THE WELL-BEING OF OLDER WIVES CARING FOR
HUSBANDS WITH ALZHEIMER'S DISEASE

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Abstract

This study was conducted to document the well-being of older wives caring for husbands diagnosed with Alzheimer's Disease. Data were collected by means of a self-administered questionnaire designed to elicit information regarding the caregivers' physical health, mental health, participation in and satisfaction with preferred activities, financial resources and health behaviours. Analyses of the data revealed that the wives were experiencing deficits in all domains of their well-being with the exception of financial resources. These deficits were significantly more profound than the deficits experienced by a sample representative of the general population and a sample of a more heterogenous group of caregivers. Normative data on the well-being of older women fail to account, in full, for the discrepancies between the study wives and the 2 comparison samples. These findings support the thesis that the caregiving experience per se is responsible, in part, for the deficits in the wives' well-being. They also demonstrate that older wives caring for husbands with Alzheimer's Disease are a group of caregivers particularly at risk to experience deficits in their well-being as a result of caregiving. The conclusions support the need for nurses to view caregivers as patients, in their own right, who require regular and frequent assessment and intervention. Community programs must incorporate the needs of caregivers into their mandate to ensure that their well-being is not at risk due to the
demands or burden of caregiving. Other implications and suggestions for further study are discussed.
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CHAPTER ONE

Introduction

Background to the Problem

Care of the chronically ill elderly has become an issue of increasing concern for health care practitioners, planners and family members (Polanksy, 1982). The foremost factors contributing to this issue are the high prevalence of chronic illness in the elderly, coupled with the shift occurring in society's age structure (Jette & Branch, 1981). Canada has witnessed an unprecedented growth rate of the population of persons in the 65 years and older age group. From 1971 to 1981, the number of aged increased by 35%, whereas the total population grew by only 13% (National Council on Welfare, 1984). Current estimates place the elderly at 10% of the population (National Council on Welfare, 1984), and it is estimated that, by the year 2001, the proportion of elderly will increase to between 11% and 13% (Statistics Canada, 1976).

Concomitant with this social trend is an increase in chronic illnesses (Jette & Branch, 1981). Persons in the 55 to 64 year old age group are 6 times more likely to suffer from a chronic illness than are people who fall within the 18 to 44 year old age group. Persons over 65 years of age are 5 times more likely to be functionally disabled than the general population (Polanksy, 1982).

One devastating chronic illness which occurs in the aging
population is deterioration in mental functioning or dementia (Kay, 1972). The most common of the dementing disorders is Alzheimer's Disease, believed to account for 50% to 70% of those suspected of suffering from dementia (Watson & Seiden, 1984). Alzheimer's Disease affects an estimated 100,000 to 300,000 Canadians (Hirst, 1981), and it is estimated that, by the year 2015, as many as one million people in Canada may be suffering from the disease (Watson & Seiden, 1984).

No definitive cause or cure for Alzheimer's Disease has been established, but it is confirmed that it is a chronic, progressive, and degenerative neurological disease (Raskind & Storrie, 1980). Structural brain damage results in progressive deterioration of memory, intellect, personality, and self-care ability over a protracted course ranging from two to ten years (Barnes, Raskind, Scott & Murphy, 1981). Thus, the management of Alzheimer's Disease is and will continue to be a major health concern given that there is no cure, the incidence increases with age, and that the over-65 population is the largest growing segment of our population (Brody, 1982; Hirschfeld, 1983).

Family caregiving, permitting the person with Alzheimer's Disease to remain in the community, is both a socially and financially attractive form of management (George, 1983). Socially, remaining in the community may optimize the level of individual functioning (Eisdorfer & Cohen, 1981) and avoid the negative effects of institutionalization. For example, studies report especially high rates of mortality amongst
those persons with Alzheimer's Disease moved to an institution (Blenker, 1967), and indicate that Alzheimer's patients show greater impairment in unfamiliar settings (Plutsky, 1974). Economically, community care may be cost-effective in that it reduces health care costs associated with institutionalization (Nardone, 1980). Most persons with Alzheimer's Disease do not reside in institutional settings but reside at home, cared for by family members until late in their illness (Brody, 1974; Sanford, 1975; Bergmann, Foster, Justice & Matthews, 1978). Families in Canada are thought to be providing care to approximately 90% of all those with Alzheimer's Disease (Alzheimer's Society of Canada, 1984).

Review of research related to management of persons with dementia in the community clearly documents that the older female spouse caring for a husband with dementia is the most common scenario (Sanford, 1975; Isaacs, 1979; Zarit, Reever & Bach-Peterson, 1980; Robertson & Reisner, 1983; Chenoweth & Spencer, 1983). These results were expected in that previous literature consistently reports that women have traditionally been the caregivers in society and that the caregiver in an elderly couple is most likely to be the female spouse (Brody, 1974; Shanas, 1979). This may well be due to women's longer life expectancy and tendency to be younger than their husbands, resulting in a situation where women are less likely to have a spouse to care for them (Shanas, 1979). However, even when a spouse is present, aged women with dementia are more likely to be institutionalized than aged
men. This phenomenon is explained by the fact that the socialization of women versus men into the caregiving role equips men less well to look after a sick spouse and run the home than does that of a woman similarly placed (Grad de Alarcon, Sainsbury & Costain, 1975).

Although community care of persons with Alzheimer's Disease is socially and economically appealing, many literature sources discuss the "burden" of family caregiving. Caregiver burden refers to the variety of effects that the family caregiver experiences as a result of the demands of caregiving (Poulshock & Deimling, 1984). The most frequently mentioned problems lie in the domains of the caregiver's physical health, psychological well-being, social life and finances (Zarit, 1982). Clinical and anecdotal reports refer to caregivers experiencing such problems as fatigue, depression, guilt, back injuries, hypertension, financial hardship, and social isolation (Vorgna, 1979; Moryc, 1980; Safford, 1980; Eisdorfer & Cohen, 1981; Mace & Rabins, 1981; Crossman, London & Barry, 1981; Colman, Sommers & Leonard, 1982; Hayter, 1982; Kapust, 1982; Sheldon, 1982; Ware & Cooper, 1982; Levine et al., 1984; Cutler, 1985; Mann, 1985; Wasow, 1985; Woods, Niederehe & Fruge, 1985).

Very few studies have systematically examined the impact caregiving has on the physical, psychological, social, and financial well-being of family caregivers (Polansky, 1982). Available research has focussed on a variety of caregivers caring for persons with varying disease processes. The
research methods and conceptualizations of well-being used have been quite disparate. The results suggest that caregiving is associated with lower perceptions of well-being (Fengler & Goodrich, 1979), decreased time for preferred social activities and increased need for social support (Zarit et al., 1980), high levels of subjective stress and low life satisfaction (S sexton, 1985), and psychological stress and limitation of preferred activities (George, 1983; 1984). Thus, while it is undoubtedly true that in public expenditure terms home care is less costly, review of the literature and research indicates that the costs to the caregivers in terms of their well-being have not been fully addressed (Rimmer, 1983).

Taken together, little is known about the well-being of caregivers in general (George, 1983), and much less is known about the well-being of older wives caring for husbands with Alzheimer's Disease. Furthermore, cross-study comparisons may not be the most appropriate data base for understanding the well-being of this particular group of caregivers for the following three reasons: (1) Benoliel (1983) suggests that research on the effects of illness on the family be disease-specific due to the unique nature of individual disease processes which may pose special problems not encountered by other caregivers; (2) Cantor (1983) argues that the closer the bond between family members the more stressful is the caregiving role, suggesting the need to study unique caregiving relationships within the family; and (3) Fengler
& Goodrich (1979) state the older caregiving wife is in the situation where the demands of caregiving are being superimposed on the stresses the older woman is already experiencing as she attempts to cope with her own aging process and its related changes.

**Problem**

Concomitant with the recognition of the primary caregiving role played by families of persons with Alzheimer's Disease has been the increased awareness that caregiving can place the caregiver at increased risk for physical health problems, psychological difficulties, restrictions in social activities, and financial strain (George, 1983). Despite the numerous clinical references to such problems, the extant research base documenting the impact of these problems on the well-being of the caregiver has been limited.

Older female spouses caring for husbands with Alzheimer's Disease constitute a large proportion of the family caregiving population providing care in the home. The nature of the wife-husband relationship, the particulars of managing Alzheimer's Disease versus other illnesses, and the likelihood that the older spouse is experiencing age-related changes suggest that the well-being of this unique group of caregivers be systematically studied.

**Purpose**

The purpose of this study is to document the well-being of older wives caring for husbands with Alzheimer's Disease.
Significance

The significance of this research for the nursing profession is that the findings may help to improve the quality of life for the caregiver as well as the quality of care the person with Alzheimer's Disease receives.

Because of nursing's concern with family-centred care, it is important that the well-being of individual family caregivers be documented to ensure their rights and needs are considered (Colman et al., 1982). Knowledge of caregiving wives' well-being will help to provide direction for the support and services needed to prevent the harmful consequences of caregiving. This may help to ensure that the caregiver is not sacrificing her own well-being and enjoyment of a reasonable quality of life (Sussman, 1979).

In addition, documentation of caregiver well-being may provide helpful insight into the quality of care which can actually be provided by the caregiving wife. This, in turn, may indicate the nature of the adjunctive services required to ensure the person with Alzheimer's Disease is receiving quality care in the home.

Finally, the ability of the spouse to continue to care for the husband with Alzheimer's Disease plays a major role in whether the patient is institutionalized (Isaacs, 1979). Therefore, appropriate support of caregiving wives will help to ensure that they are able to continue to care for their husbands in their homes, the environment in which the person with Alzheimer's Disease is likely to have the
best quality of life.

Thus, documentation of caregiving wives' well-being provides direction for the support systems they require to continue effectively in the caregiving role. This may make possible better care for the husband with Alzheimer's Disease by preventing premature institutionalization and alleviating elder abuse resulting from overwork and frustration (Colman et al., 1982). A program of home care for a person with Alzheimer's Disease can most effectively be instituted if one considers not only the afflicted person, but also the physical, psychological, social, and financial strains on the caregiver (Treas, 1977).

**Definition of Terms**

**Alzheimer's Disease**
A chronic illness characterized by chronic, progressive and degenerative neurological changes (Raskind & Storrie, 1980). Structural damage results in progressive deterioration of memory, intellect, personality, and self-care ability over a protracted course ranging from two to ten years (Barnes et al., 1981).

**Older wives**
Women over 55 years of age who are married to and residing with husbands who have Alzheimer's disease.

**Husbands with Alzheimer's Disease**
Men who have Alzheimer's disease and are married to and residing with wives over 55 years of age, who are caring for them.
Caring for

Pattern of assistance in which the wife is principally responsible for providing or coordinating resources required by the person with dementia such as, shopping, finances, personal care.

Well-being

A multi-dimensional concept referring to the caregiver's physical health, mental health, social activities, and financial resources as measured by multiple indicators (George 1983).

Assumptions

The researcher approached the proposed study with the assumptions that the well-being of the caregiving wife can be ascertained by the selected questionnaire and that the subjects will complete the questionnaire in an honest and truthful manner.

Limitations

The limitations of this study relate to the following:

1. The subjects may not be representative of the theoretical population of wives caring for husbands with Alzheimer's Disease.

2. The study documents the current status of caregiver well-being and is by no means a retrospective or longitudinal study.

3. The nature of the services received from the referring source may influence the subjects' well-being.
CHAPTER TWO

Literature Review

Overview

The well-being of family caregivers residing with relatives diagnosed with Alzheimer's Disease has received little scrutiny in the literature. No studies could be found which documented the well-being of older wives caring for husbands with Alzheimer's Disease. Furthermore, the impact of caregiving on caregiver well-being has been operationally defined and studied in numerous ways. Consequently, broad parameters were necessary to review the relevant literature.

The literature review is divided into four sections. In the first section, information summarized from various Canadian health surveys and pertinent literature on the well-being of older married women is presented to provide a normative basis for comparison.

Secondly, a large body of professional literature has developed regarding women as caregivers of the chronically ill elderly. Literature which applies to the specific situation of the older wife caring for a chronically ill husband will be addressed here. Two studies which examined the well-being of older wives caring for husbands with chronic illness are reviewed in the third section.

The fourth section is divided into 2 parts. First, a variety of sources in the professional literature describe the experience of caring for an elderly, demented relative.
Themes from literature which focussed on the particular experiences of spouses are addressed here. In the second part, several studies which provide information as to the well-being of family caregivers of an elderly, demented relative are reviewed.

Well-Being of Older Married Women

The life expectancy of Canadian women is 7.5 years longer than that of males (Lapierre, 1984). As a result of their greater longevity, however, women are subject to more chronic diseases and disabilities before death (Lapierre, 1984; Lewis, 1985). Wilkins and Adams demonstrated that a Canadian woman's disability-free life is only 3.6 years longer than a male's (Lapierre, 1984).

According to the 1978-79 Canada Health Survey, approximately 86% of elderly people reported at least one health problem (Minister of Supply and Services, 1983). The most frequent self-reported chronic conditions and impairments in older women were arthritis, hypertensive disease, and hearing and visual impairments. More specifically, 47% of women aged 65 to 74 years of age reported they had arthritis or rheumatism, 32% reported hypertension, and 5% reported cardiac disease.

There are significant discrepancies between the two sexes in the prevalence of diseases. For example, arthritis affects 23% of women beyond 45 as compared to 14% of men. Osteoporosis is four times as common in women as men.
(Faulkner, 1980). The incidence of hypertension is nearly twice as high among women aged 75 years and older (43%) than among their male counterparts (22%) (Minister of Supply and Services, 1983).

Results of the 1978-79 Canada Health Survey revealed that the proportion of persons whose major activity was partially or totally limited was estimated at nearly four times greater for those aged 65 years and older (Minister of Supply and Services, 1983). For example, 34% of the elderly female population had been partially or totally limited at some time in the previous 12 months as opposed to 9% of the population between the ages of 15 and 64 years. Although the same proportion of elderly men and women reported limited activity, elderly women versus their male counterparts were more likely to report disability days. Women, on average, reported 39 days of restricted activity of which 15 days were spent in bed while men reported 30 days of which 11 were spent in bed. These sex differences were even more substantial among those over 75 years of age.

In general, the elderly utilize health services more frequently than does the general population. Sex differences in utilization of health services among the elderly are not significant (Dulude, 1978). In terms of specific utilization patterns, results of the 1978-79 Canada Health Survey indicated that most of Canada's elderly see a physician annually. Approximately 18% of older women had not consulted a physician annually within the preceding 12 months while
approximately 25% and 55% had consulted a physician once or twice or more than three times, respectively (Minister of Supply and Services, 1978).

As women age, they increasingly become a population that is psychologically at risk (Dulude, 1978; Faulkner, 1980; Polanksy, 1980; Butler & Lewis, 1982; Porcino, 1985). Multiple role changes, losses, and the double standard of aging are but three of the explanations for this phenomenon.

