ALZHEIMER'S DEGENERATIVE BRAIN DISEASE

AN INVESTIGATION INTO THE USE OF SUPPORT SYSTEMS

BY PRIMARY CAREGIVERS AND PATIENTS

by

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ABSTRACT

The purpose of this study was to investigate the use of support systems by primary caregivers of patients with Alzheimer's degenerative brain disease. The study focused on the requirement and availability of support for both primary caregivers and patients during the three phases of the disease. Specifically, the following four research questions were considered: Does the type of support required by the primary caregiver and the patient vary with the progress of the disease? Does the type of support available to the primary caregiver and the patient vary with the progress of the disease? Do the primary caregiver and the patient believe they are receiving proper guidance and are correctly informed about medical care from the professionals whose services they require? Do the primary caregiver and the patient believe there is an increasing concern and public awareness about Alzheimer's degenerative brain disease?

The subjects were 50 primary caregivers (spouse, sibling, or adult child) of patients afflicted with Alzheimer's disease. Names of subjects were obtained from the Alzheimer Support Association, Victoria B.C. branch. Thirty-two of the caregivers were female and 18 were male. The majority (32) were between 61 and 80 years old. The caregivers also served as proxy respondents for their patients, 23 of whom were female and 27 male. The majority (38) of patients were between 71 and 90 years old. To maintain their anonymity, respondents were not required to sign their names to their returned questionnaires.

The research design used was exploratory and descriptive. The researcher-made, 10 page mailed self-administered questionnaire included yes/no questions, open-ended questions, and brief checklists for some of the demographic information. All subjects were requested to respond from their memory or experience with the patient during the phase of the disease referred to in each question.

The research compared the circumstances of caregivers of patients in the three phases of the disease and responding from three situations,

(a) the Alzheimer patient and the caregiver living at home, (b) the Alzheimer patient living in a care facility and the caregiver living at home, and (c) the Alzheimer patient deceased and the caregiver living at home. The results indicated that the type of support respondents required and their perceptions of various issues were (collectively and individually) consistently similar to findings in reports by professionals working with Alzheimer's patients and their families. The conclusions of the study were that (a) the type of support required by the primary caregiver and the patient varied with the progress of the disease, (b) the type of support believed available and actually utilized by the primary caregiver and the patient varied with the progress of the disease, (c) not all primary caregivers believed they and their patient were receiving proper guidance and were correctly informed about medical care from the professionals whose services they required, and (d) almost all of the respondents believed there is an increasing concern and public awareness about Alzheimer's disease.

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CHAPTER I

Introduction

Progressive cognitive impairment is no longer believed to be a natural part of the aging process(Health and Welfare Canada,1984; Henig,1981; Mace & Rabins,1981; Palmer,1983; Schneck, Reisberg, & Ferris,1982). Since the middle of the 1970s there has been a marked increase in research on the dementias, particularly the organic brain disease known as Alzheimer's(Loder,1985). According to Health and Welfare Canada(1984), of the overall number of elderly men and women suffering with severe intellectual impairment more than half are victims of Alzheimer's disease. After cancer, heart disease, and stroke, it is thought to be the fourth or fifth most common cause of death. Precise data are difficult to acquire however, because health events immediately prior to death are often recorded as cause of death rather than Alzheimer's disease(Health and Welfare Canada, 1984). Robertson(1985) states that it is only within the last two to three years that Alzheimer's disease has been put as cause of death on a death certificate.

Two or three percent of the general population and more than 20% of people over 80 years old are afflicted with Alzheimer's(Health and Welfare Canada,1984). Because of the growing number of people over 75 years old, Alzheimer's disease has become a priority of the National Institute of Aging in the United States(Gwyther & Matteson, 1983). Loder(1985) reports that, while funding for research in the United States has increased from under $4 million in 1970 to $37.1 million in 1985, 1000 times more is now being spent on nursing care and treatment than on research. In Canada the Medical Research Council has supported only four major projects on Alzheimer's disease with an approximate total expenditure of $400,000., yet annual costs in care are more than $1.5 billion. Major funding (nearly $1 million U.S.) for Canadian research, a three year project at the University of Western Ontario, comes from the National Institute of Aging in the United States(Loder,1985).

There is at present no known cause or cure for Alzheimer's and final confirmation of the disease requires a post-mortem examination of the brain. Other diseases can cause cognitive deterioration if chronic and untreated. Alzheimer's is a diagnosis of exclusion where all effort to rule out a reversible cause of dementia must be made(Heston & White,1983; Lawrence,1985), "since failure to do so leaves the patient with a diagnosis implying irreversible damage and a grim prognosis" (Schneck, Reisberg, & Ferris,1982,p.167). While recent findings direct research to certain areas of the brain, little is known about the disease or treatment of it(Loder,1985). The symptoms are progressive, but vary greatly in rate of change from person to person. Records indicate that death will occur between 2 to 19 years after onset. Due to a diagnosis often occurring late in the disease, the length of survival after the medical diagnosis averages 5 to 8 years(Health and Welfare Canada,1984).

Although there is a problem in determining an Alzheimer patient's life expectancy, the phases of the illness offer families some structure for caregiving(Gwyther & Matteson,1983). The first phase which may last two to four years includes changes in memory and behaviour. An afflicted individual develops problems in communication, memory loss for recent events, slow changes in ability to learn new things, difficulty in making decisions and coping with new situations, impaired judgement, and possible outbursts of temper and suspiciousness resulting from frustration(Health and Welfare Canada,1984). These changes may be so subtle that families, not recognizing anything wrong, will make excuses for their disabled relative, attributing behaviour to stress or aging. Gwyther and Matteson write that by the end of the first phase people with Alzheimer's disease are performing poorly at work, having difficulty organizing dates and time, adding and subtracting incorrectly, and forgetting various tasks. The Alzheimer's victim may be fired from his or her job without explanation and frequently with no insurance or retirement benefits. The eventual loss of employment resulting in reduced income and possibly shattered financial security may put the entire family in a state of emotional trauma.

"The family may be able to recognize the symptoms as a disease process but may be unable to face the implications"(Gwyther & Matteson,1983, p.93).

"Most relatives of Alzheimer's know little or nothing about this common disease"(Teusink & Mahler,1984,p.155). Lawrence(1985) found that many families who came to the University of British Columbia Clinic for Alzheimer's Disease and Related Disorders had reached a point of desperation before requesting an assessment, often because they were unaware of available services. During an eight week support group program for families of Alzheimer's patients still living at home, Barnes, Raskind, Scott, and Murphy(1981) found that a problem for many caregivers was the emotional stress accompanying the diagnostic process. The uncertainties associated with the diagnostic process were confusing. Families knew that something was seriously wrong yet doctors were frequently unable to explain early signs of the disease. When a diagnosis had been made, distrust and anger was felt for the doctors. "Spouses complained that physicians did not adequately explain the disease to them"(Barnes et al.,1981,p.81). Because of anxiety and denial, family members frequently found it difficult to accept or understand the implications of Alzheimer's disease when doctors adequately made an explanation. After the diagnosis was made some spouses felt that "physicians tended to pull back, communicating a sense of helplessness, and leaving the family without a source of information about how to care for the patient"(Barnes et al.,1981,p.81).

It frequently takes agonizing, frustrating months before those living with a person in the early stages of a progressive dementia realize what is happening and begin to adapt to it(Heston & White, 1983). While some families may not accept the diagnosis, others feel a sense of relief in knowing that the symptoms of the disabled relative represent a disease entity(Gwyther & Matteson,1983).

The middle phase (phase two) of the disease, during which the diagnosis is often made, may last for several years and is characterized by progressive memory loss, agnosia, aphasia, repetitive movements such as lip-licking, tapping, folding or chewing. While there is a

continual deterioration of memory functions, other aspects of intellectual ability such as writing, using language, and conducting daily activities decline. There is increased disorientation to time and place and the individual may be unable to recognize himself or herself in a mirror. There is frequent struggling to control bodily functions and some will be maintained longer than others. A loss of dexterity may interfere with self-care routines such as dressing. There may be a slowing down of body movements and the individual may physically resist help(Gwyther & Matteson,1983; Health and Welfare Canada,1984).

A major problem for families during the second phase is home management. Supervision and constant care may be required from family members. Due to the confusion, the Alzheimer victim may become insecure and "may use trusted family members as 'security blankets' never leaving them alone or out of sight"(Gwyther & Matteson,1983, p.93). Teusink and Mahler(1984) write that one of the most difficult adjustments involves role reversals. In attempting to keep the household running smoothly and in caring for the patient, his or her former family role must be assumed by another family member. Most common reversals are parent-child and husband-wife. Because of misperceptions of what is happening, the patient may react to people or objects aggressively. "It is a time of loss and grief for family members - loss of the client as the individual he or she once was, and grief over the change in family life"(Gwyther & Matteson,1983,p.93).

Heston and White(1983) found that spouses particularly seemed unwilling or unable to come to terms with the reality of the illness. From their support group project, Barnes et al.(1981) report that problems of assuming new roles, a deep sense of loss and sadness, and the devotion of a great amount of energy and time to the direct care of the demented patient led quickly to exhaustion and social isolation of the primary caregiver. It is an ongoing grief process for families of Alzheimer's patients(Teusink & Mahler,1984) and some arrangements to relieve the primary caregiver must be made(Heston & White,1983). In their experience, Heston and White have found that primary caregivers, particularly spouses, carry the care alone for too long and that other

family members may have to insist on helping. In their discussion of care for the caregivers, Gwyther and Matteson(1983) emphasize the need for phase two caregivers to schedule emergency and regular respite. "Caregivers state that their major coping stresses are their own fatigue and lack of time for themselves and their other role responsibilities"(Gwyther & Matteson,1983,p.110).

Aronson and Lipkowitz(1981) found that there is a lack of both services and adequate information for the Alzheimer patient and caregiver. They reinforce the need for support and attention for the spouse of the Alzheimer patient. The quality of care the patient receives is controlled by the spouse. Further, these authors write that rather than the condition of the patient, it is the coping skills of the spouse which determines whether and when institutionalization is required.

> The current point of entry into the health care delivery system is unpredictable. The SDAT (Senile Dementia of the Alzheimer Type) patient is often brought to the emergency room as a last resort by the distraught, frustrated family and is a source of resentment for the resident physician, who feels helpless.Aronson & Lipkowitz,1981,p.569

The third and final phase of this disease is the terminal phase. Patients frequently do not eat, become emaciated, may be incontinent, may have grand mal seizures, and are unable to communicate. The individual cannot carry a thought long enough to remember what to do next and may confuse a spouse with a parent. Severe agitation, hallucinations, delusions, and paranoid ideations may occur(Schneck et al., 1982). The reflex of sucking anything put into the mouth develops. Reaction to people or stimuli and any spontaneous movement may be completely absent(Health and Welfare Canada,1984). "Witnessing the slow extinction of the personality usually within an outwardly healthy body. . . . may be more emotionally traumatic than witnessing death itself" (Aronson & Lipkowitz,1981,p.568). With the continual grief over the loss of the individual who was the spouse and companion or the parent and support, "it is not unusual to hear a family member describe the

course of the disease as a 'funeral that never ends'"(Aronson & Lipkowitz,1981,p.568).

Twenty-four hour nursing care or hospitalization is necessary in the final phase. Families face the major decision of nursing home placement. The decision to commit the patient to an institution varies with the individual and the circumstances. Consideration includes the ability to care for a patient at home, the availability of a suitable facility, the cost, and the attitude toward placing the person in a nursing home. "The investment caregivers make in sustaining the impaired person inevitably leads to ambivalence about placement"(Lyons, 1984,p.38). Feelings of guilt and anger may develop. Some families wait until the patient no longer recognizes them before institutionalization is considered. Other families attempt institutionalization when the patient is completely unable to care for his or her personal needs or becomes violent. Lyons observes that many intrafamily problems present at the beginning of the illness may re-emerge when facing the possibility of institutionalization. Because of guilt and pain some caretakers attempt to avoid responsibility for a separation by "overextending themselves so that 'circumstances beyond our control' bring separation about"(Lyons,1984,p.38). However, placement is essentially decided by what care the caregiver can really sustain, along with what support is available, and what is the best situation the family can find, rather than conflicting assessments of the primary caregiver's ability to continue and differing views of the patient's readiness for institutionalization. Families "need consistent help in sorting out . . . what are the needs of the person giving care and the needs of the person receiving care and accepting that they do not necessarily coincide"(Lyons,1984,p.41).

Loss of income and/or medical costs associated with home care or institutionalization of the patient may result in families facing financial hardship during the terminal phase. If the Alzheimer's patient is in a nursing home and communication and recognition have ceased, feelings of grief, loss, and guilt may make it extremely painful for family members to visit(Gwyther & Matteson,1983). Lyons(1984) empha-

sizes that just as cognitively impaired patients become increasingly dependent and in need of help so do their families, particularly the primary caregivers. The primary caregivers become dependent upon other family members, upon household help, upon physicians, upon friends, upon a variety of health and social services and eventually institutional services "with all the mixed feelings which are engendered by entrusting the care of a helpless relative to strangers over whom one has little control"(Lyons,1984,p.41).

Relevance of the Study

In 1981 LaBarge wrote of a critical need to examine, discuss, and develop case studies to isolate the effects of Alzheimer's disease on patients and their relatives. Hayter(1982) reported that an article she wrote in 1974 resulted in many relatives of patients writing to express their concerns and indicated a lack of help in coping with the effects of the disease. Other authors discuss the emotional pain for both the family and the person with this devastating progressive condition(Barnes et al.,1981; G.D.Cohen,1984; Ware & Carper,1982).

The mysterious and insidious onset of Alzheimer's disease frequently results in nightmarish uncertainty for the entire family. The perhaps normal appearance and physical vigour retained by the patient even into the middle phase can make it difficult for the family and community to accept the severity of the situation and provide appropriate support(Barnes et al.,1981; G.D.Cohen,1984). With the persistent deterioration of the patient, the family is forced to keep adjusting to new levels of impairment and problems. Barnes et al. (1981) write that in attempting to provide care for an Alzheimer patient a cycle of isolation begins for many spouses.

Bennett(1983) reports that there are 10 million elderly spouse pairs living in the United States. A New York City sample determined that the majority of caregivers for the elderly were their spouses. Most of these caregivers indicated that, unless they found themselves unable to provide needed services such as dressing, bathing, or dealing with incontinence, they would continue to care for their demented

spouses. Bennett cautions that, because of the emotionally draining and physically demanding situation, these caregiver spouses are vulnerable to illness themselves. If an aggressive outreach homecare program is lacking, the caregiver and the patient as a couple may be ill and isolated. "A demented person and an ill spouse, who have no other supports, often find it impossible to negotiate the system to avail themselves of information and services"(Bennett,1983,p.256).

As both carereceiver and caregiver become dependent to some degree, Beattie(1984) advises that the object is to provide some intervention that enables the caregiver, particularly, to maintain a sense of control in his or her life. Lawrence(1985) describes the networking of families and social services at the University of British Columbia Clinic for Alzheimer's Disease and Related Disorders. After the needs of the patient and caregiver have been determined and contact with the required services has been initiated, follow up by the clinic may be necessary to ensure meeting changing needs before the caregiver becomes exhausted.

Since there are no apparent physical problems and the changes at the onset are essentially behavioural, many people are hesitant to contact a doctor. Because of large caseloads, many doctors might be too busy to keep informed on advances in medicine and specialized care of a person with dementia or feel uncomfortable caring for people with incurable chronic diseases(Mace & Rabins,1980). "Many families feel alone with this illness, unable to find doctors, other professionals, or friends who understand, and unable to get information" (Mace & Rabins,1981,p.264).

Teusink and Mahler(1984) have found that in coping with Alzheimer's disease many families of patients appear to experience an intense five-stage reaction process comparable to the reactions of families coping with death. Alzheimer's patients create an extreme burden for their caretakers because they "are in a sense intellectually dying"(Teusink & Mahler,1984,p.152). These authors discuss the necessity of helping family members, through education or at times confrontation, to deal with excessive denial or overinvolvement. Car-

rying involvement with the needs of the patient to an exaggerated degree "family members may sacrifice many aspects of their personal lives, such as their social relationships, their freedom to come and go, and even their sleep"(Teusink & Mahler,1984,p.153).

Researchers suggest that support groups for family caregivers can help them better understand the limits of caregiving(G.D.Cohen,1984; LaBarge,1981; Mace & Rabins,1981; Ware & Carper,1982). Ware and Carper(1982) state that scientists and clinicians must not only be concerned with pathogenetic research on Alzheimer's disease, but also with psychotherapeutic support for families "by informing them of community support systems, by giving them realistic expectations of the nature of the disease's insidious progression, and by giving them permission to openly express their fears and frustrations"(p.481).

Volunteer organizations have been formed by some families to meet a need for communication(Mace & Rabins,1981). People who have been involved with these groups express the importance of knowing other families who face similar problems. Mace and Rabins(1981) report that besides sharing solutions to management problems and exchanging information, individuals in these groups are involved in educating the community and supporting needed legislation and research. LaBarge (1981) evaluated the curative factors gained from participation in a group counselling situation as a sense of universality and hope, the sharing of information and development of caring techniques "and a feeling of group solidarity and catharsis"(p.141).

Support and consultation can benefit people who work with Alzheimer's patients in various settings(G.D.Cohen,1984). People who work with Alzheimer's patients in their terminal phase experience a double problem, "Not only [has the patient] lost touch with [his or her] personal history, but they have also lost the ability to convey their history to others"(G.D.Cohen,1984,p.116). To be without a history by being unknown, and unable to convey one's past to others, puts the Alzheimer's patient at a disadvantage in seeking the empathy or understanding of others.

The Purpose of this Study

The purpose of this study is to investigate the use of support systems by primary caregivers of patients with Alzheimer's degenerative brain disease. The study focuses on the requirement and availability of support for both primary caregiver and patient during the three phases of the disease. Specifically, the following questions are to be considered:

1. Does the type of support required by the primary caregiver and the patient vary with the progress of the disease?
2. Does the type of support available to the primary caregiver and the patient vary with the progress of the disease?
3. Do the primary caregiver and the patient believe they are receiving proper guidance and are correctly informed about medical care from the professionals whose services they require?
4. Do the primary caregiver and the patient believe there is an increasing concern and public awareness about Alzheimer's degenerative brain disease?

Definitions

Dementia: "An impaired intellectual functioning in a person who is clearly awake"(Mace & Rabins,1980,p.6). Deterioration of previously acquired intellectual abilities of sufficient severity to interfere with social or occupational functioning. Threshold of recognition of dementia will vary with the situation of the individual. Some of the diseases which cause a dementia are treatable and the dementing process can be stopped or reversed. Dementia of the Alzheimer's type is irreversible.

Alzheimer's degenerative brain disease: The major pathological changes are neurofibrillary tangles, neuritic plaques, and granulovacuolar bodies predominantly found in the cerebral cortex(Schneck et al.,1982). An operational definition of Alzheimer's includes observation of deterioration of cognition, recent and remote memory, language, visual/spatial perception, function of activities of daily living, personality, reasoning, orientation, arithmetic, judgement, and

emotion(Beattie,1984).

Primary caregiver: The individual, usually a spouse, sibling, or adult child upon whom falls most of the responsibility for the daily care of the chronically ill person with Alzheimer's disease.

Support system: Assistance "in the treatment plan. . . . whereby attention is paid to psychologic, social, and economic factors affecting both patient and family, in addition to the biologic aspects of the disease process"(Aronson & Lipkowitz,1981,p.571).

Diagnostic process: Each person suspected of having Alzheimer's disease should have thorough physical, neurological, and psychiatric or psychogeriatric evaluations. Tests include: complete blood count, urinalysis, electrolyte, endocrine screen, serologic tests for syphilis, blood urea nitroger, bilirubin, glucose, erythrocyte sedimentation rate, vitamins(in blood), blood and urine screen for drugs, cerebral spinal fluid, endocrine tests(free thyroxine, thyroxine uptake), electrocardiogram, electroencephalogram, chest x-ray, computerized axial tomography(CAT scan)(Heston & White,1983). Perhaps other neurological tests including the latest imaging procedures, PET(positron emission tomography), and MRI(magnetic resonance imaging). A battery of neuropsychological tests measuring attention, concentration, remote, recent and immediate memory, ability to acquire and retain new information, receptive and expressive language skills, visual-spatial functioning, and motor skills(Lawrence,1985). Other etiologies possibly responsible for dementia to be ruled out include: depression, nutritional disorders(e.g. chronic malabsorption syndrome, Vitamin B_{12} deficiency), infections(e.g. tuberculosis, encephalitis), toxic conditions(e.g. barbiturate intoxication, alcohol abuse), cerebral disease(e.g. slow growing cerebral tumors, normal-pressure hydroencephalus), endrocrine disorders(e.g. myxedema, pituitary insufficiency) (Schneck et al.,1982).

CHAPTER II

Review of the Literature

Since the early 1980s, research on patients with Senile Dementia of the Alzheimer's Type indicates an increasing awareness of the implications of the disease process. Approaches to provide support to caregivers have also received recent attention. Prior to 1980, studies on the need and use of support systems by primary caregivers of people with Alzheimer's disease have been rare(Elliot,1979; LaVorgna,1979). In 1979 Fuller, Ward, Evans, Massam, and Gardner in Great Britain wrote of the benefits of their two year support group for relatives of demented patients. They did not refer to Alzheimer's disease in their article but used the general term 'demented' and did indicate that they ultimately invited relatives of patients suffering from depression to join the group. Various other researchers have investigated community and family support for the physically and cognitively impaired elderly(Blumenthal,1979; S.J.Brody, Poulshock, & Masciocchi, 1978; Hausman,1979; Shanas,1979). However, the specific needs of families with a relative who has Alzheimer's disease were not addressed in these studies.

Although Alzheimer(cited in Kushnir,1982) first published his description of this disease in 1907 and individuals have apparently fallen victim to the disease for centuries(Torack,1983), the subject heading Alzheimer's was first entered into the Psychological Abstracts in the January/June 1973 issue. A hand search through the Psychological Abstracts and a computer search via this source indicated that articles on the subject of support systems for Alzheimer's caregivers and patients are few and far between. The Sociological Abstracts indicated no listing for Alzheimer's to date, and nothing relating to the topic under subject headings Dementia, Brain, or Organic Brain Disease is shown. The Cumulative Index to Nursing and Allied Health Literature showed no listing of the subject heading Alzheimer's prior to Volume 29,1984. Volume 28, 1983 showed a handful of articles listed under Dementia. Volume 24,1979 indicated two articles describing ap-

proaches to long term nursing care of Alzheimer's patients (Bartol, 1979; Burnside,1979) again listed under Dementia. The Education Index listed the subject heading Alzheimer's but then referred to the subject heading Brain for any articles on the subject. Volume 34 revealed one article to date (Wald,1983) relating to the topic at hand. The Social Work Research and Abstracts listed four articles under the subject heading Alzheimer's on the topic of support systems for Alzheimer's families. However, the subject heading Alzheimer's is missing in the 1982 index, and nothing prior to 1982 relating to this subject appears under Dementia or Organic Brain Disease. The Inventory of Marriage and Family Literature listed five articles since Volume 7, 1980. Prior to this date the subject heading Alzheimer's is absent from the index, and no articles relating to support systems and caring for family members with Alzheimer's disease appeared under the subject headings Dementia or Organic Brain Disease.

It is only in recent years, then, that health care professionals and clinical researchers have addressed the concerns of Alzheimer's victims and their families from a variety of perspectives. These include community support (Aronson & Lipkowitz,1981; Wald,1983; Ware & Carper,1982; Williams-Schroeder,1981), and institutional care (Palmer, 1983; Rader, Doan, & Schwab,1985; Ricci,1983; Ringland,1984). Most of the available research originates in the United States where the health care delivery system is different from that in Canada(Mace & Rabins,1981). U.S. studies suggest that required help, if available, is often too costly or inadequate(E.M.Brody, Lawton, & Liebowitz,1984; Goldberg,1985). Goldberg, director of research at the Massachusetts Rehabilitation Commission, writes:

> Under the current Medicare and Medicaid legislation homemakers services cannot be provided for Alzheimer's patients unless the patient's assets have been drained to $2000. This legislation is shortsighted because it compels many families who want to keep their elderly relatives at home to place them in nursing homes. In the long run, the federal and state government will pay exces-

sive fees to maintain Alzheimer's patients in nursing homes.p.126

On the other hand, E.M. Brody et al.(1984), researchers with the Philadelphia Geriatric Center, write:

> Increasing costs of institutional care for the aged have occasioned a variety of government cost containment measures. People with senile dementia of the Alzheimer's type(SDAT) will be the principal group to suffer from cutbacks. SDAT patients are usually eligible for Intermediate Care Facilities(ICFs), rather than Skilled Nursing Facilities(SNFs) and therefore for lower reimbursement. Because such patients require heavy care and are the ones most likely to be Medicaid dependent, nursing homes are provided with incentives to prevent admissions.p.1381
>
> In short, the SDAT patient and family are in a classic Catch-22 bind. Because of the scarcity of community support services (such as respite care, day-care, and in-home services), they get virtually no help in community living. They often cannot obtain institutional care, and in the main, will not be able to remain in hospitals beyond their need for acute care to the same extent as in the past. Their current situation is reminiscent of their no care situation during the late 1960s and 1970s.
>
> It is an inescapable conclusion that nursing home care for those with SDAT <u>should</u> cost more if they are to be cared for appropriately.p.1383

Kushnir(1982), professor of psychiatry at McGill University and author of one of the few articles originating in Canada, wrote of the Canadian situation:

> The growing geriatric segment of the population is putting a strain on existing resources. Obviously, social programs including medicare, old-age pensions, unemployment insurance, government-sponsored nursing homes and convalescent hospitals, and public education will come under more pressure as these trends continue. Who will pay for these programs in the future?p.18

As the number of people 65 years of age and over increases, so too does the prevalence of dementia. Dementia of the Alzheimer type is not part of the aging process but an organic brain disease which is now recognized as one of the five leading causes of death. Fifteen percent of people over 65 years of age suffer from a form of dementia of which only 15% to 30% are treatable(Kushnir,1982). "These statistics," writes Kushnir, "reflect a situation of near epidemic proportions in terms of actual numbers and the cost to society on the one hand, and far more significant, the tragedy of suffering, individual and collective, on the other hand"(p.18). The problems that these numbers convey is only just beginning to be acknowledged. Perhaps, Kushnir suggests, this delay has been the result of an intolerance of the dependent aged among the general population and an avoidance of difficulties associated with aging. Society is now becoming aware that there must be improvement in the quality of life for the aged "and that improvement in cognitive and physical well-being would result in more independence for them"(Kushnir,1982,p.18).

At onset people afflicted with dementia of the Alzheimer's type "bear the brunt of the disease emotionally"(LaBarge,1981,p.139). LaBarge found that emotional support through individual counselling can help patients accept their condition and perhaps help them, as cancer patients do, "to look to each day individually and live in altered frames of time with new perspectives"(1981,p.140). She noted that later, as the impairment progresses, and the patient benefits less from individual counselling, the family's stress intensifies. Then "there is evidence that group counselling can ameliorate their concerns"(LaBarge,1981,p.139).

D. Cohen, Kennedy, and Eisdorfer(1984) advised that afflicted individuals, to the extent possible, should participate in decisions about their care. If a diagnosis can be made in the early stages of the disease, patients would be in the best position to begin to deal with the impact of the disease upon their future. During the prediagnostic period, the primary needs of the patient are finding pro-

fessional help and making "sense of the mental changes that threaten his or her lifestyle"(D.Cohen et al.,1984,p12). D.Cohen et al. write that the actual experience of being diagnosed affects the self-esteem and coping ability of both family and patient.

