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# Relationships Among Provision of Care, Health and Well-Being, and Engagement in Health Promoting Activity of Older Adults Who are the Primary Caregivers for Spouses with Cancer

by

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Thesis Submitted to the
School of Graduate Studies and Research
in partial fulfilment of the requirements for the
Degree of Master of Science in Nursing

University of Ottawa

September, 1995

ISBN 0-612-04945-0

Canada

UNIVERSITÉ D'OTTAWA
UNIVERSITY OF OTTAWA

## ABSTRACT

This exploratory study investigated the relationships among the provision of care, physical and emotional health, and exercise and socialization among spousal caregivers of older adults with cancer. The Pender Health Promotion Model formed the conceptual framework for the study. Face to face interviews were conducted with sixty spousal caregivers of elderly individuals with cancer who were being cared for in their home.

Findings indicated that the majority of respondents participated in health promoting activities (exercise and socialization) both prior to and following spouses' diagnosis of cancer. There was, however, a decline in participation in all forms of physical exercise inquired about, particularly those requiring absence from the home, following spouses' diagnosis. With respect to socialization, face to face interactions with family, friends and others remained unchanged, however, social outings declined dramatically.

Caregivers perceived their overall health to have declined since their spouse's diagnosis of cancer. At the time of interview, the majority of respondents rated their physical health as good or excellent. They were however, contending with at least three physical health problems that had been diagnosed by a physician. The majority reported their emotional health as only fair or poor. These ratings were corroborated by their scores of the CES-D scale which indicated at least a mild level of depressive

symptomatology on the part of the majority of respondents.

Caregivers provided a substantial amount of assistance to their spouse in the form of personal and instrumental activities of daily living. This assistance, however, carried with it feelings of burden which related to anxiety about the future, feelings of distress and changes in spousal and other relationships. The majority of caregivers received assistance with their caregiving responsibilities from health care providers rather than family and friends. They did, however, report receiving emotional support from their family and friends.

This study also examined the strength of the major variables as predictors of participation in health promoting activity as hypothesized by the Pender model. Correlational analysis revealed a significant relationship between engagement in exercise and self rated health. This was not however the situation with respect to socialization and health. Correlational analysis also revealed a significant relationship between aspects of emotional load and self rated health. The findings of stepwise regression analysis revealed that, after controlling for perceived physical and emotional health, none of the load or support variables entered to further explain the variance in caregivers' exercise levels. A second regression revealed that only informal emotional support entered as a predictor of socialization. Indeed, the greatest predictor of health-promoting activity was prior levels of participation in exercise and socialization, which is not identified as an

important predictor of health-promoting activity in the Pender Health Promotion Model. Consequently, alterations to the Pender Model were proposed.

DEDICATED TO

MY SISTER, JUDY

## ACKNOWLEDGEMENTS

The production of this thesis was very much a collaborative effort, and I wish to acknowledge the assistance of the many persons who generously supported me throughout the process. First, my gratitude goes to my thesis supervisor, Dr. Margaret Ross, who skillfully guided me throughout the research process, and to Dr. Shirley Mills, my mentor in the field of research methodology and statistics. I express my appreciation to Bonnie Hall, CNS, who was also a member of my thesis committee. I am also indebted to Dr. Annette O'Connor and to Dr. Icoca Webster for their practical advice and assistance.

I wish to thank the individuals and agencies who made it possible to expeditiously obtain the required sample of family caregivers. Becky Hollingsworth and Beth McDonald facilitated my work through the Ottawa-Carleton Victorian Order of Nurses. Dr. Edna McHutchion, of the University of Calgary, opened up for me the gate to the West. I express special appreciation to Dr. Helen Hays and her team, particularly Reta Richert, at the Palliative Care Unit of the Misericordia Hospital, Edmonton. I say a big "thank you" to Dayle and Bernie Lambert who provided me with a home in Edmonton, and with friendship and support.

In Calgary, data collection was facilitated through the interventions of Carole-Lynne LeNavanec of the University of Calgary and Harry Plummer,

Director of Nursing of the Tom Baker Cancer Centre. I thank the Directors and staff of Tom Baker, Agape Manor, and of the Foothills and Mount View Health Units. It was a pleasure to collaborate with oncology and palliative care providers in Health Region 3, Alberta.

Friends who stood by me throughout this whole process, as always, were my tried and true friends--Larry, Bern and Don Ritz, Dawn and Bill Manning, Lorraine Perreault and Claude Lafontaine of Ottawa. I also received invaluable support from Dr. Jean Kozak, Dr. Bea Wickett, Marilyn Colton, Cynthia Shum, Marlene Gandhi, Regina Nephin, CSJ., and Mary Hearn Hendela. I acknowledge Kevin Wilmut's statistical help, and Sammy Halawa's technical assistance with this computer! My colleagues in the M.Sc.N. Program generously shared ideas, insights and good times together.

I am deeply grateful for the opportunity which this experience provided for the wonderful times I shared with my family in Calgary, Judy and Glen Roszel, and Julie, Stephen, and Glenna. I love you!

I express my thanks to all the funding agencies who were a supportive presence and offered me financial sponsorship during the two years of full-time study. These include: the National Health Research and Development Program (NHRDP), the Ontario Ministry of Education, the Canadian Cancer Society (Maurice Legault Award), the Canadian Nurses' Foundation and the Royal Canadian Legion, the Educational Centre for Aging and Health of McMaster University, the Kirshenblatt family and the Queen Elizabeth

Hospital, and the University of Ottawa who provided me with Admissions, Research, and Excellence Scholarships.

My final thanks goes to the spouses whose personal generosity made this research possible. They voluntarily shared their experiences, hopes, struggles, and heartaches with me. I thank each of you for your patience and for spending precious time and energy with me at a difficult and meaningful time in your lives. Thank you for your valued contribution to this important research on family caregivers.

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## List of Abbreviations

| | |
|---|---|
| % | Percent |
| # | Number |
| am't | Amount |
| < | Less than |
| > | Greater than |
| dk | Don't know |
| n/a | Not applicable |
| N | Total sample of 60 spousal caregivers |
| n | Sub-sample of spousal caregivers |
| M | Mean |
| SD | Standard Deviation of scores around the mean |
| Mdn | Median |
| Mid 50% | Scores within the 26th - 75th percentiles inclusive |
| p | Probability (.05, two-tailed, unless specified otherwise) |
| $r_s$ | Spearman correlation coefficient |
| t | Paired samples t-test |
| CI | Confidence Intervals (95%) |
| F | F statistic |
| PIN | Probability of F-to-enter (default is 0.05); variable must be significant @ 5% level in order to enter |
| Sig t | significance level (p level) of t test statistic |
| $R^2$ | % variation in dependent variable explained by independent variables |
| Adj. $R^2$ | $R^2$ adjusted to reflect # of independent variables used in model |
| Beta | Standardized regression coefficients |
| Incr. $R^2$ | Change in $R^2$ due to addition of an independent variable in the model |
| Dx | Diagnosis |
| ADLs | Activities of Daily Living |
| IADLs | Instrumental Activities of Daily Living |
| OARS | Scores for combined ADL and IADL Activities |
| CES-D | Centre for Epidemiologic Studies in Depression scale |

# CHAPTER 1

## INTRODUCTION

Social and economic realities are resulting in changes in the manner in which health care is delivered to Canadians. Part of this restructuring involves a pronounced shift from institution-based care to increasing emphasis on home health care. The challenge is to create greater access to cost-effective health care services, while at the same time promoting continuing quality improvement. The substantive contribution that elderly spousal caregivers make to the home care of their aging partners with advanced cancer is essential to this end. However, elderly caregivers may themselves be at risk for health problems. Health care workers, and nurses in particular, are in a position to actively support these individuals in their efforts to maintain and promote their own health while persevering in the caregiving role.

This study explores the health promoting activity of older adults who provide in-home care for their aged spouses with cancer. The investigation of caregivers' health promoting practices represents an important gap in the rapidly expanding body of caregiver literature. In particular, health promotion practices related to older spouses who provide cancer care in the home has received limited research attention. This thesis seeks to address this deficit in knowledge in particular as it relates to the experience of informal

caregivers. The relationships among caregivers' health promoting activity, their physical and emotional health, and the care that they provide are examined. Of additional interest is whether changes have occurred in the type and extent of health promoting activities engaged in subsequent to the spouse's diagnosis of cancer and the identification of predictors of engagement in health promoting activity.

## FOCUSED REVIEW OF THE LITERATURE

A focused review of the literature addresses the following three themes: a) informal caregiving in the home b) health of informal caregivers and c) health promoting activity of informal caregivers.

### Informal Caregiving in the Home

Increased numbers of older adults with advanced cancer are choosing to remain at home for supportive care, a practice that is encouraged by the Canadian health care system and made possible largely because of the enormous contribution to care by family members (Roe, 1992, Lieberman & Fisher, 1995). As recipients of care, patients with cancer become more and more dependent upon their family caregivers. Intensive physical and emotional demands are placed upon families during the period of advanced

and terminal illness (Chappell & Badger, 1989). The health of the caregivers may suffer as a result.

**Spousal Caregivers**

The majority of studies of informal caregiving have focused on caregivers with a particular relationship to the care recipient. Several researchers including Getzel (1982), Fitting et al. (1986), and Zarit et al. (1986) have studied the phenomenon of spousal caregiving. In general, it is reported that spousal caregivers report greater strain than non-spouses (Cantor, 1983; George & Gwyther, 1986) and are more prone to suffer a decline in health within the caregiving context (Tennstedt et al., 1989; Stommel et al., 1990; Pruchno & Resch, 1989a; Deimling et al., 1989; George & Gwyther, 1986; Cantor, 1983). Given that the proportion of older Canadians is escalating (Statistics Canada, 1989c) and women tend to live longer than their husbands who are typically older, women spouses comprise an important component of the caregiver population (Browning & Schwirian, 1994; Horowitz, 1985; Pruchno et al., 1990).Women caregivers also experience greater strain than men (Kramer & Kipnis, 1995).

Many spousal caregivers provide "heavy duty care" (Chappell & Badger, 1989), and older spouses may be at particular risk if they themselves are concurrently experiencing the physical and social

consequences of aging (Ross, 1991). Elderly wives tend to provide a good deal of practical assistance to their spouses, while husbands more often negotiate with service agencies in respect to care supplied by others. Husbands also provide money and household items (Archbold, 1983, Lang & Brody, 1983, Horowitz, 1985).

Early cancer studies by Hampe (1975) and Dracup and Breu (1978) identified the pressing need of spouses to be present with their dying partner. It is felt that marital closeness is fostered by maintaining the ill spouse in the home (Holing, 1986; Brown et al., 1990). Spouses who maintain a close, positive marital relationship, a concept described by Archbold et al. (1990) as mutuality, are expected to experience lower levels of role strain (Williamson & Schulz, 1990). This enhances the health of the caregiving spouse (Hirschfeld, 1983; Stetz, 1989), and promotes perseverance in the caregiver role (Sheehan & Nuttall, 1988).

**Practical Load**

Stone et al. (1987) differentiated among primary, secondary, and tertiary caregivers, restricting the term "primary caregiver" to persons having the total responsibility for the provision of care. Barer & Johnson (1990) noted the substantial contribution of informal caregivers to the care of their relatives and recommended that the types and amount of care provided to

care recipients be measured and recorded.

Horowitz (1985) described four types of services provided by informal caregivers to the elderly. Direct care services included personal care (bathing, feeding, toileting, etc.), meal preparation, transportation, housekeeping, and such health care activities as administration of medications. In a study by Oberst et al. (1989), caregivers stated that the most frequent demands on their time resulted from the need for transportation services, emotional support, and maintaining the household. Emotional support services consisted of initiating and maintaining social contacts. Another category of services was mediating with formal organizations on behalf of the care recipient to secure required services. Providing financial assistance through gifts of money and household articles was the fourth service category. There is evidence in the literature that shows that the provision of some of these services is related to the gender and relationship of the caregiver.

Bowers (1987) proposed an alternate method of describing caregiving responsibilities that reflects the multidimensional nature of care. The five distinct but overlapping categories included anticipatory caregiving that addresses potential needs of the care recipient, preventive caregiving that encompasses activities to prevent complications, supervisory caregiving that involves making arrangements for services and checking to see that care is given, instrumental caregiving that is the actual performance of tasks related

to direct care, and protective caregiving that is comprised of emotional and psychological support.

**Emotional Load**

The emotional consequences of caregiving are many and include feelings of burden. Phillips et al. (1995) pointed out the importance of identifying specific aspects of caregiver burden. According to Stetz (1987), the greatest stressors on cancer caregivers were physical care, treatments, and imposed changes, followed by the necessity of managing the household and being constantly available. Given et al. (1988) found that chronic illness, mental changes, and disruptive behaviour added to the stress of cancer caregivers. In another study of caregives of victims of cancer (Hooyman et al., 1985), family members reported that the performance of unaccustomed intimate physical care such as bathing, toiletting, etc. was particularly stressful. Hull (1990), reported that families identified patient symptoms, especially mental changes, interpersonal relationships, and concerns about themselves as the three main sources of their stress. Finally, psychological and emotional strains, such as depression (Etten & Kosberg, 1989; Gallagher, 1985), anger and anxiety (Addington-Hall, 1992), also contributed to caregiver stress.

A number of studies describe the family's experience during the advanced stages of cancer (Hampe, 1975; Wright, 1984; Petrosino, 1985; Howell, 1986; Hays & Arnold, 1986; Kristjanson, 1986; Woods et al., 1989). The priority for spouses is the patient's comfort. Spouses express concerns about the dying process, impending death, and their own health and coping abilities (Kristjanson, 1989; Keizer, 1992). There may be "hidden tasks" (Bowers, 1987) that demand expenditure of caregivers' physical and emotional energy during the terminal illness, for example, communicating with physicians and negotiating with the health care system. Kristjanson & Ashcroft (1994) report an absence of intervention studies to assist family caregivers of clients who are terminally ill.

Wilson (1992) conducted an ethnographic study of eight hospice home care families and found that caregivers were at special risk for burden when there was only one caregiver in the home, an elderly caregiver was caring for an elderly patient, and/or caregiving persisted over a prolonged period of time as in the case of a lingering death. In addition, situations of risk included times when the caregiver's outside activities were severely restricted (caregivers who were reluctant to leave the house in case the patient should die in their absence), the caregiver's sleep was consistently interrupted. Situations of risk also included periods of time when the caregivers had no one to call, the patient's symptoms were out of control, or when the patient experienced cognitive changes or seizures or frequent falls.

Furthermore, caregivers were at risk when the patient required more care than the caregiver could give. Caregivers panicked as death became imminent. As well, they became exhausted after prolonged caring and their health tended to deteriorate.

**Practical and Emotional Support**

There is evidence in the literature that caregiver assistance (George & Gwyther, 1986) and caregiver social support (Zarit et al., 1980; Pratt et al., 1985) help to offset role strain and role constriction. These outcomes of caregiving result from focusing on the caregiving role to the exclusion of other social roles and functions. Adequate and timely support and assistance serve to influence the health of caregivers in a positive direction. Caregivers, in their situation, reported that most support came from family and friends, with a good deal less from formal organizations. Fink (1995) found that mobilization of family resources promoted family well-being within the caregiving context, and Reinhard (1994) found that professional support selectively reduced caregiver burden.

Levin (1983) found that practical and instrumental help was the most effective mode of support from the formal care system. Scott et al. (1986) noted that respite care allowed caregivers to go on social outings. George (1988) found that caregivers who received relief reported increased time

spent on social and recreational activities. Hess & Waring (1980) and Strain & Chappell (1982) observed that women are more successful than men at initiating supportive relationships.

Stommel & Kingry (1991) studied 232 spouse-caregivers of cancer patients who reported that other family members tended to lend support mainly when children were present in the household. In general, spouses living alone received much less support from family, friends, and neighbours, especially when family members lived at a distance. George & Gwyther (1986) and Snyder & Keefe (1985) found that, with respect to caregivers' health, adequate social support was more important than either caregiver age or the duration of time spent in the caregiving role.

## Health of Informal Caregivers

Cancer studies still tend to focus on patient concerns and to regard caregivers' needs primarily in terms of fulfilling the caregiver role rather than investigating caregiver health and well-being for their own sake.

The relatively few longitudinal studies involving informal caregivers demonstrate inconsistent results related to their physical and emotional health. In general, findings demonstrate a worsening of depression and a decline in physical health (Brody et al., 1990; Cox et al., 1990; Townsend et al., 1989; Young & Khahana, 1989; Schulz et al., 1988; Liptzin et al., 1988;

Colerick & George, 1986; Johnson & Catalono, 1983). Cross-sectional studies (Schulz et al., 1990; Robinson, 1989; Baumgarten, 1989) support the fact that caregivers' physical and emotional health suffer during the course of caregiving. Pratt et al. (1985) found that the perception of caregiver burden was significantly related to the caregivers' perceived health status. Spousal caregivers appear to be more susceptible than other relatives and community controls to a deterioration of health (Stommel et al., 1990; Pruchno & Resch, 1989a; Deimling et al., 1989; Tennstedt et al., 1989; George & Gwyther, 1986). Robinson & Steele (1995) found that spousal caregivers had more problems with mental health and social particpation than with physical health or financial resources. The fact that a baseline evaluation of caregivers' health is often lacking, however, makes it difficult to evaluate changes subsequent to the onset of this role (Hamel et al., 1990; Baumgarten, 1989; Deimling et al., 1986).

**Physical health**

In a 2-year longitudinal study involving spousal caregivers of Alzheimer's victims and community controls, Wright (1994) found that in-home care providers experienced a decline in physical health as caregiving continued. Recent studies by Preston et al., (1990, Glasser et al. (1992), and Kiecolt-Glaser (1991) point to the conclusion that caregiver stress may lead to impaired immune functions and poor physical health. More research

is needed in this area.

**Emotional Health**

Wright (1994) also found that caregivers' moods, which had started off on a par with those of the non-caregiver controls, became more depressed, though not ranking as clinical depression, as time progressed. This finding is consistent with that of Fitting et al. (1986) and Haley et al. (1987). Wright's findings that depressed moods adversely affected the physical health of the caregivers, but that impaired health did not affect mood, concurred with study results by Pruchno & Resch (1989b). However, in a follow-up to Wright's study, Pruchno et al. (1990) found that depression predicted declines in physical health when the same sample of caregivers were re-surveyed six months later.

**The Priority of Caregiver Health**

It is now recognized that the health and well-being of the caregiver is as important as that of the care recipient. Cancer is known to be primarily a disease of the older population (Ganz et al., 1985; Given & Keilman, 1990). As a result, caregiving spouses may also be elderly and have multiple and/or serious health problems of their own. Adding to the difficulties is the fact

that many of these caregivers live alone with the patient (Nugent, 1988). The physical care requirements may also prove too much for them (Sanford, 1975; Barnes et al., 1981; Pesznecker & Zahlis, 1986, Fengler & Goodrich, 1979). It is reported that family caregivers often pay a high price in unmet personal and interpersonal needs over a prolonged period of time.

A further matter of concern is that caregivers are inclined to neglect their own health needs (Wright, 1994; Connell & Sharpe, 1990; Bunting, 1989; Snyder & Keefe, 1985). This situation makes it essential that nurses and other health workers actively monitor and intervene regarding caregivers' health, focusing on those caregivers who fit the high-risk profile identified by Davis (1992). According to Davis, caregivers at special risk are women, middle-aged or older, who live with the care recipient, who are the sole providers of care, who have personal health problems and limited personal, social, and/or financial resources. Nugent (1988) concurs that caregivers who live alone with the care recipient are at increased risk. It is imperative to examine the strategies that caregivers use to protect and to promote their own health in these high risk situations.

There is beginning evidence that a multiplicity of health problems experienced by elderly family caregivers could be moderated by a deliberative focus on health promotion. These problems include physical problems such as fatigue (Matson, 1988) and inadequate rest and sleep (Archbold, 1980; Googe & Varricchio, 1987). Bunting (1989) noted that

caregivers are often required to choose between their own needs and the needs of the care recipient, with a resultant decline in their own health. In a study by Theis et al. (1994), 24% rated their health as worse than one year previously and all of these attributed the change in health to the caregiving role. Care responsibilities interrupted caregivers' rest at least twice a night for 53% of Theis' sample. These same caregivers participated less in outside activities than they did prior to assuming the caregiving role.

## Health promoting Activity of Informal Caregivers

Shamansky & Clausen (1980) defined health promotion as activities aimed at increasing well-being and actualizing the health potential of individuals, groups, and society. The findings of Canada's Health Promotion Survey: Technical Report (Stephens & Graham, 1990) indicated that 48% of Canadians of all ages rank high on the index of leisure-time physical activities, a greater proportion of adults over 50 engage in frequent exercise than do younger individuals, and being more active is associated with better self-rated health and lower levels of stress among respondents of all ages. Two-thirds of the population believed that more exercise would benefit their health, 69% expressed the need to relax more and worry less, and half believed that spending more time with family or close friends would help them to improve their physical and emotional health.

Recent studies indicate that it is never too late to begin health promoting behavior such as physical activity and stress reduction (Muir Gray, 1992; Gelberg et al., (1990). Schmidt (1994) reports that in longitudinal studies of healthy persons up to 100 years of age, physical activity, nutrition, and stress management, along with social support and spirituality, are critical factors in maintaining health throughout the life course.

