THE UNIVERSITY OF CALGARY

THE INFLUENCE OF IMPAIRMENT AND SOCIAL NETWORKS ON THE BURDEN EXPERIENCED BY SPOUSES OF DEMENTED PARTNERS

by

Keith Warren Carlson

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

CALGARY, ALBERTA

MAY, 1989

CKEITH WARREN CARLSON, 1989



National Library of Canada

Bibliothèque nationale du Canada

Canadian Theses Service

Service des thèses canadiennes

Ottawa, Canada K1A 0N4

`anac

The author has granted an irrevocable nonexclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of his/her thesis by any means and in any form or format, making this thesis available to interested persons.

The author retains ownership of the copyright in his/her thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without his/her permission. L'auteur a accordé une licence irrévocable et non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de sa thèse de quelque manière et sous quelque forme que ce soit pour mettre des exemplaires de cette thèse à la disposition des personnes intéressées.

L'auteur conserve la propriété du droit d'auteur qui protège sa thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

ISBN 0-315-50409-9

THE UNIVERSITY OF CALGARY FACULTY OF GRADUATE STUDIES

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, the thesis entitled "The Influence of Impairment and Social Networks on the Burden Experienced by Spouses of Demented Partners", submitted by Keith Warren Carlson in partial fulfillment of the requirements for the degree of Master of Science.

Dr. S. Robertson, Supervisor Department of Educational Psychology

Professor A. Hughsón Department of Educational Psychology

nkirkull

Dr. W. Watson Faculty of Nursing

Date May

ABSTRACT

The growing incidence of dementia combined with rising institutional costs suggests that in the future, more dementia patients will be cared for in the community. This trend has implications for caregivers due to the symptomatology of dementia. In particular, spouses of dementia patients will be affected by this trend as they are most likely to be the primary caregivers of married dementia patients.

The purpose of the study was to explore the experiences of male and female spouse caregivers in three areas. The first focus concerned how caregiver objective burden (lifestyle and relationship changes) and subjective burden (attitudes and emotional reactions toward the caregiving experience) were related to an array of variables. Selected variables included (a) the level of the patient's and caregiver's impairment, and (b) the structural and functional aspects of the caregiver's social network. The second focus of the study was a more detailed exploration of the structural and functional components of caregiver social networks. The former included network size and contact frequency. The latter encompassed types of support (socializing, tangible, cognitive, and emotional support), sources of support (spouse, family, friend, and formal "subnetworks"), and perceptions of the types and sources of support (helpfulness and upset). The third study focus addressed perceived benefits of caregiving. Underlying each study focus was an examination of caregiver gender differences.

Nineteen husbands and 19 wives who provided care to partners diagnosed with dementia were interviewed in a structured format. All caregivers were retired and resided in Alberta communities. Male and female caregivers (and their demented partners) were similar on

(iii)

demographic variables and levels of impairment. Further, there were no gender differences in levels of burden or network structural measures.

Male burden was not significantly related to patient or caregiver impairment whereas female burden was predicted by patient impairment. Female burden was not predicted by any of the social network structural or functional components. However, male subjective burden was predicted by one structural measure, family contact frequency. Male burden was also predicted by several network functional components including enacted tangible assistance, perceptions of socializing support, enacted support from family members, and perceptions of friends.

Subnetworks provided different amounts of the various types of support to caregivers. Within each subnetwork, ratings of helpfulness with each type of support tended to differ while ratings of upset with the different kinds of support tended to be similar. Examination of the individual categories of support revealed that subnetworks provided different amounts of support to caregivers. Further, ratings of helpfulness with each subnetwork tended to differ while ratings of upset with subnetworks tended to be similar. There were few gender differences pertaining to subnetworks or types of support. Expectations of subnetworks in relation to support categories were also primarily similar for male and female caregivers. Most caregivers received the majority of respite from formal subnetworks. Males appeared more likely than females to take their partners with them on outings.

Several themes emerged concerning positive aspects of giving care. Limitations of the study, suggestions for future research, and implications of the results for counselling are discussed.

(iv)

ACKNOWLEDGMENTS

The completion of this study was made possible by several people. It is with great pleasure that I formally thank them for their contributions in this endeavor.

I would like to express my deepest gratitude to the 38 caregivers who consented to be interviewed about their experiences. Many of them were a source of inspiration in their demonstration of love for their partners under difficult circumstances.

I would also like to thank the individuals and agencies that initially contacted the caregivers about their willingness to participate in the study. Included in this group are Gina Rohs and Dr. Parhad (University of Calgary Dementia Clinic), Jeanne Bentley and Kjell Denhoff (Alzheimer Society of Calgary), Linda Rowswell and Marsha Vikse (Camrose Rosehaven Care Centre), Gladys Procyshen and her staff (Wetoka Health Unit), Terri Johnson (Wetaskiwin Day Care Program), Mame Hulowski and Judy Brooker (Calgary Home Domestics and Homemaker Services Ltd.), Marie Burner and Joanne Van Boeyen (Cross Bow Day Hospital), Vicki Engels and Janice Cowley (V.O.N.), Dr. De Vries (Calgary psychiatrist), Sharon Tell and colleagues (Home Care - Sherwood Park), Linda Boychuk (Home Care - Foothills), Annette McCullough and colleagues (Kerby Centre), Duncan McDonald, Cully Wilson, and staff (Alzheimer Society of Edmonton), and Bob Johnstone (Alzheimer Society of Red Deer). All provided encouragement and expressed enthusiasm and interest in the project.

I would like to thank Professor Anne Hughson and Dr. Wendy Watson for the time and effort they spent in reading this study. Their insightful questions and comments were very helpful.

(v)

A great deal of this work is related to social networks. In completing this study, I have gained a much deeper sense of appreciation for my own social network. I would like to thank Dr. Sharon Robertson for her contributions as my supervisor. Her guidance in writing this thesis was invaluable as were her timely expressions of emotional support.

Several friends maintained an interest in my work and demonstrated liberal amounts of patience and understanding throughout the process. I look forward to the resumption of more "normal" relationships with Al and Judy, Greg and Sharon, and Bob in particular. Thank you for your support.

I would like to express heartfelt thanks to my family for their support which I deeply felt despite the geographical distances involved. My parents and parents-in-law in particular provided emotional and tangible support in many different ways. Underlying these expressions of support was a belief in me that was especially helpful. I also offer my deep thanks to Roger and Cheryl, David and Jane, Greg and Shelley, Carl and Bev, Fred and Linda, and my Uncle Norman and Aunt Carol. All provided a sympathetic ear and expressed continual interest that uplifted me.

Finally, I wish to thank my wife Diane who made many sacrifices along the way. She not only typed the manuscript after work hours but lovingly provided each type of support described in this study. I love you and look forward to spending more time together as a family.

(vi)

TABLE OF CONTENTS

Pa	ge
LETTER OF APPROVAL	ii)
ABSTRACT	ii)
ACKNOWLEDGMENTS	(v)
TABLE OF CONTENTS	ii)
LIST OF TABLES	ii)
LIST OF FIGURES	ii)
CHAPTER ONE: INTRODUCTION	1
Purpose of the Study	7
CHAPTER TWO: REVIEW OF THE LITERATURE	8
Dementia	8
Physiology of SDAT and MID	9
Etiology of SDAT and MID \ldots \ldots \ldots \ldots \ldots \ldots	10
Symptoms of SDAT and MID	11
Diagnosis and Incidence of Dementia	14
Summary	16
Caregivers and Their Experiences	17
Caregivers of the Frail Elderly	17
The Experience of Providing Care to the Frail Elderly	19
Caregivers of Dementia Patients	21
Physiological costs	22
Well-being	22
Depression, other affect, and lifestyle changes	23
Burden	24
Impairment and the Experience of Giving Care to	
Demented Partners	26
· · · · · · · · · · · · · · · · · · ·	

Summary	29
Support for the Caregiver	30
Social Embeddedness	31
Network size	33
Contact frequency	33
Enacted Support	35
Respite	39
Perceived Social Support	41
Positive and negative interactions	42
Caregiver perceptions of types of support	44
Caregiver perceptions of subnetworks	46
Caregiver's expectations of subnetworks	47
Summary	48
Positive Aspects of Providing Care	49
Summary	50
Research Questions	55
CHAPTER THREE: METHOD	<u>~</u> 60
Sample	60
Research Instruments	63
Background Information Questionnaire	63
Sickness Impact Profile	64
Objective Burden	66
Subjective Burden	67
Social Network List	68
Enacted and Perceived Support Form	69
Helpfulness Ratings and Expectations of Enacted	
Support Questionnaire	73
(viii)	

.

Respite Questionnaire	73
Perceived Benefits of Caregiving Questionnaire	73
Procedure	74
First interview	74
Second interview	75
Research Design	76
Data Analysis	77
Summary	80
CHAPTER FOUR: RESULTS	81
Preliminary Analysis of Demographic Data	81
Residence	82
Dementia Diagnosis	83
Gender	83
Question Results	83
Relationships Between Burden and Selected Variables	84
Caregiver gender	84
Impairment	84
Embeddedness	86
Enacted support	87
Respite	88
Perceptions of enacted support	90
Sources of support	91
Perceptions of support sources	91
Post-hoc Correlations	93
Caregiver Social Network Descriptions	93
Embeddedness	94
Enacted support category and perceived support	

(ix)

.

category differences within subnetworks	95
Subnetwork enacted support and perceived support	
differences within support categories	104
Respite sources	113
Support category perceived helpfulness and	
caregiver expectations	115
Caregiver respite activities	119
Positive Perceptions of the Caregiving Experience	120
Positive caregiving experiences	120
Home care vs. institutionalization	121
Summary of Results	122
CHAPTER FIVE: DISCUSSION	124
Discussion of Results	124
Relationships Between Burden and Selected Variables	124
Caregiver gender	124
Impairment	125
Embeddedness	130
Enacted support	131
Respite	133
Perceptions of enacted support	133
Sources of support	136
Perceptions of subnetworks	137
Caregiver Social Network Descriptions	137
Embeddedness	138
Enacted support category and perceived support	
category differences within subnetworks	139
Subnetwork enacted support and perceived support	

(:x)

differences within support categories	141
Respite sources	143
Support category perceived helpfulness and	
caregiver expectations	145
Caregiver respite activities	148
Positive Perceptions of the Caregiving Experience	149
Positive caregiving experiences	150
Home care vs. institutionalization	150
Study Limitations and Suggestions for Future Research	151
Counselling Implications	156
Caregiver Burden	156
Social Networks	159
Perceived Benefits	161
REFERENCES	162
APPENDICES	168
Appendix A - Background Information Questionnaire	169
Appendix B - Social Network List	170
Appendix C - Enacted and Perceived Support Form	174
Appendix D - Helpfulness Ratings and Expectations of	
Enacted Support Questionnaire	178
Appendix E - Respite Questionnaire	180
Appendix F - Perceived Benefits of Caregiving	,
Questionnaire	181

LIST OF TABLES

		Page
Table 1:	Characteristics of Caregivers (CG) and their	
	Demented Partners (DP)	62
Table 2:	Correlations Between Caregiver (CG) Burden Scores	
	and Impairment and Network Structural Measures	85
Table 3:	Correlations Between Caregiver Burden and Enacted	
	Types of Support and Perceptions of Support	
	Categories	89
Table 4:	Correlations Between Caregiver Burden and Sources	
	of Support and Perception of Support Sources	92
Table 5:	Mean Enacted Type of Support Received Within	
	Subnetworks	96
Table 6:	Mean Subnetwork Enacted Support Within Support	
	Categories	106
Table 7:	Caregiver Perceptions of the Helpfulness of Support	
	Categories	116
Table 8:	Caregiver Expectations of Enacted Support from	
	Subnetworks	117
Table 9:	Caregiver Subnetwork Expectations Within Support	
	Categories	118

(xii)

LIST OF FIGURES

		Page
Figure 1:	Gender-perception-support category interaction,	
	gender-perception interaction and perception-	
	support category interaction within the	
	spouse subnetwork	99
Figure 2:	Perception-support category interaction within the	
	family subnetwork	101
Figure 3:	Perception-support category interaction within the	
	friend subnetwork	103
Figure 4:	Perception-support category interaction within the	
	formal subnetwork	105
Figure 5:	Gender-perception-subnetwork interaction and	x
	perception-subnetwork interaction within	
	socializing support	109
Figure 6:	Perception-subnetwork interaction within tangible	
	assistance	111
Figure 7:	Perception-subnetwork interaction within cognitive	
	assistance	112
Figure 8:	Perception-subnetwork interaction within emotional	
	assistance	114

(xiii)

CHAPTER 1

INTRODUCTION

The Canadian population is aging with more Canadians reaching older ages than ever before. This trend is projected to accelerate and continue well into the next century (Statistics Canada, 1985). Accompanying our aging society is an increase in the incidence of dementia. Population projections suggest that many more Canadians will be affected by this irreversible brain disease in the future because dementia primarily afflicts people over the age of 60. In both of the two most common forms of dementia, Alzheimer's disease and multi-infarct, the afflicted person usually exhibits cognitive losses and changes in personality, speech, behavior, and basic motor skills. These losses occur cumulatively over a period of time that can extend over several years. Given the nature and progression of this disease, the impact of dementia is not restricted to the victim alone. The lives of people surrounding the victim are also profoundly affected.

Most people with dementia reside in the community (Ory et al., 1985). The increased prevalence of dementia combined with escalating institutional costs suggests that in the future, even more dementia patients will reside in their homes. Family support is a critical factor in enabling demented persons to remain in the community (Brody, Poulshock, & Masciocchi, 1978; Ory et al.). Consequently, researchers have begun to examine how caring for a loved one with dementia affects the family. Unfortunately, spouses, children, other relatives, friends, and neighbors (if applicable) are often undifferentiated in data analyses obscuring possible differences in their experiences (Cantor, 1983). Cantor stated further that without isolating demographic variables such as the caregiver-dementia patient relationship, intervention strategies are difficult to formulate.

Evidence suggests that spouses are most likely to provide care for elderly frail married persons (Cantor, 1983; Johnson, 1983; Shanas, 1979a, 1979b). Despite this likelihood, much of the caregiving literature has focused on the experiences of daughter caregivers rather than spouses (Cantor, 1983; Fengler & Goodrich, 1979; Marcus & Jaeger, 1984). It would seem unlikely that the experiences of daughters would be similar to those of spouse caregivers. Indeed, George and Gwyther (1986) found that spouses reported more stress symptoms, greater use of psychotropic medications, and lower levels of life satisfaction than offspring and other kin caregivers. Therefore, spouses warrant further study to better understand their experiences. More specifically, further work is needed to explore possible differences between caregiving husbands and wives (Marcus & Jaeger).

As indicated previously, family support is a crucial element in enabling demented persons to remain at home. Yet the notion of family support is misleading in that there is a tendency for primary caregivers (regardless of relationship) to isolate themselves from other people. This tendency leads to a greater possibility of caregivers becoming more stressed and over-burdened (Johnson, 1983) which may in turn adversely affect the caregiver's quality of care.

Several authors have stated that the potential benefits of home care may be offset by potentially severe psychological costs to caregivers (Keating & Gilewich, 1985; Morycz, 1980; Novak & Guest, 1985; Zarit, Reever, & Bach-Peterson, 1980). One common description of the "costs" associated with care provision is the concept of burden. Unfortunately, caregiver burden has been defined in numerous ways in the literature and has typically been viewed unidimensionally (Poulshock & Deimling, 1984). Montgomery, Gonyea, and Hooyman's (1985) conceptions of objective burden (lifestyle and relationship changes) and subjective burden (attitudes and emotional reactions toward the caregiving experience) are reflective of a multidimensional view of burden that provides more detailed information than unidimensional burden measures.

Poulshock and Deimling (1984) emphasized the importance of determining the patient's impairment level in order to better understand caregiver experiences. Eagles, Craig, et al. (1987) reported that caregiver (relationships not differentiated) stress escalated with increased dementia severity. However, the demented patient's mental status has been reported by other researchers to have no major effect on spouse caregiver burden assessed on unidimensional measures (Fitting, Rabins, Lucas, & Eastham, 1986; Scott, Roberto, & Hutton, 1986). Therefore, the results are inconclusive in determining if impairment influences caregiver burden.

Patient impairment has usually been assessed by isolating the disease from other functional deficits that may be present. It is important to note that most people with dementia are elderly and may be afflicted with other ailments that are unrelated to dementia but nevertheless affect daily activities. Further, the elderly caregiver may also be afflicted with health problems that interfere with daily activities yet the caregiver's functional status is rarely addressed in the literature. It would be helpful to examine the functional capabilities of both dementia patients and caregivers in relation to objective and subjective burden.

In addition to impairment, another factor that may influence objective and subjective burden is the caregiver's social network. People are embedded in a social network (Mitchell & Trickett, 1980) which can include various "subnetworks" (e.g., family, friend, and formal). Another subnetwork, the demented partner, has usually been excluded in network analysis although it seems possible that he or she may be able to assist the caregiver in some way(s). Unfortunately, the typically been viewed as a singular entity without isolating the potentially unique contributions of each subnetwork.

In examining networks, many researchers have examined quantitative structural properties such as network size and contact frequency. Barrera (1986) referred to these properties as measures of a person's network embeddedness. Zarit et al. (1980) found that the frequency of contact was negatively related to a unidimensional burden measure of dementia patient caregivers (relationships were not differentiated). Subnetwork embeddedness measures were not examined by Zarit et al. nor have they been examined by other researchers. Differentiating subnetworks could provide more specific information pertaining to their influence on caregiver objective and subjective burden.

Structural properties describe the framework of networks but yield little information regarding qualitative aspects of network interactions. Thoits (1982) expressed concern that network qualitative components such as the types of support that caregivers receive have been largely ignored. Enacted support (Barrera, 1986) pertains to the types of support that are received by recipients and most commonly includes socializing, tangible, cognitive, and emotional support (Cohen & Wills, 1985). The possibility that any of these support categories

may be related to caregiver burden measures has not been explored.

c

A specific example of tangible assistance, respite, merits further exploration. Lack of relief for caregivers has been identified as a major source of distress (Rabins, Mace, & Lucas, 1982). Scott et al. (1986) reported that a brief respite was particularly appreciated by caregivers of Alzheimer's patients. However, Lundervold and Lewin (1987) cautioned that respite may not reduce burden although their small sample and limited respite availability reduce generalizability. Nevertheless, it appears that the number of respite hours should be considered in relation to caregiver burden. Examining the sources of respite may yield further information pertaining to the experiences of male and female caregivers.

In addition to enacted support, a second qualitative aspect of network interaction is the recipient's perception of support (Barrera, 1986). Unfortunately, interactions with social network members have usually been interpreted to be positive by researchers. Indeed, social support has often been used synonomously with network interaction. Few researchers have examined the negative aspects of interactions. Cohen and Wills (1985) concluded that such aspects warrant further consideration as more variance in health and well-being appears to be explained by negative social interactions than by positive interactions. Perceptions of support have not been explored in relation to caregiver burden measures in a sample of dementia patient caregivers.

Fiore, Becker, and Coppel (1983) reported that caregiver depression was related positively with perceived upset with several types of support in a sample of spouses of partners with Alzheimer's disease. Conversely, depression was not related with perceived helpfulness in any

support category. Pagel, Erdly, and Becker (1987) reported similar results in a later study. However, perceived upset in these studies was operationally defined as negative interactions and/or unmet expectations. Greater clarification of this concept would be possible by excluding negative interactions in the definition of upset.

As indicated above, caregivers have described support categories in previous studies according to perceptions of helpfulness and upset. In effect, analyses have been conducted by collapsing subnetworks. Helpfulness and upset perceptions of subnetworks could be similarly examined by collapsing support categories.

The types and sources of support may be explored in combination with each other. Each subnetwork could be examined individually to determine if there are enacted support category differences. For example, perhaps friends give more tangible assistance than cognitive guidance to caregivers. Similarly, each support category could be examined individually to determine if there are subnetwork differences. For example, perhaps caregivers receive different amounts of tangible assistance from family and formal subnetworks. In a similar vein, it is feasible to explore potential differences in caregiver perceptions of support categories within each subnetwork and further, to explore possible differences in perceptions of subnetworks within each type of support. Moreover, all of these differences could be examined in conjunction with an exploration of caregiver gender differences. Caregiver social networks have not been examined in this way before.

The caregiver's expectations could be explored in relation to the types of support they receive and the sources of support. More specifically, caregivers could identify what type of support they most

expect from each subnetwork. Caregivers could also identify which subnetwork they most expect to provide each type of support. These exploratory questions can provide information concerning ways in which network members are expected to be involved in the caregiving process.

Almost all of the literature pertaining to caregivers of demented persons has focused on the costs borne by caregivers. While caregiving difficulties are numerous, little is known about possible beneficial aspects of providing care. Some families in Chenoweth and Spencer's (1986) survey stated that the experience had drawn the family closer together. Exploration of positive aspects of caregiving may be useful in assisting caregivers to grow as a result of their experience.

Purpose of the Study

In summary, the purpose of the study was to explore the experiences of spouse caregivers who provide home care for their demented partners. Three focuses were identified in order to provide information that could assist health workers in their efforts to help spouse caregivers. The first focus centered on objective and subjective burden and their relationships with impairment and social network measures. The second focus of the study was to provide a more detailed description of caregiver social networks in terms of their structural and functional properties. The third focus was to explore the benefits that caregivers may experience through giving care to their spouses. Male and female caregivers were interviewed to determine if there were gender differences within each of the focuses.

CHAPTER TWO

REVIEW OF THE LITERATURE

Dementia is a brain disease that is afflicting increasing numbers of elderly Canadians. Moreover, dementia's symptomatology results in an even greater number of persons who are affected as the profound cognitive, personality, and behavioral changes resulting from dementia have a great impact on those who provide care to demented persons. The focus of this chapter is on these caregivers. In order to better understand their situation, the nature of dementia is described. Following this description, the experiences of caregivers are explored with particular emphasis on spouse caregivers. Finally, variables that influence the caregiver's experience are detailed with the influence of the caregiver's social network being examined in greater detail than other variables.

<u>Dementia</u>

According to the third edition of the <u>Diagnostic and Statistical</u> <u>Manual of Mental Disorders</u> (DSM-III), dementia is a brain disease in which there is a loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning (American Psychiatric Association, 1980). People afflicted with dementia are more likely to be elderly than middle-aged or younger (Robertson & Reisner, 1982) but dementia is not an inevitable concomitant of old age (Schneck, Reisberg, & Ferris, 1982). Several types of dementia have been identified including Pick's disease and Creutzfeldt-Jakob disease which are rarely diagnosed. Senile dementia of the Alzheimer's type (SDAT) and multi-infarct dementia (MID) are much more frequently diagnosed with SDAT being the most common. Given their far greater incidence

rates, only the physiologies of SDAT and MID are described here followed, by descriptions of their etiologies and symptoms. Finally, some of the difficulties associated with diagnosing dementia and determining the incidence of dementia are presented.

Physiology of SDAT and MID

SDAT is characterized by three main physiological changes in the brain: neurofibrillary tangles, senile plaques, and granulovacuolar bodies (Kent, 1983). Neurofibrillary tangles are found predominantly in the cerebral cortex and especially in the posterior hippocampus. These dense bundles of fibers are composed of twisted linear structures. The second major physiological change associated with SDAT is the presence of senile plaques found predominantly in the cerebral cortex but also in the basal ganglia, brain stem, and cerebellum. Senile plaques contain amyloid surrounded by abnormal neurites consisting of axonal and dendritic processes, paired helical filaments, lamellar lysosomes and degenerating mitochondria. The third most frequently cited change in the SDAT brain is the presence of granulovacuolar bodies found mainly in the hippocampus. Granulovacuolar bodies are nonfunctional cellular cavities filled with granules.

In their literature overview, Schneck et al. (1982) found evidence that brain atrophy was common but not always present in people with SDAT. In his review, Kent (1983) reported that there was a shrinkage and swelling of neurons; particularly those found in the cholinergic system. This system plays a key role in memory transmission as well as in other cognitive processes. Neurons in the cholinergic system release and control acetylcholine which is a brain neurotransmitter. Acetylcholine carries messages from one brain cell to another and is in

turn regulated by an enzyme (choline acetyltransferase) that stimulates acetylcholine's production and another enzyme that breaks it down (acetylcholinesterase). While the levels of both enzymes normally decrease with age, Schneck et al. cited studies indicating that SDAT patients had significantly lower levels of these enzymes than control subjects.

MID is primarily differentiated from SDAT by the presence of ischemic lesions which lead to cerebral softening. In SDAT, there is little or no ischemia present (Kent, 1983). Other differences include the more abrupt onset of MID and stepwise cognitive deterioration in MID patients which is related to the multiple cerebral infarctions (Cummings, 1987). This series of small strokes can affect some intellectual functions while leaving others intact depending on the affected area of the brain.

Etiology of SDAT and MID

Kent (1983) and Schneck et al. (1982) outlined several hypotheses that have been advanced to explain the etiology of SDAT. They include slow-acting viruses, autoimmune disturbances, elevated levels of aluminum, specific genotypes or chromosome defects, and accelerated forms of aging. There is some evidence to support each of these hypotheses but more research is needed to better understand the origins of SDAT. No incontrovertable origin of this disease has yet been identified.

As indicated previously, MID is a result of multiple cerebral infarctions. Vascular occlusion may result from a blood-clot formation, air-bubble, or some other form of obstruction (Cummings, 1987). Atherosclerosis, sustained hypertension, diabetes mellitus, inflammatory

and infectious arteritic conditions, cardiac arrhythmias, valvular disease, and prolonged hypotension producing tissue ischemia are some health conditions that may lead to MID. These diseases tend to affect different components of the vascular system. For example, atherosclerosis primarily affects large cerebral arteries; hypertension and diabetes affect small arteries and arterioles; inflammatory conditions primarily involve smaller arterioles and capillaries. Therefore, the underlying health problem can determine which blood vessels are affected which, in turn, influences the cerebral infarction location.

Unlike SDAT, some preventative steps may reduce the likelihood of developing MID. Treatment of hypertension, controlling diabetes, lowering blood lipids and triglycerids, weight control, and not smoking diminish the risk of MID (Cummings, 1987).

Other differences exist between SDAT and MID. The latter is less common in people over the age of 85 (Cummings, 1987). MID occurs more frequently in younger ages (40-60) and more frequently in males (Schneck et al., 1982). The evidence is less clear concerning SDAT gender differences with the issue largely unresolved (Cummings; Ineichen, 1987; Schneck et al.).

Symptoms of SDAT and MID

Some researchers have described phases in the progression of SDAT. The first phase was called "forgetfulness" by Schneck et al. (1982). The individual (and occasionally his/her spouse) notices that he/she has a tendency to forget names, appointments, where things are placed, etc. This forgetfulness may be accompanied by anxiety. Gwyther and Matteson (1983) emphasized the subtlety of the changes as family members may not

recognize that anything is wrong in this initial stage. Most family members who responded to a survey by Chenoweth and Spencer (1986) reported that initial symptoms such as memory loss and disorientation seemed isolated and unexplainable. However, the increased number of episodes gradually led to a picture that could not be ignored. Marples (1986) reported that if family members were not around the demented person for extended periods of time, they may have had difficulty differentiating mild forgetfulness, from severe memory deficits. Mildly demented persons are sometimes able to portray themselves "normally" during brief periods of time, thereby appearing to function better than they actually do. Talking on a superficial level can also decrease detection of gross memory limitations. A measure of denial by relatives who want the demented person to remain the same further complicates SDAT identification. Gwyther and Matteson (1983) added behavioral and personality changes to memory loss as indicative of their first stage which can last from two to four years.

Gwyther and Matteson's (1983) "middle" stage may last for several years. There is progressive memory loss, aphasia, agnosia, apraxia, wandering, and repetitiveness. It is at this time when diagnoses are most frequently made as the family begins to find home management of the patient difficult. Schneck et al. (1982) described this phase as "confusional". They detailed the impairment in cognitive functioning ability, especially concerning recent events. Memory of the more distant past may remain relatively intact during this phase. While orientation and concentration are likely affected, the SDAT patient's vocabulary may remain largely intact with some difficulty in recalling words. Until they learned more about the disease, respondents to Chenoweth and Spencer's (1986) survey believed that their demented relative had more control over his/her behavior than was displayed.

It is well documented that severely demented patients have numerous memory deficits but preliminary work by Sainsbury and Coristine (1986) examined what memory functions remain. Their subjects were unable to identify pictures of close relatives. To determine if any recognition still remained, subjects were asked which picture they liked of four presented to them. One of the four pictures was a snapshot of a close relative. Subjects most frequently chose the picture of their relative. The results suggested that while "conscious recognition" memory may be impaired, "affective" memory (named because subjects were asked who they liked) may remain intact even in severe dementia. This result can offer hope to visitors who are distressed when the demented person does not recall their name.

The third and final stage is called the terminal stage by Gwyther and Matteson (1983). By this time, SDAT patients do not eat, are emaciated, unable to communicate, and may be incontinent and/or have grand mal seizures. Schneck et al. (1982) described the final stage ("dementia" phase) as being characterized by severe disorientation and confusion. There is often motor restlessness and behavioral problems. Psychotic symptoms such as delusions, hallucinations, and severe agitation are likely to be present as well.

The changes listed above are the most frequently cited. There may be other symptoms but it is unlikely that all of the physiological and behavioral disturbances listed above will occur in every SDAT case. The duration of each phase can also vary a great deal but the downward progression usually takes several years. The last phase is usually

shorter than the others but some patients are able to live for a relatively long time if they are cared for in a supportive environment (Schneck et al., 1982).