Albert(1984) found that relatives generally do not understand the problems which people with this progressive dementia face. One example, she explains, is in the way some families respond to the memory problems which are typical of Alzheimer's disease. She has observed that some families think that by 'testing' the patient's memory daily, they can prevent the patient from becoming more forgetful and retard the progress of the disease. However, this often results in making patients very upset. Because they cannot perform well, they feel embarrassed and ashamed. Stress develops within the family which only further burdens an already difficult situation. Albert writes that since no one has helped the family members work with a patient's strengths, rather than concentrating on his or her weaknesses, the patient is being hurt rather than helped. She also advises that Alzheimer's patients almost always function more independently in an environment that is familiar and, unless necessary for reasons of health and safety, they should not be relocated. As well, a patient with limited cognitive capacities can be overwhelmed in a complex social environment. Here, Albert cautions, by manipulating the patient's environment in an attempt to help, the family member may again unintentionally cause him or her harm.

D.Cohen et al.(1984) tell how it requires a major effort, on the part of the patient with an irreversible dementia, to face each day and maintain some level of activity that optimizes function and minimizes stress. They write that some Alzheimer patients have reported being happy with a small number of activities while more stimulation is required by others. "In the early and middle stages of dementia, patients may express a desire to enjoy life as much as they can" (D.Cohen et al.,1984,p.13). In the later stages activities become more restricted, "but it is important to maintain a safe environment

for patients to continue to engage in as much activity as possible without injury"(D.Cohen et al.,1984,p.13).

Beam(1984) stated that, as unpleasant as it sounds, the family should seek legal counsel as soon as the diagnosis is known and prepare for the future before the patient becomes incompetent and cannot handle his or her own affairs. It is imperative, Beam noted, that knowledge of resources such as legal aid, financial assistance, day care, support groups, and respite care be made available to families.

Lyons(1984) discussed the ripple effect upon relationships and the gradual involvement of the entire family. There is strength and/or strain exhibited in the relationship between a primary caregiver and a supportive network. Lyons writes that the person primarily affected by changes in the impaired person is usually a spouse who is trying to find a new balance for himself or herself within the impaired family. He or she may be troubled by concerns of overprotection, underprotection, or denial from other members of the network.

Aronson, Levin, and Lipkowitz(1984) discussed the decline in family organization as a result of the gradual impairment of the victim's functional abilities and communication skills. They write that caring for an Alzheimer's patient imposes extensive emotional, physical, and financial burdens. "The most affected family member . . . is a spouse or significant other who assumes the major responsibility" (Aronson et al.,1984,p.339). As the illness progresses to a more advanced state, providing for the needs of the patient increasingly occupies this family member, who is left with little or no time for providing for his or her personal needs.

> Often feedback from the patient upon whom all this attention is lavished is almost totally absent, or, in some cases, the patient may respond with misinterpretations or negative feedback, such as paranoid accusations, despite the superhuman efforts of the caregiver.Aronson et al.,1984,p.341

These authors have found that because Alzheimer's disease resembles mental illness and perhaps fearing stigmatization, the family at-

mosphere may become one of whispered conversation, restricted spontaneity, and collusive silence(Aronson et al.,1984).

Glosser and Wexler(1985) write that the healthy family member, either by his or her own choice, or through the actions of others, often becomes progressively more isolated, precluding other intimate and social activities in order to provide full-time care for the afflicted individual.

Beattie(1984) discussed the caregiver's tolerance of the disability. She pointed out that judgement of disturbing behaviour may be different at different times of the day. For example, when a primary caregiver has had ample sleep and is less stressed, he or she is bound to be more tolerant and able to cope. Beattie, a geriatric internist and medical director of UBC's Alzheimer's Clinic, believes that whether the caregiver is a spouse, another family member, or a care facility, human interaction is the most important aspect of patient care.

Beattie and other professionals involved with Alzheimer's patients emphasize the importance of physicians being continually aware of what is happening at the interpersonal level with the patient, the primary caregiver, and the support network, as the disease progresses(Beattie, 1984; G.D.Cohen,1984; Heston & White,1983; Mace & Rabins,1981; Powell & Courtice,1983). They advise patients and families to continually question the quality of care they are receiving. Mace and Rabins(1981) counsel finding a physician who is able and willing to give the time and interest required to answer questions and closely monitor patients. Because of a diagnosis based on discounting other illnesses and conditions, Berman and Rappaport(1984) write that the initial task is helping "the patient locate a primary care physician who is accessible, knowledgeable about [dementia] and willing to spend the necessary time with the patient and family"(p.55). Heston and White(1983) write that people coping with dementia will meet several specialists each with a specific expertise. Further, these authors maintain, most will be competent and fully trained, but understanding what these medical per-

sonnel do and how they go about doing it will help patients and caregivers have the knowledge to plan and also recognize incompetent or superficial medical practice.

Beattie(1984) advises that physicians listen, even if that is all that can be done at a particular time. Physicians must help the caregiver consider and arrange for respite or time-out, e.g. day care, evening care, or night care in the home or a facility, and possibly weekend or weeklong care(Beattie,1984) Primary caregivers "need a 'prescription' to take care of themselves in order to continue their availability to the patient"(Gwyther & Matteson,1983,p.95).

Barnes et al.(1981) also found that spouses sacrificed their own health in committing their lives to caring for their ill mates. For example, instead of having a much needed rest, the spouse of one patient stayed 24 hours a day with him when he was being treated temporarily in a hospital. Goldberg(1985) writes that such commitment has the spouse "trapped with the patient in a 'no exit' situation"(p.128).

LaBarge(1981) concluded that when the primary caregiver is a spouse, losses are compounded because total responsibility for the marriage is gradually shifted to the healthy person. Perhaps the patient can no longer go to a store alone, drive a car, or even cook without supervision. Caregivers "need a constant monitoring system so that as the intellect changes proper measures are implemented to assure the health and well-being of the person with Alzheimer's disease"(LaBarge,1981,p.142). G.D.Cohen(1984) proposed that in arranging needed intervention, the mental health professional can influence a patient's ability to remain in the community and later help the resident and staff when the individual's home is an institution. The mental health professional experienced in working with cognitive disorders "could help the family or others review the patient's environment, identify potential threats to safety or sources of emotional stress and search for adaptations"(G.D.Cohen,1984,p.116).

Cantor(1983) and Storandt(1983) found that the primary concern of children and younger relatives, who were in the role of caregiver, was

obtaining necessary help. Storandt determined that caregivers' stresses in this area are severe, and most communities have few services to help them. She found that most caregivers relied on other family members, neighbours, and friends for an occasional night off. The strain, however, was still extreme. She advocated a respite program to relieve the primary caregiver for a day, a weekend, or a week. "Perhaps we cannot cure the person with Alzheimer's disease, but we can prevent the physical and mental collapse of those who bear the burden of care"(Storandt,1983,p.5). Cantor also concluded that for these younger relatives:

> . . . (most) . . . important is information on community resources and the availability of dependable, professionally supervised social services including assessment, case management, and, above all, in-home services.p.603

Elliot(1979) reported that it was primarily families who could provide care for their relatives with dementia. In 1980 Zarit, Reever, and Bach-Peterson concluded that the degree of caregiver's feelings of burden was significantly affected by the frequency of visits from other members of the family. Burden was less for the primary caregiver in situations where more visits were made to the patient by other family members. Glosser and Wexler(1985) concluded from responses to their support group evaluation, that, as well as formal support groups, intervention involving other members of the extended family would best help primary caregivers.

Zarit and Zarit(1982) discussed informal and formal support services for primary caregivers. Informal support is provided by friends and family through communicating an understanding of the situation and helping with the care. Formal support is provided by social service agencies. Of these services, Zarit and Zarit found that it is family meetings that have been most effective in reducing the primary caregiver's burden. The aims of the meeting are to identify the most pressing needs of the caregiver, to answer questions and solve problems with the family; in essence, to "bring the family's level of informa-

tion up to that of the caregiver"(Zarit & Zarit,1982,p.468) and thus develop or strengthen a family support system. These authors state that for a while individual counselling with the caregiver goes quite well. However, they conclude, a point arrives when reaching out to include the help of family and friends becomes the next treatment goal. "The timely calling of a family meeting may make the difference between termination . . . [of individual counselling with the primary caregiver] . . . with moderate gains and real success in ameliorating the problem"(Zarit & Zarit,1982,p.468). An example is given of a husband who was caring for his wife 24 hours a day. The family had no idea of how difficult it was for him until the discussion of her problems made them aware of how demanding caring for her was. Consequently, family members volunteered to take turns 'sitting' with their mother so that their father might have time away from her. "Whether it is a phone call, or actually sitting with the impaired person, the caregiver needs to know that his or her family understands what they are dealing with, and that their sympathy and support is there when it is needed"(Zarit & Zarit,1982,p.469).

However, Bennett(1983) noted that elderly people living near their children have no guarantee of a support system. The changes in living arrangements such as increased number of divorces, women working outside the home, and middle-aged people unable to support both their growing children and two pairs of elderly parents affects their ability to care for a relative who has an irreversible dementia. Goldberg (1985) wrote that the immediate caregiving family may feel abandoned by their extended family and isolated from their friends. While concern may be maintained by the extended family the primary caregiver's burden is infrequently shared with relatives who may, as the disease progresses, "shun the home lest the stigma of the disease spread to them"(Goldberg,1985,p.128). As Zarit and Zarit(1982) also pointed out, "Caregiving is a very lonely job, especially when friends no longer visit, which is usually the case"(p.469). It is perhaps for these very possibilities that Berman and Rappaport(1984) proposed

that a values issue that families needed to consider is whether decision making and care provision "should remain the domain of the family, or be shared with formal sources of support"(p.58).

Toseland, Derico, and Owen(1984) write that most referrals to social workers are usually late in the disease process when caregiver's capacities have reached their limit in maintaining their patient at home. While "casework" services can be of help in crisis situations such as these, Toseland et al. suggest that intervention (by social workers) when Alzheimer's disease is first established may be helpful in reducing the caregiver's burden and the rate of deterioration of the afflicted individual, stabilize a situation, and prevent premature institutionalization. These authors conclude that additional research is needed to test this hypothesis.

Lyons(1984) suggests that caregivers have to learn to ask for help and involve others. As both a social worker involved with Alzheimer families and as a spouse of a victim, he relates how drastically social life changes. People who find it difficult to interact with the patient withdraw. "But as I look back at some of the friends who withdrew . . . (they) . . . did so because they had no role"(Lyons, 1984,p.23). Lyons further suggests that the social worker help caregivers to organize their thinking so that they might be better able to express themselves in such situations as interviewing for help in the home. Gwyther and Matteson(1983) write, "Enlightened professionals offer more security to family caregivers than is generally acknowledged"(p.110).

Zarit and Zarit(1982) concluded that many caregivers feel guilty for having to ask for help. They often believe having someone else care for their relative is wrong. Spouses, in particular, feel that providing all the care is their responsibility and they should not expect their children to help. However, these authors have found that people are often able and willing to help, but don't know how to. Zarit and Zarit wrote that a therapist should determine the caregiver's beliefs about seeking help and then offer an alternative ra-

tionale. They suggest, as other authors have (Beattie,1984; Gwyther & Matteson,1983; Storandt,1983), that the importance of accepting help can be emphasized by impressing on the caregivers that, in addition to providing care to the Alzheimer's patient, they need to care for themselves.

Toseland et al.(1984) suggested that social workers interacting with the Alzheimer's family could help the family to co-ordinate and keep track of a schedule of services. They could organize a group meeting of informal caregivers shortly after service provision from formal sources has begun. This would serve as a forum for discussing caregiver's concerns and obtaining commitments to a plan of care for the patient. In some cases, they wrote, "a provider may have little experience in working with demented clients and may need some education or help in skill development to function effectively"(Toseland et al., 1984,p.219).

In addressing the need for respite care, Sands and Suzuki(1983) described their adult care center that was begun with the purpose of assisting families in caring for persons with Alzheimer's at home. The dual purpose was to create a meaningful situation outside the home for the afflicted individual, and support the caregivers by providing respite. Sands and Suzuki maintained:

1. That the home is preferred as a caregiving setting by many families with a member suffering from an Alzheimer's disorder;
2. That lack of insight on the part of the cognitively impaired person makes care stressful for the caregiver and leads to feelings of frustration and confinement on the part of the person afflicted;
3. That support from other family members provides relief but is frequently unavailable;
4. That persons in the early stages of a cognitively impairing illness are capable of involvement in meaningful activity;
5. That it would be desirable to create a day center which specialized in treatment of cognitive disorders.p.21

Paschke(1984) writes of one adult day care center where attending Alzheimer's patients respond well to the structured day and the one to one relationship provided by the occupational therapy students and volunteers. Paschke maintains that, although the disease itself cannot be treated, the devastating results can be slowed down and respite can be provided to families to help them keep the patient at home.

Beam(1984) has observed that there is an increase in restlessness if the patient has nothing left to do. "I become very concerned if I hear of an Alzheimer's patient left idle all day, although the family may do this without harmful intent"(Beam,1984,p.23). She writes that while some caregivers must work, some cannot afford day care, and others do not know that confusion increases if there is lack of sensory input. However, she advises that simplicity is "the key" and while repetition may bore families, raking leaves, vacuuming, and other repetitive motions make good use of perseveration. She cautions that Alzheimer's patients are confused and frustrated by sensory overload. Activities that require a lot of skill or are complex often terrify the Alzheimer patient.

Berman and Rappaport(1984) report that geriatric day care programs for Alzheimer's families can provide a source of reprieve for the primary caregiver. They write that if the patient can adjust to day care, the caregiver has an opportunity to work, earn money, and develop some social contacts outside the home.

Zarit and Zarit(1982) have found that a custodial bias has generally prevailed in the "management" of dementia patients. As the disease process cannot be stopped, physicians have little they can offer beyond the diagnosis. Also, according to Zarit and Zarit, there is a general belief that dementia patients cannot be cared for in their home. This belief, they suggest, is partly based on the pattern of decline observed in dementia patients who are in nursing homes. Yet "observations of patients kept in their homes suggest they do not always show as severe behavioural decrements as those in institutions" (Zarit & Zarit,1982,p.462). Due to their deficiency in new learning,

considerable difficulty will ensue for patients newly institutionalized learning new routines. Also, because they are having problems adjusting, they are frequently tranquillized. Zarit and Zarit write:

> . . . the drugs that are most commonly used, the phenothiazines, often exacerbate rather than alleviate problems. The bizarre behaviour of patients in nursing homes, including hallucination, agitation, motor difficulties, are frequently the reaction to the major tranquillizers, and are not usually observed in patients maintained at home on low or drug-free regimens.p.462

On the topic of drugs and the individual with Alzheimer's organic brain disease, Kushnir(1982) cautioned:

> The last thing a demented patient requires is further interruption of neurotransmission. . . . Care should be taken in prescribing other agents with central effects, for example alphamethyldopa for hypertension, benzodiazepines for anxiety or muscle spasm, and anti-parkinsonians for similar effects on neurotransmission. These agents can serve to further increase imbalances in levels of central neurotransmitters, and perhaps, in some cases, may be precipitating factors for dementia.p.21

Beam(1984) also advised that where the Alzheimer patient lives with the caregiver in his or her own home, "families who crave sleep . . . need to be cautioned against being quick to give sleeping medications: Sedatives can increase confusion and have other side effects" (p.232).

Storandt(1983) wrote that environments can be designed that promote the highest level of self-care and independence for individuals suffering from dementia. As well, support systems can be organized to lessen the load of the caregiver. She concludes that because of emotional and economic concerns, many families are reluctant to place an older relative suffering from Alzheimer's in an institutional setting until the deterioration has become severe. Zarit and Zarit(1982) also concluded that "contrary to public stereotypes, families do not readily abandon their older relative"(p.462). Nursing home placement, besides

adversely effecting the patient "does not relieve the burden of family members, but changes the type of burden they experience"(Zarit & Zarit, 1982,p.462).

Sands and Suzuki(1983) contend that nursing homes are still staffed and regulated as if all the primary needs of the Alzheimer patients were for physical care. As a reaction to the "wandering" behaviour of Alzheimer's patients, all but a few facilities have locked doors or grounds. This frequently results in the use of medication and/or restraints as a form of control which distresses family members. "Family members also seem to sense that the nursing home environment can be excessively restrictive"(Sands & Suzuki,1983,p.21).

Zachary(1984) states that it is important to let Alzheimer's patients set their own pace. She cautions against placing undue pressure on them or testing them. Most residents with Alzheimer's disease, she writes, are institutionalized because they are no longer able to function without a great amount of assistance and care. Many people believe that institutionalizing a person is a last resort and indicates a lack of hope. However, Zachary believes that something can be done for the patient within the institution by changing the environment for the patient rather than changing the patient to fit the environment. "Addressing their problems and providing them with a protected and structured environment can help maintain their current level of function"(Zachary,1984,p.61). In line with this, Sands and Suzuki(1983) advised that with a disease such as Alzheimer's that involves global impairment affecting all behaviours and that is medically untreatable, a remaining alternative is the creation of an environment which enables persons with such impairment to function at their highest level.

Zarit and Zarit(1982) and Toseland et al.(1984) also advised caregivers to allow dementia patients to do as much for themselves as possible. Because memory loss is a result of this disease, "disruption of the patient's usual habits may result in their no longer being able to perform that activity"(Zarit & Zarit,1982,p.467). One example is of the dementia patient forgetting how to dress himself or herself as a

result of being dressed by the caregiver. Toseland et al.(1984) wrote, "Caregivers should be cautioned not to ignore or dismiss what clients can do and try and assist them only to the extent that help is needed" (p.218).

Goldberg(1985) reported that while institutional care is required later in the disease process, home care with community support is preferable to early institution. Other authors noted that when the patient is institutionalized, a spouse who gives up a home or large apartment faces relocation at a time when his or her energies are depleted(Berman & Rappaport,1984; Kapust,1982). "Nursing home costs financially drain a couple and result in changed lifestyle for the healthy spouse"(Kapust,1982,p.87). Berman and Rappaport discussed the huge void that can be left in the caregiver's life as a result of the loss of the caregiving role. They have found that the caregiving spouse frequently needs help in letting go of the caregiving role and in becoming reinforced in former hobbies and activities. "A new fit between person and environment needs to be developed around wellness instead of illness"(Berman & Rappaport,1984,p.68).

Gwyther and Matteson(1983) wrote that phase three families have to be able to work through their grief over separation as the patient is moved into an institutional setting. "Families need reassurance that they continue to be important to the institutionalized relative for emotional, affectional meaning"(Gwyther & Matteson,1983,p.95). "Support groups can act as advocates for nursing home families"(Gwyther & Matteson,1983,p.110). In order to provide continuity, "nurses and social workers should be available for the caregivers throughout the illness and bereavement"(Gwyther & Matteson,1983,p.110).

Hayter(1982) found that after the death of the patient, some spouses have worked through their grief by continuing to visit an institution.

> Relatives seem to have a great deal to communicate with others who are interested in patients with Alzheimer's disease. . . . [and] . . . a surprisingly large number . . . expressed a sincere interest

in doing anything they could to further research and education pertaining to Alzheimer's disease.p.83

Goldberg(1985) and Mann(1985) emphasized that for effective planning, health care management must correspond to the stages of Alzheimer's disease. With the emphasis turning to community care and long term care, "every phase of the nursing process must include the consideration of the . . . [patient] . . . and family as a dynamic unit" (Mann,1985,p.9). Mann wrote that most caregivers suffer from chronic fatigue, depression, anger, guilt, loss of friends, and family conflict.

Teusink and Mahler(1984) describe what they found to be a series of normal responses to Alzheimer's disease. Initially there is a denial that anything is wrong, followed by overinvolvement with the patient as the family attempts to compensate for the illness. Then, when the compensation fails, anger occurs, which in turn creates a feeling of guilt. Finally there is acceptance of the problem or resolution. Teusink and Mahler equate this process with Kubler-Ross's (cited in Teusink & Mahler,1984) mourning process "which also consists of five stages: denial and isolation, anger, bargaining, depression, and acceptance"(p.153). In helping the caregiver to arrange for appropriate care, Teusink and Mahler caution professionals to differentiate between a normal and an overinvolved reaction. The relative can thus be helped to see if overinvolvement, rather than helping, is hindering the patient and the family. Teusink and Mahler note that anger within a family is frequently displaced to professionals who are trying to help. Mental health professionals, for example, must help families confront their anger and possible displacement of painful feelings resulting in accusations toward caregiving staff. As well "countertransference issues in staff must be similarly addressed, since the normal reaction to being accused of neglect is defensiveness or anger, either of which will further alienate the relatives"(Teusink & Mahler,1984,p.153). Finally, guilt may be felt for many reasons. These reasons include the possibilities that an evaluation of the pa-

tient was delayed, the lack of earlier attention to the patient, unexpressed anger from past events, or perhaps making decisions objected to by the patient. Only after the relatives understand the disease process and "have found sufficient resources within themselves and the community to deal with the increased burden of care for the patient . . . [and after having] . . . worked through their anger and guilt" (Teusink & Mahler,1984,p.154) and realized that the patient is no longer the person they knew, can acceptance come.

Having determined a need to investigate the burdens families endure in caring for relatives with Alzheimer's disease, Morycz's(1985) research focussed on whether strain experienced by caregivers of Alzheimer's patients would be strongly related to their desire to institutionalize the patient. Stress was defined as external to the caregiver and believed to result from the interaction of three sets of complex characteristics: (a) caregiver - relationship to patient, sex, race, attitudes, back problems, etc.; (b) patient - sex, age, wandering, incontinence, inability for self-care, etc.; and (c) environment - inadequate space, stairs, availability of social support, financial considerations, etc. Strain represented the affective, cognitive, and physiological changes within the caregiver brought about by the stress. Morycz proposed that the actual degree of family burden perceived as stressful by the caregiver is the resulting strain experienced. Thus, this strain may be moderated by the severity with which caregivers perceive actual stressors as presenting a problem.

> The amount of strain may not have any relation to the extent of patient disability. The degree of burden signifies how caregivers subjectively view and cope with the experience of giving care. This may be manifested by feelings of depression, anger, embarrassment, fatigue, perception of poor health, sleep disturbance, reduction of leisure and social activities, or simply in more generalized feelings that the present over all situation is not managed well, is unsatisfactory, and is burdensome. This strain experienced by relatives is actual family burden, and is

> critical in the desire of kin to institutionalize patients with senile dementia of the Alzheimer's type.Morycz,1985,p.333

Data for Morycz's(1985) study were collected from structured face-to-face interviews, and a follow up telephone survey of 80 families caring for patients with Alzheimer's disease who were living in the community. The majority of patients in this study were female (62 out of 80), white, and widowed. Their average age was 78 years.

Morycz(1985) reached the conclusion that for most caregivers, strain was the best predictor for the desire to institutionalize patients. This was significant for the entire group of 80 caregivers, and, when breaking down into the subgroups of whites, females, daughters (who represented 60% of all female caregivers and the most common relationship to the patient,N=35), spouses (who represented the next most common relationship to the patient,N=27), white daughters, and wives. However, strain was not a significant predictor for the other caregiving subgroups: males, blacks, white males, male spouses, and male nonspouses. The total number of black caregivers (N=18) was too small to break down into further analyses. Morycz suggests that it is in considering strain within the context of role that one can understand the difference between subgroups as exhibited in his sample. For males and white males, the best predictors for an increased desire to institutionalize were the patient's living arrangements (alone) and the patient's age (older). For male spouses (representing over 60% of all males), the functional deficits and physical labour required by patient behaviour were most predictive of the desire to institutionalize. The desire to institutionalize for black caregivers was best predicted by whether the caregiver argued with the patient.

For male caregivers, unexpected tasks or an unfamiliar role may not be a serious problem particularly if there is some other help available. There may be some role conflict that results in strain when the caregiving role first occurs for males. However, once there is a reconciliation of the new demands this strain is not a strong or significant factor in the desire for males to institutionalize. It

is when patients become older, live alone, or their caretaking requires more physical labour, and if the male caregiver has no other support available or it is difficult for him to get assistance, that the desire to institutionalize may be stronger(Morycz,1985).

On the other hand, women caregivers may feel guilty about not being able to provide care themselves and, because of traditional role perceptions, are reluctant to utilize help. "Thus, it is not only the availability of support that significantly relates to the experience and importance of strain in the desire to institutionalize, it is also the utilization of the support that is crucial"(Morycz,1985,p.352). Morycz contends that even when support is available to females they hesitate to utilize it. Since they would tend to be more homebound with the patient, females are frequently more exhausted and confined. Morycz concluded that not only the availability of some 'front-line help' for the patient (someone to stay with him or her) but also "the existence of back-up relief to be important associations with lower degrees of strain"(p.355). It would appear then, in Morycz's sample, that continued care of the Alzheimer's person at home is not necessarily based on the level of patient disability but also on the amount of burden experienced by the primary caregiver, which, in turn, is dependent on the amount of caregiving support available to that caregiver.

In line with Morycz's(1985) perspective of stress and strain is what Lynott(1983) referred to as a "working tension." Upon encountering questions of caregiving and of institutionalization, caregivers continually resolve this working tension "in relation to its social contingencies"(Lynott,1983,p.560). The decision to institutionalize the Alzheimer's disease patient is a concern for both caregivers and service providers. Both groups, wrote Lynott, are informed of coping and intervention strategies in what he called an "implied rational model" which appeared, as a "decisionmaking" process, to take care of the patient from the onset of the disease to an institutionalization. However, Lynott argued, a "rational model" of care-providing does not accurately represent the process of decisionmaking during the patient's

illness. "To 'speak the rational model' is to describe the reality of the decisionmaking process as generally occurring in some objective, linearly contingent, and optimizing manner"(Lynott,1983,p.562). This model is underpinned by the idea that the process of decline is regular; that there is a preordained course to behavioural changes, accompanied by fitting adjustments in care burden. To begin with, Lynott writes, the question of disease onset, which might typically inform on a consequent illness process, is subject to revised considerations when applied to Alzheimer's disease. As caregivers and noncaregivers discuss their experience in caring for patients, they perhaps remember an earlier indication of onset. The application of service provision to Alzheimer's families does not have a concrete beginning as a rational model implies. As well, as the disease progresses:

> Service providers are faced with a particular form of a general working tension in trying to relate measured burdens to given levels of decline. The tension is located in trying to rationally assess burden and tolerance when the latter are matters of ongoing interpretation.Lynott,1983,p.571

Behaviour seen as devastating or intolerable on one occasion may be regarded differently on another occasion when the caregiver perceives a void in his or her life were the patient in an institution. Differences in levels of expressed tolerance vary with the context in which they are considered. Lynott points out that practical ethical considerations further complicate tolerance. For example, at one time the caregiver might consider it a moral responsibility to care for the patient, with the thought that the patient would have done as much if the situation were the reverse. However, at other times the caregiver feels that all that can be done in providing care has been done and he or she must live too. Like social contingencies, Lynott writes, obligatory considerations confuse an attempt to describe the course of decisionmaking rationally. The factors for determining institutionalization are not arrived at in some conclusive way as suggested by the rational model. Even after institutionalization has been made, the

course of that decision is liable to reevaluation. In assisting caregivers in their decisionmaking, Lynott concluded, service providers like nurses, social workers, and physicians are better served by a model of intervention that did not view the disease as a process with required caregiving being predetermined and fixed.

Pagel, Becker, and Coppel(1985) wrote that the early symptoms of Alzheimer's disease often include mood and sleep disorders, agitation, paranoia, and belligerence. Being somewhat non-specific, these changes in behaviour cause concern to the spouse as he or she is unable to determine a definite cause to which to attribute them. However, as the disease progresses, with its profound motor and cognitive impairment, caregivers often experience a loss of control over major parts of both their spouse's behaviour and their own lives. The attempts by the caregiver to control the spouse's behaviour are often unsuccessful and frustrating, leading to feelings of guilt or shame and putting caregivers as a group at high risk for depression(Pagel et al.,1985).

