

FAMILY CAREGIVERS OF DEPENDENT OLDER PERSONS:
LIVED EXPERIENCES OF SOCIAL SUPPORT

A DISSERTATION

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF DOCTOR OF PHILOSOPHY
IN THE GRADUATE SCHOOL OF THE
TEXAS WOMAN'S UNIVERSITY

COLLEGE OF NURSING

BY

MARY PALMORE GILLILAND, MS, RN

DENTON, TEXAS

DECEMBER 1999

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

October 25, 1999
Date

To the Associate Vice President for Research and Dean of the Graduate School:

I am submitting herewith a dissertation written by

Mary Palmore Gilliland, MS, RN

entitled Family Caregivers of Dependent Older Persons: Lived
Experiences of Social Support

I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirement for the degree of Doctor of Philosophy with a major in Nursing.

Margaret T. Beard
Major Professor

We have read this dissertation
and recommend its acceptance:

Helen A. Bush
Deborah R. Garrison

Accepted

Jackie N. Thompson

Associate Vice President for Research
and Dean of the Graduate School

Copyright © Mary Palmore Gilliland, 2000
All rights reserved

ACKNOWLEDGMENTS

This study was completed with the support, guidance, understanding, patience, encouragement, and love of many individuals. I offer my gratitude and respect to all the members of my committee. I extend my appreciation to Dr. Margaret Beard who, as chairperson of my dissertation committee, provided support and guidance during the dissertation process. I am deeply grateful to Dr. Helen A. Bush. As a committee member, Dr. Bush gave of her time to provide support, guidance, and encouragement. I want to thank Dr. Deborah Garrison for her helpful comments and suggestions.

I wish to acknowledge the family caregivers who willingly gave of their valuable time to share their experiences of social support. Without their cooperation and input, the study would not have been possible.

Finally, I want to thank my husband, Carl, and our daughter, GiGi, for their love, understanding, and encouragement as I endeavored to complete the study.

**FAMILY CAREGIVERS OF DEPENDENT OLDER PERSONS:
LIVED EXPERIENCES OF SOCIAL SUPPORT**

ABSTRACT

MARY PALMORE GILLILAND, MS, RN

**TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING**

DECEMBER 1999

The domain of this study was stated as: What are the lived experiences of social support for a family caregiver who cares for a dependent older person in the home? Eleven family caregivers who could discuss their lived experiences of social support were interviewed.

The study was conducted using a phenomenological approach. Interviews were audio-tape recorded and transcribed verbatim by the researcher. The descriptions of the lived experiences of social support were analyzed using Colaizzi's (1978) phenomenological approach. Three theme categories were located: (a) assistance, (b) guidance, and (c) emotional aspects. Flowing from the theme categories were five theme clusters: (a) demands of care, (b) commitment, (c) coping, (d) loss, and (e) emotions. Twenty corresponding sub-themes were derived from the clusters.

Assistance involves direct or indirect help with the demands of care which include physical and psychological demands. Physical demands are the tasks of (a) basic and instrumental activities of daily living, (b) transporting to appointments, and (c) medical responsibilities. Psychological demands are the "mental activities" of caregiving which include (a) monitoring the care recipient's condition, (b) arranging for care and appointments, (c) decision-making, and (d) dealing with personalities and behavior problems.

Guidance is the supportive behaviors directed at increasing understanding and improving the caregivers' abilities to care for their loved ones and themselves. Guidance encompasses commitment and coping. An increased understanding of their sense of obligation and responsibility enables caregivers to make thoughtful, informed decisions that consider their needs in addition to the needs of the care recipients. Guidance about coping strategies, such as problem-solving, seeking information/advice, getting away, and writing, helps the caregiver deal more effectively with the caregiving situation.

Emotional aspects are the caring connections from supportive others to help caregivers deal with their loss and emotions. Loss includes (a) social and personal lives, (b) freedom, and (c) relationships. Emotions are (a) loneliness, (b) guilt, (c) stress, (d) anxiety, (e) sadness, (f) frustration, (g) anger, and (h) uncertainty.

TABLE OF CONTENTS

	Page
ACKNOWLEDGMENTS	iv
ABSTRACT	v
LIST OF TABLES	x
 Chapter	
I. INTRODUCTION	1
Domain of Study	3
Purpose for the Study	3
Rationale for the Study	3
Assumptions	5
Theoretical Orientation	6
Definition of Terms	11
Limitations	12
Delimitations	12
Summary	12
II. REVIEW OF THE LITERATURE	14
Caregiving	14
Consequences of Caregiving	19
Social Support as an Intervention	32
Summary	52
III. DATA COLLECTION TECHNIQUES AND TREATMENT OF DATA	58
Setting	60
Population and Sample	60
Protection of Human Subjects	62
Instruments	63

	Page
Data Collection	63
Treatment of Data	64
Value and Logic	66
IV. ANALYSIS OF DATA	69
Description of Sample	70
Significant Statements	74
Formulated Meanings	81
Theme Categories, Theme Clusters, and Sub-themes	86
Exhaustive Descriptions of Family Caregivers of Dependent Older Persons Lived Experiences of Social Support	95
Fundamental Structure	115
V. SUMMARY OF THE STUDY	118
Summary	118
Discussion of Findings	122
Conclusions and Implications	132
Recommendations for Future Studies	137
REFERENCES	139
APPENDICES	
A. Human Subjects Review Committee Permission	147
B. Graduate School Letter of Permission	150
C. Verbal Explanation of Study	152
D. Consent to Participate	155

	Page
E. Demographic Data Questionnaire	158
F. Cue Words	160
G. Complete List of Significant Statements	162
H. Complete List of Formulated Meanings	185
I. Complete List of Theme Clusters and Sub-themes	199
J. Sample of Transcribed Interview	214

LIST OF TABLES

Table	Page
1. Demographic Variables of Age, Gender, Marital Status, Race, Education, Income Level, and Employment Status	72
2. Demographic Variables of Relationship of Care Recipient, Years of Caregiving, Care Hours per Day, Days of Care per Week, Assisted Activities, and Care Recipient's Diagnosis	73
3. Examples of Significant Statements from Interviews	74
4. Examples of Formulated Meanings from Significant Statements	81
5. Theme Categories, Theme Clusters, and Sub-themes	87
6. Examples of Clusters of Themes and Sub-themes	89

CHAPTER I

INTRODUCTION

Today, there are more than 32 million Americans in the United States 65 years of age or older, accounting for 12% of the total population (DeLong, 1995). The number of Americans over the age of 65 is anticipated to increase to around 70 million by the year 2030 (Braddock, 1999; Delong, 1995; U.S. Bureau of the Census, 1996), when an estimated 23% of the population will be comprised of older persons (Baum & Rutecki, 1998; Evans, 1998). The age of older persons is also increasing. Since 1980, there has been a 9.1% increase in age groups 65 to 74, and a 14.2% increase in age groups 75 to 84 (Sayles-Cross, 1993). The fastest growing segment of the population is individuals aged 85 or older (Habel, 1998; Hellinghausen, 1997; U.S. Department of Health and Human Services, 1990), with a 21% increase in this age group since 1980 (Sayles-Cross, 1993). The “oldest old” segment is expected to double in its present size by the year 2020 (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Hellinghausen, 1997; Kamer, 1998).

As society ages, age-related diseases increase. As a result, the older person's needs will increase; therefore, an increase in the demand for familial caregivers is expected (Braddock, 1999; Robinson, 1997a). The rapidly increasing older population

recently has become an area of intense interest and concern to policymakers and the healthcare industry. In addition, the crucial role of the caregiver in providing care to the older person in the community has been recognized. The value of what caregivers do cannot be replicated by the formal healthcare system (Hellinghausen, 1997; Robinson, 1997b). The significance of the role of the family caregiver is highlighted when questions arise as to who will care for older people and where will they receive care. The resources are not available to provide institutionalized care for all older individuals who are currently cared for in the community. The absence of high-quality institutional alternatives dictates the family as the primary source of care (Ward & Carney, 1994).

Family caregiving, which permits dependent older persons to remain in the community, is a socially and financially attractive form of management of care for an aging society. Socially, the opportunity to remain in the community may optimize the level of individual functioning and allow older persons to avoid the negative effects of institutionalization. Economically, healthcare costs associated with institutionalization may be reduced with family caregivers providing care to dependent older persons in the home (Baum & Rutecki, 1998). However, the needs of family caregivers is a healthcare and, therefore, a social issue that requires more attention (Robinson, 1997b). Family caregiving is an intense and complicated activity that can result in negative consequences for caregivers who do not have adequate and appropriate support

(Chenier, 1997). Thus, this phenomenological study focused on the lived experiences of social support of family caregivers caring for dependent older persons in the home.

Domain of Study

The domain of the study was centered in one question: What are the lived experiences of social support for a family caregiver who cares for a dependent older person in the home?

Purpose for the Study

The purpose of this phenomenological study was to better understand the lived experiences of social support of the family caregiver of a dependent older person living in the home.

Rationale for the Study

Family caregivers are important in providing care for dependent older persons. Estimates are that more than 25 million Americans are currently caring for a dependent older person at home (Hellinghausen, 1997). Older individuals with healthcare problems are increasingly in need of care at home which frequently must be provided by spouses, children, or both. Caregivers assist older persons, increase the care recipients' ability to remain at home, and decrease the burden of the ill older individual on society and escalating healthcare costs. The toll of caregiving that threatens the well-being of caregivers and their ability to deliver care is well

documented (Boland & Sims, 1996; England, 1997; Hellinghausen, 1997; Worcester & Hedrick, 1997). But the provision of care does not come without costs to the caregiver. These costs have been documented as emotional, physical, social, and financial (Boland & Sims, 1996; Kleffel, 1998; Strawbridge, Wallhagen, Shema, & Kaplan, 1997). Feelings of isolation, loneliness, being overburdened, and need for support have been expressed by many caregivers. These feelings may seem relentless and overwhelming (Boland & Sims, 1996; Strawbridge et al., 1997).

As more older people survive with chronic illnesses, greater family commitment, as opposed to expensive, long-term institutional care, is required. The role of the family caregiver becomes increasingly more crucial as families provide care to more older individuals over a longer period of time. Nurses are in the position to play a pivotal part in assessing the caregiver's needs, designing and implementing interventions, and evaluating the effectiveness of interventions (Haley, 1997; Larsen, 1998). An important consideration for nurses in the area of caregiving is the ability of family caregivers to provide care without sacrificing their own health and well-being. As the demand and use of home care increases, the need to understand family caregiving is essential. Social support is one area of study that may enhance understanding of caregiving (Rose, 1997). Nurses need to be prepared to recognize and respond therapeutically to family caregivers who are at risk of the negative consequences of caregiving. Knowledge of the lived experiences of caregiving from the family caregiver's perspective will enable nurses to anticipate and provide or

recommend resources and options to decrease the negative consequences of caregiving (Winslow, 1998).

Effective strategies for decreasing stressors that threaten the health of caregivers are not addressed in the literature. Gaps in knowledge exist about whether certain types of social support are crucial for adequate functioning in particular caregiving situations. Also, knowledge is needed as to whether certain sources of support are more effective than other sources on stressors that threaten the caregivers' physical health, mental health, or both (Rose, 1997). Investigation of the contribution of social support to the caregiving experience from the caregiver's perspective will provide knowledge for health professionals to assess the needs of families and determine interventions, plan family-centered care, and become actively involved in formulating health policies that support caregivers at home (Goode, Haley, Roth, & Ford, 1998; Haley, 1997; Rose, 1997). The purpose of this phenomenological study was to understand the family caregiver's lived experiences of social support while caring for a dependent older person in the home.

Assumptions

The assumptions identified for the study are:

1. Participants are capable of communicating their experiences as caregivers.
2. Family caregiving is a common human experience.
3. Social support is a need of all caregivers.

4. Social support decreases the negative consequences of caregiving.
5. In phenomenological research, the researcher is the primary tool for data collection and analysis (Creswell, 1994).

Theoretical Orientation

Mitchell and Cody (1993) proposed that “theoretical interpretation occurs in qualitative research, even when not acknowledged as such or when clearly denied” (p. 176). Mitchell and Cody (1993) indicated that other researchers [Giorgi, 1985; Parse, 1992] agreed that “theoretical perspective permeates the research process and that interpretation of participant’s descriptions reflects the researcher’s theoretic orientation” (p. 176). “It is widely assumed that generation and development of knowledge through qualitative research must begin in the absence of theory. But, if all research is theory-driven and all knowledge theory-laden, . . . this assumption must be re-examined. If qualitative nursing research is to generate knowledge unique to nursing, a coherent theory-research linkage identifiable as nursing science must be logically established” (Mitchell & Cody, 1993, p. 170).

Thus, Kahn’s (1979) theory on the convoy of social support provided the orientation for this study. Kahn proposed the key concept of “convoy” for studying the process of aging and life-course changes. Kahn, by using this metaphorical term, implied that each individual can be thought of as moving through life surrounded by a set of significant others to whom that individual is related by giving and receiving

social support. At any point in time, a person's convoy consists of the set of people on whom the person relies for support and those who rely on that individual for support. Not all relationships, however, are symmetrical in this sense (Kahn, 1979).

The implications of this conceptual approach were summarized by Kahn in terms of the following three propositions, each of which identified a category of more specific hypotheses:

1. The adequacy of social support is a determinant of individual well-being, of performance in the major social roles, and of success in managing life-changes and transitions.
2. The formal properties of a person's convoy determine the adequacy of the social support that person receives and has the opportunity to give.
3. Demographic and situational variables, such as age, sex, race, and residence in turn determine the formal properties of a person's convoy.