The symptoms of MID are varied depending on the number, location, and extent of cerebral infarctions (Cummings, 1987). Consequently, some symptoms (e.g., aphasia and apraxia) parallel SDAT. Hallucinations and/or psychosis with persecutory delusions may occur in both MID and SDAT patients. Depression is more common in MID than in SDAT patients and the individual's personality is usually better preserved in MID patients (Schneck et al., 1982). In general, late stage SDAT produces more obvious deficits in nearly all functional domains.

Diagnosis and Incidence of Dementia

One of the major obstacles in diagnosing dementia (especially SDAT) is the absence of a test that will confirm the diagnosis with accuracy. At the present time, confirmation of an SDAT diagnosis is possible only with an autopsy. Another diagnostic obstacle is symptom similarity shared with many other conditions and diseases. Schneck et al. (1982) reported that several disorders can also cause cognitive deterioration if chronic and untreated. These disorders included, "1) toxic conditions (e.g., barbituate intoxication, alcohol abuse), 2) nutritional disorders (e.g., chronic malabsorption syndrome, vitamin B₁₂ deficiency), 3) infections (e.g., tuberculosis, encephalitis), 4) endocrine disorders (e.g., slowly growing cerebral tumors, normal-pressure hydrocephalus)" (p.167).

The correct diagnosis has important ramifications for treatment because while most of the above disorders can be remedied, dementia is

currently untreatable. Consequently, misdiagnosing a person with dementia is likely to result in few (if any) attempts to treat the actual disorder.

Diagnostic difficulty combined with the relatively low awareness of geriatric health problems had led to great difficulty in ascertaining the incidence of dementia. In his review, Ineichen (1987) highlighted five additional tabulation difficulties:

1. There is an absence of universally agreed upon criteria with particular difficulties in assessing "mild" cases.

2. Since dementia is age-related, dementia prevalence is affected by demographic changes.

3. Many studies contain methodological problems in that (a) most samples are tapped from health services thereby excluding large numbers outside the service net, (b) services are varied leading to difficulties in making comparisons between them, and (c) most studies have relatively small samples and some have high refusal rates.

4. A number of sociocultural factors including nutrition changes, level of education, family size and cohesiveness, and living arrangements may influence the extent of dementia.

5. There is uncertainty as to how long dementia patients survive.

Ineichen (1987) surveyed dementia prevalence studies in countries including Iceland, USSR, USA, West Germany, Scotland, England, New Zealand, Japan, Sweden, and Denmark. Direct comparisons between countries were impossible because of the varied samples but the overall rates of dementia (all levels of severity) ranged from 2.5% to 24.6% of the samples. Rates of severe dementia ranged from 0.6% to 7.5%. U.K. studies applying rigorous identification criteria indicated a mean dementia prevalence rate of 2.83% of all people over 65.

There are no statistics pertaining to the number of Canadians with dementia (Jeans, Helmes, Merskey, Robertson, & Rand, 1987). However, Jeans et al. calculated the frequency of dementia in Ontario institutions and extrapolated to the Canadian elderly population. Non-Canadian studies have found ratios of the number of demented patients outside institutions to the number of demented patients within institutions (noninstitutionalized: institutionalized) ranging from 1:1 to 6:1. Using a conservative ratio of 2:1, Jeans et al. calculated the prevalence of dementia. They arrived at a figure of 222,324 Canadians or 9.4% of the total Canadian population over 65 as having some form of dementia. At best, this is a "cautious estimate" as a more accurate Canadian incidence figure requires an extensive epidemiological survey.

Although exact figures are not available, it is nevertheless evident that a large number of elderly Canadians are afflicted with dementia. Moreover, since dementia is associated with aging and the number of elderly Canadians is projected to rapidly increase (Statistics Canada, 1985), it seems apparent that many more Canadians will develop dementia in the future. Consequently, it becomes imperative to study the effects of this disease to prepare for present and future needs.

Summary

The two most common types of dementia, SDAT and MID, are characterized by different physiologies and etiologies but similar symptoms. SDAT and MID cause cognitive and communication deficits as well as behavioral, emotional, physiological, and social dysfunction. While dementia is not an inevitable component of the aging process, it is more prevalent in the elderly population. This prevalence, combined

with a rapidly growing elderly population, suggests that unless a cure is discovered, more Canadians will be affected by dementia in the future.

Caregivers and Their Experiences

It is evident that dementia leads to profound changes in the afflicted person's functional status. Given the nature of these changes described above, it is not surprising that people close to the patient are also affected. The experiences of caregivers have only recently been examined by researchers. Given this dearth of information, research in this area is best reviewed in the larger context of the literature pertaining to caregivers of frail elderly patients. This literature is reviewed here with particular emphasis given to spouse caregivers. Following this overview, the effects of providing care to a demented spouse on husband and wife caregivers are examined.

Caregivers of the Frail Elderly

A variety of diseases can afflict elderly people but only around 9% of Alberta seniors reside in auxiliary hospitals or nursing homes ("Long Term," 1988). Another 6% receive support services from home care at far less cost than institutionalization. Costs for Alberta auxiliary hospitals, nursing homes, and home care for one case per year are \$39,094.00, \$17,120.00 and \$2,202.00 respectively. The total costs involved in providing institutional care to the frail elderly are high and may rise dramatically with projected increases in the elderly population. Consequently, home care is an economically attractive alternative. The economic benefits of home care coupled with the desires of the majority of seniors to remain in their own homes ("Long Term") make this alternative very attractive. However, the bulk of care in the home usually rests upon the family's shoulders (Brody et al., 1978) as home care services are generally supportive in nature and are not intended to provide full-time care responsibility. Given the attractions of home care and a growing elderly population, many more people may be involved in the provision of home care in the future. It seems important therefore to examine how they presently are affected and will be affected by these developments.

It has been well documented that family support is a critical factor in enabling elderly persons with serious physical and/or mental impairments to remain in the community (Bergmann, Foster, Justice, & Matthews, 1978; Brody et al., 1978; Johnson, 1983; Ory et al., 1985; Shanas, 1979a; 1979b). However, "family support" has been broadly defined with few researchers differentiating caregiver relationships to the patient. The homogenization of demographic variables such as the patient-caregiver relationship and the sex, age, health, and work status of caregivers obscures differences among caregiver groups and the stressors each may be experiencing (Cantor, 1983). Cantor further stated that without isolating and examining these variables, intervention modalities are difficult to formulate.

When researchers have differentiated caregivers according to some of the variables listed above, a few trends have emerged. Shanas (1979b) conducted a large American survey of noninstitutionalized people over 65. Included in her survey was a large number of housebound and bedfast persons. She identified a phenomenon she called the "principle of substitution" describing a serial order of family primary caregivers. In general, the spouse most frequently provided care for the frail elder but if she/he was unable or unavailable to assist, offspring (usually a

daughter) provided the necessary care. Additional helpers included other relatives, non-relatives, and paid help. Johnson (1983) observed this phenomenon in her sample of post-hospitalized patients as well.

Stoller and Earl (1983) interviewed a large random sample of noninstitutionalized elderly people and reported that spouses were the major source of support for married respondents who were currently impaired or who had been impaired in the past. This evidence, combined with the results from Johnson (1983) and Shanas (1979b) suggests that spouses are most likely to be the caregivers when disease and disability affects a married elderly person. Despite this likelihood, spouse caregivers have generally been overlooked by researchers (Cantor, 1983; Fengler & Goodrich, 1979; Marcus & Jaeger, 1984) while daughters of frail elderly parents have received much more attention from researchers.

The Experience of Providing Care to the Frail Elderly

Shanas' (1979b) principle of substitution is a phenomenon that has far-reaching implications as outlined by Johnson (1983):

If only one family member instead of a small primary group is available to the patient at any one time, caregiving is not a function of the family as an operational unit whose members cooperate and interchange the caregiving role. Instead, the caregiving unit refers to a dyad comprised of the donor and the recipient of support. Presumably, when only one individual provides a large portion of the care to a seriously impaired relative, the caregiver is subject to more stress and runs the risk of becoming overburdened (p.377).

Focusing on the primary caregiver is important because his or her

ability to handle the caregiving demands influences the quality of care that is given. In addition, more knowledge about caregivers will assist the helping professions in providing effective interventions enabling the patient to remain noninstitutionalized and with less caregiver stress. As indicated in the previous section, less is known about spouse caregivers than daughter caregivers. The experiences of spouses have rarely been isolated from other caregivers in the literature.

There is limited evidence suggesting that spouses may experience more difficulties than other caregivers and may also provide care longer for more severely impaired loved ones than other caregivers. Cantor (1983) found that spouses were at greater risk for strain (physical, financial, and emotional dimensions) than children, other relatives, and friends/neighbors in her sample of New York poor and frail elderly persons and their caregivers. Johnson (1983) observed that some spouse caregivers of post-hospitalized patients were actually more unhealthy than their care recipients. Still, Johnson found the risks of institutionalization were more closely related to marital status than to the number and proximity of children. Spouses were less likely to institutionalize patients indicating that severe impairments in patients were more tolerable to spouses than to children.

Fengler and Goodrich (1979) found that most wives of disabled husbands (predominantly cardiac disabilities) reported isolation, loneliness, economic hardships, and role overload. All wives had at least one chronic health problem and there were more similarities than differences between wives and husbands in overall disabling health conditions. Many of the wives were found to need help and support as much as their disabled husbands. Consequently, these wives were called

"hidden patients".

When spouse caregivers have been isolated in the literature, the caregiver's gender has been rarely identified (Aronson, 1985). Therefore, little is known about possible differences between husband and wife caregivers. Marcus and Jaeger (1984) sampled spouses of "physically ill" patients (the specific nature of these illnesses was not described). They reported that wives experienced greater burden than husbands did in providing care for their spouses. Johnson (1983) similarly observed that wives experienced more strain than husbands in caring for post-hospitalized spouses. These studies are not directly comparable as the types and severity of illnesses were not adequately described but they tentatively suggest that wives may experience more difficulties than husbands in providing care to a frail spouse. Caregivers of Dementia Patients

As indicated earlier, dementia patients are more likely to reside in the community than in institutions (Jeans et al., 1987). If the goal is to enable them to remain in the community, it would be helpful to be informed about the experiences of those people most likely to provide care - the spouses. However, the research pertaining to caregivers of dementia patients in general mirrors the trends outlined in the above section. That is, spouses of dementia patients have generally been ignored by researchers despite the greater likelihood that they are the primary caregivers. Further, more research is needed to examine differences between husband and wife caregivers as less attention has been given to male caregivers (Zarit, Todd, & Zarit, 1986). Possible differences in their experiences may indicate that different interventions may be appropriate in enabling the demented spouse to remain in the community.

While it is recognized that home care is beneficial for both the caregiver and the patient, some researchers have begun to examine the effects of caregiving on the caregiver. In some cases, the benefits of home care may be overshadowed by potentially severe "costs" to the primary caregiver (Keating & Gilewich, 1985; Morycz, 1980; Novak & Guest, 1985; Zarit et al., 1980). "Costs" have been examined by different measures including physiological, well-being, depression and other affect, lifestyle changes, and burden. Each of these caregiving costs is reviewed below. Whenever applicable, spouse gender differences are highlighted.

<u>Physiological costs</u>. Kiecolt-Glaser et al. (1987) compared caregivers of dementia patients (primarily spouses) to a sociodemographically matched group of non-caregivers. Immunological data indicated that the caregiver's immune system functioned more poorly than the matched group. These immunological differences were not attributable to smoking, nutrition, alcohol use, or caffeine intake.

<u>Well-being</u>. George and Gwyther (1986) studied a large sample (n = 510) of caregivers on the basis of their relationship to institutionalized and noninstitutionalized demented adults. Compared to adult children and other kin, spouses visited doctors more frequently and rated their health as being poorer. In addition, spouses exhibited lower levels of well-being as evidenced by reporting more stress symptoms, greater use of psychotropic medications, and lower levels of affect balance and life satisfaction. These differences between caregivers existed even after controlling for age. Furthermore, resident caregivers (regardless of relationship to patient) were more
likely to report the above symptoms than non-resident caregivers. Unfortunately, gender differences and comparisons between resident and non-resident spouses were not addressed.

Depression, other affect, and lifestyle changes. Goldman and Luchins (1984) presented three case reports of spouses with demented partners. Each spouse had developed depression requiring psychiatric hospitalization. The authors thought that the spouse's awareness of their partner's dementia and the increasing burden of care were the major precipitants of their depression. In addition to reported depression, Rabins et al. (1982) reported that a majority of their sample of caregivers (spouses were not differentiated from adult children, other relatives, friends, or paid caretakers) of dementia patients also reported feeling angry or tired most of the time. About half of the caregivers felt they had little or no time to themselves or had given up friends, hobbies, or jobs. Some also reported that they worried that they would become ill, had difficulty assuming new roles and responsibilities, and felt guilt. In a comparison between caregivers of dementia patients and matched non-caregivers, Kiecolt-Glaser et al. (1987) reported that the former were significantly more depressed than the latter. In addition, dementia patient caregivers had significantly lower general life satisfaction and poorer mental health than the comparison group.

Just over half (41% wives and 14% husbands) of the respondents to a mailed questionnaire were spouses in a Minnesota survey conducted by Chenoweth and Spencer (1986). Unfortunately, the spouses were not differentiated from other caregivers so the results must be interpreted cautiously in relation to spouses. In response to a question identifying major problems faced in giving care, 25% mentioned problems concerning the need for constant physical care and/or supervision. Almost as many (23%) reported strain on their physical and emotional health. A majority (60%) stated that their relative's dementia affected their relationships with other people. Examples were marked by friends visiting less, caregivers giving up jobs and leisure, and limited social contacts.

<u>Burden</u>. Several researchers have focused on the experience of informal caregivers in terms of the burden associated with care. There are several measures of burden but one of the most frequently used instruments was devised by Zarit et al. (1980). Questions in this inventory pertain to the caregiver's health, psychological well-being, finances, social life, and their relationship with the impaired person. On the basis of this inventory, it is evident that Zarit et al.'s concept of burden encompasses several aspects of the caregiving experience.

Caserta, Lund, Wright, and Redburn (1987) reported that their sample of spouse caregivers (gender differences were not examined) had slightly higher burden scores than non-spouse caregivers. The latter group of caregivers were predominantly daughters of demented parents. In contrast, Zarit et al. (1980) reported no differences in burden scores between spouses (primarily wives) and daughter caregivers. However, the sample in their study contained few male caregivers and was much smaller than Caserta et al.'s sample.

Several researchers have explored differences between husband and wife caregivers using the Zarit et al. (1980) burden inventory. In a study conducted by Fitting et al. (1986), differences between elderly male and female spouse caregivers of community-dwelling partners with dementia were examined. No statistically significant differences were found between husbands and wives in relation to the burden they experienced. Similarly, Zarit et al. (1980) found no burden differences between husbands and wives who provided care to community-dwelling demented spouses although their sample contained few husbands (4 husbands, 14 wives). In a later study, Zarit et al. (1986) found that female spouse caregivers of dementia patients were more burdened than male caregivers. However, a two year follow-up indicated no differences between males and females in terms of perceived burden. They suggested that in general, the caregiver's ability to tolerate problem behaviors increased as dementia progressed - particularly the female's ability.

While the Zarit et al. (1980) burden inventory has become popular, it is unidimensional in nature as feelings associated with caregiving and lifestyle changes are not differentiated. Poulshock and Deimling (1984) have decried the apparent unidimensional conception of burden in the caregiving literature. They argued that instead, burden would be better recognized as multidimensional. They envisioned "burden" as the caregiver's subjective interpretation of problems related to their loved one's impairment(s). Their model contained three components including patient impairment, caregiver burden, and the impact of providing care. The first component, impairment, may be mental and/or physical. Their impact component included an assessment of objective differences in the caregiver's family relationships, social activities, employment changes, and health since the patient's development of dementia. Burden was described as a "mediating force between elders' impairments and impact on caregivers" (p.230) in their model.

In their study, Montgomery et al. (1985) differentiated objective burden from subjective burden. Objective burden was defined as the "extent of disruptions or changes in various aspects of the caregiver's life and household" (p.21). This definition seems to parallel Poulshock and Deimling's (1984) description of the impact that caregiving has on the caregiver. Therefore, the terms "impact" and "objective burden" can be used interchangeably. Subjective burden was defined by Montgomery et al. as "the respondents' attitudes toward or emotional reactions to the caregiving experience" (p.21). This definition recognizes the subjective and emotional component of burden that Poulshock and Deimling described. Therefore, Poulshock and Deimling's depiction of burden appears similar to Montgomery et al.'s description of subjective burden. Impairment and the Experience of Giving Care to Demented Partners

As described in Poulshock and Deimling's (1984) model of burden, the patient's impairment is an important consideration in the examination of a caregiver's experience. Further, impairment severity would seem important to assess due to large variations in the health and abilities of frail people, even those with the same disease. Given the relative infancy of the dementia caregiving literature, it is not surprising that impairment has been assessed in many different ways ranging from behavioural problems to dementia severity. A further complication is that impairment has been assessed in relation to several dependent measures such as caregiver distress, depression, well-being, stress, and burden. Studies using non-burden measures are briefly described here to provide an overview of the importance of impairment assessment. The few studies that examine impairment in relation to burden are then described.

Some behaviors may be viewed by the caregiver as difficult to handle and therefore burdensome. Caregivers have identified physical violence, memory disturbances, incontinence, catastrophic reactions, hitting, making accusations and suspiciousness (in descending order) as the most problematic behaviours of demented patients (Rabins et al., 1982). Robertson and Reisner (1982) interviewed predominantly female caregivers (42% spouses; not differentiated from other caregivers) of discharged dementia patients in Saskatoon. The problems these caregivers encountered included several of those described by Rabins et al. The two most prevalent problems were being tied down and repetitive questioning but both were generally well tolerated by most caregivers. While occurring less frequently, dangerous or irresponsible behaviours were tolerated by few caregivers. Likewise, incontinence occurred infrequently but when present, it was tolerated by few caregivers. Greene, Smith, Gardiner, and Timbury (1982) found that the caregiver's (relationship to patients was not differentiated) personal distress was significantly positively correlated with the dementia patient's apathetic and withdrawn behavior. However, Greene et al. reported that other measures of impairment such as the level of cognitive functioning and incapacity to perform activities of daily living were not related with the caregiver's level of stress.

Eagles, Craig, et al. (1987) examined the well-being and stress levels of caregivers (more than half were spouses) caring for elderly demented persons in a semi-rural area in Great Britain. The authors also included a control group drawn randomly from the community. In comparing groups of caregivers of severely/moderately demented, mildly demented, and non-demented, no significant differences between

caregivers were found in terms of the presence and degree of psychiatric morbidity. However, there was a trend indicating caregivers of the severely/moderately demented were more depressed, irritable, tired, tense and worried than the non-demented control group. Co-resident caregivers of non-demented persons had significantly less stress than caregivers of the severely/moderately demented patients. Moreover, the stress reported by caregivers escalated with increasing severity of dementia. It should be noted that unlike most other samples, this sample was not gathered from mental health services. Consequently, this sample may have been coping rather well with their spouse's condition.

In a related study, Eagles, Beattie, Blackwood, Restall, and Ashcroft (1987) found no relationship between the demented patient's mental status and the spouse's psychological distress or disturbances, general health, or anxiety. A weak negative correlation between depression in husband caregivers and cognitive impairment in their wives was observed but did not exist between wife caregivers and their husbands. However, unlike Eagles, Craig, et al.'s (1987) study, this sample contained few severely demented persons and the identification of dementia was suspect as a brief diagnostic questionnaire was used. Given these concerns, the authors concluded that the lack of caregiver psychological disturbance should not be taken to indicate that caregivers were free from strain.

Dementia impairment has also been examined in relation to caregiver burden. Scott et al. (1986) and Fitting et al. (1986) found that the demented patient's mental status had no major effect on spouse caregiver burden. Zarit et al. (1980) reported that the frequency of the demented person's memory and behavior problems was not correlated with the

caregiver's (spouses and daughters) level of burden. Furthermore, the dementia's duration was not correlated with the caregiver's burden. In all of these studies, a unidimensional burden measure was used. Consequently, subjective burden was not analyzed separately from objective burden in relation to the patient's impairment.

The above discussion has focused on the dementia patient's level of impairment. However, the elderly spouse caregiver may also have health problems that interfere with his or her daily activities. Poulshock and Deimling (1984) recognized this consideration when they stated:

The characteristics of the elder's incapacity affects the caregiver's perception of burden and the impact that caregiving has on her life. The caregiver's own mental and physical well-being, however, are implicated in this relationship as well. Caregivers with lower levels of mental and physical well-being may be limited

in their capacity to respond to the rigors of caregiving. (p.231) Caregiver health impairment in relation to objective and subjective burden has not been examined in the dementia caregiving literature. <u>Summary</u>

The literature pertaining to caregivers of persons with dementia is less voluminous than the more general caregiving literature but parallels it in several ways. Demented persons are more likely to live in the community than in institutions. The apparent trend towards home care has ramifications for caregivers given the nature of dementia. While the literature suggests that spouses are most likely to be the caregivers, less research has focused on spouse caregivers than on other caregivers. Further, little is known about how experiences differ between husband and wife caregivers. Of the various measures of the costs associated with caregiving, the concept of caregiver burden is most widely used although it would be helpful if burden was more specifically defined and measured than it has been in the past. Montgomery et al. (1985) have differentiated objective from subjective burden and appear to closely mirror the respective descriptions of impact and burden in the Poulshock and Deimling (1984) model.

Poulshock and Deimling (1984) also emphasized the importance of impairment in their model. Patient impairment has been assessed in different ways. Some authors have relied on behavioral measures while others have examined cognitive deficits. Still others have rated the severity of dementia. Behavioral problems seem to pose more difficulty for caregivers than cognitive impairment but the evidence is not conclusive. A more comprehensive examination of the demented person's overall health may be beneficial in determining how the patient's impairment influences the caregiver. The overall health of dementia patients seems to be even more relevant given the fact that many are elderly and therefore likely to have other health conditions (e.g., heart disease, arthritis) that interfere with daily living. This same principle applies to caregivers making it appropriate to assess their functioning level as well. A comprehensive impairment assessment of both dementia patients and their spouses would enable direct comparisons between patients and their caregivers.

Support for the Caregiver

The caregiver's coping resources may be influenced by past experiences with old people (Marcus & Jaeger, 1984), prior experiences in handling crises, adaptability, integration, social economic status, and extended family and community support (Edstrom & Miller, 1981). Of these influences, family and community support are receiving increasing attention from researchers as they may be extremely important resources for the caregiver. In the earlier discussion about caregivers and their experiences, the importance of family support for dementia patients was established. However, Shanas' (1979b) principle of substitution in caregiving suggested that family support for the patient is better interpreted as a spouse's support (provided the patient is married). While the principle of substitution does not imply that the primary caregiver provides care in isolation, this principle suggests that one caregiver is likely to provide most of the care to the patient. At this point, little is known about who assists the caregiver, the type and . amount of assistance that is offered, or how the caregiver perceives this involvement. Barrera (1986) categorized these aspects in his review of the social support literature and labeled them respectively as social embeddedness, enacted support, and perceived social support. Each concept is discussed in relation to the social support literature and more specifically, to the caregiving literature.

Social Embeddedness

It is obvious that in order to receive support there must be a source from which to receive it. Social embeddedness "refers to the connections that individuals have to significant others in their social environments" (Barrera, 1986, p.415). This definition approached Mitchell and Trickett's (1980) definition of a social network which they defined as the total social field within which an individual is embedded. It could therefore include family, friends, neighbors, social organizations, formal institutions, etc. Consequently, the terms social embeddedness and social network can be seen as interchangeable.

Network members have rarely been differentiated in the caregiving Information pertaining specifically to family members, literature. friends, and formal care services has consequently been lost as all people have been grouped together and labeled as the recipient's social network. In examining each group according to the relationship with the recipient, it would be convenient to label each as a "subnetwork". The combined family, friend, and formal subnetworks therefore comprise the recipient's social network. Some of these subnetworks have been examined individually before in samples of caregivers. However, no single study has analyzed the influence of all three subnetworks separately nor the differences in subnetwork composition between male and female caregivers. Conceivably, each subnetwork may have a different relationship with the caregiver's objective and subjective burden. If so, intervention strategies could be geared toward a specific subnetwork in an effort to assist the spouse caregiver in prolonging his or her partner's residence in the community.

While each subnetwork is of interest, Marcus and Jaeger (1984) stated that there is a particular need for a better understanding of the interaction between caregivers and formal services. Chappell (1985) found evidence to suggest that rather than formal services substituting for informal sources of assistance, they complemented each other. Elderly persons who used home care services in Winnipeg were found to use other formal services to a greater degree than home care non-users. Also, home care users were more likely to use informal sources of assistance. Therefore, the receipt of formal services did not appear to be a substitute for receiving informal services.

The analysis of social embeddedness includes structural properties

such as the size of the network (i.e., the number of members) and frequency of contact with members (i.e., daily, weekly, etc.). These two properties could also be examined for each subnetwork to provide information pertaining to subnetwork size and subnetwork contact frequency with the caregiver. These properties are obviously dependent upon the operational definition of (sub)network membership. Stokes (1983) stated that the most frequent definition of network size was the number of people who were significant to the individual and with whom the individual interacted "regularly". In his research, Stokes operationally defined "regular" contact as occurring at least once a month.

<u>Network size</u>. Novak and Guest (1985) did not find a significant correlation between the caregiver's sense of burden (unidimensional measure) and the number of children, relatives, and friends they had. Unfortunately, they did not implement a time frame as suggested by Stokes (1983). Conceivably, people could have been included in the social network despite a lack of recent contact with the caregiver. For example, a caregiver may have several children with most living a great distance away and with very little contact with the caregiver. If included as network members despite these considerations, they could inflate the caregiver's social network size without a corresponding high contact level. Furthermore, subnetworks were not differentiated as only an overall network size was computed.

<u>Contact frequency</u>. Some researchers have observed that frequency of network contact is related to the caregiver's life satisfaction, depression, and perceived burden. Wives of husbands with predominantly cardiac disabilities were found to have greater life satisfaction if

they received visitors (Fengler & Goodrich, 1979). Fiore et al. (1983) examined a sample of spouse caregivers (aged 45-85; no age or gender differences were documented) of Alzheimer's patients. They found that the frequency of network contact (friends and family members were not differentiated) correlated inversely (r = -.30) with caregiver depression.

Marcus and Jaeger (1984) found that elderly caregivers of elderly frail family members (health problems were not specified) who reported fewer visits had "high" burden scores. Similarly, Pratt, Schmall, Wright, and Cleland (1985) found that interaction with family members was significantly related to a unidimensional measure of caregiver burden in caregivers of dementia patients (over half of the sample were spouses but relationships to patients were not differentiated). The small correlation ($\mathbf{r} = -.16$) suggested that caregivers with fewer family interactions had greater burden while those with more family contacts had less burden. Patient residence (i.e., institution or community) was not related to caregiver burden. Zarit et al. (1980) found that the amount of burden (unidimensional measure) experienced by spouse caregivers was less when relatives paid more visits to the household (\mathbf{r} = -.47). Since all of this evidence is correlational, causation can not be determined.

There is a suggestion that husband and wife caregivers may differ in terms of social network embeddedness. Johnson (1983) found that elderly male caregivers of post-hospitalized spouses tended to use formal providers of support more often than female caregivers although this tendency was not statistically significant. In addition, disabled wives tended to have more contact with children and significantly more contact

with other relatives when husbands provided care as compared to disabled husbands who received care from their wives. It is not known if such differences exist between spouses of dementia patients.

Enacted Support

It has become increasingly important for researchers to define social support in their work because the concept of social support has become insufficiently specific to be useful as a research concept (Barrera, 1986). For example, researchers have often confused social network assessment with social support assessment. Shinn, Lehmann, and Wong (1984) found these two concepts have been treated synonomously with social interaction in the general literature. This leads to confusion and interpretation difficulties and underlines the importance of clear operational definitions of social network and support variables.

As described previously, social networks are better envisioned as the framework from which support may be offered. Social support would be better conceptualized as the nature of what social network members do for the recipient. Gottlieb (1983) described social support as consisting "of verbal and/or nonverbal information or advice, tangible aid, or action that is proffered by social intimates or inferred by their presence and has beneficial behavioral effects on the recipient" (p.28-29). Gottlieb further stated that "social support is properly conceived as a multidimensional construct and should be measured accordingly" (p.61).

Barrera (1986) recognized the multidimensionality of social support in his description of enacted support as the analysis of actions performed by others when they rendered assistance. Earlier, Barrera and Ainlay (1983) had developed a measure of enacted support. Their Inventory of Socially Supportive Behaviors contained four categories of supportive behaviors that closely matched those described by Cohen and Wills (1985) in their extensive literature review. Esteem or emotional support provides an individual with the information that he/she is esteemed and accepted. Informational or cognitive support is defined as providing assistance in defining, understanding, and coping with problematic events. Instrumental support is evidenced when financial aid, material resources, or needed services are offered. Finally, social companionship refers to spending time with others in leisure and/or recreational activities. Cohen and Wills argued that although these support functions may be separated conceptually, they are rarely independent. Still, the categories are helpful in recognizing the multifaceted nature of enacted support.

Peters, Hoyt, Babchuk, Kaiser, and Iijima (1987) examined primary group support systems of a large randomly selected sample of elderly community-dwelling persons. Over 90% of respondents reported that their health condition was good or fair. The authors observed that their sample received instrumental and emotional support from a variety of people including the spouse, children, other relatives, friends, and neighbors (formal subnetwork members were not included in the data collections). There was a strong tendency to turn more often to the spouse or to an adult child than to other people. Peters et al. concluded that friends did not compensate for family when kin were unavailable. Rather, friends were often used as helpers in their own right. It cannot be determined on the basis of this study if each subnetwork gave different amounts of instrumental and emotional support (or other types of enacted support). Further, it is unknown if these

results are generalizable to a more stressed sample such as caregivers of demented spouses.