On the basis of data from a Health Opinion Survey, it was found that a greater proportion of Canadian women than men experienced frequent symptoms of anxiety and depression (Lapierre, 1984). Epidemiological studies have also demonstrated a higher incidence of depression amongst women than men (Fittings and Rabins, 1985). In terms of the elderly, 41.5% of retired males had a positive affect, 33.6% had a mixed affect, and 5.5% had a negative affect. In contrast, 35.8% of retired women had a positive affect, 34.9 had a mixed affect, and 3.8 had a negative affect.

Regardless of their age, women use more prescription medications than men (Faulkner, 1980; Lewis, 1985; Porcino, 1985). Forty-five percent of North American women take mood-regulating drugs, including 72% of the prescribed anti-depressants and 70% of the minor tranquilizers (Faulkner, 1980). It is estimated that 50% of prescription drugs are prescribed to women over the age of 60 years (Porcino, 1985). As well, it is felt that alcoholism is on the rise among older women (Porcino, 1985).
Elderly Canadian women, those aged 65 and over, generally have poor health practices. Only one out of every 20 women in this age group was classified by the 1978-79 Canada Health Survey as having a very active level of physical activity (Minister of Supply and Services, 1983). Thirty-five percent of women in the 45 to 64 age range and 50% of women 65 years of age and older had a level of activity classified as sedentary or moderately inactive. Women were more likely than their male counterparts to be classified as inactive, especially in the upper age groups.

According to the 1970-72 Nutrition Canada National Survey, the elderly population had a higher percentage of inadequate or less than adequate intake for most selected nutrients than did the younger age groups (Minister of Supply and Services, 1983). Senior women were more likely to have inadequate intake than their male counterparts, particularly in terms of protein, iron, calcium, riboflavin, and niacin.

In terms of social activities, 80% of the elderly spent time visiting or talking with friends during the week of the February 1978 Survey on Selected Leisure Time Activities (Minister of Supply and Services, 1983). The elderly were only slightly less likely to talk with friends/relatives or engage in hobbies/crafts than the younger generations. One out of every 10 elderly Canadians did unpaid volunteer work during the period of the study.

The incomes of Canada's elderly tend to be disproportionately concentrated at the lower end of the
income scale (Minister of Supply and Services, 1983). In 1981, one-half of the families with members aged 65 years and older had incomes less than $15,000. In terms of property, Canadian seniors were as likely to own a home as younger Canadians. Sixty-five percent of household heads 65 years of age and older owned their own home and nearly 6 out of 10 owned the home mortgage-free.

Elderly married women are viewed as being in a vulnerable financial position (Dulude, 1978; Polansky, 1980; Equal Opportunities Commission, 1982; Rimmer, 1983; Walker, 1983). Dulude (1978) found that, other than the old age pension they received, at least one-third of older married women in 1975 had no personal income at all. The manner in which the Canada Pension Plan is calculated is viewed as ensuring that female pensioners will receive considerably lower benefits (Dulude, 1978; Equal Opportunities Commission, 1982). Furthermore, married women are much less likely to be receiving a pension from a former employer (Dulude, 1978; Equal Opportunities Commission, 1982). For example, Dulude (1978) found that, in 1975, only 29% of all Canadian female members of the labour force participated in private pension plans. Thus, it appears that when older women's husbands die many of them will have to exist on the inherited property.
Women as Caregivers of the Chronically Ill Elderly

Women take on the burden of caregiving due to female socialization patterns and the associated societal expectations. Firstly, women have traditionally been presumed to be responsible for the well-being of their family members. Until recently, the care and well-being of the family was the only occupation of a large percentage of women in North America (Sommers, 1985). Secondly, women are susceptible to the "compassion trap." Feminists state that, by virtue of their socialization, "the nurturing skills and sensitivity to human interactions that make women as a sex more responsive to pain and suffering also make them more willing to take on arduous and often unrewarded personal duties" (Sommers, 1985, p. 10). Thirdly, community care policies are viewed as euphemisms for poorly financed systems which place the burden of care on individual family members, particularly women (Equal Opportunities Commission, 1982; Oliver, 1983; Polanksy, 1982; Walker, 1983). Thus, the often-quoted policy of community care, to enhance rather than replace family support, is viewed as ensuring the continuance of the pattern wherein the prime responsibility for caregiving is carried by women. This, in turn, sustains the sexual division of labour with regard to family caregiving and constrains the demands on home support services.

Given this state of affairs, it is felt that wives have little choice about taking on the caring commitment. There
is a universal expectation from the medical and nursing professions, social services staff, the dependent, and other family members that wives will take on the responsibility (Oliver, 1983; Polanksy, 1982). Consideration is seldom given to the wife's own state of health, other demands on her time and energy, her employment, or the state of the marriage (Oliver, 1983).

The sexual division of labour in family caregiving is based on an underlying assumption that women are more able than men to care for elderly infirm dependents (Walker, 1983). Colman et al. (1982) state that, while health care professionals will help a husband find assistance to care for an invalid wife, they will send a man in the same condition home to his wife with such words as "Isn't he lucky to have a wonderful woman like you to take care of him" (Colman et al., 1982, p. 2). It is frequently reported that the presence of a wife in the home means that a man will be discharged home earlier from hospital and receive fewer aids, adaptations to the home, and domestic services (Oliver, 1983; Polanksy, 1980; Polanksy, 1982). Polansky's study of caregivers of the chronically ill revealed that 64% of the male caregivers had the assistance of some type of formal health care services in contrast to only 42% of the female caregivers. An even greater differential between the sexes was found in relation to the amounts of home health care services the two sexes received; 47% of the male caregivers had service four to seven days per week whereas only 13% of the female caregivers
had services to that extent (Polanksy, 1982).

Feminist authors have been most concerned about the impact caregiving has on the financial situation of female caregivers (Equal Opportunities Commission, 1982; Rimmer, 1983; Walker, 1983). A 1976 survey of the elderly at home found that, among women between the ages of 40 and 59, the need to give up employment because they had to care for an infirm relative came second only to poor health as a reason for retiring (Equal Opportunities Commission, 1982). While men are given services in order to continue employment, women are expected to quit their jobs (Polanksy, 1982).

The disadvantaged financial position of elderly married women may be exacerbated by the husband's illness (Polansky, 1980; Equal Opportunities Commission, 1982; Rimmer, 1983; Walker, 1983). The costs of caregiving incurred through expenses such as supplies and homemaker assistance may be compounded by a loss of the husband's income if he was gainfully employed when his illness struck.

The situation of the female family caregiver has been aptly summarized by Golodetz et al. (1969) as follows:

She is not trained for her job, a priori. She may have little choice about doing the job. She belongs to no union or guild, works no fixed maximum number of hours. She lacks formal compensation, job advancement and even the possibility of being fired. She has no job mobility. In her work situation she bears a heavy emotional load, but has no colleagues or supervisor or
education to help her handle this. Her own life and its needs compete constantly with her work requirements. She may be limited in her performance by her own ailments... (p. 390)

Well-Being of Wives Caring for Chronically Ill Husbands

As part of a larger study to examine the special needs and problems of elderly wives caring for disabled husbands, Fengler and Goodrich (1979) studied the impact of a husband's disability on the wife's morale and lifestyle. The sample was 15 males and their spouses recruited from a volunteer workshop setting for older handicapped males. The average age of the wives was 67 years while the husbands' average age was 73 years. The predominant disabilities of the husbands were cardiac-related.

The men and their wives were administered life satisfaction scales and a series of health indicators at three separate two-month intervals. A fourth interview was completed one year later. Overall, the results indicated that the caregiving wives reported low levels of life satisfaction compared to available national norms. The authors concluded that, as the wives were rarely disabled themselves, their lower morale must be due, at least in part, to the husband's condition.

The authors attempted to investigate factors which contributed to the wives' relative lack of life satisfaction. Results revealed that low life satisfaction scores were
associated with decreased income, employment of the caregiver, caregiving responsibilities for multiple persons, lower intimacy with the husband, higher levels of social isolation, and lower levels of assistance from friends and relatives. The authors concluded that wives of elderly disabled men are "hidden patients."

Sexton and Munro (1985) studied 46 wives whose husbands had a diagnosis of chronic obstructive pulmonary disease (COPD) and 30 whose husbands did not have a chronic illness. The purpose of the study was to determine the impact of a husband's chronic illness on the spouse's life.

Data were collected by means of a mailed questionnaire which included an Illness Impact form, a Subjective Stress Scale and a Life Satisfaction Index. Data analysis indicated that the wives of men with COPD reported higher stress and lower life satisfaction than did the control group. Also, wives of COPD men rated their health lower than did those in the control group. Almost one-half (47.8%) of the COPD wives reported that they had arthritis, 28.3% had hypertension, 17.4% had cataracts, and 10.9% had heart disease. In contrast, only 33.3% of the control group reported they had arthritis and 13.3% had hypertension. Twenty-two of the COPD wives reported poor sleep. Almost one-third (30.4%) of the COPD wives reported they had given up social activities versus 13.3% of the control group who indicated that they were involved in fewer business-related activities. Sexton and Munro suggested the need for investigation of the
possibility that decreased life satisfaction and increased stress contribute to illness in the wife.

Well-Being of Caregivers of the Demented Elderly

This section is divided into 2 parts. Firstly, themes derived from analysis and synthesis of literature describing the experience of caring for an elderly, demented relative will be presented. A review of several studies of family caregivers of the demented elderly follows.

Ongoing social isolation is a pervasive theme in the accounts of caregivers caring for a demented relative (Lezak, 1978; Vorgna, 1979; Morycz, 1980; Barnes et al., 1981; Colman et al., 1982; Levine et al., 1985; Wasow, 1985). In a couples-oriented society, when a mate is too ill to socialize, the spouse is usually cut off from previous patterns of socialization (Wasow, 1985). The spouse lives in social limbo as he/she does not have a partner with whom to participate in social activities nor is he/she free to get one (Lezak, 1978). Social mores often preclude spouses from seeking other socially and emotionally gratifying relationships. Having visitors to the home of a dependent with Alzheimer's Disease and/or taking the dependent out of the home are difficult due to several factors. These include the lengthy time required to provide daily care, the fact that the dependent's behaviours may embarrass friends and relatives, and the fact that the dependent usually does best
when simple routines are maintained (Lezak, 1978; Barnes et al., 1981).

Social isolation can be exacerbated by feelings of abandonment by the extended family (Lezak, 1978; Wasow, 1985). The family often does not assist the caregiver to the extent expected. Adult children view the caregiving mother as the pivotal member of the family who always "kept things together," and expect her to continue in this role despite the change in circumstances (Crossman et al., 1981). In addition, relatives can become critical of the caregiver. Unaware of the duties and sacrifices undertaken by the caregiver, relatives may misperceive the caretaker as too protective, restrictive, neglectful, or uncaring (Wasow, 1985).

Not only is there social and familial isolation, but personal isolation as well (Colman et al., 1982). The dependent's ability to communicate verbally and non-verbally may be almost non-existent. The caregiver's sexual and affectional needs may frustrated as many dependents no longer have the full capacity for empathy and interpersonal sensitivity. Furthermore, the sexual competency and demands of the dependent may not coincide with those of the spouse (Lezak, 1978; Crossman et al., 1981).

Caregivers report the all-consuming nature of caregiving and the resultant feelings of being trapped and tied down (Lezak, 1978; Barnes et al., 1981; Collman et al., 1982; Wasow, 1985). Individuality, personal interests, and needs
become submerged by the needs of the dependent. Spouses describe their identity as tied to that of the dependent. The situation was aptly described by one spouse as being that of a "prisoner of love" (Barnes et al., 1981, p. 82). Others express being trapped by feelings of gratitude, fond memories, the marriage vow of "til death do us part," guilt, and fear of social condemnation (Lezak, 1978).

Role confusion and overload are experienced by caregivers as they assume the additional role of caregiver as well as some or all of the dependent's previous roles (Lezak, 1978; Barnes et al., 1981; Crossman et al., 1981; Kapust, 1982). Older caregivers may have more difficulty coping with role change because they have to alter long-established patterns. In essence, many caregivers assume the role of parent to their demented spouse (Wasow, 1985). One caregiver described his experience as follows:

I married a peer, and now I live with a retarded child. It is so confusing: I wash her hair and cut her nails and dress her in the mornings... and sometimes I make love to her at night (Wasow, 1985, p. 715).

The caregiving role may be particularly difficult to adopt as society does not prepare adults for the kinds of problems with which they must deal when confronted with a demented adult (Safford, 1980). As one caregiver stated:

It's funny when you consider the effort they go to to give new mothers advice as to how to handle new babies --no one tells you how to handle incontinent, senile
parents that spread faeces over the walls and wander at night. Because it's not talked about, you think you should know and then in addition to all the other pressures, you feel guilty because you can't cope with it (Equal Opportunities Commission, 1982, p. 13).

Caregivers often wonder if they are doing the right thing and if the dependents are not getting better because they, the caregivers, are not doing enough (Barnes et al., 1981; Hayter, 1982).

Feelings of loss are experienced by caregivers in the face of the dependent's steady irreversible deterioration. (Lezak, 1978; Vorgna, 1979; Barnes et al., 1981; Kapust, 1982; Cutler, 1985; Levine et al., 1985; Wood et al., 1985). The dependent's personality changes and loss of communicative ability are often experienced by the caregiver as a partial death. The person they knew is described as dying a little at a time (Kapust, 1982). It has been suggested that families with a member diagnosed with Alzheimer's Disease progress through phases comparable to the mourning process (Cutler, 1985). However, "society neither recognizes the spouse's grief nor provides the support and comfort that surrounds those bereaved by death" (Lezak, 1978, p.593).

Caregivers often experience a reactive depression (Lezak, 1978; Barnes et al., 1981; Ware & Cooper, 1982; Powell, 1985). The depression can be a chronic pall over the caregiver's life or fluctuate with the dependent's ups and downs and the amount of personal freedom and satisfaction the
caregiver can obtain. The symptoms of depression such as anxiety attacks, disturbed sleep, and loss of appetite can lead caregivers to feel they are "going crazy" (Lezak, 1978).

The demands of the caregiving situation can provoke feelings of anger and frustration in the caregiver (Barnes et al., 1981; Crossman et al., 1981; Kapust, 1982; Sheldon, 1982; Hayter, 1982; Ware & Cooper, 1982; Mann, 1985; Powell, 1985; Wood et al., 1985; Wasow, 1985). These feelings also arise when the dependent becomes disabled around the retirement years, thus robbing the spouse of his/her retirement dreams for the "golden years" (Crossman et al., 1981; Kapust, 1982). In addition, caregivers express frustration in connection with the health care system, particularly in terms of obtaining a diagnosis (Barnes et al., 1981; Hayter, 1982; Wasow, 1985). By the time a diagnosis has become clear, families are often frustrated and distrustful of the physician and the system. Furthermore, caregivers report that, once a diagnosis has been made, physicians tend to pull back, leaving the caregiver with a sense of hopelessness and no guidelines for how to care for the dependent (Barnes et al., 1981; Hayter, 1982; Wasow, 1985).