Kahn (1979) suggested that in combination, these three hypotheses define a straightforward causal sequence from demographic characteristics to the structure of the convoy; from convoy structure to the qualitative and quantitative adequacy of social support; and from the adequacy of social support to individual well-being or the lack thereof. A fourth hypothesis involves the buffering effect of social support to moderate the relationship between acute stresses and criteria of well-being.

Kahn (1979) contended that social support was important both as a direct determinant of well-being and a buffer against the effects of stressful events, but he

emphasized the direct affects of social support on health and well-being. Kahn (1979) stated, "The adequacy of social support is a determinant of individual well-being, of performance in the major social roles, and of success in managing life-changes and transitions" (p. 84). Kahn (1979) defined social support as,

interpersonal transactions that include one or more of the following:
the expression of positive affect of one person toward another; the
affirmation or endorsement of another person's behaviors, perceptions,
or expressed views; the giving of symbolic or material aid to another.
(p. 85)

Therefore, the three key components of supportive transaction proposed are affect, affirmation, and aid. The component of affective transactions is described as expressions of liking, admiration, respect, or love. Transactions of affirmation are expressions of agreement, or acknowledgment that a statement or act of another person is appropriate. Finally, included as social support are transactions of aid which refers to direct aid or assistance that is given, such as money, time, and information (Kahn, 1979).

Kahn (1979) wrote that many sources were used to develop the concept of the convoy and the related hypotheses. The most important of these were work on (a) the life course, (b) social support, (c) the measurement of social networks, (d) the goodness-of-fit between individual and situational properties, and (e) role behavior. Kahn discussed the relation of role characteristics to individual well-being, the refinement of those relationships in terms of person-environment fit, and the

importance of social support, both as a determinant of well-being and a buffer against the effects of stressful events.

Role. One of the forms of stress discussed by Kahn was that of role conflict; that is, role expectations that are mutually incompatible with the values and beliefs of an individual about what was appropriate for the role. Role conflict, according to Kahn, could result in dissatisfaction, emotional tension, and physical discomfort. The single most common form of role conflict in a work environment was overload - the pressure to do more work and the inability to finish work in an acceptable time frame. Role ambiguity was also investigated as a source of stress parallel to role conflict. Role ambiguity was viewed as the discrepancy between the amount of information individuals have and the amount they need to perform adequately in their role.

Person-environment fit. Kahn referred to the general model proposed by French, Rodgers, and Cobb in 1974 for dealing simultaneously with properties of the person and those of the environment in which the person is functioning. Person-environment fit referred to the goodness of fit between the person's needs and the supplies of the person's environment, and between the person's abilities and the demands of the environment. The thought was that without a goodness of fit between individual and situational characteristics, individuals would be dissatisfied with their roles, depressed, and show other symptoms of strain and ill health.

Buffering effect and social support. To understand the relationships between specific situational stresses and specific indicators of individual strain, interpersonal

variables that enter into those relationships were studied by Kahn. Among these were mutual confidence and trust between the individual and those with whom there were interactions. Kahn stated that social support buffers or protects individuals from many stressful life situations and transitions; however, the buffering effects of social support could not always be demonstrated, but the general trend was strong. Kahn suggested that not all stress-strain relationships were buffered by the same kind of social support.

The general assumption of Kahn's (1979) theory was that social support is negatively related to illness. Persons with adequate social support have a greater likelihood of a positive outcome; persons with inadequate social support have a greater likelihood of a negative outcome. The greater social support that an individual receives, in the form of closer relationships with family members, friends, relatives, and significant others, the less likely that the individual will experience illness. Kahn's research efforts were toward the effects of the immediate social environment on health, especially mental health. Kahn sought to discover how much of individual well-being, or the lack thereof, could be explained by characteristics of the individual's immediate social environment such as its demands, opportunities, and support.

The literature suggested to the researcher that family caregivers lived experiences of social support would be consistent with the three major concepts of social support proposed by Kahn (1979): (a) affect, (b) affirmation, and (c) aid. In keeping with Kahn's concepts of role conflict, role ambiguity, and "person-environment fit," (a) caregiver stress, (b) a knowledge deficit of the caregiver

role, and (c) dissatisfaction with the role were anticipated. Caregivers who perceive themselves to have inadequate social support to meet the physical and psychological demands of caregiving would probably express discontent in their caregiver role, experience negative emotions, and voice complaints of physical ailments. Following Kahn's proposal of the buffering effect of social support, the expectation of the researcher is that caregivers will perceive social support as important to their physical and mental well-being.

Definition of Terms

The following are the tentative conceptual and operational definitions for study terms:

1. Caregiver is conceptually defined as a provider of services in the home setting. The operational definition of caregiver is a spouse or relative, age 45 years or older, who has had the primary responsibility for providing care in the home setting for a dependent older person for at least 3 months.

2. Dependent older person is conceptually defined as an individual who is cared for by a spouse or relative. The operational definition of dependent older person is a spouse or relative, age 50 years or older, who is dependent in two or more activities of daily living, instrumental activities, or both.

3. Social support is conceptually defined by Kahn (1979) as "interpersonal transactions that include one or more of the following: the expression of positive affect

of one person toward another; the affirmation or endorsement of another person's behaviors, perceptions, or expressed views; the giving of symbolic or material aid to another" (p. 85). Social support is operationally defined by the lived experiences of family caregivers.

Limitations

The following limitations are identified for the study:

1. Recall of experiences may influence the caregivers' responses.
2. Audio-taping of interviews may influence the responses of the caregivers.
3. Participants may respond in ways to please the interviewer.
4. The findings could be subject to other interpretations.

Delimitations

The following delimitations are identified for the study:

1. Caregivers are limited to persons who can read, write, and speak English.
2. Caregivers are derived from one large metropolitan area.
3. Caregivers are limited to persons who have been caregivers to a dependent older person in the home for a minimum of 3 months.

Summary

Family caregivers, long recognized as the key to maintaining dependent older persons in the community, hold a central position in the quality of care received by

dependent older persons. Without a family caregiver, many older persons would be institutionalized prematurely or left on their own to meet their physical and emotional needs (Habel, 1998; Hellinghausen, 1997; Ward & Carney, 1994).

The increase in the number of Americans over the age of 65 is a concern for policymakers and the healthcare industry. The study of family caregivers of the elderly has become a major area of research with the realization that families provide the majority of care to the elderly in the United States (Robinson, 1997b). While some studies have focused on the effects of caregiving on the caregiver, there is still a need for more research on social support for the caregiver. As care in the home increases, nurses should support those who care for individuals at home. High quality care must extend into the lives and experiences of caregivers providing care in the home (Boland & Sims, 1996).

Research is needed to fill the gaps in knowledge about whether certain types of social support are effective for adequate functioning in particular caregiving situations and if particular sources of social support are more effective than others (Haley, 1997; Rose, 1997; Sayles-Cross, 1993). Timely and effective interventions may help prevent the caregiver from becoming exhausted and ill from the duties of caregiving and avoid the need for a caregiver for the caregiver (Haley, 1997; Larsen, 1998).

CHAPTER II

REVIEW OF THE LITERATURE

A literature review was done to assess the availability of information pertaining to social support for family caregivers. Articles were found primarily in the disciplines of nursing, psychiatry, and sociology. A majority of the articles reviewed on caregiving focused on the caregiver of the Alzheimer's disease patient. The review is presented under the subheadings of (a) caregiving, (b) consequences of caregiving, and (c) social support as an intervention. Within each category, reviews are presented chronologically.

Caregiving

Winston (1994) defined caregiving as the art and dedication of caring for another person. Pearlin, Mullan, Semple, and Skaff (1990) stated, "Whereas caring is the affective component of one's commitment to the welfare of another, caregiving is the behavioral expression of this commitment" (p. 583). Multiple demands are placed on caregivers who provide home care for dependent older persons. The demands of the role increase and become more complex and time-consuming as the care recipient becomes more dependent. Caregiving situations differ and caregivers respond to the demands of the role differently. Some caregivers report feelings of usefulness and

increased gratification; however, the negative impact of caregiving is the more commonly reported experiences found in the literature.

Gaynor (1990) chose a case control design to examine the differences between caregivers and noncaregivers' health. Three groups of wives were used for the study: (a) a long-term caregiver group ($n = 87$) whose husbands had debilitating neurological diagnoses, (b) a short-term caregiver group ($n = 38$) whose husbands had surgery for uncomplicated conditions, and (c) a noncaregiver control group ($n = 30$) whose husbands were healthy and independent in all activities. Long-term caregivers had significantly higher burden scores than the short-term caregivers. Caregivers for a short time were more similar in their responses to the noncaregiving wives. The length of time as caregiver was associated with an increase in illness occurrences, perceived burden, or both. In the long-term group, the females over 54 years old had significantly more illnesses than the other two groups. There were no significant differences between groups for the number of medications taken, number of ill days, or hospitalization days of caregivers. Sixty percent of the women in the long-term group stated their health was good, as compared to 79% of both the short-term group and control groups. Thirteen percent of the short-term group thought their health was worse than the last year compared to 18% of the long-term group. Seven percent of the control group reported their health as being worse. The long-term caregivers reported significantly more feelings of nervousness and other physical complaints. Stress is higher at specific times for caregivers, and interventions must be instituted at

those critical times. Some research efforts should focus on the younger caregiver to enable healthcare professionals and policymakers to predict long-range home care problems and implement interventions earlier to reduce stress (Gaynor, 1990).

Lindgren (1993) referred to caregiving as a career. As the demands of caregiving become greater, caregivers may feel that they are devoting their entire lives to caregiving. Caregiving typically encompasses multiple stages. The stages and the transition from one stage to another comprise a caregiving career. Lindgren defined the caregiver career as the specific time within a spouse's life in which caregiving is the central focus. During their caregiver careers, spouse caregivers often become so enmeshed in providing care for their dependent spouses that little time is left to pursue their own interests or needs. The role often continues for months or years and produces major changes in caregivers' lives. The caregiver role undertaken by spouses of individuals with dementia is referred to as a fatalistic career process. Lindgren suggested that there are three identifiable stages of the process: (a) the Encounter Stage, (b) the Enduring Stage, and (c) the Exit Stage. The Encounter Stage of the caregiving career requires significant adaptation to the major changes in their lives on the part of the caregivers. Support, comfort, and information are needed by the caregiver. Receiving and understanding the diagnosis, adjusting to the diagnosis, learning new skills, and making changes in their lifestyles are major components of the first phase.

The caregiver then moves into the Enduring Stage, or middle phase, which is characterized by hard work. Caregivers become more adjusted to their caregiver role in the Enduring Stage. As caregivers become further enmeshed in their role, they experience (a) social isolation; (b) lack of time for self, family, and friends; and (c) financial drain. Some caregivers report a "one day at a time" attitude and give little or no thought to the future for themselves (Lindgren, 1993). The final phase, or Exit Stage, was described by Lindgren as the time when the caregiver's responsibility for the care recipient decreases. In home caregiving ends or becomes less intense. This can occur when the care recipient is institutionalized or dies.

The career trajectory provides a framework for researchers to investigate caregivers' needs and effective interventions. Awareness of the stages of the caregiver career enables nurses to plan interventions that will assist the caregiver. Providing information, teaching new skills, and identifying support and coping strategies are some of the many ways nurses can help caregivers deal with their future (Lindgren, 1993). Aneshensel et al. (1995) also discussed caregiving as a career.

Globerman (1996) found that daughters-in-law are involved in caregiving to their spouses' parents out of feelings of obligation to their spouses, not to their spouses' parents. Globerman contended that caregiving, for daughters-in-law, is not an act of love but done because of their perception of their family responsibilities and what others expect of them.

Chou, LaMontagne, and Hepworth (1999) recruited 150 subjects from outpatient clinics in three hospitals in Taiwan to examine the variation of filial obligation among the types of caregivers. The daughters were found to have a higher filial obligation followed by daughters-in-law.

Guberman (1999), in a qualitative study of caregivers of French-Canadian origin, examined the family dynamics and socio-structural factors which explain how and why daughters-in-law become caregivers to their husbands' parents. The data for the study came from three separate qualitative studies in which 82 caregivers were interviewed. Ten of the caregivers were daughters-in-law who were living with their husbands and the care recipients.

An analysis to examine how each of the couples organized the sharing of responsibilities for caregiving tasks revealed three patterns. In 5 of the 10 cases, the pattern was the daughter-in-law assuming all caregiving responsibility and labor, with little or no assistance from her spouse. Three couples had adopted the pattern of the daughter-in-law having the major responsibilities for caregiving with some help from her spouse. The pattern for two couples was jointly sharing caregiving responsibilities. Daughters-in-law played a primary role in all the patterns just as daughters who were primary caregivers (Guberman, 1999).

Attitudes about care by daughters-in-law were also explored in the study by Guberman (1999). Daughters-in-law received little recognition from family or healthcare professionals for their efforts to provide care to their spouses' parents.

Instead, daughters-in-law perceived that their motives for assuming care were questioned, and that others thought they mistreated the care recipient. Guberman suggested further research to gain a better understanding of social expectations and attitudes about daughters-in-law as caregivers.

The purpose of Bar-David's (1999) qualitative study was to identify, describe, and interpret a process of self-development through the "caregiving journey." Over a four year period, 16 primary caregivers of relatives with Alzheimer's disease were interviewed 1 to 3 times. Three phases of caregiving capacity were identified: (a) development of caring capacity for the care recipient which begins when a diagnosis is made, (b) development of capacity for self-care which begins after institutionalization of the care recipients, and (c) development of caring capacity for others after the death of the care recipients with a "cause" selected by the caregivers that represents their own earlier situation. Bar-David acknowledged that further study is needed on how many caregivers continue in the role to the end, and what happens to caregivers who become embittered.