Currently, enacted support specification has received little attention in the caregiving literature. There is some evidence of enacted support classification in caregivers of cancer patients. In their pilot study, Googe and Varricchio (1981) found cancer caregivers in the community received some help from home health nurses for technical skills (i.e., injections, enemas, ambulation, and bathing). While this assistance can be defined as instrumental support, caregivers stated that the most helpful function of the home care nurse was the provision of emotional support. This was defined as giving a "sense of security, morale boost, and assurance that she is being cared for properly" (p.27). It is not known if there were differences among caregivers in terms of the relationship with the cancer patient, age, or sex of the caregiver. Despite these methodological difficulties, formal subnetwork members (home health nurses) were found to be helpful in different ways to caregivers of home-bound cancer patients.

In another study, Rose (1976) interviewed family members of 26 cancer patients who had lived at home sometime during the eight weeks preceding their deaths. Unfortunately, she did not describe her sample of family members or cancer patients indicating only that all cancer patients were over 18 and none lived alone. Consequently, generalizations to elderly caregivers are tentative at best. Most families reported that the patient's physical needs (i.e., instrumental support) were met by immediate relatives or friends as nursing assistance was evident in only one family. Physicians were expected to be primary sources of emotional support on an ongoing basis and were

expected to provide information. They were not expected to inhibit the progress of cancer or to cure it.

In a study of caregivers of Alzheimer patients, Scott et al. (1986) rated the receipt of combined instrumental (concrete forms of help including physical care and the provision of information) and social-emotional support from family members. Interviewers rated caregivers (primarily spouses without gender differentiated) on a three-point scale as to whether they received more than enough, enough, or not enough support. Caregivers rated on either extreme were found to have virtually identical mean burden scores and both were more burdened than caregivers rated as receiving enough support. This was unexpected and the authors hypothesized that perhaps caregivers who received more than enough support received it because they were at greater risk of dysfunction. Unfortunately, methodological problems such as the lack of impairment assessment, caregiver differentiation, and unreliable assessment of enacted support categories limit the generalizability of the findings.

It is of interest to note the caregiver's sources of the various types of enacted support. Of particular interest is the provision of support by formal supporters. Based on the results of Googe and Varricchio (1981), cancer caregivers appeared to appreciate emotional support from nurses. Rose (1976) found that doctors were expected to be primary sources of emotional support. Generalization of these results to spouses of demented partners is not recommended without further study of this population but these studies raise the prospect that caregivers can expect to receive more than instrumental support from formal care providers.

Another factor not examined in the literature is the type and amount of support provided by the patient as he or she is still part of the caregiver's network. Peters et al. (1987) found that the spouse (not demented) was frequently chosen over other family members and friends as the source of helping (i.e., instrumental support) and affective dimensions (i.e., emotional support). It is not known if caregivers of demented partners will similarly receive these or other types of support from their partners in light of the decreased cognitive and behavioral functioning capabilities. Conceivably, caregivers may receive some type of support from their demented partners. For example, depending on the level of impairment, it is unlikely that the demented spouse will provide cognitive guidance to the caregiver but he or she may still be able to provide some instrumental support (i.e., household tasks).

<u>Respite</u>. Respite for the caregiver is an example of instrumental support that has received increasing attention in the literature. Lack of relief and chronic fatigue for caregivers of dementia patients have been identified as major sources of distress (Rabins et al., 1982). Scott et al. (1986) found caregivers of Alzheimer's patients received very little financial assistance or help with physical tasks. Visits by family members and having persons stay with the patient thereby allowing the caregiver a brief respite were particularly appreciated by caregivers. Unfortunately, caregivers were not differentiated in this study. Most of the 21 caregivers were spouses (87%) but husbands and wives were included together in data analysis.

Most of the literature pertaining to respite focuses on its provision through various programs offered by formal service agencies. In Crossman, London, and Barry's (1981) sample of caregivers, older

women caring for disabled spouses (predominantly stroke or organic brain disease) could receive home care and respite in the day through adult day care. Overnight respite was also available through institutionalizing their husbands for brief periods of time. These opportunities to receive a brief respite were particularly appreciated by the wives as was a peer support group that was established.

Sands and Suzuki (1983) described an adult daycare program in California that assisted families in caring for a loved one with Alzheimer's disease. Besides providing a respite for caregivers, the program offered an opportunity for the impaired person to become involved in meaningful activities such as exercise and music. Monthly family support meetings, individual counselling, and referral services were also made available through the program. Family members reported that in addition to obtaining relief, they also gained insight and emotional support from fellow caregivers and the program staff.

Lundervold and Lewin (1987) argued that although respite services have widespread use, there is little empirical evidence concerning the effectiveness of them. They presented four case studies on the effects of in-home respite for caregivers of family members (relationships were not described) with Alzheimer's disease. Caregivers received either four or six consecutive hours of respite once per week. Baseline measures of the caregiver's burden, depression, and stress were obtained for three weeks before respite was offered. These measures were compared to measures taken during the four month respite period. Results indicated that four to six respite hours weekly did not decrease caregiver burden, depression, or stress. In addition, one caregiver who chose not to receive respite from this source did not differ on these

measures from the other caregivers who received respite.

Caregivers in this study did report that their perceived health improved after receiving in-home respite care. Obviously, generalizations from such a small sample are tenuous. The availability of additional respite exceeding that offered by the program as well as methodological problems such as the insensitivity of research instruments prevent generalizations concerning the effectiveness of respite. Perhaps more respite hours lead to decreased burden; four or six hours per week may not be enough to decrease burden. Finally, the impairment of both patient and caregiver was not assessed. It is possible that both partners were able to function quite well without respite (i.e., the patient's dementia was not severe enough to require 24 hour supervision and care). Similarly, the single "control caregiver" may have been giving care to a relatively well-functioning demented partner.

In general, it seems that the provision of respite can be beneficial for caregivers in some ways. The focus of research in this area has been on formal care agencies. Less is known about the informal provision of respite. The source of respite as well as the possible relationship between the number of respite hours and the caregiver's level of objective and subjective burden need to be explored further. Furthermore, it is not known if husbands and wives differ in the amount of respite they receive or in their respective sources of respite. This should be explored further as well.

Perceived Social Support

Barrera (1986) defined perceived social support as the "cognitive appraisal of being reliably connected to others" (p.416). Measures of

perceived social support therefore assess the perceived adequacy and/or satisfaction with support. Measures can assess general satisfaction on a single Likert-type scale but a few authors have taken an additional step in differentiating perceived helpfulness from perceived upset with types of support. Their work suggests that perceived helpfulness and upset are not simply opposite ends of the same scale. While the caregiver's perceptions of the types of support he or she receives has begun to attract attention, the caregiver's perceptions of his or her sources of support has not been examined. The caregiver's helpfulness and upset ratings of subnetworks may differ between their subnetworks and may be related to burden measures. One component of the upset definition proposed by Fiore et al. (1983) concerns the degree to which network members meet the caregiver's expectations. Further exploration of the expectations of caregivers in terms of the types of support they expect from each of their subnetworks and which subnetworks they expect to provide each type of support may be useful.

<u>Positive and negative interactions</u>. Unfortunately, interactions with a social network have too frequently been assumed to be positive and therefore labeled as supportive. Most researchers have focused on the positive consequences of social interactions. Consequently, the possibility that social interactions can also be a source of conflict and strain has received far less attention (Cohen & Wills, 1985; Fiore et al., 1983; Pagel et al., 1987; Rook, 1984; Shinn et al., 1984). Gottlieb (1983) described his conception of the nature of social interactions when he stated:

there is no such thing as a support system; rather individuals are embedded in a social network composed of close associates who are

important in the individual's affective life and who generate both support and stress at different times and in résponse to different life demands. (p.29)

Whether or not a network member's support is positive or negative may depend upon the recipient's perception of it.

In their recent literature review, Cohen and Wills (1985) concluded that negative social interactions deserved more study as such interactions appeared to explain more of the variance in health and well-being than positive social interactions. They found that few authors had examined the effects of positive and negative social interaction separately. They added that perceived social support is an important consideration as adequate functional support may be derived from one very good relationship but may not be available to those with multiple superficial relationships. Interaction quantity (i.e., embeddedness) is therefore best considered in relation to the perceived quality of it.

Very few researchers have specifically examined negative social interactions in the elderly population. One researcher who addressed this issue was Rook (1984) who assessed the benefits and costs of social ties on personal well-being in a sample of elderly widows. She observed that problematic social interactions (i.e. having one's privacy invaded, being taken advantage of, having promises of help broken and knowing others who consistently provided conflicts or feelings of anger) had more of an effect on well-being than supportive social interactions. The number of problematic social ties detracted substantially from well-being but the number of supportive ties was not associated with greater well-being. Friends and family members were each as likely to

contribute problems leading to lower well-being scores (formal supporters were not included in this relatively healthy sample). Background characteristics such as age, education, income, religion, health, number of years widowed and length of residence in Los Angeles did not differ between women with reported low, moderate, or high numbers of problematic social ties. In addition, there was little evidence to suggest that women with problematic ties were less socially skilled than other women. In concluding, Rook cautioned that these results may not be generalizable to a more stressed population as positive social interactions may have a more beneficial relationship with well-being in a sample experiencing a crisis.

It has been argued that caregivers of demented partners comprise a stressed population. Rabins et al. (1982) examined a sample from this population in their study of dementia patient caregivers (relationships undifferentiated). Over half of their sample reported family conflict. These caregivers felt that their family members were not helpful enough or were critical of the care they were providing to the patient.

<u>Caregiver perceptions of types of support</u>. In a study conducted by Fiore et al. (1983), caregivers of spouses with SDAT indicated their perceptions of helpfulness and upset (defined as unmet expectations of support and/or the presence of negative network input) from their social network. These negative contributions were assessed independently of perceived helpfulness in five types of social network support (emotional, instrumental, cognitive guidance, socializing, and self-disclosure). They found that caregiver depression correlated significantly (ranging from +.34 to +.55) with perceived upset in all five types of social network support. Conversely, correlations between

perceived helpfulness and depression were not significant (ranging from -.02 to +.13). In four of the support areas, perceived helpfulness and upset were not related significantly with each other (the exception was cognitive guidance where a positive relationship was found). This result suggested to the authors that caregivers differentiated perceived helpfulness from upset and secondly, these perceptions were not simply opposite ends of the same scale. Unfortunately, male and female caregivers were not differentiated nor were subnetworks identified in the study.

In a later study, Pagel et al. (1987) found that upset with one's network accounted for most of the variance (17%) in spouse caregiver depression. Rated network member helpfulness did not account for any variance in caregiver depression. Furthermore, helpful aspects of the caregiver's social network bore little or no relation to overall network satisfaction whereas perceived upset with the social network led to reduced overall network satisfaction. This was still evident in a 10 month follow-up. Overall, these results were tempered by the wide range in caregiver ages (37-81), living arrangements (community or institutionalized), and lack of subnetwork identification. Nevertheless, it can be seen that perceived upset is an important variable to assess in examining the role of social networks.

In the two studies reviewed above, perceived social support in relation to caregivers of dementia patients was examined in relation to caregiver depression. While depression in caregivers has been documented, it appears to be a confining dependent measure as clearly, not all caregivers become depressed. It would appear that caregiver burden would be a more encompassing dependent variable because there is

room for a more objective component pertaining to changes in the caregiver's lifestyle. In addition, there is a wider range of emotions and reactions represented in subjective burden as compared to the assessment of depression only. Further, it is conceivable that caregiver burden could be exacerbated if the caregiver perceived his or her network as upsetting in some way(s). In contrast, caregiver burden could be decreased if the caregiver perceived his or her subnetworks as helpful in some way(s). These possibilities could be explored further as relationships between burden measures and perceptions of support have not been addressed.

Fiore et al.'s (1983) definition of "upset" could be modified to provide greater clarity. Their definition included negative interactions and/or unmet expectations. Caregivers responded to both aspects as upsetting thereby confounding the issue of what they were actually upset about. Conceivably, a caregiver could be upset with a network member without him or her interacting negatively with the caregiver. For example, a caregiver could expect the member to be more involved in the situation and his or her failure to meet these expectations could make the caregiver upset. This is a different scenario than a member actively undermining the efforts of the caregiver. Upset, defined specifically as unmet expectations, has not been examined in the caregiving literature.

<u>Caregiver perceptions of subnetworks</u>. Since the sources of support have received little attention in the caregiving literature, it is not surprising that there are no studies that have examined perceptions of support sources. In a similar vein as the perceptions of support categories, helpfulness and upset ratings of subnetworks (collapsing

support categories) could be explored. It is conceivable, for example, that perceived upset with the family subnetwork could be related to subjective burden. In addition to possibly being related to the burden measures, subnetwork perceptions could also differ between subnetworks. For example, male caregivers could rate their friends as more helpful than their other subnetworks. Exploration of subnetwork perceptions may provide useful information pertaining to the importance of examining sources of support in designing future services and implementing them.

<u>Caregiver expectations of subnetworks</u>. As discussed above, unmet expectations could be a source of stress for the caregiver. It would be useful to explore the caregiver's expectations for each subnetwork in terms of the enacted support categories. For example, perhaps friends are expected to provide more emotional support than formal agencies or family members while formal agencies are expected to provide more instrumental support than friends.

The caregiver's general expectations of their subnetworks have rarely been addressed. Rose (1976) indicated that caregivers of cancer patients expected emotional support from physicians. However, it is not known if caregivers expected more emotional support than other types of support from the formal subnetwork in her study as Rose did not address this issue. Expectations of formal care providers may be of special interest in that expectations may not match the services that are offered.

It would seem that an initial component in offering services to caregivers would be an examination of what caregivers expect from their subnetworks. For example, if caregivers tend to expect cognitive guidance concerning their spouse's condition from friends, their questions may not be answered satisfactorily and this may exacerbate their sense of burden. Furthermore, husband and wife caregivers may have different expectations of their subnetworks which could be considered in the design and implementation of services for caregivers. <u>Summary</u>

An analysis of the caregiver's social embeddedness provides the structural framework from which the caregiver receives support. Current studies have not differentiated between subnetworks and it is not known if they differ in terms of size and/or contact frequency. In addition, while a unidimensional burden measure has not been found to be related to network size (Novak & Guest, 1985) but has been found to be related to family contact frequency (Pratt et al., 1985; Zarit et al., 1980), it would be of interest to determine how each subnetwork influences the caregiver's sense of objective and subjective burden. Furthermore, since husbands are also caregivers to demented partners, it would be of interest to determine if their subnetworks differ according to these structural properties as this has not been examined before. In assessing these variables, information could be gathered concerning the nature of caregiver's experiences. Such information might be useful in designing health care services for caregivers.

Enacted support can be categorized into four types. Thoits (1982) stated that the type and source of support were important variables to consider but they have been largely ignored by researchers. In the evidence reviewed above, some studies have included more than one type of enacted support while others have included more than one subnetwork. However, no study has examined the four categories of support and the different sources of support (i.e., subnetworks) together. More

specifically, little is known about how much of each type of support is received by caregivers or about the subnetwork source(s) from which they receive support. Furthermore, the type and source of the caregiver's support have not been examined in relation to the caregiver's sense of objective and subjective burden. Conceivably, both the type and sources of support and their relationship to objective and subjective burden may differ between husband and wife caregivers. These considerations are important in better understanding the nature of the spouse caregiver's interaction with his or her social network.

Perceptions of the support received by recipients have been demonstrated to be an important consideration in examining the influence of social networks. While negative aspects of support categories (i.e., upset ratings) have received little attention from researchers, they appear to account for more variance in the recipient's well-being and depression than perceived helpfulness of support categories. Consequently, it appears that assessing perceived helpfulness separately from perceived upset is beneficial in better understanding perceived social support. Measuring perceived upset has been confounded in the past by including negative interactions and unmet expectations in the same measure. Defining upset as unmet expectations would provide greater clarification of this concept. Caregivers' perceptions of upset and helpfulness with their subnetworks have not been explored in terms of subnetwork differences or in relation to objective and subjective burden. Similarly, caregivers' expectations of their subnetworks according to enacted support categories have not been explored.

Positive Aspects of Providing Care

Although this chapter and the caregiving literature in general have

focused on caregiver burden, providing care need not necessarily be burdensome. Marcus and Jaeger (1984) found that caregivers (71% spouses) of elderly family members (physically ill but health problems were not specified) reported satisfaction and/or pleasure from being able to cope with the situation, obtaining results and recognition through their efforts. Other positive aspects were also mentioned but not as frequently as these. While most of the families in Chenoweth and Spencer's (1986) survey described the effects of Alzheimer's disease as devastating to them and the patient, a few families said the experience had drawn the family closer together. It therefore seems worthwhile to determine what caregivers of dementia patients find positive in their experience. Positive aspects of caregiving for a demented person have not received much attention. Health professionals could use this information to reinforce such aspects of the caregiving situation.

Summary

The prevalence of dementia is increasing in a growing population of elderly Canadians. Combined with the rising costs of institutional care, it seems likely that in the future even more elderly dementia patients will be cared for in the community. It has been demonstrated that caring for a dementia patient in the community can be psychologically and/or physically "costly" for the caregiver. While the experiences of caregivers has begun to receive increased attention, much of the information concerns daughters of a parent with dementia. Less is known about the experiences of the caregivers who are most likely to provide care if the patient is married - the spouses. Furthermore, researchers have typically grouped male and female caregivers together in data analysis and therefore, relatively little is known about the

specific experiences of wives and husbands. Possible differences could be explored further in order to better understand their situations.

One measure of the "costs" associated with caregiving for dementia patients is the concept of burden. Caregiver burden has been defined in different ways but has been usually assessed as a unidimensional concept. Montgomery et al. (1985) argued that burden would be better conceptualized as multidimensional and submitted their definitions of objective and subjective burden. Poulshock and Deimling's (1984) model of burden can be modified to incorporate these terms. In their model, perceptions of burden (i.e., subjective burden) mediate between the patient's impairment and the impact on caregivers (i.e., objective burden).

In this model of caregiver burden, the patient's and caregiver's level of impairment are important considerations. Impairment of the demented person has usually been assessed in relation to dementia only (i.e., dementia severity) ignoring other possible functional deficits. Recognition of the caregiver's impairment has rarely occurred in the literature although spouse caregivers are likely to be elderly and conceivably impaired in some way. It would be helpful to utilize a behavioral dysfunction assessment instrument which could compare caregivers and dementia patients in relation to their functional capabilities. However, most impairment measures in the literature have been disease specific (i.e., dementia) thereby preventing a comparison between the caregiver's and patient's health. Without a common assessment tool, it is difficult to determine the degree to which caregivers of dementia patients fit into the "hidden patient" label offered by Fengler and Goodrich (1979).

The functional status of caregivers may be related to their sense of objective and/or subjective burden. This possibility has not been addressed in the literature as the demented person's level of impairment has received greater attention. A more detailed examination of the caregiver's health may be useful in better understanding how his or her health problems relate to the caregiving experience.

While the impairment of the spouse caregiver and his or her demented partner may influence the caregiver's experience, other factors may also influence it. The caregiving literature has begun to recognize that one of the ways in which a caregiver's sense of burden may be influenced is through contact with his or her social network. This has been demonstrated through primarily quantitative measures in a few studies examining caregivers of dementia patients. Quantitative measures constitute one of Barrera's (1986) categorizations of social support embeddedness. While providing the necessary structural framework of social interaction, embeddedness measures reveal little about the qualitative aspects of the interactions. Barrera's two other social support categories (enacted support and perceived social support) address these qualitative characteristics.

Embeddedness could be operationally defined as the measurement of social network size and frequency of contact with network members. Since a network is comprised of many people in different groups, more specific information could be gained if family, friend, and formal subnetworks were assessed individually. These three subnetworks have not been separately analyzed in any one previous caregiving study. The size and frequency of member contact could be assessed for each subnetwork to determine if caregiver burden was related to subnetwork

embeddedness measures. Possible caregiver gender differences could also be examined in relation to subnetwork embeddedness.

Thoits (1982) indicated that both the type and source of support have been largely ignored in the past. Subnetwork embeddedness measures address her latter concern while Barrera's second categorization of social support, enacted support, addresses her former concern. Four categories of enacted support (socializing, tangible assistance, cognitive guidance, and emotional) have been identified as the most common types of social support (Cohen & Wills, 1985). They could be examined in greater detail to determine if subnetworks provide different categories of support. In addition, enacted support could be explored further as the categories may be differentially related to the caregiver's sense of objective and subjective burden. Such examinations would be exploratory because they have not been examined previously.

A specific example of tangible assistance merits further exploration. Lack of relief for caregivers of dementia patients has been found to be a major source of distress (Rabins et al., 1982). The provision of a brief respite was particularly appreciated by wives of stroke and organic brain diseased patients (Crossman et al., 1981) and caregivers of Alzheimer's patients (Scott et al., 1986). However, Lundervold and Lewin (1987) cautioned that respite opportunities may not be a panacea for caregivers. Generalizations from their study are tenuous because of their small sample size and limited respite availability. Still, the number of monthly respite hours could be examined in relation to caregiver burden. The source of respite could also be explored further in determining the involvement of formal and informal supporters.

The importance of Barrera's (1986) third categorization of social support (perceived social support) is evidenced in the works of a few researchers such as Fiore et al. (1983), Pagel et al. (1987), and Rook (1984). Unlike many other researchers in this field, these authors differentiated positive from negative perceptions of social support categories in their data analysis. Fiore et al.'s results suggested that the caregiver's perceived upset was better than perceived helpfulness in predicting caregiver depression. However, their operational definition of upset included both negative interactions and unmet expectations leading to difficulties in interpreting the results. It would be useful to examine specifically how unmet expectations (perceived upset) and perceptions of helpfulness relate to the caregiver's sense of objective and subjective burden. Furthermore, it would be useful to explore if the caregiver's perceptions of his or her subnetworks are related to other types of burden or if helpfulness and upset ratings differ between subnetworks.

The caregiver's expectations of enacted support from each subnetwork could be explored further. Perhaps elderly spouses expect different types of support from each subnetwork. Male and female caregivers may also differ in their expectations of subnetworks.

The role of the dementia partner in terms of enacted support and the caregiver's perception of that support has not been documented in past research. The demented partner may still be able to provide some type(s) of support to his or her caregiving spouse. In addition, caregiver perceptions of their partner's enacted support may be related to caregiver burden. Therefore, the patient can be considered as a special "subnetwork" in the analysis of enacted and perceived support.

A final consideration in examining caregiver experiences is the possible positive aspects of providing care. This consideration has been rarely addressed by researchers as they have concentrated on the costs associated with caregiving experiences.

Research Questions

The influence of impairment and social networks on male and female caregivers of elderly demented partners is largely unknown. Consequently, the present study was considered to be exploratory in nature. Three focuses were addressed in the present study. The first concerned how selected variables were related to objective and subjective burden. The second focus encompassed a more detailed examination of caregiver social networks. The third and more minor focus addressed positive aspects of providing care to demented spouses. Underlying each focus was an exploration of caregiver gender differences. The questions that were addressed in this study follow: 1. Objective and subjective burden relationships with selected variables.

1.1 Caregiver gender.

caregivers?

1.1.1 Do male and female caregivers differ in terms of their experience of (a) objective burden and (b) subjective burden?1.2 Impairment.

1.2.1 Is the dementia patient's physical impairment, psychosocial impairment, or diagnosis length related to (a) objective burden or (b) subjective burden for male and female

1.2.2 Is the caregiver's physical or psychosocial impairment related to (a) objective burden or (b) subjective burden for male and female caregivers?

- 1.2.3 Do any impairment measures predict a significant amount of variance in (a) objective burden or (b) subjective burden for male and female caregivers?
- 1.3 Embeddedness.
 - 1.3.1 Is the network size related to (a) objective burden or (b) subjective burden for males and females?
 - 1.3.2 Is network contact frequency related to (a) objective burden or (b) subjective burden for males and females?
 - 1.3.3 Are the sizes of subnetworks related to (a) objective burden or (b) subjective burden for male and female caregivers?
 - 1.3.4 Are subnetwork contact frequencies related to (a) objective burden or (b) subjective burden for male and female caregivers?
 - 1.3.5 Do any subnetwork embeddedness measures predict a significant amount of variance in (a) objective burden or (b) subjective burden for male and female caregivers?

1.4 Enacted support.

- 1.4.1 Is any type of enacted support (collapsing family, friend, and formal subnetworks) related to (a) objective burden or (b) subjective burden for males and females?
- 1.4.2 Does any type of enacted support predict a significant amount of variance in (a) objective burden or (b) subjective burden for male and female caregivers?

1.5 Respite.

1.5.1 Is the total number of monthly respite hours (an example of tangible assistance) related to (a) objective burden or (b)

subjective burden for male and female caregivers?

1.6 Perceptions of enacted support.

- 1.6.1 Is caregiver perceived helpfulness with any type of support related to (a) objective burden or (b) subjective burden for male and female caregivers?
- 1.6.2 Is caregiver perceived upset with any type of support related to (a) objective burden or (b) subjective burden for male and female caregivers?
- 1.6.3 Do perceptions of any type of support predict a significant amount of variance in (a) objective burden or (b) subjective burden for male and female caregivers?
- 1.7 Sources of support.
 - 1.7.1 Is enacted support (collapsing support categories) from any subnetwork related to (a) objective burden or (b) subjective burden for male and female caregivers?
 - 1.7.2 Does the enacted support provided by any subnetwork predict a significant amount of variance in (a) objective burden or (b) subjective burden for male and female caregivers?
- 1.8 Perceptions of support sources.
 - 1.8.1 Is caregiver perceived helpfulness with any subnetwork related to (a) objective burden or (b) subjective burden for male and female caregivers?
 - 1.8.2 Is caregiver perceived upset with any subnetwork related to (a) objective burden or (b) subjective burden for male and female caregivers?
 - 1.8.3 Do perceptions of any subnetwork predict a significant amount of variance in (a) objective burden or (b) subjective burden

for male and female caregivers?

- 2. Caregiver social network descriptions.
 - 2.1 Embeddedness.
 - 2.1.1 Do male and female caregiver subnetworks differ in terms of embeddedness as assessed by size?
 - 2.1.2 Do male and female caregiver subnetworks differ in terms of embeddedness as assessed by frequency of member contact?
 - 2.2 Enacted support category and perceived support category differences within subnetworks.
 - 2.2.1 Do male and female caregivers receive different amounts of each type of enacted support (socializing, tangible, cognitive, emotional) within each of the (a) spouse, (b) family, (c) friend, and (d) formal subnetworks?
 - 2.2.2 Do male and female caregiver support category helpfulness ratings differ within each individual subnetwork?
 - 2.2.3 Do male and female caregiver support category upset ratings differ within each individual subnetwork?
 - 2.3 Subnetwork enacted support differences and perceived support differences within support categories.
 - 2.3.1 In examining (a)socializing, (b) tangible, (c) cognitive, and
 - (d) emotional support categories individually, is there a difference between subnetworks (spouse, family, friend, formal) in terms of the support they provide for male and female caregivers?
 - 2.3.2 Do male and female caregiver subnetwork helpfulness ratings differ within each individual support category?

2.3.3 Do male and female caregiver subnetwork upset ratings differ
within each individual support category?

- 2.4 Respite sources.
 - 2.4.1 Which subnetworks provide respite for male and female caregivers?
- 2.5 Support category perceived helpfulness and caregiver expectations.
 - 2.5.1 Which category of enacted support do caregivers perceive to be most helpful to them?
 - 2.5.2 Which category of enacted support do caregivers most expect from each of the subnetworks?
 - 2.5.3 Which subnetwork do caregivers expect to provide the most support within each of the enacted support categories?
- 2.6 Caregiver respite activities.
 - 2.6.1 What types of activities are male and female caregivers currently involved in when afforded respite?
 - 2.6.2 What type of activities would caregivers like to engage in if given more respite (if caregivers desire more respite)?

3. Positive perceptions of the caregiving experience.

- 3.1 Positive caregiving experiences.
 - 3.1.1 Do caregivers have any positive perceptions about providing care to a spouse with dementia?
- 3.2 Home care vs. institutionalization.

3.2.1 Why have caregivers chosen to provide home care?

CHAPTER THREE

METHOD

The sample and research instruments used in the present study are described. The procedure used to collect the data and the research design are detailed, followed by a description of the data analysis. <u>Sample</u>

The sample consisted of 38 spouse caregivers of partners with dementia. All spouses met the following criteria: spoke English, retired from full-time employment, resided in Alberta, married to a spouse diagnosed as having SDAT or MID, and lived with his or her spouse in the community (i.e., noninstitutionalized).

Caregivers who met the criteria were initially identified by several physicians and psychiatrists in Calgary and by various provincial agencies and services. The latter included: Camrose and Red Deer chapters of the Alberta Alzheimer Association (A.A.A.); Cross Bow Auxiliary Day Hospital (Calgary); Home Care programs in the Foothills, Mount View, and Wetoka districts; Rosehaven Day Hospital (Camrose); Victorian Order of Nurses (Calgary); and Wetaskiwin Day Care Program. To maintain client confidentiality, potential participants were contacted initially by the appropriate health care professional. The study was briefly explained to them and their participation solicited.

Other participating caregivers learned about the study in different ways. The Calgary and Edmonton chapters of the A.A.A. printed a study description in their summer newsletters. The University of Calgary dementia clinic mailed a study description to qualified caregivers. Interested caregivers contacted the researcher or the appropriate agency. In all cases, caregivers were made aware that health care

access was not contingent upon their decision to participate.