Guilt and self-reproach follow the experience of negative emotions towards the dependent (Kapust, 1982; Mann, 1985; Powell, 1985; Wasow, 1985; Wood et al., 1985). Another source of guilt for the caregiver is the prospect of institutionalization (Hayter, 1982; Kapust, 1982; Powell,
1982). Even when caregivers are totally exhausted and have no other alternative, institutionalization is associated with feelings of failure as a caregiver and guilt for abandoning the dependent.

Dependents, frustrated and frightened by their condition, can make the caregiver the focus of their bitterness and humiliation (Lezak, 1978; Cutler, 1985). Episodes of belligerence and aggression outside the dependent's control can also occur (Colman et al., 1982). Several wives in one caregiver support group were frightened of being harmed by their demented husbands. Physical struggles occurred to prevent the dependents from using guns, dangerous tools, and hazardous equipment inappropriately (Barnes et al., 1981).

The heavy physical and emotional demands of caregiving have been linked to caregivers' reports of exhaustion, heart attacks, and disintegrating knee joints and back discs (Crossman et al., 1981; Eisdorfer & Cohen, 1981; Colman et al., 1982; Moryz, 1982). Reports of exhaustion due to the dependents' day-night reversal, and wandering and pacing are particularly prevalent. Several caregiving wives reported that they tied themselves to their husbands at night so that they would awaken if he arose (Barnes et al., 1981). This constant vigilance led to exhaustion.

The stress and anguish experienced by the older caregiver may be superimposed on the caregiver's own difficult age-related changes such as declining health and
deaths of relatives and/or friends (Moryz, 1980; Woods et al., 1985). Older caregivers are likely to have their own infirmity, given that over 85% of Canadians 65 years of age and older report at least one health-related problem (Ableson, Paddon & Strohmenger, 1983). Long-term and harmful habits such as lack of exercise, poor diet, and drug/alcohol abuse may exacerbate the negative effects of caregiving (Barrow & Smith, 1979).

Caregivers may also face financial burdens (Crossman et al., 1981; Colman et al., 1982; Cutler, 1985; Wasow, 1985). When illness strikes the husband before the normal retirement age of 65, many women lose their only means of support. Severe truncation of the husband's pension benefits may also occur. Affordable and adequate community and home support services may be lacking.

Several studies which provide information as to the well-being of family caregivers of an elderly, demented relative will now be reviewed in chronological order.

In an attempt to understand the effect home care has on the people living with an elderly dependent, Grad and Sainsbury (1963) interviewed the closest relatives of 410 mentally ill elderly dependents who had been referred to a community or hospital-based service. The dependents' diagnoses classified as mental illness were organic, psychotic, neurotic and/or personality disorders. Further demographic information regarding the dependents and relatives was not provided.
An interviewer rated the effect of the dependent's illness on family income and employment, social and leisure activities of the family, domestic routine, children in the home, health of household members, and relations with neighbours. Each item was rated on a three-point scale as "not affected," "affected," or "severely affected." The criteria by which the interviewer made these decisions were not discussed.

More than one-half (60%) of the relatives reported excessive anxiety. One-fifth attributed neurotic symptoms such as insomnia and headaches to their concern regarding the dependent. The social and leisure activities of one-third of the families had been restricted and one-quarter had their income reduced by at least 10%. The incidence of these problems was higher for those relatives who had children and when the caregiving relative was a spouse.

Sanford (1975) interviewed 50 supporters of dependents who had been admitted to the geriatric units of two hospitals due to supporter inability to cope with the patient at home. Supporter was defined as the person principally involved with the dependent. Of the supporters, 22 were spouses (16 female and 6 male), 23 were offspring (19 female and 4 male), 2 were sisters, 2 were unrelated, and one was a daughter-in-law. Over one-half of the supporters were over 65 years of age.

The purpose of the interview was to identify the problems encountered by the supporters and to delineate which problems would have to be ameliorated before they would
accept the dependents back in the home. Supporters identified problems which fell into three groups: (1) dependents' behaviour patterns, (2) their own limitations, and (3) environmental and social conditions.

The majority of the problems cited were in the category of the dependents' behaviour patterns. Problems arising from the supporters' limitations accounted for only 16% of all problems identified. Among these, the most common problem (52% of the cases) was anxiety and/or depression attributed to looking after the dependent. Eleven (22%) of the supporters felt they were not physically strong enough to cope with the demands of caregiving such as lifting the dependent.

Problems associated with the environmental and social context made up only 12% of all the problems identified. Of these, restriction of social life was identified in 42% of the cases and 28% felt unable to leave the dependent for more than an hour. Sanford reported that the tolerance of problems in these two groups was good.

Sanford concluded that, since so few of the problems encountered by the elderly caregivers were related to their own limitations, the suggestion that the elderly caregiver is frail may be erroneous.

Wheatley (1980) assessed the problems encountered by a small sample of caregivers residing with an elderly demented person. Beyond stating that the research method consisted of a standardized interview, a focussed interview, and
participant observation, the author did not provide any further information regarding the research method.

The author reported that all caregivers in the sample under retirement age had varying problems regarding employment, but, in general, finances were not a source of difficulty. All caregivers were reported as having experienced considerable restriction regarding social activities. Emotional distress, nervous strain, anxiety, irritability, impatience, and frustration were reported by all subjects. Physical symptoms such as headaches, high blood pressure, weight loss, blackouts, and stomach pains were also identified.

Zarit et al., (1980) examined how 29 caregivers' feelings of burden were affected by the impairments manifested by dependents with dementia and by various aspects of the caregiving situation. Eighteen of the caregivers were spouses and 11 were daughters. All but 4 of the caregivers were female. Caregivers ranged in age from 42 to 82 years with an average age of 65. The dependents consisted of 16 males and 13 females with an average age of 76 years.

The authors expected that feelings of burden would be related to the extent of behaviour impairment manifested by the dependent. Contrary to this expectation, the results revealed that none of the dependents' behaviour variables were correlated with the level of burden. Of the remaining measures, only the frequency of family visits was significantly related to the level of burden. Caregivers of
dependents who received more visits from children, grandchildren, and siblings reported less burden. There were no significant differences between husbands and wives on the various variables.

Using an exploratory-descriptive approach, Marcus and Jaeger (1982) studied the experiences of 47 elderly caregivers caring for an elderly infirm family member. Though the diagnoses of the dependents were not provided, the study is reviewed here as it is a Canadian study and provides interesting information about female caregivers.

Seventy-one per cent of the caregivers were spouses with an unexpectedly large number (32%) being husbands. The majority (57%) of the caregivers were 75 years of age and older. The study method consisted of an interview based on an ethnographic approach in which the subjects were asked questions about caregiving and their feelings about their situation. Secondly, the caregivers were asked to rate their own health and the dependent's health. Questions were also asked about the the caregiver's and dependent's relationship. The final part of the interview enquired as to whether the caregivers had knowledge of, utilized and/or desired home support services. A Burden Interview developed by Zarit (1982) was then completed.

Content analyses of subjects' descriptions of the daily routine of caregiving revealed that almost 50% of the caregivers mentioned no activities related to self-care or their own leisure. The burden scores for these caregivers
was slightly higher than for those caregivers who indicated they did participate in self-care or leisure activities.

Four themes emerged as answers to the question "What makes a day easy/difficult?" Caregivers reported that being relieved from the routine of caregiving made the situation easier to tolerate, visitors eased the burden, caregiving was easier when the dependent was not ill, and being tied to the house was difficult to tolerate. In response to a question on the aspect of caregiving that gave the most satisfaction or pleasure, 21 caregivers reported coping, getting results, and recognition. When questioned as to their concerns about the future, 44% of the caregivers stated they lived from day to day and had no thoughts of the future. Trying not to think about the future was mentioned by more than one-half of the female caregivers versus one-quarter of the male caregivers.

Fifty-seven per cent of the caregivers rated their health as good and 15% rated their health as poor. Neither sex, age, nor burden scores were significantly related to this self-rating. Analysis of caregivers' ratings of the dependents' health status revealed that three times as many female as male caregivers rated the dependents' health as poor. The authors questioned whether this may have been due to the female caregivers caring for relatives who were more impaired or if the women were more realistic or pessimistic in their assessment than were the male caregivers. Unlike Zarit et al., (1980), these authors found that the poorer the
dependent's health was rated, the higher the caregiver's burden score.

In examining the amount of help received by the caregivers, it was found that all but two subjects received assistance, with male and female caregivers receiving proportionately the same amount. Caregivers over 75 years of age and caregivers with higher burden scores received more help. More than one-half of the sample reported having few visitors. Female caregivers and caregivers under 75 years of age reported receiving more visitors. Similar to the findings in the study conducted by Zarit et al., (1980), caregivers with high burden scores reported fewer social visits.

The scores on the Zarit Burden Interview revealed that 63% of the female caregivers as compared to 31% of the male caregivers had high burden scores. Twice as many female as male caregivers also reported that caregiving had a negative impact on their lives. Thus, the authors concluded that caregiving appeared to be more burdensome for older female than for older male caregivers. Surprisingly, one-third of the caregivers reported that caregiving had no impact on their life. The authors suggested that this may have been due to denial, philosophical attitude, or acceptance of the situation.

In another Canadian study, Pringle (1982) investigated whether the same factors influenced the psychological well-being of elderly dependents and their family caregivers. The
subjects were 140 pairs of elderly dependents and caregivers who resided together. The majority of the caregivers were spouses (71 persons) or adult offspring (69 persons). The spouses were, on average, 76 years and the adult offspring 53 years of age. The dependents ranged in age from 65 to 101 with an average age of 80.

The dependent variable was psychological well-being which was on a continuum ranging from life satisfaction to depression. The independent variables were quality of the relationship and kin relationship between the dependent and the caregiver, perception of health status, adequacy of financial resources, duration of caregiving, and amount of assistance from other family members.

The results indicated that the caregivers were moderately satisfied with life, but a mild level of depression was present. The psychological well-being of the caregivers was positively correlated with their perception of their health, the adequacy of their finances, and the quality of the interpersonal relationship between the caregiver and the dependent. Information regarding the caregivers' perceptions of their health status was not provided. The majority of the caregivers perceived that their income was sufficient. The caregivers consistently described their relationship with the dependent in more negative terms than did the dependents.

Rabins et al. (1982) interviewed the primary caregivers of 55 dependents diagnosed with irreversible dementia to
determine its impact on the family. The dependents were either inpatients or outpatients of a hospital psychiatric service. Thirty-nine of the dependents were women and 16 were men. Fifty-one per cent of the women were widowed versus 6% of the men. Dependents diagnosed with Alzheimer's Disease accounted for 60% of the cases. Almost one-half (45%) of the dependents lived with a spouse or spouse and child. The remainder lived in other settings such as a nursing home.

A questionnaire examined dependent behaviours as well as problems the family caregiver might be experiencing as a result of caring for the dependent. Forty-eight (87%) reported chronic fatigue, anger, and depression while loss of friends and hobbies and no time for self were cited by 30 (55%) of the respondents. Role changes created by assuming responsibilities that had been the dependents were reported by 16 (29%) of the respondents as a source of distress. Feelings of guilt were expressed by 14 (25%) respondents.

The primary caregivers of 26 former inpatients of a Canadian geriatric assessment unit, diagnosed with dementia, were interviewed by Robertson & Reisner (1982). All but one of the caregivers were female. A spouse was the caregiver in 11 cases and a daughter in eight cases. The average age of the supporters was 60 years. Of the 26 dependents, 14 were male and 12 were female and the average age was 78 years.

Using a study method similar to that of Sanford (1975), caregivers were asked to identify management problems they
had experienced as a result of caring for their relative. Where such problems were present, the caregivers were then asked to state if they could cope with these problems without personal stress or interference with their daily life. Knowledge of, utilization of, and expressed need for home support services was also assessed.

Seventeen (65%) of the supporters reported that their own health was good or excellent and nine (35%) reported their health as poor or fair. Being tied down was the most prevalent problem noted and was reported by 20 (80%) of the supporters. Interference with social life was noted by 15 (50%) of the supporters. As Sanford (1975) found, these problems were well tolerated by the caregivers. However, despite the caregivers' reported ability to tolerate these problems, the authors point out that 50% of the dependents had been admitted to extended care facilities within 18 months of commencement of the study. Several reasons can be offered for this phenomenon: (1) the caregivers' abilities to tolerate these problems was quickly eroded, (2) the caregivers did not truthfully indicate their ability to tolerate the problems, or (3) the manner in which the researchers measured the caregivers' tolerance of the problems was inaccurate.

Approximately one-half of the caregivers knew of available community relief services such as day care and holiday and weekend relief. Despite this, more than one-half of the supporters expressed that there was a lack of services
of this nature and very few were presently utilizing the existing services. The authors suggested that this may have been due to the services not being accessible or not meeting the perceived needs of the dependents and their supporters.

In general, over 50% of the caregivers had knowledge of home care services such as meals-on-wheels, public health nursing, and home-maker services. Just over one-half of the caregivers expressed a need for these services. Differences between the expressed need for and use of the services was small. Of particular interest is that, despite 92% of the caregivers being aware of public health nursing, only one caregiver reported using the services of a public health nurse and one other expressed the need for this service. The authors suggested that, in this sample, public health nursing was not viewed by the caregivers as a service they needed and that this may represent a missed opportunity for surveillance and preventive intervention.

Chenoweth and Spencer (1983) studied the subjective experiences of 289 families randomly selected from the mailing list of an Alzheimer's Disease support group. Over one-half (55%) of the respondents were spouses of the dependent with 41% being wives. The sample ranged in age from the late 20s to early 80s, with 55% of the respondents being 50 to 60 years of age.

Data were collected by means of an open-ended questionnaire. Details regarding the manner in which the data were analyzed are lacking. The authors reported that,
in response to the question, "What are the major problems you and your family face in caring for your relative?", many families found the emotional and physical strain of care to be exhausting and frustrating. Sixty percent of the families felt their relative's illness had affected their relationships with other people. Families reported friends no longer visited. They felt isolated and had to give up jobs, volunteer work, and leisure activities. Some family members reported their own attitudes changed toward their friends and that they themselves withdrew and became tense and anxious in their friends' presence.

Niederehe et al., (1983) compared the mental and physical health of 34 family caregivers of demented elderly relatives living in the community to that of 16 "potential" caregivers of an older relative in good health. The family caregivers of the demented relatives were recruited from a psychiatric setting. These caregivers consisted of 18 spouses (predominantly male), and 16 female, younger generation caregivers. The control group consisted of 10 sets of spouses, a pair of elderly brothers, and five parent-child pairs.

Among the caregiver outcomes measured were physical and mental health. Physical health was assessed by a physical health questionnaire and mental health was assessed by the Hopkins Symptom Checklist (SCL-90), the CES Depression Scale, and the Hamilton Depression Scale. The results indicated that the caregivers showed somewhat more depressive symptoms
than the controls, but usually not enough to warrant a clinical diagnosis of depression. Closer examination of the subscales of the SCL-90 indicated caregivers' greater symptomatology tended to be in areas of depression, anxiety, anger-hostility, and interpersonal sensitivity.