Consequences of Caregiving

Caregiving is not without consequences for caregivers. Their personal and social lives, mental and physical health, and financial status may all be affected. Social isolation and depression are commonly reported consequences of caregiving (Hellinghausen, 1997, Kleffel, 1998; McCabe, Sand, Yeaworth, & Nieveen, 1995).

The impact of caregiving on the lives of family caregivers has primarily been addressed from the overall negative effects, described and measured in terms of caregiver burden. Chenier (1997) referred to caregiver burden as (a) the number of caregiver tasks performed; (b) restricted social contact; (c) deterioration in physical health, mental health, or both; and (d) the subjective feeling of stress and strain due to the caregiving situation. The burden of caregiving is not the same for all individuals. Family roles and gender roles may influence the reactions of some individuals to their caregiving role (Miller & Montgomery, 1990). In order to answer why negative consequences are greater for some caregivers than others, investigators focused on the impact of caregiving on specific domains of caregivers' lives: (a) social life, (b) finances, (c) family relationships, and (d) mental and physical health.

Miller and Montgomery (1990) analyzed the correlates of perceived limitation in social activities of a national sample of the frail elderly and their caregivers. Data were used from the 1982 National Long Term Care Survey and the supplementary Informal Caregiver Survey sponsored by the Department of Health and Human Services and conducted by the U.S. Bureau of the Census. The caregiver sample consisted of 359 wives (mean age, 69), 200 husbands (mean age, 73.5), 481 daughters (mean age, 52.7) and 127 sons (mean age, 50.2). Measures included (a) perceived restriction in social activities, (b) objective care demands, (c) subjective appraisal of care demands, and (d) caregiver characteristics. Fifty percent of the caregivers reported social life limitations as a problem. Objective care demands focused on the

levels of the older persons' impairments and the level of the caregivers' involvement. Subjective appraisals of care demands were measured by the caregivers' appraisal of time pressure, relationship difficulties, and global stress. Greater subjective and objective time and task demands characterized caregivers who reported limitations in activities. Thus, the frail elderly persons showed one-third greater needs and caregivers performed one-third as many tasks as caregivers who reported no limitations. Caregivers reporting limitations in social life also reported (a) greater time pressures, (b) more stressful relationships with the dependent care receiver, and (c) more global stress (Miller & Montgomery, 1990).

Using a grounded theory approach, Beach (1993) examined the experiences of caregiving as reported by 10 family caregivers of older persons with terminal cancer and Alzheimer's Disease. Participants included eight spouses and two children who were primary caregivers for older persons over age 65. Eighty percent of the participants were female with an average age of 62. Semi-structured interviews, completed in the homes of the caregivers, were the primary method of data collection. Specific reference was made to (a) family roles and interactional experiences, (b) personal activity, (c) thoughts about institutionalizing the dependent elderly, (d) previous patterns of caregiving, (e) inevitability of the patient's death, and (f) bereavement. The reported experiences of the study participants merged into three categories and their corresponding sub-categories: (a) role strain (sense of responsibility, family member support, and extension of family roles); (b) sense of self

(personal activity and balancing outside work with caregiving); and (c) problem-solving/coping (institutionalization and patient personality changes). Role strain was defined as the problematic features inherent in balancing the caregiver role and other family responsibilities. Sense of self referred to the negotiation, or the lack thereof, of the caregiver's personal needs. Problem-solving/coping was defined as ways caregivers coped with the decline in care recipients' physical health, mental health, or both.

In the subcategories of role strain, most caregivers reported a strong sense of responsibility for caregiving. A majority of the caregivers indicated they had a family system in place but rarely used it as a source of support. Study participants reported they rarely received help from other family members and felt uncomfortable asking for assistance. They also reported they often hid or de-emphasized information about their physical and mental health (Beach, 1993). Most participants reported in the extension of family role subcategory that the family traditionally assumed the caregiver role. Both male and female caregivers reported cessation of personal activities in order to perform caregiving duties. Participants reported they stopped working or made significant changes in their work schedule. Emotional strain for females and physical labor for males were found to be the primary predictors of institutionalization in the sub-category for problem-solving/coping (Beach, 1993). Beach suggested further study of experiential similarities and differences between male and female caregivers.

Wykle (1994) suggested that the amount of physical and psychological stress experienced by female caregivers of older adults depended on the (a) availability of resources, (b) support from family, (c) care recipients' illness, and (d) living arrangements. Caregivers often neglect their physical and emotional health and many do not recognize that the stress and burden of caregiving may affect their health. Caregivers suffer from psychological isolation and alienation from friends and family. The stress leads to (a) feelings of fatigue, (b) sleep disturbances, and (c) headaches. Caregivers may suffer from physical strain due to caring for persons with functional disabilities; however, emotional and physical illnesses can result from the (a) anxiety, (b) frustration, (c) depression, (d) feelings of helplessness, and (e) lack of sleep that many caregivers experience. Consideration must be given to providing appropriate in home services to alleviate the stress of caregiving and to address psychosocial issues (Wykle, 1994).

Concerns about the care recipients often overshadow caregivers and their issues. Caregivers not only experience losses but also are at risk for many problems of their own. According to Holicky (1996), emotions commonly reported by caregivers were (a) anger, (b) fear, (c) loneliness, (d) resentment, (e) isolation, and (f) guilt. Caregivers may direct their anger at the care recipient for creating the situation or toward healthcare professionals for providing what caregivers feel are insufficient answers, or inappropriate care. The onset of disability undermines a basic sense of trust, leaving unanswered questions and worry that the situation might get worse.

Caregivers also worry about who is going to take care of them or the care recipient if they become ill. Loss, loneliness, and isolation are ongoing problems facing caregivers. Friends and family of caregivers distance themselves, further isolating the caregiver. Increased responsibilities leave little time for caregivers' needs. Often there is little acknowledgment of the caregivers' losses, pain, and stress which may precipitate anger and resentment, followed by guilt. Holicky recommended further research in the areas of the type of social support, either peer or professional, and the length of interventions to determine if results are short-term or long-term.

A grounded theory design was used by Boland and Sims (1996) to understand the caregiving experience from the perspective of the caregiver. The sample consisted of 17 families providing care to individuals ranging in ages 14 months to 87 years. The idea of caregiving as a solitary journey was the central theme that emerged. The central theme incorporated a number of related concepts or categories central to understanding the journey. Three of the core categories central to the theme were (a) burden or responsibility, (b) isolation, and (c) sharing of care.

The richest of the core ideas was burden or responsibility. Descriptions of burdens included emotional, physical, financial, and psychosocial components which are consistent with the traditional views. Boland and Sims (1996) found that participants' commitment to caregiving was absolute despite the reality of burden. Caregivers did not perceive that others could or would share in the care, and expressed concern that others may not be able to render the same quality of care. Caregivers

saw stress as a constant companion. Some stressors were (a) lack of support, (b) a decrease in outside support, (c) fatigue, and (d) dwindling finances. Stress related to finances was common to a majority of caregivers, as were feelings of isolation or aloneness. Suggestions for future research were the study of various age-focused populations and exploration of caregiving from a family unit perspective (Boland & Sims, 1996).

There is agreement among researchers that caregivers experience stress as a result of their caregiving roles. Stress, usually discussed in the context of burden or strain, is a frequently reported concern for the caregiver. Hawkins (1996) examined stressors experienced by caregiving daughters of frail, elderly parents and the coping mechanisms used to manage those stressors. The non-random sample of 21 caregiving daughters, ranged in ages from 36 to 64 years (mean age, 50.6). Findings included that employed caregiving daughters had significantly higher stress scores than those unemployed. There was no significant relationship between stressor scores and combined Activities of Daily Living and Instrumental Activities of Daily Living scores. The stressors experienced by caregiving daughters were assessed through areas of help most needed and concerns. The area of help most needed was with recreational/diversional activities for the care recipient (76.2%). The area of concern for most caregivers was wondering about the future (76.2%), and extra demands on time and feeling worn out (66.6%). The most used mechanism was talking with someone (76.2%) and prayer (61.9%). Keeping busy and crying were also used.

Hiding feelings from others when concerned or worried about the caregiving role was used by 47.6%. Anger, according to 28.6% of the caregivers, was expressed by (a) yelling, (b) screaming, and (c) slamming. Although the anger was reported as being directed to family members, the potential for abuse is evident. Hawkins contended that each caregiving situation should be viewed as a unique and individualized process, and that future caregiving studies must consider gender and relationship in study designs because of differences in situation appraisal.

Caregivers are prime candidates for stress-related illnesses, and thus are the untended but future "hidden patients" in the healthcare system according to Robinson (1997b). Caregivers may be isolated and burdened, resulting in a decreased immune system. Current social policy does not promote the well-being of family caregivers of older persons. Social and health benefits are allocated on the basis of the older person's needs, not those of the family caregiver. The functional status, life circumstances, and burden of the caregiver need to be considered and services planned to assist the caregiver accordingly (Robinson, 1997b).

Haley (1997) contended that caregivers who provide much of the daily care for a dependent person, such as the person with Alzheimer's disease, may do so under very trying circumstances. What often begins as part-time assistance can become a caregiving career resulting in secondary stresses, such as competing family demands and financial strains in addition to the stresses directly related to caregiving.

Caregivers, according to Haley (1997), often experience clinically significant changes in their mental and physical health. Family caregivers for patients with Alzheimer's disease experience substantial risk for depression with reported rates of depression being two to three times higher than those reported in population norms and demographically comparable control groups. The use of psychotropic medications is higher among caregivers.

Caregivers of Alzheimer's disease patients also exhibit (a) impaired immune system functioning compared with noncaregivers, (b) elevated blood pressure, (c) increased risk for cardiovascular disease, and (d) poor self-care. Lower levels of depression and high levels of life satisfaction are reported by caregivers who have greater emotional and social support. Caregivers who are actively engaged in social and recreational activities adapt to caregiving with less depression than those who are more socially isolated (Haley, 1997).

Chenier (1997) described caregiving as an intense and complicated activity. The continuous demands of caregiving and the lack of personal time lead to caregiver burden. Caregiving can lead to high levels of depression or anxiety in the caregiver. The caregivers may become so involved in the caregiving that they neglect their own physical and mental well-being. Chenier called for further research to identify variables that lead to caregiver burden and to determine the interventions that meet the needs of the caregiver.

A descriptive correlational design was used by England (1997) to survey 165 adult children caregivers, 76% of whom were women. The mean age of the participants was 47 years, with 89% having a high-school education. Subjects provided an average of 2.7 hours of parent care each day. The subjects were interviewed in their home on two occasions. On the first interview, the subjects were asked to provide information about their (a) caregiving situation, (b) subjective health, and (c) sense of self-coherence (generalized confidence resource that protects one from harmful effects of noxious stressors). Information about their emotional arousal (complaining stance), subjective health, and experiences of crisis in the last 6 months of caregiving was solicited at the time of the second interview. Forty-nine percent reported experiences of crisis in the previous 6 months of caregiving. Findings showed that subjects with crisis experience had significantly lower scores for self-coherence and significantly higher scores for emotional arousal. Lower ratings for perceived health also were reported. Findings indicated the crisis experiences had an effect on variable relationships.

There was a negative relationship between self-coherence and emotional arousal that was significantly greater in the presence of a crisis experience than in the absence of crisis experiences. There was a positive relationship between self-coherence and perceived health that was significantly greater in the presence of crisis experiences than in the absence of crisis experiences. There was a significant negative relationship

between emotional arousal and perceived health that was equally apparent in the presence and absence of crisis experiences (England, 1997).

Findings from the study suggested that self-coherence may be an important, if not a necessary ingredient, for how well adult children can sustain themselves in the caregiver role. Self-coherence seemed to have a positive effect on emotional arousal by allowing the caregiver to cope better with various elements of caregiving, especially during a crisis. England (1997) surmised that knowledge of confidence resources can help nurses target interventions to assist adult children caregivers with low self-coherence who have a difficult time coping with the demands of parent care.

Gallant and Connell (1998) examined the relationship between the demands of providing care to a spouse with dementia and caregiver health behaviors in a sample of 233 spouse caregivers of dementia patients. A model of the caregiver stress process hypothesized that personal characteristics and beliefs, objective burden, and social support would influence perceived burden, depressive symptoms, and, ultimately, caregivers' health behaviors.

Results indicated that the caregiving stress process negatively influences caregiver health behaviors. Depressive symptoms emerged as a strong predictor of health behavior change which emphasizes the strong role of psychological distress in general self-care. The results of the study supported the notion that alteration in health behavior may represent one mechanism by which the stress of caregiving leads to negative health outcome. Depression resulting from stress may lead to a decline in

personal health practices, which may then affect the caregiver's physical health. Subjective burden had no direct or indirect effects on alterations in health behavior. Neither the influence of environmental factors nor the influence of personal characteristics was mediated by subjective burden. Change in health behavior was directly influenced by objective burden, confirming that structural factors, such as lack of time, have an independent influence on health behavior performance. Objective burden did not influence subjective burden (Galland & Connell, 1998).

An unexpected finding was the weak contribution of social support to predicting change in health behavior. Social support was not a significant predictor of (a) subjective burden, (b) depression, or (c) health behavior. The findings provided some empirical rationale for the development of caregiver interventions that focus on maintaining and enhancing the health behaviors of caregivers (Gallant & Connell, 1998).