The sample was comprised of 19 wife caregivers of demented partners and 19 husband caregivers of demented partners. All participants were Caucasian. Ten male and 13 female caregivers resided in Calgary and Edmonton. Nine male and six female caregivers resided in smaller cities and towns including Camrose, High River, Leduc, Nanton, Ponoka, Red Deer, Rimbey, Sylvan Lake, and Wetaskiwin.

Table 1 presents the means and standard deviations of demographic data pertaining to caregivers and their demented partners according to gender. Male caregivers ranged in age from 62-94 while female caregivers ranged in age from 57-78. Demented partners of male and female caregivers ranged in age from 60-88 and 58-80 respectively. Most of the male caregivers ($\underline{n} = 14$) and their spouses ($\underline{n} = 13$) did not complete high school. Conversely, most of the female caregivers ($\underline{n} =$ 12) and their spouses ($\underline{n} = 12$) completed grade 12.

Two male and three female caregivers were remarried. Marriages ranged from 5 - 59 years for male caregivers and from 10-58 years for female caregivers. Most caregivers and their partners lived by themselves as only two male and three female caregivers had at least one other person living with them. With the exception of two male and one female caregivers, all had children. However, it was evident that not all of the caregiver's children lived in the same city (or at least further than a half hour drive) as the caregiver. As indicated in Table 1, the mean number of total children was not equal to the mean number of children in close proximity for both male and female caregivers.

Two female and eight male patients were diagnosed with MID. All other patients were diagnosed with SDAT. Diagnosis duration ranged from

Table 1

	Gender		
Characteristic	Male	Female	
CG age <u>M</u> <u>SD</u>	72.63 7.45	67.58 ⁻ 5.53	
DP age <u>M</u> <u>SD</u>	73.11 6.38	71.95 6.84	
CG education years <u>M</u> <u>SD</u>	9.95 3.14	11.89 3.23	
DP education years <u>M</u> <u>SD</u>	11.79 3.26	10.53 2.29	
Years married (CG) <u>M</u> <u>SD</u>	42.16 11.43	39.37 14.37	
No. of home residents (CG) ^a <u>M</u> <u>SD</u>	0.16 0.50	0.32 0.82	
No. of children (CG) <u>M</u> <u>SD</u>	2.68 1.57	3.53 1.68	
No. of children nearby (CG) ^b <u>M</u> <u>SD</u>	1.16 0.90	1.84	

Characteristics of Caregivers (CG) and their Demented Partners (DP)

^aIn addition to the spouse. ^bDefined as living in the same city/town or less than one half hour drive away.

3-96 months and the mean number of months that SDAT and MID patients were diagnosed was 37.3 and 31.0 respectively.

Research Instruments

Data were gathered through the use of eight verbally-administered measures and a self-report questionnaire which was completed between interviews. The Background Information Questionnaire (see Appendix A) designed for this study provided demographic information pertaining to caregivers and their demented partners. The Sickness Impact Profile (Conn et al., 1978) assessed the impairment of both caregivers and their demented spouses. The Objective Burden and Subjective Burden Scales (Montgomery et al., 1985) measured caregiver burden. The Social Network List (see Appendix B) was based on a list designed by Fiore et al., 1983. It was the only paper-and-pencil instrument administered and provided network structural information. The Enacted and Perceived Support Form (see Appendix C) was designed to assess the source, type, amount, and perceptions of caregiver support. The Helpfulness Ratings and Enacted Support Expectation Questionnaire (see Appendix D) was designed to measure caregiver perceptions of overall support category helpfulness and secondly, to assess caregiver expectations of subnetworks. The Respite Questionnaire (see Appendix E) was designed to measure the amount and source of respite in addition to the nature of respite activities. Finally, the Perceived Benefits of Caregiving Questionnaire (see Appendix F) was designed to explore possible benefits gained through the experience of providing care. A detailed description of each instrument follows.

<u>Background Information Questionnaire</u> (see Appendix A). This questionnaire was developed by the researcher to provide a demographic profile of caregivers and their demented partners. Information included the gender, age, and educational level of both caregivers and their spouses; place of residence; length of marriage; number of co-residents; number of children and their proximity; caregiver's perceived health and severity of health problems; patient's dementia diagnosis and duration; and recent patient hospitalizations.

<u>Sickness Impact Profile (SIP)</u>. The SIP (Conn et al., 1978) was designed to "provide a measure of perceived health status that is sensitive enough to detect changes or differences in health status that occur over time or between groups" (Bergner et al., 1981, p.787). It is applicable across types and severities of illness and across demographic variables such as age and sex. It is behaviorally based and comprised of 136 weighted items divided into 12 activity categories. Seven of these categories are combined to yield two dimension scores.

Three categories (ambulation, mobility, body care and movement) are combined to calculate the physical dimension score. Four other categories (social interaction, communication, alertness behavior, emotional behavior) are combined to calculate the psychosocial dimension. The remaining categories (sleep and rest, eating, home management recreation and pastimes) are not combined to yield a dimensional score because of their independence from each other. The twelfth category (work) was not included as participants in the present study were retired. All items are combined to yield an overall score for dysfunction. Dimension and total scores are calculated by adding the weighted items and dividing by the possible total for the dimension or total score. The scores are then multiplied by 100 and expressed as a percentage.

The SIP has been demonstrated to be reliable in three field trials of varied health conditions and varied patient ages conducted between 1973 and 1976. Test-retest reliability was .97 and internal consistency was .94 for 1976 field trials (Bergner et al., 1981).

Field trials in 1976 indicated validity levels of .63 with self-assessed sickness and .69 with self-assessed dysfunction. The validity as determined by clinician assessment was lower as levels of .40 (clinician assessments of sickness) and .50 (clinician assessments of dysfunction) were obtained in relation to the overall SIP score. Although the validity was relatively low, Bergner et al. concluded that these levels were "appropriate for an instrument that seeks to measure a characteristic for which there is no criterion" (1981, p.805). In addition, the SIP has been used successfully to describe similarities in groups of patients with the same disease and also in differentiating among groups of patients with different diseases.

The SIP was designed to be completed by the patient in either an interview format or by paper and pencil. However, in some cases where the patient is weakened or suffers from cognitive impairment, this is not possible. McCusker and Stoddard (1984) used the SIP to assess the functional status of chronically and terminally ill home-bound patients. They evaluated the use of a surrogate in responding to the SIP on the patient's behalf by administering it to both patients and their caregivers. Of 11 SIP categories (excluding the work category), only the recreation and pastimes category and sleep and rest category were scored significantly different. The overall correlation between patients and caregivers on their total SIP score was +.55 but the agreement in scores tended to be greater if the caregivers and patients resided in the same household. Overall agreement levels between patients and caregivers were moderate but the sampled patients were quite disabled and could be expected to respond somewhat unreliably due to the disease process and/or treatments. The authors concluded that a surrogate respondent was warranted under such conditions.

Pagel et al. (1985) and Pagel et al. (1987) assessed the functional status of a sample of Alzheimer patients by asking their spouses to respond to the SIP items as they described the dementia patient. Their utilization of this instrument combined with the previously cited evidence suggests that surrogate responses are warranted particularly with a disease such as dementia.

The SIP had two functions in the present study. First, scores were used as a control for the patient's functional status. Experiences of caregivers could be substantially different if, for example, some patients were bedridden while others were ambulatory. Further, any differences attributed to caregiver gender would be more accurate in light of possible patient functional differences. A second function of the SIP scores was to determine the relationship between impairment and caregiver burden. The SIP provided a uniform functional status description of both patients and caregivers that could be examined in relation to caregiver burden measures.

<u>Objective Burden Scale</u>. In this measure developed by Montgomery et al. (1985), caregivers are asked to rate how their activities, health, and relationships with family members had changed since their spouse developed dementia. There are nine items that are each rated on a five-point scale. Seven items range from a "lot more" to a "lot less" and two items range from a "lot better" to a "lot worse". These items have been identified by previous researchers as those areas most frequently affected by the caregiving experience. The total score is calculated by adding scores on each item and indicates the extent of changes (impact) in various aspects of the caregiver's life. Scores range from 9 - 45.

As this instrument is relatively new, reliability levels have not been well established. Reliability in a sample of predominantly adult children caregivers was established at .85 (Montgomery et al., 1985). This measure was not validated by Montgomery et al. and has not yet been validated in other research. However, it appears to have face validity in describing possible changes in activities, health, and relationships after a partner develops dementia.

<u>Subjective Burden Scale</u>. In this measure developed by Montgomery et al. (1985), caregivers are asked how often they have experienced certain feelings and attitudes related to their caregiving experience. The scale contains 13 items based on Zarit et al.'s (1980) unidimensional burden measure. Caregivers indicate the frequency of various feelings they have experienced on a five-point scale ranging from "rarely or never" to "most of the time". Most of the items are phrased negatively (e.g., I feel strained in my relationship with my spouse) but three items are phrased positively (e.g., I feel useful in my relationship with my spouse) and scored accordingly. The total score is calculated by adding the values for each item and indicates the caregiver's attitudes or emotional reactions to the caregiving experience. Scores range from 13 - 65.

In a sample of predominantly adult children caregivers, the reliability was established at .86 (Montgomery et al., 1985). This

scale has not yet been validated but appears to have face validity in assessing a range of different feelings associated with caregiving.

As items from the Objective and Subjective Burden Scales were read to the caregivers, a separate sheet containing the possible selections for each item was provided. In addition, selections were read by the researcher to make certain that caregivers were aware of all choices.

Montgomery et al. (1985) suggested that while objective and subjective burden were moderately related in their sample (+.34), the measures appeared to be assessing different phenomena. Therefore, the distinction between objective and subjective burden appears to be warranted and provides more descriptive information pertaining to caregiving than a unidimensional burden measure could.

<u>Social Network List (SNL)</u> (see Appendix B). This measure was adapted from an instrument designed by Fiore et al. (1983). Their instrument required caregivers of dementia patients to "list all those people who are important to you at this time in your life whether you like them or not and with whom you have some sort of contact" (p.429). These instructions were modified in three ways for the SNL.

First, "contact" was operationally defined as telephone calls, letters, and/or personal visits. Consequently, network contact was not confined to personal visits. Fiore et al. (1983) did not include an operational definition of contact in their measure. Secondly, network contact was limited only to the prior month as this was the time frame Stokes (1983) suggested as most appropriate for network assessment. This restriction limited network composition to recently contacted members and thereby excluded people with whom the caregiver seldom associated. Fiore et al. did not include a time frame in their measure. The third modification to their instrument was the division of the social network into subnetworks. Fiore et al. did not differentiate network members and their respondents were required to include all family members regardless of contact frequency. In the SNL, the social network was divided into spouse, family, friend, and formal subnetworks. For each subnetwork, caregivers supplied the member's initials, gender, relationship, closeness on a 100 point scale, and contact frequency.

The SNL assessed social embeddedness and yielded two structural measures in addition to providing the framework for the second interview. The size of each subnetwork was obtained by adding the number of people listed in each one. The second structural measure, frequency of contact, was weighted on the basis of monthly contact. Fiore et al. (1983) used a similar weighting system whereby contact frequency was weighted as follows: daily = 28; several times/week = 12; once/week = 4; a couple of times/month = 2; once/month = 1. The contact frequency of each subnetwork was calculated by adding all contact values within each subnetwork. The mean contact frequency was calculated by dividing the subnetwork contact frequency by the number of subnetwork members.

<u>Enacted and Perceived Support Form</u> (EPSF) (see Appendix C). Enacted and perceived support were included together in this measure designed by the researcher on the basis of research by Cohen and Wills (1985), Barrera and Ainlay (1983), and Fiore et al. (1983). The four categories of enacted support chosen for this instrument were based on Cohen and Wills' extensive literature review. Fiore et al. included these categories and added a fifth (self-disclosure) in their research with caregivers. However, self-disclosure has not been as well documented as

the other four categories and was not included in the EPSF.

Definitions of enacted support were based on those used by Fiore et al. Socializing was defined as being with others in enjoyable non-problem oriented interactions. Tangible assistance was described as the provision of various types of behavioral services or assistance with tasks. Cognitive guidance was described as assistance that clarified or furthered the caregiver's understanding of problems. Emotional support was defined as enabling the caregiver to feel cared about, understood, praised, sympathized with, and/or gave the sense that the network member would provide help in any way possible. Examples of each type of support were given to assist caregivers in understanding each category.

Other inventories of supportive behavior were available (e.g., Inventory of Social Supportive Behaviors, Barrera & Ainlay, 1983) but they would be very time consuming as caregivers would have to rate each behavior for each network member. Therefore, the EPSF contained descriptions of enacted support categories with examples of behaviors rather than a series of specific behaviors.

The first category of enacted support (socializing) was described and respondents were provided with a written description to facilitate their understanding. Caregivers were then asked how frequently they had received socializing support from each subnetwork member (to a maximum of the 10 closest subnetwork members as determined by the closeness scale on the SNL) in the preceding month. Caregivers were able to choose between the SNL contact frequencies (daily, several times/week, once/week, a couple of times/month, once/month) in addition to the choice of "never". (This selection was not included in the SNL because by definition, caregivers had to have contact with persons included in the SNL.) Contact frequencies were weighted in the same fashion as in the SNL and the "never" selection was given a value of 0.

Fiore et al. (1983) did not assess enacted support occurrence in their study but they did assess perceived support for each of the categories. Caregivers of dementia patients in their study indicated on separate six-point scales the degree to which they perceived each network relationship to be helpful and upsetting. Helpfulness ratings ranged from one (not helpful) to six (very helpful). Similarly, upset ratings ranged from one (not upset) to six (very upset). The same scales of perceived helpfulness and upset were used in the EPSF but "upset" was operationally defined as that due to unmet expectations. Fiore et al. also included negative interactions in their definition of upset thereby confounding this concept. Unmet expectations were chosen as the variable of interest in the EPSF because they had not been previously isolated or assessed.

After caregivers indicated the occurrence of socializing with subnetwork members (as indicated on the SNL), caregivers were asked how helpful each relationship was on a six-point scale ("not at all" to "extremely") with respect to socializing. Upon completion of helpfulness ratings, caregivers were instructed to rate how upsetting each relationship was on a six-point scale with respect to socializing.

After completing the helpfulness and upset ratings for socializing, the second category of enacted support (tangible assistance) was described. The same procedure was followed as described above for socializing and was repeated again for both of the remaining enacted support categories (cognitive guidance and emotional support).

It was possible to obtain the total and mean occurrence of each

enacted support category from each subnetwork in the EPSF. Further, the occurrence of each type of support was calculated by collapsing subnetworks (excluding spouses) and the amount of support given by each subnetwork was determined by collapsing the types of support. The total occurrence of each enacted type of support was calculated by adding all subnetwork contact (excluding spouses) within each type of support. The mean occurrence of each enacted type of support was calculated by dividing the total contact by the number of subnetwork members. Similarly, the total and mean occurrence of support (collapsing types of support) from each subnetwork were calculated. Subnetwork contact across all types of support was added for an indication of total subnetwork support and divided by the number of subnetwork contacts to obtain the mean level of subnetwork support.

Furthermore, the EPSF permitted examination of combinations of support categories and sources of support in relation to enacted support. For example, it was possible to address whether the spouse, family, friend, and formal subnetworks differed in the amount of emotional support they provided. In addition, the EPSF enabled comparisons of enacted support categories within each subnetwork (e.g., does the family provide different amounts of socializing, tangible, cognitive, and emotional support to caregivers?). Similarly, questions addressing combined types and sources of support in relation to perceptions of support categories and subnetworks could be examined.

Mean scores for perceived helpfulness and upset for each support category and subnetwork were calculated in a similar fashion as the enacted support calculations. Fiore et al. (1983) calculated mean ratings across network members for each of their support categories.

Mean perception ratings were similarly calculated in the EPSF - with the addition of mean perception ratings for each subnetwork as well.

<u>Helpfulness Ratings and Expectations of Enacted Support</u> <u>Questionnaire</u> (see Appendix D). This questionnaire was designed by the researcher to provide exploratory information pertaining to caregiver perceptions of enacted support and caregiver expectations of their subnetworks. Each category of enacted support was explained and a description sheet with behavioral examples was provided to ensure clarification.

Caregivers were asked which support category was most helpful and which was least helpful to them at the present time. Further questions addressed which categories of support they most and least expected from their spouse, family, friend, and formal subnetworks. Caregivers then indicated which subnetworks they most and least expected to provide each category of enacted support. Finally, caregivers were asked to describe services which they thought would help them look after their spouse.

<u>Respite Questionnaire</u> (see Appendix E). This questionnaire was designed by the researcher to provide information about a specific example of tangible assistance - respite. The number of respite hours during the previous month was ascertained along with the source of respite. In a series of open-ended questions, caregivers were asked to describe what they did when afforded respite, whether they would like more respite than they currently received, and the degree to which they would like to "get out" more. Finally, caregivers described what activities they would like to do more than they were currently able to.

<u>Perceived Benefits of Caregiving Questionnaire</u> (see Appendix F). This questionnaire contained open-ended questions and was designed by

the researcher to explore positive aspects of caregiving. Caregivers were asked to describe any positive aspects related to providing care for their spouses. They were also asked why they had opted for home care as opposed to institutional care.

Procedure

Names of volunteers who met the eligibility criteria were gathered by health care professionals and passed on to the researcher who in turn contacted the volunteers and arranged for an interview. To avoid subject fatigue, most (35) caregivers were interviewed twice within one week. Three caregivers (two males and one female) preferred a single interview because of convenience and/or forthcoming extended vacations. Almost all interviews were conducted in the caregiver's home to reduce caregiver travel expenses and inconveniences. One male and one female caregiver requested interviews in other locations and were accommodated.

<u>First interview.</u> Every effort was made to ensure each participant's confidentiality in compliance with requirements set by the University of Calgary Faculty of Education Research Ethics Review Committee, the University of Calgary Medical Ethics Committee, and other agencies. As described previously, client confidentiality was assured during identification procedures. Caregivers agreeing to participate were given identification numbers and the master sheet containing matching names and numbers was destroyed upon completion of the study. Upon initial contact in the first interview, participants signed a consent form containing information about the nature of the study and assurances of confidentiality. Participants were assured that they could withdraw from the study at any time and could refuse to answer any question without any adverse effect on health services they could be receiving.

After the consent form was signed, caregivers were asked several background questions pertaining to themselves and their spouses from the Background Information Questionnaire. Caregivers were then asked to provide a description of both their own and their spouse's functional status on the SIP. The SIP directions and items were read and caregivers were instructed to respond to each item first as it described their behavior and secondly, as it described their spouse's behavior. Following completion of the SIP, caregivers were asked to indicate their level of burden. The Objective Burden Scale was presented first followed by the Subjective Burden Scale.

The final component of the first interview concerned the caregiver's social network. The directions of the SNL were read to caregivers. To make certain that they understood the directions, the researcher asked for an example from each subnetwork and asked them to fill in the appropriate blanks. When it appeared that the caregivers understood the directions, they were instructed to complete the remainder of the SNL before the second interview. Caregivers were given the researcher's phone number to call if problems arose. They were asked to complete the SNL within one week and a second interview appointment was scheduled.

In summary, the following instruments were administered during the first interview: Background Information Questionnaire, Sickness Impact Profile, Objective and Subjective Burden Scales, and Social Network List. Interview lengths ranged from 50 minutes to 2.5 hours with most lasting 1.5 hours.

<u>Second interview</u>. At the beginning of the second interview, the researcher examined the SNL to check for thoroughness and correctness. Due to time restrictions, a maximum of the 10 closest persons (based on

the SNL closeness scale) from each subnetwork were included in the description of enacted and perceived support. The initials of each subnetwork member were written on the EPSF and information about each member's provision of enacted support and the caregiver's perceptions of it were obtained. Positive perceptions (helpfulness) and negative perceptions (upset) were assessed separately. After completing the EPSF, caregivers described which types of support were most helpful and described their enacted support expectations from subnetworks on the Helpfulness Ratings and Expectations of Enacted Support Questionnaire. Following this questionnaire, caregivers provided information about the respite they received on the Respite Questionnaire. Finally, caregivers described any positive experiences associated with caring for a spouse in the Perceived Benefits of Caregiving Questionnaire.

In conclusion, the second interview consisted of questions contained in the Enacted and Perceived Support Form, Helpfulness Ratings and Expectations of Enacted Support, Respite Questionnaire, and the Perceived Benefits of Caregiving Questionnaire. The length of this interview was longer than the first and was largely contingent upon the size of the caregiver's network. Most second interviews lasted approximately one and three-quarter hours ranging from one to three hours. All interviews took place between June and November, 1988. Research Design

The design was nonexperimental as in an experimental design, the researcher directly controls the situation experienced by the participants (Cozby, 1977). In the present study, it was obviously impossible to control several of the observed variables such as patient and caregiver impairment; caregiver burden; or the amount, type, and source of support received by caregivers. However, these variables could be observed as they occurred naturally. Descriptive and exploratory designs are warranted when the literature is at a formative stage (Depner et al., 1984) which reflects the present status of the caregiving literature in regard to the variables employed in the present study.

The importance of observing and reporting the nature of the caregiver's experience in light of social support was emphasized by Cantor (1983). She observed that the type and source of support were concepts that required further study and were important in developing and/or modifying services. The nonexperimental approach used in the present study was useful in providing exploratory information about caregiver experiences that could assist formal care providers. The present study's design also provides a foundation for future studies. Data Analysis

Given the exploratory nature of the present study, data were examined with inferential and descriptive statistics. All inferential statistics were analyzed with SPSS and BMDP computer programs.

Two variables, residence status and dementia diagnosis, were introduced during the sampling procedure. Possible demographic and dependent variable differences in relation to residence (i.e., large vs. small urban centers) and dementia diagnosis (i.e., SDAT vs. MID) were analyzed in a series of t-tests in a preliminary analysis of the data. To ascertain if male and female caregivers and demented spouses differed on demographic data or functional status, further preliminary t-tests were conducted. Other dependent variable differences in relation to caregiver gender were addressed by the research questions.

After completing the preliminary analysis, the research questions presented in Chapter Two were addressed. Question 1.1.1 concerned caregiver gender differences in objective and subjective burden and was analyzed with t-tests. A series of questions addressed burden measure relationships with: patient and caregiver impairment (1.2.1 & 1.2.2), network size and contact frequency (1.3.1 & 1.3.2), subnetwork size and contact frequency (1.3.3 & 1.3.4), type of enacted support (1.4.1), respite hours (1.5.1), perceptions of enacted support categories (1.6.1 & 1.6.2), subnetwork enacted support (1.7.1), and perceptions of subnetworks (1.8.1 & 1.8.2) for male and female caregivers. All of these questions were analyzed with Pearson product-moment correlations conducted separately for male and female caregivers. Several questions pertained to the prediction of burden measures for males and females from impairment assessments (1.2.3), subnetwork embeddedness measures (1.3.5), type of enacted support (1.4.2), perceptions of support categories (1.6.3), subnetwork enacted support (1.7.2), and perceptions of subnetworks (1.8.3). These questions were analyzed with separate stepwise multiple regressions for male objective burden, female objective burden, male subjective burden, and female subjective burden.

Gender and subnetwork size differences (2.1.1) were analyzed with a 2X3 repeated-measures ANOVA containing a grouping factor (gender) and a within factor (subnetwork size - family, friend, and formal). Gender and subnetwork contact frequency differences (2.1.2) were examined with a 2X3 repeated-measures ANOVA containing a gender grouping factor and a subnetwork contact frequency within factor. Gender and enacted support category differences within each subnetwork (2.2.1) were analyzed by a 2X4 repeated-measures ANOVA for each of the four subnetworks. Caregiver

gender was a grouping factor and the enacted type of support was a within factor (socializing, tangible, cognitive, and emotional) for these analyses. Differences in caregiver gender and perceptions of support categories were also examined within each subnetwork (2.2.2 and 2.2.3). A 2X2X4 repeated-measures ANOVA with a gender grouping factor, perception trial factor (helpfulness and upset ratings), and support category trial factor was conducted within each subnetwork.

Gender and subnetwork enacted support differences within each type of support (2.3.1) were examined with a 2X4 repeated-measures ANOVA for each type of support. Caregiver gender was again a grouping factor and subnetwork (spouse, family, friend, and formal) enacted support was a within factor. Differences in caregiver gender and perceptions of subnetworks within each support category were examined (2.3.2 & 2.3.3) with separate 2X2X4 repeated-measures ANOVAs. Gender was a grouping factor and perception and subnetworks were trial factors.

When significant <u>F</u> values for ANOVAs were obtained, the Newman-Kuels method of multiple comparisons was employed to determine significant differences between means. This method of mean comparisons risks a type-I error of \propto for each pair of comparisons rather than on the entire set or family of comparisons (Glass & Hopkins, 1984). Consequently, the Newman-Kuels has greater power than family comparisons but makes more type-I errors. In the present study, \propto was set at .01 rather than .05 to reduce the likelihood of committing type-I errors.

The remaining questions were examined descriptively because the nature of the questions was open-ended and they were not designed to be analyzed with inferential statistics. Respite sources (2.4.1) were described according to subnetwork categorizations. Caregiver helpfulness perceptions of support categories (2.5.1), caregiver support category expectations within subnetworks (2.5.2), and caregiver subnetwork expectations within support categories (2.5.3) results were presented descriptively as percentages of male and female caregivers choosing each selection. Current and desired respite activities (2.6.1 & 2.6.2) were presented descriptively according to similarities in activities (i.e., shopping and banking were collectively described as errands). Finally, positive perceptions of providing care (3.1.1) and reasons for providing home care (3.2.1) were presented descriptively according to evident themes contained in the responses of caregivers. Summary

Most of the 38 caregivers, divided into equal numbers of male and female caregivers, were interviewed twice in their own homes. The interviews were structured and based on several instruments assessing background information, caregiver and demented spouse impairment, objective and subjective burden, enacted and perceived types of support, enacted subnetwork support and perceptions of subnetworks, support and subnetwork expectations, respite activities, and positive aspects of the caregiving experience. The present study provided exploratory data that could be examined with inferential and descriptive statistics.

CHAPTER FOUR

RESULTS

Three variables (residence, dementia diagnosis, and gender) were examined to determine their influence on the data. Results for the research questions follow this preliminary analysis.

Preliminary Analysis of Demographic Data

As the sample contained residence and dementia diagnosis differences due to the sampling procedure, these variables were examined in relation to demographic and dependent variables. The demographic variables selected for comparison of the residence groups (large urban vs. small urban centers) and diagnosis groups (SDAT vs. MID) included: caregiver and dementia patient age and education, number of years married, number of co-residents, total number of children, number of children in close proximity (less than one half hour drive away), and length of diagnosis. The dependent variables analyzed with respect to the residence and diagnostic groups included: caregiver health self-ratings, dementia patient and caregiver physical and psychosocial SIP scores, objective and subjective burden, network and subnetwork sizes, network and subnetwork contact frequencies, types and sources of support, perceptions of types and sources of support, and the number of respite hours.

Male and female caregiver differences were also addressed in relation to all of the demographic variables listed above, health self-ratings, and SIP dependent variables. All of the other dependent variables listed above were addressed in the research questions. The preliminary analysis of the selected variables in relation to gender was undertaken to determine the degree of group similarity on these variables before examining gender differences in relevant research questions.

A series of t-tests was conducted to determine if there were significant differences between the two residence groups, two diagnosis groups, and gender groups on the selected variables described above. As the risk of making a Type 1 error increases with the number of t-tests conducted, the probability level of .01 was established as the level of significance for all t-tests. All t-test probabilities were two-tailed. <u>Residence</u>

Caregivers from the cities of Calgary and Edmonton ($\underline{n} = 23$) were compared to caregivers who resided in smaller cities and towns ($\underline{n} = 15$). T-test results indicated that there were no significant caregiver or patient differences between residence groups in relation to the demographic variables. The two groups did not differ significantly on any caregiver or patient dependent variable except for caregiver psychosocial impairment, $\underline{t}(36) = 2.77$, $\underline{p}<.01$. Mean psychosocial impairment levels were significantly lower for caregivers living in large cities than in smaller centers ($\underline{Ms} = 3.54\%$ and 7.75% respectively).

The mean psychosocial impairment levels of both groups were quite low (i.e., less than 8% of the total possible score) indicating that the sampled caregivers in both large and small Alberta centers were relatively healthy. Although there was a significant residence difference on this measure, there were no other significant demographic or dependent variable differences between residence groups. This suggested that residence had a negligible effect on the selected variables. Consequently, residence was excluded from further analysis.

Dementia Diagnosis

Most of the demented spouses were diagnosed with SDAT ($\underline{n} = 28$) while the remaining 10 were diagnosed with MID. Eleven males and 17 females were diagnosed with SDAT while eight males and two females were diagnosed with MID. To determine if the caregivers of SDAT partners differed from MID partners, several t-tests were conducted on the caregiver and patient demographic and dependent variables listed previously.

No significant differences were obtained for any demographic variable in comparing SDAT and MID caregiver groups. Dependent measure differences were also nonsignificant suggesting the diagnostic variable did not confound the data. Consequently, it was collapsed in further analyses.

<u>Gender</u>

The two groups of male and female caregivers were compared with t-tests on the demographic variables described previously (the means for most of these variables are presented in Table 1). Husband and wife caregivers and their demented partners did not differ significantly on demographic variables, health ratings, or impairment levels. Further, demented spouses had similar impairment levels. The observed demographic and impairment similarities between the two groups therefore reduced the influence of these potential confounding effects in further analyses of gender differences.