Testing a prediction from the reformulated learned helplessness (RLH) depression model of Abramson, Seligman, and Teasdale(cited in Pagel et al.,1985), Pagel et al. hypothesized that the caregiver's perceived loss of control over important events, combined with the inclination to blame themselves for such events (internal attribution), positively related to the degree of their depression. The longitudinal study involved both an initial interview with 68 spouse caregivers and 10 months later a follow-up interview with 38 of the original 68. The caregivers were rated for (a) uncontrollability of important upsetting events relating to the spouse's illness, (b) internal-external causal attribution for those events, (c) depression, (d) hostility, and (e) anxiety. Pagel et al. concluded that an interaction of control (as perceived by the caregiver) with causal attribution (self-blame) was consistently predictive of depression. The results also indicated that, while hostility and anxiety related less consistently to the indices of loss of control and causal attribution than did depression, hostility was related to causal attribution. "Thus," Pagel et al.

wrote, "our data strongly underscore the importance of attending to subjects' perceptions of their situations, as well as to the objective aspects of their situations"(p.180).

Fiore, Becker, and Coppel(1983) attempted to separately assess the perceived supportiveness of the social network, and the upset or stress perceived when the wished for support was not provided. They proposed that, in comparison with upset in any other component of social support, upset in the area of cognitive guidance would be most predictive of depression in spouse caregivers to Alzheimer's patients. They also hypothesized that frequency of requesting support and of contact with members of the network would not as strongly relate to depression as would upset with unmet expectations of support. The five components of support included: (a) socializing: interacting with others in nonproblem oriented situations involving potential enjoyment; (b) tangible assistance: concrete assistance with tasks or chores; (c) emotional support: help which results in feeling understood, cared about, and sympathized with; (d) self-disclosure: revealing thoughts, feelings, and concerns; and (e) cognitive guidance: help which clarifies or furthers the subject's understanding of problems, e.g. information about the illness course or legal problems, putting situation into perspective. Upset in the area of cognitive guidance, these authors write, would result from being given unasked for or bad advice or from not being assisted with problem solving when seeking assistance.

Fiore et al.'s(1983) sample consisted of forty-four 45 to 85 year old caregivers of 11 institutionalized and 33 noninstitutionalized spouses with Alzheimer's disease. The social network consisted of a list each caregiver was required to complete by naming all those people important at that time in his or her life, whether liked or not, and with whom the caregiver had some sort of contact. No more than 15 people could be on the list and all members of the immediate family (children, spouse, parents) had to be included. The principal finding of this research was that "the extent of upset with the social network, either as a result of unmet expectations of support or of negative in-

put from important others, was the best predictor of depression in a chronically stressed population"(Fiore et al.,1983,p.433). Also, "as predicted, upset in the area of cognitive guidance showed the strongest relationship to depression"(p.435). It may be, Fiore et al. suggest, that the type of problems facing Alzheimer's caregivers is the reason why cognitive guidance was especially related to depression. They concluded that the severity of depression did not relate to the perception of network helpfulness. However, the degree of upset experienced in relationship to members of the network in any support area, either as a result of their not meeting the caregiver's expectations of support or their negative input, clearly related to the degree of depression. "Furthermore," Fiore et al.(1983) write:

> while the finding that upset in the area of cognitive guidance related most strongly to depression may or may not be specific to this population, it points up the need to recognize the multifaceted nature of support and to separately investigate its different components and the context in which they are being sought. p.436

Various authors have investigated the effectiveness of family support groups(Aronson, Levin, & Lipkowitz,1984; Barnes et al.,1981; Glosser & Wexler,1985; Kahan, Kemp, Staples, & Brummel-Smith,1985; LaVorgna,1979; Lazarus, Stafford, Cooper, Cohler, & Dysken,1981; Safford, 1980; Steuer & Clark,1982). The earliest of these studies by LaVorgna in 1979 reported that a group started for wives of institutionalized patients with Alzheimer's disease provided the incentive and support for grieving women to look beyond their grief and begin considering themselves. Many wives learned to cope and to grow when inspired through individual introspection, the example of other members, and the help of professionals. "Thus", wrote LaVorgna(1979), "their 'rehabilitation' legitimized their concerns and facilitated their mutual aid activities"(p.221).

In 1980 Safford concluded from a support group program, that, as society generally does not prepare people for the type of problems they

face "if confronted with mental impairment," most family members need help in learning to "assume a responsible role toward their impaired kin"(p.656). Family members, she writes, potentially represent the most caring and responsible element of support to the impaired individual. By providing them with the knowledge required for caring for their impaired relative's needs as well as their own needs and by providing a significant reference group, a premature institutionalization can be avoided.

Safford's paper discussed her program for families of the mentally impaired elderly. She did not specify Alzheimer's disease, however, she wrote that a delineation of what she referred to as the multiple and interrelated psychological, physical, and social causes of mental impairment in elderly people was regarded as fundamental to the work of participants. "The distinction between acute organic syndrome or chronic, reversible or irreversible, and the need for careful diagnosis was stressed"(Safford,1980,p.657).

Lazarus et al.(1981) found that while some families deny their relative's cognitive impairment, other families, unable to accept a diagnosis, search for a disclaiming evaluation. These relatives of hospitalized patients were invited to participate in a support group. The results of the group counselling sessions showed that participating relatives were less absorbed with their family, had an increased understanding of the illness and ways of communicating with the patient, and felt more control over their lives and destiny. Lazarus et al. concluded that it was necessary to look upon the Alzheimer's patient "as a member of a complex family network that is struggling to achieve mastery of a devastating life stress, maintain homeostasis and family cohesiveness [and at the same time begin] the painful process of preparatory mourning and disengagement"(p.356).

Barnes et al.(1981) reported that the support group they initiated served as a reservoir of knowledge and experience for caregivers by providing practical information about legal and financial problems and by helping with social and behavioural problems. To avoid leaving mem-

bers more depressed as a result of continual talk of sadness and depression and to assist them in balancing their losses and feeling more hopeful, the leaders tried to emphasize the curative aspects of group therapy such as education, inspiration, support, and universality. The authors added that the families in this group in Seattle, Washington "have been instrumental in establishing six additional groups with more than one hundred members"(Barnes et al.,1981,p.85).

During a study of Alzheimer's patients and their families, Steuer and Clark(1982) reported surprise at the similarity of need and depth of emotion expressed by relatives from varying backgrounds with patients at different phases of the disease. While the study was not directed toward social emotional needs, family members wanted to discuss past and current problems with patient management and understanding, medication, desire for treatment, physician indifference, and their own negative feelings. As families visited the clinic, the authors "encountered feelings of isolation, hopelessness, frustration, entrapment, burden, anger directed towards both the patient, other family members, and health professionals, guilt at negative feelings, and fear"(Steuer & Clark,1982,p.89). Relatives experienced fear of patient aggressiveness, further deterioration, and, particularly among adult children, fear of heritability for their children and themselves. Steuer and Clark organized three support groups for family caregivers using two different formats. One group consisted of open-ended and structured sessions and two groups were time-limited with closed membership. These authors concluded that: (a) the most effective format for the exchanging of information were closed groups with only moderate amounts of focussing and structuring; (b) the most cohesiveness in member support resulted when members' relationship to the Alzheimer patient were most similar, i.e. all spouses; (c) two factors that did not seem to impede the development of group cohesion or group work were whether or not the impaired relative was institutionalized and the severity of the dementia; and (d) for some caregivers, a support group of any sort may be counter-indicated.

Aronson et al.(1984) reported that, for many caregivers attending their community-based family/patient group program, the group meetings represented the first move to rebuilding contacts outside the family. While initially group members came to the program with a patient, should the patient become too ill, be institutionalized, or die, caregivers were encouraged to continue attending.

Glosser and Wexler(1985) write that the opportunity to learn from each other, share feelings, and receive support were reported to be some of the most beneficial aspects of participating family members' contact with each other. Also, they found that "it appears that the dissemination of accurate information by professionals in a discussion group format has a direct positive effect on the attitudes and feelings of participants"(Glosser & Wexler,1985,p.235).

In their research investigating the efficacy of a group program to relieve burden experienced by Alzheimer's caregivers, Kahan et al. (1985) obtained measures of levels of depression, family burden, and knowledge of dementia for 22 subjects participating in an eight-session program. Eighteen control subjects received no treatment. Results showed a significant decrease in total family burden for the experimental subjects, while a significant increase appeared to occur for control subjects. Experimental subjects showed a significantly greater improvement in knowledge of dementia than did control subjects. Kahan et al. concluded that a relatively short but intensive training program offering practical knowledge about Alzheimer's disease, and the opportunity for discussion, can have a positive effect in reducing levels of depression and perceptions of burden in caregivers. The study's results, write Kahan et al.(1985), "point to the benefits of this type of group as one component in a range of services needed by families as they struggle to cope"(p.669).

Many of the papers reviewed for the present research described the degenerative characteristics of Alzheimer's disease (e.g. D. Cohen et al.,1984; Gwyther & Matteson,1983; Schneck et al.,1982; Toseland et al.,1984), and discussed critical diagnostic issues (Beattie,1984;

Kushnir,1982; Lawrence,1985; Ware & Carper,1982). As well, authors acknowledged that the impact of the disease extends beyond the patient to each family member involved in the patient's care(Kapust,1982; LaBarge,1981). Models of psychosocial management and strategies for community based interventions to assist professionals involved with the patient and family were described by U.S. writers(Berman & Rappaport, 1984; G. D. Cohen,1984; Teusink & Mahler,1984; Toseland et al.,1984). Judging from their publications most writers would agree with D. Cohen et al.'s(1984) proposal that understanding the disease's manifestations would enable professionals to describe therapeutic interventions specific to the patient's needs. They would also agree with Aronson and Lipkowitz's(1981) earlier statement that the course of the patient's dementia "is affected not only by their age, medical complications, and the disease itself, but also by where and with whom they live"(p.568). However, these publications for the most part have globally addressed the issues of Alzheimer's disease, using case examples rather than empirical research to support what the authors believe to be necessary for the well-being of Alzheimer's families. Cantor(1983) cautioned against the danger of global solutions to caregiving interventions. The amount of disruption and stress is very different for different caregiving groups. She maintained that the closer the bond(i.e. spouse and children) the more stressful the caregiving role.

Other researchers have published theories on stress(Morycz,1985), variables of decisionmaking(Lynott,1983), perceived attribution and depression(Pagel et al.,1983), and stressfulness of unmet support expectations(Fiore et al.,1983). Morycz proposed that the intensity of burden within the family can best be predicted by the availability of social support to the caregiver. As the number of afflicted people grows it will be crucial, he maintains, for social policymakers and health care providers to be better informed about the social costs of giving care to a family member who has Alzheimer's disease. Yet, while cited articles (e.g. D. Cohen et al,1984; Gwyther & Matteson,1983; LaBarge, 1981; Mann,1985; Schneck et al.,1982; Toseland et al.,1984) discuss

patient/caregiver needs during the different stages of the disease, they involve the authors speaking from subjective knowledge gained through their own experience with Alzheimer's patients and caregivers, not through objective research on the requirement and availability of support services as perceived by different caregiving groups.

Various authors have described adult day care programs as a good resource for Alzheimer's patients and families(Beam,1984; Paschke,1984; Zachary,1984). These reports are again from experience and observation and not from results of controlled studies measuring the need for and benefits of day care for both patient and caregiver. While Sands and Suzuki(1983) wrote that day care provided relief to families as an alternative to institutionalization of the patient during the early and middle stages of the disease, they added that "this is an assumption based on the stated intentions of family members prior to 'discovering' day care rather than a direct comparison of our clients with nursing home patients"(p.23).

Researchers reported that informal support groups are an effective intervention for caregiving families(Aronson et al.,1984; Lazarus et al.,1981; Steuer & Clark,1982;). Some of these studies have had a small sample size (e.g. N = 4 to 8, Lazarus et al.,1981; Barnes et al., 1981; Steuer & Clark,1982). Other authors emphasized that the success of informal support groups depends on their inclusion within a much broader network of support services(Glosser & Wexler,1985; Kahan et al.,1985).

While some authors in the United States have looked at the financial strain of caregiving(Berman & Rappaport,1984; Goldberg,1985; Kapust,1982), E. M. Brody et al.(1984) reported that in failing to calculate the economic costs of caregiving, the present care system in the U.S. fails to provide adequately for Alzheimer's patients. In Canada, data on the Medicare system within the Canada Health Act, available and required health care delivery systems, and financial burden on individual Alzheimer families in varying locations, have yet to be collected.

Only five articles reviewed in this paper were published in Canada (Health and Welfare Canada,1984; Kushnir,1982; Lawrence,1985; Loder,1985; Lyons,1984). While these authors discussed the need for appropriate services during all three stages of the illness, their reports are not empirical studies containing data which investigates the expression of required services by samples of different caregiving groups.

In the present study, the question of necessary support will be investigated through the perceptions of primary caregivers addressing the various issues of caregiving from their own experiences. The purpose will be to accumulate from the perspective of individuals involved in the daily care of Alzheimer's afflicted persons, information on what services caregivers believe to be available and what they believe to be lacking. For example, are primary caregivers receiving the guidance they need in caregiving? Do caregivers have access to facilities (i.e. adult day care, live-in care facilities) they believe to be structured for the care of Alzheimer's patients? Are caregivers able to attend a support group?

More specifically, the purpose of this study is to investigate the following research questions:

1. Does the type of support required by the primary caregiver and the patient vary with the progress of the disease?
2. Does the type of support available to the primary caregiver and the patient vary with the progress of the disease?
3. Do the primary caregiver and the patient believe they are receiving proper guidance and are correctly informed about medical care from the professionals whose services they require?
4. Do the primary caregiver and the patient believe there is an increasing concern and public awareness about Alzheimer's degenerative brain disease?

CHAPTER III

Method

Sample

Subjects for the present research were primary caregivers (spouse, sibling, adult child, or friend) of patients afflicted with Alzheimer's disease. Names of subjects were obtained from membership and meeting lists of the Alzheimer Support Association, Victoria B.C. branch. The names of individuals who had contacted the Alzheimer's Information Centre, Victoria B.C. were also included. All subjects had the common characteristic of caring for an individual afflicted with Alzheimer's disease. While the aim of the research was in part to compare the circumstances of caregivers responding from three different situations: (a) Category One: Alzheimer patient and caregiver living together at home; (b) Category Two: Alzheimer patient living in a care facility and caregiver living at home; and (c) Category Three: Alzheimer patient deceased and caregiver living at home, the number of individuals applicable to each of the three categories and the phase of the individual patient's disease process were unknown by the researcher prior to receiving returned questionnaires. To maintain their anonymity, respondents were not required to sign their names to their returned questionnaires.

Of the 64 prospective respondents living in the Greater Victoria area, 52 returned a questionnaire. Two of the returned questionnaires were not answered at all. The number of actual respondents to the questionnaire, then, was 50 or 78.1% of those individuals contacted. Of these 50 caregivers, 32 (64%) were female, 18 (36%) were male. The majority of caregivers, 32 (64%) were between 61 and 80 years old. Of the 50 patients, 23 (46%) were female, 27 (54%) were male. The majority of patients, 38 (76%) were between 71 and 90 years old (see Table 1). All responding caregivers were related to the Alzheimer's patient. For all three categories, 41 (82%) caregivers were spouses of patients, 3 (6%) caregivers were siblings of patients, and 6 (12%) caregivers were the adult children of patients (see Table 2).

Table 1

Respondent Characteristics

	n	%
Caregivers (n = 50)		
Female	32	64
Male	18	36
Patients (n = 50)		
Female	23	46
Male	27	54
Age		
Caregivers (n = 46)[a]		
21 - 30	1	2.2
31 - 40	1	2.2
41 - 50	3	6.5
51 - 60	2	4.3
61 - 70	12	26.1
71 - 80	20	43.5
81 - 90	7	15.2
Patients (n = 48)		
51 - 60	3	6.3
61 - 70	7	14.6
71 - 80	27	56.3
81 - 90	11	23.0

[a]For category three caregivers:age in years at patient's death.

For individuals grouped in Category One (n = 16) the average patient age was 74.2 years with a range from 56 to 84 years. The average length of time since the believed onset of the disease for this category was 5.14 years with a range of 1.5 years to 11 years. The average length of time since medical diagnosis was 2.14 years with a range of 6 months to 9 years (see Table 3).

For individuals grouped in Category Two (n = 23) the average patient age was 74.5 years with a range from 64 to 90 years of age. The average length of time since the believed onset of the disease was 5.12 years with a range from 1 year to 12 years. The average length of time since medical diagnosis was 2.86 years with a range from 11 months to 11 years. The average length of living in a care facility was 1.71 years with a range from 3 months to 7 years (see Table 3).

For individuals grouped in Category Three (n = 11) the average patient age at death was 80 years with a range from 71 years to 89 years. The average length of time since the believed onset of the disease, recorded from the date of the patient's death, was 10.06 years with a range from 4 years to 20 years. The average length of time since the medical diagnosis, recorded from the date of the patient's death, was 4.25 years with a range from 1.5 years to 10 years. The average length of living in a care facility, recorded from the date of the patient's death, was 3.89 years with a range from 6 months to 8 years. The average length of time since the patient died was 2.37 years ranging from 2 months to 10.5 years (see Table 3).

Forty-five of the 50 caregivers reported living in the Greater Victoria area with the patient since the believed onset of the disease. The remaining 5 caregivers reported living in the Greater Victoria area with the patient for an average of one-half the length of time since the believed onset of the disease.

Procedures for Data Collection

Data for this study were collected from responses to mailed questionnaires sent to 64 persons who were or had been primary caregivers to family members afflicted with Alzheimer's disease. Consent for this

Table 2

Respondent Characteristics by Category

	Patient lives with caregiver (n = 16)		Patient lives in care facility (n = 23)			Patient deceased (n = 11)		
Patients	n	%		n	%		n	%
Female	7	44		13	57		3	27
Male	9	56		10	43		8	73
Caregivers								
Wife	9	56	Wife	9	39	Wife	8	73
Husband	6	38	Husband	7	30	Husband	2	18
Sister	1	6	Brother	2	9	Daughter	1	9
			Daughter	4	17			
			Son	1	4			

Table 3

Respondent Characteristics by Category and Phase

	Category One									Category Two								
	Phase 1			Phase 2			Phase 3			Phase 1				Phase 2				Phase 3			
Years	PA[a]	SBO[b]	SMD[c]	PA	SBO	SMD	PA	SBO	SMD	PA	SBO	SMD	LCF[d]	PA	SBO	SMD	LCF	PA	SBO	SMD	LCF
	72	4	2	82	10	-	83	4	2¼	78	1	1	⅓	74	1	-	-	83	4	1½	⅔
	79	3	1	73	3	2	73	6	3					73	6	2	1	58	12	11	5
				64	4	3½	72	7	3					75	4	1	1	73	12	4	3
				59	3	1½								64	7	4	¼	72	12	8½	5½
				75	9	-								78	10	2	1	71	8	7	7
				66	11	9								76	10	4	1	78	8	5	3
				56	1½	½								77	9	4	2	90	4	3	1
				65	3½	2½												74	5	1½	½
				82	10	1												69	7	11/12	5/12
				84	10	1												77	4	1½	5/12
				77	4	½												87	-	2	¼
																		69	7	6	5
																		67	8	8	½
																		77	5	5	1
																		73	11½	6½	1½
Average	75.5	3.5	1.5	71	6.2	2.3	76	5.6	2.7	78	1	1	⅓	73.8	6.7	2.8	1	74.5	7.6	4.7	2.3

[a] Patient's Age
[b] Since Believed Onset
[c] Since Medical Diagnosis
[d] Living in Care Facility

Table 3 continued

Respondent Characteristics by Category

Category Three					
Years	PA[a]	SBO[b]	SMD[c]	LCF[d]	SD[e]
	71	9	1½-2	3	10½
	-	-	-	-	6½
	73	12	10	5	¼
	79	8	-	⅔	4
	87	11	2	2 5/12	⅓
	-	-	-	-	2
	72	12½	-	½	1
	89	20	-	8	1/6
	80	4	2½	3½	1/6
	87	8	5	2	1
	82	-	-	-	¼
Average	80	10.06	4.25	3.89	2.37

Note. All years recorded from the date of the patient's death.

[a]Patient's Age
[b]Since Believed Onset
[c]Since Medical Diagnosis
[d]Living in Care Facility
[e]Since Deceased

study was received from the Victoria Alzheimer's Support Association after an explanation of the research and its purpose was given at one of the group's meetings. Voluntary participation of the subjects was furthered assured by a phone call to prospective subjects explaining the research and inquiring whether the individual would, as a primary caregiver, consent to receive a mailed questionnaire. Upon receiving the mailed questionnaire, which contained an explanatory covering letter (see Appendix A), the primary caregiver again was free to choose whether or not to respond to and return the questionnaire.

The researcher-made questionnaire was designed to investigate four research questions (see page 39) through the responses of primary caregivers both from their own situations and as proxy respondents for the Alzheimer afflicted individual. All subjects were requested to respond from their memory or experience with the patient during the phase of the disease referred to in each question.

The 10 page questionnaire (see Appendix B) included a combination of yes/no questions, open-ended questions, and brief checklists for some of the demographic information. Prior to distribution, the questionnaire was proofread for ease of comprehension by three members of the Alzheimer Information Centre and the Alzheimer Support Association in Victoria and a fourth individual who was a member of the Support Association.

A mailed self-administered questionnaire was chosen to both assure anonymity to respondents and to allow them to, as Sudman and Bradburn (1983) write of mailed questionnaires, "study the material in detail at their convenience"(p.272). Following Sudman and Bradburn's suggestion, a booklet format was used with individual question categories and answer space placed on each page except for the back cover, page 10, which was open to allow respondents room to write further comments apropos any question or other opinions they might want to make.

All questionnaires were mailed to prospective subjects within a four day period. The covering letter requested the completed questionnaire be returned in an enclosed stamped, researcher addressed envelope by a given date which was a month from the mailing date. This allowed

a week for the questionnaire to reach the respondent by mail, two weeks for the respondents to complete the questionnaire, and a week for the document to be returned to the researcher by mail. The covering letter also suggested hours of the day when the researcher would be available by phone for further explanation of any question.

CHAPTER IV

Results

An analysis of the data will compare responses relative to the phase of the disease process in which the patient is described as being. In the case of Category Three respondents, all patients are described as having progressed to, and being in, Phase Three at the time of death. For a description of the phases of the disease see Appendix B.

A comparison will also be made between the three categories of caregivers: (a) Category One: patient and primary caregiver living at home; (b) Category Two: patient living in a care facility and primary caregiver living at home; and (c) Category Three: patient deceased and primary caregiver living at home. All caregivers were requested to respond in the way they felt described their situation when the patient was in the phase of the disease referred to in the question. Tables describing the subjects and the number of years involved in caregiving are given in Chapter III (see Tables 1, 2, and 3).

Research questions one and two will be addressed with regard to five areas of concern (a) Activities and Day Care, (b) Home Help, (c) Support Groups, (d) Legal Services, and (e) Institutions. Data addressing the third and fourth research questions will follow.

Research Question One: Does the type of support required by the primary caregiver and the patient vary with the progress of the disease?

Research Question Two: Does the type of support available to the primary caregiver and the patient vary with the progress of the disease?

Activities and Day Care

Research Question One: requirement of support. (see Table 4)

H.2 Would your Alzheimer person make use of an adult day care facility?

Of the low number of Phase One caregivers (3), two responded "yes" to this question. Of Phase Two caregivers, only 18.6% of the respond-

ing caregivers believed "yes," while caregivers of patients who were in Phase Three showed a marked increase to 52% of respondents to the item checking "yes" to the possible use of a day care facility. It could be that, having observed the further deterioration with the disease's progression, caregivers of patients in this later phase believed that provision of a day care center would have benefitted their patient while he or she was still functionally able to enjoy the activities. As can be seen in Table 5 (in response to H.3), 9 of the responding Phase Three caregivers, compared with 3 of the responding Phase Two caregivers, checked "yes" to their patient attending or having attended an adult day care facility.

Between categories, 40% of those caregivers in Category Three where the patient was now deceased, with hindsight, checked "yes" to the possible use of a day care facility. Category One, where the patient and primary caregiver lived at home, had the lowest percentage (28.6%) of responding caregivers checking "yes" to this item. The greatest number of respondents within Category One were those caring for patients in phase two of the disease, and, interestingly, 9 out of 10 replied "no," they believed the patient would not make use of a day care facility. As seen in Table 5 (in response to H.1) all 9 responding caregivers with patients in this phase at home, checked "yes" to the availability of an adult day care facility within a reasonable distance. This particular response to H.2 (concerning possible use of a day care facility) could imply that the known facility did not provide for, or accept, individuals afflicted with Alzheimer's disease. Another reason for this high negative response to the possible use of a day care facility could be because the patient did not want to attend. Again looking at Table 5, 9 of the 11 caregivers responding to H.3 in this phase and category checked "no" to actual patient attendance at an adult day care facility. Yet, in response to H.5(b) and H.6(b), high percentages (70% and 80% respectively) of these Category One, Phase Two caregivers reported difficulties with provision of patient activities during phase one and their present phase (two).

The highest percentage of caregivers checking "yes" to the pos-

Table 4

Responses to Research Question One Regarding Activities and Day Care

Item	Respondents to item			Category					
				One		Two		Three	
	n	%		Yes	No	Yes	No	Yes	No
H.2	43	86%		(14/16)[a]		(19/23)		(10/11)	
			Phase One	1	–	1	–	–	–
			Phase Two	1	9	2	4	–	–
			Phase Three	2	1	7	5	4	6
			Total	4	10	10	9	4	6
H.5(a)	47	94%		(15/16)		(22/23)		(10/11)	
			Phase One	1	1	1	–	–	–
			Phase Two	7	3	3	3	–	–
			Phase Three	3	–	12	3	10	–
			Total	11	4	16	6	10	0
H.5(b)	41	82%		(15/16)		(17/23)		(9/11)	
			Phase One	1	1	1	–	–	–
			Phase Two	7	3	3	2	–	–
			Phase Three	2	1	7	4	6	3
			Total	10	5	11	6	6	3
H.6(a)	46	92%		(15/16)		(20/23)		(11/11)	
			Phase One	–	1	–	–	–	–
			Phase Two	–	11	1	6	–	–
			Phase Three	–	3	2	11	2	9
			Total	0	15	3	17	2	9
H.6(b)	41	82%		(14/16)		(18/23)		(9/11)	
			Phase One	1	–	–	–	–	–
			Phase Two	8	2	6	–	–	–
			Phase Three	3	–	9	3	7	2
			Total	12	2	15	3	7	2
H.7	43	86%		(15/16)		(19/23)		(9/11)	
			Phase One	–	2	–	1	–	–
			Phase Two	4	6	2	4	–	–
			Phase Three	1	2	7	5	3	6
			Total	5	10	9	10	3	6

[a]Numbers in parentheses indicate number of respondents to item/respondents within category.

sibility of a patient using a day care facility were those caregivers in Category Two (52.6%), where the patient now lived full time in a care facility. This response could suggest that these caregivers see their patient occupied to some degree in the facility they live in and perhaps would have kept the patient living at home with them longer if an activity center had been available for Alzheimer's patients on an outpatient basis and if the patient had consented to attend such a facility.

H.5(a) Is (was) your Alzheimer person able to occupy himself or herself with some meaningful on-going activities during the first phase of this illness?

Two of the 3 responding caregivers of Phase One patients checked "yes." Of the 16 responding Phase Two caregivers, 62.5% reported "yes." Of the 28 responding Phase Three caregivers an even greater percentage (89.3%) checked "yes," the patient had been able to occupy himself or herself during the first phase of the illness.

By category, it is interesting to note that the similarity in percentages of responding caregivers for Category One (93.8%) and Category Two (95.7%) continues in a comparison of percentages of caregivers responding "yes," 73.3% in Category One and 72.7% in Category Two. However, Category Three shows an increase to 100% of responding caregivers recalling "yes," the patient had been able to occupy himself or herself with some meaningful on-going activity during the first phase of Alzheimer's disease.