Factors that may obviate caregivers' participation in health promoting activity include higher levels of physical impairment of the care receiver (Deimling & Bass, 1986; Johnson & Catalano, 1983; Noelker & Poulshock, 1982), emotional strain (Robinson, 1989), greater involvement in caregiving tasks (Montgomery et al., 1985; Robinson & Thurnher, 1979), and care that confines the caregiver in time and place (Chappell & Badger, 1989). Hileman et al. (1992) discovered a negative correlation between caregivers' emotional health and care recipients' activity levels in a sample of 492 cancer caregivers. Clayton (1982) found that clinical depression compromised caregivers' ability to maintain themselves adequately in their role, and several studies have shown that depression and stress in caregivers vary positively with symptom level of the care recipient (Eagles et al., 1987; Gilleard et al., 1984; Levin, 1983; Wade et al., 1986). There is increasing evidence that caregivers' perceptions of stress can be of greater importance than the objective circumstances in which they find themselves (Zarit et al., 1986; Cox et al., 1990; Morris et al., 1988; Motenko, 1989; Singer &

Irvin, 1989).

While there is a growing body of knowledge in the field of health promotion, the observation of Valentine (1984) holds true today--little is known about the health promoting activity of family caregivers. One study by Killeen (1989 ) measured participation in health promoting practices of 120 caregivers of older adults with dementia. The most frequent activities that caregivers engaged in were related to the use of substances, followed by nutrition, relaxation, and general health promotion practices. Exercise was the activity least frequently engaged in. While Killeen reported a rank ordering in health promotion activities, actual levels of participation were not specified. Killeen found that caregivers' perceptions of their health were negatively related to the extent of care provided, and positively related to caregivers' participation in health promotion activities.

Stewart & Archbold (1992) called for intervention research studies designed to stimulate innovations with family caregivers to relieve the stress of caregiving and make the work of caregiving easier and more satisfying. Petrick (1991) also advocated comprehensive assessment of the demands inherent in the caregiving construct in order that interventions may be designed specifically to promote the physical and emotional health of informal caregivers. In response to this challenge, it is hoped that the present study will serve as an impetus to empower caregivers through engagement in health promotion activity.

## Summary of the Literature Review

Literature on informal caregiving yields conflicting reports regarding many aspects of this phenomenon. The vast majority of studies involving informal caregivers has been carried out in the field of gerontology. Therefore, the application of the research findings to the fields of oncology and palliative care--where a paucity of research has been carried out--must be made with caution. As Petrick (1991, p. 14) states, "although gerontological research provides important insights into the caregiving experience, it would be erroneous to generalize these findings to caregivers of persons with advanced cancer...because of the nature of the disease and limited life expectancy".

The preponderance of studies reveals that the physical and emotional health of informal caregivers may be inversely related to caregiving demands and to pre-existing risk factors such as prior health problems, ambivalent relationships, and inadequate patterns of coping. Caregivers in the older age group often suffer from chronic illnesses and, as a result, may be particularly vulnerable in the demanding caregiver role.

The context of informal caregiving, the identifying characteristics of the caregivers, and the concept of caregiver burden have been extensively studied. Less work has been done on formal and informal support systems for family caregivers. Intervention studies designed to assist caregivers to

cope effectively, and to maintain their own physical and emotional health in the caregiving milieu, are lacking. In particular, the health promoting activity of informal caregivers and its relationship to the caregiving context and to caregivers' physical and emotional health has received scant attention. Given that Canadians will become increasingly dependent upon family caregivers to provide home health care, it is crucial that researchers investigate the health promoting activities of such caregivers.

## UNDERLYING ASSUMPTIONS OF THE STUDY

This research study is based upon the following assumptions:

1. Caregiving is physically taxing and emotionally stressful.
2. The work and stress of caregiving may adversely affect caregivers' physical and emotional health, especially that of older caregivers who may be experiencing health problems of their own.
3. Persons with good physical and emotional health will more likely engage in health promoting activity than will persons who are in poor health.

## Theoretical and Conceptual Framework: The Pender Model

Pender's Health Promotion Model (1982; 1987), based on Bandura's (1986) social learning theory, provides the overall conceptual framework for this study. This model addresses the role that individual and environmental factors play in predicting the health promoting components of lifestyle and has been used to study health activities and their determinants in a variety of populations, including studies of older persons (Duffy & MacDonald, 1990; Walker et al., 1988; Speake et al., 1989). Figure 1 portrays the conceptual framework employed in this study.

**Figure 1**

**CONCEPTUAL FRAMEWORK**

| MODIFYING FACTORS | PRIMARY MOTIVATORS | HEALTH PROMOTING ACTIVITIES |
|---|---|---|
| **Cargiving Situation:** | **Perceptions of Health:** | **Exercise** |
| Practical Load | Self-rated Physical Health | |
| Emotional Load | Self-rated Emotional Health | **Socialization** |
| Practical Support | | |
| Emotional Support | | |

Adapted from Pender, 1987.

According to Pender's model, cognitive-perceptual factors are the primary motivators of the likelihood of engaging in health promoting behaviour. Modifying environmental factors, such as situational variables, are hypothesized to predict such behaviour indirectly. More specifically, situational variables in the environment are hypothesized to impact on people's perceptions, and these perceptions in turn are hypothesized to influence their likelihood of engaging in health promoting activity. However, more recent findings (Pender, 1990a; Pender 1990b; Johnson et al., 1993; Lusk et al., 1994) have suggested that modifying variables may also directly impact on health promoting behaviour.

In this study, the health promoting activities of interest are patterns of exercise and socialization of spousal caregivers of older adults with cancer. The primary motivators hypothesized to influence caregivers' participation in exercise and socialization are perceptions of their physical and emotional health. The modifying environmental factors under assessment relate to the caregiving situation and include both caregiver load and caregiver support.

Caregiver load includes both practical and emotional load. Practical load is conceptualized as the type and extent of caregiving tasks carried out by the caregiver for their spouse. Emotional load is conceptualized as feelings of burden associated with the caregiving role.

Caregiver support is also practical and emotional. Practical support is conceptualized as assistance received with caregiving tasks from informal

and formal networks. Emotional support is conceptualized as encouragement provided by informal and formal networks.

## RESEARCH OBJECTIVE AND QUESTIONS

The primary objective of this study is to investigate the health promoting activties of individuals who are providing care in the home to elderly spouses with cancer. More specifically, this study is designed to answer the following research questions:

1. What is the type and extent of health promoting activity engaged in by individuals who provide care in the home to spouses with cancer?
2. What are their levels of self-rated physical and emotional health?
3. What is the nature of their caregiving situation?
4. What are the relationships among aspects of the caregiving situation, self-rated physical and emotional health and engagement in health promoting activity?
5. To what extent do observed relationships among the above mentioned variables provide support for Pender's model of health promotion?

## DEFINITION OF TERMS

| | |
|---|---|
| Informal Caregivers | spouses who assumed primary responsibility for the total care of their ill partner |
| Practical Load | type and extent of caregiving tasks carried out by caregivers |
| Emotional Load | feelings of burden associated with the caregiving role |
| Practical Support | assistance received with caregiving tasks from formal and informal networks |
| Emotional Support | encouragement provided by informal and formal networks |
| Physical Health | self-rated physical health and medical diagnoses |
| Emotional Health | self-rated emotional health and depressive symptomatology |
| Health Promoting Activity | nature and extent of physical exercise and socialization (social interactions and outings) engaged in by caregivers |

## Overview of the Remaining Chapters

The following chapter presents the method, including the manner in which the study sample was selected, a description of the sample, data collection procedures, ethical considerations, and measures utilized.

Chapter three presents the study findings. These are organized according to the caregiving situation, caregivers' physical and emotional health, and engagement in exercise and socialization. In addition, the relationships among the situational variables and caregivers' health and health promoting activity are presented.

Chapter four discusses the study findings and indicates the strengths and limitations of the study. The thesis concludes with directions for future research and implications for nursing.

# CHAPTER 2

# METHODS

## Design

This study employs a descriptive, correlation design involving face to face interviews with older adults who were providing care at home for spouses with cancer.

## Settings and Sample Selection

Individuals who were fifty years of age or older, married to or cohabitating with their partner, and providing care at home for a spouse with advanced cancer, were eligible to participate in this study. Those who were not fluent in English, or whose spouses were so ill as to preclude their participation were not invited to participate. Participants lived in Ottawa, Calgary and Edmonton. In Ottawa, participants were recruited through the Ottawa-Carleton Branch of the Victorian Order of Nurses. Participants from Western Canada were recruited through the Palliative Care Service of the Misericordia Hospital, Edmonton, and through the Mount View and Foothills Health Units, Agape Manor Hospice, and the Tom Baker Cancer Centre in Calgary.

Frontline nurses or other health professionals in each setting screened their caseloads for appropriate referrals and made the initial contacts with caregivers. Once caregivers gave their verbal consent, the researcher contacted them by phone to provide further information about the study and make arrangements for interviews. Health professionals reported that they did not approach caregivers who appeared too distressed or whose spouses were critically ill. In addition, four caregivers stated at the initial contact that that they preferred not to be involved in the study for various reasons, such as lack of time (N = 1) or fatigue (N = 3). Upon the second contact, which was made by the researcher, two persons declined to participate. Reasons given were not being able to spare the time for an interview (N = 1) and lack of interest (N = 1). Once interviews had been arranged, only one caregiver cancelled because the spouse had suddenly taken a turn for the worse. The overall response rate was 88%. A final sample of 60 adults who met the study's eligibility criteria and who agreed to participate were involved in the study. Twenty-eight percent of these caregivers lived in Ottawa, 50% in Edmonton, and 22% in Calgary.

## Data Collection Procedures and Ethical Considerations

The study proposal received certification by the Human Research Ethics Review Committee of the Faculty of Health Sciences of the University

of Ottawa (Appendix A). Letters of Authorization to conduct the research were obtained from the health care providers (Appendix B). Letters of Information and Consent Forms were issued to frontline staff and spousal caregivers who chose to be involved in the study (Appendixes C through F). Data were collected verbally and recorded by the researcher in interviews conducted in caregivers' homes using the Caregiver Interview Schedule (Appendix G). Every effort was made to ensure privacy by meeting in a room distant from the spouse so as to protect the privacy of both caregiver and spouse and to encourage the caregiver to speak freely. On average, interviews lasted one hour and fifteen minutes.

## Description of the Sample

Socio-demographic data collected for the study included: gender of caregivers and care recipients, duration of the spousal relationship, time since the spouse's diagnosis, ages of care recipients and caregivers, country of birth of caregivers and care recipients, cultural/ethnic heritage of caregivers and care recipients, caregivers' religious affiliation, caregivers' highest level of education, caregivers' past and present employment status, caregivers' major occupation, and annual family income. Table 2.1 provides a sociodemographic profile of study participants.

Forty-three women (71.7%) and seventeen men (28.3%) who

provided home care for spouses with advanced cancer participated in this study. The mean age for both caregivers and care recipients was 68 years. Caregivers ranged in age from 50 to 82, with 65% at or above the mean age. Care recipients' ages ranged from 47 to 88 years, with 58% at or above the mean age.

Couples had been married from 6 to 64 years. Their average time together was 40 years. Seventeen couples (28.3%) shared their home with another person, usually a son or a daughter.

Care recipients had been diagnosed with cancer from 2 months and 10 years. The average length of time since diagnosis was 30.2 months. A small proportion (18%) of diagnoses had occurred less than 6 months prior to interview and a smaller proportion (10%) of care recipients had been living with cancer between 5 and 10 years.

The majority of caregivers (57%) were born in Canada. Fourteen caregivers (23%) declared English ancestory, nine (15%) German, eight (13%) Scottish ancestory, five (8%) French, and the remainder were from a wide variety of ethnic backgrounds. 63% of care recipients were Canadian-born. One-fifth were of English origin and the others were from a wide variety of ethnic groups.

Caregivers reported their religious affiliation as Protestant (71.7%), Roman Catholic (15%), all other religions (3.3%), and 10% of respondents said they had no church affiliation. Education ranged from grade 4 to Ph.D.

level, with 56% having at least high school education.

The majority of respondents (68%) had worked full-time during their careers, and another nine (15%) had been employed on a part-time basis. Nine respondents (15%) worked outside the home at the time of the interview, ten said that they were not currently working, and two-thirds (67%) were retired. Previous occupations included professional and managerial (25%), semi-professional (37%), sales and service (13%), labor and domestic work (12%) and full-time homemaking (15%). The average family income was reported to be between $20,000 - $39,000 (33.3%), with 25% below $20,000 and 17% of families with incomes above $60,000.

In closing this section, it should be noted that the above profile not only provides a context for interpreting the findings reported in chapter three, but also describes a specific population of caregivers that have previously received little research attention.

## TABLE 1

## SOCIO-DEMOGRAPHIC CHARACTERISTICS

| | | N | % |
|---|---|---|---|
| | | 60 | 100 |
| a) | **CAREGIVER GENDER** | | |
| | Female | 43 | 71.7 |
| | Male | 17 | 28.3 |
| b) | **AGE OF CAREGIVER** | | |
| | 50 - 54 | 6 | 10.0 |
| | 55 - 59 | 4 | 6.7 |
| | 60 - 64 | 8 | 13.3 |
| | 65 - 69 | 13 | 21.7 |
| | 70 - 74 | 15 | 25.0 |
| | 75 - 79 | 11 | 18.3 |
| | 80 plus | 3 | 5.0 |
| | Range: 50 - 82 Mean age: 68.08 Standard Deviation: 8.49 | | |
| | Median age: 69.0 Modal age: 71.0 | | |
| c) | **AGE OF CARE RECIPIENT** | | |
| | 50 - 54 | 4 | 6.7 |
| | 55 - 59 | 5 | 8.3 |
| | 60 - 64 | 7 | 11.7 |
| | 65 - 69 | 16 | 26.6 |
| | 70 - 74 | 13 | 21.7 |
| | 75 - 79 | 9 | 15.0 |
| | 80 plus | 6 | 10.0 |
| | Range: 47 - 88 Mean age: 68.68 Standard Deviation: 8.9 | | |
| | Median age: 69 Modal age: 65 | | |
| d) | **LIVING ARRANGEMENT** | | |
| | Couple home alone | 43 | 71.7 |
| | Someone else lives in | 17 | 28.3 |

e) **NUMBER OF YEARS MARRIED**

| | | |
|---|---|---|
| 20 years or less | 5 | 8.3 |
| 21 - 39 years | 17 | 28.3 |
| 40 - 64 years | 36 | 63.3 |
| 48 plus years | 18 | 30.0 |

Range: 6 - 64 Mean: 39.8 Standard Deviation: 11.9
Median: 41.5 Mode: 48

f) **MONTHS SINCE DIAGNOSIS**

| | | |
|---|---|---|
| 2 - 6 months | 11 | 18.3 |
| 7 - 12 months | 11 | 18.3 |
| 13 - 24 months | 15 | 25.0 |
| 25 - 48 months | 9 | 15.0 |
| 49 - 60 months | 8 | 13.3 |
| 61 - 120 months | 6 | 10.0 |

Range: 2 - 120 Mean: 30.2 Standard Deviation: 29.6
Median: 18.0 Mode: 60

g) **CAREGIVER'S COUNTRY OF BIRTH**

| | | |
|---|---|---|
| Canada | 34 | 56.7 |
| Other | 26 | 43.3 |

h) **CARE RECIPIENT'S COUNTRY OF BIRTH**

| | | |
|---|---|---|
| Canada | 38 | 63.3 |
| Other | 22 | 36.7 |

i) **MAIN ANCESTRY OF CAREGIVER**

| | | |
|---|---|---|
| English | 14 | 23.3 |
| German | 9 | 15.0 |
| Scottish | 8 | 13.3 |
| French | 5 | 8.3 |
| All other | 24 | 40.0 |

j) **MAIN ANCESTRY OF CARE RECIPIENT**

| | | |
|---|---|---|
| English | 13 | 21.7 |
| German | 10 | 16.7 |
| Scottish | 5 | 8.3 |
| French | 7 | 11.7 |
| All other | 25 | 41.7 |

| | | | |
|---|---|---|---|
| k) | **CAREGIVER'S RELIGIOUS AFFILIATION** | | |
| | Protestant | 43 | 71.7 |
| | Roman Catholic | 9 | 15.0 |
| | Other religions | 2 | 3.3 |
| | No religion | 6 | 10.0 |
| l) | **HIGHEST EDUCATION OF CAREGIVER** | | |
| | Grade 8 or less | 13 | 21.7 |
| | Some high school | 13 | 21.7 |
| | Completed high school | 19 | 31.7 |
| | Some college/technical school | 6 | 10.0 |
| | Finished college/some university | 4 | 6.7 |
| | Bachelor's degree or higher | 5 | 8.3 |
| m) | **CURRENT EMPLOYMENT** | | |
| | No | 10 | 16.7 |
| | Yes | 10 | 16.7 |
| | Retired | 40 | 66.7 |
| n) | **PAST EMPLOYMENT** | | |
| | Full-time | 41 | 68.3 |
| | Part-time | 9 | 15.0 |
| | Full-time Homemaker | 9 | 15.0 |
| | n/a | 1 | 1.7 |
| n) | **MAJOR OCCUPATION** | | |
| | Professional/managerial | 15 | 25.0 |
| | Semi-professional | 22 | 36.7 |
| | Sales/service | 8 | 13.3 |
| | Laborer/Domestic | 7 | 11.7 |
| | Full-time Homemaker | 8 | 18.3 |
| o) | **TOTAL FAMILY INCOME** | | |
| | Under $20, 000 | 15 | 25.0 |
| | $20,000 - $39,999 | 20 | 33.3 |
| | $40,000 - $59,999 | 13 | 21.7 |
| | $60,000 plus | 10 | 16.7 |
| | Refused to answer | 2 | 3.3 |

## MEASURES

Several considerations guided the choice of measures. The exploratory nature of the study and its potentially practical implications called for the use of a broad band of assessment instruments. Where available, measures with known reliability were used to allow for comparison with data gathered in studies involving similar populations. Where appropriate, some of these measures were modified to better address the population of interest and the research objectives. Finally, for the same reasons, a number of measures were created specifically for the study. For example, single item indicators were developed to measure types of physical exercise, the nature and frequency of social interactions and outings, the nature and extent of practical care rendered to care recipients, the frequency of assistance received by caregivers with personal and instrumental care tasks, and the the measurement of caregivers' medical diagnoses. Single item indicators asking for global ratings of a particular concept are congruent with the emphasis in nursing on wholism and individualism, and are known to provide acceptable psychometric properties (Youngblut & Casper, 1993). In sum, the instruments included in this study are believed to be of both conceptual and practical relevance to an examination of the situation where older adults are providing care at home to spouses with cancer.

The interview schedule (Appendix G) consisted of 58 questions inquiring about socio-demographic characteristics, aspects of the caregiving situation, physical and emotional health, and health promoting activities. A brief description of these measures, along with a rationale for their selection, follows.

## Socio-Demographics

A description of the measures of socio-demographic data (Questions 49-58), comprising the final section of the interview schedule, were included in the description of the study sample.

## The Caregiving Situation

The caregiving situation is described in terms of caregiver load and caregiver support.

### Caregiver Load

Caregiver load included both practical and emotional load. Practical load is conceptualized as the type and extent of care provided to spouses. Emotional load is conceptualized as feelings of burden related to the

caregiving role.

**Practical Load**

The type and extent of care provided by respondents was measured by a scale derived from the Older American Resources and Services (OARS) scale (Maddox, 1977) (Questions 26-38). This scale was first designed to assess older individual's levels of functioning and their need for home care services. Respondents were asked whether they had provided assistance with 7 personal (eating, dressing, grooming, moving about, getting in and out of bed, bathing, and toileting) and 5 instrumental (telephoning, meal preparation, travel, medication management, finances) activities of daily living (0 = no help, 1 = some help, 2 = caregiver performed task). They were also asked how often they had assisted with these tasks during the past week (0 = none, 1 = less than once a day, 2 = once or twice a day, 3 = three, four or more times a day). In addition, they were asked about how much time on a daily basis it took to accomplish each task (0 = none, 1 = 1-29 minutes, 2 = 30-59 minutes, 3 = 60 or more minutes). Fillenbaum & Smyer (1981) reported an overall alpha of 0.86 on the OARS scale. Cronbach's alphas for the present study are as follows: ADLs = 0.80, IADLs = 0.74, total care = 0.86. The amount of time spent assisting with tasks was calculated by multiplying the number of times a week respondents performed each task

by the number of minutes it took to accomplish the task. Respondents were also asked whether their spouse could be left alone while someone else was in the house (1 = yes, 2 = no), could be left alone unsupervised (1 = yes, 2 = no), and how often they got up at night to attend to their spouse (Question 38a-c). Respondents also had the opportunity to provide verbatim descriptions of the care they provided.