The emotional stress of the caregivers was reportedly very apparent to the research team and the authors queried if there was some denial of affect among them. It was suggested this could be due to the situational demand for the caregivers to keep their resources mobilized for the daily care of the relative and not to become absorbed with their own troubled emotions.

Comparison of the averages of the same-generation caregivers to younger generation caregivers within the treatment group indicated the younger generation experienced a greater strain. It was hypothesized that the treatment group may have been less inclined to openly acknowledge experiencing social and psychic distress.

George (1983; 1984) studied family caregivers of persons with Alzheimer's Disease or a related disorder to document the degree to which the well-being of caregivers is affected by their responsibilities. Four dimensions of well-being (physical health, mental health, satisfaction with and participation in social activities, and financial resources) which could be compared to average levels in the general population were assessed via a questionnaire.

Normative data for available indicators of well-being
were compiled from multiple surveys by George (1983). The primary data source was the Survey of the Well-Being of Older People in Cleveland, Ohio (Comptroller General, 1977). The sample was 1609 Cleveland residents 65 years of age and older. Other sources included the Harris Survey of the Myth and Reality of Aging (N=4254 adults age 18 and older) (Harris, 1975), and the Duke University Second Longitudinal Study (George, 1983), which had a sample of 502 adults between the ages of 45 and 71. Though George (1983) recognized the difficulties of comparisons of means across studies, it was felt these comparison samples were of high quality.

The caregiver sample was 501 informal caregivers of impaired older persons suffering Alzheimer's Disease or a related disorder. The majority of the sample (71%) was female. The age range of the sample was 21 to 90 years with an average age of 57 years. The majority (59%) of the dependents were male. The dependents ranged in age from 47 to 97 years with an average age of 70 years. The results indicated the caregivers experienced three times as many stress symptoms, were two to three times more likely to take prescription psychoactive drugs, participated in fewer social and recreational activities, and were less satisfied with the quality of their leisure activities than the general population.

Significant differences between the male and female caregivers in terms of mental health and social/recreational
participation were identified. Women caregivers were more likely than their male counterparts to take psychoactive drugs, reported a larger number of stress symptoms, participated in fewer social and recreational activities, and were less satisfied with the quality of their leisure time. Spousel caregivers versus child caregivers had poorer health, were more likely to take psychotropic drugs, had more financial problems, and spent less time in leisure activities.

Gilhooly (1984) examined a variety of factors expected to influence the psychological well-being of family caregivers caring for a relative with senile dementia. The sample was 20 co-resident supporters (mean age of 62.9 years) and 17 non-resident supporters (mean age of 50.9). Nine of the caregivers were spouses, 19 were children, 4 were sisters, and 8 were daughters-in-law. The dependents living with the co-residents were described as being more impaired.

The dependent variable, psychological well-being, was assessed by the Kutner Morale Scale and the OARS Multidimensional Functional Assessment Questionnaire Mental Health Scale. The independent variables assessed were the dependent's level of impairment, frequency of contact with family members and friends, satisfaction with help from relatives, help from support services, and the quality of the relationship between supporter and dependent.

The morale of the caregivers was reported as being at the lower end of the eight-point Kutner Morale Scale. Scores on the mental health scale indicated that, on average,
caregivers were in good mental health or only mildly impaired. Sex of the dependent was the only characteristic significantly correlated with supporter's morale and mental health, with care of a female by either a male or female caregiver associated with higher morale and mental health.

In terms of supporter characteristics, co-resident supporters had slightly lower morale and poorer mental health than the non-resident supporters. Sex of the supporters was found to be significantly correlated to supporter's morale as males were found to have higher morale than females. In an addendum, the author stated that there were three possible explanations for the males having higher morale than the female caregivers. Firstly, the men in the sample appeared less emotionally involved with the dependent than were the female supporters. Secondly, the men were more willing to leave the dependent unattended, meaning that they were less socially isolated. Finally, the author suggested that it may be that the males were less willing to admit distress than were the female caregivers.

Analysis of variance revealed no significant associations between marital status and supporters' morale or mental health. The caregivers were then categorized as spouses, children, and other. This measure of the "distance" in the blood/role relationship between supporter and dependent was found to be negatively correlated with morale and mental health. The closer the blood-relationship, the lower the caregiver's morale and mental health.
Correlations between duration of care-giving and morale and mental health were both significant, but not in the expected direction. The longer the supporter had been a caregiver, the higher the supporter’s morale and mental health. The author suggested that this may have been due to the caregiver having had time to learn to adjust and cope.

Frequency of contact with friends and relatives was not significantly correlated with supporter morale or mental health, whereas satisfaction with help received from relatives was. Correlational analysis revealed that home help service was correlated with both high morale and mental health. More frequent visits from a community health nurse were associated only with higher morale.

Gilhooly concluded from these findings that there is marginal support for the assumption that the impact of caregiving is negative. This is quite contrary to the findings of the majority of the studies discussed in this review.

Using a qualitative approach, Larsen (1985) examined the experiences of six older wives caring for husbands with chronic confusion. The wives and the husbands ranged in age from 68 to 85 years. The themes in the caregivers' accounts revolved around three concerns: management of the husband's dependency, maintenance of the family as a unit, and acceptance of the caregiving situation. These will be discussed in turn.

In terms of managing the husbands' dependency, Larsen
found that changes in the husbands' functioning and the resultant caregiving tasks had three major effects on the wives: fatigue, confinement, and strain. The husbands' incontinence and nocturnal restlessness were the major factors contributing to fatigue. Two of the wives relied regularly on sleeping medications to aid them to sleep while two others used them less frequently.

Confinement was expressed as the wives perceived that their lives revolved around their husbands. The need to constantly supervise their husbands, difficulty in engaging in activities that took place outside the home, and the husbands' loss of interest and social withdrawal were identified as the aspects of the caregiving situation which led to confinement. Accounts of emotional and physical "strain" were inherent in all the caregivers' experiences. Confinement thwarted the development of ways to manage the strain.

With respect to maintenance of the family unit, Larsen identified that the dependents' confusion affected the marital relationship and changed the caregivers' role. All the wives reported that their marital relationships had changed. Communication between the husbands and wives had deteriorated with conversation being almost unilateral in two families. The husbands lacked the ability to respond to the wives' concerns which compounded the confinement.

The wives found the transition to being responsible for all decision-making very difficult to deal with, particularly
in terms of financial matters. Independence became a necessary attribute for the wife to develop if she was going to maintain the husband at home. At times, the wives' independence led them to reject initial overtures of help from health professionals.

Despite the profound impact on their well-being, Larsen notes the wives accepted the caregiving situation and were resolved to keep their husbands at home. They attempted to show acceptance of the situation by overlooking the dependent's lost abilities and by de-emphasizing the effects of confusion. "Consequently, the realities of each husband and wife appeared to differ considerably from one another. The husband seemed unaware of the wife's added responsibilities and burden. Instead, he expected that she would continue in the same role as always toward him" (Larsen, 1985, p. 61).

It was observed by Larsen that the caregiving role was highly valued by the wives. They considered that accepting the role and the attendant sacrifices was their "duty" as wives. Guilt feelings in the wives occurred if they perceived they were not fulfilling their wifely obligation.

Institutionalization was viewed by the wives with distress and they felt "morally obligated to try and prevent it at the expense of their own comfort" (Larsen, 1985, p. 66). The wife derived comfort from the decision to care for her husband by "putting herself into his position and hoping that her husband would have made the same sacrifices as she
had made if their positions had been reversed" (Larsen, 1985, p. 65).

**Summary**

A broad range of literature was reviewed to place the research question in a theoretical context. Normative data on the well-being of older women in general revealed that older women experience age-related changes such as an increased prevalence of chronic health problems, increased use of prescription medications, poor dietary practices, and financial hardship. The socialization patterns of women were described as placing older caregiving women in a disadvantaged position in comparison to their male counterparts. Thus, it appears that the older caregiving wife may be more predisposed to deficits in well-being due to both age-related changes and socialization patterns.

In general, the literature and research on the well-being of family caregivers of the demented elderly indicates that caregiving may have a profound effect in all domains of their well-being. It appears that the stress of caregiving may predispose caregivers to develop new health problems or may exacerbate existing problems. A wide range of distressing and negative feelings such as guilt, anxiety, and depression appear to be experienced by caregivers. The demands of caregiving are seen to preclude them from participating in social and leisure activities. Finally, caregiving may lead to financial problems due to the expenses associated with caring in the home and by precluding employment.
Several of the studies suggested that caregiving may have a more deleterious effect on the well-being of female caregivers, spousal caregivers, and co-resident caregivers. However, no studies specifically addressed the well-being of older wives caring for husbands with Alzheimer's Disease. Thus, this thesis is designed to provide such documentation.
CHAPTER THREE

Research Design

Overview

This study was an exploratory descriptive survey of the well-being of older wives caring for husbands with Alzheimer's Disease. The data were gathered by means of a self-administered questionnaire. The questionnaire, sample selection criteria, sample, data collection, subjects' rights, and data analysis are described in this chapter.

Questionnaire

Data were collected by means of the Caregiver Questionnaire developed by George (1983). In addition to items designed to elicit data regarding caregiver well-being, several other kinds of information not related to this study were included in the original questionnaire. Therefore, permission was given by George to adapt it as follows: (1) categories of questions not related to the purpose of this study were excluded, and (2) three open-ended questions were included regarding recurrence or exacerbation of long-standing health problems, recent development of health problems, and recent changes in patterns of alcohol consumption.

Thus, the questionnaire used in this study consists of 78 questions designed to gather basic demographic information, elicit data in terms of each of the four domains of well-being, and obtain information about caregiver health
behaviours. Forty-three of the questions require responses on three multi-item scales and 35 response categories are a combination of open and fixed alternatives. A more detailed description of the questionnaire is now provided and a copy of the revised instrument is presented in Appendix A.

Basic Caregiver Demographic Information

The first nine questions address standard survey demographic items. These include caregiver age, education, employment status, main job, household size, household composition, number of children, and number of children living in the local area.

Physical Health

The next seven questions are designed to elicit information about the physical health of the caregiver by determining: health services utilization, number of days too ill to perform usual activities, use of psychoactive medications and alcohol, and whether the caregiver has developed any new health problems or worsening of previous health problems. Three questions obtain data about more subjective aspects of physical well-being.

Mental Health Symptoms and Indicators

The next 24 questions address issues of mental health and psychiatric symptomatology. Included are self-ratings of frequency of worry and usual spirits, and a Caregiver's Stress Symptoms Scale which taps perceptions of stress and psychological distress (George, 1983).

Subjective well-being is assessed by means of a ten-item
Affect Balance Scale and a single-item life satisfaction measure, both developed by Bradburn (1969). The scale assesses transitory aspects of emotion while the life satisfaction measure assesses more enduring feelings of subjective well-being (George, 1983).

Health Behaviours

Appropriate health behaviours may help to decrease the negative effects caregiving has on physical health. However, the role demands of caregiving may be such that caregivers may not be able to follow health regimens (George, 1983). Thus, five questions are included in the questionnaire to elicit data about selected health behaviours.

Participation In And Satisfaction With Preferred Activities

The next 10 questions seek information about several kinds of social and leisure activities, and include a set of subjective questions comprising a Caregiver's Satisfaction with Social Activities Scale (George, 1983).

Financial Resources

The remaining eight questions seek both objective and subjective information about financial resources. The six subjective questions make up a single scale called the Perceived Economic Status Scale (George, 1983).

Scoring of the Questionnaire

The information on the Caregiver Questionnaire cannot be compressed or summarized into a single number nor can the
various indicators in each domain of well-being. Scoring patterns for the instrument are described in Appendix B.

Validity and Reliability

Validity refers to the extent to which a tool measures that which it is intended to measure (Brink & Wood, 1983). George (1983) did not discuss the validity of the instrument. It is seen by this researcher to have both face and content validity.

Face validity exists when it is apparent that the questionnaire is relevant to what the researcher is trying to measure (Selltiz, Wrightsman & Cook, 1976). The Caregiver Questionnaire has face validity as it was designed to measure well-being in terms of four domains, which was the purpose of this study. Content validity exists when the items in the instrument are representative of the known content in the literature (Selltiz et al., 1976). The questionnaire has content validity in that the four domains of well-being have been identified as sources of caregiver problems in the literature.

Reliability is a measure of the instrument's consistency, stability, and repeatability (Brink & Wood, 1983). Various measures of reliability exist. The criterion of internal consistency was applied to the four scales in the questionnaire. Internal consistency refers to the extent to which all items pertaining to a concept measure the concept (Brink & Wood, 1983). An alpha coefficient with a range of
.60 to .80 is indicative of good reliability (Lord & Novaick, 1968). The alpha coefficients for three of the four scales are as follows:

1. Caregiver's Stress Symptoms .85
2. Caregiver's Satisfaction with Social Activities Scale .77
3. Perceived Economic Status Scale .85

Furthermore, many of the items not included in the above three scales were taken from data collection sources which had been previously demonstrated to be reliable in measuring the concept in question (George, 1983).

Selection Criteria

In order to be eligible to participate in the study, the subjects were required to: (1) be wives over 55 years of age who were currently caring for a husband with Alzheimer's Disease and had been doing so for a period of at least six months, (2) reside in their own home with their husband in the Lower Mainland area of British Columbia or Vancouver Island, and (3) read and write English.

Sample

It was originally anticipated that a convenience sample of 40 to 50 subjects could be recruited through three Alzheimer's Support Association Groups and one Caregiver Support Group. A combination of factors resulted in this not being feasible, the primary reason being that the majority of people attending these groups were those whose partners had
been placed in a care facility. There were also a small number of husbands caring for a wife with Alzheimer's Disease. Finally, a number of the group attenders had spouses who had health problems other than Alzheimer's Disease, for example, confusion caused by a stroke.

Thus, over a period of two months a convenience sample of 29 subjects was recruited through a total of 13 agencies:

1. Two Alzheimer's Support Association Groups in the Lower Mainland area of British Columbia.
2. One Caregiver Support Group operating in the Vancouver area.
3. Three Alzheimer's Support Association Groups from Vancouver Island.
4. Four Adult Day Cares situated in Vancouver.
5. One Adult Day Care situated in North Vancouver.
6. One Adult Day Care situated in Burnaby.
7. One Alzheimer's Clinic operating out of a suburban hospital in Vancouver.

Data Collection

The procedure by which subjects were recruited from the agencies varied. Subjects from the two Alzheimer's Support Association Groups in the Lower Mainland area and the Caregiver Support Group in Vancouver were recruited in the following manner.

The researcher obtained permission from the appropriate persons to attend a meeting held by each of the groups. At
the meeting the researcher verbally described the proposed research project, the criteria for subject selection, and what was required of subjects. Those who met the criteria and wished to participate were asked to remain after the meeting to complete the data collection instrument. A written letter of consent accompanied the data collection tool. The researcher was present during completion of the questionnaire to provide assistance if required. A total of six subjects was recruited in this manner. Several of the subjects requested to complete the questionnaire in their own homes and returned the completed questionnaire by mail. The return rate for these participants was 100%.