H.5(b) Did providing meaningful diversional activities present an on-going problem during the first phase?

Contrary to responses to H.5(a) where 37 out of 47 (78.7%) of the responding caregivers had reported "yes" to the patient being able to occupy himself or herself during the first phase of the illness, 27 out of 41 (65.9%) of the caregivers responding to H.5(b) reported "yes," providing meaningful diversional activities during the first phase of the illness had presented a problem. Little fluctuation showed in caregiver responses by phase with 66.6% of Phase One caregivers, 66.6%

of Phase Two caregivers, and 65.2% of Phase Three caregivers replying "yes" to the question.

The results again showed a consistent pattern of agreement by category whereby 66.6% of those caregivers with the patient living at home (Category One), 64.7% of those caregivers of patients now living in a care facility (Category Two), and 66.6% of those caregivers whose patient was now deceased (Category Three) checked "yes," providing meaningful diversional activities had presented a problem during the first phase of the illness.

An observation to be made here is the remarkable similarity in percentages of caregivers, whether grouped by the patient's disease phase or living arrangement (category), reporting having experienced difficulties with the provision of meaningful diversional activities during the first phase.

Thus, while the patient was perhaps functionally able to occupy himself or herself, as reported by 78.7% of all caregivers responding to H.5(a), two-thirds (65.9%) of all caregivers responding to H.5(b) had difficulty providing meaningful activities. These responses suggest that occupational therapy and settings providing activities suited to individual interests are required by Alzheimer victims as the disease progresses through the first phase.

H.6(a) Is (was) your Alzheimer person able to occupy himself or herself with some meaningful on-going activities during the second phase of this illness?

The total number of respondents for Phases Two and Three was 45, of whom only 5 answered "yes," the patient had been able to occupy himself or herself with some meaningful on-going activities during the second phase. There were no "yes" responses from Phase One caregivers although 1 caregiver whose patient may have been exhibiting symptoms of phase two responded "no."

By category, 100% of the caregivers responding with the patient living at home (Category One) checked "no" to the patient being able to occupy himself or herself during the second phase of the illness.

A very small number, only 3 (15%) of the 20 caregivers responding in Category Two checked "yes" to H.6(a), and only 2 (18.2%) of the 11 caregivers in Category Three checked "yes."

For all caregivers responding to this question only 11% reported "yes." This is in marked contrast to caregiver responses to H.5(a) where 78.7% checked "yes" for the first phase. It can be implied that as the disease progresses into the second phase, afflicted individuals are less able to independently occupy themselves with meaningful activity.

H.6(b) Did providing meaningful diversional activities present an on-going problem during the second phase?

A consistent increase can be observed in percentages of respondents reporting an on-going problem in providing meaningful diversional activities during the second phase, compared with the results for H.5(b) which concerned the first phase.

The 1 Phase One caregiver responding to H.6(b) checked "yes." Of Phase Two caregivers, 87.5% of those responding to the item compared with 72.2% of Phase Three caregivers responding to the item checked "yes," providing meaningful diversional activities presented an on-going problem during the second phase.

In Category One, where the individual afflicted with Alzheimer's disease lived at home, 85.7% of caregivers responding to the item checked "yes." Where the Alzheimer afflicted individual lived in a care facility, 83.3% of Category Two caregivers responding to the item checked "yes." Where the Alzheimer afflicted individual had died, 77.7% of Category Three caregivers responding to the item, remembered "yes," providing activities during the second phase of the disease had been a problem.

Thus, in line with the responses to H.6(a) are the responses to H.6(b) which again indicate an increase in the problem of patient recreation as the disease progresses. The responses to H.6(a) and H.6(b) suggest that activities and environments specifically planned for individuals afflicted with Alzheimer's disease are required both for the patients and their caregivers, to provide settings where the

former may function to the best of their abilities, and to assist the latter with on-going caregiving and respite.

H.7 Do you believe that your Alzheimer person would benefit (would have benefitted) from an on-going self-help group with other Alzheimer's patients during the first phase of this illness?

To the question of whether a self-help group during the first phase of the illness would have benefitted the patient, only 17 caregivers out of 43 over-all responding to the item checked "yes" for the patient. Two Category One, Phase Two caregivers wrote "not sure" and "possibly." One Category Two, Phase One caregiver wrote "with coaxing." All 3 possible respondents for Phase One patients checked "no." However, 37.5% of respondents for Phase Two patients checked "yes," while 45.8% of those respondents for Phase Three patients believed "yes," the patient would have benefitted from a self-help group in the first phase of the illness. These results suggest that, in retrospect, an increasing number of caregivers considered such a patient group would have been of benefit in the early stages of the disease.

Representation by category shows a slightly different picture. It is in Category Two, where the patient is living in a care facility, that the highest percentage of respondents (47.4%) considered "yes" to a patient self-help group in phase one. Category One and Category Three coincidentally show the same results with 33% of the responding caregivers in each case checking "yes."

H.8 Have you any opinions you would like to share with regard to finding appropriate activities and recreation for an individual afflicted with Alzheimer's disease?

Caregivers' responses to this open-ended question re opinions about appropriate activities and recreation for an individual afflicted with Alzheimer's disease illuminated the difficulties as the disease progressed. Individuals responding from all three categories wrote:

Category One: patient and primary caregiver living at home.

Phase One:

"Has to follow me everywhere."

Phase Two:

"My husband is not interested in any activities."

"My husband was not interested in any diversion so no problem. I have wondered whether or not rug hooking might be suitable or some such quiet pursuit - this is not much help to you. I have trouble interesting him in a walk in the garden to pick flowers for the house. And he loved flowers."

"Getting harder and harder to suggest anything to occupy himself with."

"This subject is somewhat difficult to deal with as each patient would have different interests. In our case the only interest of the patient is a car ride. She is really not interested in any activities or recreation."

"This is a major problem in my opinion. I am afraid of damaging the patient's self-esteem."

"My patient is blind and almost deaf and he has not been told he has Alzheimer's as his doctor does not feel he could accept it."

"I'm his only source of entertainment. He has difficulty filling his time except for minor gardening. He always wants to be on the go in the car or shopping. I'd appreciate 2 or 3 hours at home by myself 3 times a week or more."

Category Two: patient living in a care facility and primary caregiver living at home.

Phase Two:

"He bowled for a while, now he just watches television. If he is led into activities and helped with them, he would be happier doing something."

"(husband newly in care facility) I still do not know if we have done the right thing. If we had lived in a house we maybe could have hired home help - but the apartment was too confining - no longer reads or watches T.V. so we were out all the time - says to me he doesn't like the hospital, but he takes part in activities and has visits with friends. We will give it time and see how it works out."

"I have not been involved in day care endeavors for Alzheimer's so I cannot offer suggestions for or against. However, I have an older friend whose husband suffered from this ailment and the 24 hour care she was giving him took a severe toll on her health. In her case day care was an untold blessing."

Category Three: patient deceased and primary caregiver living at home.

"My husband was not a 'joiner.' He was content to be with me and share in my interests after he became ill. He was conscious of the gradual deterioration in mental ability and trusted in my ability to cope."

"I found that just leaving articles around that he could pick up and carry around seemed to satisfy (junk mail, etc.). He seemed to want something in his hands and it kept him from getting into other things."

"Before his illness, my husband enjoyed an active social life and was involved in several boards and committees. One of the first signs of his illness was his withdrawal from all groups."

Research Question Two: availability of support. (see Table 5)

H.1 Is there an adult day care facility available within a reasonable distance to you?

Forty-one out of 45 responding caregivers over-all checked "yes" to this item. By phase, the 4 respondents who checked "no" were caregivers of Phase Three patients. By category, 3 of the "no" respondents were caregivers of patients who lived in a care facility (Category Two), and the fourth "no" response came from Category Three.

Therefore, a very high percentage (91%) of caregivers for all categories, caring for patients in all three phases of the disease's progression, reported knowing of an adult day care facility within a reasonable distance to them. However, as is indicated by the responses to H.3, the availability of such a centre does not presume attendance by the Alzheimer patient.

H.3 Does your Alzheimer person attend an adult day care facility?

Of the 48 caregivers from all three categories responding to this item, only 13 replied "yes," their patient attended or had attended a day care facility. By phase, the highest percentage (33.3%) of patients reported to have attended a day care facility were to be found in Phase Three. Recalling results to H.2, it was in Phase Three that the highest percentage (52%) of respondents perceived, in retrospect, that the patient would have made use of a day care facility (see Table 4). Of Phase Two respondents, only 16.6% answered "yes" and in Phase One, 1 out of the 3 caregivers checked "yes" to H.3, the patient

Table 5

Responses to Research Question Two Regarding Activities and Day Care

Item	Respondents to item			Category					
				One		Two		Three	
	n	%		Yes	No	Yes	No	Yes	No
H.1	45	90%		(13/16)[a]		(22/23)		(10/11)	
			Phase One	1	-	1	-	-	-
			Phase Two	9	-	7	-	-	-
			Phase Three	3	-	11	3	9	1
			Total	13	0	19	3	9	1
H.3	48	96%		(16/16)		(22/23)		(10/11)	
			Phase One	1	1	-	1	-	-
			Phase Two	2	9	1	6	-	-
			Phase Three	2	1	4	10	3	7
			Total	5	11	5	17	3	7
H.4(a)	22	44%		(6/16)		(12/23)		(4/11)	
			Phase One	1	-	1	-	-	-
			Phase Two	3	-	2	-	-	-
			Phase Three	-	2	7	2	3	1
			Total	4	2	10	2	3	1
H.4(b)	21	42%		(8/16)		(10/23)		(3/11)	
			Phase One	1	-	-	-	-	-
			Phase Two	4	-	1	1	-	-
			Phase Three	1	2	5	3	3	-
			Total	6	2	6	4	3	0

[a]Numbers in parentheses indicate number of respondents to item/respondents within category.

actually attending a day care facility.

By category, a slight similarity appears between the percentages of respondents whose patient lives at home (Category One) and those whose patient has deceased (Category Three), with 31.3% of the responding caregivers in the former and 30% in the latter checking "yes" to patient attendance. The actual numbers are very low with 5 and 3 patients, respectively. In Category Two, only 22.7% of the responding caregivers reported that their patient had attended a day care facility. Yet, it is in this group that the highest proportion (52.6%) believed the patient would make use of such a facility (see H.2, Table 4).

A comparison between what might be required, as suggested by Category Two responses to H.2, and what is available, as suggested by responses to H.3, as well as the over-all low percentage of patients (27%) reported as actually having attended a day care facility, could imply that there are not enough adult day care facilities available that accept individuals with Alzheimer's disease. Or, perhaps the need for adult day care facilities is such that there is a waiting list with the result that when the Alzheimer person's name came up to begin attending, the disease might have progressed to a point where he or she was no longer able to take advantage of the situation.

H.4(a) Does this adult day care facility offer appropriate individual activities for Alzheimer patients?

Perhaps resulting from the low number of caregivers (13) who reported patient attendance at an adult day care facility (see H.3), only 22 of the possible respondents answered question H.4(a). Nine of these caregivers are perhaps then not necessarily responding from the experience of the patient actually attending a day care facility but responding with what they perceived to be the situation in the facility they knew of.

Seventy-seven percent of the responding caregivers believed "yes" to available appropriate individual activities for Alzheimer patients. By phase, all of the responding caregivers (7) for Phase One and Phase Two believed "yes." However, the majority of respondents to this question were Phase Three caregivers of whom one-third (5) believed "no,"

the activities available in the facility they knew of were not suited to the individual Alzheimer patient.

By category, the majority of responding caregivers in each of Category One (66.6%), Category Two (83.3%), and Category Three (75%) perceived "yes," the known day care facility provided appropriate individual activities for people afflicted with Alzheimer's disease. This is the reported experience of comparatively small percentages of caregivers when considering the entire group. Of the possible 50 respondents, 25% (4) of the Category One caregivers, 43.5% (10) of the Category Two caregivers, and 27.3% (3) of the Category Three caregivers answered "yes" to H.4(a), appropriate individual activities for Alzheimer patients.

H.4(b) Does this adult day care facility offer appropriate group activities for Alzheimer's patients?

As in H.4(a), a low number of caregivers (21) responded to H.4(b). Seventy-one percent of these believed "yes" there were available appropriate group activities for Alzheimer's patients. By phase, 6 of the responding caregivers in Phase One and Phase Two combined believed "yes," while the 7th respondent in Phase Two, Category Two checked "no." Again, the majority of respondents by phase were in Phase Three (14) where 35.7% reported "no."

By category, the majority of responding caregivers in each of Category One (75%), Category Two (60%), and Category Three (100%) perceived "yes," the known day care facility provided appropriate group activities for individuals afflicted with Alzheimer's disease. This again is the reported experience of comparatively small percentages of caregivers when considering the entire group. Of the possible 50 respondents, 37.5% (6) of the Category One caregivers, 26.1% (6) of the Category Two caregivers, and 27.3% (3) of the Category Three caregivers answered "yes" to H.4(b), appropriate group activities for Alzheimer patients.

H.8 Have you any opinions you would like to share with regard to finding appropriate activities and recreation for an individual afflicted with Alzheimer's disease?

Some caregivers expressed their attempts to make available activities that the patient appeared to be interested in; other caregivers described day care and institutional activities.

Category One: patient and primary caregiver living at home.

Phase Two:

"I have found suggesting a walk by the sea - or a car drive helpful to my husband - when he is disoriented, a walk by the sea always helps."

"gardening"

Phase Three:

"Using [day care] facility now but often curtailed as she disturbs others at the Geriatric Day Hospital who are normal. Attendance restricted to a four hour period. Object to give caregiver a rest. As my wife's condition became known, friends and neighbours ceased to contact us as frequently as before. In an attempt for her to continue contact with individuals, I managed to arrange for her to attend Oak Bay Lodge day center for one day a week. Later after an extensive examination at the Royal Jubilee Hospital, Dr._____ arranged for my wife to attend the Geriatric Day [Care] at the hospital 3 days a week. But as Dr._____ stated, this was for my benefit as sole careperson. I appreciate this and depend on it greatly."

Category Two: patient living in a care facility and primary caregiver living at home.

Phase Two:

"In my opinion the activities and recreational facilities encouraged by the management and staff at the Geriatric Division could be very helpful to any individual afflicted, however much would depend on the personality of the patient, e.g. willingness to participate - hesitancy to join in with strange people - unawareness of the meaningfulness of the activity."

"At present her one pleasure is walking, so I take her for a walk three times a week."

"My husband and another Alzheimer patient seem happy looking at picture type magazines and books (British Columbia pictures). This seems to interest them and my husband loves a magazine to fold and fold! I wonder sometimes if they would like to paint and colour with crayons - will try one of these days and let you know. The various Canadian Legion clubs bring them on bus rides - sometimes for lunch and din-

ner and they enjoy this very much."

Phase Three:

"Walking - discussion of things on walks."

"Walking in attractive surroundings."

"Enjoys tea and church service in the hospital."

"On nice days take outside for walks, etc. That seems to be very important to my Mother."

"Walking in attractive surroundings. The lack of companionship is devastating. We have been married for 40 years and I am beginning to see why they call this disease 'The 10,000 day funeral'."

Category Three: patient deceased and primary caregiver living at home.

"Enjoys having pictures of family on walls. Also family visits. Seems to like radio and T.V. Enjoys visiting former home by bus. Enjoys walks in wheelchair on street and to shopping areas for simple treats. Enjoys tea and church services in the hospital."

Less than one-third (26%) of the caregivers in the entire sample reported experience with an adult day care facility (see H.3). In Category One, where the patient lived at home and 13 respondents reported an adult day care facility within a reasonable distance (see H.1), only 5 caregivers reported that the patient actually attended a day care facility (see H.3). This response could suggest that the facilities referred to in H.1 were not available to individuals suffering from a progressive cognitive impairment like Alzheimer's disease or perhaps became available too late in the disease's progression for the applicant to benefit from the activities.

The high negative response to day care attendance by Phase Three, Category Two respondents and Category Three respondents (see H.3) compared to the high affirmative responses to H.1 by these two groups of caregivers could again imply that a day care facility providing for individuals with Alzheimer's disease was not available when the afflicted person could have had use of it.

Home Help

Research Question One: requirement of support.(see Table 6)

Table 6

Responses to Research Question One Regarding Home Help

Item	Respondents to item			Category					
				One		Two		Three	
	n	%		Yes	No	Yes	No	Yes	No
J.6	37	74%		(12/16)[a]		(18/23)		(7/11)	
			Phase One	-	1	-	1	-	-
			Phase Two	5	3	-	5	-	-
			Phase Three	1	2	-	12	4	3
			Total	6	6	0	18	4	3

[a]Numbers in parentheses indicate number of respondents to item/respondents within category.

J.6 Are you in need of home help?

Thirty-seven caregivers responded to this question. By phase, the 2 responding Phase One caregivers checked "no." Less than one-half (38.5%) of the responding Phase Two caregivers checked "yes." However, it is notable that these latter caregivers (5) reporting need of home help are in Category One with the patient at home. Although a low percentage (22.7%) of the responding Phase Three caregivers answered "yes" to J.6, 4 of these caregivers reporting need represented over one-half (57.1%) of those responding in Category Three and recalling their situation before the patient was deceased. The 5th Phase Three caregiver answering in the affirmative was in Category One.

By category, 50% of the caregivers responding with the patient living at home (Category One) checked "yes" to requirement of home help. Over one-half (57.1%) of those responding caregivers recalling their situation when their patient was alive (Category Three) checked "yes" to requirement of home help. However, where the patient was now living full time in a care facility (Category Two), all the responding caregivers (18) checked "no" to need of home help.

J.7 A major problem for families during the second phase of this illness is home management. Supervision and constant care may now be required. It has been found that primary caregivers tend to carry the care alone for too long and in some situations other family members may have to insist on helping. Would you please comment on this?

The comments offered by caregivers in all categories paralleled issues raised by authors reviewed in Chapter II. Caregivers expressed a need for reliable homemaker services and information on resources they would need in their future (Phase Two and Phase Three, Category One). While some caregivers wrote that they felt thankful they could manage at their present time (Phase One and Phase Two, Category One) and in the early stages (Phase Two, Category Two), other caregivers wrote that, as the disease progressed, the years of constant caregiving had taken their toll on the respondent's health (Phase Two and Phase Three, Category One; Phase Two and Phase Three, Category Two; Category Three). Caregivers wrote of the stress of caregiving alone (Phase Two

and Phase Three, Category One; Phase Two and Phase Three, Category Two; Category Three), the stress and guilt experienced when acquiring outside help (Phase Two and Phase Three, Category One; Phase Three, Category Two), and the isolation of the patient and primary caregiver from their family and friends even in the early stages of the illness (Phase One and Phase Two, Category One; Phase Two and Phase Three, Category Two; Category Three).

Category One: patient and primary caregiver living at home.

Phase One:

"I think I can manage this problem. I regret the fact so many of our friends do not associate with us. They almost consider it as contagious; as 'cancer' or 'aids' (even our own children). I thank the 'Lord' she does not know her condition."

Phase Two:

"I have managed so far by myself. My son takes me to places if I need someone and I can leave my husband for that length of time. But would like to know where I could put him in case of say I had to go to hospital, or say I wanted to go see a sick brother or sister or one of the family. But as I stated before, he refuses to get into the car so how would you handle that?"

"This situation of when extra caregiving is needed depends on the caregiver. Their health and just their own temperament in dealing with Alzheimer's. For myself, my husband is very easy to manage, to me he is so thus far. This problem hasn't occurred yet. I am truly thankful."

"Agree. Heavy stress upon the caregiver. While family members are willing to assist, very often they don't, or lack full appreciation of the problem. General feeling is, if situation becomes major, institutional approach is the best. In meanwhile, the health of caregiver suffers as the care becomes more demanding, stressful, and full-time. Inadequate or substandard performance of health care agencies' personnel adds to the stress."

"I think in the beginning families feel they can cope and want to spend more time with a loved one who has Alzheimer's disease. There is a breaking point when the caregiver must have outside help. In my mother's case her doctor advised it as he was concerned about [the primary caregiver's] mental health."

Phase Three:

"When the caregiver is the wife one's pride makes one feel they have to do the caring alone for as long as possible, also the love of one's mate makes you want to do as much as you can for as long as you can."

"Yes very much so - I have carried on far too long, for I have nursed my wife for over two years. I tried a private nursing home but of necessity she was confined with extreme cases and I know that I was robbing her of her last rational periods, so brought her back home after a few days. This fact is always in one's mind, can you let your wife enjoy her last rational moments at home in her known surroundings before being placed in an institution. There is such an urgent need for a place or person, to which the distraught careperson can turn for succor. I record (these circumstances) to emphasize the need for intermediate or halfway care centres or at least clinics."

Category Two: patient living in a care facility and primary caregiver living at home.

Phase Two:

"I was able to manage at home and was able to cope with the various changes that were occurring during this phase, some were rather 'scaring.' We slept in separate rooms and I often found my wife fully dressed during the night, packing a suitcase or emptying the bathroom cabinet. We would talk over a cup of tea and I was able to get through to her that we would finish packing in the morning and she would then go back to bed and sleep. Of course there was no recollection in the morning and I learned that to say nothing of these happenings was the best way to act. The only time that I asked for family help was when the 'wandering' periods started, but with the aid of locks she could not open or reach I had no need for their help then."

"Frankly, I was disappointed that my husband's family did not help a little more - his brother lives right across the way and it was when my husband became violent with me that I had to ask for help. He was then admitted to hospital under Emergency."

"If the patient weren't in a rest home I would need assistance in the home and for respite. He is just showing symptoms of Phase Two."

Phase Three:

"One of the biggest problems was the guilt my mother felt

when she couldn't cope (with the caregiving alone)."

It has been found that primary caregivers tend to carry the care alone for too long "probably correct in most situations" In some situations other family members may have to insist on helping "possibly."

"I would advise seeing a counsellor, your social worker. It helps to understand your patient's problems, how to cope with them."

"Totally agree. Primary caregivers feel a great guilt and feel very uncomfortable asking other family members for help."

"You try to cope on your own for as long as possible without putting a patient into a home. This problem is true."

"Up until the time my mother was admitted to an intermediate care facility my father was the primary caregiver. For about 2 years prior he had been totally caring for her in their apartment. She could no longer cook, clean, and required assistance dressing, etc. It was not until my Dad had an aneurism that I realized the stressfulness of looking after her was too much for him to cope with, and while he was recovering in hospital, with the help of people at Long Term Care, I was able to get Mum into _____. My Dad was so relieved and thankful that I had made the decision for him. I think that one of the most important things is that families sit down together during each of the three stages and discuss exactly what is happening and how they should deal with it."

Category Three: patient deceased and primary caregiver living at home.

"It was not a problem with me and I firmly believe that as long as can be managed, the patient is much better off and easier to control in the home in a familiar environment."

"Encourage family members to share if possible. For one thing they will better understand what the primary caregiver is coping with day in and day out."

"Many families have no family members living near that can help. When _____ needed constant supervision I was provided 6 hours per month gardening help by extended care. Very much needed. I feel caregivers would like to keep their patients home longer if they could get more in home help. I don't feel that day centres are the best places for an Alzheimer patient. They are too restless. I found that medication (drugs) did the patient no good. Just mixed him up more."

"Face the facts immediately as we did, and have application in for full-time care."

> "In retrospect I can see that I should have accepted more help from family members. I was not employed and have no children so gave 'full time' and, unwittingly increased my husband's childlike dependency on me. I in no way resented this and would probably do it again."
>
> "I did not require any help. I am afraid I am a very independent person and was able to look after my husband at home. I was offered help if I wanted."
>
> [spouse/patient 87 years old at death, deceased 1 year] "I took care of him for 7 years till I had a breakdown. I had no help so was not able to sleep, just napped. He needed help to dress, bathe, shave, and his vision failed so his food had to be cut in small portions."

The responses to J.6 and J.7 imply that assistance early in the disease process which schedules relief for the primary caregiver is required and becomes more emphasized as Alzheimer's progresses.

Research Question Two: availability of support.(see Table 7)

J.1 Has a regular period of respite been possible for you?

Of the 45 respondents to this question, 35.6% (16) checked "no" to a regular period of respite being possible. By phase, the group with the most respondents reporting "no" was 52.9% (9) of those caregivers of Phase Two patients, of whom 6 were in Category One. All three Phase One caregivers checked "yes" to regular respite. The remaining caregivers reporting lack of regular respite were 7 of those caring for Phase Three patients. However, 72% of Phase Three caregivers reported "yes" to the availability of regular respite for themselves. The majority of Phase Three caregivers checking "yes" were in Category Two where the patient was now living in a care facility.

By category, the largest proportion (50%) of responding caregivers reporting inability to schedule a period of respite for themselves were to be found in Category One where the patient lived at home. In Cate- Two, an increase to 68.2% of the responding caregivers reported "yes" to regular respite. However, an equal number (7) of Category Two caregivers as of Category One caregivers reported "no" to availability of regular respite. These Category Two respondents, representing 43.8%

Table 7

Responses to Research Question Two Regarding Home Help

Item	Respondents to item			Category					
				One		Two		Three	
	n	%		Yes	No	Yes	No	Yes	No
J.1	45	90%		(14/16)[a]		(22/23)		(9/11)	
			Phase One	2	-	1	-	-	-
			Phase Two	3	6	5	3	-	-
			Phase Three	2	1	9	4	7	2
			Total	7	7	15	7	7	2
J.2(a)	17	34%		(5/16)		(9/23)		(3/11)	
			Phase One	1	-	-	-	-	-
			Phase Two	2	1	4	1	-	-
			Phase Three	-	1	3	1	3	-
			Total	3	2	7	2	3	0
J.2(b)	26	52%		(7/16)		(14/23)		(5/11)	
			Phase One	1	-	1	-	-	-
			Phase Two	4	-	5	-	-	-
			Phase Three	2	-	7	1	5	-
			Total	7	0	13	1	5	0

[a]Numbers in parentheses indicate number of respondents to item/respondents within category.

of all caregivers checking "no" to J.1, may be reporting from their experience when the patient was living at home, or they could be presently spending that much time with their institutionalized patient that they are unable to schedule regular respite for themselves. In Category Three, where the patient was now deceased, the majority (77.7%) of the responding caregivers answered "yes," they had been able to make available a regular period of respite for themselves.

J.2(a) If "yes" to a regular period of respite, is this through family help?

Of 17 caregivers over-all responding to this question, 13 answered "yes" to available family help for a regular period of respite. By phase, the 1 responding Phase One caregiver checked "yes." Coincidentally, 75% of the responding caregivers in Phase Two (6 of 8) and in Phase Three (6 of 8) checked "yes."

By category, the largest proportion of respondents reporting regular family help were 7 of the 9 caregivers responding in Category Two where the patient now lived in a care facility. In Category One, where the patient lived at home, only 5 of the 16 caregivers responded, and of these only 3 reported available family help for a regular period of respite. In Category Three, where the patient was now deceased, 3 responding caregivers checked "yes" to available family help.

This question may have been confusing as caregivers may have a combination of family and outside help and were not certain as to how to respond. Nine caregivers recorded available help from both family (J.2a) and outside (J.2b):

Category One, Phase Two - 1 caregiver checked "yes" to both.
Category Two, Phase Two - 4 caregivers checked "yes" to both.
Category Two, Phase Three - 2 caregivers checked "yes" to both.
Category Three - 2 caregivers checked "yes" to both.

One Category Two, Phase Two caregiver checked "no" to both J.2a and J.2b and added "not until he was in a care facility."

J.2(b) If "yes" to a regular period of respite, is this through outside help?

Of the 26 caregivers over-all responding to this question, 96%

answered "yes" to available outside help for a regular period of respite. By phase, 2 out of 2 responding caregivers in Phase One, 9 out of 9 responding caregivers in Phase Two, and 14 out of 15 responding caregivers in Phase Three checked "yes" to regular outside help.