Data obtained from interviews with 22 family caregivers of individuals with Alzheimer's disease were used by Mac Rae (1998) to examine caregiving as emotion work. Findings indicated caregivers were (a) heavily engaged in an extensive amount of intense emotion work, (b) aware of "feeling rules," and (c) stressed when they failed to conform to the rules. Failure in emotional management was found to negatively affect the caregiver's sense of self. Success in managing feelings also had adverse effects. Caregivers who controlled or suppressed their feelings were at risk of losing the capacity to feel. Future research, according to Mac Rae, should focus on

the extent to which emotion work contributes to the stress and burden of caregiving, and on strategies that caregivers can use to deal with emotion management.

Paoletti's (1999) study was part of a larger study in which data were collected in central Italy from women over 50 years through semi-structured, in-depth interviews. The interviews focused on the tasks involved with caregiving and the impact on the caregivers' life style and health. Caregivers included (a) those who were living with and caring for a relative, (b) volunteer caregivers, and (c) paid professional caregivers. There was a noticeable difference in the perspectives of the two groups. Caregivers caring for a relative described the task of caring as very stressful, as well as a source of physical and psychological health problems. Daughters caring for their disabled mothers, in particular, showed signs of severe health problems. Relative caregivers felt confined and isolated. The volunteer and paid caregivers described caring as a source of satisfaction and good health. They viewed caregiving as a way of "being out" and working.

Caregivers who experienced the most physical and psychological stress from their role saw alternative solutions as not feasible or even conceivable. Even when sharing tasks with paid help, the responsibility of caring was entirely the family caregivers. Paoletti stated that while services such as day care and respite are useful, these services are not sufficient to alleviate the difficulties of caregivers who resist any type of help. Knowledge about the caring relationship can help healthcare

professionals understand and find coping strategies for caregivers in their situations (Paoletti, 1999).

Identifying at risk caregivers for negative consequences of caregiving and providing appropriate supportive services before the caregiver is at a crisis point is essential. Nurses practicing in the community or clinical setting are often in a position to intervene in the needs of the caregiver as they can observe the caregiver's response to the caregiver role. The intensity of the response is very significant in that it can signal the need for community services.

Social Support as an Intervention

Social support was defined by Cobb (1976) as the provision of information that leads individuals to believe they are cared for, loved, esteemed, valued, and a member of a network of communication and mutual obligation. Cobb suggested that social support might have a protective function, serve as a buffer to stress, and be related to positive health outcomes. The lack of social support has been linked with a variety of illnesses and conditions (Lin, Ensel, Simeone, & Kuo, 1979). The linkage of social support with aspects of health is of particular importance to health professionals in developing interventions to help maintain the physical and mental health of caregivers.

There has been substantial research interest in social support and its role in the stressor-illness relationship, either as an antecedent factor or as a buffering factor. As an antecedent factor, social support reduces the likelihood of undesirable life changes

occurring. As a buffering factor, social support, following the occurrence of life changes, controls interpretations of the events and emotional responses to them (Lin et al., 1979).

Fiore, Becker, and Coppel (1983) examined the social network as a potential source of both stress and support. Forty-four caregivers to spouses with Alzheimer's disease were chosen in order to have a stressed subject population considered at high risk for depression. The perceived helpfulness of five types of social network support was assessed separately from stress perceived when the network failed to provide "wished for" support or provide negative input. These perceptions were then related separately to severity of depression. Five overlapping components of support were examined. The first component, cognitive guidance, was referred to as the need for information, guidance, and advice from the network. Emotional support, the second component, was the need for strong, dependable relationships. Third, socializing was defined as having a network of friends with whom a person shares common interests. The fourth component, tangible assistance, referred to the provision of concrete behavioral services or assistance with chores rendered beyond the role expectations such as financial assistance. The last component of social support was the availability of an individual to be a confidant (Fiore et al., 1983). A major finding of the study was that the extent of upset with the social network, due to unmet expectations of support or negative input from important others, was the best predictor of depression in a chronically stressed population. The perception of social network helpfulness did

not relate to severity of depression, but the degree of upset experienced in relationship to network members in any area of support did relate to severity of depression. Fiore et al. explained that their findings are consistent with a process in which individuals, experiencing a chronic life stress, attempt to cope by looking to their social network for various kinds of support. A network may be viewed as helpful or as not meeting certain support expectations. Based on the degree that expectations are not met, individuals experience more stress, are more likely to be depressed, and report low overall satisfaction with their support network (Fiore et al., 1983).

Robinson (1988) commented that a positive relationship between high social support and both mental and physical health had been documented in previous studies. Research indicated that when caregivers' needs were the highest, their social support was often low. Various reasons for the situation were given by caregivers which included (a) becoming over-involved in the care of an individual and ignoring their own relationships, (b) friends stopped visiting because of their inability to cope with Alzheimer's disease, and (c) the now dependent person may have been the main source of support to the caregiver. A pilot intervention study, with 20 participants, was done to explore whether there was a difference in caregiving burden for caregivers of mentally impaired elderly who received social skills training, and caregivers who did not. The intervention program focused on social skills and behavioral skills. The social skills were how to develop relationships and form new connections. Behavioral skills were (a) using assertive behavior, (b) starting conversation about caregiving,

(c) requesting help, (d) accepting help and providing instructions, (e) expressing appreciation for assistance or offer of assistance, and (f) saying no before becoming overloaded. Results at pretest revealed no significant difference between the treatment group and the control group. Posttest results revealed a significant decrease in both objective and subjective burden for the treatment group. The results indicated that further studies about how to best support the primary caregivers of older persons are of major importance (Robinson, 1988).

Emotional support was one of three categories identified in Morgan and Zimmerman's (1990) qualitative study of factors which helped to ease the transition for the caregiver when admission of the dependent older person to a nursing home was inevitable. Ten male and female spouse caregivers discussed how their social life had been curtailed and how their friends drifted away over a period of time. Negative remarks about friends exceeded positive comments. Caregivers acknowledged that often they were too tired to contact friends or, as caregiver responsibilities increased, they declined more and more social invitations. Feelings of abandonment because of the lack of contact by former friends were common among caregivers. A positive relationship with adult children was viewed by most caregivers as a major source of support.

Whitlatch, Zarit, and von Eye (1991) did a reanalysis of an intervention study of caregivers of dementia patients published in 1987 by Zarit, Anthony, and Boulaelis.

Subjects, 113 primary caregivers with a mean age of 62 years, were randomly assigned to one of three time-limited conditions: (a) individual and family counseling, (b) support group, or (c) wait list. The individual and family counseling and support group conditions, the treatment conditions, were oriented toward (a) increasing caregivers' knowledge of the care recipients' illnesses, (b) improving caregivers' abilities to manage problem behaviors, and (c) helping caregivers to identify and utilize more formal and informal supports. The wait list served as the control condition in which no changes were made in the caregivers' routines. The findings of the reanalysis differed from findings reported in the previous investigation in which the treatment and control groups made similar improvement. Findings from this study suggested that a program of individual and family counseling may have certain benefits in decreasing stress for caregivers compared to caregivers who receive no interventions. Findings also indicated that individuals in support groups were just as likely to have unsuccessful outcomes as successful outcomes. Two implications of the findings were that (a) caregivers may benefit more from psychoeducational interventions than previously thought, and (b) interventions designed for caregivers who are highly distressed may not be appropriate for caregivers experiencing low levels of distress. Based on the findings of this study compared to those of previous studies, Whitlatch et al. suggested a re-evaluation of previous reports on the efficacy of caregiver interventions.

The relationship between health and social support in spouses who care for husbands with dementia was explored by Robinson and Steele (1995). They contended family members perceived the caregiver as able to provide care without assistance, and more social support and physical assistance was not necessary until the caregiver showed signs of a decline in physical or mental health. Interviews of 75 significant others identified by the caregiver were done to determine their views of the caregivers' health and social support to gain an understanding of how they began seeking help for caregivers. The major assumption underlying the study was that when the significant other perceived a decline in health, social support, or both, they would take action to increase caregiver support. It was anticipated that significant others believed that healthy caregivers needed and received less support. The study hypotheses were not supported by the findings. The results for the hypothesis, which stated that wife caregivers perceived as ill by the significant other would be seen as having a larger social network, were opposite from what was predicted. Findings indicated that caregivers, thought to be healthy, were perceived to have more individuals in their social network (Robinson & Steele, 1995).

A study by McCabe et al. (1995) was focused on the perceived availability and utilization of services by rural and urban caregivers of Alzheimer's disease patients. They contended the caregivers and the patients had a tendency to become socially isolated and not use social supports and services available to them. The purpose of their study was to answer three questions pertaining to (a) a relationship between

selected demographic characteristics, environmental, community, and personal characteristics; (b) a relationship between selected demographics, financial, environmental, and personal characteristics; and (c) the range of services available and used by caregivers in rural communities compared to urban communities (McCabe et al., 1995).

Data analysis was based on 108 returned questionnaires out of the 212 that were mailed to recipients of the Alzheimer's newsletter. The average age of respondents was 65.18. Seventy-one percent of the care was given by a female family member who reported spending an average of 16.6 hours per day providing care for the person with Alzheimer's disease. Twenty-eight percent of the primary caregivers stated they had no one to call for assistance. Twenty-four percent indicated they had health problems. Nine service options were presented to all caregivers and seven were identified as not available by 65% of participants. Sixty-two percent of the overall sample reported use of nursing homes. Support groups were used by 43% of the sample and rural caregivers used available services proportionately more than urban caregivers. In response to the first question, 28% of the primary caregivers reported having no one to call on for assistance, and 24% reported health problems. The majority of the respondents to the second question stated that the financial status of the care recipient was adequate to meet their financial obligations (McCabe et al., 1995). The next question pertained to the range of available services in rural communities compared to urban areas. Rural caregivers reported that most services were not

available except for nursing homes. Nursing home and support groups were services most frequently used in both urban and rural areas. The data from the study supported findings of prior research that caregivers of family members with Alzheimer's disease were unaware of the various services available to them (McCabe et al., 1995).

The aim of the study by Almberg, Grafstrom, and Winblad (1997) was to describe burnout among caregivers of older demented relatives and their coping strategies for dealing with strain. Interviews of 46 male and female caregivers focused on the caregivers' descriptions of their major strain and what they did, thought, and felt in these situations. Findings were that caregivers' emotions and feelings were wide-ranging and individualistic. Different strategies were used to help the caregiver situation and sometimes more than one strategy was used. The study showed that problem-focused strategies or mixed strategies, such as (a) accepting the caregiving situation, (b) seeking information about the problem, and (c) seeking social support from spouses, friends, or professionals, combined together, were effective coping strategies. Another finding was that the caregiver's gender appeared to have an effect on the coping strategy. Further research is needed in this area. The findings in this study indicate that interventions for coping may be planned by nurses who recognize the psychosocial, emotional, and mental support needs of family caregivers (Almberg et al., 1997).

Using a grounded theory approach, 30 family caregivers were interviewed about obtaining respite while caring for older persons with severe cognitive or physical

impairments (Worchester & Hedrick, 1997). Caregivers reported a few positive respite experiences, but the process of utilizing respite was overwhelmingly perceived as more stress producing than beneficial. Worchester and Hedrick recommended further research to determine the use and effectiveness of respite programs as caregiver support to reduce factors, such as (a) physical fatigue, (b) mental exhaustion, (c) depression, and (d) social isolation.

A qualitative approach was used by Rose (1997) to investigate caregivers' perceptions of social support and interactions with healthcare professionals as a condition affecting their coping. Semi-structured open-ended interviews were conducted with each of 15 caregivers of psychiatric inpatients. Four support services were identified: (a) professional/system, (b) friends, (c) family/extended family, and (d) spiritual. Effective and limited support were identified within these support services.

Caregivers were appreciative of and expected information and advice from professionals on how to cope and how to respond to the patient. Professional support was perceived by caregivers as not helpful if goals for the patient differed or if professional goals were inadequately explained. Failure to include family caregivers in treatment issues or absence of advice were sources of stress. Hospitalization provided the caregiver with respite support. Caregivers described support from the healthcare system in negative or guarded terms. Emotional support from friends was most valued when caregivers believed that concern from friends was genuine and that it was safer

to express their true feeling. Extended family members provided tangible aid and emotional support. Advice from extended family on daily management issues were viewed as not helpful. Some caregivers derived a feeling of emotional strength from religious faith. The social network of the church was viewed as a safe source of friend support (Rose, 1997).

The findings of the study emphasized the need for continued support of caregivers. Future research must continue the investigation of caregivers' experiences of social support. Exploration of the contribution of social support to the caregiving experience will enhance the ability of healthcare professionals to assess the needs of caregivers and provide assistance to them in managing the burdens of the caregiving role (Rose, 1997).

The aim of Winslow's (1997) qualitative case study was to describe an experience of the wife of a patient with Alzheimer's disease with the use of formal community support services. Four themes emerged from interviews done over a three month period. The first theme was identified as developing the need for caregiving assistance. Categories of care receiver dependency, problem behaviors, and the caregiver's emotional response, such as anger and anxiety, precipitated the need for assistance. Sensing community while sustaining caregiving was the second theme. Benefits, derived from formal support and caregiver characteristics, that assisted the caregiver in sustaining her role, were named, such as (a) learning information,

(b) sharing experiences, and (c) personal faith. The third theme, receiving renewal while being assured of the patient's well-being, provided some explanation of how formal support benefited the caregiver and the care recipient. The outcomes were a sense of (a) freedom, (b) relief, (c) renewal, and (d) the quality of care and effect of formal support on the care receiver. Experiencing transitions in the caregiving relationship was the final theme to emerge and suggested a positive relationship between formal support and the facilitation of residential placement (Winslow, 1997).