Question Results

Results for each of the study questions are presented in order of their appearance in the second chapter. The results of questions pertaining to the first study focus, relationships between burden and

selected variables, are presented. These are followed by results related to the second focus, caregiver social networks. Finally, positive perceptions of the caregiving experience are presented. <u>Relationships Between Burden and Selected Variables</u>

The first focus of the study addressed relationships between the type of burden and: gender, impairment, embeddedness, enacted support, respite hours, perceptions of enacted support, sources of enacted support, and perceptions of support sources. It should be noted that objective and subjective burden were not significantly related for males $(\underline{r} = -.14, \underline{p} > .05)$ or females $(\underline{r} = .35, \underline{p} > .05)$.

<u>Caregiver gender</u>. Question 1.1.1 was concerned with possible caregiver gender differences in relation to objective and subjective burden. T-test results indicated that there were no significant differences in the degree of objective burden experienced by male and female caregivers ($\underline{M}s = 33.0 \& 33.1$ respectively). Similarly, there were no significant differences between male and female caregivers in subjective burden ($\underline{M}s = 24.1 \& 27.4$ respectively).

<u>Impairment</u>. Question 1.2.1 addressed the relationships between burden measures and dementia partner impairment. As evidenced in Table 2, male and female objective burden was not significantly related to the demented partner's level of physical or psychosocial impairment. A second impairment criterion, length of diagnosis, was not significantly related to objective burden for males but was for females, $\underline{r} = .53$, $\underline{p} < .05$.

Subjective burden was not significantly related to the partner's physical impairment for either gender. Subjective burden was significantly related to the partner's level of psychosocial impairment

Table 2

<u>Correlations Between Caregiver (CG) Burden Scores and Impairment and</u> <u>Network Structural Measures</u>

Measure	Objective Burden		Subjective Burden	
	Male	Female	Male	Female
 DP ^a physical impairment ^b	.25	20	22	23
DP psychosocial impairment ^b	.41	.15	.15	.47*
Length of dementia diagnosis	34	.53*	23	.39
CG physical impairment ^b	.38	.26	.23	.17
CG psychosocial impairment ^b	.17	.04	.38	.23
Network size	12	21	.03	02
Network contact frequency	13	.15	.36	.15
Subnetwork size				
Family	28	22	.13	.03
Friend	09	14	02	15
Formal	.23	.04	08	.19
Subnetwork contact frequency				
Family	40	.26	.55*	.21
Friend	05	28	03	06
Formal	.17	.03	.00	14

^aDemented Partner. ^bSickness Impact Profile.

*<u>p</u><.05.

for females only, $\underline{r} = .47$, \underline{p} <.05. Diagnosis length was not significantly related to subjective burden for males or females.

The relationships between burden measures and caregiver impairment measures were examined in question 1.2.2. Objective and subjective burden were not significantly related to the caregiver's physical or psychosocial impairment for either gender (Table 2).

Stepwise multiple regression analyses were conducted to determine which impairment measures best predicted (a) male and female objective burden and (b) male and female subjective burden (question 1.2.3). Patient physical and psychosocial impairment levels, length of diagnosis, and caregiver impairment levels were entered into the equations. In addition, caregiver ages and the number of respite hours were entered as control factors.

None of the impairment or control variables accounted for a significant amount of variance in male objective burden. However, the length of the partner's diagnosis predicted female objective burden, $\underline{F}(1,17) = 6.59$, \underline{p} <.05. The relationship, $\underline{r} = .53$, accounted for 28% of the total variance in female objective burden.

None of the impairment or control variables accounted for a significant amount of variance in male subjective burden. Female caregiver subjective burden was predicted by the partner's psychosocial impairment, $\underline{F}(1,17) = 4.87$, $\underline{p}<.05$ and length of diagnosis, $\underline{F}(2,16) = 6.68$, $\underline{p}<.01$. The former relationship ($\underline{r} = .47$) accounted for 22% of the variance while the latter relationship ($\underline{r} = .49$) accounted for an additional 23% of the total variance in female subjective burden.

<u>Embeddedness</u>. Questions 1.3.1 and 1.3.2 pertained to the relationships between burden and social network embeddedness measures.

Results are displayed in Table 2. The caregiver's network size and network contact frequency was not significantly related to objective or subjective burden for male or female caregivers. To provide more detailed network structural information, subnetworks were examined (questions 1.3.3 and 1.3.4). None of the three subnetwork sizes was significantly related to male or female caregiver burden measures. Contact frequency with subnetworks was not significantly related to objective burden for either gender or to female subjective burden. However, male subjective burden was significantly related to contact with family members, $\underline{r} = .55$, $\underline{p} < .05$.

The frequency of contact was assessed by adding the monthly contact frequencies for all subnetwork members. Consequently, it could be affected by the subnetwork size. To address this possible confounding effect, the mean contact frequency for each subnetwork was calculated. Relationships between mean subnetwork contact frequencies and burden paralleled the results for subnetwork contact frequencies reported above. The only significant relationship was between mean family contact and male subjective burden, $\underline{r} = .48$, $\underline{p} < .05$.

Subnetwork sizes, subnetwork contact frequencies, caregiver age, and respite hours were entered into a multiple regression predicting burden scores of male and female caregivers (question 1.3.5). None of the variables predicted a significant amount of variance in male or female objective burden or female subjective burden. However, family contact frequency predicted male subjective burden, $\underline{F}(1,17) = 7.34$, \underline{p} <.02. The relationship ($\underline{r} = .55$) accounted for 30% of the variance in male

Enacted support. Subnetworks were collapsed (excluding spouses) and

the enacted types of support in relation to objective and subjective burden were examined with Pearson product-moment correlations (question 1.4.1). As evidenced in Table 3, none of the enacted support categories was significantly related to objective burden for males or females or female subjective burden. However, tangible assistance was significantly related to male subjective burden, $\underline{r} = .53$, $\underline{p} < .05$.

All four types of enacted support were entered into stepwise multiple regression analyses to predict objective and subjective burden for male and female caregivers (question 1.4.2). The caregiver's age, number of respite hours, and partner's diagnosis length were also entered as control factors. For both males and females, none of the enacted support categories predicted a significant amount of variance in objective burden. For females, the length of diagnosis best predicted objective burden (as presented earlier in section 1.2.3). None of the enacted support categories predicted objective burden when diagnosis length was excluded in an additional multiple regression for females.

Male subjective burden was predicted by enacted tangible assistance, $\underline{F}(1,17) = 6.47$, $\underline{p}<.05$ and the length of diagnosis, $\underline{F}(2,16) = 6.36$, $\underline{p}<.01$. Enacted tangible assistance accounted for 28% of the variance (\underline{r} = .53) and diagnosis length accounted for an additional 17% of the variance in subjective burden ($\underline{r} = -.43$). None of the variables accounted for a significant amount of variance in female subjective burden.

<u>Respite</u>. The approximated number of respite hours that caregivers had received during the month ranged from 0-200 ($\underline{m} = 46.74$). As evidenced in Table 3, the number of respite hours was not significantly related to either burden measure for males or females (question 1.5.1).

Table 3

Correlations Between Caregiver Burden and Enacted Types of Support and Perceptions of Support Categories

Measure	Objective Burden		Subjective Burden	
	Male	Female	Male	Female
Enacted support category ^a				
Socializing	23	.05	.31	.14
Tangible	.08	.13	.53*	03
Cognitive	22	.17	.42	.32
Emotional	07	.14	.14	.09
Total respite hours	17	40	01	07
Support category helpfulness ratingsa				
Socializing	57*	07	.17	14
Tangible	17	01	.37	30
Cognitive	27	.32	.20	08
Emotional	30	.34	.23	01
Support category upset ratings ^a				
Socializing	40	25	.67**	27
Tangible	01	24	.27	06
Cognitive	01	07	17	.07
Emotional	27	32	12	27

.^aCollapsed subnetworks excluding the spouse.

*<u>p</u><.05. **<u>p</u><.01.

<u>Perceptions of enacted support</u>. Subnetworks (excluding spouses) were collapsed in examining the relationships between burden measures and enacted support category perceived helpfulness and upset (questions 1.6.1 & 1.6.2). Results contained in Table 3 indicate that male objective burden and socializing support helpfulness ratings were significantly related, $\underline{r} = -.57$, $\underline{p} < .05$. Support category helpfulness ratings were not significantly related to female objective burden or to subjective burden for either gender. Support category upset ratings were not significantly related to objective burden for either gender or to female subjective burden. However, socializing upset ratings were significantly related to male subjective burden, $\underline{r} = .67$, $\underline{p} < .01$.

Helpfulness and upset ratings of support categories along with the control factors were entered into stepwise multiple regression analyses to predict objective and subjective burden for male and female caregivers (question 1.6.3). Male objective burden was predicted by socializing helpfulness ratings, $\underline{F}(1,17) = 8.35$, $\underline{p}<.01$ and caregiver age, $\underline{F}(2,16) = 16.92$, $\underline{p}<.001$. The former accounted for 33% of the variance ($\underline{r} = -.57$) and the latter for an additional 39% of the variance in male objective burden ($\underline{r} = .63$). Female objective burden was predicted by their partner's diagnosis length as reported previously (1.2.3). Support category perceptions did not account for a significant amount of variance in female objective burden when this variable was excluded from a second multiple regression analysis.

Male subjective burden was best predicted by socializing upset ratings, $\underline{F}(1,17) = 13.64$, $\underline{p}<.01$. Of the total variance in subjective burden, 45% was accounted for by this variable ($\underline{r} = .67$). None of the variables entered into the regression equation accounted for a

significant amount of variance in female subjective burden.

<u>Sources of support</u>. Support categories were collapsed to examine the relationships between caregiver burden and the sources of enacted support for males and females (question 1.7.1). The results contained in Table 4 demonstrate that the amount of support from each subnetwork was not significantly related to objective burden for either gender or to female subjective burden. The relationship between male subjective burden and support received from the family was significant, $\underline{r} = .54$, $\underline{p} < .05$.

The enacted support received from each subnetwork and the control factors were entered into stepwise multiple regression analyses to predict male and female burden measures (question 1.7.2). None of the variables accounted for a significant amount of objective burden for males. As evidenced previously (1.2.3), diagnosis length best predicted female objective burden. None of the variables accounted for a significant amount of variance in female objective burden after removal of diagnosis length in an additional regression.

Male subjective burden was predicted by the amount of support received from families, F(1,16) = 7.13, p<.02. The relationship (r = .54) accounted for 30% of the total variance. None of the variables accounted for a significant amount of female subjective burden.

<u>Perceptions of support sources</u>. The last questions related to burden (1.8.1 - 1.8.3) concerned the perceptions of subnetworks. As evidenced in Table 4, subnetwork helpfulness ratings were not significantly related to objective burden for either gender or to female subjective burden. Male subjective burden was significantly related to formal subnetwork helpfulness ratings, $\underline{r} = .46$, $\underline{p}<.05$. Subnetwork upset

Table 4

Correlations Between Caregiver Burden and Sources of Support and

Perceptions of Support Sources

Measure	Objective Burden		Subjective Burden	
	Male	Female	Male	Female
Subnetwork enacted support ^a	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	•		
' Spouse	26	05	.22	.07
Family	35	.26	.54*	.17
Friend	.07	21	.08	06
Formal	.21	.05	.02	.06
Subnetwork helpfulness ratings ^a				
Spouse	44	30	.38	16
Family	44	01	.12	16
Friend	39	.41	.27	.22
Formal	.17	.03	.46*	12
Subnetwork upset ratings ^a				
Spouse	27	.12	.51*	05
Family	25	09	.30	13
Friend	33	34	.68**	27
Formal	02	45	.19	19

^aTypes of support collapsed.

*<u>p</u><.05. **<u>p</u><.01

ratings were not significantly related to objective burden for husband or wife caregivers or to female subjective burden. In contrast, male subjective burden was significantly related to spouse and friend upset ratings ($\underline{r} = .51$, \underline{p} <.05 and $\underline{r} = .68$, \underline{p} <.01 respectively).

Helpfulness and upset ratings of subnetworks and the control factors were included in stepwise multiple regression analyses to determine if any of them accounted for variance in male and female burden measures (1.8.3). All variables were nonsignificantly related to male objective burden. Aside from the length of dementia diagnosis (1.2.3), variance in female objective burden was not accounted for by any of the variables entered into the equation. An additional regression analysis excluding diagnosis length yielded similar results.

Friend upset ratings best predicted male subjective burden, F(1,17)= 14.41, p<.01. The relationship (<u>r</u> = .68) accounted for 46% of the variance in subjective burden. No other variables were entered into the equation. Female subjective burden was not predicted by any of the variables included in the regression analyses.

Post-hoc Correlations

In order to determine if perceptions of helpfulness and upset were interrelated, post-hoc Pearson product-moment correlations were conducted. Correlations between helpfulness and upset ratings within support categories were all nonsignificant for both males and females. Correlations between helpfulness and upset ratings within subnetworks were nonsignificant for both genders except female perceptions of their families, $\underline{r} = -.55$, $\underline{p} < .05$.

Caregiver Social Network Descriptions

Caregiver social networks were explored in greater detail.

Caregiver gender differences and network differences were examined in terms of embeddedness, types of enacted support and perceptions of support categories within each subnetwork, subnetwork enacted support and perceptions of subnetworks within each type of support, respite sources, perceptions and expectations of subnetworks, and respite activities.

<u>Embeddedness</u>. Gender and subnetwork size differences (question 2.1.1) were assessed by a 2 X 3 repeated-measures ANOVA with a grouping factor (gender) and a within factor (size of family, friend, and formal subnetworks). There was no significant gender-subnetwork size factor interaction. While the gender main effect was not significant, the subnetwork main effect was, $\underline{F}(2,72) = 24.32$, $\underline{p}<.001$. The mean size of the formal subnetwork ($\underline{M} = 2.84$) was significantly smaller than the mean size of the family and friend subnetworks ($\underline{Ms} = 7.29$ and 7.58 respectively). The mean sizes of the family and friend subnetworks were not significantly different from each other.

A 2 X 3 repeated-measures ANOVA was conducted to examine possible gender and subnetwork differences in contact frequency (question 2.1.2). Gender was a grouping factor and contact frequency with family, friend, and formal subnetworks was a within factor. There was no significant interaction between the gender and subnetwork contact frequency factors. There was no significant gender main effect but contact frequency differed significantly between subnetworks, $\underline{F}(2,72) = 18.09$, $\underline{p}<.001$. Caregivers had significantly less contact with formal subnetwork members ($\underline{M} = 13.18$) in the month prior to the interviews than with friend and family subnetworks ($\underline{M}s = 44.00$ and 48.21 respectively). Contact with friend and family members did not differ significantly.
As subnetwork size may affect contact frequency, the total contact frequency within each subnetwork was divided by the number of subnetwork members to obtain subnetwork mean contact frequencies. A post-hoc 2 X 3 repeated-measures ANOVA similar to the one described above was conducted to examine gender and mean subnetwork contact frequency differences. Similar to the previous results, there were no interactions or gender main effects but a significant subnetwork difference emerged, E(2,72) =5.28, p<.01. Caregivers had significantly less mean contact with their formal subnetworks ($\underline{M} = 4.27$) than their family and friend subnetworks ($\underline{Ms} = 6.83$ and 7.10 respectively). Mean contact frequency with the latter two subnetworks was not significantly different. These results therefore mirror the previous results denoting differences in subnetwork contact frequencies but not between genders.

Enacted support category and perceived support category differences within subnetworks. Gender and enacted support category differences within subnetworks were examined (question 2.2.1). A 2 X 4 repeated-measures ANOVA with one grouping factor (caregiver gender) and one within factor (type of enacted support) was performed for each of the four subnetworks. Results from the four ANOVAs demonstrated that there were no significant interaction effects between gender and enacted support categories or significant gender main effects. There were support category main effects within each subnetwork. Table 5 contains the mean enacted type of support received within each subnetwork. As there were no significant gender differences, this variable was collapsed and not included in the table.

Demented partners provided significantly different amounts of support categories to caregivers, F(3,108) = 31.06, p<.001. Caregivers

Table 5

Subnetwork	Enacted support category	<u>M</u>
Spouse .	Socializing Tangible Cognitive Emotional	19.26 11.24 0.05 5.32
Family ,	Socializing Tangible Cognitive Emotional	48.21 14.68 7.53 40.29
Friend	Socializing Tangible Cognitive Emotional	44.00 8.61 3.61 38.39
Formal	Socializing Tangible Cognitive Emotional	3.55 13.18 4.71 6.97

Mean Enacted Type of Support Received Within Subnetworks

<u>Note</u>. Enacted type of support values for spouses ranged from 0 (no enacted support category contact within the previous month) to 28 (daily enacted support category contact). Enacted type of support values for family, friend, and formal subnetworks ranged from 0 (no enacted support category within the previous month) to 280 (daily enacted support category contact with each of a maximum of 10 subnetwork members). received significantly less cognitive guidance from their spouses than emotional, tangible, and socializing support. Further, they received significantly less emotional support than tangible and socializing support and significantly less tangible than socializing support from their partners.

Families also provided caregivers with significantly different amounts of enacted support categories, $\underline{F}(3,108) = 56.56$, $\underline{p}<.001$. Family members provided significantly less cognitive guidance to caregivers than all other types of support. The amount of tangible support from family members was significantly less than the amount of emotional and socializing support. Families gave the caregivers significantly less emotional than socializing support.

Friends similarly gave caregivers significantly different amounts of enacted support categories, $\underline{F}(3,108) = 45.28$, $\underline{p}<.001$. The amount of cognitive support was similar to tangible support but was significantly less than the amount of emotional and socializing support. Caregivers received significantly less tangible assistance than emotional and socializing support from friends. The amount of emotional and socializing support from friends was similar.

The formal subnetwork also provided significantly different amounts of enacted support categories to caregivers, $\underline{F}(3,108) = 10.06$, $\underline{p}<.001$. There was no significant difference in the amount of socializing and cognitive support but significantly less socializing than emotional and tangible support was provided. The amount of cognitive and emotional support given by formal subnetworks was similar but significantly less cognitive support than tangible support was given. Caregivers received significantly less emotional support than tangible support from formal

subnetworks.

Gender and perceived support category differences within subnetworks were examined as outlined in questions 2.2.2 and 2.2.3. A 2 X 2 X 4 repeated-measures ANOVA with a grouping factor (gender) and two trial factors was conducted for each subnetwork. The first trial factor, perception, had two levels (helpfulness and upset ratings) whereas the second trial factor, support category, had four levels (socializing, tangible, cognitive, and emotional).

There was a significant gender-perception-support category three-way interaction within the spouse subnetwork, $\underline{F}(3,108) = 3.13$, $\underline{p}<.05$. There were two significant two-way interactions: between gender and perception, $\underline{F}(1,36) = 7.01$, $\underline{p}<.05$ and between perception and support type, $\underline{F}(3,108) = 7.68$, $\underline{p}<.001$. The perception main effect was significant, $\underline{F}(1,36) = 39.65$, $\underline{p}<.001$ as was the support category main effect, $\underline{F}(3,108) = 22.51$, $\underline{p}<.001$ but both main effects are subsumed by the interactions.

Figure 1 demonstrates the nature of the three-way interaction for spouses. The upset ratings for socializing ($\underline{m} = 1.16$), tangible ($\underline{m} =$ 1.11), cognitive ($\underline{m} = 1.00$), and emotional support ($\underline{m} = 1.00$) were similar for males. However, female caregivers rated upset for cognitive ($\underline{m} = 1.00$) and emotional support ($\underline{m} = 1.21$) significantly lower than socializing ($\underline{m} = 1.58$) and tangible support ($\underline{m} = 1.58$). Male caregiver helpfulness ratings differed between support categories with cognitive ratings ($\underline{m} = 1.11$) significantly lower than other support category ratings. Male helpfulness ratings for emotional support ($\underline{m} = 2.05$) were significantly lower than tangible ($\underline{m} = 3.16$) and socializing support ratings ($\underline{m} = 3.95$) and the socializing ratings were significantly higher

<u>Figure 1</u>. Gender-perception-support category interaction, genderperception interaction, and perception-support category interaction within the spouse subnetwork.



Perception

Support Category

than tangible support ratings. Female helpfulness ratings for cognitive support ($\underline{m} = 1.21$) were significantly lower than other support category ratings. Helpfulness ratings for emotional support ($\underline{m} = 1.89$) were significantly lower than tangible ($\underline{m} = 2.24$) and socializing support ratings ($\underline{m} = 2.47$) while the latter two categories were rated similarly by females. For both male and female caregivers, helpfulness ratings were significantly higher than upset ratings within each support category except cognitive support. Male helpfulness ratings of socializing and tangible support were significantly higher than female ratings. Conversely, female upset ratings of these types of support were higher than male ratings.

The overall male helpfulness ratings ($\underline{m} = 2.57$) and upset ratings ($\underline{m} = 1.06$) were more varied than the ratings for females ($\underline{m}s = 1.95 \& 1.34$ respectively) as demonstrated in the gender-perception disordinal interaction in Figure 1 (as well as in the three-way interaction). In the perception-support category interaction, helpfulness ratings were higher than upset ratings within socializing support ($\underline{m}s = 3.21 \& 1.37$ respectively), tangible support ($\underline{m}s = 2.70 \& 1.34$), and emotional support ($\underline{m}s = 1.97 \& 1.11$). Cognitive support helpfulness ratings were similar to upset ratings ($\underline{m}s = 1.16 \& 1.00$). This interaction is also evidenced in the three-way interaction suggesting the pattern is similar for males and females.

The perception-support category interaction was significant within the family subnetwork, $\underline{F}(3,108) = 26.74$, $\underline{p}<.001$. The perception main effect was significant, $\underline{F}(1,36) = 188.65$, $\underline{p}<.001$ as was the support type main effect, $\underline{F}(3,108) = 35.14$, $\underline{p}<.001$. As evidenced in Figure 2, all support category upset ratings were significantly lower than all







helpfulness ratings. Support category upset ratings were not significantly different from each other unlike most helpfulness ratings. Mean upset ratings of socializing, tangible, cognitive, and emotional support were 1.23, 1.25, 1.09 and 1.16 respectively. Helpfulness ratings of cognitive support ($\underline{m} = 2.66$) were significantly lower than all other support category ratings. Tangible support helpfulness ratings ($\underline{m} = 3.78$) were significantly lower than socializing ($\underline{m} = 4.43$) and emotional support ($\underline{m} = 4.56$) ratings. However, helpfulness ratings for socializing and emotional support were not significantly different. The perception and support type main effects are both subsumed by the significant interaction.

The perception-support category interaction was significant within the friend subnetwork, F(3,108) = 19.05, p<.001. Both the perception main effect, F(1,36) = 247.64, p<.001 and the support category main effect, F(3,108) = 28.99, p<.001 were significant. The interaction in Figure 3 demonstrates that all support category upset ratings were significantly lower than support category helpfulness ratings. Socializing upset ratings $(\underline{m} = 1.28)$ were significantly higher than tangible (m = 1.06), cognitive (m = 1.05), and emotional support ratings $(\underline{m} = 1.05)$. The latter types of support were rated similarly. Cognitive support helpfulness ratings ($\underline{m} = 2.39$) were significantly lower than the other three category ratings. Tangible support helpfulness ratings (m = 3.42) were significantly lower than emotional (m = 4.19) and socializing support ratings (m = 4.43). Helpfulness ratings for emotional support were significantly lower than ratings for socializing support. Both main effects are best examined within the context of the significant interaction.

Figure 3. Perception-support category interaction within the friend subnetwork.





The perception-support category interaction was significant within the formal subnetwork, $\underline{F}(3,108) = 14.16$, $\underline{p}<.001$. The perception and support category main effects were both significant, $\underline{F}(1,36) = 139.09$, $\underline{p}<.001$ and $\underline{F}(3,108) = 15.06$, $\underline{p}<.001$ respectively. Support category upset ratings were significantly lower than helpfulness ratings as evidenced in the interaction in Figure 4. There were no significant differences between upset ratings for socializing ($\underline{m} = 1.08$), tangible ($\underline{m} = 1.17$), cognitive ($\underline{m} = 1.12$), and emotional support ($\underline{m} = 1.02$). Socializing helpfulness ratings. Emotional support helpfulness ratings ($\underline{m} = 3.39$) were significantly lower than cognitive ($\underline{m} = 3.71$) and tangible support ratings ($\underline{m} = 4.05$). Cognitive support helpfulness ratings were significantly lower than tangible support ratings. The significant interaction subsumes both main effects.

<u>Subnetwork enacted support and perceived support differences within</u> <u>support categories</u>. Gender and subnetwork enacted support differences within support categories were examined (question 2.3.1). A 2 X 4 repeated-measures ANOVA with a grouping factor (caregiver gender) and subnetwork within factor (spouse, family, friend, and formal) was performed for each category of enacted support. There were no significant gender-subnetwork interactions or gender differences in any of the four ANOVAs. There were significant subnetwork differences within all support categories except tangible support as demonstrated in Table 6.

Caregivers received significantly different amounts of socializing support from their subnetworks, $\underline{F}(3,108) = 28.15$, $\underline{p}<.001$. Caregivers received significantly less socializing from formal subnetworks than





Table 6

Mean Subnetwork Enacted Support Within Support Categories

nacted Support		
Category	Subnetwork	M
Tangible'	Spouse Family Friend Formal	11.24 14.68 8.61 13.18
Socializing	Spouse Family Friend Formal	19.26 48.21 44.00 3.55
Cognitive	Spouse Family Friend Formal	0.05 7.52 3.61 4.71
Emotional	Spouse Family Friend Formal	5.32 40.29 38.39 6.97

Ε

<u>Note</u>. Subnetwork enacted support values for spouses ranged from 0 (no enacted support category contact within the previous month) to 28 (daily enacted support category contact). Subnetwork enacted support values for family, friend, and formal subnetworks ranged from 0 (no enacted support category contact within the previous month) to 280 (daily enacted support category contact with each of a maximum of 10 subnetwork members).

other subnetworks. Significantly less socializing was received from spouses than friend and family subnetworks. The latter two subnetworks provided similar amounts of socializing support.

Subnetworks provided significantly different amounts of cognitive guidance to caregivers, $\underline{F}(3,108) = 7.86$, $\underline{p}<.001$. Caregivers received significantly less cognitive guidance from spouses than other subnetworks. Caregivers received similar amounts of cognitive guidance from their friend and formal subnetworks but received significantly less from friends than family members. Caregivers received significantly less cognitive guidance from the formal subnetwork than from family members.

Significantly different amounts of emotional support were supplied by subnetworks, $\underline{F}(3,108) = 31.43$, $\underline{p}<.001$. The amount of emotional support from the spouse and formal subnetworks were similar but spouses provided significantly less emotional support than friends and families. Formal subnetworks provided significantly less emotional support than friends and family members. The latter two subnetworks provided similar amounts of emotional support to caregivers.

Gender and subnetwork perception differences within support categories were addressed in questions 2.3.2 and 2.3.3. A 2 X 2 X 4 repeated- measures ANOVA with a grouping factor (gender) and two trial factors was conducted for each support category. The first trial factor, perception, had two levels (helpfulness and upset ratings) while the second trial factor, subnetwork, had four levels (spouse, family, friend, and formal).

Socializing support had a significant gender-perception-subnetwork interaction, F(3,108) = 5.85, p<.001. The perception-subnetwork

interaction was significant, $\underline{F}(3,108) = 29.51$, $\underline{p}<.001$. The perception main effect, $\underline{F}(1,36) = 175.81$, $\underline{p}<.001$ and the subnetwork main effect, $\underline{F}(3,108) = 38.76$, $\underline{p}<.001$, were significant but both are best examined in the context of the interactions.

Figure 5 demonstrates the nature of the three-way interaction within socializing support. The upset ratings of the spouse, family, friend, and formal subnetworks were similar for males ($\underline{m}s = 1.16, 1.17, 1.25, \&$ 1.09 respectively). However, female upset ratings of spouses (m = 1.58)were significantly higher than family, friend, and formal subnetwork ratings ($\underline{ms} = 1.28, 1.32, \& 1.07$ respectively). Subnetwork upset ratings were similar for both genders with the exception of spouses which females rated as significantly more upsetting than males. Males and females rated formal subnetwork helpfulness ($\underline{ms} = 1.69 \& 2.06$ respectively) significantly lower than other subnetworks. Further, husbands and wives rated spouses as significantly less helpful (ms = 3.95 & 2.47) than friends ($\underline{ms} = 4.36$ & 4.51) and family ($\underline{ms} = 4.42$ & 4.43). Friend and family subnetworks were rated similarly by both genders. As evidenced in the three-way interaction, spouses were rated as significantly more helpful by males than females for socializing support. Conversely, the formal subnetwork was rated significantly more helpful by females than males. As evidenced in the perceptionsubnetwork interaction (as well as in the three-way interaction) in Figure 5, helpfulness ratings were significantly higher than upset ratings within each subnetwork. This was evidenced in helpfulness and upset ratings with the spouse ($\underline{ms} = 3.21 \& 1.37$ respectively), family $(\underline{ms} = 4.43 \& 1.23)$, friend $(\underline{ms} = 4.43 \& 1.28)$, and formal subnetworks (ms = 1.87 & 1.08).

<u>Figure 5</u>. Gender-perception-subnetwork interaction and perception-subnetwork interaction within socializing support.