By category, 7 out of 7 responding caregivers in Category One, 13 out of 14 responding caregivers in Category Two, and 5 out of 5 responding caregivers in Category Three checked "yes" to regular outside help.

Responses to both J.2(a) and J.2(b), and remarks written by respondents in the margin indicated a variation in the amount of assistance available to caregivers. Some reported no help at all, others reported help from both family and outside. In Category One, Phase Two, one caregiver wrote "pending," another wrote "No formal help," and still another "Do not know of any help over all."

For the short answer questions involving:

J.3 What home help has been made available to you?

J.4 What health care personnel are available to you (for caregiving to your patient) during (a) a regular period of respite? (b) emergency respite?; and

J.5 What health care facilities do you believe are available to you (for accommodating your patient) for (a) a regular period of respite? (b) emergency respite?,

the following number of respondents within phases by category left the questions completely unanswered:

Category One:

Phase One:

One out of 2 possible respondents.

Phase Two:

Three out of 11 possible respondents. In a single response to J.3, J.4, and J.5, a 4th respondent wrote "No formal help." A 5th respondent wrote that they "do not know of any help over all," and a 6th respondent marked a "?" in each of the blank spaces.

Phase Three:

One of 3 possible respondents left all spaces blank.

Therefore, in Category One, where the patient and caregiver lived

together at home, 8 of the 16 possible respondents (50%) either chose not to respond to questions J.3, J.4, and J.5 regarding available home help or they were unable to answer due to actual lack of respite and emergency resources or knowledge of same.

Category Two:

Phase One:

The one possible respondent left all spaces blank.

Phase Two:

Three of 7 possible respondents left all spaces blank. In a single response to J.3, J.4, and J.5, a 4th caregiver responded to J.1 that a regular period of respite was not possible and wrote "not until he was in a care facility."

Phase Three:

Four out of a possible 15 caregivers left all spaces blank, and as well had checked "no" to J.1 and whether a regular period of respite had been possible. A 5th caregiver left all spaces blank save J.3 and what home help has been made available to which this respondent wrote "none."

In Category Two, then, where the patient now lived in a care facility, 10 out of the 23 possible respondents (43%) either chose not to respond to questions J.3, J.4, and J.5 regarding available home help or they were unable to answer due to actual lack of respite and emergency resources or knowledge of same.

Category Three:

Four of the 11 possible respondents left questions J.3, J.4, and J.5 unanswered. Two of these 4 checked "no" to J.1 and whether a regular period of respite had been possible. A 5th respondent left blank J.3, what home help had been made available.

Thus, in Category Three, where the patient was now deceased, 36% of the caregivers either chose not to respond to questions regarding respite and emergency resources or were unable to respond due to unavailability of same when their patient was alive.

It appears that the highest percentage of caregivers who were

either not receiving help or chose not to respond to J.3, J.4, and J.5 were one half of those in Category One (50%) with the patient living at home. Exactly those caregivers who would be in a present position to need home help and necessarily have knowledge of regular and emergency respite resources. Although these 8 caregivers are 2 less than the 10 recorded as not responding in Category Two, the latter caregivers might also have chosen not to respond because they perceived their situation as not applicable.

For all three categories, 22 of the 50 possible respondents (44%) did not report health care personnel or facilities available for regular or emergency respite. For those caregivers reporting available resources the following responses were recorded by phase within categories:

J.3 What home help has been made available to you?

Category One:

Phase One:

The 1 responding caregiver reported a commercial homemaker twice a week.

Phase Two:

The available and utilized help varied with the following responses from 6 caregivers:

"Homemaker help - 4 hours weekly pending"

"Homemaker twice a month"

"Hired someone privately - agency person proved unsuitable"

"Approximately 12 hours per day Monday to Friday with a home care service and help from the family on weekends."

"When the situation was CRITICAL help came in."

"_____ is in the assessment stage and goes to the Memorial Pavilion Monday and Wednesday."

A 7th caregiver wrote:

"I don't have any help, so far I have managed by myself."

Phase Three:

The 1 responding caregiver wrote:

"Homemaker 3 times a week."

Thus, 31% (5) of the caregivers in Category One, where the patient lived at home, reported actual available home help. The majority of respondents in Category One were caring for patients in Phase Two of the disease (see Table 3, page 46). Only 3 Phase Two caregivers reported actual home help.

Category Two:

Phase One:

No responses.

Phase Two:

Three of the 5 responding caregivers reported having had commercial homemakers, but did not record any time frequency. A 4th caregiver wrote:

> "I did not request help, this is something I regret because I was also having medical troubles."

A 5th caregiver wrote:

> "I have a retired orderly 8 hours a week. I had a home attendant from C.R.D. [Capital Regional District] services 3 mornings each week."

Phase Three:

The available and utilized help varied with the following responses from 10 caregivers:

> "Haven't needed."
>
> "none was acceptable to patient"
>
> "2 daughters took father for the day plus a week while caregiver went on holiday"
>
> "Homemaker services 5 days a week in months prior to hospitalization"

One caregiver wrote "not applicable" and 2 caregivers wrote "none." Three caregivers reported commercial homemakers and 2 of these latter were obtained through Long Term Care.

Thus, 39% (9) of the caregivers in Category Two, where the patient now lived in a care facility, reported the actual available help when the patient was living at home. The majority of respondents in Category Two were caregivers of patients in Phase Three of the disease (see Table 3, page 46), of whom only 5 (33.3%) reported the available

help, family or outside. However, over one-half (4) of the Phase Two caregivers reported that outside help had been available and utilized before the patient lived in a care facility.

Category Three:

One male caregiver who had been 80 years old at the time of the 80 year old patient's death, wrote "nil" to J.3 and the question of available home help. Another female caregiver to a spouse patient who was 87 years old at time of his death wrote:

> "I have had a homemaker twice weekly to wash and clean. I had no time to myself; had to be alert night and day."

Responses from 5 other caregivers whose patient was deceased again varied:

> "Hired practical nurse (1975!)."
>
> "Through friends I found a capable woman to help with housework and stay with my husband."
>
> "Homemaker and live-in help"
>
> "Orderly type (male) home caregiver"
>
> "I did not recognize the need, so did not request help (should have done so!)."

Thus, 45% (5) of the caregivers in Category Three, where the patient was now deceased, reported the help they had utilized before the patient was living in a care facility. It appears, as is evidenced in Table 3 (see page 47), that the progression of the disease necessitated a degree of patient care that became impossible for the primary caregiver to manage at home. This is observed in Table 3 by the 8 of 11 Category Three caregivers reporting the patient living in a care facility for the last years or partial year of his or her life.

J.4 What health care personnel are available to you (for caregiving to your patient) during:

Category One:

Phase One:

(a) A regular period of respite?

No responses.

(b) Emergency respite?

No responses.

Phase Two:

(a) A regular period of respite?

The 3 responding caregivers wrote:

"live-in situation Monday to Friday"

"Homemaker services = Helping Hands very capable"

"none"

(b) Emergency respite?

The first 2 caregivers responding to (a) wrote:

"family help or agency contact"

"family member"

Phase Three:

(a) A regular period of respite?

Only 1 caregiver responded with:

"Paramed = homemaker"

(b) Emergency respite?

The 1 caregiver responding to (a) responded to (b) with:

"no"

A 2nd caregiver responding to (b) wrote:

"Through commercial companies only, such as Alpha Home Care Services Ltd."

Thus, 3 (18.8%) caregivers of patients who lived at home (Category One) reported knowledge of health care personnel available to them for caregiving to their patient during a regular period of respite. As well, only 3 Category One caregivers reported health care personnel they believed to be available for caregiving to their patient during emergency respite.

Category Two:

Phase One:

(a) A regular period of respite?

No responses.

(b) Emergency respite?

No responses.

Phase Two:

(a) A regular period of respite?

The 4 responding caregivers wrote:

"I had contact with the Dept. of Gerontology, but never made use of it."

"not needed"

"I had help from Community Health Care Services."

"The day care visit to Beckley Farm twice a week"

(b) Emergency respite?

Three of the caregivers responding to (a) wrote:

"Long Term Care"

"not needed"

"Community Health Care Services were available when needed in emergency."

A 4th caregiver responded with:

"Family"

Phase Three:

(a) a regular period of respite?

Five caregivers responded with:

"Homemaker"

"Took use of swing beds at Oak Bay Lodge"

"none for in home"

"companionship"

"Para-med"

(b) Emergency respite?

Three of the caregivers responding to (a) wrote:

"none at the time"

"none, no places unless booked well in advance"

"None for in home, but two week periods were available in a rest home."

Thus, 6 (26.1%) caregivers of patients who lived in a care facility (Category Two) reported knowledge of health care personnel that had been available to them for caregiving to their patient during a regular period of respite. Three (13%) of the Category Two caregivers

reported health care personnel they believed to have been available to them during emergency respite.

Category Three:

(a) A regular period of respite?

Two caregivers responded with:

"home caregiver four times per week"

"Hospital"

(b) Emergency respite?

No responses.

Therefore, 2 (18.2%) caregivers of patients who were now deceased (Category Three) recalled health care personnel available to them for caregiving to their patient during a regular period of respite.

J.5 What health care facilities do you believe are available to you (for accommodating your patient) for:

Category One:

Phase One:

(a) A regular period of respite?

The 1 caregiver responding wrote:

"Sidney Personal Care Home"

(b) Emergency respite?

The 1 respondent to (a) wrote:

"Central Saanich Hospital"

Phase Two:

(a) A regular period of respite?

The 5 responding caregivers wrote:

"Access to health care facilities is limited as key to availability relies upon Human Resources Assessment Program."

"There is a government program that gives family members 3 weeks respite per year."

"My doctor gave me three names."

"The Long Term Care can make arrangements."

"I don't know but would like to know."

(b) Emergency respite?

Three of the caregivers responding to (a) wrote:

"local emergency unit at the district hospital"

"none that I know of"

"My daughter also could phone the Long Term Care."

Phase Three:

(a) A regular period of respite?

Of the 2 caregivers responding, 1 wrote, "Homemaker 3 times per week 6 hours each time," which meant that the respite facility was actually the home of the patient with the outside careperson coming in. The 2nd responding caregiver wrote, "Through commercial companies only, such as Alpha Home Care Services Ltd.," which again implied the careperson coming to the patient's home and not an available facility outside the home for the patient to go to.

(b) Emergency respite?

The 1st caregiver who had responded to (a) wrote "no," implying that he did not believe there were any care facilities available to accommodate the patient in an emergency. The 2nd caregiver who had responded to (a) again wrote "Through commercial companies only," which implied the necessity of an outside person being able to come to the home in an emergency, and also indicated that this second respondent perceived no available facility to accommodate his patient in the event of an emergency.

Thus, in Category One the responses to the question of facilities believed to be available for a regular period of respite varied. However, out of 8 caregivers commenting, only 4 suggested knowledge of such respite facilities being available outside of the home. Of the entire Category One group, then, only 25% reported knowledge of facilities outside their home that might accommodate their patient during a regular period of respite.

Of the 6 caregivers in Category One responding to J.5(b), only 3 reported knowledge of facilities for accommodation of their patient in the event of an emergency. For 2 of the latter caregivers the responses implied that the emergency was with the patient (i.e. "local

emergency unit of the district hospital") rather than possibly with the caregiver (e.g. caregiver suddenly falling ill). The 3rd latter response necessitated the careperson contacting a secondary source for access to the emergency facility and implied that the caregiver believed emergency services were available through the Long Term Care Program.

Category Two:

Phase One:

(a) A regular period of respite?

No responses.

(b) Emergency respite?

No responses.

Phase Two:

(a) A regular period of respite?

The 3 responding caregivers wrote:

"Long Term Care"

"Nursing homes"

"not needed"

(b) Emergency respite?

The 1st respondent to (a) again wrote "Long Term Care," which implied that the caregiver believed emergency services were available through the Long Term Care Program.

Phase Three:

(a) A regular period of respite?

The 4 responding caregivers wrote:

"Not applicable now."

"Made use of Day Care facility 2 times a week at Oak Bay Lodge."

"Most have waiting lists."

"very few"

(b) Emergency respite?

Only 2 responses. The 1st caregiver responding in (a) again wrote:

"Not applicable now."

The 2nd caregiver wrote:

"There was a program through Long Term Care."

Therefore, of the 23 possible respondents in Category Two, only 3 (13%) of the caregivers reported possible sources of accommodation that had been available for a regular period of respite. Only 2 (8.7%) of the Category Two caregivers answered to the question of patient accommodation during emergency respite, and their responses implied that they believed emergency services were available through the Long Term Care Program.

Category Three:

(a) A regular period of respite?

The 4 responding caregivers wrote:

"I understood the 'health care system' but found from experience that relatives and friends served better in our situation."

"Long-term placement for one or two weeks - live in from homemakers."

"?"

"Day care . . . for three months."

(b) Emergency respite?

Two respondents wrote:

"swing beds"

"?"

Thus, only 3 (27%) of the Category Three respondents recalled facilities available for regular periods of respite. Only 1 caregiver described a source of accommodation in the event of an emergency.

The responses to J.1, J.2(a)(b), J.3, J.4(a)(b), and J.5(a)(b) indicate that the type of help available to the primary caregiver and the patient varies with the progression of the disease (phase), the living arrangement (category), and the individual caregiver's access to resources.

In Category One, as can be seen in Table 6 (page 64), 50% of the responding caregivers required home help (see J.6, p.64). The major-

ity of these were Phase Two caregivers. Again 50% of the respondents in Category One, where the patient lived at home, reported an inability to schedule a regular period of respite for themselves (see J.1, Table 7, page 70). The largest single group of respondents, in the entire sample of 50 caregivers, checking "no" to J.1 and a regular period of respite being possible were Phase Two caregivers in Category One. Only 18.8% (3) of all Category One primary caregivers responded "yes" to J.2(a), that help for a regular period of respite came from other family members; while less than one-half (7) responded "yes" to J.2(b), that help for a regular period of respite was available from outside sources. Only 1 of the 16 Category One caregivers checked "yes" to both J.2(a) family and J.2(b) outside sources as available help for a regular period of respite.

In Category Two, as can be seen in Table 6, none of the caregivers required home help (see J.6, p.64). Thirty-two percent of the respondents in Category Two, where the patient now lived in a care facility, reported an inability to schedule a regular period of respite for themselves (see J.1, Table 7, p.70). Just over one-half of these latter respondents (4 of 7) were caregivers of patients in Phase Three of the disease. Thirty percent (7) of all Category Two primary caregivers responded "yes" to J.2(a), that help for a regular period of respite came or had come from other family members; while 56.5% (13) responded "yes" to J.2(b), that help for a regular period of respite was available or had been available from outside sources. Six of the 23 Category Two caregivers checked "yes" to both J.2(a) and J.2(b), that family and outside sources have been available help for a regular period of respite. On the other hand, 5 caregivers expressed in comments to J.7 (see Research Question One, pp.66,67) that their ability to care for the patient at home alone had reached limits before resorting to institutional placement.

In Category Three, as can be seen in Table 6, 57.1% of the responding caregivers recalled that they had been in need of home help. Twenty-two percent of the respondents in Category Three reported that

they had been unable to schedule a regular period of respite for themselves (see J.1, Table 7, p.70). Twenty-seven percent (3) of all Category Three primary caregivers responded "yes" to J.2(a), that help for a regular period of respite had been available from other family members; while 45.5% (5) responded "yes" to J.2(b), that help for a regular period of respite had been available from outside sources. Two of the 11 Category Three caregivers checked "yes" to both J.2(a) and J.2(b), that family and outside sources had been available help for a regular period of respite. Eight of the 11 respondents report their patient living in a care facility during the last years or partial year of his or her life (see Table 3,p.47), thus implying that the disease had progressed to a point that care of the patient at home was no longer manageable.

The amount of available caregiving assistance appears to vary greatly with caregivers in all three categories reporting no available help, caregivers reporting help available only when the situation became critical, and few caregivers reporting availability of home help covering the entire week (see J.3). Relatively few caregivers in all phases and categories reported knowledge of health care personnel and health care facilities that were available for caregiving to their patient when he or she was living at home, during periods of regular respite or emergency respite (see J.4(a)(b) and J.5(a)(b)). What is clear is that as the disease progresses, more help is necessary as is evidenced by the increase in the number of Phase Three patients in Category Two who are living in care facilities, implying that it became impossible for the individual caregiver to acquire needed help and/or sustain the afflicted person at home.

J.7 A major problem for families during the second phase of this illness is home management. Supervision and constant care may now be required. It has been found that primary caregivers tend to carry the care alone for too long and in some situations other family members may have to insist on helping. Would you please comment on this?

The respondents' comments to J.7 indicated an availability or lack of home help:

Category One: patient and primary caregiver living at home.

Phase Two:

"Family and friends all on mainland - if we were there I would have no problem in arranging free time. However, now in process, homemaker services will be available 4 hours weekly soon, whereby I will be free. I'm sure I'll need this service twice weekly before long mainly to be away without worry. At present I am away not more than 3 hours weekly 'all told' and worry."

"That's where we are now."

"I need home help to do some of my work as I have a paralyzed right arm (85%) from a fracture 2 years ago. My help comes in a half day per week."

"Up until 3 months ago, I was the only person who really understood the problems my husband was having. Since then family and friends have been more supportive."

Phase Three:

"My family members have their own families to take care of and are working at a job and are not able to be of much help which is understandable."

"There are no family members available to request help. When I have been at the limit of my endurance I have called in night nurses from the Alpha Company in order to get a few nights rest before carrying on again. More recently, though, my wife might get up at night to look for her parents, to dress, go home, etc. from 4 to 15 times. I have found the better arrangement is to have the homemaker in during the days, when my wife is not attending Geriatric Day Hospital."

Category Two: patient living in a care facility and primary caregiver living at home.

Phase Two:

"After 6 weeks in the hospital, the social worker arranged for her [the patient who was a widow] to go to the extended care home where she is now."

Phase Three:

"True but no family in area."

"Fairfield Homemaker Services were excellent."

"Feel that in my case the family do not understand the problem."

insist on helping "Who is insisting?? No one wants to get involved!!!"

Category Three: patient deceased and primary caregiver living at home.

"Day care arranged partly for my benefit. This was cancelled after three months as patient was confused by new setting and strange people. He was then admitted to full time care."

Support Groups

Research Question One: requirement of support. (see Table 8)

K.2 Would you be in favor of having regular meetings with other caregivers in the same position as yourself?

Of 40 caregivers responding to this question, the majority (82.5%) checked "yes." By phase, 2 of the 3 responding Phase One caregivers checked "yes." While 5 caregivers in Phase Two and 5 caregivers in Phase Three chose not to respond to K.2, 92.3% of the responding Phase Two caregivers compared with 79.2% of the responding Phase Three caregivers checked "yes," they would be in favor of having regular meetings with caregivers in the same position as themselves.

By category, high proportions of those caregivers responding in each category, 75% in Category One, 84.2% in Category Two, and 88.8% in Category Three, checked "yes" to K.2. However, the number of responding caregivers believing "yes" to K.2 compared to possible respondents in each category indicates a less similar approach to such a support group. In Category One, slightly over one-half (56.3%) of the possible respondents checked "yes." In Category Two, an increase to 69.6% of the possible respondents checked "yes," while in Category Three, the highest percentage of possible respondents (72.7%) checked "yes" in favor of regular meetings with caregivers in a like position as themselves. While an informal support group may be counter-indicated for some caregivers, perhaps the relatively lower proportion of affirmative responses in Category One (9 of 16) compared to Categories Two (16 of 23) and Three (8 of 11) is due not only to Category One re-

Table 8

Responses to Research Question One Regarding Support Groups

Item	Respondents to item			Category					
				One		Two		Three	
	n	%		Yes	No	Yes	No	Yes	No
K.2	40	80%		(12/14)[a]		(19/23)		(9/11)	
			Phase One	1	1	1	-	-	-
			Phase Two	6	1	6	-	-	-
			Phase Three	2	1	9	3	8	1
			Total	9	3	16	3	8	1

[a]Numbers in parentheses indicate number of respondents to item/respondents within category.

spondents choosing not to be in favor of such meetings, but also because they do not perceive themselves as able to take the time away from the patient to attend them. As seen in Table 6, 50% of the responding Category One caregivers checked "yes" to J.6 and the requirement of home help (see page 64). As well, 50% of the Category One caregivers responding to J.1 checked "no" that a regular period of respite had not been possible for them (see Table 7, p.69).

K.1 Caregivers state that their major coping stresses are their own fatigue and lack of time for themselves and their other responsibilities. What would you say are your major coping stresses?

The respondents' expressions of their experiences again paralleled observations and opinions of authors reviewed in Chapter II. Caregivers wrote of their increasing fatigue and need for respite (Phase Two and Phase Three, Category One; Phase Two and Phase Three, Category Two; Category Three); isolation (Phase Two and Phase Three, Category One; Phase Three, Category Two); stress with the progressive deterioration and behavioural changes (Phase Two and Phase Three, Category One; Phase Two and Phase Three, Category Two); concern about decisions in caregiving and requirement of professional advice (Phase Three, Category One; Phase Three, Category Two).

Category One: patient and primary caregiver living at home.

Phase One:

"Not serious."

Phase Two:

"Exactly the above."

"Fatigue and complete freedom for a day or so now and again."

"I believe if any of the above it would be fatigue."

"Fatigue, lack of time for myself, insufficient sleep and/or rest, boredom - unable to communicate or get away to different environment, constant interruptions."

"Fatigue and emotional stress."

"Unwilling to go out."

"The above."

"Fatigue and lack of time for myself are major problems, but

it is the coping with his irritability that is wearing me down. I find most days very frustrating and unrewarding."

Phase Three:

"Fatigue, lack of communication with people, time for oneself."

"The constant care of my wife and my household duties."

"My major stress factors have been: Firstly, the lack of advice by medical and other professional persons. Secondly, the inability to readily and quickly identify and contact persons with the professional knowledge to advise me. Thirdly, knowing if and when my wife might be admitted for better professional care than I could render."

Category Two: patient living in a care facility and primary caregiver living at home.

Phase Two:

"As above, also watching their deterioration."

"Feelings of frustration and regret as there is little one can do to help the situation."

"I would agree with the above statement. My husband became very, very aggressive - apt to wander during the night which made me absolutely exhausted. I find now with my husband being in hospital and myself getting a good night's sleep and more rested that I really enjoy and look forward to being with him."

fatigue and lack of time for themselves and their other responsibilities.

"As above as well as travelling to and from the hospital."

Phase Three:

"Frustration and lack of information for the caregivers at the time."

"1)lack of sleep; 2)lack of understanding by non-family members; 3)guilt losing patience with person; 4)no time left for self; 5)why did this happen to me?; 6)loss of sharing with spouse; 7)no support from spouse."

"fatigue, lack of sleep because patient was not on same sleep schedule e.g. early to bed, very early to awake. Mental anguish because no advice from L.T. [Long Term] care."

"emotional and physical tiredness"

"Incontinence at night. Frustration through obstinacy always."

"No time for self."

"Guilt about not spending enough time with the patient."

"Anger and frustration at no longer being able to cope adequately due to fatigue."

"Lack of mobility of patient and loss of bowel and urine control."

Category Three: patient deceased and primary caregiver living at home.

"The 36 hour day. One gets tired and discouraged but with proper support from family and a faithful housekeeper (paid by hour) love will find a way."

"lack of sleep, unable to concentrate on other responsibilities."

"the above"

Research Question Two: availability of support.(see Table 9)

K.3 Do you attend any meetings organized for Alzheimer's patients and their families?

Of 47 caregivers responding, 72% (34) checked "yes." By phase, 2 of the 3 responding Phase One caregivers answered "yes." While there were a higher number of caregivers attending in Phase Three (17 of 26 responding) compared to the Phase Two group of caregivers which had the highest proportion of affirmative responses (15 of 18 respondents), it is notable that 6 of the Phase Three respondents are from the group of caregivers in Category Three. The 66.6% of responding Category Three caregivers checking "yes" to K.3 indicates that caregivers remain involved in a support group after their patient has died. One Category Three respondent who checked "yes" to meeting attendance added, "after patient's death. I did not know of any meetings before that."

By category, the highest proportion of responding caregivers attending available meetings are in Category Two (81.8%). This indicates that caregivers do make use of an available support group when their patient is living in a care facility. Steuer and Clark (1982) advised that a support group may be counter-indicated at times for some caregivers. One Phase Two, Category Two caregiver wrote the following comment:

"We used to attend A.S.A. [Alzheimer's Support Association]

Table 9

Responses to Research Question Two Regarding Support Groups

Item	Respondents to item			Category					
				One		Two		Three	
	n	%		Yes	No	Yes	No	Yes	No
K.3	47	94%		(16/16)[a]		(22/23)		(9/11)	
			Phase One	1	1	1	-	-	-
			Phase Two	8	3	7	-	-	-
			Phase Three	1	2	10	4	6	3
			Total	10	6	18	4	6	3

[a]Numbers in parentheses indicate number of respondents to item/respondents within category.

> meetings regularly but after my wife was admitted to the nursing home I found the stress of practically reliving the caring again and found it very upsetting."

All possible Category One caregivers (16) responded; however, over one-third (37.5%) checked "no" to meeting attendance. These latter caregivers, who might be in a position to take advantage of the experiences of other caregivers, perhaps could not attend due to the necessity of remaining at home to care for the patient. One Phase Two, Category One respondent who checked "yes" to support group attendance added: "It helps some people a lot, others not at all." Other Phase Two, Category One caregivers responded to K.3 with the following additional comments:

> "An extra stress would be attending the meetings."
>
> "No - I volunteer phone - but I can't get away to attend meetings."
>
> "sometimes"
>
> "I have been to Alzheimer's daytime only."
>
> "Sometimes, but I don't feel enough support."

One Category One respondent caring for a patient in Phase Three of the disease wrote:

> "It is too difficult to get away."

Legal Services

Research Question One: requirement of support. (see Table 10)

L.1 Were you made aware at the onset of this disease that there would be problems regarding the patient's affairs that would require legal services?

Of the 45 respondents, 64% (29) checked "yes" to L.1. By phase, all 3 Phase One caregivers answered in the affirmative. Just over one-third (6 of 16) responding Phase Two caregivers and 10 of 26 responding Phase Three caregivers checked "no," they had not been made aware at the onset of the disease that there would be problems regarding the patient's affairs that would require legal services.

By category, 50% of those caregivers responding in Category One

Table 10

Responses to Research Question One Regarding Legal Services

Item	Respondents to item			Category					
				One		Two		Three	
	n	%		Yes	No	Yes	No	Yes	No
L.1	45	90%		(14/16)[a]		(23/23)		(8/11)	
			Phase One	2	-	1	-	-	-
			Phase Two	5	4	5	2	-	-
			Phase Three	-	3	11	4	5	3
			Total	7	7	17	6	5	3

[a]Number in parentheses indicate number of respondents to item/respondents within category.

checked "no" they had not been made aware. This latter group included 4 Phase Two caregivers and all 3 Phase Three caregivers in Category One. One Category One caregiver of a Phase Two patient wrote, "not at onset but more recently - yes." Another Category One caregiver of a Phase Three patient wrote, "No I took action myself, as soon as I realized my wife's condition. The matter was never mentioned to me." In Category Two, all possible respondents answered with 73.9% checking "yes." Eleven of these latter affirmative responses were from caregivers of Phase Three patients. One Phase Three, Category Two caregiver who answered "no" added "not early enough." Another Phase Three, Category Two caregiver wrote that awareness of required legal services had come "through reading articles." In Category Three, 65.2% of the responding caregivers reported "yes," they had been aware at the onset of the eventual need of legal services.

When comparing affirmative responses with the number of possible respondents in each category, Category Two has the highest percentage of caregivers (73.9%) indicating they were informed early in the disease process that legal services would be required. However, less than one half of the possible respondents in both Category One (43.8%) and Category Three (45.5%) checked "yes" to such awareness at the disease onset.