The relationship between formal support and family caregiving is of particular interest to healthcare professionals. Nurses are in a key position to assess family caregivers' needs and to provide information and referrals. Qualitative research that seeks to understand the caregiving experience of formal support may help to conceptualize benefits of formal support for both caregiver and care receiver (Winslow, 1997).

In the study conducted by Song, Biegel, and Milligan (1997), the predictors of depressive symptomatology among caregivers of persons with chronic mental illness were examined. In-person interviews with 103 family caregivers of adults with chronic mental illness who received services from mental health case management agencies. Results of the study indicated that insufficiency of overall social support was the strongest predictor of caregiver depressive symptomatology. Caregiving burden, related to client behavioral problems and lack of family and agency support, contributed significantly to such depressive symptomatology. Neither caregiver gender

or race were significantly related to caregiver depressive symptomatology or burden. The results of the study provide important information to healthcare professionals in the development of specific interventions designed to address caregivers' needs (Song et al., 1997).

Qualitative data obtained from 40 caregivers participating in focus groups were used by Kleffel (1998) to evaluate a caregivers' support program. Initially, caregivers reported (a) isolation, (b) fatigue, (c) lack of personal time, and (d) physical and emotional tolls. At the end of the focus groups, socialization and self-care activities were reported to be the most beneficial components of the caregiver support program.

Larsen (1998) examined the effectiveness of offering individual support strategies, such as counseling and education, as interventions to help caregivers of chronically ill elderly relatives. Four participants attended eight weekly individual counseling sessions. Results of scores indicated three of the four participants experienced reductions in burden. Two of the participants experienced reductions in personal strain, and all participants experienced reductions in role strain. All participants were very satisfied with the program and would recommend the program to other caregivers. Findings suggested that offering individual support interventions help caregivers deal with the burden and stressors associated with caregiving. The success of the counseling and education programs may be due to the fact that the treatment approach focused on the diverse needs and specific goals of each caregiver.

An important challenge is the ongoing development and evaluation of appropriate interventions for caregivers (Larsen, 1998).

Recent studies indicate an interest in the use of electronic interventions as means of support for family caregivers. Strawn, Hester, and Brown (1998) examined the utility of Telecare, a telephone intervention, to provide assistance and support to 14 family caregivers of patients with dementia. Weekly telephone contacts were made from a "caring caller." One of the purposes of Telecare was to serve as a source of social support and caring human interaction. Participants experienced less (a) general distress, (b) hostility, and (c) obsessive thoughts. Those receiving weekly calls found caregiving less burdensome (Strawn et al., 1998).

In a 12-month experiment, Bass, McClendon, Brennan, and McCarthy (1998) examined the buffering effect of a computer support network on caregiver strain. An experimental group of 102 randomly assigned caregivers had access to ComputerLink, whereas a control group did not. Caregivers in the experimental group had greater reductions in certain types of care-related strain if caregivers also (a) had larger informal support networks, (b) were spouses, or (c) did not live alone with the care recipient. Greater use of ComputerLink was related to significantly lower strain among caregivers who lived alone with care recipients, for non-spouse caregivers, and for caregivers who were more stressed initially. Wright, Bennet, and Gramling (1998) contended that further research regarding the (a) efficacy of electronic interventions, (b) effects of the lack of personal contact, (c) safety, and (d) privacy issues is needed.

Colantonio, Cohen, and Corlett (1998) used data from telephone interviews with 84 study participants to determine the extent to which elderly caregivers of persons with dementia engaged in self-help/mutual aid activities, such as groups and telephone support. Eighteen (21.4%) of the 84 caregivers utilized face to face groups, and 17 (25.8%) of the 66 caregivers who had not participated in such a group stated they would be interested in doing so. Fifteen (88%) of the 17 caregivers who had not participated discussed barriers to participating in face-to-face groups, such as time constraints (53.3%) and transportation (46.7%). Of the 47 participants who were not interested in groups, time constraints (44.7%), and not being comfortable with groups (17%) were commonly cited reasons. Fewer of the participants used telephone support lines. Of those not using the service, 44 (57.1%) would like to use it if staffed by a professional and 47 (57.3%) if staffed by another caregiver. Seventeen (20.2%) participants received newsletters or other information by mail about help with caregiving, and 49 (73%) wanted to receive the newsletter. Thirteen (15.5%) caregivers had access to a computer, and 14 caregivers (16.7%) were interested in receiving information and support via the computer.

A greater demand is expected for such services as the population ages and the younger populations, who are more open to these strategies, become seniors themselves. More research is necessary on support and information provided via telephone and by other methods, such as newsletters and computers (Colantonio et al., 1998).

Garity (1999) investigated four learning styles of 76 caregivers caring for relatives with Alzheimer's disease: (a) the accommodator who relies on others for information, (b) the diverger who likes to generate new and creative ideas, (c) the assimilator whose focus is on ideas and concepts, and (d) the converger whose preference is technical tasks and problems. The diverger learning style was the predominant style (55.5%). The next most frequently occurring style was the assimilator (18.6%), and the least frequently occurring style was the converger learning style (11.4%). Female caregivers were primarily divergers (62%) with 18% as accommodators. Male caregivers demonstrated a greater variety of learning styles with 40% demonstrating the diverger learning style, 35% the assimilator learning style, and 20% the converger learning style. According to Garity, gender is an important variable in studies of family caregivers. The learning style and gender differences of caregivers have teaching-learning implications for healthcare professionals who provide information to caregivers.

Chang (1999) used 65 caregiver-care recipient dyads to examine the effects of an 8-week cognitive behavioral intervention. The intervention was designed to provide caregivers with the knowledge and skills to improve the dressing and eating abilities of person with dementia. Caregiving dyads were randomly assigned to cognitive behavioral or attention-only groups. The intervention for the cognitive-behavioral group consisted of two parts: (a) videotapes demonstrating assisted modeling behavior (eating and dressing) for viewing at home, and (b) a Nurseline support program which

consisted of structured calls to address caregiver uncertainties about implementation of strategies and caregivers' feelings regarding the care recipients' behaviors.

Information was also provided to assist the caregiver in cognitive reframing and problem-solving. Caregiver referrals were provided when appropriate. Phone calls to assess the general well-being of the caregiver were made to the attention-only group. No specific strategies for dressing or eating were offered.

Measures were taken at baseline, 4 weeks, 8 weeks, and 12 weeks that indicated a time by group interaction in depression. The cognitive-behavior group remained consistent over time showing no increase in depression; the attention-only group showed a significant increase in depression between the 4th and 12th week. Both groups experienced a significant reduction in anxiety. There was a significant consistent decrease in satisfaction over time, but there were no differences between groups. Caregiver burden scores showed no significant differences. Both groups showed a significant decrease in the use of emotion-focused coping. There was no difference in the use of problem-focused coping over time or between groups. There was significant deterioration in the overall function rating of the persons with dementia over time in both groups. The increase in scores in behavioral disturbances reached statistical significance; the physical activities of daily living subscores did not (Chang, 1999).

Chang (1999) recommended further studies and that components of the cognitive-behavioral intervention be isolated and examined. The portion of the

multifaceted cognitive-behavioral intervention that was the most effective for caregivers and for which kinds of behavioral responses in person with dementia should be identified in future studies.

The purpose of the study by Roberts et al. (1999) was to determine the effectiveness of individualized problem-solving counseling by nurses for caregivers and the expenditures of healthcare utilization. Study participants were 77 caregivers of the cognitively impaired living at home. The participants were randomized to a counseling group and a non-counseling group. Measures of psychosocial adjustment to the (a) relative's illness, (b) psychological distress, (c) burden, (d) coping skills, and (e) expenditures were done at the end of 6 months and 1 year. On the average, no improvement was indicated in (a) psychosocial adjustment, (b) psychological distress, or (c) burden. Caregivers, however, found counseling helpful. Counseling was effective for those indicating infrequent use of logical analysis coping skills. Results showed this subgroup had decreased psychological distress and improved psychosocial adjustment after 1 year. Caregivers in control and counseling groups whose relatives were institutionalized improved their psychosocial adjustment 23% on the average. Caregivers who continued to provide care at home decreased their psychosocial adjustment by 8%. In the counseling group, almost half as many relatives entered nursing homes (5 versus 9). Caregivers in the counseling group and their relatives, compared to those in the control group, had greater annualized per person expenditures for health and social services.

Roberts et al. (1999) contended that counseling may encourage caregivers with good problem-solving skills to continue to provide care in the home; however, Roberts et al. found healthcare expenditures to be high and the quality of life to be poor for those caregivers. Caregivers with frequent logical analysis skills not receiving counseling placed their relative in a nursing home and indicated improved quality of life.

Wilkins, Castle, Heck, Tanzy, and Fahey (1999) examined the effects of an 8-week structured psychoeducational intervention designed to improve psychological and immune function. Eleven women, primary caregivers for their spouses who had dementia, participated in the study. Self-report measures of mood, anxiety, perceived burden, and immune function were completed by the caregivers one week before the start of the intervention, at the end of the intervention, and at 1-month follow-up. The sessions were held weekly for 8 weeks. In addition, each participant received a phone call once a week from a group leader to reinforce the information provided at the sessions and to provide additional support. The sessions focused on (a) building coping skills through stress reduction training, (b) teaching cognitive-behavioral interventions to decrease depression and anxiety, (c) providing information about resources, and (d) providing a supportive environment to address caregiver concerns. Day care was provided for the caregivers' spouses during the group sessions.

Wilkins et al. (1999) reported a significant decline in the spouse caregivers immune status from baseline to completion of the intervention. The deterioration was

associated with increases in anxiety, perceived burden, and depressed mood. All caregivers rated the psychoeducational intervention as highly beneficial. Wilkins et al. speculated the high rating could be attributed to caregivers' relief at having time away from the burden of caring for their spouses.

According to Wilkins et al. (1999), the results of the study may have been attributed to three factors: (a) Psychological symptoms may have initially worsened because the psychoeducational process increases caregivers' awareness of the severity of their situations, thus causing stress, (b) the caregivers' experience of the decline in their husbands' mental function may outweigh any benefits from the intervention, and (c) the decline in immune and psychological function could be the result of the anticipated loss of weekly support group sessions. Wilkins et al. suggested further investigation about the potential for psychoeducational interventions to decrease immune and psychological functions during early treatment.

Grounded theory methods were used by Szabo and Strang (1999) for the secondary analysis of qualitative data collected for a 1995 caregiver study. The purpose of the descriptive study was to describe the experience of control in order to determine how caregivers manage care in the home setting. Twenty-one family caregivers living with and providing care for persons with dementia were asked to describe their perceptions of the experience of control related to how they managed or coped with their caregiving situation. The dimensions of control were characterized as (a) maintaining control and (b) lacking control. Caregivers who manifested the

dimension of "maintaining control" had control and worked continuously at maintaining control. Caregivers in the "lacking control" dimension appeared unable to cope with the demands of their caregiving situation. Evidence indicated that caregivers did not necessarily remain on one dimension but made a cognitive shift between the two. The movement from the dimension of maintaining control to that of lacking control was referred to as "losing control." The caregivers assessed their internal sources by looking at their competency. External resources were assessed by seeking support from family, friends, and health professionals (Szabo & Strang, 1999).

Szabo and Strang (1999) recommended further research to explore in greater depth the dimensions of (a) maintaining control, (b) lacking control, (c) losing control, and regaining control by caregivers. Information is needed to determine why caregivers have difficulty seeking help, what types of caregivers have difficulty, and how health professionals can assist caregivers to ask for help when needed (Szabo & Strang, 1999).

A sample of 45 volunteer caregivers participated in a study by Robinson and Clemons (1999) to gather information on how to develop a successful volunteer caregiver program. Participants attended an all day training workshop for respite care. Follow-up telephone interviews revealed resistance from participants to actually provide respite care. The desire for more training and more information about services needed, and the need to meet and get to know the care recipient, were areas discussed by participants. Participants verbalized a fear of persons with Alzheimer's disease

indicating a need for more interaction with the individuals (Robinson & Clemons, 1999).

Summary

While the purposes of studies differed, there was agreement on the importance of social support for the caregiver. The major concepts discussed were (a) research focus on social support, (b) caregiving as a career, (c) health of the caregiver, (d) consequences of caregiving, and (e) interventions.

Focus

Healthcare providers have increasingly focused their practice and research interests on the phenomenon of caregiving to frail elderly in the community (Robinson, 1997b; Ward & Carney, 1994). A need for more research on how best to support the caregiver was identified by researchers, such as Colantonio et al. (1998), Paoletti (1999), Song et al. (1997), and Wright et al. (1998).

Fiore et al. (1983) reported that five components of support were needed by caregivers: (a) cognitive guidance in the form of information and advice, (b) emotional support, (c) a network of friends, (d) help with chores and financial assistance, and (e) a confidant. Rose (1997) explored effective and limited support with four support services: (a) professional/system, (b) friends, (c) family/extended family, and (d) spiritual. Winslow (1998) described the experience of a caregiver with the use of a formal community support system. Socialization and self-care activities were

considered by two focus groups to be the most beneficial components of a caregiver support program (Kleffel, 1998).

Career

Aneshensel et al. (1995), Haley (1997), and Lindgren (1993) referred to caregiving as a “career” and agreed that caregiver support is important. Lindgren (1993) contended that addressing caregivers’ needs from the career trajectory perspective is a way for caregivers to maintain their health and well-being. Lindgren stated that (a) support, (b) comfort, and (c) information are needed by the caregiver. Bar-David (1999) discussed caregivers’ three phase development of caring capacity through the “caregiving journey.” Boland and Sims (1996) described caregiving as a solitary journey.