**Emotional Load**

The Zarit Burden Inventory (Zarit, 1980) was used to measure feelings of burden (Questions 48: 1-29). This inventory consists of 29 questions designed to provide information about respondents' perceptions of the impact of caregiving on their lives (1 = rarely, 2 = sometimes, 3 = often, 4 = most times). Zarit and colleagues reported an alpha of 0.94 and analysis resulted in an alpha of 0.88 in the present study. The five dimensions of the Burden Interview and the alpha coefficients are as follows: subjective feelings of distress 0.70, role mastery 0.69, impact on spousal relationships 0.82, impact on other relationships 0.83, and anxiety about the future 0.79. A total burden score was calculated by summing responses to how often respondents experienced both burdensome and positive feelings related to caregiving. Respondents were also asked to rate on a scale of 0 (not difficult) to 10 (exceedingly difficult) their level of difficulty in providing care

(Question 49).

**Caregiver Support**

Caregiver support included both practical and emotional support provided by informal and formal networks. Practical support was conceptualized as assistance with caregiving tasks. Emotional support involved the receipt of encouragement, praise and reassurance.

**Practical Support**

The type and extent of assistance received from informal and formal networks with caregiving tasks were measured (Questions 39:i-iv and a-p). Respondents were asked to identify the amount of assistance they received from informal and formal networks with the provision of personal and instrumental care to their spouse (0 = none, 1 = monthly, 2 = weekly, 3 = several times a week, 4 = daily). Respondents were also asked about their need for and the availability of respite services. These questions were three part in nature and inquired about whether (1 = yes, 2 = no) they would benefit from respite care, whether they knew someone who could provide respite, and whether they had actually received respite services (Questions 40-42).

## Emotional Support

The source, and perceived extent and adequacy of emotional support received by respondents were measured. Respondents were asked to indicate the amount of emotional support (0 = none, 1 = a little, 2 = a fair amount, 3 = a great deal) they received from their spouse (Question 44). They were asked to identify other sources of emotional support and to indicate on a monthly basis how often they spoke with these individuals (Questions 43, 45). They evaluated the adequacy (1 = not nearly enough, 2 = not enough, 3 = right amount, 4 = too much, 5 = far too much) of emotional support they were receiving from their formal and informal networks (Question 46). Respondents also rated on a scale of 0 (no support at all) to 10 (a great deal of support) the overall adequacy of their emotional support (Question 47).

## Caregiver Health

Caregiver health included overall health and both physical and emotional health. Physical health was conceptualized as self-rated health and the presence of medical diagnoses. Emotional health involved self-rated emotional health and responses to the Centre for Epidemiologic Studies in Depression (CES-D) scale.

**Overall Health**

Respondents were asked to rate (1 = poor, 2 = fair, 3 = good, 4 = excellent) their overall health (Question 25).

**Physical Health**

A single item question asking respondents to rate their overall physical health (1 = poor, 2 = fair, 3 = good, 4 = excellent) was used to measure their self rated physical health (Question 23a). Respondents were also asked whether or not (1 = yes, 2 = no) they had been diagnosed by a physician as suffering from a series of health problems and if so, how long they had experienced the problem (Question 20a-l). They were asked how their current physical health compared (1 = much better, 2 = somewhat better, 3 = unchanged, 4 = somewhat worse, 5 = much worse) with their health prior to the spouse's diagnosis of cancer (Question 23b). They were also asked to indicate whether (1 = yes, 2 = no) an established list of factors had influenced their current physical health (Question 23c).

## Emotional Health

A single item question asking respondents to rate (1 = poor, 2 = fair, 3 = good, 4 = excellent) their overall emotional health was used to measure their self rated emotional health (Question 24a). The Centre for Epidemiologic Study of Depression Scale (CES-D) was used to measure depressive symptomatology (Question 19a-t). The CES-D is a balanced scale of 20 items that contains both positively and negatively oriented indicators of emotional health. As such, it reduces the likelihood of response bias while assessing both positive and negative affect, somatic and retarded activity and interpersonal distress (Liang, 1989). The scale was originally developed to investigate the relationship between affective distress and other variables across population sub-groups (Radloff, 1977). It has been used widely in many studies of community samples that showed consistency of results with older adults and provided extensive normative data ( see Hsu & Marshall, 1987, for a review). Respondents were asked to indicate the frequency with which they had felt or behaved in specified ways during the previous week (1 = rarely or never, 2 = sometimes, 3 = fairly often, 4 = most of the time). An total score was calculated by summing the responses to the 20 items. Scores were also collapsed according to a typology suggested by Barnes & Prosen (1984) to identify levels of depressive symptomatology. The Barnes & Prosen study achieved an overall alpha of 0.89, whereas the alpha

coefficient in the present study was established as 0.84. In addition, respondents were asked to compare (1 = much better, 2 = somewhat better, 3 = unchanged, 4 = somewhat worse, 5 = much worse) their current emotional health with their emotional health prior to their spouse's diagnosis of cancer (Question 24b). They were also asked to identify from a list of factors those that had influenced their emotional health (Questions 24c).

**Health Promoting Activity**

Health promoting activity included exercise aimed at maintaining or improving health and socialization involving interaction with family, friends and others and social outings.

**Exercise**

Questions asking about the type and extent of exercise derived from a falls prevention study conducted with community dwelling seniors (Edwards, 1993). Respondents were asked how often during a typical week they engaged in a variety of exercises and to estimate in minutes the length of time they spent carrying out each exercise (Question 1a-k). They were also asked to evaluate the adequacy of their exercise (1 = far too little, 2 = too little, 3 = the right amount, 4 = far too much), whether they would like to

exercise more (1 = yes, 2 = no), and to identify from an established list of factors those that interfered with their exercising (Question 5a-c).

**Socialization**

Socialization measures derived from previous studies involving seniors (Ross, 1991; Statistics Canada, 1985). Respondents were asked to identify the individuals (1 = yes, 2 = no) with whom they were in regular contact (Question 7). They were also asked about the frequency of this contact (Question 8). Type and weekly frequency of social outings were measured by a series of questions asking about outings with others, attendance at church and participation in social clubs (Questions 12-15). Respondents were asked to appraise (1 = far too little, 2 = too little, 3 = right amount, 4 = too much, 5 = far too much) the adequacy of their socialization (Question 17b). They were also asked whether they wished in to increase their level of socialization (1 = yes, 2 = no) and to identify from an established list of factors those influencing their level of socialization (Question 17c,d).

## Approach to Data Analysis

Quantitative data were analysed by means of univariate, bivariate, and multivariate techniques. Univariate analyses included frequencies, percentages, and measures of central tendency, including means, medians, modes, variances and standard deviations for the continuous variables. Bivariate analyses consisted of Spearman rank-order correlation procedures, and standardized z-scores and paired sample t-tests for changes over time. Multivariate techniques consisted of stepwise regression analyses.

## Conclusion to Chapter Two

This chapter has outlined the methodology for the study. This outline included the study design, setting and sample, and the approach to data management, as well as a description of the measures used to investigate the health promoting activities of caregivers, their health, and key aspects of the caregiving situation.

# CHAPTER 3

# FINDINGS

Study findings are organized according to the caregiving situation, caregivers' physical and emotional health, their health promoting activities and relationships among these sets of variables.

## The Caregiving Situation

The caregiving situation includes the practical and emotional load experienced by caregivers and the practical and emotional support they received with the care they provided to their spouses.

### Practical Load

Practical load refers to the type and extent of care that respondents provided to their spouse on a daily basis. On average, respondents provided assistance with 14 caregiving tasks each day. This represented a daily average of 9 hours of care. The activities of daily living (ADL) and instrumental activities of daily living (IADL) that respondents provided assistance with are presented in Table 2.

**Table 2**
**Practial Load**
**N = 60**

| Type of Task | Respondents N | Respondents % | Extent of Task Performance Mean hours/day | S.D. |
|---|---|---|---|---|
| ADL | | | | |
| Eating | 21 | 35 | 1.17 | .64 |
| Dressing | 36 | 60 | .31 | .16 |
| Grooming | 18 | 30 | .39 | .29 |
| Moving about | 32 | 53 | .83 | .39 |
| Getting in & out of bed | 26 | 43 | .45 | .28 |
| Bathing | 32 | 53 | .54 | .27 |
| Toileting | 27 | 45 | .42 | .24 |
| IADL | | | | |
| Telephoning | 12 | 20 | .25 | .00 |
| Travel | 43 | 72 | 1.90 | .34 |
| Meal preparation | 57 | 95 | 2.50 | .91 |
| Medications | 45 | 75 | .30 | .14 |
| Finances | 50 | 83 | .09 | .06 |

NOTE: Categories are not mutually exclusive.

The majority of respondents provided assistance with four instrumental activities of daily living (meal preparation, travel, medications and finances) and three activities of daily living (dressing, bathing and moving about). A substantial proportion also provided assistance with toiletting and getting in and out of bed. Fewer respondents reported providing assistance with eating, grooming, and telephoning.

The activity requiring the greatest amount of time per day was meal preparation. This was followed by travel and assistance with eating. Travel included accompanying spouses to physicians' offices, doing errands and taking

trips to relieve the boredom of their spouse. Although care associated with the administration of medications did not require a substantial amount of time per day, respondents reported that supervisory activities associated with medication use demanded their constant attention. In addition, they felt that the well-being of their spouse was dependent on being free of pain and symptoms, which they felt in large measure resulted from medication use. Similarly, although bathing and toiletting did not require a substantial time investment on the part of respondents, they reported that the provision of this type of care was particularly taxing, both physically and psychologically. Many of these tasks were also carried out several times a day.

In addition to the performance of tasks, an open ended question asked for further elaboration of dimensions of care. A substantial proportion of respondents (60%) reported that spouses could not be left unsupervised for more than 2 hours at a time. They also reported that they had to get up at night to attend to their spouse. Indeed, close to two thirds (60%) reported getting up at least three times a night for their spouse. Slightly more than half (53%) also stated that they were required to remain at home at all times to keep an eye on their spouse. These individuals were essentially housebound.

**Emotional Load**

Emotional load refers to feelings of burden and respondents' perceptions about the impact of caregiving on various dimensions of their life. Their scores on the Zarit Burden Interview ranged from a low of 32 to a high of 84, out of a possible total of 87, with an average score of 48.7. Both the median and modal score were 47. The middle 50% of caregivers had scores in the 40 - 55, or moderate, range. The overall average score for single items on each dimension of the Burden Interview (range per item being 0 - 3 with higher scores indicating greater burden) are presented in Table 3.

**TABLE 3**
**Zarit Burden Interview**
**N = 60**

| Dimensions of Burden | Item Mean | S.D. |
|---|---|---|
| Anxiety about the future | 2.18 | .94 |
| Subjective distress | 1.86 | .53 |
| Impact on spousal relationship | 1.71 | .67 |
| Impact on other relationships | 1.47 | .50 |
| Caregiver role mastery | 1.39 | .46 |

The major impact of caregiving related to anxiety about the future. Respondents felt afraid about what the future held for both their spouse (74%) and for themselves (63%). This was followed by feelings of subjective distress and

changes in relationships, both spousal and others. Respondents (95%) found it painful to watch their spouse battle with cancer. A substantial proportion (52%) reported that their spouse depended excessively on them for assistance. One third also reported feeling stressed as a result of having to balance caregiving with other types of responsibilities. The dimension of their life least affected by caregiving was mastery of the role of caregiver. Nevertheless, a substantial minority (25%) reported that they were uncertain about what to do for their spouse.

**Practical Support**

Practical support refers to assistance received with specific caregiving responsibilities from both formal health care providers and from family and friends. The freqency with which respondents reported practical assistance is presented in Table 4.

**Table 4**
**Frequency of Practical Support**
**N = 60**

| | Sources | | Frequency | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | Monthly | | Weekly | | Sev/Wk | | Daily | |
| | N | % | N | % | N | % | N | % | N | % |
| Nurses | 44 | 73 | 9 | 15 | 10 | 17 | 13 | 22 | 12 | 20 |
| Homemaker | 25 | 42 | 8 | 13 | 7 | 12 | 7 | 12 | 3 | 5 |
| Family | 18 | 30 | 5 | 8 | 5 | 8 | 0 | 0 | 13 | |
| Friends | 4 | 7 | 3 | 5 | 1 | 2 | 0 | 0 | 0 | 0 |

NOTE: Categories are not mutually exclusive.

All but eleven respondents received at least a degree of practical support in providing care to their spouses. The major source of practical assistance derived from nurses and homemakers. There was little practical support received from family and friends. The frequency of practical support from nurses was almost equally divided among daily, serveral times a week, weekly and monthly visits. Homemakers provided practical support less frequently than nurses, and families and friends still less frequently. Respondents reported that nurses helped with personal care tasks such as bathing, grooming, dressing and more medically oriented responsibilties such as the managment of medications. Homemakers provided assistance with bathing, laundry and housekeeping. Families and friends helped out mainly with supervision of spouses, travel and meal preparation. Respondents reported receiving little help with feeding their spouse, a personal care task they reported as occupying a large proportion of their time.

**Adequacy of Practical Support**

Although respondents were not asked to evaluate the nature of the practical support they received from informal and formal networks, responses to questions about their need for additional services provided an indication of the adequacy of the assistance they were receiving with respect to the care of their spouse. Fully half of the respondents (50%) reported that they could have benefitted by having someone come into their home to relieve them for a few hours from time to time.

Only 33% reported the availability of this type of support and these individuals reported using such support an average of 5 times during their spouse's entire illness. A small proportion (20%) felt that they could also benefit from several days of respite care. Although fully one quarter of respondents (25%) reported the availability of this type of service, only a few (12%) had taken advantage of the service. Nine per cent of respondents reported that they could also benefit from overnight respite care. While a quarter of respondents reported the availability of over night respite care, only 5% had taken advantage of such support.

**Emotional Support**

Emotional support refers to assistance of an emotionally supportive nature deriving from encouragement, praise or reassurance received from formal and informal networks. All but one respondent reported receiving emotional support from at least one individual. The number and proportion receiving support from their informal and formal networks are presented in (Table 5).

**TABLE 5**
**Emotional Support**
**N = 60**

| Source | N | % |
|---|---|---|
| Family | 54 | 90 |
| Nurses | 44 | 73 |
| Physicians | 41 | 68 |
| Friends | 34 | 57 |
| Clergy | 18 | 30 |
| Others | 8 | 13 |

Note: Categories are not mutually exclusive.

The vast majority of caregivers reported receiving emotional support from family members whom they perceived as their mainstay of support. Nurses and physicians were also major sources of emotional support and over half of the respondents reported receiving emotional support from friends. A small proportion of respondents reported that they had received emotional support from individuals such as lawyers, accountants and tradespeople.

**Adequacy of Emotional Support**

Respondents rated the adequacy of their emotional support on a scale of 0 (low) to 10 (high). Their average score was 6.9 with a standard deviation of 2.7. The vast majority of respondents (85%) responded that they were receiving the right amount of emotional support from family. Fifty-three percent reported receiving the right amount of emotional support from friends and 79% reported receiving the right amount from health professionals.

## Caregiver Health

The health of respondents entailed reports of both physical and emotional dimensions of health. In addition, respondents described factors that influenced their current levels of health.

### Physical Health

Respondents rated their physical health and identified medical diagnoses that had been reported to them by physicians.

### Self-Rated Physical Health

The majority of respondents rated their physical health as either good or excellent (73.4%) and as unchanged (71.7%) since their spouse's diagnosis. While a small proporton (8.4%) stated that their health had actually improved, a worrisome proportion (20%) reported a decline in their health since the spouse's diagnosis of cancer.

### Medical Diagnoses

Respondents identified health problems that had been diagnosed by a physician with which they were contending (Table 6).

**Table 6**
**Caregiver's Medical Diagnoses**
**N = 60**

| Diagnoses | N | % |
|---|---|---|
| Back, foot, spinal problems | 36 | 61.5 |
| Arthritis | 30 | 50.7 |
| High blood pressure | 27 | 45.7 |
| Visual/hearing problems | 16 | 42.1 |
| Cancer | 19 | 32.5 |
| Heart trouble | 18 | 30.8 |
| Osteoporosis | 11 | 18.6 |
| Breathing problems | 14 | 24.2 |
| Diabetes | 6 | 10.5 |

NOTE: Categories are not mutually exclusive.

Disorders of the back and foot and spinal problems were the most frequently cited medical diagnoses. In addition, a substantial proportion of respondents reported that they were contending with arthritis, high blood pressure, and visual and hearing problems. Of particular interest is the proportion of respondents (13.2%) whose back, foot and spinal problems had been diagnosed following their spouse's diagnosis of cancer.These are health problems that could reasonably be expected to result from, or at least interfere with, the performance of caregiving responsibilities. Indeed, data provided such evidence. For example, one caregiver reported that she had fractured several vertebrae while trying to prevent her husband from falling. Another respondent stated that she had developed bleeding ulcers as a result of the stress of caring for her husband. Still another respondent attributed the development of a chronic cough to the stress of caregiving.

## Emotional Health

Respondents provided a self-rating of their emotional health and responded to the CES-D scale for depressive symptomatology.

### Self-rated Emotional Health

The majority of respondents (58.4%) reported their emotional health as good or excellent at the time of interview. A substantial proportion (30%), however, rated their emotional health as fair and a lesser proportion (11.7%) as poor. Although forty-eight per cent of respondents reported no change or a change for the better, it is noteworthy that over half (51.7%) reported that their emotional health had worsened since their spouse's diagnosis of cancer.

### Depressive Symptomatology

Respondents' scores on the CES-D scale ranged from a low of 0 to a high of 37 out of a possible total of 60, with a mean of 15.9 (S.D. = 9.5) and a mode of 16. Table 7 presents respondents' scores according to level of depressive distress.

**Table 7**
**Level of Depressive Distress**
**N = 60**

| Level | Scores | N | % |
|---|---|---|---|
| None | 0-15 | 29 | 48 |
| Mild | 16-20 | 11 | 18 |
| Moderate | 21-30 | 16 | 27 |
| Severe | 31 + | 4 | 7 |

The majority of respondents' (52%) achieved CES-D scores that are suggestive of some degree of depressive symptomatology. Indeed, the most frequently occurring or modal score of 16 indicated a mild level of depressive distress among caregivers as a whole. However, when scores were collapsed, only 7 per cent of respondents' scores fell into the level of severe depressive symptomatology. Nevertheless, more than one quarter (27%) fell into the level of moderate depressive symptomatology.

**Factors Influencing Overall Health**

In response to a single item question asking respondents to identify factors that had influenced their overall health, fully half (50%) acknowledged that worry about their spouse had had a deleterious impact on their health. A substantial proportion also cited deterioration of their spouse (34%) and the stress of providing care (27%). A smaller proportion (23%) referred to factors related to aging.

## Health Promoting Activity

Health promoting activity included exercise aimed at maintaining or improving health and socialization involving face to face contact with family, friends and others and participation in social outings.

### Exercise

Respondents provided information about the type, extent and adequacy of exercise in which they engaged.

### Types of Exercise

The number and proportion of respondents who participated in various types of exercise are presented in Table 8.

**Table 8**
**Exercise**
**N = 60**

| Type | Prior to Diagnosis N | Prior to Diagnosis % | Following Diagnosis N | Following Diagnosis % | z-value |
|---|---|---|---|---|---|
| Walking | 57 | 95 | 44 | 75 | 3.25* |
| Gardening | 42 | 70 | 38 | 63 | .77 |
| Dancing/aerobics | 16 | 27 | 1 | 2 | 3.93* |
| Stretching/relaxation | 15 | 25 | 9 | 15 | 1.37 |
| Bicycling | 13 | 22 | 3 | 5 | 2.69* |
| Bowling | 12 | 20 | 0 | 0 | 3.65* |
| Golfing | 9 | 15 | 3 | 5 | 1.82* |
| Swimming | 8 | 13 | 1 | 2 | 2.42* |
| Aquafitness | 5 | 8 | 1 | 2 | 1.68* |

NOTE: Categories are not mutually exclusive. *Significant at alpha = .05

The majority of respondents cited walking and gardening as the type of exercise they engaged in both prior to and following their spouse's diagnosis. However, as with all forms of exercise, a smaller proportion continued to engage in these activities following their spouse's diagnosis of cancer. The decline in the proportion of caregivers who engaged in activities that were engaged in away from the home, such as bicycling and dancing/aerobics, is particularly striking. In contrast, the decline in those participating in exercise that can be pursued at home, such as gardening and relaxation/stretching, is less dramatic.

**Extent of Exercise**

The total amount of time that respondents engaged in exercise was calculated by multiplying the number of exercise sessions they engaged in each week by the amount of time in hours per session. These data are shown in Table 9.

**Table 9**
**Extent of Exercise**
**Hours Per Week**
**N = 60**

| | Mean | Range | t | p |
|---|---|---|---|---|
| Prior to Diagnosis | 13.9 | 2-43 | -4.93 | .000 |
| After Diagnosis | 7.3 | 0-24 | 95% CI (-9.318, -3.936) | |

Respondents reported less time spent in exercise following their spouse's diagnosis. Indeed, the total amount of exercise engaged in per week declined by almost half. Paired t-tests revealed that this decline, which represented a decrease in the amount of time spent in each of the nine exercise activities inquired about, was statistically significant.

**Adequacy of Exercise**

Respondents were asked to evaluate the adequacy of the exercise they were achieving. Less than half (45%) reported that they were achieving the right amount of exercise at the time of interview.The majority (78%), however, reported that they had achieved the correct amount of exercise prior to their spouse's diagnosis. In addition, a substantial proportion (42%) felt that they were receiving too little exercise at the time of interview. This compares with 19% who felt that they had received too little exercise prior to their spouse's diagnosis. Those (8%) who at interview felt they were getting too much exercise qualified this by saying: "It's not the right type of exercise", (i.e., not health promoting). Finally, close to two thirds (63%) reported that they would like to get more exercise.