Gender-perception-subnetwork interaction

There was a significant perception-subnetwork interaction within tangible assistance, $\underline{F}(3,108) = 5.03$, $\underline{p}<.01$. The perception and subnetwork main effects were significant, $\underline{F}(1,36) = 221.78$, $\underline{p}<.001$ and $\underline{F}(3,108) = 3.60$, $\underline{p}<.05$ respectively. As evidenced in the interaction in Figure 6, all subnetwork upset ratings were significantly lower than helpfulness ratings. Spouse, family, friend, and formal subnetwork upset ratings were similar ($\underline{m}s = 1.34$, 1.25, 1.06, & 1.17 respectively). Helpfulness ratings of spouses ($\underline{m} = 2.70$) were significantly lower than other subnetwork ratings. Friend helpfulness ratings ($\underline{m} = 3.42$) were significantly lower than the family ($\underline{m} = 3.78$) and formal subnetwork ratings ($\underline{m} = 4.05$) which were similar. Both main effects are subsumed in the interaction.

The perception-subnetwork interaction was significant within cognitive guidance, $\underline{F}(3,108) = 25.16$, $\underline{p}<.001$. Perception and subnetwork main effects were both significant, $\underline{F}(1,36) = 115.68$, $\underline{p}<.001$ and $\underline{F}(3,108) = 31.86$, $\underline{p}<.001$ respectively. The subnetwork upset ratings were significantly lower than all subnetwork helpfulness ratings except spouses as demonstrated in Figure 7. Differences between upset ratings of the spouse, family, friend, and formal subnetworks were nonsignificant ($\underline{m}s = 1.00$, 1.09, 1.05, & 1.12 respectively). Spouse helpfulness ratings ($\underline{m} = 1.16$) were significantly lower than other subnetwork ratings. Friend helpfulness ratings ($\underline{m} = 2.39$) were significantly lower than family ($\underline{m} = 2.66$) and formal subnetwork ratings ($\underline{m} = 3.71$) and family ratings were significantly lower than formal subnetwork ratings. Main effects were best explained in the context of the interaction.

The perception-subnetwork interaction was significant within







emotional support, $\underline{F}(3,108) = 18.79$, $\underline{p}<.001$. The perception main effect, $\underline{F}(1,36) = 289.05$, $\underline{p}<.001$ and subnetwork main effect were significant, $\underline{F}(3,108) = 20.24$, $\underline{p}<.001$. Figure 8 demonstrates that all subnetwork upset ratings were significantly lower than the helpfulness ratings. Upset ratings of the spouse, family, friend, and formal subnetworks were similar ($\underline{m}s = 1.11$, 1.16, 1.05 & 1.02 respectively). Spouse helpfulness ratings ($\underline{m} = 1.97$) were significantly lower than other subnetwork ratings of emotional support. Formal subnetwork helpfulness ratings ($\underline{m} = 3.39$) were significantly lower than friend ($\underline{m} =$ 4.19) and family ratings ($\underline{m} = 4.56$). Friend helpfulness ratings were significantly lower than family ratings. Both main effects were subsumed by the interaction.

<u>Respite sources</u>. Caregivers were asked if they had received respite and if so, the source of respite as outlined in question 2.4.1. Seven males and one female stated that they had not received any respite in the previous month as their spouses accompanied them wherever they went. One husband and six wives stated that they had no one to provide respite and when they had to leave the house, they left their spouses alone. In addition, four males and eight females who recieved some respite stated that their spouses were left alone at times. The number of approximate monthly hours that caregivers' spouses were alone ranged from 2 - 40 with most caregivers stating that their spouses were alone for less than 10 hours.

Eight caregivers (five males) received respite from home care or community care agencies whereas 11 caregivers (five males) utilized day hospitals at least one day per week. Family members (predominantly adult children) provided some respite to four males and three females.





Friends provided limited respite to three males and one female.

<u>Support category perceived helpfulness and caregiver expectations</u>. Descriptive data pertaining to the categories of enacted support that caregivers reported were most helpful to them (question 2.5.1) are contained in Table 7. Approximately equal percentages of male caregivers stated that they found socializing, tangible, and emotional support most helpful to them. At least three female caregivers described each of the four types of support as most helpful.

Caregivers were asked which type of support they most expected from each of their subnetworks (question 2.5.2). As evidenced in Table 8, the types of support that husbands most expected from their subnetworks resembled what wives most expected from their subnetworks. While percentages rarely matched exactly, the pattern of responses within each subnetwork was similar for male and female caregivers. Both genders expected their spouses to primarily provide socializing and tangible support whereas the majority of caregivers expected their families to be a source of emotional support. Friends were most expected to provide socializing support, particularly by husbands. Four more wives than husbands most expected their friends to provide emotional support. Formal subnetworks were most expected to provide and tangible support by both male and female caregivers.

Caregivers described which subnetwork they most expected to provide each category of enacted support (question 2.5.3). Table 9 demonstrates that one third of the males most expected socializing support from each of the spouse, family, and friend subnetworks but the pattern was different for females. Over half of the females most expected socializing support from their family while one third of the females

Table 7

Caregiver Perceptions of the Helpfulness of Support Categories

	En	Enacted Support Category		
Caregivers	Socializing	Tangible	Cognitive	Emotional
	1.1999 Margan (1999) Margan	Most helpful	(%)	
Males	32	26	5	37
Females	21	32	16	32
Total	26	29	11	34

Note. Percentages may not total 100% due to rounding.

Table 8

Subnetwork	Types of Support				
	Socializing	Tangible	Cognitive	Emotional	
	Most expected (%)				
Spouse					
Male caregivers	53	37	0	11	
Female caregivers	58	27	0	16	
Total	55	32	0	13	
Family					
Male caregivers	16	16	11	58	
Female caregivers	s 11	16	0	74	
Total	13	16	5	66	
Friend			,		
Male caregivers	84	5	0	11	
Female caregivers	63	0	5	32	
Total	73	3	3	21	
Formal					
Male caregivers	0	42	42	16	
Female caregivers	s 0	42	47	11	
Total	0	42	45	13	

Caregiver Expectations of Enacted Support from Subnetworks

Note. Percentages may not total 100% due to rounding.

Table 9

Support Category	Subnetwork			
	Spouse	Family	Friend	Formal
	Most expected (%)			
Socializing				
Male caregivers ^a	33	33	33	· 0
Female caregivers	11	58	32	0
Total	22	46	32	0
Tangible				
Male caregivers	28	39	6	28
Female caregivers	5	32	5	58
Total	16	36	5	43
Cognitive				
Male caregivers	0	17	. 0	83
Female caregivers	0	32	0	68
Total	0	24	0	76
Emotional				
Male caregivers	6	61	22	11
Female caregivers	5	68	16	11
Total	5	65	19	11

Caregiver Subnetwork Expectations Within Support Categories

Note. Percentages may not total 100% due to rounding.

^aOne male refused to answer these questions ($\underline{n} = 18$).

reported that they most expected it from friends. Approximately one third of the males and females most expected tangible assistance from their families but there were dissimilarities between genders according to the formal and spouse subnetworks. More than half of the females and a quarter of the males most expected tangible assistance from formal subnetworks and more than one quarter of the males and only one female most expected it from their spouses. A majority of caregivers stated cognitive guidance was most expected from formal subnetworks and a minority responded with the family. Approximately two thirds of the caregivers most expected emotional support from family members.

<u>Caregiver respite activities</u>. Almost all caregivers receiving respite described several kinds of activities that they engaged in during their breaks (question 2.6.1). Most caregivers explained that they did a variety of errands such as shopping, banking, etc. Three quarters of the males and one fifth of the females who received respite took the opportunity to work in a volunteer capacity and/or to assist people in various ways. A few males and females participated in recreational activities. One fifth of the women stated that they enjoyed an opportunity to rest and relax. Half of the wives and almost one quarter of the husbands stated that they participated in social activities.

Caregivers were also asked what kinds of activities they would like to do if provided with more respite (question 2.6.2). One quarter of both the males and females stated they were content with the respite they already received. About one third of both males and females would like to travel more. Opportunities to spend time alone, rest and relax, and pursue hobbies were mentioned by half of the females but rarely by

males. A few females expressed an interest in increased shopping opportunities. One quarter of the males would like to work or volunteer more if they were provided with more respite. One quarter of the females and a few males expressed a desire to socialize more. Over one third of the males mentioned a preference for increased exercise opportunities. This preference was rarely mentioned by females. <u>Positive Perceptions of the Caregiving Experience</u>

Caregivers were asked if they could describe any benefits or positive aspects of their caregiving experience in question 3.1.1. They were also asked why they had chosen to provide home care for their spouses rather than institutionalization (question 3.2.1).

<u>Positive caregiving experiences</u>. Two males and four females stated that there was nothing positive about their caregiving experience. However, many caregivers offered more than one positive aspect about their situations. Almost one quarter of the husband caregivers felt closer to their wives than before whereas only one wife described a similar change in the relationship. Almost one quarter of the males enjoyed the increased amount of time spent with their spouses and some caregivers gained satisfaction and/or pride in helping their spouses.

Some caregivers (primarily wives) noted positive changes in their spouse's behavior. Examples included a more gentle manner, an increased desire to be more helpful and to please the caregiver, decreased domineering characteristics, and increased mortality references leading others to think more about their own mortality. Several caregivers (predominantly wives) mentioned that they had changed in positive ways through their caregiving experiences. For example, some mentioned the emergence of underlying strengths, growing self-confidence levels,

resourcefulness, greater independence in making decisions, greater patience, less selfishness, more caring, and greater empathy. A few caregivers were philosophic about their experiences as exemplified by some becoming resigned to accept things as they came because there was "nothing else you can do". Others lived for the present rather than worrying about the next day.

<u>Home care vs. institutionalization</u>. A wide variety of responses was offered by caregivers when asked why they had chosen home care for their spouses. In many cases, institutions were seen as last resorts. Reasons for this were diverse but some caregivers mentioned that they feared what would happen to their spouses if institutionalized. For example, caregivers feared their spouses would: rapidly deteriorate in their functioning capabilities, feel abandoned, or exhibit embarrassing behaviors in a public place. A few caregivers felt their spouses would receive better care and/or more attention at home than anywhere else. Some caregivers felt their spouses were happy at home and it was important to these caregivers to maintain their spouse's happiness. Others felt that their spouses were presently too healthy to enter nursing homes.

A few caregivers appreciated the conveniences of living with their spouses as they did not have to travel to visit them. Almost one quarter of the males but none of the females mentioned that they appreciated their wives' company and felt it was important to be together. Just over one tenth of the caregivers viewed home care as a continued fulfillment of their wedding vows ("for better or for worse, in sickness and in health"). Others added that it was their duty or job to provide care for their spouses.

Summary of Results

In the first study focus, burden measures were examined in relation to several variables. Analyses suggested there were no gender differences in the levels of objective and subjective burden. However, male and female burden levels were predicted by different variables. Patient impairment predicted female objective burden (length of dementia diagnosis) and subjective burden (psychosocial impairment) but neither of the burden measures for males. Caregiver impairment was not related to burden measures. None of the network structural or functional properties was related to female burden levels. One embeddedness measure (family contact frequency) and one type of enacted support (tangible assistance) predicted male subjective burden. Perceived helpfulness ratings of socializing support predicted male objective burden whereas perceived upset ratings of socializing support predicted male subjective burden. When sources of support were examined, family subnetwork enacted support and perceived upset with friends predicted male subjective burden.

The second study focus addressed caregiver social networks in greater detail. Embeddedness measures differed as formal subnetworks had fewer members and caregivers had less contact with these members than with family and friend subnetworks. Network functional measures pertaining to the types and sources of support were also assessed. Enacted support category differences emerged within each subnetwork. Helpfulness ratings of support categories were more varied than upset ratings within subnetworks. Caregiver gender interacted with support category perceptions in the spouse subnetwork but not in any other subnetwork. Support categories were examined individually and analyses indicated that subnetworks provided caregivers with different amounts of support with the exception of tangible assistance. Helpfulness ratings of subnetworks were more varied than upset ratings within support categories. Subnetwork perceptions were similar for males and females within each support category except socializing where gender interacted with perceptions and subnetworks.

Several questions yielded descriptive data. A larger number of males than females brought their demented partners with them on outings and indicated they had little need for respite. Of those caregivers receiving respite, males and females received it predominantly from formal subnetworks. None of the support categories was selected by a majority of caregivers as being most helpful to them. Caregiver subnetwork expectations in relation to the expected enacted types of support were varied as were support category expectations in relation to the expected subnetwork providers of support. Finally, there was a variety of current and desired activities that caregivers engaged in (or wished to be engaged in) when afforded respite. A larger number of males than females described work-related activities in response to these latter questions.

The third focus of the study addressed positive perceptions of the caregiving experience. The majority of caregivers identified at least one perceived benefit in their caregiving experience and in total, provided a variety of positive perceptions. Similarly, several themes arose pertaining to the choice of providing home care rather than institutionalizing the demented partners.

CHAPTER FIVE

DISCUSSION

Results for each study focus are discussed in relation to the relevant research. Limitations of the present study and suggestions for further research are also presented. Finally, implications for counselling are discussed on the basis of the results obtained in the present study.

Discussion of Results

There were two major focuses in this exploratory study. The first concerned how caregiver burden was related to impairment and the social networks of caregivers. The second focus was a more specific exploration of the structural and functional properties of caregiver social networks. A third and more minor focus concerned the positive aspects of providing home care to demented partners. Underlying these central themes was an exploration of caregiver gender differences. Relationships Between Burden and Selected Variables

The relationships between burden measures and caregiver gender, impairment, and social networks for males and females are discussed within the context of the caregiving literature. Since most studies have utilized unidimensional burden measures, the results of the present study must be interpreted cautiously in relation to other studies.

<u>Caregiver gender</u>. Sampled husband and wife caregivers had similar levels of objective burden and subjective burden (question 1.1.1). This suggests that male and female caregivers experience similar changes in their lifestyles and relationships after their partners develop dementia. Further, male and female caregivers appear to experience similar attitudes and emotional reactions toward the caregiving experience.

These results provide general support and expand upon the results of Fitting et al. (1986), Pratt et al. (1985), and Zarit et al. (1980) who found no caregiver gender differences on a unidimensional burden measure. Although Zarit et al. (1986) found that wives of demented spouses had higher burden scores than husband caregivers, a two year follow-up interview revealed similarities in husband and wife burden scores. The present study did not address gender differences over time but a longitudinal study such as Zarit et al.'s (1986) would be beneficial in determining if there are gender differences in objective and subjective burden during the progression of dementia.

<u>Impairment</u>. In their examination of burden, Poulshock and Deimling (1984) outlined the importance of examining the frail person's and caregiver's level of impairment. Their description of impairment included physical and mental functional status components which were operationalized in the present study by the physical and psychosocial SIP dimension scores. A second type of patient impairment measure, diagnosis length, was included in stepwise multiple regression analyses to predict burden measures for male and female caregivers (question 1.2.3).

Female objective burden was best predicted by the patient's diagnosis length. Longer diagnosis lengths were associated with greater objective burden but causality cannot be inferred. It would appear more logical to assume that longer periods of dementia lead to greater objective burden than vice versa. However, such a statement is premature at this point as it is also possible that other factors account for the observed relationship.

It is not clear from the data why the length of diagnosis did not predict male objective burden as it did for females. The dementia diagnosis lengths were similar for husband and wife caregivers as were all patient and caregiver impairment levels. Therefore, these potential influences can be ruled out. One possible explanation for the observed gender difference is that a larger number of males brought their spouses with them on outings. Consequently, male lifestyles and relationships may not have been interrupted to the same degree as those of female caregivers after the development of the partner's dementia. At this point, the length of diagnosis in regard to burden has received little attention in the literature. Zarit et al. (1980) reported that dementia duration was unrelated to a unidimensional burden measure but husband and wife caregivers were not differentiated in their analysis.

It should be noted that the diagnosis length is a somewhat arbitrary measure as it depends on several factors not assessed in the present study. For instance, some caregivers may have recognized symptoms earlier than others and therefore brought their partners to the attention of the health care system more quickly. Further, diagnostic skills of health professionals likely vary across the province. Such factors make it conceivable that some caregivers of partners who had been diagnosed for many months could actually have been giving care for less time than some caregivers of partners diagnosed more recently. Nevertheless, the diagnosis length is a clearer marker than approximating the duration of the disease as caregivers find it difficult to pinpoint when dementia begins (Fiore, Coppel, Becker, & Cox, 1986).

Diagnosis length was not significantly related to either patient

impairment measure suggesting that longer dementia diagnoses are not necessarily linked to greater physical or psychosocial impairment. Consequently, it seems that longer diagnosis lengths should not be confused with greater impairment.

The psychosocial impairment of patients best predicted female subjective burden. The positive relationship suggests that wives of partners with greater levels of psychosocial impairment experience greater subjective burden. As the evidence is correlational, it is not possible to determine if greater patient psychosocial impairment leads to increased subjective burden. However, this direction seems more plausible than the reverse alternative suggesting that greater subjective burden leads to greater spouse psychosocial impairment. The physiological etiology of dementia would seem unlikely to be caused by caregiver subjective burden. It is also possible that more highly burdened caregivers perceive their spouses as having greater psychosocial impairment than less burdened caregivers. However, this explanation would have greater support if there was a significant relationship between physical impairment and subjective burden but this was not observed.

Results in the caregiving literature are inconclusive concerning patient psychosocial impairment. Scott et al. (1986) found no relationship between the mental status of the patient and a unidimensional burden measure. Combined cognitive and physical deterioration measures of patients were not found to be related to caregiver unidimensional burden by Zarit et al. (1980) but a different combined measure was found to be significantly and positively related to burden by Novak and Guest (1985). Fitting et al. (1986) reported that later stages of dementia (i.e., greater impairment) were associated with greater perceived burden in "younger" caregiver wives aged 50-66 and "older" caregiver husbands aged 67-90 but not older wives or younger husbands. Zarit et al. (1986) reported that dementia patient cognitive impairment was not initially associated with caregiver burden but two years later, there was evidence of a significant and positive relationship.

The results reviewed above appear to be contradictory but direct comparisons between studies are impossible given the diversity of the burden and impairment measures. The correlational evidence in these studies revealed relationships that accounted for less than 17% of the variance in "burden". In the present study, patient psychosocial impairment accounted for 22% of the variance in female subjective burden. Therefore, it seems apparent that in the present study as in the above studies, other variables in addition to impairment influence caregiver burden measures.

In addition to patient psychosocial impairment, length of diagnosis accounted for a significant amount of the variance in female subjective burden. Female subjective burden was positively related to diagnosis length. It seems more plausible to state that greater subjective burden arises out of longer periods of time providing care rather than vice versa. However, other variables may conceivably account for this relationship and any causal inferences are speculative at this time.

The length of dementia diagnosis has been examined by other researchers in relation to varied dependent measures incorporating caregiver feelings. Dementia duration has not been found to be significantly related to: a unidimensional burden measure (Zarit et al., 1980); caregiver well-being measures (George & Gwyther, 1986); or caregiver depression, psychological functioning, and symptomatology (Fiore et al., 1986). Gilhooly (1984) conversely found that adult daughters and spouse caregivers (not differentiated) who had been giving care for longer periods of time had higher morale and better mental health than caregivers of more recently diagnosed patients. Perhaps the latter caregivers were experiencing difficulties in accepting the patient's diagnosis whereas the caregivers who had been giving care for longer periods of time had dealt with the diagnosis. It is also possible that including daughter caregivers in the sample influences the overall nature of the relationship between caregiver dependent variables and diagnosis length. Nevertheless, the results of the present study do not support the results of the studies described above.

Although several caregivers in the present study reported that their partners had physical problems that affected their abilities to perform daily activities, the partner's physical impairment did not predict caregiver burden measures. It is not clear why this occurred. Perhaps these cases were overshadowed by other caregivers who remarked on the physical health of their spouses. Therefore, the sample may have been generally healthy in a strictly physical sense. Perhaps more physically impaired dementia patients may affect caregiver burden measures.

Caregiver impairment measures were not significantly related to male or female burden measures. Caregiver impairment has not been examined in other studies but the results of the present study should not be interpreted in a manner to encourage this oversight. It is possible that the sampled caregivers are more healthy than the general spouse caregiver population. Perhaps more impaired caregivers would experience greater levels of burden than the sampled caregivers.

<u>Embeddedness</u>. Structural measures including network size and contact frequency were examined in relation to burden measures (questions 1.3.1 and 1.3.2). Caregiver network size was not significantly related to either burden measure for males or females. Although not directly comparable because of different dependent measures, these results provide some support for the findings of Novak and Guest (1985). They reported that the number of people in the spouse caregiver's informal support network (formal subnetworks were not included) was not significantly related to a unidimensional burden measure.

The second embeddedness measure, frequency of contact with network members, was not significantly related to either type of burden for male or female caregivers. This result expands on information from other studies employing different network structural measures and dependent variables. Gilhooly (1984) reported that the frequency of contact with family, friends, and neighbors (grouped together and excluding formal subnetworks) was not significantly related to caregiver well-being. Unfortunately, spouse and adult children caregivers were not differentiated in their analyses. Fiore et al. (1983) examined spouse caregivers specifically and found that network contact (excluding formal subnetworks) was negatively related to caregiver depression. Unlike the present study, however, Fiore et al. did not restrict network membership to those that had been in contact with the caregiver in the past month.

To more fully explore if embeddedness measures predicted burden measures (question 1.3.5), the network was divided into subnetworks. Subnetwork sizes did not predict burden scores for males or females and
subnetwork contact frequency did not predict female subjective burden. However, male subjective burden was predicted by the amount of family contact during the month preceding the interviews. The positive relationship suggests that greater contact with family members is associated with higher levels of subjective burden for males. It cannot be determined from the data if male caregivers with greater subjective burden encourage more interaction with family members than caregivers with less subjective burden. Alternatively, greater contact with family members could be an undesired distraction leading to increased subjective burden. It is also possible that other unexamined variables may account for this relationship.

The positive relationship between male subjective burden and family contact appears to contradict Zarit et al.'s (1980) results. They reported that the frequency of family visits with the caregiver's demented spouse was significantly and negatively related to caregiver burden. Unfortunately, male ($\underline{n} = 4$) and female caregivers ($\underline{n} = 14$) were grouped together in their analysis and their burden measure was unidimensional. In addition, it is not clear if family members in their study visited with caregivers as well as with the demented spouses. In the present study, the focus was solely on caregiver contact with subnetworks. Another methodological difference is in the operational definition of contact. In the present study, telephone and letter contact are included with personal contact. The latter was the only type of contact in Zarit et al.'s study.

<u>Enacted support</u>. Multiple regression analyses (question 1.4.2) revealed that for both husband and wife caregivers, none of the enacted support categories accounted for a significant amount of variance in objective burden. This suggests that caregiver lifestyle and relationship changes occurring after the development of the partner's dementia is not influenced by the amount of socializing, tangible, cognitive, or emotional support that they had received in the past month.

Female subjective burden was not predicted by any of the variables but the amount of tangible assistance predicted male subjective burden. The positive relationship suggests that husband caregivers receiving more tangible assistance have greater subjective burden. It is not possible to determine if networks of burdened male caregivers increase their tangible assistance in an effort to reduce the husband's subjective burden. It seems less likely that receiving increased tangible assistance would increase male subjective burden; although it is possible that husbands may respond to increased assistance by perceiving themselves as being unable to cope independently which perhaps leads to greater subjective burden.

This follows one of Barrera's (1986) descriptions of a mechanism by which adverse effects of receiving help may arise. Receiving assistance may lower one's self-esteem if it is seen as a sign of personal incompetence. Receiving support could also lead to obligatory feelings to repay the assistance. Alternatively, it is possible that the support was delivered in a demeaning fashion. Unfortunately, these possibilities could not be explored within the interview time constraints.

It is difficult to determine why tangible assistance is the only type of support significantly related to male subjective burden. It should be noted that with the exception of emotional support, all

relationships between male subjective burden and enacted support categories were positive and above .30. Therefore, it is possible that there could have been more significant relationships in a larger sample.

<u>Respite</u> (question 1.5.1). Caregivers in the present study received a wide range of respite hours but the number of respite hours in the past month was not significantly related to burden measures for either gender. These results provide support and expand Lundervold and Lewin's (1987) results which suggested that caregiver burden is not influenced by the number of respite hours. Most caregivers in the present study received more than the four to six hours of respite per week that Lundervold and Lewin's sample received. Further, a multidimensional burden measure was used in the present study.

The results do not suggest that respite is not an important issue with caregivers. Several caregivers underscored the importance of breaks in their caregiving by commenting that respite was essential to their well-being. This was not universally stated, however, as other caregivers (predominantly male) who received very little or no respite stated that they brought their wives with them wherever they went. It is not known how these caregivers would respond if their spouses became more impaired and experienced greater mobility difficulties.

<u>Perceptions of enacted support</u>. Helpfulness and upset ratings of support categories were entered into multiple regression equations for males and females to predict caregiver burden measures (question 1.6.3). Of the helpfulness and upset ratings, socializing support helpfulness ratings best predicted objective burden for husband caregivers. The relationship was negative but it cannot be determined if low socializing helpfulness ratings contribute to greater objective burden. In

contrast, another explanation is that males with greater objective burden may have less time to socialize with network members and consequently, perceive their network as less helpful in this way. These explanations are speculative at this point and are not meant to be exhaustive as other variables may also account for the observed relationship.

In contrast to objective burden, male subjective burden was best predicted by socializing support upset ratings. Higher socializing upset ratings were associated with higher subjective burden for males but it cannot be determined if greater socializing upset caused greater subjective burden. Alternatively, perhaps males who are experiencing high levels of subjective burden perceive their networks as failing to meet their expectations in regard to socializing.

The results concerning perceptions of enacted support and burden raise several questions. For example, it is not clear why helpfulness and upset perceptions did not account for a significant amount of variance in female burden. Further, the relationships between perceived upset and burden measures were, with one exception, nonsignificantly related whereas relationships between caregiver upset and depression in other studies have been found to be significantly related.

In the first study to examine positive and negative perceptions of support categories separately, Fiore et al. (1983) reported significant relationships between spouse caregiver depression and upset ratings of support categories. Conversely, support category perceived helpfulness was not significantly related to depression. In a later study, Pagel et al. (1987) replicated Fiore et al.'s results after controlling for age, sex, and the patient's level of impairment. Pagel et al. suggested that

upsetting relations with one's network were important in the etiology and maintenance of emotional problems but this was not evidenced for subjective burden in the present study.

One possible explanation for the predominance of nonsignificant relationships between burden and perceived upset in the present study concerns social network list membership. Unlike other studies, social network membership eligibility requirements stipulated that caregivers were in contact with members during the previous month. In the present study, some caregivers stated they were upset with some family members and friends but they had not had recent contact with them in the past month. These "upsetting" people were therefore excluded from the SNL. Fiore et al. (1983) also required the inclusion of all immediate family in their social network measure despite the current contact status. Further, network membership was limited to 15 members. Therefore, it is possible that the "upset" reported by their sample was more representative of family members than other subnetworks.

Another explanation of the discrepancy in results is the definition of upset which was defined in the present study as unmet expectations rather than in conjunction with negative interactions as in other studies. Perhaps caregivers felt their networks met their expectations for each support category. Several caregivers stated they did not expect anything from their networks and were therefore by definition not upset with them. It is also possible that caregivers were reluctant to state they were upset with their network members. This possibility cannot be dismissed although caregivers were assured of confidentiality and caregivers did not express reluctance in rating some of their network members as not being helpful.

The obtained support category upset ratings had restricted ranges with all mean support category upset ratings falling between 1.0 and 2.53 on the six point scale. The majority of ratings (59%) were 1.0 signifying that caregivers were not upset with the types of support they received. Support category mean upset ratings ranged from 1.08 to 1.23 across the four support categories. These mean ratings appear to be lower than the range of 1.5 to 2.2 reported by Pagel et al.'s (1987) sample of spouse caregivers. The apparently lower upset ratings in the present study may be attributable to the more specific upset definition. Similar to Pagel et al., upset ratings in the present study had lower means and more narrow ranges than helpfulness ratings within each support category.

Post-hoc analyses revealed that helpfulness and upset ratings within each support category were not significantly related for males or females. Although Fiore et al.'s (1983) upset definition was different, they reported similar results with the exception of one support category. Such evidence suggests that perceived helpfulness and upset are not merely opposite ends of the same scale. If they were, it could be expected that there would be significant negative relationships between helpfulness and upset ratings. Further, these results speak of the complexity in human relationships (Fiore et al.).

<u>Sources of support</u>. The sources of support have generally been disregarded in the literature (Thoits, 1982) and subnetworks have not been examined in comparison with each other. Some researchers have focused on a specific subnetwork (i.e., family) but not in comparison with others. Other researchers have included family, friend, and formal subnetworks but have not differentiated between them in their data

analyses. Furthermore, spouses have rarely been examined as a potential source of support.

In this section, subnetworks were analyzed separately and support categories were collapsed. None of the sources of enacted support predicted objective burden for males or females (question 1.7.2). This suggests that the source of support may not be a significant factor in examining the extent of changes in caregiver lifestyles and/or relationships. However, greater male subjective burden is associated with increased family support. This result essentially replicates the positive relationship between family contact frequency and male subjective burden reported earlier (1.3.5).

The results of the present study provide limited support to Pratt et al.'s (1985) finding that help from the extended family was significantly and positively related to a unidimensional burden measure. However, their sample contained a large number of non-spouse caregivers and male and female caregivers were not differentiated.

<u>Perceptions of subnetworks</u>. Helpfulness ratings of subnetworks did not predict male or female burden measures but upset ratings of friends predicted male subjective burden. The positive relationship indicates that higher upset ratings of friends are associated with greater subjective burden. Perhaps unmet expectations of friends increases male subjective burden. Alternatively, high levels of subjective burden may lead males to think that their friends are not meeting their expectations (although this explanation would garner more support if subjective burden was similarly related with other subnetwork upset perceptions).