Several group members indicated they knew of wives not in attendance at the meeting whom they felt would be interested in participating in the study. The procedure for recruiting these subjects was as follows.

A letter explaining the circumstances under which the researcher obtained their name was mailed to each of the potential subjects. After a suitable time period, the researcher contacted the subjects by phone. At this time, the research project was explained and any questions were answered. Subjects agreeing to participate in the study were mailed the questionnaire and letter of consent. A stamped addressed envelope was included for return of the completed questionnaire. A total of seven eligible subjects was contacted in this manner, of whom six agreed to participate. Only three of these subjects returned the completed
questionnaire.

Subjects from the remaining sources were recruited in a manner similar to the above except that the agency contact person obtained permission from potential subjects for the researcher to contact them by phone. Each of the 21 eligible subjects contacted agreed to participate and all but one returned the completed questionnaires. Thus, 29 subjects were recruited in total.

Subjects' Rights

A verbal and written description of the study and the researcher's expectations of the subjects was given to the subjects prior to obtaining their written consent to participate. A copy of the written material is provided in Appendix C.

Data Analysis

Completed questionnaires were coded, edited, and placed on a computer file. The data were categorized and analyzed in terms of demographic information, the four domains of well-being, and caregiver health behaviours. Descriptive statistics were used to analyze the data with frequency distributions, measures of central tendency, and dispersion being most frequently employed.

The one-sample t-test was performed on the means of selected measures of well-being for the sample and a general population comparison sample in order to determine group differences. The two-sample t-test was performed on means of
the sample and a comparison sample of caregivers. A significance level of less than or equal to .05 was used.
CHAPTER FOUR

Presentation and Discussion of Findings

Overview

The purpose of this chapter is to present and discuss the findings of this study. The results of the analysis of responses to the Caregiver Questionnaire will be discussed in terms of demographic characteristics, physical health, mental health symptoms and indicators, health behaviours, participation in and satisfaction with preferred activities, and financial resources.

As there was no way to measure the wives' well-being before they commenced caregiving, it is not known to what degree their well-being was changed by the caregiving experience per se. However, comparison of the well-being of the sample to the well-being of the general population and other caregiver samples provides useful information. The general population comparison sample referred to in this discussion is the one described by George (1983; 1984). The main caregiver sample is also George's (1983; 1984). Though both of these samples are American, the similarities between Canadian and American society are such that the comparisons are appropriate.

Demographic Information

The age range of the 29 caregiving wives who participated in the study was 57 to 81 years with an average
age of 67 years. The caregivers had, on average, completed 11 years of schooling with seven of the caregivers having completed some college education. In terms of employment status, three of the wives were currently employed outside the home. The motivating factor behind their employment does not appear to be financial as these wives viewed their financial situation positively with the exception of one wife who felt she would not have enough money to meet her future needs. In conversation, one of these women stated that being able to work outside the home was "the only way she could keep her sanity." It may well be that employment outside the home was a means by which these three women could better cope with the caregiving situation. The remainder of the wives identified themselves as being retired or housewives.

Twenty-seven (93.1%) of the respondents lived alone with their husbands who ranged in age from 59 to 89 years and who were, on average, 72 years old. One subject's 27-year old daughter lived at home while another subject had a 23-year old son and a 20-year old daughter at home. Though the subjects reported an average of 2.38 children, relatively few children (average 1.14) were locally available.

Twenty-five of 28 participants (89%) reported they were the sole caregivers for their husbands, including the two wives who had children residing with them. Thus, it is questionable if having children at home would alter the wives' perceptions of their sole caregiving role. As Crossman et al., (1981) point out, adult children view the
mother as a "pivotal" member of the family who will "keep things together" despite a change in circumstances.

The average length of caregiving reported was 42 months with a range of 12 to 108 months. Many of the respondents indicated on the questionnaire that they estimated the length of caregiving on the basis of when the husband was diagnosed with Alzheimer's Disease. Thus, it is conceivable that the average number of months of caregiving is, in fact, longer than reported.

**Physical Health**

The means of measures assessing the physical health of the study wives are reported in Table 1. Comparison of the study sample means on selected measures of physical health to those of the general population and comparison caregiver samples are presented in Table 2.

Eight of 28 respondents (28.6%) stated they had not seen a physician in the past six months while three (10.7%) reported five physician visits. Respondents reported an average of 1.82 physician visits in the past six months. This pattern is similar to that of the majority of Canada's elderly, who, on average, visit a physician at least yearly (Minister of Supply and Services, 1983). However, it is interesting to note that the wives saw a physician less often than did the subjects in both American comparison samples. The differences in utilization patterns may be partly explained by the fact that both comparison samples were more heterogenous. Patterns of health care utilization vary
widely across the lifespan. It may also be that the role demands of caregiving are such that they preclude the caregivers from arranging to see their physicians more often. Also, many physicians and other health care professionals have been less than sympathetic to the plight of the female family caregiver (Polansky, 1980). This may have prevented the wives in the sample from visiting their physicians to discuss their health concerns.

Table 1
Caregiver Physical Health

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visits to physician in past six months</td>
<td>1.82</td>
</tr>
<tr>
<td>Hospital days in past six months</td>
<td>.50</td>
</tr>
<tr>
<td>Days sick in past six months</td>
<td>2.19</td>
</tr>
<tr>
<td>Longstanding health problems worsened</td>
<td>.41*</td>
</tr>
<tr>
<td>New health problems developed</td>
<td>.24*</td>
</tr>
<tr>
<td>Caregiver takes psychotropic drugs</td>
<td>.45*</td>
</tr>
<tr>
<td>Pattern of alcohol consumption changed</td>
<td>.17*</td>
</tr>
</tbody>
</table>

*Scales: 0=no, 1=yes

Self-rated health 2.48
(1=poor, 2=fair, 3=good, 4=excellent)

Current health compared to past 1.60
(1=worse, 2=same, 3=better)

Health limitations 1.80
(1=not at all, 2=some, 3=a great deal)
Table 2  
Comparison of Means on Physical Health Measures: Study Sample, General Population and Comparison Caregiver Sample  

<table>
<thead>
<tr>
<th>Variable</th>
<th>Study Sample Mean</th>
<th>General Population Mean</th>
<th>Caregiver Sample Mean</th>
<th>a</th>
<th>b</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visits to physician</td>
<td>1.82</td>
<td>2.91</td>
<td>2.31</td>
<td>*</td>
<td>-</td>
</tr>
<tr>
<td>Use psychotropic drugs</td>
<td>.45</td>
<td>.19</td>
<td>.28</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Self-rated health</td>
<td>2.48</td>
<td>2.82</td>
<td>2.99</td>
<td>*</td>
<td>*</td>
</tr>
</tbody>
</table>

a = one sample t-test  
b = two sample t-test  
*= significant at p = .05  
-= not significant at p = .05  

The majority (86.2%) of the participants had not experienced hospitalization in the past six months; however, two (6.9%) participants had been hospitalized for a 6- to 7-day period.  

The average number of reported days sick such that participants were unable to carry out their normal activities was 2.18, the range being 0 to 14 days. The majority of the 27 participants (63%) who completed this item reported that they had not been ill. This is markedly lower than the number of disability days reported by older women in the
Several of the study wives indicated on the questionnaire and in conversation that they "had no time to be sick." Thus, it is quite conceivable that the wives' caregiving responsibilities did not enable them to have disability days and that, if they were relieved of their caregiving responsibilities, they might report more disability days.

The wives reported health concerns similar to those reported by the wives of husbands with COPD (Sexton & Munro, 1985) and by the supporters of the mentally infirm elderly described by Wheatley (1980). Twelve (41.4%) of the participants reported that long-standing health problems had reappeared or gotten worse in the past six months. Hypertension, arthritis, and cardiac conditions accounted for 50%, 25%, and 16.7% of the cited health problems, respectively. Other problems reported by individual participants were conditions such as a back problem, depression, recurrent cancer, bowel irritation, a hernia, and fatigue. Seven (24.14%) of the participants cited one health problem only, four (13.80%) reported two health problems, and one respondent listed three.

Seven (24.14%) of the women reported that new health problems had developed in the past six months. Arthritis was the most frequently cited problem, accounting for 42.9% of the new health concerns. Individual participants cited new health concerns such as chronic pain, nausea, bowel irritation, a skin rash, fatigue, and a cardiac condition. It
should be noted that the health problems discussed above were self-reported and not substantiated by medical diagnosis.

The degree to which the caregiving experience contributed to the incidence of chronic health concerns amongst the study wives is difficult to estimate given that 86% of Canadians 65 years of age and older report at least one chronic health problem (Ableson et al., 1983). In addition, the two most common problems reported by the wives in the study, arthritis and hypertension, are the two most prevalent health problems in older women (Minister of Supply and Services, 1983). However, it is interesting to note that the most frequent problem listed, hypertension, is generally thought to be stress-related to some degree (Faulkner, 1980). The data pertaining to the wives' mental health substantiate the high degree of stress they were under. Furthermore, it is quite feasible that the heavy physical demands of caregiving such as toileting, bathing, and dressing the dependent may be responsible, in part, for the prevalence of arthritis among the study wives.

Thirteen (44.83%) of the respondents reported using psychotropic drugs. Each medication was verified as being a prescription psychoactive medication. Data indicate that the drugs were used mainly for the purpose of assisting the respondents to sleep. Each of the 13 respondents was only using one psychotropic drug. Two respondents indicated they used over-the-counter medications such as antihistamines and acetaminophen to assist them to sleep.
This rate of psychotropic drug use is significantly greater than is true for both the comparison samples. The difference in means is explained, in part, by the fact that women, in general, have a high rate of psychotropic drug use. For example, George (1983) reports that the National Center for Health Statistics in the United States estimated that 8 to 10% of the general public used psychoactive drugs during a six-month period, whereas 45% of North American women take mood-altering drugs and 50% of prescription drugs are prescribed to women over the age of 60 years (Porcino, 1985). Thus, the rate of psychotropic drug use by the study wives is similar to that of older women in general. However, the stress of caregiving, at some point, may further elevate the study wives' rate of psychotropic drug use.

In terms of changes in patterns of alcohol consumption, the majority of the sample (82.8%) reported no change. Three subjects reported their consumption had decreased, whereas two reported an increase in their alcohol use. The stigma attached to excessive alcohol intake may have resulted in the subjects being less willing to accurately report their alcohol use.

On average, respondents rated their health between fair (51.7%) and good (44.8%). Seventeen of 28 women (60.7%) felt their health was the same as five years ago and 11 (39.3%) felt their health was worse. Thirteen (44.8%) of the sample felt their health problems prevented them, to some degree, from doing the things they wanted to. Eleven (37.9%)
respondents felt their health did not interfere with their activity at all while five (17.2%) participants reported their health interfered a great deal.

Subjective health ratings have been shown to be congruent with physicians' assessments of health. However, whenever there is an incongruency between the subjective and physician health assessment, the tendency is for the individual to have overestimated his/her health status (Maddox & Douglas, 1983). Therefore, it is possible that, in some cases, the study wives' health was actually poorer than reported.

The wives' self-health rating is significantly lower than that of the general population and the comparison caregiver samples. Low self-health ratings relative to a comparison sample were also found in Sexton and Munro's study (1985). The caregivers in Marcus and Jaeger's (1982) study reported self-health ratings similar to those for subjects in this study. However, the caregivers in Robertson and Reisner's (1982) study rated their health as good to excellent.

Mental Health

Based on the results of previous research (Grad & Sainsbury, 1963; Sanford, 1975; Wheatley, 1980; Rabins et al., 1982; Niederehe et al., 1983; George, 1983; 1984) the primary determinant of well-being expected to be affected by caregiving is mental health, an expectation supported by the descriptive data in Tables 3 and 4.
Table 3 presents data on 2 mental health indicators, frequency of worry and general level of spirits. In terms of frequency of worry, the sample mean is 2.41 which lies between fairly often and very often. The mean level of general spirits is 2.64 which lies between low and good spirits.

Table 3

Mental Health Indicators

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of worry</td>
<td>2.41</td>
</tr>
<tr>
<td>(1=never, 2=fairly, 3=very often)</td>
<td></td>
</tr>
<tr>
<td>Usual spirits</td>
<td>2.64</td>
</tr>
<tr>
<td>(1=very low, 2=low, 3=good, 4=very good)</td>
<td></td>
</tr>
</tbody>
</table>

The 22 items in Table 4 are the psychiatric stress symptoms, the first twenty-one of which comprise the Caregiver's Stress Symptom Scale. The 22nd item, lack of appetite, is an extra item not included in the construction of the scale. The scale has a potential range of 0 to 21. The actual range for the subjects in this study was 2 to 20, with a mean of 11.17, which reveals the subjects were experiencing a severe degree of stress.

The six most prevalent symptoms reported by the subjects are as follows: Twenty-six (89.7%) of the participants reported feeling overwhelmed by responsibility, 25 (86.2%) had trouble getting to sleep or staying asleep, 24 (82.8%)
Table 4

Psychiatric Stress Symptoms

<table>
<thead>
<tr>
<th></th>
<th>Scale: (0=no, 1=yes)</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overwhelmed by responsibility</td>
<td>0.90</td>
<td></td>
</tr>
<tr>
<td>Trouble getting or staying asleep</td>
<td>0.86</td>
<td></td>
</tr>
<tr>
<td>Bothered by nervousness or tension</td>
<td>0.83</td>
<td></td>
</tr>
<tr>
<td>Worry a lot of the time</td>
<td>0.76</td>
<td></td>
</tr>
<tr>
<td>Sleep is fitful and disturbed</td>
<td>0.75</td>
<td></td>
</tr>
<tr>
<td>Bothered by feelings of guilt</td>
<td>0.66</td>
<td></td>
</tr>
<tr>
<td>Wake up without feeling rested</td>
<td>0.65</td>
<td></td>
</tr>
<tr>
<td>Feel alone, even among friends</td>
<td>0.63</td>
<td></td>
</tr>
<tr>
<td>Find life uninteresting</td>
<td>0.62</td>
<td></td>
</tr>
<tr>
<td>Wonder whether life is worthwhile</td>
<td>0.59</td>
<td></td>
</tr>
<tr>
<td>Bothered by feeling hot all over</td>
<td>0.56</td>
<td></td>
</tr>
<tr>
<td>Feel can't take care of things</td>
<td>0.52</td>
<td></td>
</tr>
<tr>
<td>Feel personal worries are affecting health</td>
<td>0.49</td>
<td></td>
</tr>
<tr>
<td>Troubled by heart pounding or SOB</td>
<td>0.49</td>
<td></td>
</tr>
<tr>
<td>Bothered by restlessness</td>
<td>0.45</td>
<td></td>
</tr>
<tr>
<td>Bothered by acid stomach</td>
<td>0.38</td>
<td></td>
</tr>
<tr>
<td>Have balance problems</td>
<td>0.25</td>
<td></td>
</tr>
<tr>
<td>Feel weak all over</td>
<td>0.22</td>
<td></td>
</tr>
<tr>
<td>Feel no one understands</td>
<td>0.22</td>
<td></td>
</tr>
<tr>
<td>Troubled by headaches</td>
<td>0.18</td>
<td></td>
</tr>
<tr>
<td>Bothered by &quot;cold sweats&quot;</td>
<td>0.14</td>
<td></td>
</tr>
<tr>
<td>Have poor appetite</td>
<td>0.10</td>
<td></td>
</tr>
<tr>
<td>Mean for Caregiver's Stress Symptom Scale</td>
<td>11.17</td>
<td></td>
</tr>
</tbody>
</table>
were bothered by nervousness or tension, 22 (75.9%) reported they worried a lot of the time, 21 of 28 (75%) stated sleep was fitful, and 19 (65.5%) were bothered by feelings of guilt.