## Socialization

Socialization refers to face to face interaction with family, friends and others, social outings, and respondents' evaluations of the adequacy of their socialization.

### Face to Face Interaction

The number and proportion of respondents who participated in face to face interactions with family members, friends and others in a typical week is presented in Table 10.

**Table 10**
**Face to Face Interaction**
**N = 60**

| Type | Prior to Diagnosis | | Following Diagnosis | | z-value |
|---|---|---|---|---|---|
| | N | % | N | % | |
| Family | 59 | 98 | 58 | 97 | .585 |
| Friends | 45 | 75 | 44 | 73 | .209 |
| Others | 6 | 10 | 15 | 25 | -2.16* |

NOTE: Categories are not mutually exclusive. *Significant at alpha = .05

The majority of respondents engaged in face to face interactions with family members and friends during a typical week both prior to and following their spouse's diagnosis. Although the numbers are small, it is notable that the proportion of respondents who reported face to face interactions with persons

other than family and friends more than doubled following diagnosis. This can be attributed to an increase in interaction with individuals such as clergy, accountants and lawyers as a result of the spouse's diagnosis of cancer.

## Frequency of Interaction

The frequency of face to face interactions was calculated by averaging the number of interactions respondents reported with family, friends and others during the course of a typical week. These findings are presented in Table 11.

**Table 11**
**Frequency of Interactions**
**N = 60**

| | Mean | df | t | p |
|---|---|---|---|---|
| Prior to Diagnosis | 3.34 | 59 | 1.91 | .06 |
| Following Diagnosis | 3.74 | | 95% CI (-0.020, .815) | |

Respondents participated in a slightly greater number of social interactions during the course of a typical week following their spouse's diagnosis. This was largely due to an increase in visits from family and relatives. Interactions with friends decreased following the diagnosis. Paired t-tests revealed a non-significant but meaningful increase in frequency of face to face interactions.

## Social Outings

Respondents also reported on their social interactions outside the home. The proportion of respondents who engaged in such outings are reported in Table 12.

**Table 12**
**Social Outings**
**N = 60**

| | Prior to Diagnosis | | Following Diagnosis | | |
|---|---|---|---|---|---|
| Type of Outing | N | % | N | % | z-value |
| Outings with Others | 43 | 72 | 19 | 32 | 4.38* |
| Attendance at Church | 33 | 55 | 19 | 32 | 2.58* |
| Participation in Social Clubs | 29 | 48 | 13 | 22 | 3.06* |

NOTE: Categories are not mutually exclusive. *Significant at alpha = .05

Participation in social outings declined following spouses' diagnosis of cancer. A substantially greater number of individuals participated in varous types of social interactions outside the home prior to their spouse's diagnosis. The majority of respondents reported participating in outings with others, attending church and close to half reported participating in social clubs prior to their spouse's diagnosis of cancer. At the time of the interview, however, less than one third reported participating in social outings.

## Frequency of Outings

Frequency of outings were calculated by averaging the number of outings experienced monthly. Frequency of social outings is presented in Table 13.

Table 13

Frequency of Social Outings

N = 60

| Type of Outing | Prior to Diagnosis Mean | Following Diagnosis Mean | t | p |
|---|---|---|---|---|
| Outings with Others* | 4.8 | 2.5 | -3.4 | .001 |
| Attendance at Church** | 1.9 | 1.1 | -3.67 | .001 |
| Social Clubs*** | 1.6 | .88 | -1.9 | .06 |

*95% CI (-3.682, -.957) **95% CI (-1.287, -.379) ***95% CI (-1.547, .033)

There was a statistically significant decline in respondents' perceptions that their participation in outings with others and attendance at church following their spouse's diagnosis of cancer had declined. Their reports of a decline in participation in social clubs approached statistical significance. In general, the frequency of participation in social outings at the time of the interview almost halved.

## Adequacy of Socialization

The majority of respondents (55%) reported that they would like to socialize more at the time of interview. A relatively small proportion (35%) reported that the amount of socializing in which they engaged at the time of interview was just the right amount. This compares with 65% who evaluated their pre-diagnosis socialization as just right. As further indication of their perceptions of the adequacy

of their socialization, twenty per cent of respondents with children reported that they would like to see them more often and one third (36%) stated that they would like to see their grandchildren more often. Close to one quarter (22%) also stated that they would like to see their friends more often. These findings were corroborated by reports of loneliness on the part of 42% of respondents.

## Relationships Among Variables

This section of the chapter explores the relationships among variables, i.e., the caregiving situation, self-rated physical and emotional health and engagement in health promoting activity.

### Self-Rated Health and Health Promoting Activity

According to Pender's model, engagement in health promoting activity is expected to be related to self-rated physical and emotional health. The results of correlational analysis between hours of exercise and number of social interactions per week and self rated physical and emotional health are presented in Table 14.

**Table 14**
**N = 60**
**Self Rated Health and Engagement in Health Promoting Activities**

| | Exercise | Socialization |
|---|---|---|
| Self Rated Physical Health | .28 (p = .03) | -.03 (p = .83) |
| Self Rated Emotional Health | .25 (p = .05) | -.12 (p = .36) |

**NOTE:** All correlations are Spearman Rank-Order, p = two tailed.

There was a statistically significant and positive relationship between engagement in physical exercise and self rated physical and emotional health. That is, increased time spent in exercise was associated with positive self ratings of physical and emotional health. This was not so, however, with the relationship between socialization and physical and emotional health. Indeed, there was an inverse relationship between socialization and physical and emotional health. This relationship was not, however, statistically significant.

**Caregiving and Self Rated Health**

According to Pender's model, self rated physical and emotional health is expected to be related to situational variables such as the caregiving situation. Practical load of caregiving reflected the total number of hours that respondents spent providing care to their spouse. The emotional load involved responses to the

Zarit Burden Interview. Assistance with ADLs and IADLs involved the average amount of time spent providing assistance to spouses with activities of daily living. Informal and formal support involved the total number of family members, friends and others providing respondents with encouragement. The results of the correlational analyses are presented in Table 15.

**Table 15**
**Caregiving and Self-Rated Health**
**N = 60**

| | Physical Health | | Emotional Health | |
|---|---|---|---|---|
| **Practical Load** | | | | |
| ADL Tasks | .01 | (NS) | .07 | (NS) |
| IADL Tasks | .19 | (NS) | -.06 | (NS) |
| **Emotional Load (Burden)** | | | | |
| Subjective Distress | -.30 | (.05) | -.48 | (.00) |
| Spousal Relationship | .03 | (NS) | -.23 | (NS) |
| Other Relationships | -.03 | (NS) | -.19 | (NS) |
| Caregiver Role Mastery | -.14 | (NS) | -.22 | (NS) |
| Anxiety About the Future | -.34 | (.01) | -.46 | (.00) |
| **Practical Support** | | | | |
| Assistance with ADLs | .13 | (NS) | .05 | (NS) |
| Assistance with IADLs | .05 | (NS) | -.11 | (NS) |
| Other Assistance | .07 | (NS) | .12 | (NS) |
| **Emotional Support** | | | | |
| Informal Support | .04 | (NS) | .09 | (NS) |
| Formal Support | .03 | (NS) | .26 | (.05) |

**NOTE:** All correlations are Spearman Rank-Order. NS indicates non significance. P = two=tailed.

Findings revealed a statistically significant relationship between feelings of burden and more specifically, feelings of subjective distress and anxiety about the future and both self rated physical and emotional health. It seems that the greater the subjective distress and anxiety about the future, the poorer the ratings of physical and emotional health. With respect to practical and emotional support received from informal and formal networks, the only association to reach significance was between the number of supportive individuals in the formal network and caregivers' perceptions of their emotional health. Those with a greater number of formal helpers perceived their emotional health as better than those with a fewer number of formal helpers.

**Relationship to Pender's Model**

To determine the degree to which caregiving load and caregiver support were related to participation in exercise and socialization after physical and emotional health had been accounted for (as hypothesized in Pender's model), two stepwise regression analyses were conducted (Table 16). In the first step of each of these regressions, emotional and physical health were entered as a block. The caregiver load and support variables were then allowed to enter in a stepwise fashion. Findings revealed that after self rated physical and emotional health had been taken into account, no other variables were found to be statistically associated with the amount of exercise (Table 16a) in which caregivers engaged at

the time of interview. With respect to socialization (Table 17a), after self rated physical and emotional health had been accounted for, the only other variable associated with interaction with family, friends and others was informal emotional support. Consequently, the caregiving load and support variables essentially failed to explain further variance in respondents' participation in health promoting activity.

**A Proposed Alternate**

Regression was then conducted to examine the variance in respondents' health promoting activities according to an alternate model, namely, with self rated physical and emotional health and respondents' level of exercise and socialization prior to spouses' diagnosis taken into account. Findings revealed that a good deal more of the variance in respondents' participation in health promoting activity was explained by such an alternate model and the results achieved significance at the .05 level in each case. When exercise prior to spouse's diagnosis was taken into account along with self rated physical and emotional health (Table 16b), an additional 30% of the variance in exercise following diagnosis was explained ($F = 3.39$, $p = .02$). Similarly, when socialization prior to spouses' diagnosis was taken into account along with self rated physical and emotional health (Table 17b), an additional 65% of the variance in socialization at interview was explained ($F = 111.62$, $p = .000$).

In the case of exercise, no further variables entered into the equation. However, with respect to socialization, assistance with ADL tasks entered. This indicates that frequency of assistance received by caregivers with activities of daily living explained a further 5% of respondents' participation in face to face interactions following spouses' diagnosis ($F = 33.89$, $p = .000$) when prior level of socialization was taken into account along with caregivers' self rated physical and emotional health.

# Table 16
(N = 60)

STEPWISE REGRESSION ANALYSES: EXERCISE

16a) **Exercise on Physical and Emotional Health and Load and Support: (PENDER HEALTH PROMOTION MODEL)**

| Step | Variable | Beta | p-value |
|---|---|---|---|
| 1 | physical health | .2417 | .0959 |
| 1 | emotional health | .0942 | .5123 |

$R^2$ = .09 $R^2$adj. = .06 F = 2.77, p = .07

Variables not in the Equation

| | | |
|---|---|---|
| ADLT@WK | -.0016 | .9903 |
| IADLT@WK | .1217 | .3572 |
| ZARIT | .0073 | .9588 |
| ADLAS@WK | -.1442 | .2606 |
| IADAS@WK | .0908 | .4827 |
| OTHAS@WK | .0561 | .6622 |
| INF.ES.A | -.0854 | .5069 |
| FOR.ES.A | -.1301 | .3246 |

End Block 1. All requested variables entered.
Block 2. Method Stepwise. Criteria PIN .05
No variables entered/removed for this block.

16b) **Exercise on Physical Health, Emotional Health and Prior Exercise and Load & Support: (ALTERNATE MODEL)**

| Step | Variable | Beta | p-value |
|---|---|---|---|
| 1 | physical health | .1837 | .1999 |
| 1 | emotional health | .1012 | .4690 |
| 1 | exercise before | .2614 | .0423 |

$R^2$ = .39 $R^2$adj. = .11 F = 3.39, p = .02

Variables not in the Equation

| | | |
|---|---|---|
| ADLAS@WK | -.1554 | .2123 |
| ADLT@WK | -.0099 | .9369 |
| FOR.ES.A | -.1284 | .3172 |
| IADAS@WK | .1323 | .2973 |
| IADLT@WK | .1122 | .3929 |
| INF.ES.A | -.1083 | .3879 |
| OTHAS@WK | .0917 | .4657 |
| ZARIT | -.0259 | .8503 |

Method: Stepwise Criteria PIN .05 limits reached.
No variables entered/removed for this block.

**TABLE 17 (N = 60)**
**STEPWISE REGRESSION ANALYSES: SOCIALIZATION**

**17a) Socialization on Physical and Emotional Health and Load and Support: (PENDER HEALTH PROMOTION MODEL)**

| Step | Variable | Beta | p-value |
|---|---|---|---|
| 1 | physical health | .0027 | .9856 |
| 1 | emotional health | .0991 | .5080 |
| | $R^2$ = .0096 | $R^2$adj. = -.0252 | F = .2759, p = .7599 |
| | Variables in the Equation | | |
| 2 | physical health | -6.260E-04 | .9965 |
| 2 | emotional health | - .136981 | .3352 |
| 2 | informal emotional support | .356696 | .0061 |
| | $R^2$ = .14 | $R^2$adj. = .09 | F = 2.92, p = .0419 |
| | Variables not in the Equation | | |
| | ADLT@WK | .0043 | .9736 |
| | IADLT@W | -.0482 | .7427 |
| | ZARIT | -.0832 | .5459 |
| | ADLAS@WK | .1962 | .1262 |
| | IADAS@WK | .2059 | .1106 |
| | OTHAS@WK | .0451 | .7258 |
| | FOR.ES.A | .1448 | .3577 |

Method: Stepwise Criteria PIN .05 limits reached.
No variables entered/removed for this block.

TABLE 17 (CONTINUED)
STEPWISE REGRESSION ANALYSES: SOCIALIZATION

17b) Socialization on Physical Health, Emotional Health and Prior Exercise and Load & Support: (ALTERNATE MODEL)

| Step | Variable | Beta | p-value |
|---|---|---|---|
| 1 | physical health | .0531 | .5417 |
| 1 | emotional health | -.0863 | .3219 |
| 1 | socialization before | .8158 | .0000 |

$R^2$ = .66 $R^2$adj. = .65 F = 111.62, p = .0000

Variables not in the Equation

| | | |
|---|---|---|
| ADLAS@WK | .1988 | .0087 |
| ADLT@WK | .0073 | .9255 |
| IADLT@WK | .0079 | .9212 |
| ZARIT | -.0264 | .7559 |
| IADAS@WK | .1101 | .1657 |
| OTHAS@WK | .0682 | .3789 |
| INF.ES.A | .1349 | .0928 |
| FOR.ES.A | .1645 | .0395 |

End Block 1. All requested variables entered.
Method Stepwise. Criteria PIN .05
Variable(s) Entered on Step Number 2..ADLAS@WK

$R^2$ = .71 $R^2$adj. = .69 F = 33.89, p = .0000

Variables in the Equation

| | | | |
|---|---|---|---|
| 2 | physical health | -.0702 | .3964 |
| 2 | emotional health | -.0639 | .4401 |
| 2 | socialization before | .7999 | .0000 |
| 2 | assistance with ADL Tasks | .1988 | .0087 |

$R^2$ = .71 $R^2$adj. = .69 F = 33.89, p = .0000

Variables not in the Equation

| | | |
|---|---|---|
| ADLT@WK | .0624 | .4237 |
| FOR.ES.A | .1511 | .0467 |
| IADAS@WK | -.0013 | .9889 |
| IADLT@WK | .0238 | .7550 |
| INF.ES.A | .0977 | .2108 |
| OTHAS@WK | -.0388 | .6468 |
| ZARIT | .0261 | .7457 |

End Block 2. PIN .05 Limits Reached.

## Conclusion to Chapter Three

This chapter has presented findings in relation to the caregiving situation, caregivers' health and their patterns of exercise and socialization. The interrelationships among variables were also presented. The results of two stepwise regression analyses to determine the extent to which the study data fit the Pender Health Promotion Model were reported. Finally, an alternate model was proposed which took into account prior level of health promoting activity (i.e. exercise and socialization) in addition to caregivers' perceptions of their current physical and emotional health. This latter model explained a substantially greater proportion of the variance in caregivers' current levels of participation in exercise and socialization than was demonstrated by the application of the traditional Pender model.

# CHAPTER 4

# DISCUSSION

The final chapter begins with a discussion of the findings, continues with the strengths and limitations of the study and concludes with directions for research and the practice of nursing.

## Discussion of Study Findings

The discussion of findings is organized according to the major themes of the study, i.e., health promoting activities, physical and emotional health, the caregiving situation and relationships among these variables.

### Health Promoting Activities

The findings of this study are consistent with other studies that have investigated health promotion practices and more specifically the health promotion activities of informal caregivers. Respondents reported a decrease in the amount of exercise in which they engaged following their spouse's diagnosis of cancer. They were also, in large measure, dissatisfied with the amount of exercise they were achieving and expressed a need for more exercise and for more socialization with family. These findings concur with the findings of Canada's Health Promotion Survey: Technical Report

(Stephens & Graham, 1990) which concluded that the majority of Canadians felt a need for an increase in health promoting activity, in particular, exercise and socialization. In large measure, respondents in this study had ceased to engage in activities that took them away from their home.They attributed this change to the demands of the caregiving role and their concern for the well-being of their spouse. This finding is consistent with the general caregiver literature that reveals the demands of caregiving and suggests reasons for curtailing health related activities that include physical impairment of the care recipient (Diemling & Bass, 1986), involvement in caregiving tasks (Montgomery et al., 1985), and care that confines the caregiver in time and space (Chappell & Badger, 1989).

**Physical and Emotional Health**

Findings related to the physical and emotional health of caregivers are also consistent with the gerontological and caregiving literature. This literature reveals that caregivers in later life must deal not only with their spouse's advancing age and deteriorating health, but their own as well. Although the majority of caregivers in this study reported their health as good or excellent both prior to and following their spouse's diagnosis, they also reported a number of diagnoses for which they were receiving medical treatment. The majority were also experiencing at least a mild degree of

depressive symptomatology. In addition, a minority (twenty percent) of caregivers in this study had developed health problems of their own that they attributed to the demands of caregiving. This finding is similar to that of Theis (1994) who found that a similar proportion of caregivers attributed health problems to the stress of caregiving. These findings are also congruent with other studies that demonstrate the physical and emotional consequences of caregiving (Brody, et al., 1990; Cox et al., 1990; Schutz et al, 1990). These consequences may be seen to be particularly prevalent in the situation of advanced cancer where there is little likelihood of recovery and the demands on the caregiver can only increase.

**The Caregiving Situation**

This study revealed that caregivers made a significant contribution to the care of their spouse in the form of assistance with personal and instrumental activities of daily living and with more medically oriented tasks such as the management of medications. Respondents carried out approximately twice as many instrumental activities of daily living as personal care tasks. This finding is similar to the type of care carried out by respondents in a study by Obert et al, 1989. These findings are also congruent with those of Horowitz (1985) who found that caregivers of older adults provided a substantial amount of direct care and indirect care.

Respondents in this study, as in the Horowitz study, reported that medication management was particulary taxing to them. They attributed this to the importance of medications for the control of spouses' symptoms. Medication management also required negotiation with health care providers, a task that was at times problematic. Such negotiation can be seen as part of the invisible nature of caregiving noted by Bowers (1987). Medication management was also reported to require constant vigilance and supervision, an aspect of care reported as stressful. The need to be constantly available was also found by Stetz (1987) to be difficult for caregivers. This responsibility for constant supervision can also be considered one of the invisible tasks of caregiving. Caregivers in this study, as in a study by Hooyman (1985), also reported that assisting with intimate personal care such as toiletting and bathing was psychologically and emotionally distressing. They also had to get up at night to attend to the needs of their spouse. In general, caregivers in this study as in others carried a heavy load with respect to caregiving responsibilities. Their scores on the Zarit Burden Interview reflected their responses to the load associated with caring for spouses with advanced cancer and were congruent with studies that demonstrate the burden of care (Chappell, 1989).

The majority of caregivers in this study reported receiving both practical and emotional support from health care providers, in particular, nurses and homemakers. They also received emotional support, but little

practical support, from their family and friends. Indeed, the majority of caregivers expressed the need for additional practical support in their home. These findings are consistent with those of other studies including one by Stommel & Kingry (1991) who reported that caregivers who live alone with their spouse receive little instrumental support. Nevertheless, it may be that emotional support is particularly important to caregivers. A study by George & Gwyther (1986) reported that emotional support is more important than either age or time spent in the caregiving role. Not only were caregivers in the present study largely satisfied with their degree of emotional support, this variable was the only predictor of their level of socialization, a factor that has been shown to be important in the continuing ability of caregivers to provide care.

**Relationships Among Variables**

Findings related to relationships among health promoting practices, self rated physical and emotional health and the provision of care in this study are, in large measure, congruent with those of other studies. For example, a study by Killeen (1989) found that perceptions of health were negatively related to the extent of care provided by older caregivers to individuals with dementia and positively related to general measures of health promotion. Although it was also reported that exercise was the form

of health promotion least engaged in by respondents, the type and extent of exercise was not specified. The present study specifies the type of exercise and demonstrates a decline in all forms of exercise following the diagnosis of a spouse with cancer, a positive relationship between self rated physical and emotional health and engagement in health promoting activity and an inverse relationship between caregiving and self rated health.

The findings regarding the influence of prior levels of exercise and socialization on current levels are of special interest. This study builds on the work of Pender by demonstrating the importance of prior levels of exercise and socialization on current levels. In fact, Pender has foreseen the need for revisions to the health promotion model (Pender et al., 1990c) that will endorse stronger associations between situational factors, demographic characteristics, and the likelihood of engaging in health promoting activity. These revisions are indicated in the light of recent findings (Pender, 1990a; Pender, 1990b; Johnson et al., 1993; Lusk et al., 1994) which suggest that modifying variables may also directly impact on health promoting behaviour.