Globerman (1996) and Guberman (1999) found that daughters-in-law have a primary role in the care of parents-in-law. Care is provided out of feelings of obligation to their spouses and not to the parents-in-law. Chou et al. (1999) found that among the types of caregivers, daughters have a higher filial responsibility, followed by daughters-in-law.

Health

Caregivers are more healthy if they have more individuals in their social network (Robinson & Steele, 1995). Cobb (1976) suggested that social support might

(a) have a protective function, (b) serve as a buffer for stress, and (c) be positively related to health outcomes.

Caregivers experience (a) stress in the form of social isolation and mental pain; (b) lack of time for self, family, and friends; and (c) financial drain, which result in alterations in the physical and emotional health of the caregiver (Chenier, 1997; Haley, 1997; Wykle, 1994). Chenier (1997) and Wykle (1994) commented that caregivers neglected their own physical and mental health, while Beach (1993) found that caregivers often hid or de-emphasized information about their physical and mental health.

Gallant and Connell (1998) found that social support is not a significant predictor of health behavior. Robinson (1997b) contended that social and health benefits should consider the needs of the caregiver as well as the care recipient.

Consequences

According to Miller and Montgomery (1990) and Hellinghausen (1997), some of the most frequently reported consequences of caregiving are social isolation and depression. Beach (1993) reported cessation of personal activities by caregivers. Holicky (1996) identified (a) loss, (b) loneliness, and (c) isolation as ongoing problems for caregivers. Boland and Sims (1996) also disclosed that caregivers reported feeling alone and isolated. Paoletti (1999) reported that caregivers expressed feelings of

confinement and isolation. Worchester and Hedrick (1997) found that caregivers perceived the process of using respite as more stressful than beneficial.

The core idea that emerged in Boland and Sims (1996) qualitative study was burden and responsibility. Caregivers in Beach's (1993) study also reported a strong sense of responsibility for caregiving. Song et al. (1997) found that caregiver burden contributed significantly to depressive symptomatology. Gaynor (1990) agreed that burden is a major problem. Gallant and Connell (1998) found that objective burden directly influenced health behavior, while subjective burden had no direct or indirect effects.

Miller and Montgomery (1990) referred to the limitations on the social life of the caregiver, the pressures on time, and a possibility of a stressful relationship with the care receiver. They noted that family and gender roles may influence the caregiver role. Almberg et al. (1997) and Garity (1999) reported that gender appeared to have an effect on caregivers' coping strategies. Gaynor (1990) found that the length of time as caregiver was also a factor. Women with longer caregiving experience had more physical problems, while younger women found caregiving more psychologically burdensome.

Mac Rae (1998) examined caregiving as emotion work in which caregivers experienced stress at failure to conform to "feeling rules." England (1997) discussed the positive effect of self-coherence on emotional arousal by allowing the caregiver to cope better with various elements of caregiving. Lin et al. (1979) discussed social

support as a buffering factor which, following the occurrence of life changes, controls interpretations of the events and emotional responses to them.

Morgan and Zimmerman (1990) indicated that emotional support from others is important to assist with the feelings of abandonment. Hawkins (1996) reported that the most used coping mechanism by caregivers was talking with someone. Caregivers who had few or no persons in their network were depressed. Song et al. (1997) found that insufficiency of overall social support was the strongest predictor of caregiver depressive symptomatology.

Interventions

Recognition that caregivers are an essential component of healthcare calls for more attention to their problems and their concerns. McCabe et al. (1995) determined that caregivers lacked the knowledge they need about the support services available to them.

Robinson (1988) disclosed that caregivers who received social skills training showed a significant decrease in both subjective and objective burden. Robinson and Clemons (1999) found that volunteer caregivers needed more training and more information about services needed. Volunteers also wanted to meet and get to know the care recipient. Volunteers verbalized a fear of persons with Alzheimer's disease indicating a need for more interactions with the care recipients.

Larsen (1998), Chang (1999), Roberts et al. (1999), and Wilkins et al. (1999) examined the effectiveness of individual support strategies as interventions. Recent studies have examined the interest in using electronic interventions, such as telephones and computers, as means of support for caregivers (Bass et al., 1998; Colantonio et al., 1998; Strawn et al., 1998). Whitlatch et al. (1991) found that a program of individual and family counseling had certain benefits in decreasing stress for caregivers compared to caregivers who received no interventions. Szabo and Strang (1999) contended that information is needed to determine the type of caregivers who have difficulty seeking help and why the difficulty.

There is general agreement that further research should be directed toward designing interventions to reduce the caregiver's stress and to promote coping behaviors. The future need for caregivers to maintain frail, older persons in the community presents an urgent problem for nurses. Therefore, it is imperative that effective interventions to support caregivers in coping with the consequences of caregiving be available. The emphasis of nursing research, in the future, needs to be on (a) identifying strategies for case finding, assessment, and interventions with family caregivers, and (b) research that evaluates outcomes of interventions (Sayles-Cross, 1993). Research on family caregiving can guide clinicians and policymakers beyond just having sympathy for the plight of family caregivers and toward constructive efforts at intervention (Haley, 1997).

CHAPTER III

DATA COLLECTION TECHNIQUES AND TREATMENT OF DATA

The phenomenological approach according to Colaizzi (1978) was used in the study. The aim of the phenomenological approach is to describe phenomena from the perspective of those who experience them (Davis, 1978; Oiler, 1982).

The design for this qualitative study was descriptive using a phenomenological approach. The traditional scientific method has been predominantly used for the study of family caregivers (Brandriet, 1994). However, human experiences cannot be adequately described with quantitative methods alone because the nature of human beings is so complex (Davis, 1978; Morse, 1991). Nurse researchers have investigated the phenomenological approach as an alternative to the traditional scientific method to understand human experience as it is lived (Burns & Grove, 1993; Oiler, 1982; Omery, 1983). Phenomenology is referred to as a mode of philosophical inquiry as well as scientific inquiry (Mitchell & Cody, 1993; Oiler, 1986; Omery, 1983). The development of phenomenological philosophy as a school of thought and as a method has primarily been attributed to the insights and innovations of Husserl (Omery, 1983; Reed, 1994; Valle & King, 1978). Husserl's (1962) phenomenology is essentially a

scientific method. Husserl thought of the phenomenologist as one who would study human phenomena from a detached, rather than an emotionally involved stance. For Husserl, the study of (a) feelings, (b) thoughts, and (c) emotions is to be achieved by the description of the immediate experiences or perceptions of the objects which give rise to these feelings or to which the feelings are directed. Husserl believed that thoughts are always directed to objects. Husserl's phenomenology followed the Cartesian tradition of thinking of the human situation as a subject being in a world of objects. Human thought is directed towards these objects. Husserlian phenomenologists believe that while self and world are mutually shaping, it is possible to bracket oneself from one's belief to see the world firsthand. To accomplish bracketing, prejudgments and values are eliminated by the researcher (Husserl, 1964).

Heidegger (1962) reacted against this subject-object division and questioned the notion that one's experience of things was always subjective, and argued that human contact with the world was primarily in and of the world rather than subjects in a world of objects. Heidegger referred to this situation as "being-in-the-world." Therefore, being human is a situation in which things are encountered and managed (Heidegger, 1962). Heideggerian phenomenologists believe that (a) each person is a self within a body, (b) each one's world is different, and (c) each has qualitatively different concerns. The body, the world, and the concerns of each person are the context within which the individual can be understood. The purpose of Heidegger's phenomenology was to reveal the significance and nature of the world (Reed, 1994).

Heidegger (1962) did not consider bracketing of ideas, notions, or experiences possible or even desirable in order to know the real world. He believed that an individual's interactions with others made any understanding of the world possible and one could not separate or bracket oneself from the world. Mitchell and Cody (1993) agreed with this line of thought: ". . . it must be recognized that, by nature, inquiry, discovery, and theoretical interpretation coexist and must be recognized as such if the theory-research linkage is to advance nursing science through qualitative inquiry" (p. 177). The researcher's knowledge via the literature and family experience as a caregiver formed a background which supports the acknowledgment of the use of existing theory in qualitative research.

Setting

The study took place in a large metropolitan area in north Texas. Family caregivers were interviewed by the investigator regarding their lived experiences of social support. Participants for the study were recruited from support groups for family caregivers and through referrals from professional associates. Interviews were conducted in the participant's home or at a mutually agreed upon location.

Population and Sample

The population consisted of family caregivers who were currently or had been the primary caregiver to a spouse or relative for at least 3 months. Participants were selected from the population of family caregivers (a) age 45 or older, (b) who lived

with the care recipients, and (c) who had the primary responsibility for providing care in the home setting for older persons age 50 or older. The care recipient was dependent in two or more activities of daily living, instrumental activities of daily living, or both, such as (a) bathing, (b) feeding, (c) cooking, (d) laundry, (e) dressing, and (f) transportation to a physician.

A purposive sampling technique was used in the selection of the study participants. Purposive sampling was chosen to maximize discovery of the patterns of social support for the family caregiver. "Experience with the investigated topic and articulateness suffice as criteria for selecting subjects" (Colaizzi, 1978, p. 58). Through purposive sampling, the broadest range of information is exposed, increasing the researcher's ability to identify emerging themes. Information rich cases are selected from which to uncover a multitude of heterogeneous, specific data (Lincoln & Guba, 1985). Family caregivers were selected who met the study criteria stated previously, volunteered to be participants, and agreed to have their interviews audio-tape recorded.

Eleven family caregivers were selected as participants for the study. The phenomenological method involves the study of a small number of subjects (Creswell, 1994; Oiler, 1986) to develop patterns and relationships of meaning (Oiler, 1986). There are no set rules for the sample size as the researcher seeks quality or the richness of information rather than quantity or volume (Erlandson, Harris, Skipper,

& Allen, 1993): Colaizzi (1978) contended that the number of participants selected for a study is contingent on various factors that the researcher must try out in each research project. Interviews were conducted individually and continued until common themes were clearly identified.

Protection of Human Subjects

The research was submitted to the Human Subjects Review Committee of the Texas Woman's University to ensure protection of the rights of the participants (Appendix A). Permission was received from the graduate school to conduct the study (Appendix B). Verbal and written descriptions of the study, including the purpose, risks, and benefits, were given to each potential participant (Appendix C). After agreeing to voluntarily participate, participants were informed of their rights, including the right to discontinue participation in the study at any time without any repercussions. Informed consent was obtained from each participant which included permission to audio-tape record each interview (Appendix D). The participants were free to ask questions before, during, and after the interviews.

The names of participants were known only to the researcher. The interviews were conducted and transcribed verbatim by the researcher. Tapes and transcripts were numerically coded to protect the identity and maintain the confidentiality of participants. Participants' names were not used in reports of study results.

Instruments

Two instruments were used to collect data for this study: (a) a demographic data sheet, and (b) the researcher as an instrument. A researcher-developed demographic data sheet (Appendix E) was used to collect data to describe the participants. Data requested were (a) age, (b) gender, (c) marital status, (d) race, (e) education, (f) length of time in caregiver role, (g) hours of care each day and days per week, (h) income, (i) employment status, (j) relationship to care recipient, (k) activities for which care was rendered, and (l) diagnosis of care recipient.

According to Creswell (1994), the researcher is the primary data collection instrument in qualitative research. The researcher was the “human instrument” for this study. Individual interviews were conducted by the researcher. Participants were asked to share anything and everything connected with social support in taking care of the care recipient. Probes or cue words, such as (a) feelings, (b) problems, (c) changes, and (d) assistance, were used when needed to elicit a full description of the caregivers lived experiences of social support (Appendix F).

Data Collection

Data collection was accomplished through a demographic data sheet, audio-taped interviews, and observations. Demographic information was gathered before the interview to allow time for the caregiver to relax and feel comfortable with the researcher.

Interviews were conducted over a 10-week period. Interviews were conducted with each participant in the home or at a mutually agreed upon location. Participants were interviewed individually and asked to give narrative accounts of their lived experiences of social support. The use of probes or cue words depended on the responses of the participants. Questions were asked for clarification of statements. Each interview was audio-taped and lasted from 34 minutes to 68 minutes. Observations of caregivers' behavioral responses to and interactions with the researcher were documented immediately after each interview.

Treatment of Data

Marshall and Rossman (1995) described data analysis as a way of bringing order, structure, and meaning to the data collected. A system was established for organizing, coding, and labeling data from audio-taped interviews transcribed verbatim. Codes were assigned to each participant. Each participant's audio-taped interview was coded and labeled to separate data and to maintain confidentiality. Copies of transcriptions were arranged in a three-ring binder according to the participant's code. The researcher listened to audio-tapes and read transcriptions as many times as necessary to become thoroughly familiar with the data. Significant statements were highlighted, coded, and numbered to reduce the volume of data. Meanings emerging from the significant statements were organized on 3 x 5 cards to allow theme categories and clusters of themes to emerge. Theme categories and theme clusters

were labeled and arranged on 3 x 5 cards. Themes were reviewed for alternative explanations.

The written report consisted of a description of the study sample and findings. Findings were presented according to each step of data analysis to include important statements, meanings, and themes. Eight of the participants were asked to compare their transcribed interviews to the prepared descriptive report to verify the accuracy of their reported experiences.