L.4 Have you any opinions you would like to share about legal services and the particular position families with Alzheimer's patients find themselves in?

Category One: patient and primary caregiver living at home.

The comments rendered by caregivers in Category One indicated their growing realization of the afflicted individual's eventual inability to independently manage his or her personal business affairs.

Phase Two:

> "I would like help and guidance."
>
> "....everything is now in joint accounts including ownership of home, etc. - but should I die before my Alzheimer husband and he at that time be unable to sign documents legally - then what? This problem I think is very important and the

answer should be clarified in simple terms - I'm working on that aspect."

"No, I do not know anything more than most anyone would know."

"(a) Some lawyers are not familiar with the law regarding estate planning; (b) banking institutions or others tend to disregard power of attorney and insist that the patient sign for herself despite the fact that she is unaware of what she is signing or understanding it."

"Very important that will, enduring power of attorney, etc. be attended to while still time."

Phase Three:

"I think families of Alzheimer's patients should get the patient to sign important documents before they get unable to do so which makes it expensive to do later."

"I suggest action should be taken very early whilst one can still reason and explain to the patient. Power of attorney should be attained to assist in dealing with legal matters later."

Category Two: patient living in a care facility and primary caregiver living at home.

Respondents in Category Two emphasized acquiring legal advice early.

Phase One:

"Obtain power of attorney as soon possible. (Someone who can be completely trusted.)"

Phase Two:

"I think it is very important and necessary to obtain power of attorney for the patient so that bank, paying of bills, and most financial matters can be taken care of."

"A matter that has not been brought up is seeking power of committee for the patient and the expenses involved here. We have been informed that it is expensive!"

Phase Three:

"Get a will and a general continuing power of attorney completed as early as possible in Phase One."

"I have joint power of attorney but there is money in a personal account that I cannot get because my husband cannot sign his name. I deposit his pension in the joint account but this is not enough to cover the nursing home. Husband

was suspicious when we went to see the lawyer."

"Get help before patient loses ability to write name."

"Very valuable advice to Alzheimer families to get that legal advice early."

"Make sure that stock certificates are changed into 'street' form as the patient can no longer sign their name, as required on certificate, if it is sold."

"Have more than one power of attorney and arrange this early - STAGE ONE."

Category Three: patient deceased and primary caregiver living at home.

Respondents in Category Three recalled the need for legal advice concerning the afflicted person's personal business affairs, and, as with caregivers in Category Two, emphasized acquiring it as early in the disease's progress as possible.

"I fully agree with the power of attorney route - it has been right in every way for me."

"I think it is up to the patient's doctor to advise the family or caregiver to contact their lawyer and to make sure the patient's will is in order before he or she completely loses memory and is unable to write his or her name."

"As soon as Alzheimer's is diagnosed get all papers signed that will be needed for transferring properties. Very soon the patient can't communicate."

"Get power of attorney immediately."

Research Question Two: availability of support.(see Table 11)

L.2 Were you able to contact a lawyer who was sympathetic to the patient's and your needs?

All of the possible (3) Phase One caregivers answered "yes," while 3 caregivers of Phase Two patients and 5 caregivers of Phase Three patients checked "no" to L.2. However, equal percentages of the responding caregivers, 78.6% in Phase Two and 78.3% in Phase Three, reported "yes" to the availability of a lawyer sympathetic to their needs.

In a comparison by category, Category One had the lowest percentage (69.2%) of responding caregivers, as well as the lowest percentage (56.3%) of possible respondents, who checked "yes" to L.2. Category

Table 11

Responses to Research Question Two Regarding Legal Services

Item	Respondents to item			Category					
				One		Two		Three	
	n	%		Yes	No	Yes	No	Yes	No
L.2	40	80%		(13/16)[a]		(18/23)		(9/11)	
			Phase One	2	-	1	-	-	-
			Phase Two	6	2	5	1	-	-
			Phase Three	1	2	9	2	8	1
			Total	9	4	15	3	8	1
L.3	35	70%		(12/16)		(16/23)		(7/11)	
			Phase One	1	-	1	-	-	-
			Phase Two	5	3	4	2	-	-
			Phase Three	-	3	5	4	3	4
			Total	6	6	10	6	3	4

[a]Numbers in parentheses indicate number of respondents to item/respondents within category.

Two indicated the next highest percentage (83.3%) of responding caregivers, who were 65.2% of the possible Category Two respondents, checking "yes." Category Three had the highest percentage (88.8%) of responding caregivers and the highest percentage (72.7%) of possible respondents reporting "yes" to the availability of a lawyer sympathetic to the patient's and caregiver's needs.

L.3 Was there a source of help in finding a sympathetic lawyer?

In a comparison by phase, the 2 responding Phase One caregivers, 64.3% (9 of 14) of the responding Phase Two caregivers, and 42.1% (8 of 19) of the responding Phase Three caregivers reported "yes" to a source of available help in finding a sympathetic lawyer.

By category, 50% of the responding caregivers in Category One checked "yes." Two Category One, Phase Two caregivers wrote:

> "I found the lawyer very helpful who made the tape for Alzheimer's [Information Centre]."
>
> "The Alzheimer's Association had a lawyer as a speaker and he answered many questions."

An increase to 62.5% of the responding caregivers in Category Two answered "yes" there had been a source of help in finding a lawyer. One Category Two, Phase Two caregiver commented:

> "As we are getting along in years our regular lawyers have passed away. Others have been fortunate in acquiring the services of an understanding and reasonable lawyer."

Two Category Two, Phase Three caregivers wrote:

> "Few lawyers know all the ramifications."
>
> "It has helped a great deal to find a sympathetic lawyer."

Of the Category Three respondents, only 3 of the 7 responding caregivers checked "yes" to L.3 and the use of a source of help in finding a sympathetic lawyer.

A comparison of the responses to questions L.2 and L.3 suggest that, when seeking legal advice, two-thirds of the Category One caregivers and two-thirds of the Category Two caregivers who checked "yes" to L.2, had a source of available help in finding a lawyer who understood their situation. However, a like comparison in Category Three suggests that just over one-third (37.5%) of those caregivers who

checked "yes" to L.2 had had a source of help in finding a lawyer.

For all categories, 80% (32) of the caregivers responding to L.2 checked "yes" to contact with a lawyer who understood their circumstances. For all categories, 54% (19) of the caregivers responding to L.3 checked "yes." Thus, a comparison of the responses to L.2 and L.3 suggests that just over one-half (59.4%) of all caregivers checking "yes" to L.2 had an available source of help in seeking a lawyer who was sympathetic to their needs.

Institutions

Research Question One: requirement of support.

M.10 Do you have any comments on institutions you would like to make at this time?

Category One: patient and primary caregiver living at home.

Responses by caregivers in Category One suggest they anticipate possible need of a facility where the patient would be able to live and receive nursing care over and above the care they are able to sustain at home.

Phase Two;

> "Difficult to sort out waiting lists versus eligibility, pre-immediate need. We've had a 'close-call' with institutionalization (which turned out to be only necessary as a temporary measure) but STILL don't know how to go about being on a list, so when need arises, her name is in place."
>
> "My patient would not go into any facility unless forced to do so by his doctor."
>
> "I would like to know if there is a place for people with Alzheimer's disease and how much it would cost."

Phase Three:

> "For those in authority over your patient, not to feel you are being critical of them when enquiring about the health or things you notice about the patient, you are only worried and need reassurance."
>
> "I would like to see institutions especially for Alzheimer's sufferers. In each I would expect the patient to be separated according to the stage of the disease the person is experiencing. In my lay opinion, to accommodate and confine

a person slightly affected with others extremely so is detrimental to the recent victim. I visualize night care only for some patients being available over short periods of time perhaps. If I was to place her for the nights under professional care for one week or so monthly, I would be able to carry on indefinitely."

Respondents in Category Two and Category Three indicated their concern for their relative who had moved into the facility and care by other people and, as with respondents in Category One, Phase Three, suggested what they believed was required in an institutional setting for individuals afflicted with Alzheimer's disease.

Category Two: patient living in a care facility and primary caregiver living at home.

Phase Two:

"I would like to see more visits made to the institutions by neurologists and family physicians who made the decision for 24 hour care and facility care."

"The patient isn't in an Alzheimer's facility at this time. He is changing to one but I think a change is required when patient is nearer Phase II." [The patient is in a rest home.]

"It would be nice to have a volunteer agency to visit the elderly in nursing homes to relieve them of the monotony of everyday living. Dad sits and does nothing except watch T.V. because there is no stimulus in his environment. It also would be nice if rest homes were a little more sanitary (or a little less smelly)."

Category Three: patient deceased and primary caregiver living at home.

"Need for institutions where patient can safely wander both inside and in a garden area."

"I think the matrons or head nurses should try and learn more about the disease."

"We should not have Alzheimer patients in the acute care wards of hospitals after they no longer need acute-care. It is not fair to nurses, doctors, families, patients, and tax-payers. See the article on Baycrest Centre - North York (Reader's Digest for April, 1986) 'A Place Where the Aged Feel at Home' pp.179-184."

"I think Alzheimer's patients should be in a place of their own - ward or facility - also away from white uniforms. Patients who have glasses and hearing aids - the help or nurses who look after them should know what it is to have to look

after and help patients who use them - not find them in the drawer mixed up with the vaseline, etc. No T.V. blaring all day. Last of all they need lots and lots of love."

Research Question Two: availability of support.(see Table 12)

M.1 Is your patient in a care facility?

Of 44 caregivers responding, 28 (64%) checked "yes" to M.1. By phase, 1 of 3 Phase One caregivers, 47.1% of the responding Phase Two caregivers and 79.2% of the responding Phase Three caregivers checked "yes."

By category, 13.3% of the responding Category One caregivers answered "yes." The 1 Category One, Phase Two caregiver and 1 Category One, Phase Three caregiver reported "yes" for the patient having been in a rest home for a temporary stay during a period of respite. One hundred percent of the responding caregivers in Category Two and 62.5% of the responding caregivers in Category Three answered "yes."

With the progression of the disease, there is a higher number of caregivers reporting the patient in a care facility as observed in percentages of caregivers with patients in Phase Three compared with caregivers of Phase Two patients who checked "yes" to M.1.

M.2 Are you happy with the facility for your patient?

The 1 responding Phase One caregiver checked "yes." Six of the 7 Phase Two caregivers and 18 of the 20 Phase Three caregivers checked "yes."

By category, the 1 caregiver responding in Category One, 90.5% of those responding in Category Two, and 83.3% of those responding in Category Three checked "yes."

Thus, while not all caregivers whose patient had been, or presently was, living in a care facility (see Table 3, pp.46,47) responded to M.2, a high percentage (89%) of those who did respond answered "yes" to being happy with the facility for their patient.

M.3 Is your care facility geared to the care of the Alzheimer patient?

By phase, 1 of 2 responding Phase One caregivers, 75% of the responding Phase Two caregivers, and 65% of the responding Phase Three

Table 12

Responses to Research Question Two Regarding Institutions

Item	Respondents to item			Category					
				One		Two		Three	
	n	%		Yes	No	Yes	No	Yes	No
M.1	44	88%		(15/16)[a]		(21/23)		(8/11)	
			Phase One	-	2	1	-	-	-
			Phase Two	1	9	7	-	-	-
			Phase Three	1	2	13	-	5	3
			Total	2	13	21	0	5	3
M.2	28	56%		(1/16)		(21/23)		(6/11)	
			Phase One	-	-	1	-	-	-
			Phase Two	-	-	6	1	-	-
			Phase Three	1	-	12	1	5	1
			Total	1	0	19	2	5	1
M.3	30	60%		(2/16)		(22/23)		(6/11)	
			Phase One	-	-	1	1	-	-
			Phase Two	1	-	5	2	-	-
			Phase Three	1	-	9	4	3	3
			Total	2	0	15	7	3	3
M.4	29	58%		(3/16)		(20/23)		(6/11)	
			Phase One	-	-	1	-	-	-
			Phase Two	-	1	5	-	-	-
			Phase Three	1	1	7	7	4	2
			Total	1	2	13	7	4	2
M.5	28	56%		(2/16)		(20/23)		(6/11)	
			Phase One	-	-	1	-	-	-
			Phase Two	1	-	5	-	-	-
			Phase Three	1	-	13	1	5	1
			Total	2	0	19	1	5	1
M.6	30	60%		(2/16)		(22/23)		(6/11)	
			Phase One	-	-	-	1	-	-
			Phase Two	-	1	-	7	-	-
			Phase Three	-	1	2	12	1	5
			Total	0	2	2	20	1	5

[a] Numbers in parentheses indicate number of respondents to item/respondents within category.

Table 12 continued

Responses to Research Question Two Regarding Institutions

Item	Respondents to item			Category					
				One		Two		Three	
	n	%		Yes	No	Yes	No	Yes	No
M.7	26	52%		(2/16)[a]		(18/23)		(6/11)	
			Phase One	-	-	1	-	-	-
			Phase Two	1	-	4	2	-	-
			Phase Three	1	-	9	2	3	3
			Total	2	0	14	4	3	3
M.8	28	56%		(2/16)		(20/23)		(6/11)	
			Phase One	-	-	1	-	-	-
			Phase Two	1	-	5	2	-	-
			Phase Three	1	-	11	1	5	1
			Total	2	0	17	3	5	1
M.9	25	50%		(2/16)		(18/23)		(5/11)	
			Phase One	-	-	1	-	-	-
			Phase Two	-	1	2	4	-	-
			Phase Three	-	1	8	3	2	3
			Total	0	2	11	7	2	3

[a]Numbers in parentheses indicate number of respondents to item/respondents within category.

caregivers believed "yes," the care facility was geared to the care of the Alzheimer patient.

By category, the 2 caregivers responding in Category One, 62.2% of the responding caregivers in Category Two, and 50% of the responding caregivers in Category Three checked "yes." Thus, approximately one-third (7) of the responding Category Two caregivers, and one-half (3) of the responding Category Three caregivers answered "no," the care facility available to their relative was not geared to the care of the Alzheimer patient. Interestingly, 22% less of the responding caregivers in Category Two (where the patient is presently living in a care facility) checked "yes" to question M.3, whether they believed the facility was geared to the care of the Alzheimer person, than "yes" to question M.2, about being happy with the facility. In Category Two, of all the possible respondents reporting the patient living in a care facility (see Table 3, p.46), 65.2% believed the facility was geared to the care of their relative. In Category Three, of all the caregivers reporting the patient as having lived in a care facility (see Table 3, p.47), only 37.5% believed "yes," the facility had been geared to the care of their Alzheimer afflicted relative.

Of all caregivers responding to question M.3, 66.6% believed "yes," the care facility their Alzheimer afflicted relative had been, or was presently, living in was geared to the care of the patient. Interestingly, this is 22.4% less than the percentage (89%) of those caregivers over-all three categories responding "yes" to M.2.

M.4 Did you find you had a choice of institutions?

By phase, the 1 responding Phase One caregiver checked "yes." While the largest group of Phase Two patients (11) were in Category One and living at home (see Table 3, p.46), for the group of Phase Two patients (7) living in a care facility, 5 of the 6 (83.3%) responding caregivers checked "yes," they had had a choice of institutions. One Phase One, Category Two caregiver commented "Long waiting lists." Phase Three comprised the largest group of patients (23) reported as living, or having lived, in a care facility and slightly over one-half (54.5%) of the responding caregivers answered "yes" to a choice of institutions.

By category, 1 of only 3 responding caregivers in Category One checked "yes" to a choice of institutions. While the number of responding caregivers differed in Category Two (20) and Category Three (6), almost equal proportions, 65% and 66.6% respectively, answered "yes," they had had a choice of institutions. However, when compared with the number of patients reported as living in, or having lived in, a care facility (see Table 3, pp.46,47), it was just over one-half (56.5%) of the possible respondents in Category Two and one-half (50%) of the possible respondents in Category Three who answered "yes" to a choice of care facilities for their patient.

M.5 Does the institution encourage interaction between you and the patient?

High proportions of caregivers responded "yes" when grouped by illness phase or category. By phase, the 1 responding Phase One caregiver, 100% of the responding Phase Two caregivers, and 90.5% of the responding Phase Three caregivers answered "yes" to M.5.

By category, the 2 responding Category One caregivers, 95% of the responding Category Two caregivers, and 83.3% of the responding Category Three caregivers reported "yes," the care facility encouraged interaction between the caregiving relative and the patient.

M.6 Is transportation to and from the institution a problem when you visit?

Responses when grouped by illness phase and category indicated that only a few caregivers experienced difficulty with transportation to and from the care facility. By phase, the 1 responding caregiver in Phase One, 100% of the responding caregivers in Phase Two, and 85.7% of the responding caregivers in Phase Three checked "no."

By category, the 2 responding caregivers in Category One, 90.9% of the responding caregivers in Category Two, and 83.3% of the responding caregivers in Category Three answered "no" to M.6. Of the 3 respondents who reported difficulty with transportation when visiting, 1 caregiver was in Category Three, and 2 caregivers were in Category Two with Phase Three patients.

M.7 Are appropriate individual activities offered in your patient's facility?

By phase, the 1 responding Phase One caregiver checked "yes." While numbers of responding caregivers differed in Phase Two (7) and Phase Three (18), the proportions of those believing "yes" to M.7 are almost equal, 71.4% and 72.2% respectively. All possible Phase Two respondents whose patient now lived in a care facility responded. However, when considering the number of responding Phase Three caregivers answering "yes" compared with the number of Phase Three respondents reporting the patient living in a care facility (see Table 3, pp.46,47), the proportion becomes just over one-half (56.5%) believing "yes," appropriate individual activities were available to the Alzheimer's patient.

By category, the 2 responding Category One caregivers, 77.8% of the responding Category Two caregivers and 50% of the responding Category Three caregivers answered "yes" to M.7. The two latter percentages become lower when comparing the affirmative responses with the number of respondents who reported the patient as having lived in, or presently living in, a care facility. Where the patient was presently living in a care facility (Category Two), 60.9% of the possible respondents believed "yes," suitable individual activities were available for the Alzheimer's patient in his or her institution. Where the patient was reported as having lived in a care facility but was now deceased (Category Three), only 37.5% of the possible respondents believed "yes," appropriate individual activities had been available for the Alzheimer's patient in his or her institution.

M.8 Are appropriate group activities offered in your patient's facility?

By phase, the 1 responding Phase One caregiver, 75% of the responding Phase Two caregivers, and 89.5% of the responding Phase Three caregivers checked "yes."

By category, the 2 responding Category One caregivers, 85% of the responding Category Two caregivers, and 83.3% of the responding Category Three caregivers believed "yes," the facility the patient was pres-

ently living in, or had lived in, offered suitable group activities.

As can be seen in Table 12, 2 more caregivers responded to question M.8 than M.7. Also, 13% (5) more of all caregivers responding to M.8 believed "yes" to suitable available group activities than the over-all percentage responding "yes" to question M.7 (73%) and caregiver belief that suitable individual activities were available for the Alzheimer patient in his or her care facility.

Thus, of all caregivers in Category Two who might have responded to M.8, 73.9% believed "yes" to appropriate available group activities, compared to 60.9% of the possible Category Two respondents believing "yes" to M.7, appropriate individual activities were available. Of all caregivers in Category Three who might have responded to M.8, 62.5% believed "yes" compared to 37.5% of the possible Category Three respondents believing "yes" to M.7.

M.9 Did your patient have to be unsuitably placed because of a lack of a suitable available facility?

The 1 responding caregiver in Phase One checked "yes." This single Phase One respondent is in Category Two. Of Phase Two caregivers, 2 of 7 (28.6%) responding caregivers answered "yes," while in Phase Three, a relatively greater proportion, 10 of 17 (58.8%) responding caregivers reported "yes," the patient had to be unsuitably placed because of a lack of a suitable facility.

By category, neither of the 2 responding Category One caregivers answered "yes," whereas, 11 of the 18 (61.1%) Category Two caregivers responding and 2 of the 5 Category Three caregivers responding reported "yes," because of the lack of a suitable facility, the patient had to be unsuitably placed.

The highest proportion of respondents who checked "yes" to M.9 (unsuitable placement) are those caregivers of patients presently living in a care facility (Category Two). The largest single group responding "yes" are those Category Two caregivers of Phase Three patients (8 of 11 responding). This could suggest that these caregivers experience a lack of the sort of care facility they would want for their patient during the third phase of the illness. Alternatively, an affirmative response

to M.9 does not necessarily indicate that the unsuitable placement is the patient's present facility. The latter case, where the patient may have had to change residences more than once, implies some serious upset for both the patient and the caregiver who are faced with such relocations, when having the patient first move into institutionalized care was a major decision in itself.

M.10 Do you have any comments on institutions you would like to make at this time?

The respondents' comments indicate their concern for their relative in institutional care. Some caregivers expressed satisfaction with the available facility that had become home for their patient. Most of the responses discussed present facility care and provided advice on preferred care and facilities specific to the support of their Alzheimer afflicted relative.

Category One: patient and primary caregiver living at home.

Phase Two:

"No comment as of now (1986) April."

"Maybe names should not be mentioned, but I would like to praise Resthaven Lodge in Sidney. The most excellent facility in just every way. My husband was in one other, his first respite bed, and I will not mention a name here, but should this facility be the only one available when I asked for help I would rather stay home than put him in there. It was a disaster. He has been in Resthaven twice. In August, I have a week planned and Resthaven was not available, so he will be in another facility and I hope it will be good."

Category Two: patient living in a care facility and primary caregiver living at home.

Phase One:

"There are not enough facilities in this city. Far too long a waiting list and patients, while in a holding area, are moved too frequently and it is very upsetting for them."

Phase Two:

"I find the institution my wife is in is excellent. It is clean and homey, she is taken care of in a kind and loving way, and she loves the entire staff."

"We chose Memorial Pavilion because it offers exercises and games - crafts and has concerts and outings. The building is old and hospital like but has good staff (on the whole) and facilities."

"There are no institutions here for any Alzheimer's patient, nor do any give any special service to such a patient."

Phase Three:

"I think the B.C. Long Term Care Program and the people involved with it are doing the best they can with the resources available to them."

"1) Not enough stimulation promotes vegetation of the person; 2) no encouragement to walk, tied in a wheelchair for convenience of staff and safety of patient; 3) bladder control - encouraged to wet self instead of using bottle which patient will use when family comes in (the one my husband is in); 4) not enough institutions; 5) poorly staffed institutions; 6) not enough time for patients to eat their meals; 7) no individual activity for Alzheimer patients."

"Understaffed."

"Oak Bay Kiwanis Pavilion and Memorial Pavilion are absolutely excellent care facilities with caring and competent staff. They have kept Mom alive and in as high quality of life as possible. Our entire family deeply appreciates it."

"Geriatric ghetto."

"Too many patients, not enough staff to give proper attention."

Category Three: patient deceased and primary caregiver living at home.

"Very often the Alzheimer patient does not want to take part in activities no matter how suitable."

"When _____ became ill there was no choice, he would have been sent to Vancouver. I kept him home 'til the last 6 months."

"When I put my husband's name in for a care home, I was told I had two choices, 1 and 2. Wish I did. He was in intermediate care at this time and then there was a change to extended care. Then I found out he had to go back to the bottom of the list and start all over again. With the result I had to take second choice and probably be a year before I could get him into the one I wanted. It was about a year and 2 months and he was only in there about 3 weeks when he passed away. I understand now that they are not going to transfer patients. I guess there is such a demand for care homes. I know that if my husband had been allowed to go to the extended care I picked as number one, he would have been a lot happier in his last year."

Research Question Three: Do the primary caregiver and the patient believe they are receiving proper guidance and are correctly informed about medical care from the professionals whose services they require? (see Table 13)

I.1 Is there a health care person who visits your patient on a regular basis?

Of 43 caregivers responding to this question, only 30% (13) answered "yes." By phase, 1 of the 3 caregivers of patients in Phase One, 12.5% (2) of the responding Phase Two caregivers, and 41.7% (10) of the responding Phase Three caregivers answered "yes."

By category, all possible caregivers in Category One responded and only 6.3% (1) answered "yes" to regular visits from a health care person. This 1 affirmative response was a Phase One caregiver. In Category Two, just over one-half (57.9%) of the responding caregivers answered "yes," while in Category Three only 12.5% (1) of the responding caregivers recalled "yes" to question I.1.

Thus, of all possible respondents in Category Two, less than one-half (47.8%) reported "yes," a health care person visited their patient on a regular basis. Perhaps those 4 caregivers in Category Two who did not respond to question I.1 believed that, as the patient was living in a care facility, regular visits by a health care person were considered expected. However, interestingly, almost one-third (8) of all Category Two caregivers answered "no" to I.1. Three Category Two caregivers of Phase Two patients also remarked:

> "I say 'no' because during one of my visits I had occasion to put some socks and shoes on my wife and the condition of her feet needed treatment from a podiatrist."
>
> "Possibly but she can't tell us."
>
> "His doctor makes regular visits to the hospital."

Of all caregivers in Category Three, only 9.1% (1) reported "yes" to having had regular visits from a health care person, while over one-half (63.6%) answered "no."

Table 13

Responses to Research Question Three Regarding Medical Guidance

Item	Respondents to item			Category					
				One		Two		Three	
	n	%		Yes	No	Yes	No	Yes	No
I.1	43	86%		(16/16)[a]		(19/23)		(8/11)	
			Phase One	1	1	-	1	-	-
			Phase Two	-	11	2	3	-	-
			Phase Three	-	3	9	4	1	7
			Total	1	15	11	8	1	7
I.2	46	92%		(15/16)		(22/23)		(9/11)	
			Phase One	2	-	1	-	-	-
			Phase Two	7	3	4	3	-	-
			Phase Three	1	2	12	2	7	2
			Total	10	5	17	5	7	2
I.3	25	50%		(8/16)		(12/23)		(5/11)	
			Phase One	1	-	-	-	-	-
			Phase Two	2	2	4	-	-	-
			Phase Three	3	-	4	4	2	3
			Total	6	2	8	4	2	3
I.4	41	82%		(12/16)		(21/23)		(8/11)	
			Phase One	1	-	-	1	-	-
			Phase Two	4	4	4	3	-	-
			Phase Three	1	2	9	4	4	4
			Total	6	6	13	8	4	4
I.5	41	82%		(11/16)		(22/23)		(8/11)	
			Phase One	1	-	1	-	-	-
			Phase Two	6	1	4	3	-	-
			Phase Three	2	1	11	3	5	3
			Total	9	2	16	6	5	3

[a] Numbers in parentheses indicate number of respondents to item/respondents within category.

I.2 Is your family doctor knowledgeable about Alzheimer's disease?

Of 46 caregivers responding, 74% (34) believed "yes" to I.2. By phase, all 3 of the Phase One caregivers, 64.7% of the responding Phase Two caregivers, and 76.9% of the responding Phase Three caregivers answered "yes." An equal number of Phase Two respondents (6) as Phase Three respondents (6) believed "no."

By category, 66.6% of those responding in Category One, 77.3% of those responding in Category Two, and 77.7% of those responding in Category Three believed "yes," their family doctor was knowledgeable about Alzheimer's disease. While only 1 caregiver in each of Category One and Category Two chose not to respond to question I.2, 5 respondents in each of these categories answered "no," they believed their family doctor was not knowledgeable about Alzheimer's disease. Three caregivers of Category One, Phase Two patients remarked, "Also makes house calls," "I don't know," and "He isn't a great help." Two caregivers of Category Two, Phase Three patients also added, "Somewhat," and "Present Dr. yes, previous Dr. no." One Category Three respondent commented, "He [the doctor] said he preferred 'to consider the symptoms as part of the aging process'!"

I.3 If your family doctor was not knowledgeable about Alzheimer's disease, did he or she refer you to someone who was?