Thus, this study proposes an alternate to the established health promotion model to account for the direct influence of past health promoting activity on current participation levels. Neuberger et al. (1994) also employed the Health Promotion Model to study determinants of exercise in outpatients with arthritis, taking into account prior exercise pattern. Although those authors observed that respondents who exercised in their youth perceived

more benefits in relation to exercise and health, they failed to establish whether the past exercise pattern in and of itself directly influenced current levels of performance and/or how direct and indirect effects of prior exercise pattern compared in the ability to influence current exercise performance. The findings of the present study demonstrate not only that past exercise and socialization patterns do influence present levels of activity but that this was the strongest predictor of current levels of exercise and socialization for this particular sample of spousal caregivers.

## Strengths and Limitations

This study makes a contribution to a neglected area of knowledge, i.e, the health promoting activities of elderly caregivers prior to and following a spouse's diagnosis of cancer. In doing so, the study provides an important link among the fields of gerontology, oncology and palliative care. It was important to investigate the health promoting activities of older caregivers of spouses with advanced cancer for a variety of reasons. It is known that death and dying from a variety of health problems including cancer more predictably occurs in old age. The provision of care in the home to such individuals will predictably increase because the population is aging and there are increasing fiscal constraints within the health and social service sector. Finally, such care depends in large measure on the availability of

family members, many of whom are experiencing the health and social consequences of advancing age concomitantly with the health and social consequences of informal caregiving. This study provides a portrait of health promoting activities and the contribution to care in the home by spouses of elderly persons with advanced cancer. This study also adds to the body of knowledge about the Pender's model of health promotion by revealing the importance of prior participation in exercise and socialization to current levels of participation in health promoting activities.

Despite these strengths, implications of the study must be considered within the context of the study's limitations. Although sample selection is geographically broad and includes respondents from Ottawa, Calgary and Edmonton, the number of respondents in this study is relatively small and there is no control group. Generalization is thus precluded beyond the study sample. Nevertheless, findings should be regarded as transferable, in the sense that it is likely that other caregivers of relatives with cancer will also identify similar experiences and responses. In addition, the nature of the data gathered about the period of time prior to spouses' diagnosis involved recall on the part of respondents. Such data are subject to recall error, particularly in situations in which the diagnosis occurred months or years prior to data collection. Finally, findings resulting from the use of measures created specifically for this study cannot be compared with other studies.

## Directions for Research

There is a dearth of studies investigating the health promoting activities of informal caregivers. This is particularly so with respect to caregivers of elderly relatives who have advanced cancer. The present study provides direction for further research that is both substantive and methodological.

### Substantive

There is a need for increased research concerning the type and extent of health promoting activities engaged in by those who provide care in the home to elderly family members with cancer. Such research may ultimately contribute to ways of helping informal caregivers sustain their caregiving responsibilties. There is also a need to determine the factors that influence participation in health promoting activities and their impact on the physical and emotional health of informal caregivers. It is also important that the particular circumstances of informal caregivers be considered in future research. For example, it seems reasonable to suggest that the experience of caring for persons with disorders such as cancer, heart disease or Alzheimer's disease may be similar in some respects but may also differ in others. These similarlies and differences may be important with respect to

participation in health promoting activities while providing care.

There is also a need to expand and refine theoretical constructs related to the provision of informal care in the home. While the notion of caregiver burden has been well explored, there has been less attention paid to the more positive aspects and meaning associated with the provision of care. Finally, attention needs to be directed at intervention studies that offer the potential of improving the lot of informal caregivers of elderly family members with advanced cancer who require care in the home.

### Methodological

Studies that link health promotion and the provision of informal care are only beginning to surface. Consequently, there is a need for an increase in the repertoire of research tools available to study the health promoting activity of informal caregivers. This is particularly so in the field of gerontology. More attention also needs to be placed on the use of reliable and valid instruments for measuring conceptual and clinical constructs associated with informal caregiving, particularly with respect to caring for those with cancer. Although the number of instruments related to the provision of care has dramatically increased since the ealy 1980s, a great deal of inconsistency in their application and interpretation has seriously obviated attempts at generalization. Increased consistency in the use of

available instruments and comparisons among studies in the variety of disciplines that study the process of caregiving and health promotion would strengthen the knowledge base accruing from such studies. There is also a need for longitudinal studies that examine change over time in participation in health promoting activities and the influence of caregiving responsibilities on the type and extent of such participation. Finally, attention needs to be directed to intervention studies that aim to increase the participation of informal caregivers in health promoting activities. Such studies need to employ powerful interventions, control groups and sophisticated methods of analysis.

## Directions for Nursing

The findings of the present study have important implications for nurses who practise at the advanced level - Clinical Nurse Specialists, Nurse Practictioners, and Expanded Role Nurses. Health promotion and the provision of care, both formal and informal, are activities that are central to the practice of nursing. This study combines both domains of interest by examining relationships among health promoting activities, physical and emotional health and the provision of informal care.

Findings related to caregivers' perceptions that their physical health declined following their spouses' diagnosis and that at least some physical

health problems were partially attributable to circumstances inherent in the caregiving situation are worthy of note. The provision of care in the home to elderly and disabled family members requires substantial time and expenditure of energy. Advanced practice nurses can help to lessen the deleterious effect on caregivers' physical health by carrying out in-depth assessments of caregivers' health in order to identify informal caregivers who may be at increased risk for developing and/or accentuating physical health problems.

Aspects of personal and instrumental care that caregivers find particularly taxing have implications for nursing. Nurses can provide direction with respect to specific tasks that respondents find problematic and thus alleviate some of the stress and uncertainty associated with the role. Education aimed at the safe provision of care will help to prevent injuries among family caregivers. Nurses also play an important role by informing informal caregivers about resources that may help to sustain them for the long term in their caregiving role.

Nurses need to be actively involved in the political process and lobby governmental agencies to provide adequate home care and respite programs to supplement the efforts of informal caregivers. Creative strategies for remunerating caregivers for their work also need to be developed.

Excessive workload, stress and fatigue create physical and emotional difficulties for caregivers. A variety of workable respite options are required

to meet the needs of families with differing needs and lifestyles. It is also crucial that nurses discover ways of assisting caregivers to utilize respite care, an issue that would be an excellent topic for an intervention study.

Findings related to the presence of depressive symptomatology among the majority of caregivers are worrisome. Nurses need to be aware of the heavy physical and emotional load experienced by informal caregivers and observe for the presence of depressive symptomatology. Advanced practice nurses need to perform assessments of high-risk clients utilizing valid, reliable clinical tools in order to identify when caregivers are getting into difficulty. Once factors which contribute to distressful symptomatology have been determined, nurses and caregivers can collaborate in developing workable strategies aimed at lightening the load of family caregivers and/or assisting them to mobilize external resources to prevent the development or escalation of depressive symptoms. It is crucial that, when emotional difficulties arise, nurses address them directly with clients and other health care providers.

The study findings show that nurses provide the bulk of practical support and substantial emotional support to informal caregivers. This provides motivation for nursing to continue to provide both practical and emotional support to clients, despite increasing environmental and fiscal constraints. Technology, such as cellular phones, can enable nurses to remain accessible to clients when it is not feasible to make a home visit.

Findings related to caregivers' decline in participation in health promoting activities following spouses' diagnosis of cancer are also worrisome. Caregivers must also be viewed as clients, with their personal health valued for its own sake. Nurses need to attend to the health and well-being of informal caregivers by encouraging them to actively participate in exercise and social activities as a method of helping them maintain their own health and persist in the caregiving role. Technological devices such as cellular phones, walkie-talkies, Lifeline, etc. will make it more possible for caregivers to be outside of the home for extended periods and still remain in contact with their ill relative. Such devices alleviate caregivers' stress and enable them to participate in exercise and social activities outside the home. This prevents respondents from becoming increasingly housebound as the caregiving career progresses.

Finally, in assisting respondents to implement a practical health promotion program for the duration of the caregiving career, it is important to build on their prior health practices and to design an acceptable program for each individual client, taking into account the specifics of their personal situation. These findings reveal the importance of communicating with caregiving clients about their prior history of health promotion activities by providing evidence of the centrality of historical information to nursing. Such information needs to inform not only the practice of individual advanced practice nurses, but also the entire nursing profession.

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# APPENDIXES

# APPENDIX A

UNIVERSITÉ D'OTTAWA
UNIVERSITY OF OTTAWA

FACULTÉ DES SCIENCES DE LA SANTÉ
FACULTY OF HEALTH SCIENCES

# CERTIFICATION OF INSTITUTIONAL HUMAN RESEARCH ETHICS COMMITTEE FACULTY OF HEALTH SCIENCES

This is to certify that the Institutional Human Research Ethics Review Committee of the Faculty of Health Sciences has examined the research proposal by **Mary C. Keizer,** a Master of Science in Nursing Programme student from the School of Nursing for the project entitled : **"The relationships among the provision of care, health and well-being, and engagement in health-promoting activities of older women who are the primary informal caregivers for spouses with advanced cancer"** and concludes that, in all respects, in the proposed research protocol meets the appropriate standards of ethical acceptability, at a Category 1A level.

## MEMBERS OF THE COMMITTEE

| Name (Optional) | Position held | Department of discipline |
|---|---|---|
| Claire-Jehanne Dubouloz | Professor | Programme of Occupational Therapy |
| Nadia Lebreux | Student | Human Kinetics |
| Marie Loyer | Chair | Human Research Ethics Committee & School of Nursing |
| Ian MacKay | Professor | Audiology/Speech Language Pathology |
| Joan McComas | Professor | Programme of Physiotherapy |
| Jacqueline Neatby | Member-at-Large | |
| Daniel Proulx | Professor | Faculty of Law |
| Frank Reardon | Professor | Human Kinetics |

27/5/94
Date

Marie A Loyer
**Committee Chairperson - Marie des Anges Loyer, Ph.D**

CABINET DE LA DOYENNE/OFFICE OF THE DEAN
451 SMYTH, OTTAWA, ONTARIO, CANADA K1H 8M5
(613) 787-6705 FAX: 787-6725 TÉLÉCOPIEUR

# APPENDIX B

## Letters of Authorization

VON CANADA

Victorian Order of Nurses | Infirmières de l'Ordre de Victoria
OTTAWA-CARLETON BRANCH
SUCCURSALE D'OTTAWA-CARLETON

Caring for Life
Souci de la Vie

May 17, 1994

Marie des Anges Loyer, PhD
Chair, Human Research Ethics Committee
Faculty of Health Sciences
University of Ottawa
451 Smyth Road
Ottawa, Ontario K1H 8M5

Dear Dr. Loyer:

This letter is written to inform you that VON Ottawa-Carleton Branch will provide both the site and sample for Mary Keizer to pursue her research on the informal caregivers of people with cancer. She has our authorization to collaborate with both nurses and family caregivers who volunteer to participate in her research project.

Sincerely yours,

Elisabeth McDonald
Executive Director

cc: Mary Keizer

5335 Canotek Road
Gloucester, Ontario
K1J 9L4
(613) 749-7557

MISERICORDIA HOSPITAL
16940-87 AVE EDMONTON ALBERTA CANADA T5R 4H5 (403) 484-8811
Fax No. (403) 930-5774

August 15, 1994

Marie des Anges Loyer, R.M., Ph.D.
Chair, Human Research Ethics Committee
Faculty of Health Sciences
University of Ottawa
451 Smyth Road
Ottawa, Ontario
K1H 8M5

Dear Dr. Loyer:

This letter is written to inform you that the Palliative Care Service at the Misericordia Hospital has agreed to provide Mary Keizer with a sample of family caregivers in the pursuit of her research on the informal caregivers of people with cancer. Mary has our authorization to collaborate with our nurses and family caregivers who volunteer to participate in her research.

Sincerely,

Helen Hays

Helen Hays, C.M.
M.D., F.C.F.P., C.C.F.P.
Director
Palliative Care Service

HH:mc

AGAPÉ
MANOR
H·O·S·P·I·C·E

July 4, 1994

Marie des Anges Loyer, R.N., Ph.D.
Chair, Human Research Ethics Committee
Faculty of Health Sciences
University of Ottawa
451 Smyth Road
Ottawa, Ontario K1H 8M5

Dear Dr. Loyer,

This letter is written to inform you that Agape Manor in Calgary has agreed to provide Mary Keizer with a sample of family caregivers in the pursuit of her research on the informal caregivers of people with cancer. Mary has our authorization to collaborate with our nurses and our family caregivers who volunteer to participate in her research project.

Sincerely yours,

Irene Kahler-Huff, R.N., M.Sc.N.
Executive Director
Agape Manor1402 - 8th Avenue N.W.
Calgary, Alberta

*Mailing Address:*
The Salvation Army Agapé Manor Hospice
1302 - 8th Avenue N.W.
Calgary, Alberta T2N 1B8
Telephone (403) 284-0200
Fax (403) 284-1778

*Agapé is sharing God's Love with others.*

MVHU
# MOUNT VIEW HEALTH UNIT
SUITE 200, 6715 - 8th STREET N.E., CALGARY, ALBERTA T2E 7H7
Phone: 221-8000 • Fax: 274-1925

File No.

SUB OFFICES

BOX 3757
AIRDRIE, AB
T4B 2B9
Tel: 948-4105
Fax: 948-3104

BOX 117
DIDSBURY, AB
T0M 0W0
Tel 335-3233
Fax 335-8361

BOX 428
CANMORE, AB
T0L 0M0
Tel 678-5656
Fax. 678-5068

BOX 459
OLDS, AB
T0M 1P0
Tel 556-8441
Fax 556-8842

BOX 432
COCHRANE, AB
T0L 0W0
Tel: 932-2353
Fax: 932-7219

BOX 101
SUNDRE AB
T0M 1X0
Tel 638-4063
Fax 638-4460

Calgary, AB
August 2, 1994

Marie des Anges Loyer, R.N., Ph.D.
Chair, Human Research Ethics Committee
Faculty of Health Services
University of Ottawa
451 Smyth Road
OTTAWA, ONTARIO
K1H 8M5

Dear Dr. Loyer:

This letter is written to inform you that Mount View Health Unit in Alberta has agreed to provide Mary Keiser with a sample of family caregivers in the pursuit of her research on the informal caregivers of people with cancer. Mary has our authorization to collaborate with our nurses and our family caregivers who volunteer to participate in her research project.

Sincerely,

Lola Gilchrist

Lola Gilchrist, R.N.
Director, Home Care Program

LG/ojw

# FOOTHILLS HEALTH UNIT

P.O. BOX 5638
310 MACLEOD TRAIL
HIGH RIVER, ALBERTA
T1V 1M7
PHONE 652-3297 . FAX 652-2537


OUR FILE:

August 4, 1994

Marie des Anges Loyer, R.N., Ph.D.
Chair, Human Research Ethics Committee
Faculty of Health Sciences
University of Ottawa
451 Smyth Road
Ottawa, ON
K1H 8M5

Dear Dr. Loyer:

This letter is written to inform you the Foothills Health Unit in High River has agreed to provide Mary Keizer with a sample of family caregivers in the pursuit of her research on the informal caregivers of people with cancer. Mary has our authorization to collaborate with our nurses and our family caregivers who volunteer to participate in her research project.

Yours truly,

Linda Walsh

Linda Walsh, R.N.
Palliative/Supportive Coordinator

cc: file


HOME CARE PROGRAM
BOX 5190
HIGH RIVER
T1V 1M4
PHONE: 652-3200
FAX: 652-2461

*DISTRICT OFFICES:*
VULCAN
BOX 214 T0L 2B0
PHONE 485-2285
FAX 485-2639

BLACK DIAMOND
BOX 34 T0L 0H0
PH/FAX 933-4335

NANTON
BOX 812 T0L 1R0
PH/FAX 646-2277

OKOTOKS
BOX 758 T0L 1T3
PHONE 938-4911
FAX 938-2783

ALBERTA CANCER BOARD

TOM BAKER CANCER CENTRE
SOUTHERN ALBERTA CANCER PROGRAM

# LETTER OF AUTHORIZATION TO CONDUCT RESEARCH

October 19, 1994

Dr. Francis Reardon
Chair
Faculty of Health Sciences - Human Research Ethics Committee
University of Ottawa
451 Smyth Road
Ottawa, Ontario
K1H 8M5

Dear Dr. Reardon,

This letter is written to certify that The Tom Baker Cancer Centre will provide Mary Keizer with a portion of her sample of spousal caregivers for the study, "The relationships among the provision of care, health and well-being, and engagement in health-promoting activities of older adults who are the primary informal caregivers for spouses with advanced cancer". Mary has our authorization to collaborate with both designated staff and family caregivers who volunteer to participate in her research project.

Sincerely yours,

Harry Plummer
Director of Nursing
The Tom Baker Cancer Centre
1331 - 29 Street N.W.
Calgary, Alberta
T2N 4N2

cc. Mary Keizer, Principal Investigator
Dr. Margaret Ross, Thesis Supervisor

# APPENDIX C

## Letter of Information for Nurses

Victorian Order of Nurses
Infirmières de l'Ordre de Victoria
OTTAWA-CARLETON BRANCH
SUCCURSALE D'OTTAWA-CARLETON
Caring for Li
Souci V
de la
VON CANADA

May 20, 1994

To: All Full-time RN Staff

Mary Keizer, a graduate student in Nursing at the University of Ottawa, is doing a study to determine the health-promoting activities of family caregivers who are providing home care for VON clients with cancer. Mary is interested in interviewing women, 50 years of age and older, who are the primary family caregivers for husbands with cancer. Her thesis supervisor is Dr. Margaret Ross, who is a research scholar with VON Canada and Associate Professor at the University of Ottawa.

I have authorized Mary to conduct the study through the Ottawa-Carleton Branch of the Victorian Order of Nurses. The study will be conducted over the next several months, beginning in May 1994.

The study has received ethical approval from the Faculty of Health Sciences Human Research Ethics Committee. Whenever a research project is undertaken with human subjects by a member of the University of Ottawa, the Ethics Committee of the University requires the written consent of the participants. This ensures that participants are aware of the nature of the study and that they are fully informed about their rights as research participants.

As a provider of VON services, you are being invited to participate by letting Mary know about eligible respondents who may be interested in taking part in the study. If you agree to participate, you will be asked to take these caregivers a letter of information about the study and to get their permission for Mary to call them to tell them more about the study and invite them to participate in an interview.

Any information that you provide will be kept strictly confidential and your name will never be associated with the information. In the same way, any information from the respondents will be held in strict confidence and their names will never be associated with the information.

Of course, your participation is entirely voluntary, and your relationship with VON is in no way dependent upon your participation in the study. Should you agree to participate, you will be asked to read and sign a consent form as an indication of mutual agreement. The consent will outline what is expected of you and what you can expect from the researchers.

If you have any questions or concerns about the study at any time, you may contact the principal investigator, Mary Keizer at (613) 231-5279. As well, you may contact Dr. Margaret Ross at (613) 787-6596 or at 233-5694. In addition, you may also contact Dr. Marie Loyer, Chairperson of the Faculty of Health Sciences Human Research Ethics Committee, 451 Smyth Road, Ottawa, ON K1H 8M5, (613) 787-6596. Of course you may feel free to approach me or Becky Hollingsworth at any time as well.

I invite you to participate in this research study in collaboration with the School of Nursing at the University of Ottawa.

Sincerely yours,

Elizabeth McDonald, RN, BScN
Executive Director

cc: Mary Keizer, Principal Investigator
Dr. Margaret Ross, Thesis Supervisor
Dr. Marie Loyer, Chair,
Faculty of Health Sciences Human Research Ethics Committee

# APPENDIX D

## Nurses' Consent Form

VON CANADA

# Nurses Consent Form

## *Health-Promoting Activities of Wives who Provide Home Care for Spouses with Cancer*

Whenever a research project is undertaken with human subjects by a member of the University of ottawa, the Ethics Committee of the University requires the written consent of the participants. This ensures that participants are aware of the nature of the study and that they are fully informed about their rights as research participants.

This form, which you are being asked to read and sign, is an indication of agreement to participate in the study. The consent outlines what is expected of you and what you can expect of the researchers.

I, _____, agree to participate in the study of health-promoting activities of wives who provide home care for spouses with cancer, which is being conducted beginning in May 1994 by Mary Keizer, a graduate student at the School of Nursing of the University of Ottawa. The purpose of the study is to determine family caregivers' participation in health-promoting activities, caregivers' health and well-being, and aspects of caregiving which influence caregivers' ability to engage in health-promoting activities.

I understand that I will be asked to review my caseload of adult men with cancer to determine if they have a spousal caregiver over 50. Once these caregivers are identified, I will be asked to provide the caregivers with a letter of explanation about the study, and inquire if they agree to have Mary Keizer, principal investigator, telephone them to tell them more about the study and to invite them to take part in a short interview in their home at a time that is convenient to them.

I understand that this process will be initiated during a regularly scheduled planning meeting at the Branch. I understand that my participation in the study is voluntary, and that my relationship with the VON will not be affected by whether or not I choose to participate. I also understand that I may choose to withdraw from the study at any time.

I understand that the client's receipt of VON services is in no way dependent on my participation in the study; nor is receipt of services dependent on their participation.

I understand that all information from me and from the client and family will be kept strictly confidential and neither my name nor the client's names will be associated with the information.