Audio-taped interviews and observation notes were transcribed verbatim, and analyzed by following the seven steps outlined in Colaizzi's (1978) method for phenomenological analysis:

1. Transcriptions were read in their entirety to acquire a feeling for the person's descriptions of his/her experiences.
2. Significant statements, phrases, or sentences were extracted from each pertinent description.
3. Meanings were formulated as they emerged from the significant statements.
4. The formulated meanings were organized into clusters of themes.
 - (a) The clusters of themes were validated by referring back to the original participants' descriptions. This validated that no data had been added or ignored.
 - (b) If discrepancies in themes were found, the researcher proceeded with the conviction that what cannot be explained may be real and valid.

5. An exhaustive description of the investigated topic was generated from the results of the analysis.

6. The exhaustive description was formulated into a statement of identification of its fundamental structure.

7. Two methods for validation were used:

(a) A validation was conducted by returning to the participants and asking them to compare the descriptive results with their experience. The final descriptive product included any changes offered by participants.

(b) Another nurse researcher, with experience in qualitative research, also analyzed the data and the results were compared with those of the researcher. Periodic discussions between the two nurse researchers were held to review the results of analysis. While minor compromises were made, theme categories, theme clusters, sub-themes, and the fundamental structure were in congruence.

Value and Logic

Criteria against which the trustworthiness or value and logic of qualitative research can be evaluated are (a) truth value of the study or credibility, (b) its applicability or transferability, (c) the consistency of procedures or dependability, and (d) the neutrality of findings or confirmability (Erlandson et al., 1993; Lincoln & Guba, 1985; Marshall & Rossman, 1995).

The goal of credibility is to show that the study was conducted in such a way as to ensure that the participants' experiences were accurately identified and described. Verification of the data and interpretations by the study participants and another nurse researcher contributes to the credibility of this study.

Transferability refers to the extent to which a study's findings can be applied to another context or with other participants (Lincoln & Guba, 1985). Transferability depends on the similarities between sending (original study) and the receiving (later study) contexts. Transferability is dependent on a detailed description of the sending context; therefore, thick description of data in contexts are collected and reported with sufficient detail and precision to allow judgments about the possibility of a transfer (Erlandson et al., 1993).

Purposive sampling is used to obtain specific, precise information from and about that context. "The logic and power of purposeful sampling lies in selecting information-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research" (Erlandson et al., 1993, p. 82). "Because the foundation of transferability is an adequate description of the sending context, the search for data must be guided by processes that will provide rich detail about it" (Erlandson et al., p. 33). Thick description gathered in this study, through (a) interviews, (b) observations, and (c) the use of purposive sampling, facilitate transferability.

Erlandson et al. (1993) contended that dependability of a study is contingent upon the consistency with which a study is done. To demonstrate dependability, a study must provide the reader with evidence that if it were repeated with the same or similar subjects in the same or similar circumstances, the findings would be similar. An audit of the process by which the study was conducted is done to determine the dependability of a study. The dependability audit is made possible through an audit trail of the study documentation, so adequate records must be maintained throughout the study (Erlandson et al., 1993). Dependability was made possible in this study through (a) audio-taped interviews, (b) verbatim transcriptions, (c) observation notes, and (d) 3 x 5 cards on which formulated meanings, theme categories, theme clusters, and sub-themes were labeled and arranged.

Confirmability refers to whether the study findings could be confirmed by someone else. The confirmability of the study data means that data can be tracked to the sources of the data. The researcher must ask if the data helped confirm the general findings and lead to the implications (Marshall & Rossman, 1995). Confirmability is ascertained through a confirmability audit to determine if the conclusions, interpretations, and recommendations can be traced to their sources and if they are supported by the study (Erlandson et al., 1993). Collaboration with an experienced qualitative researcher, who independently analyzed the data, verified the correctness of the identified theme categories, theme clusters, and sub-themes.

CHAPTER IV

ANALYSIS OF DATA

A description of the study sample and findings of the study are discussed in this chapter. Demographic data were collected immediately before the interviews and included (a) age, (b) gender, (c) marital status, (d) race, (e) education, (f) income level, (g) employment status, (h) relationship of care recipients, (i) years of caregiving, (j) care hours per day, (k) days of care per week, (l) assisted activities, and (m) care recipients' diagnoses.

Data analysis was conducted in conjunction with data collection in order to determine the need for further collection of data. The data analyzed in this study included the (a) demographic data of caregivers, (b) audio-taped interviews, (c) verbatim typed transcripts, (d) observation notes, and (e) additional comments from participants at the time of information verification. Data analysis followed Colaizzi's (1978) method for phenomenological analysis. Phenomenological analysis of data produces interpretations from within the data itself. The aim is to uncover and understand meanings and to identify major themes. The researcher's own thinking serves as a tool of analysis, and the results that emerge from this process are produced in interaction with the data itself (Anderson, 1991; Knaack, 1984).

The findings are described according to each of the seven steps identified by Colaizzi (1978) for data analysis. The audio-taped interviews and verbatim transcriptions were reviewed repeatedly to acquire a feeling for the participants' descriptions of the lived experience of social support. Significant statements were extracted and meanings formulated as they emerged from the statements. The formulated meanings were organized into theme categories and theme clusters. An exhaustive description was generated from the results of the analysis and formulated into a statement of identification of its fundamental structure.

Description of Sample

Purposive sampling was used to identify caregivers who lived with and cared for older persons dependent in two or more activities of daily living and/or instrumental activities of daily living. Participants were recruited from (a) caregivers attending an Alzheimer's disease support group, and (b) caregivers referred by professional associates. Information was presented to each potential participant and interviews were scheduled with the caregivers who volunteered to participate. The sample consisted of 11 family caregivers aged 50 to 86 years and included 4 males (36%) and 7 females (64%). Five (46%) of the 11 participants were married, 4 (36%) were widowed, 1 (9%) was divorced, and 1 (9%) was single. All of the participants were Caucasian with all having completed high school. Two (18%) participants had high school diplomas, 7 (64%) had a baccalaureate degree, and 2 (18%) had education

levels above the baccalaureate degree. The reported income levels were widely distributed with 1 (9%) respondent reporting less than \$15,999 and 4 (36%) reporting over \$60,000. Six (55%) of the caregivers were retired; 2 (18%) were unemployed at the present time; 2 (18%) were employed full time; and 1 (9%) was attending college full time. Table 1 shows the demographic variables of (a) age, (b) gender, (c) marital status, (d) race, (e) education, (f) income level, and (g) employment status.

Table 2 indicates that (a) 6 (55%) of the caregivers provided care for spouses, (b) 4 (36%) for their wives, and (c) 2 (18%) for their husbands. One of the spouse caregivers also had been caregiver to a parent and parent-in-law. Five (45%) caregivers provided care for their parents. Two of the parent caregivers had provided care for both parents at some point in time. Nine (82%) of the 11 caregivers lived alone with the care recipient. Participants had been primary caregivers to an older dependent person in the home setting from 7 months to 11 years, providing from 3 to 24 hours of care per day, 7 days a week. Ten (91%) of the caregivers provided assistance with five or more activities of daily living, instrumental activities of daily living, or both. Nine (82%) of the caregivers performed one or more healthcare tasks which included (a) management of medication, (b) a respirator, (c) oxygen therapy, and (d) wound care. The three leading diagnoses of care recipients were (a) Alzheimer's disease/dementia, (b) emphysema, and (c) congestive heart failure. Three care recipients had more than one diagnosis (27%). Demographic variables of (a) relationship of care recipient, (b) years of caregiving, (c) care hours per day, (d) days

Table 1

Demographic Variables of Age, Gender, Marital Status, Race, Education, Income Level, and Employment Status

Participant	Age	Gender	Marital Status	Race	Education	Income Level	Employment Status
1	86	Male	Married	White	Baccalaureate degree	\$41,000-\$59,999	Retired
2	56	Female	Divorced	White	High school	< \$15,999	Full-time student
3	69	Male	Married	White	Graduate school	> \$60,000	Retired
4	52	Female	Married	White	Baccalaureate degree	> \$60,000	Unemployed
5	81	Male	Widowed	White	Graduate school	> \$60,000	Retired
6	71	Male	Married	White	Baccalaureate degree	> \$60,000	Retired
7	50	Female	Single	White	High school	\$26,000-\$32,999	Full-time
8	65	Female	Widowed	White	Baccalaureate degree	\$41,000-\$59,999	Full-time
9	74	Female	Widowed	White	Baccalaureate degree	\$26,000-\$32,999	Retired
10	52	Female	Married	White	Baccalaureate degree	\$26,000-\$32,999	Unemployed
11	77	Female	Widowed	White	Baccalaureate degree	\$26,000-\$32,999	Retired

Table 2

Demographic Variables of Relationship of Care Recipient, Years of Caregiving, Care Hours per Day, Days of Care per Week, Assisted Activities, and Care Recipient's Diagnosis

Participant	Relationship of care recipient	Years of caregiving	Care hours per day	Days of care/week	Assisted activities	Care recipient's diagnosis
1	Spouse	2	3	7	B-C-L-D-T-M	Diabetes
2	Parent	4	3	7	B-C-L-T-M	Emphysema, Ulcerative colitis, CHF
3	Spouse	1 1/2	24	7	C-L-D-T-M	Dementia
4	Parent	1	24	7	B-C-L-D-T	Dementia
5	Spouse	7	12	7	B-F-C-L-D-T-M	Alzheimer's disease
6	Spouse	7 months	24	7	B-F-C-L-D-T-M	Emphysema
7	Parent	11	14	7	B-F-C-L-D-T-M	CHF
8	Spouse	2	5	7	F-C-L-T	Cancer
9	Spouse	5	24	7	B-F-C-L-D-T-M	Cortico-basal Degeneration
10	Parent	4 1/2	24	7	C-L-D-T-M	Osteoarthritis, Osteoporosis, Dementia, Alzheimer's disease
11	Parent	3	24	7	B-F-C-L-D-M	Old age

Note. B = bathing; F = feeding; C = cooking; L = laundry; D = dressing; T = transportation; M = medical responsibilities.

of care per week, (e) assisted activities, and (f) care recipient's diagnosis are also presented in Table 2.

Significant Statements

Significant statements were extracted from the interviews. Examples of significant statements from each interview are displayed in Table 3. A complete list of significant statements is found in Appendix G.

Table 3

Examples of Significant Statements from Interviews

Participant 1

1. I've always worked up until I needed to be home to take care of her, and I quit work, and since that time, I've devoted practically my whole life to looking after her.
2. The thing that helps most is having this nurse come once a day to do her legs, also to fill these syringes with insulin.
3. I feel like it's the love I have for her, and it's my duty.
4. It's changed her life and changed my life too, because we liked to see things and go places after we retired.

Participant 2

1. I've been taking over more and more.
2. I wear a beeper all the time, everywhere I go, and so I'm tethered in a sense.

(table continues)

3. My main thing is watching her suffer. That's tough; that's difficult.
 4. Faith, I have strong faith it will work out. God will get me through whatever does come up that I can't handle on my own.
-

Participant 3

1. We saw a neurologist, social workers, doctors. Looked at depression as a possible source of the problem. Saw a therapist on our own who thought that she was unhappy with being here and this was her way of dealing with it.
 2. My daughter who lives a mile and a half away, she's good.
 3. Watching her so that I can go somewhere else.
 4. I'm looking forward to this place. That support group that is run by P., just built a place nearby, if they strike me as being good people. What would help me is for me to know that she is getting the right kind of attention. I mean, I can't give her all the right I can I can't give her all the attention she needs, and I can't give her the right kind. But maybe in a group, maybe people that know what's going on. So I'm looking forward to some day care there. That would help.
-

Participant 4

1. But I've seen them kick somebody out up there that if they even gave them a chance. I mean this place is supposed to be for Alzheimer's and this is the problems that go with dementia. They don't remember what is socially acceptable, and you have to be patient with them.
2. I don't know if he starts acting like he did when he was back with my sister, there's going to come a time that we would not, he would have to get a place somewhere, because we just can't have that.
3. We've had a couple of people, volunteers from different organizations, but I, you know, unless its an emergency, I wouldn't feel comfortable letting them, just because he's apt to take his clothes off or something.

(table continues)

4. My husband, we can't go a lot of places together now, so he will stay home and baby-sit and then he can go out and I baby-sit.
 5. It would be nice to have a baby-sitting service. If you could get a student nurse or something like that that would understand or where you could drop them off at day care in the evening and stuff rather but you have to find someone to pay.
 6. You attend support groups if they allow you to drop them off and have them taken care of at some place else.
-

Participant 5

1. She had managed the checkbook, bank statements, and so on and I had to help her and finally take over that particular chore. She continued to do rather simple cooking, but, eventually, I had to take over that particular role also. I made a point of going with her when she drove and came to the conclusion she was no longer a safe driver.
2. I bought a potty chair for her so that it was right beside the bed but she never did learn to use it herself, so I would have to position her on it and that seemed to work pretty well. Also fed her. At first, she was able to use her knife and spoon and fork and so on, but gradually she started using her hand, not using the fork anymore, sometimes using the spoon, and using her hands to pick up food. She developed difficulty in swallowing. Found it necessary to, to puree her food. I guess that's what you call it. In later stages, it was necessary to use a syringe.
3. Let me say that I, in general, felt very pleased with the level of help I received. I had no complaints. One thing that did happen, however, a social worker appeared on the scene and I, he interviewed me about the care I was giving. When he found out that I sometimes left D. alone in the house, and I'll tell you when I did that. When she reached the point where she was completely bedfast and could not walk; so, he was upset. He said what if there was a fire? When you consider all the care that I'm giving her, its tremendous. That was upsetting. I resented it very much. That was the only really negative experience.