Of 25 caregivers responding, 64% (16) answered "yes." By phase, the 1 responding Phase One caregiver, 75% of the responding Phase Two caregivers, and just over one-half (56.3%) of the responding Phase Three caregivers answered "yes."

By category, 75% of the responding Category One caregivers, 66.6% of the responding Category Two caregivers, and 40% of the responding Category Three caregivers reported "yes," their family doctor had referred them to someone who was knowledgeable about Alzheimer's disease. One Phase Two, Category Two caregiver added, "My family doctor made the recommendation with a Neurologist for diagnosis." Of the responding caregivers answering "no" to question I.3 (36%), 2 were for Phase Two, Category One patients, 4 for Phase Three, Category Two patients. One Phase Three, Category Two caregiver added, "Daughter found

out who to see." One of the 3 Category Three caregivers who answered "no" to I.3 wrote, "When I suggested a second opinion, he said it was not needed."

I.4 In treating the Alzheimer's patient do you believe the medical professionals whose services you require offer proper guidance to you as the patient's illness progresses?

Of 41 caregivers responding, just over one-half (56%) believed "yes." By phase, 1 of the 2 responding Phase One caregivers, 53.3% of the responding Phase Two caregivers, and 58.3% of the responding Phase Three caregivers answered "yes."

By category, one-half (50%) of those responding caregivers in Category One, a slightly higher percentage (61.9%) of those responding Category Two caregivers, and again one-half (50%) of those responding caregivers in Category Three felt "yes," they were receiving, or had received, proper medical guidance as the patient's illness progressed. One Phase Two, Category Two caregiver who answered "no," added "not so far."

The percentages are even lower when considering affirmative responses against the number of possible respondents in each category. In Category One, just over one-third (37.5%) of the possible respondents checked "yes," they believed they were receiving proper medical guidance. In Category Two, just over one-half (56.5%) of the possible respondents answered "yes" to proper medical guidance. In Category Three, as in Category One, just over one-third (36.4%) of the possible respondents answered "yes," they felt they had received proper medical guidance as the illness progressed.

I.5 Do you feel you are receiving adequate medical help?

As in question I.4, 41 caregivers responded. However, a higher percentage (73%) believed "yes," they were receiving adequate medical help than those respondents who believed "yes" (56%), they were receiving proper medical guidance as the illness progressed (see I.4). By phase, the 2 responding caregivers in Phase One, 71.4% of the responding caregivers in Phase Two, and 72% of the responding caregivers in

Phase Three answered "yes" to adequate medical help.

By category, 81.8% of the caregivers responding in Category One checked "yes." Category One contained the largest number of caregivers choosing not to respond to question I.5 - 1 caregiver of a patient in phase one of the illness and 4 caregivers of patients in phase two. As well, 2 caregivers in Category One believed "no" to I.5. In Category Two, 72.7% of the responding caregivers checked "yes," while 6 answered "no," they believed they were not receiving adequate medical help. Two Phase Two, Category Two caregivers added, "I received an immediate response when I requested an assessment," and "There is nothing anyone can do about Alzheimer's except live with it." In Category Three, 62.5% of the responding caregivers felt "yes," they had received adequate medical help. In this latter category, 3 caregivers responded "no" and 3 chose not to respond. Two Category Three caregivers also wrote in response to I.5:

> "I had no help. I couldn't send him to the corner store or leave him alone, so had to take him with me everywhere I had to go."
>
> "No, but partly because A.D. was not recognized in late '60s."

Thus, 56.3% of the possible respondents in Category One believed "yes" to I.5 and receipt of adequate medical help compared to 37.5% of those respondents answering "yes" to I.4, receipt of proper medical guidance. Of the possible respondents in Category Two, 69.6% believed "yes" to I.5 compared to 56.5% who answered "yes" to I.4. In Category Three, 45.5% of all possible respondents believed "yes," they had received adequate medical help, compared to a lower percentage (36.4%) who checked "yes" to I.4 and proper medical guidance.

In Category One, 18.2% (2) of those caregivers actually answering question I.5 (adequate medical help) checked "no" and 31.3% of the possible respondents did not respond to the question. However, 50% (6) of those actually answering the previous question, I.4 (proper medical guidance) checked "no" and 25% of the possible respondents did not respond to the question.

In Category Two, 27.3% (6) of those caregivers actually answering

question I.5 (adequate medical help) checked "no" and 4.3% of the possible respondents did not respond to the question. In response to question I.4, 38.1% (8) of those actually answering checked "no," and 8.7% of the possible respondents did not answer the question.

In Category Three, 37.5% (3) of those caregivers actually answering question I.5 (adequate medical help) checked "no" and 27.3% of the possible respondents did not respond to the question. In response to question I.4 (proper medical guidance), 50% of those actually answering checked "no" and 27.3% of the possible respondents did not respond to the question.

For all categories, 26.8% of those actually answering question I.5 concerning adequate medical help checked "no" and 18% (9) of the possible respondents chose not to respond to the question. However, in response to question I.4 concerning proper medical guidance, a higher percentage (43.9%) of those actually responding checked "no" and, again, 18% of the possible respondents chose not to respond to the question.

I.6 Have you any comments you would like to make at this time in regard to what medical guidance you would like to be provided with in caring for the Alzheimer's patient?

The comments offered by the respondents indicated how necessary they believed to be regular contact with medical professionals knowledgeable about Alzheimer's disease and the ramifications of its process.

Category One: patient and primary caregiver living at home.

Phase One;

> "Please be advised, [the] (CRD) [Capital Regional District] are up to date as to _____'s condition."

Phase Two:

> "I was unaware until Feb.25/86 that there could be an assessment. Our doctor suggested that I might put in for an assessment which I agreed. It's in process at this time. I have bought The 36-Hour Day and Alzheimer's Disease: A guide for families (at the onset) and find referring to them and our family doctor quite adequate (for the present)."
>
> "I don't know about medical guidance except for something to quieten him down."
>
> "Feel my husband has good care and attention - however, I feel

the caregivers are in need of professional help in dealing with the emotional feelings we go through - over and over again. I feel more help is needed on a one-to-one rather than a large group - no more than 10 to a group to get the most support."

"The spouse of the patient is reluctant to face the situation and therefore isn't pressing for medical guidance."

"I would like to comment on questions 3 and 4. I believe that my mother's family doctor was knowledgeable about Alzheimer's disease but did not offer any support or advice to the immediate family members. I think doctors should realize that Alzheimer's is as devastating to the family as it is to the patient. I felt that her doctor was very indifferent over the situation. She now has an excellent young doctor who gives her a checkup on a regular basis, is always available to talk with the family, and has been an invaluable source of information and advice."

"Partly because of unwillingness of spouse to seek it [medical guidance] or have the disruption."

"Patient would not agree to anyone coming in to help as he doesn't want anyone to know that he [has other physical problems] , so it makes it very difficult for me."

Phase Three:

"To be told what is happening to the Alzheimer patient as the disease progresses."

"For the uninitiated like myself there is a great need for information in printed form describing the conditions the patient will experience as the disease progresses. It should be in printed form for repeated reference and study. I suggest a sole careperson needs constant, possibly daily coaching or advice from experts. I consider the lack of information and a source to seek professional advice is the greatest cause of nervous breakdown on the part of the careperson. The first two times I have broken down was when my wife was in great pain and I was in need of advice and I was obviously stalled by the telephone answering service. On both occasions I was in a state of exhaustion from lack of sleep for days, and worry in not knowing what to do for the best. I have held positions of great responsibility, I managed easily for I could identify the problem - but trying to nurse a sick mental patient is not possible without advice."

Category Two: patient living in a care facility and primary caregiver living at home.

Phase Two:

"To the caregiver at home there is a limit to how much you can

do for the patient. If you find the task getting beyond your capabilities, waste no time in seeking medical help for your own peace of mind also. I found the benefits of the help of the Geriatric Department, which I was guided to by my doctor."

"If all were as fortunate as I am in this respect they would be fortunate. My doctor has helped me, counselled me, and really helped me through the real hard times. He is in constant touch with me and continually relating to me what to expect as we go along. He asks me if I care to talk and I can talk and relieve some of the pressures. He is just a very young man but a terrific doctor."

"It seems medical help is limited to using pills for sedation purposes - unfortunately necessary in this kind of environment."

Phase Three:

"Family physician should know more about the disease and what channels to send the family to."

"More homes, more room to walk."

"I think the family should be advised more of the many problems involved - how to cope with the many situations."

"Would like to share comments in about 6 months."

"In question 5 'yes' because we are now receiving excellent medical help. At the onset of the disease, her doctor (at that time, we've changed since) did nothing and didn't care about Mom's trouble. That's a comment against the doctor though, not the medical profession. No other comments. I believe the various medical staff we've been involved with are doing the best they can on a subject that is baffling."

Category Three: patient deceased and primary caregiver living at home.

"I believe most caregivers should be told by the doctors what to expect as a patient advances through the three stages of Alzheimer's disease. Specific well-known symptoms and how to deal with the problems which arise should be indicated by the physician. Each doctor should have a copy of The 36-Hour Day or some similar book to lend to the caregiver. Advise the caregiver to join a support group."

"Whenever possible a patient is better in a familiar home environment. They need a space to walk around freely."

"I think families should be aware of the Alzheimer's Support Group and good books and pamphlets - e.g. Thirty-six hour day etc."

"Anyone with an Alzheimer's patient should be given someone to

> stay with him or her, so the wife or husband could get away for short times. I had no one to call so it resulted in a breakdown."
>
> "I had to look after him (my husband) at home. That meant up every night - one or two times a night I had to change bedding etc. until June of '84. Until one night he just exploded. I couldn't do anything with him so called an ambulance and took him to emergency."

The results to questions I.1 through I.6 indicate that assistance from medical professionals is varied among caregivers and between categories. As seen in the results of question I.1, only 30% of the 43 responding caregivers checked "yes" to regular patient visits from a health care person. The category with the most affirmative responses was Category Two where just over one-half (11) of those actually responding checked "yes." However, where the patient was living at home (Category One), only 1 caregiver responded "yes" to regular patient visits from a health care person. As well, only 1 caregiver of a patient who was now deceased (Category Three) recalled "yes," a health care person had visited the patient on a regular basis.

In the results of question I.2, 74% of the 46 respondents believed "yes," their family doctor was knowledgeable about Alzheimer's disease. The proportions of caregivers responding in the affirmative varied little across categories with 66.6%, 77.3%, and 77.7% of those answering in Categories One, Two, and Three respectively, checking "yes."

In response to question I.3 and doctor referral to someone who was knowledgeable about Alzheimer's disease, 64% of the 25 caregivers responding checked "yes." The highest percentage of caregivers reporting a further doctor referral were 75% of those caring for the patient at home (Category One). The next highest percentage reporting "yes" to a knowledgeable doctor referral were 66.6% of those caregivers of a patient now living in a care facility (Category Two), while the lowest percentage reporting a further referral were 40% of those caregivers of patients who were now deceased (Category Three).

In the results of question I.4, it is interesting that, in comparison to the responses of questions I.2 and I.3, only 56% of the 41 re-

sponding caregivers believed "yes," they were receiving proper medical guidance. The highest percentage of affirmative responses to question I.4 were 61.9% of those responding caregivers of patients now living in a care facility (Category Two). However, only one-half (50%) of those responding caregivers of patients living at home (Category One) and one-half (50%) of those responding caregivers of patients who were now deceased (Category Three) believed "yes," they were presently receiving, or had received, appropriate medical guidance.

In response to question I.5, it is again interesting that, in comparison to the responses of question I.4, 73% of the 41 caregivers responding believed "yes," they were receiving adequate medical help. The highest percentage of responding caregivers answering in the affirmative were 81.8% of those caring for patients at home (Category One). The next highest percentage checking "yes" were 72.7% of those responding caregivers of patients living in a care facility, while the lowest percentage of affirmative responses were 62.5% of those responding caregivers of patients who were now deceased (Category Three). However, when taking percentages of possible respondents answering in the affirmative to I.5, the results become 56.3%, 69.6%, and 45.5% in Categories One, Two, and Three respectively responding "yes" to adequate medical care.

Thus, in response to Research Question Three, in light of the results from questions I.1 through I.5, and with reference to the comments in question I.6, it appears that caregivers' belief that they are receiving appropriate guidance and medical care information is dependent upon their initial contact with a doctor knowledgeable in the disease's process, and willing to offer families the advice they need. The comments to I.6 suggest that if such medical contact is lacking for the patient and the primary caregiver, and/or they fail to find a doctor knowledgeable in Alzheimer's disease and its familial ramifications, the burden in giving care becomes so much more magnified as not only the patient's health but also the caregiver's health becomes at risk.

Research Question Four: Do the primary caregiver and the patient be-

lieve there is an increasing concern and public awareness about Alzheimer's degenerative brain disease. (see Table 14)

N.1 Do you believe there is a greater awareness in the general public of Alzheimer's disease now than there was three years ago?

All caregivers in Category One, where the person afflicted with Alzheimer's lived at home, believed "yes" there is a greater awareness in the general public now than there was three years ago. In Category Two, where the Alzheimer afflicted individual lived in a care facility 86.9% (20) of the possible respondents believed "yes." One Phase Two, Category Two caregiver felt "no" and 2 Phase Three, Category Two caregivers chose not to respond. In Category Three, where the Alzheimer afflicted person was now deceased, 90.9% of the possible respondents believed "yes" to greater public awareness and 1 caregiver chose not to respond.

Thus, 98% (46) of the responding caregivers, or 92% of all possible respondents, believed "yes," there is a greater awareness among the general public, of Alzheimer's disease, now than there was three years ago.

N.2 Do you believe there is an increase in the concern of the public to be educated about Alzheimer's degenerative brain disease than there was three years ago?

Again, as in response to question N.1, all possible Category One caregivers believed "yes," there is an increase in the concern of the public to be educated about Alzheimer's disease. In Category Two, 73.9% of the possible respondents believed "yes," while 1 Phase Two, Category Two caregiver and 2 Phase Three, Category Two caregivers felt "no." Three Phase Three, Category Two caregivers chose not to respond. In Category Three, 81.8% of the possible respondents believed "yes" to question N.2, while 2 Category Three caregivers chose not to respond.

Therefore, 93% (42) of the responding caregivers, or 84% of all possible respondents, believed "yes," there is an increased concern in the public to be educated about Alzheimer's degenerative brain disease

Table 14

Responses to Research Question Four Regarding Public Awareness

Item	Respondents to item			Category					
				One		Two		Three	
	n	%		Yes	No	Yes	No	Yes	No
N.1	47	94%		(16/16)[a]		(21/23)		(10/11)	
			Phase One	2	-	1	-	-	-
			Phase Two	11	-	6	1	-	-
			Phase Three	3	-	13	-	10	-
			Total	16	0	20	1	10	0
N.2	45	90%		(16/16)		(20/23)		(9/11)	
			Phase One	2	-	1	-	-	-
			Phase Two	11	-	6	1	-	-
			Phase Three	3	-	10	2	9	-
			Total	16	0	17	3	9	0

[a]Numbers in parentheses indicate number of respondents to item/respondents within category.

than there was three years ago.

N.3 Have you any other observations you would like to make about increasing public concern and awareness of Alzheimer's disease?

As with the results of N.1 and N.2, the respondents' comments indicate that they believe there is an increasing concern and public awareness about this disease. While emphasizing the continuation of research and public education, the contributions by caregivers to both question N.3 and question N.4 poignantly illuminate the multiple stresses (psychological, social, and economic) and the encompassing changes that are brought about when a family member is stricken with Alzheimer's disease.

Category One: patient and primary caregiver living at home.

Phase Two:

"I feel the general public seem to be aware and concerned about Alzheimer's - possibly because all dementias seem to be classified under Alzheimer's."

"Yes - stressing the degenerative brain disease, rather than the name Alzheimer's."

"There are families who have someone in their home or institution and don't wish others to know, or talk about it. If they had talked about it this would be helpful in increased public concern and awareness. I have found that many persons are interested in the disease as they grow older in case they should end up with it."

"I would like to see a great deal of research on causes and prevention if possible."

"There are so many blank walls yet to be written on but I do believe there has been progress even within the last few years."

Phase Three:

"I think T.V. is doing quite a bit."

"The afflicted aged and the dying cannot act, but their families and carepersons have a potential to bring about improvements. I suggest all such persons in no way withhold any details of the conditions of the patient or the horrific struggle of caring for them. Most people do not know, they should be told in every detail - withhold nothing that might shock people into action and support. Treatment of the patient and facilities for the careperson must be examined and improved."

Category Two: patient living in a care facility and primary caregiver living at home.

Phase Two:

"We who have spouses or relatives affected directly are aware of the intense research interest, another change is occurring. In the past families tended to keep the ailment a secret. Now people are discussing it openly."

"It is very much needed - no one seems to know much about the disease."

"I find people and friends are very much more aware of Alzheimer's disease than say 2 years ago."

"Television and newspapers are the best solution, not too many people are aware unless involved."

Phase Three:

"Still a great amount of misconception regarding the age factor."

Category Three: patient deceased and primary caregiver living at home.

"I believe it could have more financial support from agencies like the United Way."

"It is only through awareness and publicity that funds will be made available for research."

"I watched the Fifth Estate one night. It was like living my husband's illness all over again. Should be more discussion on this illness."

"When the diagnosis of suspected Alzheimer's was made about 1973, it was a completely new word to me and to most of the nursing staff."

N.4 It is only through public recognition of the enormity of the problem of Alzheimer's disease and its emotional impact on the family and on society that new funding and adequate resources will become a government priority. Loss of income and/or medical costs associated with home care or institutionalization of the patient may result in families facing financial hardship. Do you have anything to say about this?

Category One: patient and primary caregiver living at home.

Phase One:

"This is of prime concern for pensions do not go far these days."

Phase Two:

"I feel strongly that an Alzheimer's phone support should be in service for longer hours than at present - Alzheimer's is a frightening situation for both the patient and the caregiver - with good supportive doctor care - along with supportive family concerns and access on occasion to phone support from Alzheimer's group, living is much easier. At present there is no phone support over a weekend nor in morning nor in evening daily - such support could be well organized through volunteers - need not be a government burden. I'll volunteer to speak from my home if that would help."

"That's why, or one reason why I want to take care of him as long as I can - I don't want to be left penniless, especially at my age. I can't go to work any more at this stage. People with Alzheimer's disease are sick people and therefore I think they should be treated like any other sick folk that are placed in a hospital. So they would be on the same rate of pay or hospitalization. Hope you understand what I mean."

"I am sure this problem of Alzheimer's disease where loss of income etc. etc. and all the other facets you mentioned are being looked after better all the time. I would like to see more respite beds available as it is difficult to reserve where you wish, only if it is done months and months in advance."

"I tend to agree with this principle. The cost in our situation is approximately $1700. per month (5 days per week of home care) which is a heavy burden. The yardstick the government uses in determining who should get free care and who should pay seems to be unfair."

"Yes, we definitely need more facilities for Alzheimer's patients. The nursing homes our family has picked for my mother have a one and a half to two year waiting list. (Not all nursing homes accept Alzheimer's patients.) Our family is fortunate that we can afford outside help."

"I feel that this could be a big problem with many families."

Phase Three:

"Yes, I agree."

"For example, I am resigned to selling my home and reducing my standards to an absolute minimum, for my wife is physically healthy and may live a long time. It is correct that I should contribute all that I can and I accept this. But in return I would like to see the required medical and professional treatment rendered to my wife. At times I have doubts

regarding the attention, but it does rank when one recalls that the Alzheimer's patients I have seen in the _____ care center, most probably in their earlier days asked for little but contributed unselfishly to the emergence of Canada to its eminence today."

Category Two: patient living in a care facility and primary caregiver living at home.

Phase Two:

"I have paid into a Government group surgical medical insurance plan since I retired from the Armed Forces (1962). I was in contact with the D.N.D. [Department of National Defence] Ottawa and Mutual Life Insurance of Canada regarding reimbursement of my wife's placement. I contacted L.T.C. [Long Term Care] , C.R.D. [Capital Regional District] , my member of Parliament's office locally, D.V.A. [Department of Veteran Affairs] , who directed me to Health and Welfare. I had been informed by D.N.D. Ottawa and Mutual Life of Canada that the placement my wife was, is not recognized as a hospital under the B.C. Medical Act and in consequence no claims can be considered. The representative of Health and Welfare informed me of a scheme whereby I could apply for an 'Involuntary Separation' from my wife. To me this seemed an insult. I cannot claim a cent for the premiums that I have paid for 24 years until my wife's condition deteriorates to a stage where she is completely immobile and possibly she might be recommended for placement in an Extended Care Hospital."

"I think our government should help more in this area."

"I do not feel a 'yes - no' can do justice to the ailment - unlike cancer in which huge sums are spent and some lives saved and many more prolonged in years of agony, Alzheimer's does not seem to have any treatment even of a temporary nature to expend huge sums on. Apparently, this condition has been around for a long time but was not spoken of. Today, everyone you talk to knows someone who has acquired it."

"Lucky the patient here is retired and has pensions adequately to cover the monthly rate of the home, but there is little left over for the maintenance of the spouse."

"Books available on the subject of Alzheimer's are helpful in understanding the various phases of the disease. Most of them can be obtained through the Alzheimer's Support Association."

Phase Three:

"I agree with both statements - the Alzheimer's society and media coverage are steps to help."

"Expensive but see no alternative - 'User Pays'."

"More homes."

"It is costing me over $6,000./year and luckily I can afford this."

"I think it extremely important that governments and medical profession give more consideration in finding causes/cure for Alzheimer's disease - it is incredible just how many people I know who have relatives who are afflicted with it. I know it has to be one of the most common diseases affecting those in the middle to late years."

Category Three: patient deceased and primary caregiver at home.

"When _____ got this disease no one had ever heard of it. It took 4 years for the doctors to put a name to it. I feel I received excellent help through the extended care program. I feel that caregivers would like to keep their patients home longer if they could get more in home help."

"Yes I do. It should be put on the same priority as cancer or any other illness that involves families."

"This is true but not unlike the problems of other long term illness. In some cases patients are eligible for disability pensions (stroke patients maybe) but I have not known this for A.D. patients. As the society grows, pressure may be developed so that some programs of financial assistance may be implemented."

CHAPTER V

Conclusion

Research Question One

The results of this study indicate that the type of support required by the primary caregiver and the patient varies with the progress of the disease. D. Cohen et al.(1984) and LaBarge(1981) discuss how, in the early stages of the disease, it requires a major effort on the part of the Alzheimer patient to face each day and maintain some level of activity. They advised that afflicted individuals to the extent possible should participate in decisions about their care. In the present research the majority of respondents said that, while the patient had been able to occupy himself or herself with activities during the first phase, the provision of meaningful diversion had been an on-going problem during that phase. Among the comments regarding recreation, one respondent believed that "the first phase could be prolonged by professional advice and group attendance." Various authors described adult day care as a good resource for Alzheimer patients(Beam,1984; Paschke, 1984; Zachary,1984). However, to the question of whether the patient would make use of an adult day care facility, only 18 primary caregivers responded "yes" and of these only 4 of the patients were living at home. Caregivers expressed that the provision of activities was a difficult subject "as each patient would have different interests." The question of finding appropriate activities was, as one respondent wrote, a major problem for fear "of damaging the patient's self-esteem."

With the problem of providing activities becoming more emphasized as the disease progressed through phase two, respondents wrote, "Getting harder and harder to suggest anything to occupy himself with," and "I am his only source of entertainment." LaBarge(1981) found that, in the early stages of the disease, individual counselling offered patients emotional support and helped them look to each day individually. As there is presently no cure for Alzheimer's disease, the essential treatment is in helping a victim maintain a purpose in daily living. Considering that over one half of the respondents experienced on-going

problems with patient recreation (27 caregivers said "yes" to the difficulty during phase one and 34 caregivers, during phase two) and the number of caregivers (25) who believed the patient would not make use of an adult day care, a solution could be to have recreational therapists go to patients' homes. Recreational therapists working one-to-one with the patient in his or her own home environment (possibly for 2½ to 3 hours twice a week) could provide meaningful diversion suited to individual interests. Such in-home occupational therapy could work as an alternative or adjunct to an adult day care facility and at the same time, as the illness resulted in the increased dependency of the Alzheimer patient, serve as a source of respite for the primary caregiver.

In the present study many caregivers wrote that a preference had been to keep the patient living at home for as long as possible. This confirms opinions by Goldberg(1985) and Sands and Suzuki(1983) that the home is preferred as a caregiving setting by many families with a member suffering from Alzheimer's disease. A primary caregiver of a patient now deceased wrote, "I firmly believe that as long as can be managed, the patient is much better off and easier to control in the home in a familiar environment." Albert(1984) advised that Alzheimer's patients almost always function more independently in an environment that is familiar. However, as the disease progresses into the second phase a major problem for primary caregivers is home management as constant supervision and care may be required for the patient(Gwyther & Matteson,1983). The present study also supports findings that as the care becomes more stressful and full-time the primary caregiver's burden is infrequently shared by relatives (Goldberg,1985), former friends may no longer visit (Lyons,1984; Zarit & Zarit,1982), and the caregiver becomes isolated(Glosser & Wexler,1985).

While other family members have been described as potentially the best source of help to the primary caregiver and the patient (Elliot, 1979; Glosser & Wexler,1985; Safford,1980; Zarit & Zarit,1982), only 13 respondents in this study answered that they were able to count on family help for regular periods of respite. One respondent advised

encouraging families to share if possible. Another respondent wrote that primary caregivers felt a great guilt and were very uncomfortable asking for help from other family members. Zarit and Zarit(1982) had found that family meetings have been most effective in reducing caregiver's burden. A respondent in the present research believed that "one of the most important things is that families sit down together during each of the three stages and discuss exactly what is happening and how to deal with it." However, other caregivers commented that "Many families have no family members living near that can help" (a problem noted by Bennett,1983) and, "While family members are willing to assist very often they don't, or lack full appreciation of the problem."

Thus, while some primary caregivers are able to rely on other family members for help, for many all the assistance required to keep the patient at home must come from other outside sources. Gwyther and Matteson(1983) and others (e.g., Heston & White,1983) emphasized the need in phase two for caregivers to be scheduling emergency and regular respite. In the present study, of 12 Category One primary caregivers responding to the question of required home help, one-half reported needing home help and 5 of those were caring for patients in phase two of the illness. Of the 7 Category Three caregivers responding to this question, 4 recalled a need for home help. One Category Three caregiver wrote, "I took care of him for 7 years 'til I had a breakdown. I had no help so was not able to sleep, just napped." It is only in Category Two, where the patient is presently living in a care facility, that all 18 responding caregivers reported not needing home help. However, comments by Category Two caregivers indicate that the caregiver's own health had reached a breaking point before full-time facility care was considered or realized as necessary. Such responses are consistent with findings by Barnes et al.(1981) that primary caregivers sacrificed their own health in committing their lives to caring for their patients, and by Lyons(1984) that as patients became increasingly dependent and in need of help, so did the primary caregivers. Findings of the present research also point out that in order that a primary caregiver might care for an Alzheimer afflicted person at home, help is necessary to

assist with (a) recreational diversion suited to the patient's purpose and level of impairment and (b) required supervision and care resulting from the increasing dependency of the ill individual.

The responses in this study concerning the possibility of institutional care for the Alzheimer's patient are consistent with Zarit and Zarit's(1982) finding that patients are not readily institutionalized and that, because of all the previous care invested in sustaining the ill person, primary caregivers feel ambivalent about full-time placement (Lyons,1984). One elderly caregiver caring for his wife (who was in the third phase of the illness) 24 hours a day and barely surviving wrote, "This fact is always in one's mind, can you let your wife enjoy her last rational moments at home in her known surroundings before being placed in an institution." Another Category One caregiver stated, "We've had a 'close call' with institutionalization (which turned out to be necessary as a temporary measure)."