If I have any questions or concerns about the study I may contact the principal investigator, Mary Keizer at (613) 231-5279, Dr. Margaret Ross at (613) 787-6596 or at 233-5694 or Dr. Marie Loyer, Chairperson of the Faculty of Health Sciences Human Research Ethics Committee, 451 Smyth Road, Ottawa, ON K1H 8M5, (613) 787-6596.

Respondent: _____

Witness: _____

Investigator: _____

Date: _____

# APPENDIX E

## Letter of Information for Caregivers

UNIVERSITÉ D'OTTAWA
UNIVERSITY OF OTTAWA

FACULTÉ DES SCIENCES DE LA SANTÉ
FACULTY OF HEALTH SCIENCES

## LETTER OF INFORMATION TO FAMILY CAREGIVERS

**Study of Health Activities Engaged in by Adults who provide Home Care for Spouses**

Dear Family Caregiver,

I am Mary Keizer, a graduate student in Nursing at the University of Ottawa. To complete my Masters degree in Nursing, I am required to conduct a research study and I have chosen to study **MEN AND WOMEN, 50 AND OLDER, WHO PROVIDE CARE AT HOME FOR A SPOUSE WITH CANCER.** I am interested in how you, the caregiver, are able to carry out health activities and maintain your own health while fulfilling your caregiving role. I feel that it is important to support family caregivers who fulfil such a vital role in our society.

My thesis supervisor is Dr. Margaret Ross, who is an Associate Professor of Nursing at the University of Ottawa. This study has received full ethical approval by the Ethics Committee of the University of Ottawa and has also received authorization by Dr. Helen Hays at the Palliative Care Unit, Misericordia Hospital.

Your participation in the study is completely voluntary. You are also free to withdraw from the study at any time or to choose not to answer questions in the interview which you prefer not to answer. Your spouse's care will not be affected in any way, now or in the future, if you choose not to participate or if you decide to withdraw from the study. Any information that you share will be held in strict confidence and your name, or your spouse's name, will not be associated with the information at any time.

If you agree to take part in a short interview, which will not exceed one hour, you will be asked to read and sign a consent form that will describe the study and will ensure that you are fully aware of your rights. The consent will indicate your agreement to take part in the study and to participate in a private interview to be conducted in your home (or place of your choice) by Mary Keizer at a convenient time.

If you need further information about the study or wish to make arrangements to have an interview, **please call Mary Keizer, principal investigator, at (403) 293-2235 in Calgary.** You may also leave a message at the Palliative Care Unit of Misericordia Hospital c/o Dr. Helen Hays or Rita at (403) 484-8811.

I WELCOME YOU TO PARTICIPATE IN A SHORT INTERVIEW **DURING THE LAST WEEK OF JULY 1994.** YOUR ASSISTANCE WILL BE GREATLY APPRECIATED!

Sincerely yours,

Mary C. Keizer, R.N., B.Sc.N.

ÉCOLE DES SCIENCES INFIRMIÈRES/SCHOOL OF NURSING
451 SMYTH, OTTAWA, ONTARIO, CANADA K1H 8M5
(613) 787-6596 TÉLÉCOPIEUR/FAX: (613) 787-6757

# APPENDIX F

## Caregiver Consent Form

UNIVERSITÉ D'OTTAWA
UNIVERSITY OF OTTAWA

FACULTÉ DES SCIENCES DE LA SANTÉ
FACULTY OF HEALTH SCIENCES

# FAMILY CAREGIVER CONSENT FORM

## Study of Health Activities Engaged in by Wives who provide Home Care for Husbands

Whenever a research study is undertaken with people by a member of the University of Ottawa, the Ethics Committee of the University requires the written consent of the participants. This ensures that you are aware of the nature of the study and that you are fully informed about your rights in relation to the study.

This form, which you are being asked to read and sign, indicates that you freely agree to participate in the study. The consent outlines what is being asked of you and what you can expect from the person(s) conducting the research.

I, _____, agree to participate in the study of health activities engaged in by wives who provide home care for husbands, which is being conducted beginning in May 1994 by Mary Keizer, a graduate student at the School of Nursing of the University of Ottawa. The purpose of the study is to determine to what extent women who are providing home care for their husbands are able to engage in health activities. The study will also explore how the caregivers' health and aspects of the caregiving situation influence the women's ability to engage in health activities.

I understand that my participation in this study is completely voluntary. I will be asked to participate in a single private interview in my home, at a time that is convenient for me. The interview will ask questions concerning my health, health activities, and aspects of providing home care for my husband that influence to what extent I am able to engage in health activities. I am free to choose not to respond to any questions that I prefer not to answer or that may make me feel uncomfortable.

I understand that any information that I choose to share will be held in strict confidence and that neither my name nor my husband's name will be associated with the information.

I understand that I am free to withdraw from the study at any time, and that my husband's care or my care, will not be affected, now or in the future, if I choose not to participate or if I decide to withdraw from the study.

ÉCOLE DES SCIENCES INFIRMIÈRES/SCHOOL OF NURSING
451 SMYTH, OTTAWA, ONTARIO, CANADA K1H 8M5
(613) 787-6596 TÉLÉCOPIEUR/FAX: (613) 787-6757

UNIVERSITÉ D'OTTAWA
UNIVERSITY OF OTTAWA

FACULTÉ DES SCIENCES DE LA SANTÉ
FACULTY OF HEALTH SCIENCES

If I have any questions or concerns about the study, I may contact Mary Keizer, principal investigator, at (613) 231-5279, Dr. Margaret Ross at 787-6596 or at 233-5694, or Dr. Marie Loyer, Chairperson of the Faculty of Health Sciences Human Research Ethics Committee at 787-6596.

Respondent: _____

Witness: _____

Investigator: _____

Date: _____

ÉCOLE DES SCIENCES INFIRMIÈRES/SCHOOL OF NURSING
451 SMYTH, OTTAWA, ONTARIO, CANADA K1H 8M5
(613) 787-6596 TÉLÉCOPIEUR/FAX: (613) 787-6757

# APPENDIX G

## Interview Schedule

## CAREGIVER INTERVIEW SCHEDULE

Date of Interview DD/MM/YR ___/___/___ ID#_____
Interview Start Time: ___:___ AM PM Gender: 1 = Male 2 = Female
What is your relationship to the person you are looking after?
1 = married 2 = common law 3 = separated 4 = divorced
How long is it since your spouse was diagnosed? _____ weeks _____ months _____ years

## SECTION 1. HEALTH-PROMOTING ACTIVITIES: EXERCISE & SOCIALIZATION

"I am interested in how much exercise, and how much socializing with family and friends you are usually able to engage in. **Exercise refers to physical activity, such as walking, sports, gardening, or dancing that you participate in either alone or with others. I will ask you about common types of exercise and you can add any other type of exercise that you do in the course of a typical week".**

**First, thinking back to the time before your husband/wife was diagnosed, what types of exercise and how much exercise, did you get on a regular basis during a typical week *at this time of the year*? Please rate each activity as light, moderate, or vigorous exercise according to the following definitions: [CUE CARD]**

- **LIGHT exercise** is physical activity where *your breathing becomes only slightly faster than normal* and *you do not perspire or perspire only slightly*.
- **MODERATE exercise** means that *your breathing is a lot faster but you can still talk* and/or *you perspire moderately*.
- **VIGOROUS exercise** is when *your breathing becomes so fast that you cannot speak* and/or *you perspire a great deal*.

### 1A. PARTICIPATION IN PHYSICAL EXERCISE PRIOR TO BEING A CAREGIVER

| CALCULATE WEEKLY 1.Type of Exercise | # Times per week | Time spent on each occasion? 1-15min | 16-30min | >30min | precise am't time | Intensity L/M/VIG |
|---|---|---|---|---|---|---|
| a relaxation/stretching exercises | ____ | ____ | ____ | ____ | ____ | ____ |
| b walking briskly | ____ | ____ | ____ | ____ | ____ | ____ |
| c aquafitness | ____ | ____ | ____ | ____ | ____ | ____ |
| d stair climbing | ____ | ____ | ____ | ____ | ____ | ____ |
| e aerobics or dancing | ____ | ____ | ____ | ____ | ____ | ____ |
| f bicycling | ____ | ____ | ____ | ____ | ____ | ____ |
| g.swimming | ____ | ____ | ____ | ____ | ____ | ____ |
| h bowling | ____ | ____ | ____ | ____ | ____ | ____ |
| i.golfing | ____ | ____ | ____ | ____ | ____ | ____ |
| j.gardening | ____ | ____ | ____ | ____ | ____ | ____ |
| k other exercise (specify): | | | | | | |
| 1. _____ | ____ | ____ | ____ | ____ | ____ | ____ |
| 2. _____ | ____ | ____ | ____ | ____ | ____ | ____ |
| 3. _____ | ____ | ____ | ____ | ____ | ____ | ____ |

2. **Overall, do you consider that the amount of physical exercise that you used to get, before your husband/wife was diagnosed, was the right amount for you, or do you think that it was too little or too much?**

1 = far too little 2 = too little 3 = the right amount 4 = too much 5 = far too much

## 1B. PARTICIPATION IN EXERCISE WHILE BEING A CAREGIVER

**"Now, I am going to ask you to think back over the past month about your usual patterns of exercise during a typical week *since your husband/wife was diagnosed.* I would also like to know how much of this activity was light exercise, and how much was moderate and vigorous exercise." [CUE CARD]**

**During the past month, how much time did you spend in a typical week on the following:**

| CALCULATE WEEKLY<br>3.Type of Exercise | # Times per week | Time spent on each occasion? 1-15min | 16-30min | >30min | precise am't time | Intensity L/M/VIG |
|---|---|---|---|---|---|---|
| a.relaxation/stretching exercises | ____ | ____ | ____ | ____ | ____ | ____ |
| b.walking briskly | ____ | ____ | ____ | ____ | ____ | ____ |
| c.aquafitness | ____ | ____ | ____ | ____ | ____ | ____ |
| d.stair climbing | ____ | ____ | ____ | ____ | ____ | ____ |
| e.aerobics or dancing | ____ | ____ | ____ | ____ | ____ | ____ |
| f.bicycling | ____ | ____ | ____ | ____ | ____ | ____ |
| g.swimming | ____ | ____ | ____ | ____ | ____ | ____ |
| h.bowling | ____ | ____ | ____ | ____ | ____ | ____ |
| i.golfing | ____ | ____ | ____ | ____ | ____ | ____ |
| j.gardening | ____ | ____ | ____ | ____ | ____ | ____ |
| k other exercise (specify):<br>1. _____<br>2 _____<br>3. _____ | ____<br>____<br>____ | ____<br>____<br>____ | ____<br>____<br>____ | ____<br>____<br>____ | ____<br>____<br>____ | ____<br>____<br>____ |

COMMENTS _____

_____

_____

_____

_____

4. How much light, moderate, and vigorous exercise do you get <u>ON A TYPICAL OR AVERAGE DAY</u> *through your caregiving activities*?

| | none | <1hr | 1 -2' | 2-3' | 3 -4' | 4-5' | 5-6' | 6-7' | 7-8' | precise am't time | dk | n/a |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| a.Light | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | _____ | 98 | 99 |
| b. Mod. | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | _____ | 98 | 99 |
| c. Vig. | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | _____ | 98 | 99 |

**COMMENTS:**

_____
_____
_____
_____

5a. **Overall, do you consider that the amount of physical exercise that you now get is the right amount for you, or is it too little or too much?**

1 = far too little 2 = too little 3 = the right amount 4 = too much 5 = far too much

5b. **Would you like to be exercising more?**

1 = yes ___ 2 = no ___ 8 = dk ___ 9 = n/a ___

5c. **What things keep you from exercising more?**
**[Choose up to 3 things, in order of importance.]** **[CUE CARD]**

1 = reluctance to leave spouse
2 = caregiving responsibilities
3 = caregiver ill health/injury/handicap
4 = lack of energy
5 = lack of incentive/motivation
6 = prefer other activities/hobbies
7 = costs involved
8 = no facilities nearby / no transportation
9 = no one with whom to exercise/do sports
10 = lack of time
11 = lack necessary skills
12 = other (specify) _____
_____

reason #1 _____ reason #2 _____ reason #3 _____

6. **Do you think that you get about the same amount of exercise as you did before your husband/wife was diagnosed, or do you now get less exercise or more exercise?**

1 = much less 2 = a little less 3 = about the same 4 = a little more 5 = much more

**COMMENTS:**

_____
_____
_____

## 1C. SOCIALIZATION

7a. Now I am going to ask you some questions about how often you are able to be in touch with your family and friends..."Would you please tell me how many of each of the following **YOU SEE AND/OR HEAR FROM ON A REGULAR BASIS (i.e. at least once a year)?**

**[CUE CARD]**

**0 = none**
**1 = daughter ___ son-in-law ___**
**2 = son ___ daughter-in-law ___**
**3 = sister ___**
**4 = brother ___**
**5 = niece ___**
**6 = nephew ___**
**7 = grandchildren ___**
**8 = friends ___**
**9 = other (specify) _____**

7b. **How many of these people live nearby (i.e. within a 1 hour drive from your home)?**
8a. **How often did you see and/or talk on the phone to them *before* (date spouse diagnosed)?**
8b. **How often do you see and/or talk on the phone to them *now*?**

| | CALCULATE ON A MONTHLY BASIS<br>Supportive Persons<br>Family | live near | BEFORE<br>see (per wk/mo/yr) | <br>phone (per wk/mo/yr) | NOW<br>see (per wk/mo/yr) | <br>phone (per wk/mo/yr) |
|---|---|---|---|---|---|---|
| 1. | | | | | | |
| 2. | | | | | | |
| 3. | | | | | | |
| 4. | | | | | | |
| 5. | | | | | | |
| 6. | | | | | | |
| 7. | | | | | | |
| 8. | | | | | | |
| 9. | | | | | | |
| 10. | | | | | | |
| Total | | | | | | |
| | Friends | | | | | |
| 1. | | | | | | |
| 2. | | | | | | |
| 3. | | | | | | |
| 4. | | | | | | |
| 5. | | | | | | |
| Total | | | | | | |
| | Others (specify) | | | | | |
| 1. | | | | | | |
| 2. | | | | | | |
| 3. | | | | | | |
| 4. | | | | | | |
| 5. | | | | | | |
| Total | | | | | | |
| GRAND TOTAL | | | | | | |

9. **Who, if anyone, lives with you and your husband/wife?**

0 = no one  1 = someone [specify] 1. _____ 2. _____

10. Do you consider that you see your children and grandchildren the right amount, or do you feel that you see them either less or more than you would like?

i) children
1 = much less 2 = a little less 3 = the right amount 4 = a little more 5 = much more

ii) grandchildren
1 = much less 2 = a little less 3 = the right amount 4 = a little more 5 = much more

11. Do you consider that you see your friends the right amount, or do you feel that you see them less or more than you would like?

1 = much less 2 = a little less 3 = the right amount 4 = a little more 5 = much more

COMMENTS _____
_____

CALCULATE MONTHLY (Questions 12a,b; 13a,b)

12a. Thinking back to the time *before your husband was diagnosed*, about how many times in a typical week *at this time of year* did you go out alone to shop, to a movie, or some other outing(s)? e. to play bingo, cards, attend a course or a sports event...?

# outings alone before _____

12b. About how many times in a typical week *now* do you go out alone to shop, to a movie, or some other outing(s)? e.g. to play bingo, cards, attend a course or a sports event...?

# outings alone now _____

13a. *Before your husband was diagnosed*, about how many times in a typical week *at this time of year* did you go out with others to shop, to a movie, or some other outing(s)?

# outings with others before _____

13b. About how many times, in a typical week *now* do you go out with others to shop, to a movie, or some other outing(s)? e.g. to play bingo, cards, to a course, sports event...?

# outings with others now _____

14a. *Before your spouse was diagnosed*, how often did you attend church services/ functions?

0 = never 1 = once a year 2 = several times/yr 3 = monthly 4 = weekly 5 = 2+weekly

14b. *In your present situation*, how often do you attend church services/functions?

0 = never 1 = once a year 2 = several times/yr 3 = monthly 4 = weekly 5 = 2+weekly

15a. **What clubs, or groups do you belong to? (e.g. bridge club, seniors' group, etc.)**

15b. **How often did you attend each of these groups *before your spouse's diagnosis*?**

15c. **How often do you attend each group *now*?**

| 15. | CALCULATE MONTHLY | BEFORE (per wk/mo/yr) | NOW (per wk/mo/yr) |
|---|---|---|---|
| | Group 1 _____ | _____ | _____ |
| | Group 2 _____ | _____ | _____ |
| | Group 3 _____ | _____ | _____ |

COMMENTS _____

_____

16a. ***Before your husband/wife became ill*, about how often did you feel lonely? Would you say rarely or never, occasionally or little, fairly often, or most of the time?**

1 = rarely 2 = occasionally 3 = fairly often 4 = most of the time

16b. ***In your present situation*, about how often do you find yourself feeling lonely? Would you say rarely or never, occasionally or little, fairly often, or most of the time?**

1 = rarely 2 = occasionally 3 = fairly often 4 = most of the time

17a. **Overall, do you consider that the amount of socializing that you *used to do, before your spouse was diagnosed*, was the right amount for you, or do you feel that it was too little or too much?**

1 = far too little 2 = too little 3 = the right amount 4 = too much 5 = far too much

17b. **Overall, do you consider that the amount of socializing *that you now* do is the right amount for you, or do you feel that it is too little or too much?**

1 = far too little 2 = too little 3 = the right amount 4 = too much 5 = far too much

17c. **Would you like to be socializing more?**

1 = yes ___ 2 = no ___ 8 = dk ___ 9 = n/a ___

17d. **What things keep you from socializing more?**
**[Choose up to 3 things, in order of importance.] [CUE CARD]**

1 = reluctance to leave spouse
2 = caregiving responsibilities
3 = caregiver ill health/injury/handicap
4 = lack of energy
5 = lack of incentive/motivation
6 = prefer other activities/hobbies
7 = costs involved
8 = no facilities nearby/lack of transportation
9 = no one with whom to socialize
10 = lack of time
11 = lack of social/communication skills
12 = other (specify) _____

reason #1 _____ reason #2_____ reason #3 _____

COMMENTS _____

18. **Do you think that you socialize about the same amount as you did *before your husband /wife was diagnosed*, or do you now socialize more or less than you did before?**

1 = much less 2 = a little less 3 = about the same 4 = a little more 5 = much more

## SECTION 2. CAREGIVER HEALTH: EMOTIONAL HEALTH SYMPTOMATOLOGY

19. Here are ways caregivers sometimes feel. **For each statement, please tell me how often you felt this way in the past week: rarely/never, sometimes, often, or most of the time. [CUE CARD]**

**1 = rarely/never** **3 = fairly often** **8 = don't know**
**2 = sometimes** **4 = most of the time** **9 = n/a**

| | | rarely | s/times | often | most/times |
|---|---|---|---|---|---|
| a. | I was bothered by things that don't usually bother me | 1 | 2 | 3 | 4 |
| b. | I did not feel like eating; my appetite was poor | 1 | 2 | 3 | 4 |
| c. | I felt that I could not shake off the blues even with help from family or friends | 1 | 2 | 3 | 4 |
| d | I felt that I was just as good as other people | 1 | 2 | 3 | 4 |
| e | I had trouble keeping my mind on what I was doing | 1 | 2 | 3 | 4 |
| f. | I felt depressed | 1 | 2 | 3 | 4 |
| g | I felt that everything I did was an effort | 1 | 2 | 3 | 4 |
| h | I felt hopeful about the future | 1 | 2 | 3 | 4 |
| i. | I thought my life had been a failure | 1 | 2 | 3 | 4 |
| j | I felt fearful | 1 | 2 | 3 | 4 |
| k | My sleep was restless | 1 | 2 | 3 | 4 |
| l | I was happy | 1 | 2 | 3 | 4 |
| m | I talked less than usual | 1 | 2 | 3 | 4 |
| n | I felt lonely | 1 | 2 | 3 | 4 |
| o | People were unfriendly | 1 | 2 | 3 | 4 |
| p | I enjoyed life | 1 | 2 | 3 | 4 |
| q | I had crying spells | 1 | 2 | 3 | 4 |
| r. | I felt sad | 1 | 2 | 3 | 4 |
| s. | I felt that people disliked me | 1 | 2 | 3 | 4 |
| t. | I could not "get going" | 1 | 2 | 3 | 4 |

## 2B. MEDICAL DIAGNOSES

**20. Has your doctor told you that you have any of the following health conditions? If so,how long have you had these problems?**

| | CALCULATE TIME IN MONTHS | YES | LENGTH OF TIME | NO | DK |
|---|---|---|---|---|---|
| a. | high blood pressure | ___ | _____ | ___ | ___ |
| b. | arthritis | ___ | _____ | ___ | ___ |
| c. | heart trouble | ___ | _____ | ___ | ___ |
| d. | cancer (any type) | ___ | _____ | ___ | ___ |
| e. | diabetes | ___ | _____ | ___ | ___ |
| f. | osteoporosis (aging bone loss) | ___ | _____ | ___ | ___ |
| g. | breathing problems (asthma, emphysema) | ___ | _____ | ___ | ___ |
| h. | parkinson's disease | ___ | _____ | ___ | ___ |
| i. | visual or hearing problems (glaucoma, cataracts, etc.) | ___ | _____ | ___ | ___ |
| j. | depression (emotional problems) | ___ | _____ | ___ | ___ |
| k. | back, foot, spine problems | ___ | _____ | ___ | ___ |
| l. | other health problems (specify) | | | | |
| | 1. _____ | ___ | _____ | ___ | ___ |
| | 2. _____ | ___ | _____ | ___ | ___ |
| | 3 _____ | ___ | _____ | ___ | ___ |