Caregiver Social Network Descriptions

The second study focus addressed structural and functional properties of male and female caregiver social networks in more detail. The amount of each type of enacted support received and the perceptions of each type of support were examined within individual subnetworks. Similarly, subnetwork enacted support and perceptions of subnetworks were explored within each support category. Respite sources, caregiver perceptions of support categories, and expectations of subnetworks and support categories were also explored. Finally, current and desired respite activities were examined.

<u>Embeddedness</u>. Male and female caregivers had similarly sized family, friend, and formal subnetworks (question 2.1.1). Moreover, both males and females had significantly fewer formal subnetwork members than family and friend members. The mean sizes of the latter two subnetworks indicated that between seven and eight members had been in contact with the caregiver at least once during the month preceding the interviews. This is comparable to descriptive data from Pagel et al. (1987) who reported that an average of 5.8 social network members had been in contact with their sample of caregivers within a two week period. Perhaps this average would have more closely approximated the mean network size in the present study if the time frame was a one month period. Of their total network membership, 49% were kin which approximated the percentage obtained in the present study (43%).

The total and mean monthly contact with subnetworks were similar for male and female caregivers (question 2.1.2). Both groups had similar contact frequencies with family and friends and both males and females had significantly less contact with formal subnetwork members than with the other subnetworks. These gender results are difficult to compare to

other studies given different measures and methodologies. Zarit et al. (1980) reported that male spouses of demented partners had significantly fewer family visits than female caregivers. The present study did not support these results but only four husbands were included in Zarit et al.'s study which reduces the generalizability of their results. Further, "contact" in their study was restricted to visits only whereas phone and letter contact were also included in the present study.

<u>Enacted support category and perceived support category differences</u> <u>within subnetworks</u>. Husband and wife caregivers received similar types of support within each of their subnetworks (question 2.2.1). This result supports and expands upon Miller's (1987) observation that the amount of emotional support and "concrete help" (i.e., tangible assistance) received from adult children was similar for male and female spouse caregivers. Unfortunately, other types of support and sources of support were not explored by Miller.

Caregivers generally received (in descending order) socializing, emotional, tangible, and cognitive support from their family and friend subnetworks. Miller (1987) similarly determined that caregivers received more emotional support than "concrete help" from adult children (i.e., family). Gilhooly (1984) found that her sample of caregivers (spouses included with other non-resident caregivers) did not receive a "great amount" of "practical help" or emotional help from friends or relatives. Although different operational definitions and assessment techniques of support were used, the present study provides some support to these descriptive results and extends them in that more types and sources of support were examined.

Spouses varied slightly from the pattern outlined above by giving

less emotional than tangible support to caregivers. Formal subnetworks varied considerably from other subnetworks in providing less socializing and cognitive support than emotional and tangible support. In total, these results suggest that both male and female caregivers receive different amounts of support categories within each of their subnetworks.

Support category helpfulness and upset ratings were examined within each subnetwork (questions 2.2.2 and 2.2.3). Male and female caregivers had similar perception ratings of subnetworks except with spouses. Males rated their spouses as being more helpful in socializing and tangible assistance than females whereas females rated their spouses as being more upsetting in these two categories than males. It is unclear why males and females had different perceptions of these types of assistance from their spouses. Perhaps males rely more on their spouses for these types of support than females and therefore rate their contributions as more helpful. Conversely, females may be more upset at their spouses in terms of tangible assistance because their spouses may interfere with their regular routines established through the years as a homemaker. Perhaps husbands who are now at home may want to "help" their wives with household chores which counters the female's expectations of her husband. Miller (1987) reported that female spouse caregivers experienced a loss of control over their home environment in association with their husband's continuous intrusions. Several females in the present study similarly indicated they had problems in regard to assuming control but this could not be systematically examined due to time restraints.

Helpfulness ratings of support categories within subnetworks had

several similarities. In the spouse, family, and friend subnetworks, caregivers rated cognitive guidance as less helpful than other types of support. Not surprisingly, the formal subnetwork was excepted from this pattern as socializing was rated as less helpful than other types of support. Socializing and emotional support were rated by caregivers as most helpful in both of the family and friend subnetworks while within the spouse subnetwork, caregivers rated socializing support as most helpful. The formal subnetwork helpfulness ratings again differed from this pattern as caregivers rated tangible and cognitive support as more helpful than other categories. It is conceivable that the kinds of formal services sampled in this study influenced the ratings as the agencies were primarily service and information oriented.

Upset ratings of support categories within each subnetwork except friends were not significantly different from each other. In the friend subnetwork, caregivers reported more upset with socializing than other types of support suggesting that caregivers felt their friends were not meeting their expectations in terms of socializing. Miller (1987) reported that her caregivers experienced less contact with friends as time progressed. Several caregivers in the present study expressed similar experiences and indicated they had previously socialized a great deal with some of their friends. Consequently, their expectations were unmet and they were by operational definition upset.

<u>Subnetwork enacted support and perceived support differences within</u> <u>support categories</u>. Each support category was examined individually in the same manner as subnetworks were examined previously. In this series of ANOVAs, it was evident that subnetworks provided varied amounts of each type of support (question 2.3.1). There were similarities between males and females in the subnetwork provision of each type of support.

Unlike any other support category, similar amounts of tangible assistance were provided by subnetworks. This result implies that spouses can be a source of tangible support although it must be noted that the measures were of a quantitative nature only. Therefore, it cannot be assumed that the quality of support given by spouses approximated that given by other subnetworks. In some cases, the spouse's "help" was more of a hindrance according to caregivers. Nevertheless, several caregivers explained that their demented spouse's "help" seemingly gave the spouse a sense of pleasure which made the exercise worthwhile for both partners.

Not surprisingly, caregivers received the least amount of socializing support from their formal subnetworks. They received the most from friends and family members. Less cognitive support was received from spouses than other subnetworks. Family members provided the most cognitive guidance. The importance of the family in providing cognitive guidance was exemplified by several caregivers who commented that they were uncertain where to turn for advice other than to kin. The key issue for these caregivers appeared to be trust.

Less emotional support was received from the spouse and formal subnetworks than from friends and family members. It is not surprising that families provided the most emotional support given their role in nurturing. However, the amount of emotional support from the formal subnetwork may have been biased in that no caregivers were drawn from mental-health related agencies (e.g., counselling). Most caregivers were receiving tangible assistance from their formal subnetworks (e.g., house cleaning, respite, etc.). Given their nature, these types of

services are unlikely to provide a great deal of emotional support.

Helpfulness and upset perceptions of subnetworks were explored in examining support categories individually (questions 2.3.2 and 2.3.3). Males rated their demented spouses as more helpful for socializing support than females. Perhaps this difference is related to the greater number of males who brought their spouses with them on outings. Spouses therefore seem to play a more important role for husbands than wives for socializing.

For each remaining type of support, spouses were rated as less helpful than other subnetworks. Formal and friend subnetworks were rated as more helpful than other subnetworks in providing tangible assistance. Formal subnetworks were rated as more helpful than other subnetworks in providing cognitive guidance which is not surprising given the nature of several of the formal agencies (e.g., Alzheimer Society). Family and friends were both rated as more helpful than formal and spouse subnetworks in providing emotional support. As discussed previously, it is possible that the formal subnetworks were biased against emotional support.

<u>Respite sources</u> (question 2.4.1). It is not clear why more male than female caregivers took their demented partners with them on outings. This discrepancy cannot be attributed to caregiver or patient impairment differences between genders. Perhaps it is easier for males to physically handle their partners than it is for female caregivers who conceivably may be smaller and/or weaker than their demented partners. Alternatively, perhaps more males could drive which would lead to greater ease in travel for husband caregivers.

Almost half of all caregivers left their spouses alone at times.

Caregivers cited several reasons for this including greater convenience, the spouse's refusal and/or inability to leave the home, difficulty in finding someone to stay with the spouse, and refusal of spouses to allow anyone else but their partners to be with them. In all cases, it appeared that caregivers left their spouses alone for short periods of time (i.e., less than two hours). In most cases, caregivers appeared unconcerned about doing this but a few caregivers expressed guilt. Most stated it was unavoidable at times. Unlike Miller's study (1987), males did not appear to be more likely than females to leave their spouses alone. The discrepancy in results may be related to the different sample sizes as her sample (<u>N</u> = 15) was small.

It is evident that of the male and female caregivers receiving respite, the majority of respite came from formal agencies such as home care and day hospitals. Far less respite was provided by family members and even less by friends although it must be noted that the sample was gathered through formal agencies. Perhaps caregivers who have less or no contact with formal subnetworks rely more strongly on informal sources of respite. However, according to some unsolicited statements in the present study, there appeared to be a reluctance in approaching family and friends for respite.

Several caregivers expressed reluctance in asking family members to stay with their spouses due to their family's "busy schedules". Others indicated their family members were unable to provide respite as they were too uncomfortable with their spouse's condition and/or they were unable to handle the dementia patient. Caregivers provided similar reasons for the lack of respite from friends. It is not known how representative these comments are of the general caregiving population.

Indeed, as they were not systematically solicited, it is not known how representative these comments are of the sample itself.

Perhaps some caregivers were reluctant to seek or accept respite due to their perceived inability to reciprocate the assistance fully. This possibility is in keeping with Shumaker and Brownell's (1984) reciprocity model of social support. They posited that in situations where help is needed over extended periods of time, the recipient's inability to reciprocate fully may lead to difficulties in asking for help and/or receiving help. Although not addressed in the present study, it is possible that caregivers do not have such reservations with formal agencies and therefore seek respite from them.

The apparent reliance on formal subnetworks for respite may have implications for future services in terms of the type of support offered. Demographic trends may also influence respite provision. For instance, families are smaller and more mobile than they were a generation ago (Gibson, 1980) which may lead to less respite opportunities. There also seemed to be a stronger reluctance to approach friends than family members for respite. This could perhaps change as more elderly people reside in environments where seniors are in closer proximity to other seniors (i.e., senior housing developments).

<u>Support category perceived helpfulness and caregiver expectations</u>. It is evident that no single type of support is seen as most helpful by a majority of caregivers (question 2.5.1). Due to time constraints, caregivers were not asked why they found a specific type of support particularly helpful. Perhaps responses were reflective of a particular need at the time. Caregivers could possibly have responded differently

at another time or if they were in a different situation (i.e., the impairment of the patient changed, the caregiver's social network's functional properties changed, etc.). Such possibilities are speculative at this time without further study.

Caregivers described which type of support they most expected from each individual subnetwork (question 2.5.2). With the exception of the friend subnetwork, husband and wife caregivers appeared to have similar subnetwork expectations. While friends were most expected by the majority of caregivers to provide socializing, a few more females than males most expected their friends to provide emotional support. It cannot be determined if this gender difference is statistically significant but clearly, few caregivers most expect their friends to provide tangible or cognitive support. This does not suggest that friends are never expected to give these types of support to caregivers but rather, friends are expected to play a more important role in socializing. The majority of caregivers most expected spouses to provide socializing support but expectations seemed understandably low. given the conditions of spouses. Family members were most expected by a majority of the caregivers to provide emotional support which is not surprising in light of the nurturing that families typically provide.

Caregivers were almost evenly split concerning formal subnetwork expectations. Almost half most expected their formal subnetworks to provide cognitive guidance with slightly fewer caregivers most expecting tangible assistance. A few caregivers most expected their formal subnetworks to provide emotional support. Perhaps this percentage would have been greater if more caregivers would have been drawn from mental health-related agencies. It seems apparent at any rate that

expectations of formal subnetworks vary between caregivers.

Caregivers were asked which subnetwork they most expected to provide each individual type of support (question 2.5.3). Socializing support was most expected from spouses, families, and friends by equal numbers of the males. Approximately the same percentage of females most expected socializing from friends but a few more females than males most expected it from the family. Conversely, a few more males than females most expected socializing support from their spouses. This trend may be related to the earlier discussion concerning respite sources (question 2.4.1) pertaining to the greater number of males who regularly brought their spouses along with them on outings. However, without further study, this speculation cannot be supported.

More than half of the females and one quarter of the males most expected tangible assistance from formal subnetworks. A similar percentage of males most expected this type of support from their spouses in contrast to only one female. Perhaps this apparent gender difference can be attributed to pre-dementia lifestyles. Most of the female patients and female caregivers were housewives and presumably, did most of the domestic chores. Male caregivers may expect a continuation of this pattern to some degree even if their spouse's impairment limits the type of chores that can be completed. Female caregivers would not seem as likely to expect domestic assistance from their spouses as husbands may have had little experience in performing such activities. Therefore, wives may expect tangible assistance from other sources more readily than husband caregivers.

Tangible assistance expectations may be influenced by several variables. For instance, the impairment of spouses may render them

incapable of offering tangible support. The proximity of network members may also be an important consideration. For example, a caregiver cannot expect family members to provide cooking assistance if they all live a great distance away. Unfortunately, there was not enough time to determine if tangible support was influenced by these factors (or others).

Cognitive support was most expected from the formal subnetwork by the majority of caregivers and in particular by males. A few more females than males most expected cognitive guidance from family members. It should be noted that cognitive guidance was defined as any type of information and was therefore not necessarily related to dementia. If the category had been restricted to dementia information, it seems likely that more caregivers would have responded with the formal subnetwork.

Emotional support was most expected from the family by the majority of caregivers. This may be in keeping with the nurturing properties of families as discussed previously. Further, family members may possibly be more conveniently available to respond to emotional difficulties and/or to encourage caregivers. Fewer caregivers most expected emotional support from their friend and formal subnetworks although as indicated previously, the sampling procedure may have introduced a bias against formal subnetworks. Nevertheless, it is evident that a few caregivers most expect emotional support from the formal subnetwork rather than from family and friends. More research is needed to determine what influences formal subnetwork expectations in regard to emotional support.

Caregiver respite activities. For most caregivers , respite

afforded an opportunity to complete errands (question 2.6.1). More males than females described exercise and sport participation. Further, more males talked about working during their caregiving breaks as they took pleasure in a variety of volunteer projects. Miller (1987) similarly reported that her small sample of male caregivers found it more helpful to use their free time for interests unrelated to their family situation.

Social activities and/or relaxation were mentioned by a majority of females and several males as activities they participated in when afforded respite. More females described club activities. In total, these results provide some support for Miller (1987) who indicated that more females participated in caregiver meetings and social activities.

Caregivers were asked what types of activities they would engage in if provided more respite (question 2.6.2). Of those who desired more respite (one quarter did not) it seemed that in general, males tended to express greater interest in more physical or work-related activities than females. Females seemed to express more of a need for a break to recuperate, relax, or socialize. Approximately equal numbers of males and females expressed an interest in traveling. More males than females expressed a desire to increase their sport participation. Therefore, it seemed that the desired activities mirrored the current respite activities for males and females.

Positive perceptions of the caregiving experience

Two open-ended questions were asked at the end of the interview. The first (question 3.1.1) addressed positive perceptions of the caregiving experience. The second (3.2.1) concerned reasons for choosing to provide home care rather than institutionalization for the

demented partners.

Positive caregiving experiences. The majority of caregivers described multiple and varied positive experiences. Several caregivers emphasized how their marriage relationships had become closer in some ways. This seems surprising given the nature of the disease which influences the nature of communication between spouses. In addition, it would seem that most pre-dementia relationships would already have been close and strong in order to sustain the difficulties associated with providing care for a demented person. A few more males than females stated that their relationships had become closer which provides tentative support for Fitting et al.'s (1986) results. They hypothesized that the apparent gender difference may be reflective of different life trajectories. Females, as traditional caregivers to children, have to resume the caregiving role upon the onset of their partner's dementia. In contrast, male caregivers are changing their focus from work to the home and consequently, the husband enters a new "provider" role in assisting his spouse. The hypothesized different life trajectories can be explored in further studies.

Perhaps caregiver perceptions of improved relationships are reflective of the changed status of the patient and/or the caregiver. Several caregivers described how their spouse's behavior and/or personality had changed in positive ways. Other caregivers (primarily females) described changes in themselves that they considered to be positive. It seemed that many of the changes concerning female caregivers were related to a growing sense of independence and self-confidence.

Home care vs. institutionalization. A group of caregivers chose

home care because they were critical of the quality of institutional care. For most of this group, an institution was clearly the last resort to be considered only if there was a sharp decline in their own health or their partner's health. Some caregivers in the present study were concerned that institutionalization would exacerbate psychosocial problems in their partners. An underlying theme to these critiques of institutions appeared to be the equating of abandonment with institutionalization.

Other caregivers opted for home care because of the perceived benefits in living together. Continued companionship was mentioned by several males as a reason for providing home care. Others viewed home care as an obligation or a sense of duty in providing some support for Fitting et al.'s (1986) study. Husbands in their study (as in the present study) spoke of their wives as having been good homemakers and mothers. Husbands wanted to reciprocate by giving care. Some caregivers felt home care was a continuation of their lifelong commitment to each other expressed initially during their wedding vows. If today's higher divorce rates are indicative of relationship commitments, it remains to be seen the degree to which spouses will provide home care to demented partners in the future.

Study Limitations and Suggestions for Future Research

It is recognized that the sample was not randomly selected. The sampling procedure limits generalizability of the results to caregivers who are receiving formal assistance and are willing to be interviewed. It is possible that caregivers who choose not to receive formal care services experience fewer difficulties or perhaps have greater contact with informal subnetworks. Caregivers choosing not to be interviewed may be managing quite differently than those who volunteered. However, health care workers can not be expected to force unwilling qualified caregivers to participate in a research project.

The experiences of non-Caucasian caregivers are not addressed and further reduces generalizability. Indeed, the experiences of caregivers with different racial backgrounds requires further research (Chenoweth & Spencer, 1986).

The first study focus centered on relationships between burden and selected variables. Research using correlational analyses contains two major limitations which must be recognized when interpreting the results. These limitations concern cause-and-effect directionality and the third variable problem (Cozby, 1977). The direction of cause-and-effect is ambiguous in correlational analyses because of an inability to manipulate variables. The third variable problem addresses the possibility that a third phenomenon may cause an observed relationship between two variables under consideration. In the present study, efforts were made to include as many potential confounding variables as possible to reduce these limitations. Multiple regression analyses are also helpful in reducing these limitations as they take interrelationship variance into account when predicting dependent variables. Unfortunately, the sample size prevented entering a large number of variables into the equations.

Zarit et al. (1986) reported changes in their sample's unidimensional burden measure over a two year period. A longitudinal study would be useful in determining if either objective or subjective burden changes over time and more specifically, what appears to influence possible changes. As the two burden measures are unrelated, it would be useful to determine if changes in either measure occur in relation to the dementia process.

The second study focus largely entailed analyses of variance. Again, the sample size may have had a bearing on the results as the size of the sample influences the likelihood of obtaining interaction effects between variables (Depner et al., 1984). Some of the statistically nonsignificant trends that were obtained could be researched further with larger samples to better understand the complexities of interactions.

The cross-sectional design of the present study provides a social network snapshot of what is more realistically an ongoing drama of constantly changing interactions. The caregiver's social networks may mobilize at some times and dissipate at other times (Gwyther & George, 1986). Several caregivers commented that their network composition had changed through loved ones moving away or dying, for example. Whether or not contact frequency decreased or increased (rarely mentioned except in regard to formal subnetworks), the nature of interactions may also change. For example, perhaps social network members currently provide different types of support than they did prior to the patient's dementia. Although longitudinal studies have difficulties (Depner et al., 1984), they would be useful in examining how the quantity and quality of a caregiver's support changes after the development of a partner's dementia.

The caregiver's reception of support was examined in the present study. While it was assumed that caregivers gave support to their spouses, they may also give assistance to other network members as well (Peters et al., 1987) as social support is usually given as well as received (Tardy, 1985). For example, in the present study several caregivers babysat or did odd jobs for their families. Providing support to people in addition to the demented spouse may contribute to a caregiver's burden. This could be explored further as most research has focused solely on the caregiver's support given to patients.

Shinn et al. (1984) reported that stressful life events can influence the availability of support. They offered the opinion that a potential helper's discomfort with dementia may reduce or increase his or her willingness to provide help. Network members were not interviewed in the present study so it is impossible to determine their motivations for providing assistance. For that matter, it is not known if network members concurred with the caregiver's perceptions about the types of support they provided. It should be noted that measures of enacted support more accurately assess "perceived-received" support as such measures rely on the respondent's retrospective evaluations (Barrera, 1986). Interviewing as many members of the caregiver's network descriptions (although it would also be very time consuming).

Shinn et al. (1984) stated that caregivers may elicit or discourage support simultaneously or sequentially, particularly if it endures over time. With dementia being a chronic disease, it would be interesting to examine how caregivers encourage or discourage support from their network. Several caregivers stated they did not expect anything from their subnetworks and it is therefore possible that they discouraged network involvement. Continued discouragement could lead to the refusal of members to provide support when it is solicited by caregivers at a future date. Interviewing network members would provide more data about

the caregiver's influence on network members in terms of providing support.

The results of the present study in relation to social networks were limited to those members with whom the caregiver had contact during the previous month. This operational definition of social network membership is important in discussing perceived upset in particular as several caregivers mentioned that they were upset with people excluded from the SNL (i.e., they had not had contact with them during the past month). It is not known to what extent these people contributed to the caregiver's sense of burden. Perhaps future research could include such persons through a different operationalization of network membership:

Effects attributed to impairment or the social network may be more accurately explained by unmeasured variables. While several variables were included in the present study, perhaps an important unmeasured variable concerns the caregiver's coping skills. Indeed, Thoits (1986) conceptualized social support as coping assistance. Dunkel-Schetter, Folkman, and Lazarus (1987) described a coping technique called positive reappraisal (e.g., looking on the bright side). Some caregivers in the present study described such a philosophy during the course of the interviews but since the information was unsolicited, it was not examined in greater detail. Coping skills could be explored further to determine their effect on the caregiver's level of objective or subjective burden and/or social network involvement.

The influence of the caregiver's expectations being met or unfulfilled was partially explored in relation to perceived upset. Further research could explore what expectations are based upon. Perhaps some caregivers have unrealistic expectations which are unlikely

to be fulfilled. By including network members in a future study, the degree to which caregivers' expectations and the member's ability to fulfill them are congruant, could be determined.

General subnetwork expectations were briefly explored and could be examined more specifically through rating scales as opposed to the most/least expectation differentiations in the present study. For example, caregivers could be asked the degree to which they depend on their family for socializing on a five point scale (not at all...depend entirely). Such scales would permit inferential statistical analysis that was not possible in the present study.

Counselling Implications

Results from each of the study focuses have implications for counselling. Implications of results from the caregiver burden focus, social network focus, and perceived benefits of caregiving focus are discussed below.

<u>Caregiver Burden</u>

Objective and subjective burden appear to be unrelated. Consequently, it seems advantageous for counsellors to differentiate caregiver lifestyle and relationship changes from attitudes and feelings toward caregiving. Although males and females had similar levels of objective and subjective burden, different variables predicted the burden measures for husband and wife caregivers. More specifically, counsellors could perhaps explore female subjective burden in relation to her spouse's psychosocial impairment. Female objective burden could be explored in terms of the length of time their partners have been diagnosed with dementia. Obviously, the diagnosis length cannot be altered but counsellors could explore the nature of the changes in the caregiver's relationships and/or lifestyle since the onset of dementia. The results do not suggest that counsellors should ignore patient impairment measures in relation to a husband caregiver's experience. Rather, this variable may not be as important a consideration for males as for females.

Caregiver impairment was not related to burden measures for either gender. It would be presumptuous to conclude at this point that caregiver impairment should not be considered by counsellors as the absence of relationships may rather be indicative of a healthy sample of caregivers. Elderly caregivers may have health problems that interfere with the wide range of caregiving duties they perform. For example, several caregivers in the sample were unable to bathe their spouses or had weak hearts that virtually eliminated excursions outside the home. Counsellors should be aware of existing health problems that may alter the type of care that caregivers can provide.

Subnetwork size was not significantly related to caregiver burden measures suggesting that it may not be fruitful for counsellors to encourage a highly burdened caregiver to become more involved with more people. Indeed, most caregivers do not have the time to pursue such a strategy. Further the majority of caregivers were content with the number of subnetwork members they had been in contact with during the previous month.

The positive relationship between male subjective burden and family contact is not readily explained by the data. Counsellors could explore this with male caregivers who appear to have high levels of subjective burden. The positive relationship obtained in the present study is in contrast to Zarit et al.'s (1980) results and their suggestions of

increasing informal contact for highly burdened caregivers. While their suggestion may be applied in some cases, it should not necessarily be applied to all situations. One difficulty in advocating increased subnetwork contact frequency is that the nature of the interactions may actually be harmful for caregivers.

In general, it would appear worthwhile for counsellors to ascertain what type(s) of support caregivers are receiving. One support category, tangible assistance, was significantly and positively related to male subjective burden. It is possible that with a larger sample, other categories may also have been related to male subjective burden as the directions of all relationships suggested that receiving greater amounts of support categories was related to greater subjective burden. Causation cannot be determined on the basis of the data but counsellors could explore a husband's level of subjective burden in relation to the amount of each type of support he is receiving.

The number of respite hours was not related to caregiver burden although several caregivers emphasized how important respite was in their lives. Lundervold and Lewin's (1987) conclusions are supported in the present study in that it should not be automatically assumed that caregivers will be best assisted by increasing respite availability. Rather, the optimal amount of respite seems individually determined as for example, several male caregivers were content without respite as their spouses accompanied them on outings. Consequently, counsellors should perhaps explore the meaning of respite to caregivers rather than assume a given amount of respite is optimal for all caregivers.

Perceptions of support categories were significantly related to male burden measures. This suggests that counsellors could explore perceptions of the support that is received in addition to the amount received. As helpfulness and upset ratings were not significantly related to each other, they appear to be unique measures. Therefore, counsellors can obtain more detailed information about caregiver perceptions by differentiating them rather than utilizing a general satisfaction scale. Exploration of helpfulness and upset perceptions can provide a depiction of the strengths and weaknesses of a caregiver's network.

Results tentatively suggest that perhaps counsellors should consider the sources of support in relation to male subjective burden in particular. The amount of family support appears to be an important consideration in exploring male subjective burden as do ratings of upset with friends.

Social Networks

It seems relevant for counsellors to explore subnetworks individually and in particular, the amount of support of various types as well as caregiver perceptions of support from spouses. The contributions of spouses should not be ignored as they provide as much tangible assistance as other subnetworks - although the quality of support from spouses may not approximate that of the other subnetworks. With the exception of socializing support, perceptions of support categories from spouses are similar for male and female caregivers. Socializing support from spouses appears to be perceived as more helpful by males demonstrating that the nature of the spouse-caregiver relationship may be different for male caregivers than it is for female caregivers.

Caregiver expectations of subnetworks were varied. This suggests

that counsellors should be aware of individual differences pertaining to expectations. Further, examining expectations may provide helpful information concerning future network involvement.

The above emphasis on examining the caregiver's social network may lead to the conclusion that counsellors should advocate network therapy or interventions. This stance has been taken by both Zarit et al. (1980) and Fiore et al. (1986). The latter authors promoted network therapy as a means to increase support from some members, reduce troublesome actions from members, and/or reduce caregiver's expectations or alter their perceptions of what is being received. However, several authors have cautioned against establishing social network interventions as a panacea.

Chapman and Pancoast (1985) identified three potential barriers in implementing these types of intervention strategies. The first relates to the caregiver as he or she may resist input from formal care providers. Brownell and Shumaker (1985) voiced similar concerns as some individuals may resist depending on anyone or sharing problems with other persons. Further, descriptive evidence in the present study suggests that in general, caregivers may expect particular kinds of support from subnetworks but expectations appear to be subject to individual differences. The second barrier in implementing network intervention strategies concerns the caregiver's social network. Some members may not be interested in increasing their levels of support or changing their relationships with caregivers. Garrison and Howe (1976) emphasized the importance of determining if a client's network has resources that could be beneficial. If there are such resources, the helping professional should determine the degree of openness that

members express toward being involved in a network approach. The third potential barrier pertains to agencies. Obviously, there is a significant time commitment in organizing network members that individual caregiver counselling would not require.

Despite these potential barriers in implementing social network interventions, counsellors can at least monitor changes in a caregiver's social network. Social networks are not static as many caregivers in the present study described network changes of a structural and/or functional nature.

Perceived Benefits

While the problems associated with providing care to a spouse with dementia are manifold and varied according to each caregiver's situation, counsellors should be aware that all dementia-related changes are not necessarily negative. The majority of caregivers in the present study described positive changes in their marriage relationships, partners, and/or themselves. It may be beneficial to encourage caregivers to think about such aspects rather than focus on the negative aspects of the disease.

Several caregivers expressed unfavourable opinions about nursing homes and indeed, several identified this as a reason for keeping their spouses at home. Although not specifically addressed in the present study, it would seem that if institutionalization occurred, these caregivers could experience guilt and/or feelings of abandonment of their spouses. Consequently, exploring caregiver feelings and attitudes toward placement of their spouses may be a form of preventative counselling.