Stress symptoms related to difficulty with sleep have exceptionally high occurrence. This is consistent with the subjects' reports that the major reason for using psychoactive drugs was to assist them to sleep. While it has been documented that older individuals experience night-time awakening (Hayter, 1983), it is most likely that the wives' poor sleep may be due, in some cases, to the husbands' day-night reversal, wandering, and pacing. The stress of having an ill person in the home, in itself, may have resulted in some of the difficulty the wives experienced regarding obtaining a restful sleep. Difficulty with sleep was also noted among the wives in Sexton & Munro's study (1985). The authors suggested that this was most likely due to the husbands' compromised breathing due to COPD.

Table 5 presents a comparison of the study wives' mean and the 2 comparison sample means on the Caregiver's Stress Symptom Scale. Significant discrepancies are noted. The wives averaged almost four times as many stress symptoms as the general population. Sexton and Munro (1985) also reported higher levels of subjective stress in the wives caring for a husband with COPD versus a comparison sample of wives whose husbands did not have a chronic illness.
Table 5

Comparison of Means on Psychiatric Stress Symptoms: Study Sample, General Population and Comparison Caregiver Samples.

<table>
<thead>
<tr>
<th></th>
<th>Study Sample Mean</th>
<th>General Population Mean</th>
<th>Caregiver Sample Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver's Stress Symptom Scale</td>
<td>11.17</td>
<td>3.04</td>
<td>8.34</td>
</tr>
</tbody>
</table>

a = one sample t-test
b = two sample t-test
*= significant at p = .001

These discrepancies also hold true when comparing the sample to George's caregiver samples. The subjects in this study experienced approximately one-third more stress symptoms than George's caregiver sample. This is consistent with George's (1984) findings that women caregivers reported a larger number of stress symptoms than did the male caregivers. Zarit (1982), in a conference presentation reported by Fittings and Rabins (1985), reported that wives who care for demented spouses reported more psychological distress than did male spouses in the same situation. Marcus and Jaeger (1982) also reported that the burden scores were higher amongst the women in their sample of caregivers. Investigators such as Niederehe et al. (1982) and Gihooly (1984) suggest that reports of more distress by female caregivers may be due to male caregivers being less willing to admit distress. Reports of less stress by male caregivers
may also be due to the fact that male caregivers have been reported to receive more assistance than their female counterparts (Polansky, 1982).

Table 6 presents data pertaining to participants' subjective well-being.

Table 6

Measures of Subjective Well-being

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single-item rating of life Satisfaction</td>
<td>1.31</td>
</tr>
<tr>
<td>(1=not satisfying, 2=fairly, 3=very satisfying)</td>
<td></td>
</tr>
<tr>
<td>Affect Balance Scale</td>
<td></td>
</tr>
<tr>
<td>Scale: (0=no, 1=yes)</td>
<td></td>
</tr>
<tr>
<td>Positive: excited or interested</td>
<td>.41</td>
</tr>
<tr>
<td>Negative: restless</td>
<td>.39</td>
</tr>
<tr>
<td>Positive: proud because complimented</td>
<td>.79</td>
</tr>
<tr>
<td>Negative: lonely or remote from others</td>
<td>.49</td>
</tr>
<tr>
<td>Positive: pleased about accomplishing something</td>
<td>.79</td>
</tr>
<tr>
<td>Negative: bored</td>
<td>.45</td>
</tr>
<tr>
<td>Positive: on top of the world</td>
<td>.14</td>
</tr>
<tr>
<td>Negative: depressed or very unhappy</td>
<td>.72</td>
</tr>
<tr>
<td>Positive: feel things going your way</td>
<td>.28</td>
</tr>
<tr>
<td>Negative: upset because of criticism</td>
<td>.31</td>
</tr>
<tr>
<td>Extra: angry or impatient</td>
<td>.87</td>
</tr>
<tr>
<td>Affect Balance Scale total mean score</td>
<td>5.20</td>
</tr>
</tbody>
</table>
The sample mean for the Bradburn single-item rating of overall life satisfaction is 1.31, which lies between not satisfying and fairly satisfying. The majority of the respondents (20 or 69%) reported they found life to be unsatisfying. The wives' rating of their life satisfaction as unsatisfactory is consistent with the high number of stress symptoms experienced and their almost negative affect. It may be that the wives' low life satisfaction is related to the caregiving situation.

The second measure of subjective well-being is the Bradburn Affect Balance Scale. The scale has a potential range of 0 to 10. The range for the subjects in this sample was 1 to 10 with a sample mean of 5.2. This indicates the subjects had only a very slight predominance of positive affect, a finding consistently documented in other studies of caregivers (Sanford, 1975; Pringle, 1982; Rabins et al., 1982; Niederehe et al, 1983).

In terms of individual items, feelings of anger and impatience were the most prevalent negative emotions expressed by the subjects. It is interesting to note that this item was an extra item not included in the calculation of the mean of the Affect Balance Scale. If this item were incorporated in the scale the affect of the subjects would be negative. The high degree of anger and impatience experienced by the subjects in this study is of particular salience given the increasing concern regarding elder abuse by caregivers.

Twenty of 28 subjects (71.4%) reported feeling depressed
or very unhappy. Only seven of 25 participants (28%) felt things were going their way and only four subjects (13.8%) felt on top of the world. Twenty-two of 28 subjects (78.6%) did report feelings of pride and accomplishment. Similar to the caregivers in Marcus and Jaeger's (1982) study, several of the subjects indicated that the source of these feelings was solving problems related to the care of their dependent. Thus, it appears that meeting the challenges of caregiving may enhance some caregivers' self-esteem.

Table 7 presents a comparison of the study sample means on measures of subjective well-being to the means of the 2 comparison samples. The wives' life-satisfaction is significantly lower than that of the general population and George's caregiver sample. Fengler & Goodrich (1978) also found that the life satisfaction of the wives in their caregiver sample was lower than in the general population. The study wives' life satisfaction is lower than the caregivers in Pringle's (1982) study.

The affect of the study wives is also significantly more negative than that of the general population and George's caregiver sample. The fact that epidemiological studies demonstrate that women report more symptoms of depression than men (Fitting & Rabins, 1985) does not fully account for the highly significant differences in affect between the wives and the comparison samples.
Table 7

Comparison of Means on Subjective Well-Being Measures: Study Sample, General Population and Comparison Caregiver Sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>Study Sample Mean</th>
<th>General Population Mean</th>
<th>Caregiver Sample Mean</th>
<th>a</th>
<th>b</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life Satisfaction</td>
<td>1.31</td>
<td>2.46</td>
<td>1.97</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Scale</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(1=not satisfying, 2=fairly, 3=very satisfying)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affect Balance</td>
<td>5.20</td>
<td>7.07</td>
<td>5.95</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>(0=totally negative affect, 5=balanced affect, 10=totally positive affect)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a= one sample t-test</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b= two sample t-test</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>*= significant at p=.05</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Health Behaviours

Means for the health behaviour items included in the questionnaire are presented in Table 8. There is considerable variation in the self-reports of health behaviours. Twenty-one (72.4%) of the subjects do not exercise regularly, a situation reportedly common amongst older women (Minister of Supply and Services, 1983). However, the demands of caregiving may exacerbate the tendency of the wives to be sedentary by leaving them too physically exhausted or with too little time to pursue
physical exercise. Nineteen (65.5%) participants reported receiving regular medical checkups. Twenty-five respondents (86.2%) reported that they ate regular and nutritious meals. Receiving less sleep than needed is reported by 15 respondents (51.7%) although an almost equal number of respondents (13 or 44.8%) stated they had sufficient sleep. In terms of reported self-care, on average, the participants felt they took fairly good care of themselves. Five (17.2%) respondents felt they neglected their own health.

Table 8

Health Behaviours

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participates in regular exercise (0=no, 1=yes)</td>
<td>0.28</td>
</tr>
<tr>
<td>Caregiver has regular checkups (0=no, 1=yes)</td>
<td>0.65</td>
</tr>
<tr>
<td>Amount of sleep</td>
<td>1.96</td>
</tr>
<tr>
<td>(1=less than needed, 3=right amount)</td>
<td></td>
</tr>
<tr>
<td>Eat nutritious meals</td>
<td>2.86</td>
</tr>
<tr>
<td>(1=never, 2=sometime, 3=most of the time)</td>
<td></td>
</tr>
<tr>
<td>Adequacy of self-care</td>
<td>2.04</td>
</tr>
<tr>
<td>(1=neglect self, 2=fairly well, 3=very well)</td>
<td></td>
</tr>
</tbody>
</table>
Participation in and Satisfaction with Preferred Activities

Caregiving has been found to have negative effects upon the caregivers' ability to participate in social and leisure activities at preferred levels (Grad & Sainsbury, 1963; Sanford, 1975; Marcus & Jaeger, 1982; Rabins et al., 1982; Chenoweth & Spencer, 1983; George, 1983, 1984). The descriptive data presented in Table 9 support this finding.

In terms of contact with friends and relatives, respondents, on average, talked on the phone with family and friends slightly more than two to three times weekly and visited with them slightly less than once per week. Thirteen of 28 participants (46.4%) reported having social visits less than weekly. The mean level of satisfaction with the amount of contact with friends and relatives is 2.41, which lies between dissatisfied and satisfied. Eighteen (62.1%) of the subjects reported dissatisfaction.

The respondents indicated that, on average, they rarely attended church, but would like to attend church on an occasional basis. The mean level of attendance at social groups or clubs is 2.21, which lies between rarely and occasionally. Ten (34.5%) of the participants reported that they never attended meetings of social groups. Again, respondents indicated they attended such functions less often than they would like to; seventeen of 28 subjects (60.7%) reported they would like to go to such meetings on an occasional basis.
Table 9
Participation In and Satisfaction with Preferred Activities

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of telephone contact</td>
<td>2.93*</td>
</tr>
<tr>
<td>Frequency of visits with friends and family</td>
<td>1.71*</td>
</tr>
<tr>
<td>Satisfaction with contact</td>
<td>2.41**</td>
</tr>
<tr>
<td>Church attendance</td>
<td>2.10***</td>
</tr>
<tr>
<td>Desired church attendance</td>
<td>2.93***</td>
</tr>
<tr>
<td>Club attendance</td>
<td>2.21***</td>
</tr>
<tr>
<td>Desired club attendance</td>
<td>2.93***</td>
</tr>
<tr>
<td>Hours per week spent in personal hobbies</td>
<td>.28</td>
</tr>
<tr>
<td>Satisfaction with time spent in hobbies</td>
<td>2.45**</td>
</tr>
<tr>
<td>Hours per week spent relaxing</td>
<td>10.22</td>
</tr>
<tr>
<td>Satisfaction with time spent relaxing</td>
<td>2.62**</td>
</tr>
<tr>
<td>Satisfaction with Social Activities Scale</td>
<td>7.48</td>
</tr>
</tbody>
</table>

* Scale: 1= less than weekly, 2= at least weekly, 3= 2-3 times weekly, 4= daily.

** Scale: 1= very dissatisfied, 2= dissatisfied, 3= satisfied, 4= very satisfied

*** Scale: 1=never, 2=rarely 3=occasionally, 4=regularly

The low attendance at clubs was clearly evidenced in the difficulty the investigator had in locating subjects through local caregiver support associations. The researcher questions if the low attendance of caregiving wives at the
support groups is reflective of their not being aware of support services or their being unable to avail themselves of them. For example, the wife may not be able to locate someone to remain with the husband while she attends the support group. Robertson and Reisner (1982) suggested that the low utilization of existing services by the caregivers in their study may have been due to the services not being accessible or not meeting the perceived needs of the dependents and their supporters. It may also be that if and when caregiving wives get some "time off" they may not choose to spend it attending a support group.

Respondents averaged an alarmingly low 0.28 hours weekly pursuing personal hobbies. Twenty-seven respondents reported that an average of 10.22 hours weekly were spent relaxing or taking it easy. For both of these activities, the mean level of satisfaction lay between dissatisfied and satisfied.

The Caregiver's Satisfaction with Social Activities Scale has a potential range of 4 to 12. The range for this sample was 4 to 12, with a mean of 7.48. This indicates that, despite the degree to which the wives were socially restricted, they were only moderately dissatisfied with their participation in preferred activities. It may be that the wives' sense of duty and socialization into the caregiving role precluded them from expressing more dissatisfaction. The little amount of time the wives spent in social activities prevented them from using these diversional activities as a method of dealing with the high level of
stress they were experiencing. In addition, the limited social contact may prevent the subjects from benefiting from the positive aspects of social support. However, the extent to which social support alleviates caregiver burden is inconclusive. For example, Zarit et al., (1980) reported that the frequency of family visits was significantly related to level of burden experienced by caregivers of dependents with dementia. Gilhooly (1984), however, found that frequency of social contact was not correlated with supporter morale or mental health.