COMMENTS: _____

_____

**21. How much do your health problems stand in the way of your doing the things you want to do? Would you say not at all, only a little, a fair amount, or a great deal?**

0 = not at all  1 = only a little  2 = a fair amount  3 = a great deal

**22. How often have you visited your doctor within the past year?**

frequency or # visits to doctor _____

## 2C. CAREGIVER SELF-REPORT OF OVERALL HEALTH AND WELL-BEING

**23a. How would you rate your overall physical health *at the present time*? Is it...**

4 = excellent 3 = good 2 = fair 1 = poor

**23b. How is your physical health now, compared with how it was *before your husband/wife was diagnosed?* [If diagnosed more than 2 years ago, say, "How is your physical health now, compared with how it was 2 years ago?"]**

1= much better 2 = somewhat better 3 = unchanged 4 = somewhat worse 5 = much worse

**23c. Which of the following things, if any, are influencing your physical health *at the present time?* [Check up to 3 things, in order of importance.] [CUE CARD]**

1 = physical work / demands of caregiving
2 = stress related to caregiving situation
3 = worry about my spouse
4 = changes in spouse (physical or mental)
5 = change in my lifestyle practices
6 = change in my medical care
7 = lack of social support
8 = my age or factors related to aging
9 = personal illness / injury / handicap
10 = cost of living and/or medical care
11 = lack of relief/assistance with caregiving
12 = lack of time to engage in self-care
13 = lack of self-care skills (e.g. physical care skills, management of stress, etc.)
14 = other responsibilities and concerns
15 = other stresses [specify]_____
16 = other [specify] _____

factor # 1 _____ factor # 2 _____ factor # 3_____
COMMENTS: _____

**23d. Which of these things, if any, helped to BRING ABOUT A CHANGE in your physical health from before the time you were a caregiver [or, during the past 2 years]? [Check up to 3 things, in order of importance.] [CUE CARD]**

1 = physical work / demands of caregiving
2 = stress related to caregiving situation
3 = worry about my spouse
4 = changes in spouse (physical or mental)
5 = change in my lifestyle practices
6 = change in my medical care
7 = lack of social support
8 = my age or factors related to aging
9 = personal illness / injury / handicap
10 = cost of living and/or medical care
11 = lack of relief/assistance with caregiving
12 = lack of time to engage in self-care
13 = lack of self-care skills (e.g. physical care skills, management of stress, etc.)
14 = other responsibilities and concerns
15 = other stresses_____
16 = other [specify] _____

factor # 1 _____ factor # 2 _____ factor # 3 _____
COMMENTS: _____

**24a. How would you rate your overall emotional health *at the present time*? Is it...?**

4 = excellent 3 = good 2 = fair 1 = poor

**24b. How is your emotional health now, compared with how it was *before your husband/wife was diagnosed?* [If diagnosed more than 2 years ago, say, "How is your emotional health now, compared with how it was 2 years ago?"]**

1= much better 2 = somewhat better 3 = unchanged 4 = somewhat worse 5 = much worse

24c. **Which of the following things, if any, are influencing your emotional health at the present time? [Check up to 3 things, in order of importance.] [CUE CARD]**

1 = physical work / demands of caregiving
2 = stress related to caregiving situation
3 = worry about my spouse
4 = changes in spouse (physical or mental)
5 = change in my lifestyle practices
6 = change in my medical care
7 = lack of social support
8 = my age or factors related to aging
9 = personal illness / injury / handicap
10 = cost of living and/or medical care
11 = lack of relief/assistance with caregiving
12 = lack of time to engage in self-care
13 = lack of self-care skills (e.g. physical care skills, management of stress, etc.)
14 = other responsibilities and concerns
15 = other stresses [specify] _____
16 = other [specify] _____

factor # 1 _____ factor # 2 _____ factor # 3 _____

COMMENTS: _____

24d. **Which of these things, if any, helped to BRING ABOUT A CHANGE in your emotional health from before the time you were a caregiver [or, during the past 2 years]? [Check up to 3 things, in order of importance.] [CUE CARD]**

1 = physical work / demands of caregiving
2 = stress related to caregiving situation
3 = worry about my spouse
4 = changes in spouse (physical or mental)
5 = change in my lifestyle practices
6 = change in my medical care
7 = lack of social support
8 = my age or factors related to aging
9 = personal illness / injury / handicap
10 = cost of living and/or medical care
11 = lack of relief/assistance with caregiving
12 = lack of time to engage in self-care
13 = lack of self-care skills (e.g. physical care skills, management of stress, etc.)
14 = other responsibilities and concerns
15 = other stresses [specify] _____
16 = other [specify] _____

factor # 1 _____ factor # 2 _____ factor # 3 _____

COMMENTS: _____

25. **So, how is your overall health now, compared with how it was *before your husband/wife was diagnosed?* [or, how it was 2 years ago?]**

1= much better 2 = somewhat better 3 = unchanged 4 = somewhat worse 5 = much worse

## SECTION 3. THE CAREGIVING SITUATION3A. EXTENT OF CARE PROVIDED

Now, I want to ask you about how your spouse manages his/her daily tasks. Regarding each of the following tasks, I want you to say if your spouse can manage this without your help, if he/she needs some help from you, or if you have to do it completely for him/her."

**For all responses, even if the husband/wife can do a task, ask:**

b) "How often have you helped him/her with (the task) during the past week?"

c) "About how long does this take each day?"

26a. **Can your husband/wife eat... without any help, with some help from you (cut food, help feed), or do you feed him/her?**

0 = no help 1 = some help 2 = caregiver does task

b how often have you helped your husband/wife with eating during the past week?

0 = no 1 = < once/day 2 = 1 - 2 times/day 3 = 3-4+ times/day

c about how much time does this take each day?

0 = n/a 1 = 1-29 minutes 2 = 30 - 59 minutes 3 = 60+ minutes

27a. **Can your husband/wife dress and undress... without any help, with some help from you (pick out clothes, help dress/undress), or do you completely dress/undress him/her?**

0 = no help 1 = some help 2 = caregiver does task

b how often have you helped your husband/wife with dressing/undressing during the past week?

0 = no 1 = < once/day 2 = 1 - 2 times/day 3 = 3-4+ times/day

c about how much time does this take each day?

0 = n/a 1 = 1-29 minutes 2 = 30 - 59 minutes 3 = 60+ minutes

28a. **Can your husband/wife take care of his/her own appearance, for example, combing hair; shaving/applying makeup... without any help, with some help from you, or do you look after his/her grooming needs?**

0 = no help 1 = some help 2 = caregiver does task

b how often have you helped your husband/wife with his/her appearance and grooming during the past week?

0 = no 1 = < once/day 2 = 1 - 2 times/day 3 = 3-4+ times/day

c about how much time does this take each day?

0 = n/a 1 = 1-29 minutes 2 = 30 - 59 minutes 3 = 60+ minutes

29a. **Can your husband/wife move about the house... without any help, with some help from you, or do you have to help him/her walk and move about?**

0 = no help 1 = some help 2 = caregiver does task

b. how often have you helped your husband/wife move about the house during the past week?

0 = no 1= < once/day 2 = 1 - 2 times/day 3 = 3-4+ times/day

c. about how much time does this take each day?

0 = n/a 1 = 1-29 minutes 2 = 30 - 59 minutes 3 = 60+ minutes

30a. **Can your husband/wife get in and out of bed... without any help, with some help from you, or do you have to help him/her to get in and out of bed?**

0 = no help 1= some help 2 = caregiver does task

b. how often have you helped your husband/wife move about the house during the past week?

0 = no 1= < once/day 2 = 1 - 2 times/day 3 = 3-4+ times/day

c about how much time does this take each day?

0 = n/a 1 = 1-29 minutes 2 = 30 - 59 minutes 3 = 60+ minutes

31a. **Can your husband/wife take a bath or shower... without any help, with some help from you, or do you have to help him/her to bathe?**

0 = no help 1 = some help 2 = caregiver does task

b. how often have you helped your husband/wife take a bath or shower during the past week?

0 = no 1= < once/day 2 = 1 - 2 times/day 3 = 3-4+ times/day

c about how much time does this take each day?

0 = n/a 1 = 1-29 minutes 2 = 30 - 59 minutes 3 = 60+ minutes

32a. **Can your husband/wife use the bathroom or toilet... without any help, with some help from you, or do you have to help him/her to use the bathroom?**

0 = no help 1 = some help 2 = caregiver does task

b. how often have you helped your husband/wife use the bathroom during the past week?

0 = no 1= < once/day 2 = 1 - 2 times/day 3 = 3-4+ times/day

c. about how much time does this take each day?

0 = n/a 1 = 1-29 minutes 2 = 30 - 59 minutes 3 = 60+ minutes

33a. **Can your husband/wife use the telephone... without any help, with some help from you (answer phone, dial out, finding numbers), or do you have to help him/her to use the phone?**

0 = no help 1 = some help 2 = caregiver does task

b. how often have you helped your husband/wife use the telephone during the past week?

0 = no 1= < once/day 2 = 1 - 2 times/day 3 = 3-4+ times/day

c. about how much time does this take each day?

0 = n/a 1 = 1-29 minutes 2 = 30 - 59 minutes 3 = 60+ minutes

34a. **Can your husband/wife get to places out of walking distance ... without any help (manage bus or drive the car), with some help from you (arranging for transportation), or do you have to drive him/her?**

0 = no help 1 = some help 2 = caregiver does task

b. how often have you helped your spouse with transportation in the past week?

0 = no 1= < once/day 2 = 1 - 2 times/day 3 = 3-4+ times/day

c. about how much time does this take each day?

0 = n/a 1 = 1-29 minutes 2 = 30 - 59 minutes 3 = 60+ minutes

35a. **Can your husband/wife prepare his/her own meals ... without any help (can plan and cook full meals), with some help from you (can do some things but unable to cook full meals), or do you prepare all his/her meals?**

0 = no help 1 = some help 2 = caregiver does task

b how often have you helped to prepare your husband's/wife's meals during the past week?

0 = no 1= < once/day 2 = 1 - 2 times/day 3 = 3-4+ times day

c about how much time does this take each day?

0 = n/a 1 = 1-29 minutes 2 = 30 - 59 minutes 3 = 60+ minutes

36a. **Can your husband/wife prepare and take his/her own medicines ... without any help (in the right doses at the right times), with some help from you (you prepare them and/or remind him/her), or do you prepare and give all his/her medicines?**

0 = no help 1 = some help 2 = caregiver does task

b. how often have you helped to prepare and give your spouse's medicines during the past week?

0 = no 1= < once/day 2 = 1 - 2 times/day 3 = 3-4+ times/day

c. about how much time does this take each day?

0 = n/a 1 = 1-29 minutes 2 = 30 - 59 minutes 3 = 60+ minutes

37a. **Can your husband/wife manage his/her own money... without any help (pay bills, write cheques, do banking), with some help from you (manages day-to-day buying but needs help with chequebooks, banking), or do you look after all his/her financial matters?**

0 = no help 1 = some help 2 = caregiver does task

b. how much time do you spend helping your husband/wife with finances ***each month***?

0 = n/a 1 = 1-29 minutes 2 = 30 - 59 minutes 3 = 60+ minutes

c. is the type and amount of help you give your spouse with finances about the same as it was *before your spouse became ill*, or do you now help him/her less or more with financial matters?

1 = much less 2 = a little less 3 = about the same 4 = a little more 5 = much more

38a. **Can your husband/wife be left alone at all (remain at home unsupervised for 30 minutes to 2 hours) while someone is in the house?**

1 = yes ___ 2 = no ___ 8 = dk ___ 9 = na ___

b. **Can your spouse be left unsupervised 30 minutes to 2 hours when no one is at home?**

1 = yes ___ 2 = no ___ 8 = dk ___ 9 = na ___

c. **How often do you get up at night (i.e. most nights) to give care to your husband/wife?**

# times up with spouse at night _____

COMMENTS _____

_____

_____

_____

## 3B. ASSISTANCE GIVEN TO THE CAREGIVER

39. Now I am going to ask you about the help you are given with your spouse's care. First, I will ask you who comes in to help you, how often these people come, and what they do to help.

| | | | |
|---|---|---|---|
| i) | **Does a VON, Home Care, or other nurse come in to help?**<br>How often does the nurse come? [Circle appropriate category]<br>What does the nurse do to help? [Circle tasks, next page] | **1 = yes** | **2 = no** |
| ii) | **Does a HOMEMAKER come to help? Home Care Program?**<br>How often does the home support worker come? [Circle category]<br>What does the homemaker do to help? [Circle tasks] | **1 = yes** | **2 = no** |
| iii) | **Do FAMILY/FRIENDS/NEIGHBOURS help? [specify]**<br>How often do these people come? [Circle category]<br>What do they do to help? [Circle tasks] | **1 = yes** | **2 = no** |
| iv) | **Does ANYONE ELSE help you? [specify]**<br>How often do these people come? [Circle category]<br>What do they do to help? [Circle tasks] | **1 = yes** | **2 = no** |
| v) | **Does your spouse receive PALLIATIVE CARE/HOSPICE** services, either at home or in hospital? [CUE CARD]<br>**Specify PCS** _____ | **1 = yes** | **2 = no** |
| vi) | **Does spouse receive other HOSPITAL services?**<br>**Specify hospital services** _____ | **1 = yes** | **2 = no** |
| vii) | **Does your spouse receive COMMUNITY services?**<br>**e.g. Meals on Wheels? Specify service:** _____ | **1 = yes** | **2 = no** |

### SOME HEALTH CARE SERVICES IN OTTAWA-CARLETON

**PALLIATIVE CARE SERVICES** (examples)
- .Regional Palliative Care Unit
- .Elizabeth Bruyere Health Centre (chronic pal)
- .Riverside Hospital
- .Queensway-Carleton Hospital
- .Ottawa Civic Hospital
- .Ottawa General Hospital
- .Grace Hospital
- .National Defence Medical Centre(NDMC)

**COMMUNITY HOSPICES** (examples)
- .Jewish Hospice
- .Hospice of All Saints

**HOSPITAL SERVICES** (examples)
- .Symptom Control Clinic (Ottawa Civic H.)
- .Hospital Social Services
- .Day Hospital
- .Physiotherapy/Occupational Therapy
- .Other hospital services/clinics

**COMMUNITY SERVICES** (examples)
- .Victorian Order of Nurses (VON) Regional Home Care Program
- .Nursing Agencies
- .Meals on Wheels
- .Para Transpo

**ASK ABOUT SIMILAR SERVICES IN THE EDMONTON & CALGARY REGIONS**

39. (cont'd) **ASSISTANCE RECEIVED BY FAMILY CAREGIVER**

| AMOUNT OF HELP RECEIVED | | CAREGIVER HELPERS | |
|---|---|---|---|
| 0 = none | 3 = 2-3 times a week | hm = homemaker | cs = community service |
| 1 = once a month | 4 = daily (at least 5/week) | rn = nurse | hs = hospital service |
| 2 = once a week | 9 = n/a (help not needed) | fa = family | cpc = c'ty-based pal care |
| | | fr = friend | hpc = hospital-based |
| | | ne = neighbour | palliative care |

| | TASK | amount help | hm | rn | fa | fr | ne | cs | hs | cpc | hpc | dk | na |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| a. | eating | 0 1 2 3 4 9 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 98 | 99 |
| b. | dressing | 0 1 2 3 4 9 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 98 | 99 |
| c. | grooming | 0 1 2 3 4 9 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 98 | 99 |
| d. | move about | 0 1 2 3 4 9 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 98 | 99 |
| e. | in/out bed | 0 1 2 3 4 9 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 98 | 99 |
| f. | bath/shower | 0 1 2 3 4 9 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 98 | 99 |
| g. | toileting | 0 1 2 3 4 9 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 98 | 99 |
| h. | telephoning | 0 1 2 3 4 9 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 98 | 99 |
| i. | travel | 0 1 2 3 4 9 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 98 | 99 |
| j. | shopping | 0 1 2 3 4 9 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 98 | 99 |
| k. | make meals | 0 1 2 3 4 9 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 98 | 99 |
| l. | laundry | 0 1 2 3 4 9 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 98 | 99 |
| m. | housework | 0 1 2 3 4 9 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 98 | 99 |
| n. | medicines | 0 1 2 3 4 9 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 98 | 99 |
| o. | finances | 0 1 2 3 4 9 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 98 | 99 |
| p. | supervision | 0 1 2 3 4 9 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 98 | 99 |

FORMAL SERVICES/AGENCIES: [circle all that apply]: VON(6/7)____ Home Care(6/7) _____
Nursing Agency (specify) (6) _____ Meals on Wheels (6) _____
Palliative Care (specify): community (8) or hospital (9) based _____
Other services (specify): _____

40a. **Do you feel that you would benefit by having someone come in to relieve you for a few hours from time to time?**

1 = yes ___ 2 = no ___ 8 = dk ___

b. **Do you have someone who could come in to relieve you for a few hours?**

1 = yes ___ 2 = no ___ 8 = dk ___

c. **Up to now, how often has someone actually come in to relieve you for a few hours?**

0 = never 1 = < once a month 2 = monthly 3 = weekly 4 = > once a week

41a. **Do you feel that you would benefit by having someone come in to relieve you overnight from time to time?**

1 = yes ___ 2 = no ___ 8 = dk ___

b. **Do you have someone who could come in to relieve you overnight?**

1 = yes ___ 2 = no ___ 8 = dk ___

c. **Up to now, how often has someone actually come in to relieve you overnight?**

frequency _____

42a. **Do you feel that you would benefit by having someone come in to relieve you for a few days from time to time?**

1 = yes ___ 2 = no ___ 8 = dk ___

b. **Do you have someone who could come in to relieve you for a few days?**

1 = yes ___ 2 = no ___ 8 = dk ___

c. **Up to now, how often has someone actually come in to relieve you for a few days?**

frequency _____

COMMENTS: _____

_____

_____

## 3C. EMOTIONAL SUPPORT RECEIVED BY THE CAREGIVER

"Over and above your contacts with family, friends, and other individuals, which of these people give you **emotional support**?" [e.g. they **listen** to you, offer you words of **encouragement, praise...**]

"Whom do you **rely upon** in time of need?" [to rely upon is to be **able to turn to them** in an emergency or in time of need for **practical help** or for **advice**]

0 = no one
1 = daughter ___ son-in-law ___
2 = son ___ daughter-in-law ___
3 = sister ___
4 = brother ___
5 = niece ___
6 = nephew ___
7 = grandchildren ___
8 = friends ___
9 = other (specify) _____

43a. *Before your spouse was diagnosed:* Who supported you?
43b. *Before your spouse was diagnosed:* Whom did you rely upon?
43c. *In your present circumstances:* Who supports you?
43d. *In your present circumstances:* Whom do you rely on?

| | BEFORE DIAGNOSIS | | POST DIAGNOSIS | |
|---|---|---|---|---|
| | SUPPORT | RELIANCE | SUPPORT | RELIANCE |
| FAMILY | Supp = support | Rel = reliance | y = yes | n = no |
| 1._____ | Supp y n | Rel y n | Supp y n | Rel y n |
| 2._____ | Supp y n | Rel y n | Supp y n | Rel y n |
| 3._____ | Supp y n | Rel y n | Supp y n | Rel y n |
| 4._____ | Supp y n | Rel y n | Supp y n | Rel y n |
| 5._____ | Supp y n | Rel y n | Supp y n | Rel y n |
| 6._____ | Supp y n | Rel y n | Supp y n | Rel y n |
| 7._____ | Supp y n | Rel y n | Supp y n | Rel y n |
| 8._____ | Supp y n | Rel y n | Supp y n | Rel y n |
| 9._____ | Supp y n | Rel y n | Supp y n | Rel y n |
| 10._____ | Supp y n | Rel y n | Supp y n | Rel y n |
| Totals [yes] _____ | Supp: yes ___ | Rel: yes ___ | Supp: yes ___ | Rel: yes ___ |
| FRIENDS | | | | |
| 1._____ | Supp y n | Rel y n | Supp y n | Rel y n |
| 2._____ | Supp y n | Rel y n | Supp y n | Rel y n |
| 3._____ | Supp y n | Rel y n | Supp y n | Rel y n |
| 4._____ | Supp y n | Rel y n | Supp y n | Rel y n |
| 5._____ | Supp y n | Rel y n | Supp y n | Rel y n |
| Totals [yes] _____ | Supp: yes ___ | Rel: yes ___ | Supp: yes ___ | Rel: yes ___ |

HOW MANY PEOPLE TURN TO YOU for support/practical help? Supp=___ Rel=___

43e. **HEALTH CARE PERSONNEL & OTHER PROFESSIONALS AS SOURCES OF SUPPORT AND RELIANCE [specify professionals] [CUE CARD]**

Which health care personnel, such as **DOCTORS**, **NURSES**, **HOMEMAKERS**, and other professionals such as a **MINISTER**, **PRIEST**, or **LAWYER** give you **emotional support**?