REFERENCES

- American Psychiatric Association. (1980). <u>Diagnostic and statistical</u> <u>manual of mental disorders</u> (3rd ed.). Washington, DC: Author.
- Aronson, J. (1985). Family care of the elderly: Underlying assumptions and their consequences. <u>Canadian Journal on Aging</u>, <u>4</u>, 115-125.
- Barrera, M., Jr. (1986). Distinctions between social support concepts, measures, and models. <u>American Journal of Community Psychology</u>, <u>14</u>, 413 - 445.
- Barrera, M., Jr., & Ainlay, S.L. (1983). The structure of social support: A conceptual and empirical analysis. <u>Journal of Community</u> <u>Psychology</u>, <u>11</u>, 133-143.
- Bergmann, K., Foster, E.M., Justice, A.W., & Matthews, V. (1978). Management of the demented elderly patient in the community. <u>British</u> <u>Journal of Psychiatry</u>, <u>132</u>, 441-449.
- Bergner, M., Bobbitt, R.A., Carter, W.B., & Gilson, B.S. (1981). The Sickness Impact Profile: Development and final revision of a health status measure. <u>Medical Care</u>, <u>19</u>, 787-805.
- Brody, S.J., Poulshock, S.W., & Masciocchi, C.F. (1978). The family caring unit: A major consideration in the long-term support system. <u>The Gerontologist</u>, <u>18</u>, 556-561.
- Brownell, A., & Shumaker, S.A. (1985). Where do we go from here? The policy implications of social support. <u>Journal of Social Issues</u>, <u>41</u>, 111-121.
- Cantor, M.H. (1983). Strain among caregivers: A study of experience in the United States. <u>The Gerontologist</u>, <u>23</u>, 597-604.
- Caserta, M.S., Lund, D.A., Wright, S.D., & Redburn, D.E. (1987). Caregivers to dementia patients: The utilization of community services. <u>The Gerontologist</u>, <u>27</u>, 209-214.
- Chapman, N.J., & Pancoast, D.L. (1985). Working with the informal helping networks of the elderly: The experiences of three programs. Journal of Social Issues, 41, 47-63.
- Chappell, N.L. (1985). Social support and the receipt of home care services. <u>The Gerontologist</u>, <u>25</u>, 47-54.
- Chenoweth, B., & Spencer, B. (1986). Dementia: The experience of family caregivers. <u>The Gerontologist</u>, <u>26</u>, 267-272.
- Cohen, S., & Wills, T.A. (1985). Stress, social support, and the buffering hypothesis. <u>Psychological Bulletin</u>, <u>98</u>, 310-357.

Conn, J., Bobbitt, R.A., & Bergner, M. (1978). Administration

procedures and interviewer training for the Sickness Impact Profile. Seattle: Department of Health Services, University of Washington.

- Cozby, P.C. (1977). <u>Methods in behavioral research</u>. Palo Alto, CA: Mayfield Publishing Company.
- Crossman, L., London, C., & Barry, C. (1981). Older women caring for disabled spouses: A model for supportive services. <u>The</u> <u>Gerontologist</u>, <u>21</u>, 464-470.
- Cummings, J.L. (1987). Multi-infarct dementia: Diagnosis and management. <u>Psychosomatics</u>, <u>28</u>, 117-126.
- Depner, C.E., Wethington, E., & Ingersoll-Dayton, B. (1984). Social support: Methodological issues in design and measurement. <u>Journal of</u> <u>Social Issues</u>, <u>40</u>, 37-54.
- Dunkel-Schetter, C., Folkman, S., & Lazarus, R.S. (1987). Correlates of social support receipt. <u>Journal of Personality and Social Psychology</u>, <u>53</u>, 71-80.
- Eagles, J.M., Beattie, J.A.G., Blackwood, G.W., Restall, D.B., & Ashcroft, G.W. (1987). The mental health of elderly couples: The effects of a cognitively impaired spouse. <u>British Journal of Psychiatry</u>, <u>150</u>, 299-303.
- Eagles, J.M., Craig, A., Rawlinson, F., Restall, D.B., Beattie, J.A.G., & Besson, J.A.O. (1987). The psychological well-being of supporters of the demented elderly. <u>British Journal of Psychiatry</u>, <u>150</u>, 293-8.
- Edstrom, S., & Miller, M.W. (1981). Preparing the family to care for the cancer patient at home: A home care course. <u>Cancer Nursing</u>, <u>4</u>, 49-52.
- Fengler, A.P., & Goodrich, N. (1979). Wives of elderly disabled men: The hidden patients. <u>The Gerontologist</u>, <u>19</u>, 175-183.
- Fiore, J., Becker, J., & Coppel, D.B. (1983). Social network interactions: A buffer or a stress. <u>American Journal of Community</u> <u>Psychology</u>, <u>11</u>, 423-439.
- Fiore, J., Coppel, D.B., Becker, J., & Cox, G.B. (1986). Social support as a multifaceted concept: Examination of important dimensions for adjustment. <u>American Journal of Community Psychology</u>, <u>14</u>, 93-111.
- Fitting, M., Rabins, P., Lucas, M.J., & Eastham, J. (1986). Caregivers for dementia patients: A comparison of husbands and wives. <u>The</u> <u>Gerontologist</u>, <u>26</u>, 248-252.
- Garrison, J.E., & Howe, J. (1976). Community intervention with the elderly: A social network approach. <u>Journal of the American</u> <u>Geriatrics Society</u>, <u>24</u>, 329-333.

- George, L.K., & Gwyther, L.P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. <u>The Gerontologist</u>, <u>26</u>, 253-259.
- Gibson, M.J. (1980). Family support for the elderly in international perspective: Part II, policies and programs. <u>Ageing International</u>, <u>7</u>, 13-19.
- Gilhooly, M.L.M. (1984). The impact of care-giving on care-givers: Factors associated with the psychological well-being of people supporting a dementing relative in the community. <u>British Journal of</u> <u>Medical Psychology</u>, <u>57</u>, 35-44.
- Glass, G.V., & Hopkins, K.D. (1984). <u>Statistical methods in education</u> <u>and psychology</u> (2nd ed.). Englewood Cliffs, New Jersey: Prentice-Hall, Inc.
- Goldman, L.S., & Luchins, D.J. (1984). Depression in the spouses of demented patients. <u>American Journal of Psychiatry</u>, <u>141</u>, 1467-1468.
- Googe, M.C., & Varricchio, C.G. (1981). A pilot investigation of home health care needs of cancer patients and their families. <u>Oncology</u> <u>Nursing Forum, 8</u>, 24-28.
- Gottlieb, B.H. (1983). <u>Social support strategies: Guidelines for</u> <u>mental health practice</u>. Beverly Hills, CA: Sage Publications.
- Greene, J.G., Smith, R., Gardiner, M., & Timbury, G.C. (1982). Measuring behavioral disturbance of elderly demented patients in the community and its effects on relatives: A factor analytic study. <u>Age</u> <u>and Ageing</u>, <u>11</u>, 121-126.
- Gwyther, L., & Matteson, M. (1983). Care for the caregivers. <u>Journal</u> of <u>Gerontological Nursing</u>, <u>9</u>, 93-95, 110.
- Ineichen, B. (1987). Measuring the rising tide. How many dementia cases will there be by 2001? <u>British Journal of Psychiatry</u>, <u>150</u>, 193-200.
- Jeans, E.R., Helmes, E., Merskey, H., Robertson, J.M.D., & Rand, K.A. (1987). Some calculations on the prevalence of dementia in Canada. <u>Canadian Journal of Psychiatry</u>, <u>32</u>, 81-86.
- Johnson, C.L. (1983). Dyadic family relations and social support. <u>The</u> <u>Gerontologist</u>, <u>23</u>, 377-383.
- Keating, N.C., & Gilewich, G. (1985). Alzheimer's disease: The burden of family caring. <u>Alberta Psychology</u>, <u>14</u>, 17-18.

Kent, S. (1983). What causes Alzheimer's? Geriatrics, 38, 35-36, 41.

Kiecolt-Glaser, J.K., Glaser, R., Shuttleworth, E.C., Dyer, C.S., Ogrocki, P., & Speicher, C.E. (1987). Chronic stress and immunity in family caregivers of Alzheimer's disease victims. <u>Psychosomatic</u> <u>Medicine</u>, <u>49</u>, 523-535.

Long term care controversy. (1988, October). News for Seniors, p.1.

- Lundervold, D., & Lewin, L.M. (1987). Effects of in-home respite care on caregivers of family members with Alzheimer's disease. <u>Journal of</u> <u>Clinical Experimental Gerontology</u>, 9, 201-214.
- Marcus, L., & Jaeger, V. (1984). The elderly as family caregivers. <u>Canadian Journal on Aging</u>, <u>3</u>, 33-43.
- Marples, M. (1986). Helping family members cope with a senile relative. <u>Social Casework</u>, <u>67</u>, 490-498.
- McCusker, J., & Stoddard, A.M. (1984). Use of a surrogate for the Sickness Impact Profile. <u>Medical Care</u>, <u>22</u>, 789-795.
- Miller, B. (1987). Gender and control among spouses of the cognitively impaired: A research note. <u>The Gerontologist</u>, <u>27</u>, 447-453.
- Mitchell, R.E., & Trickett, E.J. (1980). Task force report: Social networks as mediators of social support. <u>Community Mental Health</u> <u>Journal</u>, <u>16</u>, 27-44.
- Montgomery, R.J.V., Gonyea, J.G., & Hooyman, N.R. (1985). Caregiving and the experience of subjective and objective burden. <u>Family</u> <u>Relations</u>, <u>34</u>, 19-26.
- Morycz, R.K. (1980). An exploration of senile dementia and family burden. <u>Clinical Social Work Journal</u>, <u>8</u>, 16-27.
- Novak, M., & Guest, C. (1985). <u>Social correlates of caregiver burden</u>. Unpublished manuscript, University of Winnipeg, Winnipeg.
- Ory, M.G., Williams, T.F., Emr, M., Lebowitz, B., Rabins, P., Salloway, J., Sluss-Radbaugh, T., Wolff, E., & Zarit, S. (1985). Families, informal supports, and Alzheimer's disease. <u>Research on Aging</u>, <u>7</u>, 623-644.
- Pagel, M.D., Becker, J., & Coppel, D.B. (1985). Loss of control, self-blame and depression: An investigation of spouse caregivers of Alzheimer's disease patients. <u>Journal of Abnormal Psychology</u>, <u>94</u>, 169-182.
- Pagel, M.D., Erdly, W.W., & Becker, J. (1987). Social networks: We get by with (and in spite of) a little help from our friends. <u>Journal of</u> <u>Personality and Social Psychology</u>, <u>53</u>, 793-804.

Peters, G.R., Hoyt, D.R., Babchuk, N., Kaiser, M., & Iijima, Y. (1987). Primary-group support systems of the aged. <u>Research on Aging</u>, <u>9</u>, 392-416.

- Poulshock, S.W., & Deimling, G.T. (1984). Families caring for elders in residence: Issues in the measurement of burden. <u>Journal of</u> <u>Gerontology</u>, <u>39</u>, 230-239.
- Pratt, C.C., Schmall, V.L., Wright, S., & Cleland, M. (1985). Burden and coping strategies of caregivers to Alzheimer's patients. <u>Family</u> <u>Relations</u>, <u>34</u>, 27-33.
- Rabins, P.V., Mace, N.L., & Lucas, M.J. (1982). The impact of dementia on the family. <u>Journal of the American Medical Association</u>, <u>248</u>, 333-335.
- Robertson, D., & Reisner, D. (1982). Management of dementia in the elderly at home: Stress and the supporter. <u>Canada's Mental Health</u>, <u>30</u>, 36-38.
- Rook, K.S. (1984). The negative side of social interaction: Impact on psychological well-being. <u>Journal of Personality and Social</u> <u>Psychology</u>, <u>46</u>, 1097-1108.
- Rose, M.A. (1976). Problems families face in home care. <u>American</u> <u>Journal of Nursing</u>, <u>76</u>, 416-418.
- Sainsbury, R.S., & Coristine, M. (1986). Affective discrimination in moderately to severely demented patients. <u>Canadian Journal on Aging</u>, <u>5</u>, 99-104.
- Sands, D., & Suzuki, T. (1983) Adult day care for Alzheimer's patients and their families. <u>The Gerontologist</u>, <u>23</u>, 21-23.
- Schneck, M.K., Reisberg, B., & Ferris, S.H. (1982). An overview of current concepts of Alzheimer's Disease. <u>American Journal of</u> <u>Psychiatry</u>, 139, 165-173.
- Scott, J.P., Roberto, K.A., & Hutton, J.T. (1986). Families of Alzheimer's victims: Family support to the caregivers. <u>Journal of</u> <u>the American Geriatrics Society</u>, <u>34</u>, 348-354.
- Shanas, E. (1979a). Social myth as hypothesis: The case of the family relations of old people. <u>The Gerontologist</u>, <u>19</u>, 3-9.
- Shanas, E. (1979b). The family as a social support system in old age. <u>The Gerontologist</u>, <u>19</u>, 169-174.
- Shinn, M., Lehmann, S., & Wong, N.W. (1984). Social interaction and social support. <u>Journal of Social Issues</u>, <u>40</u>, 55-76.
- Shumaker, S.A., & Brownell, A. (1984). Toward a theory of social support: Closing conceptual gaps. <u>Journal of Social Issues</u>, <u>40</u>, 11-36.
- Statistics Canada. (1985). <u>Population projections for Canada, Provinces</u> <u>and Territories, 1984-2006</u> (Catalogue 91-520): Ottawa: Author.
- Stokes, J.P. (1983). Predicting satisfaction with social support from social network structure. <u>American Journal of Community Psychology</u>, <u>11</u>, 141-152.
- Stoller, E.P., & Earl, L.L. (1983). Help with activities of everyday life: Sources of support for the noninstitutionalized elderly. <u>The</u> <u>Gerontologist</u>, <u>23</u>, 64-70.
- Tardy, C.H. (1985). Social support measurement. <u>American Journal of</u> <u>Community Psychology</u>, <u>13</u>, 187-202.
- Thoits, P.A. (1982). Studying social support as a buffer against life stress. <u>Journal of Health and Social Behavior</u>, <u>23</u>, 145-159.
- Thoits, P.A. (1986). Social support as coping assistance. <u>Journal of</u> Consulting and <u>Clinical Psychology</u>, <u>54</u>, 416-423.
- Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. <u>The Gerontologist</u>, <u>20</u>, 649-655.
- Zarit, S.H., Todd, P.A., & Zarit, J.M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. <u>The</u> <u>Gerontologist</u>, <u>26</u>, 260-266.

APPENDICES

Appendix A

Background Information Questionnaire

I would like to start by asking you some general questions about yourself and your spouse.

<u>Caregiver</u>	number	Spouse	number	
	male (0) female (1)	!	male (0 <u>)</u>	female (1)
	age	•	age	. /
	education (years)	. ,	education (ye	ars)
	place of residence			(city/town/country)
	•			
How long h	ave you been married?		years	
Does anyon	e else live with you and you	r spouse?	Yes/No	
Who?	Relat	ionship t	o you?	
·				
How many c	hildren do you have?			
How many c	hildren live less than a 1/2	hour dri	ve away?	• .
_				,
For someon	e your age, would you say yo	ur health	is generally	
excellent	(4) good (3) f	air	(2) or poor	· (1)
.		· ·		
Are there	any health problems that int	erfere wi	th your every	day activities?
Specify.				
	de vou fool this pushlom is	2(1 - 1)	ich+ 2 - 001	
How severe	Display teel unis problem is	(1 = S)	19111, 2 = 500	ere, 5 = very
Health	Problem	<u>sever1</u>	<u>L Y</u>	
<u> </u>				
		· · · · · · · · · · · · · · · · · · ·		
	······································		· · ·	
What type	of dementia does your shouse	have?		
How many m	onths ago was he/she diagnos	ed as hav	ing this dise	ase?
Has your s	nouse entered the hosnital f	for a peri	od longer the	in one week in the
nas jour s	? Yes/No How long?	or a peri	(davs)	
When?			(23)	
How many d	avs in the past month has he	/she been	at home sinc	e his/her last
hospitaliz	ation?	y 5110 50001		
	·····			

Appendix B

Social Network List

You may have contact with many people in one month. These people may be family members, friends or other people who help you as part of their job or volunteer position. Please indicate who these people are on the following pages. Include anyone who is important to you at this time in your life whether you like them or not. Include only those persons that you have had some contact (i.e., telephone calls, letters, visits) with in the <u>past month</u>. Please use the guidelines below to fill in the following pages.

- (a) In space (a), write the initials of the person who meets the above qualifications.
- (b) In space (b), indicate the person's gender.
- (c) In space (c), indicate the person's relationship to you.
- (d) In space (d), indicate how close you feel to the person on a scale of 0-100.

e	extremely close		. ez	xtremely distant
C) 2	5 50) 7!	5 100

(e) In space (e), indicate approximately how frequently you have contact (letters, telephone calls, visits) with this person.

Choose one from below:

- (1) daily
- (2) several times per week
- (3) once per week
- (4) twice per month
- (5) once per month

1. SOCIAL NETWORK LIST - FAMILY MEMBERS

Please list all your <u>family members</u> (including your spouse) who are important to you at this time in your life - whether you like them or not - and with whom you have had some sort of contact in the <u>past month</u>. Do not feel obligated to fill in all the spaces provided.

1.	(a) Initials (d) Closeness	(b) Gender (c) (e) Contact	Relationship
2.	(a) Initials (d) Closeness	(b) Gender (c (e) Contact) Relationship
3.	(a) Initials (d) Closeness	(b) Gender (c (e) Contact) Relationship
4.	(a) Initials (d) Closeness	(b) Gender (c (e) Contact	Relationship
5.	(a) Initials (d) Closeness	(b) Gender (c (e) Contact) Relationship
6.	(a) Initials (d) Closeness	(b) Gender (c (e) Contact) Relationship
7.	(a) Initials (d) Closeness	(b) Gender (c (e) Contact) Relationship
8.	(a) Initials (d) Closeness	(b) Gender (c (e) Contact) Relationship
9.	(a) Initials (d) Closeness	(b) Gender (c (e) Contact) Relationship
10.	(a) Initials (d) Closeness	(b) Gender (c (e) Contact) Relationship
11.	(a) Initials (d) Closeness	(b) Gender (c (e) Contact) Relationship
12.	(a) Initials (d) Closeness	(b) Gender (c (e) Contact) Relationship
13.	(a) Initials (d) Closeness	(b) Gender (c (e) Contact) Relationship
14.	(a) Initials (d) Closeness	(b) Gender (c (e) Contact) Relationship
15.	(a) Initials (d) Closeness	(b) Gender (c (e) Contact) Relationship

2. SOCIAL NETWORK LIST - FRIENDS

Please provide the same information for your <u>friends</u> who are important to you at this time in your life and with whom you have had some sort of contact with in the <u>past month</u>. You may not always like them but if they are important to you, please include them. Do not feel obligated to fill in all the spaces provided.

1.	(a) Initials (d) Closeness	(b) Gender (c) (e) Contact	Relationship <u>friend</u>
2.	(a) Initials (d) Closeness	(b) Gender (c) (e) Contact	Relationship <u>friend</u>
3.	(a) Initials (d) Closeness	(b) Gender (c) (e) Contact	Relationship <u>friend</u>
4.	(a) Initials (d) Closeness	(b) Gender (c) (e) Contact	Relationship <u>friend</u>
5.	(a) Initials (d) Closeness	(b) Gender (c) (e) Contact	Relationship <u>friend</u>
6.	(a) Initials (d) Closeness	(b) Gender (c) (e) Contact	Relationship <u>friend</u>
7.	<pre>(a) Initials (d) Closeness</pre>	(b) Gender (c) (e) Contact	Relationship <u>friend</u>
8	(a) Initials (d) Closeness	(b) Gender (c) (e) Contact	Relationship <u>friend</u>
9.	(a) Initials (d) Closeness	(b) Gender (c) (e) Contact	Relationship <u>friend</u>
10.	(a) Initials (d) Closeness	(b) Gender (c) (e) Contact	Relationship <u>friend</u>
11.	(a) Initials (d) Closeness	(b) Gender (c) (e) Contact	Relationship <u>friend</u>
12.	(a) Initials (d) Closeness	(b) Gender (c) (e) Contact	Relationship <u>friend</u>
13.	(a) Initials (d) Closeness	(b) Gender (c) (e) Contact	Relationship <u>friend</u>
14.	(a) Initials (d) Closeness	(b) Gender (c) (e) Contact	Relationship <u>friend</u>
15.	(a) Initials (d) Closeness	(b) Gender (c) (e) Contact	Relationship <u>friend</u>

172

3. SOCIAL NETWORK LIST - OTHER HELPERS

Please list any <u>helpers</u> that you have been in contact with in the past month. Examples of helpers may include nurses, doctors, social workers, pastors or priests, Meals On Wheels volunteers, volunteer visitors, etc. Please include anyone that you have had contact with in the <u>past month</u> - even if you have already included some of them as friends in the previous list. Do not feel obligated to fill in all the spaces provided. Please fill in the blanks the same way as before except for blank (c). In blank (c) indicate what agency the person is from.



Appendix C

Enacted and Perceived Support Form

People can support us in many ways but for now, I would like to look at four basic ways. I am going to take the initials of the people you listed in the Social Network List. After I describe one way that people can support us, I would like you to tell me how frequently each person has supported you in that way in the past month. This will become clearer as we go through the ways people can support us.

The first way a person can support you is by <u>socializing</u> with you. (show description sheet) By this, I mean enjoyable interactions with you in situations that are not related to problems you may have. This could include any activity you may enjoy such as having a meal together, chatting, playing cards, recreational activities, etc. Does this make sense to you?

In the past month, approximately how often has ______ socialized with you?
(show sheet with the range of choices)
(daily = 28; several times/week = 12; once/week = 4; twice/month = 2; once/month
= 1; never = 0)

THIS QUESTION IS REPEATED FOR EACH NETWORK MEMBER.

In regard to <u>socializing</u>, how helpful do you think your relationship with _______ is on this scale of 1 (not helpful) to 6 (very helpful)? (show the scale to the respondent)

THIS QUESTION IS REPEATED FOR EACH NETWORK MEMBER.

Sometimes people do not meet our expectations. This can make us upset with that person. In regard to <u>socializing</u>, how upset are you with ______ because he/she did not meet your expectations? The scale ranges from 1 to 6. (show the scale to the respondent)

THIS QUESTION IS REPEATED FOR EACH NETWORK MEMBER.

THE ENTIRE PROCEDURE WILL BE REPEATED FOR EACH OF THE OTHER THREE CATEGORIES OF SOCIAL SUPPORT.

The second area of support we will look at is <u>tangible assistance</u>. These are any types of behaviors or services that a person may provide for you. This can include providing financial assistance, giving you rides, looking after your spouse so you can get away, cooking, etc. Does this make sense?

The third area of support is <u>cognitive guidance</u>. This refers to times when a person clarifies something for you or helps you to better understand a problem you may have. For example, someone giving you information about your spouse's illness or giving you advice on how to better help your spouse would be giving you <u>cognitive guidance</u>. Does this make sense?

The last area of support is <u>emotional support</u>. A person who gives you help that makes you feel cared for, understood, praised, sympathized with and generally gives you the sense that he/she would provide help in any way they could would be giving you <u>emotional support</u>. Does this make sense?

<u>Socializing</u>

- enjoyable interactions <u>not</u> related to problems you may have
- examples include:
 - having a meal together
 - chatting
 - playing cards
 - recreational activities, etc.

Tangible Assistance

- behaviors and/or services that a person provides for you
- examples include:
 - financial assistance
 - giving you a ride somewhere
 - cooking
 - cleaning
 - looking after your spouse so you can get away, etc.

<u>Cognitive Guidance</u>

- someone clarifies something for you or helps you understand a problem

- examples include:
 - giving information about the progression of your spouse's dementia
 - giving advice about ways to help your spouse
 - giving you information about problems you have, etc.

Emotional Support

- help given you that makes you feel:
 - like he/she would provide help in any way possible
 - cared for
 - understood
 - praised
 - sympathized with, etc.

Enacted Support, Perception Ratings, and Sources of Support Guidelines176



<u>Helpful</u>



Upset (doesn't meet my expectations)



Sources of Support

Spouse Family Members Friends Other Helpers

		Enacted and Perceived Support Scores													
		SOCIALIZ	ING	TANG	<u>AIBLE</u>	COGN	VITIVE	<u>EMO</u>	TIONAL	_	<u>TOTAL</u>	.	_	MEAN	
	Initials	Enac He	Up	Enac	<u>He Up</u>	<u>Enac</u>	<u>He</u> Ur	<u>Enac</u>	<u>He U</u>	<u>p Enac</u>	<u>He</u>	<u>qU</u>	<u>Enac</u>	<u>He</u>	Up
	Spouse														
-	1.		•			<u> </u>			<u> </u>	<u> </u>				<u> </u>	
	2.	·				. <u> </u>						<u> </u>			
F	3.							<u></u>			<u></u>				
Α	4.						<u> </u>				<u> </u>				<u> </u>
M	5		·	<u> </u>								<u> </u>			
I	6														
L	7								<u> </u>						
Y	8				<u> </u>						<u> </u>				
	9								<u></u>				<u>.</u>	<u> </u>	
	TOTAL	<u> </u>										<u></u>			
	MEAN				<u> </u>	<u></u>	<u> </u>		<u> </u>						
		<u></u>		· · · · · · · · · · · · · · · · · · ·	<u> </u>								· · · · · · · · · · · · · · · · · · ·		
	1	<u> </u>					<u> </u>		<u> </u>		<u> </u>				<u></u>
F	2			<u> </u>			 —		<u> </u>			<u> </u>			
R	3	<u> </u>	. <u></u>		<u> </u>	·	<u> </u>		<u> </u>						<u>_</u>
Ï	4	<u> </u>	·	<u> </u>			<u> </u>		<u> </u>			<u> </u>			
E	5	<u> </u>	. <u></u>		<u></u>				<u> </u>			<u> </u>	<u> </u>		<u> </u>
N	6						<u> </u>				<u> </u>	<u> </u>			<u></u>
D	/	<u></u>	• <u></u>		<u> </u>		<u> </u>			- '					
S	8	<u> </u>			<u> </u>			<u> </u>	<u> </u>			<u> </u>		<u>-</u>	
	9	<u> </u>	. <u></u>				<u> </u>				<u></u>	<u></u>			
		<u> </u>		<u> </u>			<u> </u>								
	IUIAL	<u></u>				<u> </u>		- `							
	MEAN	<u> </u>		<u> </u>											
								<u></u>					······.		
	·	<u></u>		·								<u> </u>		·	
С	2	<u> </u>		·			<u>`</u>								
	3	<u> </u>		·			<u> </u>							<u> </u>	
U D	4. E	<u></u>	· ,			·			<u></u>						
K M	5	<u> </u>		·	<u> </u>				<u> </u>						
	7	<u> </u>		<u> </u>										<u></u>	
- A	/·	<u> </u>				<u> </u>			<u> </u>						
L	°	<u></u> <u></u>		·	······		······		<u> </u>			·			
	10			·										· · ·	- <u></u>
	10. TOTAI			·					<u> </u>	<u> </u>					
	MEAN	·		·					· · · · · · · · · · · · · · · · · · ·	<u> </u>			·		
	nem	<u> </u>	-	·			<u> </u>								
	TEGORY TOTAL											<u> </u>			<u></u> .
0P C M	TEGORY MEAN	•	· ·······			<u> </u>	<u> </u>								
UP				<u> </u>		<u></u>	<u> </u>		<u> </u>						

•

•

•

177

•

· · ·

Appendix D

Helpfulness Ratings and Expectations of Enacted Support Questionnaire

We have talked about four kinds of support that you receive. The first kind was socializing (show EPSF description sheet) which was when other people interacted with you in an enjoyable way. The second kind was tangible assistance which happened when someone gave you assistance with some of your chores and/or tasks. The third kind of support was cognitive guidance which was when someone helped you understand a problem you had. The fourth kind of support was emotional support which led you to feel cared about and understood. I will leave this description sheet here for you to answer the next questions.

1. At this time, which of these four kinds of support is most helpful for you?

At this time, which of these is <u>least</u> helpful for you?

2. At this time, which of these kinds of support do you most expect from your spouse?

At this time, which of these kinds of support do you <u>least</u> expect from your spouse?

3. At this time, which of these kinds of support do you <u>most</u> expect from your other family members?

At this time, which of these kinds of support do you <u>least</u> expect from your other family members?

4. At this time, which of these kinds of support do you most expect from your friends?

At this time, which of these kinds of support do you <u>least</u> expect from your friends?

5. At this time, which kind of support do you <u>most</u> expect from other helpers you described earlier?

At this time, which kind of support do you <u>least</u> expect from other helpers you described earlier?

So far, we have talked about four sources of support. They are your spouse, family, friends and other helpers. (show EPSF sheet with sources) Of these four sources:

6. Which one do you most expect to provide you with socializing?

Which one do you <u>least</u> expect to provide you with <u>socializing</u>?

- 7. Which one do you <u>most</u> expect to provide you with <u>tangible assistance</u>? 179 Which one do you <u>least</u> expect to provide you with <u>tangible assistance</u>?
- 8. Which one do you <u>most</u> expect to provide you with <u>cognitive guidance</u>? Which one do you <u>least</u> expect to provide you with <u>cognitive guidance</u>?
- 9. Which one do you <u>most</u> expect to provide you with <u>emotional support</u>? Which one do you <u>least</u> expect to provide you with <u>emotional support</u>?
- 10. What are some services that would help you look after your spouse?

Appendix E

Respite Questionnaire

- 1. Approximately how many hours in the past month were you able to leave the house?
- 2. Who stayed with your spouse when you left the house in the past month? no one - patient does not require constant attention



- 3. What activities do you tend to do during this time away from home?
- 4. Would you like to be able to "get away" from your home more frequently than you do now? Yes No
- 5. If yes, would you like to get out of the house:
 - much more frequently (3)
 - more frequently (2)
 - about the same number of times (1)

6. What activities would you like to do more than you do now?

Appendix F

Perceived Benefits of Caregiving Questionnaire

1. Have you experienced any benefits in providing care for your spouse?

2. Is there anything else that you have found beneficial in your caregiving experience?

3. Why have you decided to provide care for your spouse at home?

,

÷