Table 10 presents a comparison of the means on selected measures of social well-being for the study sample and the 2 comparison samples. In comparison to the general population, the wives were markedly less able to pursue social and recreational activities for all the indicators of social activity with the exception of the number of phone calls they received. The differences between the sample and the general population are particularly striking for time spent in hobbies and relaxing. The general population spent 45 times more time pursuing hobbies and approximately twice the amount of time relaxing. Normative data reporting that older Canadians were slightly less likely to participate in social activities (Minister of Supply and Services, 1983) does not fully account for the degree to which the wives in the sample were socially restricted.
Table 10

Comparison of Means on Social Activities Measures: Study Sample, General Population and Comparison Caregiver Sample.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Study Sample Mean</th>
<th>General Population Mean</th>
<th>Caregiver Sample Mean</th>
<th>a</th>
<th>b</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of Phone Contacts</td>
<td>2.93</td>
<td>3.17</td>
<td>2.75</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency of Visits</td>
<td>1.71</td>
<td>2.65</td>
<td>1.91</td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>(1=less than weekly, 2=at least weekly, 3=2-3 times weekly, 4=weekly)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Church Attendance</td>
<td>2.10</td>
<td>3.18</td>
<td>3.09</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Club Attendance</td>
<td>2.21</td>
<td>2.99</td>
<td>2.62</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>(1=never, 2=rarely, 3=occasionally, 4=regularly)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hours spent in Hobbies</td>
<td>0.28</td>
<td>12.63</td>
<td>6.12</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Hours spent Relaxing</td>
<td>10.22</td>
<td>21.17</td>
<td>10.02</td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Satisfaction with Social Activities Scale</td>
<td>7.48</td>
<td>NA</td>
<td>8.06</td>
<td>NA</td>
<td></td>
</tr>
</tbody>
</table>

a= one sample t-test
b= two sample t-test
*= significant at p=.05
-= not significant at p=.05
The wives were significantly more socially restricted in terms of attendance at social clubs and church and time spent in hobbies than George's caregiver sample. This is consistent with George's (1984) findings that women caregivers were more likely to participate in fewer social activities and that spouses versus children were more likely to give up social activities. Gilhooly (1984) also suggested that male caregivers were less socially isolated. The sense of duty and guilt which is experienced if women share their burden of caregiving may have influenced the amount of services the sample accepted to enable them to pursue activities outside the home. Despite being more socially restricted than George's caregiver sample, the study wives did not report a significant difference in overall satisfaction with time spent in preferred activities. This supports the thesis that the wives may have been hesitant to express more dissatisfaction.

Financial Resources

Descriptive data for financial indicators of well-being provided in Table 11 suggest little economic burden among participants in this study. Considering the literature which discusses the vulnerable financial position of elderly married women caring for an ill spouse (Dulude, 1978; Equal Opportunities Commission, 1982; Rimmer, 1983; Walker, 1983), this finding is somewhat unexpected.
Table 11

Financial Indicators

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Own home (0=no, 1=yes)</td>
<td>.66</td>
</tr>
<tr>
<td>Own outright</td>
<td>.82</td>
</tr>
<tr>
<td>Assets sufficient to meet emergencies</td>
<td>.93</td>
</tr>
<tr>
<td>Enough money for extras</td>
<td>.90</td>
</tr>
<tr>
<td>Enough money for future</td>
<td>.85</td>
</tr>
<tr>
<td>How well money covers bills</td>
<td>2.93</td>
</tr>
<tr>
<td>(1=cannot meet bills, 2=barely, 3=easily covers bills)</td>
<td></td>
</tr>
<tr>
<td>Money meets needs</td>
<td>2.32</td>
</tr>
<tr>
<td>(1=poorly, 2=fairly well, 3=very well)</td>
<td></td>
</tr>
<tr>
<td>Finances compared to peers</td>
<td>2.04</td>
</tr>
<tr>
<td>(1=worse, 2=about the same, 3=better)</td>
<td></td>
</tr>
<tr>
<td>Perceived Economic Status Scale</td>
<td>9.96</td>
</tr>
</tbody>
</table>

Nineteen (65.5%) of the respondents owned their own home and 14 of these subjects owned it outright. This is consistent with the situation of the majority of older Canadians (Minister of Supply and Service, 1983).

One subject did not complete the subjective items (the last 6) in Table 11, therefore the sample size for the following financial indicators discussed is 28. Twenty-six (92.9%) perceived their financial resources were sufficient to meet emergencies and pay household bills. On average, participants felt they were financially comparable to other
people their age and that their needs were being met fairly well to very well. Of the 26 wives that completed the item determining concern about future finances, only 4 had concerns. The wives' lack of concern regarding their future financial situation may be due, in part, to their coping behaviour of living from day to day and not thinking about the future. More than one-half of the female caregivers in Marcus and Jaeger's (1982) study reported this as a means of coping with the stress of caregiving.

The subjective items in Table 11 comprise the Perceived Economic Scale which has a potential range of 3 to 12. The range for the subjects was 4 to 12 with a mean of 9.96, indicating that the participants were quite positive about their financial situation.

Table 12 presents a comparison of sample means on measures of financial resources for the study sample and the 2 comparison samples. In comparison to the general population and George's caregiver sample, the wives in this study were significantly more positive about their financial situation. The vastly different system of health care funding in Canada may have prevented the financial hardship expressed by the subjects in the American caregiver sample. For example, British Columbia's Long Term Care Program funds services such as homemaker assistance and Adult Day Cares. Pringle's (1982) Canadian study of caregivers of the elderly also reported positive perceptions in terms of financial resources.
Table 12

Comparison of Means on Financial Measures: Study Sample, General Population and Comparison Caregiver Sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>Study Sample Mean</th>
<th>General Population Mean</th>
<th>Caregiver Sample Mean</th>
<th>a</th>
<th>b</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived Economic Scale</td>
<td>9.96</td>
<td>6.47</td>
<td>9.09</td>
<td>*</td>
<td>*</td>
</tr>
</tbody>
</table>

a = one sample t-test
b = two sample t-test
*= significant at p = .005

Cronbach's alpha was used to determine the reliability of the four scales for this sample. All of the coefficients were well within the acceptable range of .60 to .80 (Lord & Novick, 1968). The scales and the corresponding alpha coefficients are as follows:

(1) Caregiver's Stress Symptoms Scale .80
(2) Affect Balance Scale .71
(3) Participation in and Satisfaction with Social Activities Scale .84
(4) Perceived Economic Status Scale .91

Summary

The results revealed that the sample of older wives caring for a husband with Alzheimer's Disease were experiencing deficits in all the domains of well-being with the exception of financial resources. Comparison of the
sample means to a general population sample and a more heterogenous group of caregivers revealed that the deficits in the study wives' well-being were, in general, significantly more profound, particularly in the domains of mental health and participation in and satisfaction with social activities. Normative data on the well-being of older Canadian women in general accounts, in part, for only some of these discrepancies. Thus, the results suggest that the caregiving experience per se may have a negative impact on the caregiver's well-being and that older wives caring for husbands with Alzheimer's Disease are particularly at risk for such deficits.

Considering the prevalence of chronic illnesses, mental stress symptoms, essentially negative affect, and the degree to which the caregivers' social activities were restricted, one wonders how effectively the wives in the sample were able to carry on with their caregiving responsibilities. The identification of who is the caregiver and who is the dependent becomes difficult. The findings of the study are congruent with Fengler & Goodrich's (1978) summation that older wives of disabled men are "hidden patients."
CHAPTER FIVE

Summary, Conclusions, Implications
and Recommendations for Future Research

Summary

The purpose of this study was to document the well-being of older wives caring for husbands with Alzheimer's Disease. The older wife has an increased chance of finding herself in this caretaking role due to the rising incidence of Alzheimer's Disease, popularity of home care for the chronically ill elderly, and socialization of women into the caregiving role. Because of nursing's concern with family-centred care, it is of interest to document the well-being of family caregivers to ensure their rights and needs will be considered. The lack of research in this area was a stimulus for investigation of these concerns.

Well-being was conceptualized in terms of four domains: physical health, mental health, participation in and satisfaction with social activities, and financial resources. A review of the literature substantiated that caregiving may lead to deficits in well-being, particularly for the older caregiving wife.

The study method was an exploratory descriptive survey. Twenty-nine women, 55 years of age and older, who were married to and residing with husbands diagnosed with Alzheimer's Disease comprised the sample. The subjects were drawn from 13 agencies in the Lower Mainland area of British
Columbia and Vancouver Island. The subjects ranged in age from 57 to 81 years, with an average age of 67 years. On average, the wives had been caring for their husbands for 42 months and were the sole caregivers.

The subjects completed a self-administered Caregiver Questionnaire that consisted of 78 questions designed to elicit data regarding demographic information, the four domains of well-being, and caregiver health behaviours. Forty-three of the questions made up four multi-item scales and 35 of the questions were a combination of open and fixed alternative items. A variety of schemata were used to interpret the scores on the items.

Completed questionnaires were coded and placed on computer file. Descriptive statistics were used to analyze the data. Analysis of the data indicated that the subjects had deficits in all the domains of well-being with the exception of financial resources.

In terms of physical health, twelve (41.4%) of the caregivers reported that a variety of health problems had reappeared or worsened in the past six months. Of these, arthritis and hypertension were the most common. Reports of new health concerns were also noted by seven (24.1%) participants with arthritis being the most common. On average, the wives rated their health between fair and good. Thirteen (45%) of the subjects reported using psychotropic drugs, mainly to assist them to sleep. Caregiver health behaviours were less than desirable in terms of having
regular physical exercise and adequate sleep.

In terms of mental health, the respondents' mean score on the Caregiver's Stress Symptom Scale was 11.14, indicating a severe degree of stress. The overall life satisfaction index revealed that subjects described their lives as not satisfying to fairly satisfying. The mean on the Affect Balance Scale was 5.20, indicating the caregivers had only a very slight predominance of positive affect.

The amount of time caregivers had to spend in pursuing preferred activities was strikingly low. For example, the wives spent only 0.28 hours weekly pursuing hobbies and 10.22 hours relaxing. The mean on the Caregiver's Satisfaction with Social Activities Scale was 7.48 indicating the caregivers were moderately dissatisfied with their participation in preferred activities. The wives were experiencing no perceived deficits in terms of finances.

Comparison of sample means on selected indicators of well-being with those of the general population revealed that the study sample had markedly greater deficits in all domains of well-being, again with the exception of financial resources. These differences were statistically significant at p = .05. Results were similar when the sample was compared to another sample of caregivers and the majority of these differences were also statistically significant at p = .05.
Conclusions

The following are conclusions to be drawn from the findings of the study:

1. The sample of older wives caring for husbands with Alzheimer's Disease experienced major deficits in all domains of well-being with the exception of financial resources.

2. These deficits were more pronounced than those experienced by the 2 comparison samples representative of the general public and a more heterogeneous group of family caregivers.

3. Normative data on the health of older women in general does not fully account for the deficits in the study wives' well-being or the differences in means between the study sample and the comparison samples. This suggests that the caregiving experience per se may be responsible, in part, for the deficits in the study wives' well-being, and that older women caring for husbands with Alzheimer's Disease are particularly at risk for deficits in well-being.

Implications

The study results provide direction for nursing practice. Of primary importance is the need for nurses to recognize that the burden of caregiving, superimposed upon age-related changes in older women, may result in major deficits in the well-being of an older caregiving wife. Caregivers must be viewed as clients, in their own right,
who require assessment on a frequent and regular basis. Many community home support programs do not fully address this need. For example, in British Columbia, a large proportion of demented elderly and their family caregivers are cared for under the Long Term Care program. According to people who work in the program, the mandate of the Long Term Care program and the caseload of the health professionals working in the program are such that frequent and regular visits by Long Term Care staff are not feasible. The norm is that the majority of these dependents and their family caregivers are seen once to twice yearly. More frequent visits by Long Term Care staff or referral to Home Care Nursing for closer surveillance often only occurs as a result of a crisis in the caregiving situation. Thus, community home support programs should incorporate the needs of family caregivers into the mandate of their programs and develop formal ways to provide the frequent assessment and intervention that family caregivers require.

The need to recognize the problems experienced by caregivers is also of crucial importance to nurses working in institutional settings. Dependents are often discharged home without systematic enquiry about the family caregiver's desire and capacity to provide the care. Discharge planning for a dependent should involve a thorough assessment of the caregiver's well-being and capacity to provide the required care. Further nursing actions may involve being an advocate for the caregiver to ensure that appropriate community home
support services have been arranged.

The study results provide direction as to the nature of nursing assessments and interventions that could be conducted during visits with the caregiver. Considering the prevalence of chronic physical problems among the study wives, nursing assessments should determine the presence of such problems. Interventions specific to the chronic illness(es) the wife is experiencing could then be instituted. For example, wives with arthritis could be taught appropriate body mechanics to prevent stress on body joints while women with cardiovascular problems could be counselled regarding matters such as their diet and medications.

Knowing that the rate of psychotropic drug use is high among caregiving wives, the nurse is directed to monitor the caregiver's use of such drugs. Interventions could involve teaching the wife techniques of stress reduction and non-pharmaceutical means to potentiate sleep.

The study results indicated that symptoms of mental health stress were exceedingly high among the subjects. Thus, nurses could undertake assessment for symptoms of stress, particularly feelings of being overwhelmed, tension, and worry. Difficulty getting to and staying asleep is another major stress symptom that needs to be ascertained by the nurse. Considering that the affect of the study wives was only slightly positive, nurses should assess caregiver affect with particular attention to feelings of anger, impatience, and depression.
Nursing visits can provide the wife with the opportunity to express emotions, such as those described above, to a non-judgemental person. This may assist in lessening the burden of these uncomfortable emotions. Assisting the wife to understand anger as a reaction to frustration is of particular importance. The wife could be assisted to learn techniques to minimize frustration such as physical exercise, imagery, and sharing feelings with a confidante. Effectively dealing with anger will help interrupt the vicious cycle of anger/guilt and may prevent the anger from being used destructively. The wife needs to understand that feelings of guilt are normal and may often be related to having expressed anger towards the spouse. Interventions related to expression of depressive feelings may involve assisting the wife to acknowledge and grieve the multiple losses she is incurring.

An important nursing intervention regarding all the emotions discussed above is to help the wife articulate what aspect of the caregiving situation is resulting in these emotions. Specific problem-solving techniques to alter the identified aspect(s) of the caregiving situation could then be instituted.

The study results indicated that some wives may derive satisfaction and pride from aspects of the caregiving situation, such as solving problems related to the care of the husband. This can be explored with the wife and the wife's caregiving efforts acknowledged. Discussion of the
positive aspects of caregiving may help to balance the negative emotions.

Analysis of the research data pertaining to the study wives' health behaviours indicated that the demands of caregiving may exacerbate the generally poor health practices of older women. Nurses need to enquire as to the wife's health behaviours such as regular exercise, annual medical checkups, and obtaining adequate sleep. Caregivers require education regarding the importance of such health behaviours. The wives must understand that attention to their own needs will improve their well-being, which in turn will better equip them to cope with the demands of caregiving.

Directed by the study results to view caregivers as socially restricted, the nurse can determine the caregiver's participation in and satisfaction with preferred activities such as phone calls and visits from friends and attendance at social clubs or groups. Of particular importance is the need for the nurse to assess the amount of time the caregiver has to pursue hobbies and to relax.

A primary nursing intervention in terms of social health is to encourage the wife to seek rewards and recognition outside the immediate caregiving experience. Services could be arranged such that the wife is provided with time to pursue hobbies, relax, and participate in preferred activities. The nurse can inform the wife of available home support services such as adult day care programs for the husband, respite and homemaker services, and
coordinate these services to assist the caregiving wife. The apparent lack of financial hardship experienced by the caregivers may enable them to use some of their financial resources to fund additional support services.

If a suitable caregiver support group is available, the nurse can assist the wife to arrange support services so that she can attend. Discussing emotions and concerns with others who thoroughly understand the situation communicates empathy and a feeling that the caregiver is not alone in her struggles. It also provides an environment in which caregivers serve as role models for each other as they relate the varied ways they have learned to cope. The recognition and mutual support the caregivers gain from each other may have a positive effect on their self-esteem. For many caregivers, attending the caregiver support group may be an important social outlet. Social support can also be provided through frequent visits from the nurse.