However, with the progression of the disease requiring 24 hour nursing care, many caregivers turned to institutional care for the patient (23 of 29 caregivers of patients in phase three of the illness reported the patient as presently living in, or having lived in a care facility before they died). Sands and Suzuki(1983) and Zachary(1984) advised that a disease like Alzheimer's, affecting all behaviours and presently medically untreatable, requires an environment which enables persons with such impairment to function at their highest level. The environment, Zachary states, should be changed to fit the Alzheimer patient, not the patient changed to fit the environment. In the present research, respondents also emphasized the requirement of "institutions especially for Alzheimer's sufferers" and that there was a "need for institutions where patients can safely wander both inside and in a garden area."

Research Question Two

Responses indicate that support available to the primary caregiver and the patient varies with the progress of the disease. With 41 respondents reporting knowledge of an adult day care facility within a

reasonable distance and only 13 caregivers reporting actual pat. attendance at such a center, research is warranted into why so m Alzheimer's families were hesitant to use such a facility. Paschk (1984) maintains that, if structured to meet the needs of the Alzheimer patient, attendance at an adult day care can slow down the devastating results of the disease and at the same time provide respite to families to help them keep the patient at home(Berman & Rappaport,1984). Only 2 of the 8 Category Three primary caregivers whose patient had died within the preceding two years reported that the patient had attended a day facility for recreation and care when living at home. Interestingly, in Category Two, twice as many caregivers (10) now believed that the patient would make use of an adult day care facility than that number of caregivers (5) reporting previous patient attendance. Do these respondents believe they might have managed to keep the patient living at home longer had the patient been able to adjust to day care and/or had the patient and caregiver been given individualized assistance from in-home recreational therapists?

Another reason for such a low attendance at an adult day care may be that caregivers are approaching the L.T.C.(Long Term Care) program in the later stages of Alzheimer's disease. Attendance at an adult day care facility in the Greater Victoria area presently requires previous assessment through Long Term Care and perhaps caregivers only approach the L.T.C. program when the care of the patient has progressed to a state of dependency that can no longer be managed alone. As one primary caregiver of a patient (in phase three of the disease) living at home commented, "Using (day care) facility now but often curtailed as she disturbs others at the Geriatric Day Hospital who are normal. Attendance restricted to a four hour period. Object to give caregiver a rest." Another caregiver whose patient was now deceased wrote, "Day care arranged partly for my benefit. This was cancelled after three months as patient was confused by new setting and strange people. He was then admitted to full time care."

Berman and Rappaport(1984) proposed that a values issue that families needed to consider early is whether decision making and care

provision "should remain the domain of the family, or be shared with formal sources of support"(p.58). Toseland et al.(1984) wrote that most referrals to social workers are usually late in the disease process when the caregiver's capacities have reached their limit in maintaining their patient at home. While services can be of help in crisis situations such as these, Toseland et al. suggest that intervention (by social workers) when Alzheimer's disease is first established may be helpful in reducing the caregiver's burden and the rate of deterioration of the afflicted individual, stabilize a situation, and prevent premature institutionalization.

The results of the present study confirm that caregivers' stresses in seeking home help are extreme. Professionals working with Alzheimer's families have emphasized that arrangements must be made to regularly relieve the primary caregiver as the disease moves into the middle phase(Beattie,1984; Heston & White,1983). Comments by caregivers of phase two patients living at home included, "At present I am away not more than 3 hours weekly all told and worry," and "There is a breaking point when the caregiver must have outside help." One caregiver of a phase two patient now living in a care facility wrote, "You cope for as long as possible without putting a patient into a home." The group with the highest number of caregivers reporting an inability to avail themselves of needed support for a regular period of respite were 6 caregivers of patients in phase two of the illness and living at home. This latter group of phase two patients yet living at home (Category One) is 1 patient less than the number of phase two patients (7) living full-time in a care facility (Category Two). If the amount of home help required for the care of these institutionalized phase two patients had been available to their caregivers, would the choice and possibility have been to have kept the Alzheimer afflicted person living at home?

Present results indicate that the diversity in available home help may be because most caregivers cannot afford the help they require. One caregiver of a phase two patient living at home reported the home help to be commercial care service (at great expense) 12 hours daily Monday

to Friday and family help on weekends. A phase three caregiver attempting to keep the patient at home as long as possible wrote, "I am resigned to selling my home and reducing my standards to an absolute minimum." Other caregivers of patients in phase two and living at home reported available home help ranging from none, to when the situation was critical, to "4 hours weekly pending." One Category One caregiver of a phase two patient wrote, "I want to take care of him as long as I can - I don't want to be left penniless at my age. I can't go to work any more at this stage." The present study confirms reports that with the persistent deterioration of the patient, caregivers are forced to keep adjusting to new levels of impairment and problems(Barnes et al.,1981; G.D.Cohen,1984). The financial costs of supporting the Alzheimer patient successfully in his or her home as this disease progresses warrants investigation.

With 24 hour nursing care or hospitalization necessary in the final phase, families face the major decision of nursing home placement(Lyons, 1984). In this study, responses by caregivers are in agreement with Zarit and Zarit(1982) that having the patient move into institutional care changes the type of burden experienced by primary caregivers but does not remove it. Gwyther and Matteson(1983) wrote, "Families need reassurance that they continue to be important to the institutionalized relative for emotional, affectional meaning"(p.95) and have to be able to work through their grief over separation as the patient is moved into an institutional setting. In the results of the present research, of the 23 respondents whose patient was now living in a care facility (Category Two), 16 primary caregivers were in favor of having regular support meetings with other caregivers in a similar caregiving position as themselves and 18 of these primary caregivers of now institutionalized patients actively attended support meetings.

Sands and Suzuki(1983) and Zarit and Zarit(1982) criticized nursing homes as generally maintaining a custodial bias in the "management" of dementia patients. Due to their deficiency in learning as a result of the disease, newly institutionalized Alzheimer patients will experience considerable difficulty learning new routines. Zarit and Zarit contend

that because patients are having problems adjusting they are frequently tranquillized and the drugs most commonly used, rather than alleviating problems, often exacerbate them. The last thing an Alzheimer patient requires, Kushnir(1982) cautions, is further disturbance of his or her neurotransmission through the use of controlling medication as "the agents used can serve to further increase imbalances in levels of central neurotransmitters, and perhaps, in some cases, may be precipitating factors for dementia"(p.21). Sands and Suzuki(1983) reported that the use of medications and/or restraints as a reaction to the wandering behaviour of Alzheimer's patients and as a form of control distresses family members.

In the present study only two respondents raised the issue of restraints remarking, "no encouragement to walk, tied in wheelchair for convenience of staff and safety of patient," and "It seems medical help is limited to using pills for sedation purposes - unfortunately necessary in this kind of environment." More caregivers expressed concerns of understaffing and difficult communications with hospital personnel in their relative's facility. Twenty-four primary caregivers of 31 patients reported as presently living in, or having lived in, institutional care responded that they were happy with the facility for their patient. Eighteen of these caregivers reported that they believed their patient's institution was geared to the care, while 10 caregivers believed their patient's institution was not geared to the care of Alzheimer's patients. While it is not entirely clear whether respondents are referring to the patient's present facility or a previous one, it is notable that 13 (57% of those responding) of these primary caregivers reported that the patient had to be unsuitably placed because of a lack of a suitable facility. As one Category Three caregiver wrote, "I had to take second choice. I know that if my husband had been allowed to go to the extended care I picked as number one, he would have been a lot happier in his last year." Another caregiver in Category Two wrote, "There are not enough facilities in this city. Far too long a waiting list and patients, while in a holding area, are moved too frequently and

it is very upsetting for them." A caregiver of a patient living at home (Category One) noted a long waiting list for respite beds, and wrote of much satisfaction for one facility experienced, but of another where her husband had stayed for a brief interval she commented, "I would rather stay home than put him in there." While not all respondents offered comments, of those 4 whose remarks expressed confidence in the patient's care facility, caregivers used such phrases as "clean and homey," care offered "in a kind and loving way," "exercises, games, crafts, concerts, and outings," and "caring and competent staff."

Of caregivers in Category Two (patient presently living in a care facility) responding to the question of patient recreation, the most frequent activity referred to (noted by 5 of the 8 respondents commenting) as giving the patient pleasure, was walking. Jones(1986) emphasized that the best thing for patients is exercise and that every person with Alzheimer's disease should have a walking program performed with the same dedication as eating and washing. For example, Jones advises that by preceding meals with pleasant walking, the patient is able to approach eating more calmly and independently. Jones's advice agrees with other reports (Sands & Suzuki,1983; Zachary,1984; Zarit & Zarit, 1982) which state that confinement of Alzheimer's patients by physical restraint or medication can be avoided by structuring an environment that provides a safe wandering space "both inside and in a garden area" (as phrased by a present respondent) and permits the patient to set his or her own pace. In response to the present questionnaire, the comment most frequently repeated by primary caregivers regarding institutional care was that expressing a need for care facilities especially for people suffering from Alzheimer's disease.

Research Question Three

The results indicate that not all primary caregivers believe they and their patient are receiving proper guidance and are correctly informed about medical care from the professionals whose services they require. While 74% (34 of 41) of the responding caregivers believed their family doctor was knowledgeable about Alzheimer's disease and 16 of 25 caregivers answered that they had received a further referral if their

family doctor was not knowledgeable about the disease, just 56% (23 of 41) of those caregivers responding to a question regarding medical guidance believed they were offered proper guidance as the patient's illness progressed. Only 6 of these latter affirmative responses were from caregivers whose patients presently lived at home.

In their reports, medical professionals working with Alzheimer's patients advised patients and their caregivers to continually question the quality of care they are receiving(Beattie,1984; Berman & Rappaport, 1984; G.D.Cohen,1984; Heston & White,1983; Mace & Rabins,1981; Powell & Courtice,1983). The initial task, they stated, was to find a physician who was able and willing to give the time and interest required to answer questions and closely monitor patients. In the present research, this level of contact with a physician was described by several respondents. One caregiver of a patient now living in a care facility (Category Two) wrote, "If all were as fortunate as I am in this respect, they would be fortunate. My doctor has counselled me and really helped me through the hard times, continually relating to me what to expect as we go along." Another Category Two respondent wrote that their former family doctor "did nothing and didn't care" but with their present doctor they were "now receiving excellent help." A respondent whose Alzheimer afflicted relative lived at home described how their previous doctor "did not offer any support or advice to the immediate family members" but the patient "now has an excellent young doctor who gives her a checkup on a regular basis, . . . is always available to talk to the family and has been an invaluable source of information and advice."

Other primary caregivers revealed less satisfactory circumstances with comments like "I don't know" and "He isn't a great help" from caregivers (of patients living at home) concerning their physician's knowledge of Alzheimer's disease. Two respondents whose patients were now deceased (Category Three) described how, when requesting a further referral, "He [the doctor] said he preferred 'to consider the symptoms as part of the aging process'!" and "When I suggested a second opinion he said it was not needed." A primary caregiver whose patient was in phase two of the illness and living in a care facility (Category Two)

answered "no" to the question of proper medical guidance and added "not so far." Another Category Two caregiver of a patient in phase three advised that the "Family physician should know more about the disease and what channels to send the family to."

The comments by respondents expressing a need for continual practical guidance and accurate information about what to expect as the disease progresses are consistent with issues raised in other reports (Fiore et al.,1983; Glosser & Wexler,1985; Kahan et al.,1985; Ware & Carper,1982). In their research, Fiore et al. found that upset in the area of cognitive guidance was most predictive of depression in spouse caregivers to Alzheimer's patients. Cognitive guidance was defined as help which clarifies or furthers the subject's understanding of problems, for example, providing information about the illness' course. In the present study, several primary caregivers stressed that families should be advised more of the many problems involved, how to cope, and what to expect as the disease progresses. A respondent caring for a patient living at home and in phase three of the illness wrote, "I consider the lack of information and a source to seek professional advice is the greatest cause of nervous breakdown on the part of the careperson." Another respondent whose patient was now deceased advised, "as a patient advances through the three stages of Alzheimer's disease, specific well-known symptoms and how to deal with the problems which arise should be indicated by the physician." Such statements agree with those made by health care providers(G.D.Cohen,1984; Goldberg,1985; Gwyther & Matteson,1983; Mann,1985) that for continuity, health care management must correspond to the stages of Alzheimer's disease with nurses, mental health professionals, and social workers available throughout the illness and bereavement. With increasing attention being paid to educating medical professionals and support providers about Alzheimer's degenerative brain disease, the gap between the medical guidance Alzheimer's patients and their caregivers require and what individual families at present are receiving will narrow.

Research Question Four

The results indicate that almost all of the respondents to the

questionnaire believe there is an increasing concern and public awareness about Alzheimer's degenerative brain disease. One respondent whose patient was now deceased (Category Three) wrote that when the patient had become afflicted no one had even heard of Alzheimer's disease and, "It took doctors 4 years to put a name to it." Another Category Three caregiver wrote that around 1973 when a diagnosis of suspected Alzheimer's disease was made, the name was a completely new word to this respondent and most of the nursing staff. Yet another Category Three caregiver wrote that recently watching a television program on Alzheimer's disease had been like living her husband's illness all over again. She advised that there should be more discussion of this disease. A caregiver of a phase two patient living at home (Category One) knew of "families who have someone in a home or institution and don't wish others to know or talk about it." Talking about it, this respondent advised, would help in increasing public concern and awareness. The experience of a caregiver of a phase two patient living in a care facility (Category Two) has been that as well as the increased research interest (Loder,1985) another change is occurring. "In the past," this respondent wrote, "families tended to keep the ailment a secret. Now people are discussing it openly."

There are indications of increased awareness in the general public about Alzheimer's disease demonstrated by news items, televised documentaries on the subject, Alzheimer's disease being entered as the cause of death on the death certificate, and more people availing themselves of information through the Alzheimer's Support Association. However, the high affirmative response to research question four could possibly be biased because of the closed population selected. Due to their own increasing awareness through contact with support services, these primary caregivers may resultantly believe that the larger society is also more aware and concerned.

The comments offered by caregivers with regard to their individual economic plights point out the necessity to investigate (a) the legal/moral rights of the patient and primary caregiver and policies regard-

ing support and financial assistance, and (b) the costs of providing the most appropriate care to people afflicted with Alzheimer's disease.

Limitations of the Present Study

One limitation of this research is that the sample was nonrandom. All subjects had at some time contacted the Victoria Alzheimer Support Association or Information Centre. There are undoubtedly situations where the caregiver has not been able to seek support and information through such a centre. This problem was raised by Bennett(1983) who cautioned that because of the emotionally draining and physically demanding situation, caregiving spouses are vulnerable to illness themselves. If an aggressive outreach homecare program is lacking, the caregiver and the patient as a couple may be ill and isolated. "A demented person and an ill spouse who have no other supports," Bennett wrote, "often find it impossible to negotiate the system to avail themselves of information and services"(p.256). It would be helpful to know how Alzheimer's caregivers who had not contacted an Alzheimer's support centre coped, and if and how their needs varied from those caregivers who did seek information about the disease from the centre.

Another limitation was the necessity for some subjects to respond to some questions through recall. Sudman and Bradburn(1983) write that recall questions are subject to memory error. They also advised that while open-ended questions cause little difficulty in face-to-face interviews, because they require the respondent to write rather than speak "they are far more difficult [to answer on] mail and self-administered surveys [and] they should be used rarely or avoided"(p.266). However, the saliency of the present topic to the respondents was indicated by both the number of primary caregivers who chose to respond to the questionnaire (78.1% of those contacted) and their many informative comments in the open-ended questions.

For the majority of respondents the experience of providing care to the Alzheimer afflicted person was either on-going or very recent (8 of the 11 patients in Category Three died within the two years preceding this questionnaire). All caregivers responded to the

questionnaire with the accumulated knowledge of years of providing daily care to an individual through part or all of the process of Alzheimer's disease. The type of support they required and their perceptions of various issues were (collectively and individually) consistently similar to reports in articles by professionals working with Alzheimer's patients and their families. This consistency in the responses of subjects both with each other and with published reports suggests that the type of support required by the primary caregivers in the present study could be generalized to support required by Alzheimer's caregivers and patients in similar caregiving situations.

Research to further understand the specific needs of Alzheimer's afflicted persons could be done in longitudinal studies taking one area of concern, i.e. recreation, home help, institutional care (both for respite and full-time), or medical guidance and investigating the experience of primary caregivers and patients at the onset of its requirement to the completion of its need. Such research would help in advising how best to provide support for Alzheimer afflicted individuals in the early stages of the illness and for the primary caregivers upon whom the course of the disease progressively renders its victims dependent.

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APPENDIX A

The Covering Letter

646 Ridgebank Crescent
Victoria, British Columbia V8Z 4Y3
April 4th, 1986

Dear Primary Caregiver,

The purpose of this research is to help determine the requirement and availability of support systems and resources for the individual afflicted with Alzheimer's disease, and his or her primary caregiver, as the disease progresses.

I am a volunteer with the Alzheimer's Information Centre at 841 Fairfield Road, Victoria, and I am also compiling this study for a master's thesis through the University of Victoria. It is only through public recognition of the enormity of the problem of Alzheimer's disease and its emotional impact on the family and on society that adequate resources and funding will become a government priority. Your response to this questionnaire will provide useful material by helping to inform health care personnel and the general public of requirements and conditions necessary for support of the Alzheimer's patient and the person primarily responsible for his or her daily care - that is, the primary caregiver. If your patient lives in a care facility, for the purpose of this research, you are still regarded as the primary caregiver having been established in that position in the earlier phases of the disease.

You are not required to sign your name to the returned questionnaire, and the anonymity of you and the individual afflicted with Alzheimer's disease will be maintained as there is no other identifying factor associating your questionnaire to your name.

I would appreciate very much if you would complete the questionnaire as soon as possible and return it to me by May 5th, 1986. If you find a question confusing please just omit it and continue with the next item. However, if you wish for further explanation on any question, you can phone me in the afternoon between the hours of 3:00 and 5:00, or in the evening between the hours of 7:00 and 9:00. My phone number is 479-2017.

Thank-you for your responses and your co-operation in providing this information. It will be useful in assessing the adequacy of current services, and setting a direction for the future.

Sincerely,

Dorothy D. Peet

APPENDIX B

The Questionnaire

A. (Please check spaces that apply to you and your patient.)

1. ____Alzheimer patient at home. (and) ____Primary caregiver at home.
2. ____Alzheimer patient in a care facility. ____Primary caregiver at home.
3. ____Alzheimer patient deceased. (and) ____Primary caregiver at home.

B. If you are the primary caregiver are you in relation to the patient?:

_____husband _____wife

_____daughter _____son

_____brother _____sister

_____other (please explain)_____

C. Is the victim of Alzheimer's disease _____male or _____female?

D. 1. Present age of Alzheimer's victim? _____years.

2. Present age of primary caregiver? _____years.

E. 1. (Number of) years since believed onset of Alzheimer's disease? _____.
2. (Number of) years since medical diagnosis of Alzheimer's disease? _____.
3. (If applicable) years since Alzheimer patient has (had) been in an institution? _____.
4. (If applicable) years since Alzheimer patient has been deceased? _____.

F. 1. Have you lived in Victoria since the onset of this illness?

_____yes _____no

2. Where did you live, if not in Victoria, at the onset of this illness?

_____city _____province _____country

3. How long have you lived in Victoria as relates to the course of this illness? _____years.

The phases of Alzheimer's disease:

Phase One:

An afflicted individual develops problems in communication, memory loss for recent events, slow changes in the ability to learn new things, difficulty in making decisions and coping with new situations, impaired judgement, and possible outbursts of temper and suspiciousness resulting from frustration. By the end of the first phase people with Alzheimer's disease are having difficulty organizing dates and time, adding and subtracting incorrectly, and forgetting various tasks. It is during the first phase, if the Alzheimer's individual is employed that he or she is usually performing poorly at work and will eventually discontinue the employment.*

Phase Two:

An afflicted individual's memory functions continue to deteriorate. There is a decline in other aspects of intellectual ability, including language and the ability to communicate and to conduct daily activities without supervision or guidance. Due to misperceptions of what is happening, the person may respond to people or objects in an aggressive way. (For example, someone approaching quickly to help with dressing may be seen as a threat, particularly if the approach is from behind or from one side (at the edge of the person's field of vision)). There is increased disorientation to time and place and the individual may be unable to recognize himself or herself in a mirror. There is frequent struggling to control bodily functions and some will be maintained longer than others. A loss of dexterity may interfere with self-care routines such as dressing. Restlessness particularly at night may occur. There may be a slowing down of body movements and the individual may physically resist help.*

Phase Three:

In this phase 24 - hour nursing care is usually necessary. Hospitalization may be required to treat the increasing occurrence of physical disabilities and illness. The ability to speak or communicate disappears. There is increased immobility. Loss of bowel and urine control greatly increases. Twitches or jerking may develop, and seizures may occur. There may be a complete absence of any spontaneous movement or reaction to people or other stimuli. Reflexes develop, such as the one that causes sucking of anything put into the mouth.*

G. 1. Into which of these three phases would you place the Alzheimer patient now?

_____Phase One

_____Phase Two

_____Phase Three

_____Alzheimer patient deceased.

* Alzheimer's Disease: A Family Information Handbook, Health and Welfare Canada, 1984.

(Please answer the following questions as they apply to you and your Alzheimer patient. If your Alzheimer patient has deceased please respond to the questions in the way that you feel describes your situation when your patient was alive.)

H. 1. Is there an adult day care facility available within a reasonable distance to you? _____yes _____no

2. Would your Alzheimer person make use of such a facility?

_____yes _____no

3. Does your Alzheimer person attend an adult day care facility?

_____yes _____no

4. Does this adult day care facility offer appropriate individual activities _____yes _____no and group activities _____yes _____no for Alzheimer patients?

5. Is (was) your Alzheimer person able to occupy himself or herself with some meaningful on-going activities during the first phase of this illness? _____yes _____no. Did providing meaningful diversional activities present an on-going problem during this phase? _____yes _____no.

6. Is (was) your Alzheimer person able to occupy himself or herself with some meaningful on-going activities during the second phase of this illness? _____yes _____no. Did providing meaningful diversional activities present an on-going problem during this phase? _____yes _____no.

7. It is believed by some people that Alzheimer's patients respond better to discussion of memory problems than avoidance of the topic. Do you believe that your Alzheimer person would benefit (would have benefitted) from an on-going self-help group with other Alzheimer's patients during the first phase of this illness? _____yes _____no.

8. Have you any opinions you would like to share with regard to finding appropriate activities and recreation for an individual afflicted with Alzheimer's disease?:

I. 1. Is there a health care person who visits your patient on a regular basis? _____yes _____no.

2. Most people have a family doctor. Is your family doctor knowledgeable about Alzheimer's disease? _____yes _____no.

3. If your family doctor was not knowledgeable about Alzheimer's disease did he or she refer you to someone who was? _____yes _____no.

4. In treating the Alzheimer's patient do you believe the medical professionals whose services you require offer proper guidance to you as the patient's illness progresses? _____yes _____no.

5. Many families reach a point of desperation before requesting an assessment, often because they are unaware of services available to them. Do you feel that you are receiving adequate medical help?

_____yes _____no

6. Have you any comments you would like to make at this time in regard to what medical guidance you would like to be provided with in caring for the Alzheimer's patient?:

J. It has been said that primary caregivers need a "prescription" to take care of themselves in order to continue their availability to the patient. It is important that you, the primary caregiver, schedule a regular period of respite or "time-out" for yourself from caregiving.

1. Has this been possible for you? _____yes _____no.

2. If yes, is this through family help? _____yes _____no.
   or outside help? _____yes _____no.

3. What home help has been made available to you? _____

   _____

4. What health care personnel are available to you (for caregiving to your patient) during:
   (a) a regular period of respite? _____

   _____

   (b) emergency respite? _____

   _____

5. What health care facilities do you believe are available to you (for accommodating your patient) for:
   (a) a regular period of respite? _____

   _____

   (b) emergency respite? _____

   _____

6. Are you in need of home help? _____yes _____no.

7. A major problem for families during the second phase of this illness is home management. Supervision and constant care may now be required. It has been found that primary caregivers tend to carry the care alone for too long and in some situations other family members may have to insist on helping. Would you please comment on this?:

K. 1. Caregivers state that their major coping stresses are their own fatigue and lack of time for themselves and their other responsibilities. What would you say are your major coping stresses?

2. Caregivers may not be feeling as well as age peers, but they may get genuine recognition for coping and surviving from other families who have been on that road before. Would you be in favour of having regular meetings with other caregivers in the same position as yourself?

_____yes _____no

3. Do you attend any meetings organized for Alzheimer's patients and their families? (i.e.) Such as a monthly meeting organized by the Alzheimer's Support Association?

_____yes _____no

L. 1. Were you made aware at the onset of this disease that there would be problems regarding the patient's affairs that would require legal services?

_____yes _____no

2. Were you able to contact a lawyer who was sympathetic to the patient's and your needs?

_____yes _____no

3. Was there a source of help in finding a sympathetic lawyer?

_____yes _____no

4. Have you any opinions you would like to share about legal services and the particular position families with Alzheimer's patients find themselves in?:

M. 1. Is your patient in a care facility? _____yes _____no.
(If yes, please respond to points 2. through 9.
Please consider point 10. if you have any comments.)

2. Are you happy with the facility for your patient? _____yes _____no.

3. Is your care facility geared to the care of the Alzheimer's patient? _____yes _____no.

4. Did you find you had a choice of institutions? _____yes _____no.

5. Does the institution encourage interaction between you and the patient? _____yes _____no.

6. Is transportation to and from the institution a problem when you visit? _____yes _____no.

7. Are appropriate individual activities offered in your patient's institution? _____yes _____no.

8. Are appropriate group activities offered in your patient's institution? _____yes _____no.

9. Did your patient have to be unsuitably placed in a care facility because of a lack of a suitable available facility? _____yes _____no.

10. Do you have any other comments on institutions you would like to make at this time?:

N. 1. Do you believe there is a greater awareness in the general public of Alzheimer's disease now than there was three years ago?

_____yes _____no

2. Do you believe there is an increase in the concern of the public to be educated about Alzheimer's degenerative brain disease than there was three years ago?

_____yes _____no

3. Have you any other observations you would like to make about increasing public concern and awareness of Alzheimer's disease?:

4. It is only through public recognition of the enormity of the problem of Alzheimer's disease and its emotional impact on the family and on society that new funding and adequate resources will become a government priority. Loss of income and/or medical costs associated with home care or institutionalization of the patient may result in families facing financial hardship. Do you have anything to say about this?

Thank-you for responding to this questionnaire. If you find you have other opinions you would like to share, or previous points you would like to further comment on, please continue on the other side of this page and note the number of the question you might be referring to.

VITA

Surname: PEET Given Names: DOROTHY DOBBIE

Place of Birth: VANCOUVER, B.C. Date of Birth: MAY 30, 1947

Educational Institutions Attended, with Dates of Entering and Leaving:

UNIVERSITY OF SASKATCHEWAN, SASKATOON	1965 to 1967
UNIVERSITY OF VICTORIA, B.C.	1968 to 1969
UNIVERSITY OF SASKATCHEWAN, SASKATOON	1971 to 1972
UNIVERSITY OF VICTORIA, B.C.	1981 to 1987

Degrees, Diplomas, Etc., Awarded, with Dates and Names of Institutions:

Standard "A" Teaching Certificate	1967	Saskatchewan Ministry of Education
B.A.	1978	University of Saskatchewan
Professional "A" Teaching Certificate	1979	Saskatchewan Ministry of Education
Professional Teaching Certificate (Non-Expiring)	1982	British Columbia Ministry of Education

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ALZHEIMER'S DEGENERATIVE BRAIN DISEASE

AN INVESTIGATION INTO THE USE OF SUPPORT SYSTEMS

BY PRIMARY CAREGIVERS AND PATIENTS

Author: [redacted]

DOROTHY DOBBIE PEET

April 10th, 1987