Which professionals can you rely upon to assist you in an **emergency or time of need**?

Are there some **professionals who have not been supportive?**

Are there **some that you could not rely upon** to assist you in an emergency or time of need?

S = supportive N = neutral NS = not supportive

R = can rely upon DK = don't know NR = cannot rely upon

| HEALTH CARE & OTHER PROFESSIONALS | | | | | | |
|---|---|---|---|---|---|---|
| 1. _____ | S | N | NS | R | DK | NR |
| 2. _____ | S | N | NS | R | DK | NR |
| 3. _____ | S | N | NS | R | DK | NR |
| 4. _____ | S | N | NS | R | DK | NR |
| 5. _____ | S | N | NS | R | DK | NR |
| Totals_____ | ___ | ___ | ___ | ___ | ___ | ___ |

COMMENTS _____

_____

43f. **ALL OTHER PERSONS AS SOURCES OF SUPPORT [Specify]**

S = supportive N = neutral NS = not supportive

R = can rely upon DK = don't know NR = cannot rely upon

| OTHER PERSONS | | | | | | |
|---|---|---|---|---|---|---|
| 1. _____ | S | N | NS | R | DK | NR |
| 2. _____ | S | N | NS | R | DK | NR |
| 3. _____ | S | N | NS | R | DK | NR |
| Totals_____ | ___ | ___ | ___ | ___ | ___ | ___ |

COMMENTS _____

_____

44. **How much emotional support are you receiving from your spouse at the present time?**

0= none 1 = little 2 = a fair amount 3 = a great deal 8 = dk 9 = n/a

45a. **Not counting your husband/wife, how many people do you know that you really trust and talk over personal matters with?**

0 = no [Go to # 43a] 1 = at least one person 8 = dk 9 = n/a

b. **How often do you see or talk to this/these person(s)?** CALCULATE MONTHLY

Confidante 1. _____ Frequency of contact _____
Confidante 2. _____ Frequency of contact _____
Confidante 3. _____ Frequency of contact _____
Confidante 4. _____ Frequency of contact _____
Confidante 5. _____ Frequency of contact _____

COMMENTS _____
_____
_____

46a. **Overall, do you consider the amount of emotional support that you get from your *family and relatives* to be about the right amount, or is it not enough or too much?**

1 = not nearly enough 2 = not enough 3 = right amount 4 = too much 5 = far too much

b. **Do you consider the amount of support that you get from *friends* to be...**

1 = not nearly enough 2 = not enough 3 = right amount 4 = too much 5 = far too much

c. **Do you consider the amount of support that you get from *professional personnel* to be...**

1 = not nearly enough 2 = not enough 3 = right amount 4 = too much 5 = far too much

47. **On a scale of 0 to 10, [0 being no support and 10 being a great deal of support], how would you rate the overall emotional support you are receiving at the present time?**

0 1 2 3 4 5 6 7 8 9 10

COMMENTS _____
_____

## 3D. FEELINGS ASSOCIATED WITH CAREGIVING

"Here is a list of statements which describe how people sometimes feel when taking care of another person. Some of these questions may make you uncomfortable, because you think you shouldn't have these feelings, but the reason I am asking them is that they are very normal feelings for someone in your situation." [CUE CARD]

48. **After I read each statement, please indicate how often you feel this way: rarely or never, some of the time, fairly often, or most of the time."**

| | | rarely | some/t | often | most times |
|---|---|---|---|---|---|
| 1 | How often do you feel that your husband/wife makes requests which are over and above what he/she needs? | 1 | 2 | 3 | 4 |
| 2 | How often do you feel that, because of your involvement with your spouse, you don't have enough time for yourself? | 1 | 2 | 3 | 4 |
| 3 | How often do you feel stressed between caring for your spouse and trying to meet other responsibilities? | 1 | 2 | 3 | 4 |
| 4 | How often do you feel embarrassed over any aspect of your husband's/wife's behavior? | 1 | 2 | 3 | 4 |
| 5 | How often do you feel angry or resentful about your interactions with your spouse? | 1 | 2 | 3 | 4 |
| 6 | How often do you feel that your spouse is affecting your relationship with other family members or friends in a negative way? | 1 | 2 | 3 | 4 |
| 7 | How often do you feel resentful of other relatives who could but do not do things for your husband? | 1 | 2 | 3 | 4 |
| 8 | How often do you feel afraid of what the future holds for your spouse? | 1 | 2 | 3 | 4 |
| 9 | How often do you feel afraid of what the future holds for you? | 1 | 2 | 3 | 4 |
| 10 | How often do you feel guilty about your interactions with your spouse? | 1 | 2 | 3 | 4 |
| 11 | How often do you feel your health has suffered because of your involvement with your husband's/wife's care? | 1 | 2 | 3 | 4 |
| 12 | How often do you feel pleased about your interactions with your husband/wife? | 1 | 2 | 3 | 4 |
| 13 | How often do you wish that you and your spouse had a better relationship? | 1 | 2 | 3 | 4 |
| 14 | How often do you feel that you don't have as much privacy as you would like, because of your spouse's illness? | 1 | 2 | 3 | 4 |

| | | rarely | some/t | often | most times |
|---|---|---|---|---|---|
| 15 | How often do you feel that your social life has suffered because you are caring for your husband/wife? | 1 | 2 | 3 | 4 |
| 16 | How often do you feel nervous, depressed, or strained about your interactions with your spouse? | 1 | 2 | 3 | 4 |
| 17 | How often do you feel uncomfortable about having friends over, because of your husband/wife? | 1 | 2 | 3 | 4 |
| 18 | How often do you feel that your husband/wife seems to expect you to take care of him/her as if you were the only one he/she can depend upon? | 1 | 2 | 3 | 4 |
| 19 | How often do you feel that you are contributing to the well-being of your spouse? | 1 | 2 | 3 | 4 |
| 20 | How often do you feel that it is painful to watch your spouse battle with illness? | 1 | 2 | 3 | 4 |
| 21 | How often do you feel that you don't have enough money to care for your spouse, in addition to your other expenses? | 1 | 2 | 3 | 4 |
| 22 | How often do you feel that you will be unable to take care of your husband/wife much longer? | 1 | 2 | 3 | 4 |
| 23 | How often do you feel that you have lost control of your life since your husband's/wife's diagnosis? | 1 | 2 | 3 | 4 |
| 24 | How often do you feel useful in your interactions with your husband/wife? | 1 | 2 | 3 | 4 |
| 25 | How often do you feel dissatisfied because of a change in sexual relations since your spouse became ill? | 1 | 2 | 3 | 4 |
| 25 | How often do you wish you could just leave the care of your husband/wife to someone else? | 1 | 2 | 3 | 4 |
| 26 | How often do you feel uncertain about what to do about your spouse? | 1 | 2 | 3 | 4 |
| 27 | How often do you feel you should be doing more for your spouse? | 1 | 2 | 3 | 4 |
| 28 | How often do you feel you could do a better job in caring for your husband/wife? | 1 | 2 | 3 | 4 |
| 29 | How often do you feel that your spouse does not appreciate what you are doing for him/her as much as you would like? | 1 | 2 | 3 | 4 |

**49. Overall, how difficult is it, physically and emotionally, for you to care for your husband/wife? How would you rate the level of difficulty on a scale of 0 to 10? (0 = not difficult; 10 = extremely difficult).**

0 1 2 3 4 5 6 7 8 9 10

## SECTION 4. SOCIODEMOGRAPHIC DATA

"Now, I'd like to know a little about you and your husband's/wife's backgrounds."

**50.** **How many years have you and your husband/wife been married? _____years.**

**51.** **How old is your husband/wife? ____**

| | |
|---|---|
| 1 = under 50 | 4 = 70 - 79 years |
| 2 = 50 - 59 | 5 = 80+ years |
| 3 = 60 - 69 | 6 = refused to answer |

**52.** **How old are you? ____**

| | |
|---|---|
| 1 = under 50 | 4 = 70 - 79 years |
| 2 = 50 - 59 | 5 = 80+ years |
| 3 = 60 - 69 | 6 = refused to answer |

**53a.** **Were you born in Canada?** 1 = Yes ___ 0 = No ___
(specify country) _____

**53b.** **To what ethnic/cultural group do you (caregiver) belong? (If they don't understand, say: For example, are you English, French, Jewish, Polish, Chinese...)**

**Caregiver's culture/ethnicity:** _____/_____/_____

**54a.** **Was your spouse born in Canada?** 1 = Yes ___ 0 = No ___
[specify country] _____

**54b.** **To what ethnic/cultural group does your spouse belong?**

**Spouse's culture/ethnicity:** _____/_____/_____

**55.** **What is your religion?**

0 = no religion 1 = Protestant 2 = Catholic 3 = Jewish 4 = other (specify)_____

**55.** **What is the highest grade/ level of education that you have you completed?**

1 = no formal schooling **Grade/Level** _____
2 = some primary school
3 = finished primary school
4 = some high school
5 = finished high school
6 = some community /technical college /CEGEP
7 = finished college
8 = some university
9 = Bachelor's degree or higher

**56a. Are you currently employed outside the home?**

0 = no  1 = yes  8 = dk  9 = n/a (e.g. retired)

**56b. During most of your life, were you a full-time homemaker, or were you employed either full-time or part-time outside the home?**

1 = FT homemaker (Go to # 61)  2 = PT employment  3 = FT employment  9 = n/a

**57. What has been your major occupation during most of your life?**

**Caregiver Occupation** _____

The final question is about family income. Whenever a health survey is being carried out, a question is included about family income to ensure that all segments of the population are being represented.

**58. When you and your spouse combine your incomes, to which annual income bracket (before taxes) do you belong?**

1 = no income
2 = less than $20,000
3 = $20,000-$40,000
4 = $40,000-$60,000
5 = over $60,000
7 = refused to answer
8 = don't know

We have now completed our interview. Interview completion time: ___:___

*"THANK YOU VERY MUCH FOR PARTICIPATING IN THIS STUDY!"*

# APPENDIX H

## Tasks of Daily Living

## APPENDIX H

### TIME WEIGHTINGS FOR TASKS OF DAILY LIVING

| TASKS | TIME REQUIREMENT PER SESSION | |
|---|---|---|
| | ASSISTING WITH TASK | PERFORMING TASK |
| Eating | 10 minutes | 30 minutes |
| Dressing | 10 minutes | 20 minutes |
| Grooming | 5 minutes | 15 minutes |
| Moving about House | 5 minutes | 15 minutes |
| In and Out of Bed | 5 minutes | 10 minutes |
| Bath/shower | 10 minutes | 30 minutes |
| Toiletting | 5 minutes | 15 minutes |
| Telephoning | 5 minutes | 10 minutes |
| Travel | 60 minutes | 60 minutes |
| Preparing Meals | 15 minutes | 45 minutes |
| Medication Duties | 10 minutes | 30 minutes |
| Finances | 5 minutes | 15 minutes |

Note: Daily time allotments for tasks of daily living were calculated by multiplying time weightings per session by the number of times a particular task was accomplished each day.

# APPENDIX I

## Task Performance

APPENDIX I

CAREGIVERS WHO PERFORMED DAILY TASKS AND FREQUENCY OF ASSISTANCE
(N = 60)

| DAILY TASKS | n | % | MODE (# TIMES/DAY) |
|---|---|---|---|
| ADL TASKS | | | |
| Eating | 21 | 35% | 3-4+ |
| Dressing | 36 | 60% | 1-2 |
| Grooming | 18 | 30% | 1-2 |
| Moving about | 32 | 53% | 3-4+ |
| In/out of bed | 26 | 43% | 3-4+ |
| Bathing | 32 | 53% | 1-2 |
| Toileting | 27 | 45% | 3-4+ |
| IADL TASKS | | | |
| Telephoning | 12 | 20% | 1-2 |
| Travel | 43 | 72% | < once |
| Meal preparation | 57 | 95% | 3-4 |
| Medications | 45 | 75% | 3-4 |
| Finances | 50 | 83% | n/a |

Note: Numbers may not add up to 60 or percentages to 100 because categories are not mutually exclusive.

# APPENDIX J

## Hours of Task Performance

APPENDIX J

DAILY TASK PERFORMANCE AND HOURS SPENT
(N = 60)

| A. NUMBER OF TASKS | MEAN | SD | MDN | RANGE |
|---|---|---|---|---|
| ADL TASKS | 7.7 | 6.0 | 7.0 | .00-18.0 |
| IADL TASKS | 6.4 | 2.2 | 6.6 | .14-10.1 |
| TOTAL TASKS | 14.0 | 7.4 | 13.1 | 1.1-28.1 |
| B. HOURS SPENT | | | | |
| ADL TASKS | 1.8 | 1.6 | 1.5 | .00-5.0 |
| IADL TASKS | 4.1 | 1.6 | 4.6 | .14-6.1 |
| TOTAL TASKS | 5.9 | 2.3 | 5.8 | 1.0-10.6 |

Note. Categories of tasks are not mutually exclusive.

# APPENDIX K

## Responses to Burden Interview

APPENDIX K

RESPONSES TO THE BURDEN INTERVIEW (ZARIT)
(N = 60)

| NO. | DIMENSIONS OF BURDEN<br>SUBJECTIVE DISTRESS | rarely /never | sometimes | often | almost always |
|---|---|---|---|---|---|
| | **IMPACT ON SPOUSAL RELATIONSHIP** | | | | |
| 1 | spouse makes requests | 56% | 27% | 5% | 12% |
| 5 | angry with spouse | 62% | 27% | 8% | 3% |
| 10 | guilty re: spouse | 70% | 23% | 2% | 5% |
| 12 | pleased...interactions | 12% | 20% | 23% | 45% |
| 13 | wish better relationship | 63% | 20% | 7% | 10% |
| 18 | spouse expects..only one | 48% | 10% | 8% | 34% |
| 30 | not appreciated | 72% | 20% | 5% | 3% |
| | **IMPACT ON OTHER RELATIONSHIPS** | | | | |
| 2 | no time for self | 52% | 25% | 15% | 8% |
| 3 | stress/responsibilities | 37% | 30% | 22% | 11% |
| 4 | embarrassed...behaviour | 78% | 12% | 5% | 5% |
| 6 | negative...with family | 80% | 13% | 5% | 2% |
| 7 | resentful of relatives | 85% | 8% | - | 7% |
| 11 | health has suffered | 68% | 22% | 3% | 7% |
| 14 | lack of privacy | 72% | 13% | 8% | 7% |
| 15 | social life has suffered | 63% | 20% | 12% | 5% |
| 17 | uncomfortable...friends | 87% | 6% | 5% | 2% |
| 21 | not enough money to care | 73% | 15% | 5% | 7% |
| 25 | change..sexual relations | 84% | 10% | 3% | 3% |
| | **CAREGIVER ROLE MASTERY** | | | | |
| 19 | spouse's well-being | - | 5% | 10% | 85% |
| 24 | useful interactions | 2% | 8% | 15% | 77% |
| 27 | uncertain what to do | 50% | 25% | 20% | 5% |
| 28 | feel should do more | 71% | 17% | .7% | 5% |
| 29 | feel should do better | 80% | 17% | 2% | 2% |
| | **ANXIETY ABOUT THE FUTURE** | | | | |
| 8 | afraid for spouse | 37% | 38% | 14% | 11% |
| 9 | afraid for self | 26% | 23% | 28% | 23% |

# APPENDIX L

## Support Received with Caregiving Tasks

APPENDIX L

WEEKLY SUPPORT PROVIDED WITH CAREGIVING TASKS
(N = 60)

| | FORMAL SUPPORT | | INFORMAL SUPPORT | |
|---|---|---|---|---|
| ADL TASKS | NURSE | HOMEMAKER | FAMILY | FRIENDS |
| Eating | 5% | - | - | - |
| Dressing | 10% | 5% | 5% | - |
| Grooming | 13% | 6% | 6% | - |
| Moving about | 3% | 5% | 5% | - |
| In/out of bed | 8% | 5% | 5% | - |
| Bathing | 20% | 15% | 3% | - |
| Toileting | 8% | 2% | 5% | - |
| IADL TASKS | | | | |
| Telephoning | 2% | 2% | - | - |
| Travel | - | - | 5% | 3% |
| Meal preparation | - | 5% | 4% | 1% |
| Medications | 21% | - | 5% | - |
| Finances | - | - | 2% | - |
| OTHER TASKS | | | | |
| Shopping | - | 2% | 5% | - |
| Laundry | 3% | 10% | 5% | - |
| Housekeeping | - | 30% | 4% | 3% |
| Supervision | 2% | - | 10% | 6% |

Note. Percentages represent the proportion of respondents who received weekly support with each specified task from the various sources.
NURSE = Registered Nurse

# APPENDIX M

## Factors Influencing Physical Health

APPENDIX M

FACTORS INFLUENCING CAREGIVERS' PHYSICAL HEALTH
(N = 60)

| INFLUENCING FACTORS | n | % |
|---|---|---|
| Worry about spouse | 30 | 50% |
| Physical and/or mental changes in spouse | 20 | 34% |
| Stress of caregiving situation | 16 | 27% |
| Changes in caregiver's lifestyle | 11 | 18% |
| Age/factors related to aging | 14 | 23% |
| Physical work/demands of caregiving | 11 | 18% |
| Other sources of stress | 3 | 5% |
| Illness of caregiver | 7 | 12% |

NOTE: Numbers do not add up to 60 or percentages to 100 because categories are not mutually exclusive.

# APPENDIX N

## Responses to CES-D Scale

APPENDIX N

DEPRESSIVE SYMPTOMATOLOGY (CES-D)
(N = 60)

| | rarely /never | sometimes | often | most of the time/always |
|---|---|---|---|---|
| SOMATIC & RETARDED ACTIVITY | | | | |
| Bothered by things | 37% | 38% | 18% | 7% |
| Poor appetite | 63% | 18% | 5% | 14% |
| Everything an effort | 55% | 25% | 8% | 12% |
| Sleep was restless | 37% | 18% | 18% | 27% |
| Couldn't get going | 57% | 23% | 10% | 10% |
| Couldn't concentrate | 48% | 37% | 15% | - |
| Talked less | 58% | 18% | 7% | 17% |
| DEPRESSED AFFECT | | | | |
| Couldn't shake blues | 62% | 17% | 12% | 10% |
| Felt depressed | 38% | 40% | 10% | 12% |
| Felt lonely | 50% | 33% | 10% | 7% |
| Crying spells | 50% | 35% | 13% | 2% |
| Felt sad | 18% | 37% | 30% | 15% |
| Felt fearful | 53% | 27% | 12% | 8% |
| Life a failure | 87% | 8% | 2% | 3% |
| POSITIVE AFFECT | | | | |
| Felt as good as others | 5% | 7% | 7% | 82% |
| Hopeful about future | 44% | 10% | 23% | 23% |
| Felt happy | 37% | 17% | 22% | 25% |
| Enjoyed life | 48% | 8% | 24% | 20% |
| INTERPERSONAL | | | | |
| People unfriendly | 82% | 13% | 3% | 2% |
| People disliked me | 92% | 8% | - | - |

NOTE: Numbers in sub-scales do not add up to 60 or percentages to 100 because categories are not mutually exclusive.

# APPENDIX O

## Factors Influencing Emotional Health

APPENDIX O

FACTORS INFLUENCING CAREGIVERS' EMOTIONAL HEALTH
(N = 60)

| INFLUENCING FACTORS | n | % |
|---|---|---|
| Worry about spouse | 40 | 67% |
| Physical/mental changes in spouse | 28 | 47% |
| Stress of caregiving situation | 16 | 27% |
| Changes in caregiver's lifestyle | 7 | 12% |
| Age/factors related to aging | 3 | 5% |
| Physical work/demands of caregiving | 3 | 5% |
| Illness of caregiver | 5 | 8% |

NOTE: Numbers do not add up to 60 or percentages to 100 because categories are not mutually exclusive.

# APPENDIX P

## Barriers to Health Promoting Exercise

APPENDIX P

BARRIERS TO EXERCISE POST DIAGNOSIS (N = 60)

| | n | % |
|---|---|---|
| Reluctance to leave spouse | 37 | 61.7 |
| Caregiving responsibilities | 30 | 50.0 |
| Lack of time | 16 | 26.7 |
| Lack of energy | 11 | 18.3 |
| Caregiver ill health | 8 | 13.3 |
| Lack of motivation | 8 | 13.3 |
| No one with whom to exercise | 7 | 11.7 |
| Prefer other activities | 6 | 10.0 |
| No facilities/ no transportation | 2 | 3.3 |
| Lack necessary skills | 2 | 3.3 |

NOTE: Numbers do not add up to 60 or percentages to 100 because categories are not mutually exclusive.

# APPENDIX Q

## Overall Health versus Physical and Emotional Health

APPENDIX Q
N = 60

OVERALL HEALTH VS PHYSICAL AND EMOTIONAL HEALTH

| | Overall Health |
|---|---|
| **Emotional Health** | |
| Self-Rated Emotional Health | .37 (p = .004) |
| Depressive Symptomatology | -.37 (p = .003) |
| **Physical Health** | |
| Self-Rated Physical Health | .30 (p = .018) |
| Medical Diagnoses | -.30 (p = .02 |

Note. N = 60. All correlations are Spearman Rank-Order, p = two-tailed.