In his/her endeavors to assist the caregiver to be less socially restricted, the nurse must be sensitive to the fact that the socialization patterns of older women and the inherent sense of duty and guilt may result in many wives being hesitant to accept the supports they need to pursue preferred activities. The nurse may need to explore this phenomenon with the caregiving wife.

Considering the deficits in the caregivers' well-being, it cannot be assumed that older wives are able to provide effective care for the demented husbands. Therefore, nursing
assessment needs to address the quality of care that is being provided to the patient by the caregiving wife.

Ongoing visits by the nurse in which the above assessments and interventions are followed will assist the nurse to identify caregivers at risk for pronounced deficits in well-being. The nurse must be able to determine when the demands of caregiving are going to exceed the caregiver's physical and emotional capacities. This will provide the nurse with a stronger data base upon which to counsel the wife regarding the need for increased home support service and/or institutionalization of the husband.

In conclusion, the caregiving wife needs an advocate who is concerned about her well-being. The professional nurse can fulfill this role in the following manner:

1. Nurses can advocate for improvements in community resources such that they are designed to effectively prevent deficits in caregiver well-being.

2. Nurses can organize and lead caregiver support groups.

3. Nurses can influence public policy by emphasizing the need for caution when considering policy recommendations based upon the premise that the older wife can serve as a basic provider for care of the husband with Alzheimer's Disease in the home.

Recommendations for Future Research

The findings of the study stimulate suggestions for further research which are as follows:
1. A longitudinal study to determine what bearing caregiving has on the life course of older wives caring for husbands with Alzheimer's Disease.

2. Studies in which the wife's well-being can be correlated to the husband's level of impairment and various aspects of the caregiving situation. Studies of this design would assist in clarifying if, and to what extent, these factors influence caregiver well-being.

3. A study comparing the well-being of older wives caring for husbands with Alzheimer's Disease to a matched sample of older wives without caregiving responsibilities. Such a study may help to clarify the extent to which the aging process itself contributes to deficits in well-being.

4. A study comparing the well-being of older wives caring for husbands with Alzheimer's Disease to a matched sample of older wives caring for husbands with conditions other than Alzheimer's Disease. Such a study may assist to further clarify the extent to which the nature of the illness of the patient influences caregiver well-being.

5. Given the number of male spousal caregivers the investigator encountered during subject recruitment, a study should document the well-being of older males caring for wives with Alzheimer's Disease.

6. Program evaluation research to determine the effectiveness of various support services in positively influencing caregiver well-being.

7. Studies to examine if the quality of patient care
provided by family caregivers is affected by the caregiver's level of well-being.

8. Research to develop a reliable and valid tool to screen for caregivers who are at risk for deficits in well-being as a result of caregiving.

In conclusion, this study has demonstrated that older wives caring for husbands with Alzheimer's Disease are particularly at risk for the development of deficits in their well-being. This is an area in which nurses can make a significant contribution and in which further study is needed.
References

Perspectives on health. Ottawa: Supply and Services Canada.


Golodetz, A., Evans, R., Heinritz, G., & Gibson, R. The care of chronic illness: The "responsor role." Medical Care, 12 (5), 385-394.


Appendix A

Caregiver Questionnaire

GENERAL INSTRUCTIONS: The questionnaire has been designed to be as easy to fill out as possible. In general, you will only need to circle the number beside the best answers or fill in a blank. This is not a test, and there are no right or wrong answers. The questions ask only for factual information or for your opinions. In order for the research to be complete, please answer every question.

(1) How old are you?

_______years of age

(2) How many years of formal schooling have you completed?

_______years of schooling

(3) Which of the following best describes you?

1. Currently employed
2. Retired
3. Housewife
4. Non-employed

IF CURRENTLY EMPLOYED: Please describe your current position and major job duties:

_________________________________________________________________

_________________________________________________________________

IF RETIRED: Please describe your position and major job duties for the job you had most of your life.

_________________________________________________________________

_________________________________________________________________

(4) Including yourself, how many people live in your household?

_______people
(5) For each person in your household, OTHER THAN YOURSELF, please list his or her age, sex, and relationship to you.

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<thead>
<tr>
<th>AGE</th>
<th>SEX</th>
<th>CHILD</th>
<th>SISTER/</th>
<th>GRAND-</th>
<th>OTHER</th>
<th>FRIEND</th>
<th>PAID</th>
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(6) How many children have you had?

_______children

(7) Not counting any children who live with you, how many of your children live within an hour's drive?

_______children

(8) How long have you been the caregiver for your husband?

_______months

(9) Are you the sole caregiver for your husband?

1. No
2. Yes

(10) How many times have you seen a doctor during the past six months, not counting the times you stayed overnight in the hospital?

_______times

(11) How many days altogether in the past six months were you in a hospital for health problems?

_______days in hospital

(12) During the past six months, how many days were you so sick that you were unable to carry on your usual activities—such as working around the house or going to work?

_______days
(13) Have any long-standing health problems reappeared or gotten worse in the last six months?

1. No
2. Yes

IF YES: please state the name of the problem(s)

(14) Have you developed any new health problems in the past six months?

1. No
2. Yes

IF YES: please state the name of the problem(s)

(15) Are you currently taking any medications—either prescription medicines or over-the-counter drugs—to calm you down, raise your spirits, or to help you sleep? Include medicines you take occasionally, as well as those you take regularly.

1. No
2. Yes

IF YES: What drugs are you taking, even on an occasional basis, and what is the purpose of each drug?

NAME OF DRUG | CALM YOU DOWN | RAISE YOUR SPIRITS | HELP YOU SLEEP

(16) Has your pattern of alcohol consumption changed in the past six months?

1. No
2. Yes

IF YES, how?
(17) How would you rate your overall health at the present time—excellent, good, fair, or poor?

1. Excellent
2. Good
3. Fair
4. Poor

(18) Is your health any better now, about the same, or worse than it was five years ago?

1. Better
2. About the same
3. Worse

(19) How much do health problems stand in the way of your doing the things you want to do—not at all, a little (some), or a great deal?

1. Not at all
2. A little (some)
3. A great deal

(20) How often would you say you worry about things—very often, fairly often, or hardly ever?

1. Very often
2. Fairly often
3. Hardly ever

(21) In general, would you say that most of the time you are in very good spirits, good spirits, low spirits, or very low spirits?

1. Very good spirits
2. Good spirits
3. Low spirits
4. Very low spirits

(22) Do you wake up fresh and rested in the mornings? Yes No

(23) Is your life full of things that keep you interested? Yes No

(24) Does it seem that no one understands you? Yes No

(25) Have you had periods of days, weeks, or months where you couldn't take care of things because you couldn't "get going?" Yes No

(26) Is your sleep fitful and disturbed? Yes No

(27) Do you feel weak all over much of Yes No
(28) Are you troubled by headaches? Yes No
(29) Do you sometimes have difficulty in keeping your balance while walking? Yes No
(30) Are you sometimes troubled by your heart pounding or shortness of breath? Yes No
(31) Do you sometimes feel hot all over? Yes No
(32) Do you sometimes have periods of great restlessness where you cannot sit still very long? Yes No
(33) Would you say your appetite is good? Yes No
(34) Are you the worrying type? Yes No
(35) Are you sometimes bothered by nervousness or tenseness? Yes No
(36) Do you ever have trouble in getting or staying asleep? Yes No
(37) Are you bothered by acid stomach? Yes No
(38) Are you "occasionally" bothered by "cold sweats?" Yes No
(39) Are you occasionally bothered by feelings of guilt? Yes No
(40) Do you sometimes feel overwhelmed by responsibility? Yes No
(41) Do you have personal worries that are getting you down physically? Yes No
(42) Do you feel somewhat alone, even among friends? Yes No
(43) Do you sometimes find yourself wondering if anything is worthwhile anymore? Yes No
(44) Do you participate in any regular exercise or sports activity? Yes No
(45) Do you go to the doctor for check-ups on a regular basis? Yes No
(46) Would you say that generally you get less sleep than you need, more sleep than you need, or just about the right amount?
1. Less than needed
2. More than needed
3. About the right amount

(47) Would you say that you eat balanced nutritious meals—most of the time, some of the time, or hardly ever?
1. Most of the time
2. Some of the time
3. Hardly ever

(48) In general, how well would you say that you take care of yourself—very well, fairly well, or would you say that you neglect your own health and well-being?
1. Very well
2. Fairly well
3. Neglect own health

During the past few weeks did you ever feel:

(49) —particularly excited or interested in something? Yes No
(50) —so restless that you couldn't sit long in a chair? Yes No
(51) —proud because someone complimented you on something you had done? Yes No
(52) —very lonely or remote from other people? Yes No
(53) —pleased about having accomplished something? Yes No
(54) —bored? Yes No
(55) —angry or impatient? Yes No
(56) —on top of the world? Yes No
(57) —depressed or very unhappy? Yes No
(58) —that things were going your way? Yes No
(59) —upset because someone criticized you? Yes No
(60) Taking all things together, how would you say you find life these days—very satisfying, fairly satisfying, or not satisfying?

1. Very satisfying  
2. Fairly satisfying  
3. Not satisfying

(61) About how often do you talk on the telephone with friends and relatives for SOCIAL purposes?

1. Daily  
2. 2-3 times per week  
3. At least once a week  
4. Less than once a week

(62) About how often do you visit with friends and relatives for social purposes—that is, how often do you go to visit them, they come to visit you, or even go out together?

1. Daily  
2. 2-3 times per week  
3. At least once per week  
4. Less than once per week

(63) How satisfied are you with the amount of contact you have with friends and relatives for social purposes? Would you say that you are very satisfied, satisfied, dissatisfied, or very dissatisfied?

1. Very satisfied  
2. Satisfied  
3. Dissatisfied  
4. Very dissatisfied

(64) How often do you attend church or religious services—regularly, occasionally, rarely, or never?

1. Regularly  
2. Occasionally  
3. Rarely  
4. Never

(65) How often would you like to attend church or religious services—regularly, occasionally, rarely, or never?

1. Regularly  
2. Occasionally  
3. Rarely  
4. Never
How often do you attend meetings of social groups, clubs, or civic organizations—regularly, occasionally, rarely, or never?
1. Regularly
2. Occasionally
3. Rarely
4. Never

How often would you like to attend meetings of social groups, clubs, or civic organizations—regularly, occasionally, rarely, or never?
1. Regularly
2. Occasionally
3. Rarely
4. Never

About how many hours a week do you spend on recreation or personal hobbies?

______ hours

How satisfied are you with the amount of time you spend in recreational activities or on your personal hobbies—very satisfied, satisfied, dissatisfied, or very dissatisfied?
1. Very satisfied
2. Satisfied
3. Dissatisfied
4. Very dissatisfied

About how many hours a week do you spend relaxing or just taking it easy?

______ hours

How satisfied are you with the amount of time you spend relaxing or just taking it easy—very satisfied, satisfied, dissatisfied, or very dissatisfied?
1. Very satisfied
2. Satisfied
3. Dissatisfied
4. Very dissatisfied

Do you own your own home?
1. No
2. Yes
IF YES: do you own it outright or are you still paying a mortgage?

1. own outright
2. still paying

(73) Are your assets and financial resources sufficient to meet medical and household emergencies?

1. No
2. Yes

(74) Are your expenses so heavy that you cannot meet your bills (or household expenses) or can you barely meet your bills, or are your bills no problem to you?

1. Cannot meet my bills
2. Can barely meet my bills
3. Bills are no problem

(75) How well do you think you (and your family) are doing financially as compared to other people your age--better, about the same, or worse?

1. Better
2. About the same
3. Worse

(76) How well does the amount of money you have take care of your needs--very well, fairly well, or poorly?

1. Very well
2. Fairly well
3. Poorly

(77) Do you usually have enough to buy those little "extras"--that is, those small luxuries?

1. No
2. Yes

(78) Do you feel that you will have enough for your needs in the future?

1. No
2. Yes

THIS IS THE END OF THE QUESTIONNAIRE. PLEASE ENSURE YOU HAVE ANSWERED ALL THE QUESTIONS. MY RESEARCH COULD NOT BE COMPLETE WITHOUT YOUR PARTICIPATION.
Appendix B

Scoring of Questionnaire

The manner in which the four scales in the questionnaire are scored is as follows. In completing the Caregiver Stress Symptom Scale, respondents indicate either yes or no to 21 items. A score of 0 is assigned to the affirmative responses and a +1 to negative responses, resulting in a possible range of 0 to 21. An affirmative answer to each of the items is indicative of stress. The higher the number, the stronger the evidence (George, 1983).

The Affect Balance Scale comprises five items which tap positive affect and five items which tap negative affect. Respondents are asked to agree or disagree with the 10 statements. Negative responses are assigned a score of 0 and affirmative responses, a score of +1. Thus, the scale has a potential range of 0 to 10. A score of 0 represents totally negative affect, a score of 10 indicates totally positive affect, and a score of 5 represents a balance between the two (George, 1983).

Three items concerning satisfaction with time spent in preferred activities comprise the Social Activities Scale. A score of +1, +2, +3 and +4 is assigned to the responses of "very dissatisfied," "dissatisfied," "satisfied," and "very satisfied," respectively, thus the scale has a potential range of 4 to 12. A score within the lower ranges of the scale indicates dissatisfaction, while scores in the upper ranges of the scale indicate satisfaction (George, 1983).
Six items eliciting the respondents' opinions about their economic status comprise a Perceived Economic Status Scale. Three of the items require the respondent to answer either yes or no. A response in the negative is assigned a score of 0 and an affirmative response, a score of +1. The other three questions require respondents to indicate their perceptions on a three-point scale. Negative perceptions are scored with a +1 and positive perceptions receive a score of +3. Thus, the scale has a potential range of 3 to 12. Scores in the range of 3 to 6 indicate negative perceptions of economic status while those in the 9 to 12 range indicate positive perceptions (George, 1983).
Appendix C

Letter of Information and Consent

THE WELL-BEING OF OLDER WIVES CARING FOR HUSBANDS WITH ALZHEIMER'S DISEASE

My name is Pam Brown. I am a registered nurse who is working on a Master's degree in nursing at the University of British Columbia. For my Master's thesis I am interested in learning about the impact that caring for a husband with Alzheimer's Disease has on the well-being of the wife. My interest in this developed when I was working as a community health nurse, and I could find little information about this matter.

If you are a wife over fifty-five years of age who is currently caring for, and have been caring for a period of at least six months, a husband who has Alzheimer's Disease, I would like you to participate in the study by fully completing the attached questionnaire. The questionnaire will take approximately twenty minutes of your time to complete. No identifying information is required on the questionnaire, and anonymity is guaranteed. I will communicate to you a summary of the results if you are interested.

You are under no obligation to participate in this study. Whether you participate or not, will have no effect whatsoever on the present or future health care services you or your husband may receive.

I anticipate that by learning about the well-being of wives caring for husbands with Alzheimer's Disease, I can