of other relatives who could but do not help ________

Factor 4 Score ________

20. I feel embarrassed over my care receiver's behavior ________
21. I feel ashamed of my care receiver ________
22. I resent my care receiver ________
23. I feel uncomfortable when I have friends over ________
24. I feel angry about my interactions with my care receiver ________

Factor 5 Score ________

Total Burden Score ________

APPENDIX E*

Revised version of the Dementia Behavior Disturbance Scale (Baumgarten, Becker, & Gauthier, 1990)

Instructions:

For each question discuss how:

(1) Does _________ exhibit this problem? How often? If yes, how do you cope with it?

(2)If _________ were to exhibit this problem. how would you cope with it?

1. Shows lack of interest in daily activities.
   Yes______ No _______ How often __________
   How would you cope if He/She did ______________________________________
2. Makes unwarranted accusations.
   Yes______ No _______ How often __________
   How would you cope if He/She did ______________________________________
3. Is verbally abusive, curses.
   Yes______ No _______ How often __________
   How would you cope if He/She did ______________________________________
4. Empties drawers or closets.
   Yes______ No _______ How often __________
   How would you cope if He/She did ______________________________________
5. Dresses inappropriately.
   Yes______ No _______ How often __________
   How would you cope if He/She did ______________________________________
6. Exposes himself/herself indecently.
   Yes______ No _______ How often __________
   How would you cope if He/She did ______________________________________
7. Screams for no reason.
   Yes______ No _______ How often __________
   How would you cope if He/She did ______________________________________
8. Makes physical attacks (hits, bites, scratches, kicks, spits).
   Yes______ No _______ How often __________
   How would you cope if He/She did ______________________________________
9. Makes inappropriate sexual advances.
   Yes______ No _______ How often __________
   How would you cope if He/She did ______________________________________

APPENDIX E (CON'T)

10. Paces up and down.

Yes______ No _______ How often __________

How would you cope if He/She did ______________________________________

11. Moves arms or legs in a restless or agitated way.

Yes______ No _______ How often __________

How would you cope if He/She did ______________________________________

12. Gets lost outside.

Yes______ No _______ How often __________

How would you cope if He/She did ______________________________________

13. Wakes up at night for no obvious reason.

Yes______ No _______ How often __________

How would you cope if He/She did ______________________________________

14. Wanders in the house at night.

Yes______ No _______ How often __________

How would you cope if He/She did ______________________________________

15. Sleeps excessively during the day.

Yes______ No _______ How often __________

How would you cope if He/She did ______________________________________

16. Overeats.

Yes______ No _______ How often __________

How would you cope if He/She did ______________________________________

17. Refuses to eat.

Yes______ No _______ How often __________

How would you cope if He/She did ______________________________________

18. Cries or laughs inappropriately.

Yes______ No _______ How often __________

How would you cope if He/She did ______________________________________

19. Refuses to be helped with personal care tasks, such as bathing, dressing, brushing teeth.

Yes______ No _______ How often __________

How would you cope if He/She did ______________________________________

20. Throws food.

Yes______ No _______ How often __________

How would you cope if He/She did ______________________________________

APPENDIX E (CON'T)

21. Wanders aimlessly outside or in the house during the day.

Yes______ No ______ How often _________

How would you cope if He/She did ______________________________

22. Hoards things for no obvious reason.

Yes______ No ______ How often _________

How would you cope if He/She did ______________________________

23. Destroys property or clothing, breaks things.

Yes______ No ______ How often _________

How would you cope if He/She did ______________________________

24. Loses, misplaces, or hides things.

Yes______ No ______ How often _________

How would you cope if He/She did ______________________________

25. Asks the same question over and over again.

Yes______ No ______ How often _________

How would you cope if He/She did ______________________________

26. Repeats the same action (e.g., wiping table) over and over again.

Yes______ No ______ How often _________

How would you cope if He/She did ______________________________

* Permission to revise scale was granted by the principal author in a phone conversation in May, 1993.