(table continues)

4. Also went to one of these Alzheimer's support groups and when I listened to the other people and the problems they had, I thought I was fortunate. I always felt much more sorry for D. than for myself. I really had it easy compared with what a lot of people might have had to deal with.
 5. I kept some notes during the time of D.'s illness, and I actually wrote them up. This one is titled "D.'s Talking," and I broke it down by years and indicated roughly the times, and it's all in dialogue form.
 6. I have a brother that lives in town, and I wish he'd come over more often to visit and keep up with things, but that's about the only thing I missed.
-

Participant 6

1. I have an intercom here, I, we got one out in the garage and she's got one on her bed. It gets a little tiring.
 2. My son stays with her some and helps when he is here but that's not very often. He's on the road most of the time.
 3. We get the hairdresser, and she comes here and does W.'s hair.
 4. I have a neighbor that would come over anytime, but she's been sick. There are those that call and check on us like J., the nurse who is a friend.
 5. If I had somebody, just somebody to come stay when I need to go somewhere, buy groceries, something like that.
 6. This dog takes me for walks everyday. Gets me out.
-

Participant 7

1. I turned around and called a couple of other nurses that I knew and they referred me to a person who worked at VNA, and, by that weekend, I had home healthcare set up.

(table continues)

2. Within a week I had Dad in Texas, Mom in Texas, and I was caring for both of them.
 3. I called Dr. H. or Dr. S. and they had set up the home healthcare, the oxygen, the hospital bed, everything within that 24-hour period. Bless their hearts.
 4. In the last year, Mom's health has deteriorated so much that I do have to have help getting her out of the car and everything. S. and B. came over and helped me get her out of the car and into the house.
 5. The state pays for her care and Meals on Wheels.
 6. Gave up a social life. I mean when you are interested in a guy and he finds out you're taking care of your mother. Oh, how old is she? Oh, 80 something. You know, they're like oh, I don't want to be saddled with that and off they go.
 7. I was use to taking off after work and going somewhere. I guess now I have to come home and check on Mom, make sure she has something to eat, but to me they are just minor inconveniences. You just have to work around them.
-

Participant 8

1. I am not sure that the doctors are always honest in these situations. He asked them how long he would have because there were some things that he needed to take care of and they told him that he would have about two years. Well, that is not what happened. He died in three months, so I don't think that is right. I know that they don't know exactly, but they should be more honest about it with their patients.
2. I had a nurse and a home health aide that came and took care of him during the day and the aide was really the most help to me.
3. Friends would call to see if we needed anything and that helped.
4. I don't have any family that lives near here so I didn't have them to lean on, and that may have been a good thing too because one of my daughters came and stayed for a week and he was glad when she left and so was I. It was good to have her for a while.

(table continues)

5. They did call pretty often to check on us but its not the same as getting out and seeing your friends and doing things. Because you just have to make so many changes and give up most of your social life, really it can be very lonesome. We couldn't go and do things like we did before he got sick, so you can feel like you are all alone.
 6. I did attend a support group one time at the church but it wasn't for me and I never went back, and you don't have the time either.
 7. My caregiving did not last long but I can tell you that it was hard work and very tiring. I would go to work, cause I had to work, and then come home and start taking care of his needs and that really leaves no time for you. You, you are just on a merry-go-round for a while or that is what it feels like. Just having something to give me a break from that would have helped.
-

Participant 9

1. I just had to be with him all the time. I mean there was no way of getting out of it.
 2. I had to have special locks put on the doors. That way he couldn't get out and because he'd get up in the middle of the night, maybe roam around.
 3. They chatted and when he forgot to call the friend, then the friend didn't call and that was really upsetting. He didn't know the difference but I knew.
 4. I had taken him down there a couple of times and all they would say is that I was doing such a good job, and he looks wonderful, taking care of him that I needed to continue doing it and, on the other hand, my Internist and my Orthopedic surgeon were telling me I was killing myself and that I couldn't do that.
 5. I was always tired after, you know, about a year and a half of being totally confined all the time.
 6. My daughter who lived a block and a half away was excellent support.
-

(table continues)

Participant 10

1. I said if it will not jeopardize your job, get home. I'm going to have a nervous breakdown.
 2. Our church offered a course on parenting your parents and that had seemed like a good idea to me. Maybe I'd learn something here.
 3. Our minister was by to visit and said something, "Your mother is a very lovely lady." And there was two things that brought me up short. One I don't see the lovely lady because I'm so busy. I walk in the door and it's "I need." That's what she hits me with, "I need." So I rarely see this lovely lady and yet this is the gracious lady persona that strangers see.
 4. I just thought it was pure stubbornness because along with everything else, she's a stubborn lady.
 5. She's my mother and she isn't. She's not the same person that my mother was.
 6. Just knowing that somebody else actually really relates to it, not just sits there and says I can see you've got a problem or that kind of thing. Really relates to it.
 7. Accessing the Internet has made it a lot easier to get information. That's been helpful.
 8. I gave up my consulting job because when something happened to Mother I had to call my clients and reschedule appointments and that was frustrating to me and the client.
-

Participant 11

1. She got to where she couldn't remember anything, so I served as her memory board.
2. Sometimes I would get real angry with her.

(table continues)

3. We did not have enough friends to drop in like she wanted them to.
 4. One thing I needed desperately from them or anyone was baby-sitting.
 5. Nobody wants to baby-sit an elderly person. They're, they're scared.
 6. We did find a lady from T. that would come out and sit with her but she charged \$10 a time, an hour to sit . . . but at \$10 an hour, you didn't run out whenever you really wanted to.
 7. My neighbor across the street would sit with Mama, and I trusted her.
 8. The people from her church were wonderful.
 9. I really needed to dump on someone, and I feel better after talking.
-

Formulated Meanings

Meanings were formulated from the significant statements. Examples of formulated meanings for the significant statements from each interview are presented in Table 4. A complete list of formulated meanings is found in Appendix H.

Table 4

Examples of Formulated Meanings from Significant Statements

Participant 1

1. Making frequent trips to the hospital was tiring and hard.
2. Some tasks are difficult for him because of his age and disabilities.
3. Quit his job to become a full-time caregiver.

(table continues)

4. I do this for her because she would do it for me.
 5. The caregiver feels a sense of loss.
-

Participant 2

1. Feels a sense of responsibility for her mother.
 2. As time passes, she has to assume more responsibility.
 3. Can never get away from the responsibility, no matter where she goes.
 4. Perceived knowledge deficit in the medical community about geriatric care.
 5. Seeking outside help is her only option because she has no family to support her.
-

Participant 3

1. Reaching out for professional help for an answer but not getting it.
 2. His wife is becoming progressively harder to care for and he is losing her mentally.
 3. He is doing all he can for her and is trying to deal with each problem as it arises.
 4. The relationship that once existed is gone, and the wife he used to know is gone, and he is now living her life and his life, and it is not easy.
 5. He needs to get away from the situation sometimes.
 6. He does not feel he can provide her everything she needs and is hoping to find someone that he trusts to help because he is stressed.
-

(table continues)

Participant 4

1. The situation is stressful, and she is trying to make the situation less complicated.
 2. Taking desperate measures to maintain some means of control and privacy.
 3. Caring for him day and night is difficult and she cannot get any sleep.
 4. Frustrated with the staff's level of knowledge about Alzheimer's patients.
 5. Worries about the future as there is a limit as to what she can ask of her family.
 6. Hesitant to accept help from volunteers who may not understand dad's behavior.
 7. Can only participate in support groups if they have staff to care for her dad.
-

Participant 5

1. Demands of care increase as he gradually loses her.
 2. Problem-solving to cope with the demands of care.
 3. Found friends and paid help as a means of having time away.
 4. He wants to be recognized for his hard work, not criticized.
 5. Recognizes that his situation isn't as bad as some others in the support group.
 6. It helped to document the changes that were occurring.
 7. The healthcare system provided helpful information.
 8. Visits from brother would have been appreciated.
-

(table continues)

Participant 6

1. The freedom to come and go at will is gone.
 2. When she is difficult, he has a hard time coping.
 3. Services that are rendered in the home reduce the stress.
 4. Needs help to come to his house to give him some time away.
 5. The dog kept him from being so lonely.
-

Participant 7

1. Clergy offered no help when approached.
 2. Nurses provided direction to get immediate help.
 3. Has the responsibility of caring for both parents.
 4. After working all day, there is still everything to do when getting home.
 5. Caregiving is not easy.
 6. Has no confidant and is lonely, so finds comfort in talking to the cat.
-

Participant 8

1. Work was a way to get away from the situation.
 2. Maintaining contact with friends is difficult.
 3. Well-meaning family can also cause additional stress.
 4. Attending support groups takes time and does not always meet needs.
 5. A break is necessary in order to cope with the hard work of caregiving.
-

(table continues)

Participant 9

1. There was no way to get out of being with him all the time.
 2. His friend abandoned him when he got sicker which hurt.
 3. The neighbors would offer to help, but she wasn't sure they could care for him.
 4. I was told to continue to take care of him, but my doctor said I was killing myself.
 5. I had to get up with him all the time which interfered with sleep.
 6. She still feels the need to watch out for him.
 7. Attended the support group that was convenient and provided care so she did not have to find someone to stay with him.
 8. It is good to have someone concerned about the caregiver.
-

Participant 10

1. Feels guilty that she put her mother in a nursing home.
2. Did not know where to find caregiving information.
3. Caregivers need reassurance.
4. Uncertainty is a part of each day.
5. Spousal support and recognition of efforts are important to the caregiver.
6. The caregiver needs confirmation from someone that is also a caregiver.
7. It is difficult to get help from the medical profession and it is frustrating.
8. The Internet makes access to information easier.

(table continues)

9. Family members are not prepared for the caregiver role.
-

Participant 11

1. Inability to cope can result in anger.
 2. It would be helpful if there was someone to baby-sit.
 3. People are afraid to sit with an older person.
 4. There is no time to meet her own needs.
 5. She is very angry at some family members for not visiting.
 6. Church members were very attentive.
 7. There is little time for anything other than caregiving.
 8. I feel better after being able to talk to someone.
-

Theme Categories, Theme Clusters, and Sub-themes

Grouping of formulated meanings of social support from each interview yielded three theme categories. The theme categories merged into 5 theme clusters and 20 corresponding sub-themes. The theme categories, theme clusters, and sub-themes are shown in Table 5.

Table 5

Theme Categories, Theme Clusters, and Sub-themes

Theme Categories	Theme Clusters	Sub-themes
Assistance	Demands of care	Physical
		Psychological
Guidance	Commitment	Obligation
		Responsibility
	Coping	Problem-solving
		Seeking information/ advice
		Getting away
Emotional Aspects	Loss	Writing
		Social life
		Personal life
		Freedom
		Relationships
	Emotions	Loneliness
		Guilt
		Stress
		Anxiety

(table continues)

Theme Categories	Theme Clusters	Sub-themes
		Sadness
		Frustration
		Anger
		Uncertainty

The formulated meanings were organized into clusters of themes and sub-themes. The themes and sub-themes were validated by referring back to the original interviews to determine the completeness and accuracy of the themes. The results of the analysis were integrated into clusters of the phenomenon of lived experiences of social support of family caregivers of dependent older persons. Examples of clusters of themes and sub-themes are shown in Table 6. A complete list of the theme clusters and sub-themes is shown in Appendix I.

Table 6

Examples of Clusters of Themes and Sub-themesA. Demands of Care(a) Physical Demands

1. Making frequent trips to the hospital was tiring and hard.
2. Frequency with which medications must be administered is hard on him.
3. Chores, such as grocery shopping, require so much time.
4. After working all day, there is still everything to do when getting home.
5. Caring for him was very difficult with him being wet so often.
6. What helps most is having a nurse do leg dressings and fill syringes with insulin.

(b) Psychological Demands

1. Working through the system to get the right help is frustrating.
2. Worries that care for wound is correct and about the time to care for wound.
3. He tried an assisted living facility with an Alzheimer's unit, but was not satisfied.
4. Regrets that she could not spend more leisure time with her mother.
5. She is overwhelmed and now has billing errors to correct which takes time.

(table continues)

6. When she is difficult, he has a hard time coping.

B. Commitment

(a) Obligation

1. I do this for her because she would do it for me.
2. Feels an obligation to care for wife because of duty and love for her.
3. Has a duty and responsibility to honor his marriage vows.
4. It is a duty and obligation to care for one's parents.

(b) Responsibility

1. The neighbors would offer to help, but she wasn't sure they could care for him.
 2. Can never get away from the responsibility, no matter where she goes.
 3. As time passes, she has to assume more responsibility.
 4. The direct care is over but the responsibility is still there.
-

C. Coping

(a) Problem-solving

1. Getting help from the system was difficult, so a State Senator helped me.
2. He got assistance through the doctor which lessened his care demands.
3. It is difficult to take care of him so looking for ways to make it easier.

(table continues)

4. Fears he won't hear her go to the bathroom and will have to clean up after her.
5. Special locks were placed on the doors to protect him.

(b) Seeking Information/Advice

1. There are professionals and personal friends she can turn to for help.
2. Recognized that he had to have help and sought professional advice.
3. I was told to continue to care for him, but my doctor said I was killing myself.
4. Someone has to have been in the situation to understand.
5. People offered suggestions about the use of various services.
6. The Internet makes access to information easier.

(c) Getting Away

1. Having respite weekends was a "Godsend."
2. Found friends and paid help as a means of having time away.
3. Day care gave her time alone which was restful even though she had things to do.
4. Work was a way to get away from the situation.

(d) Writing

1. It helped to document the changes that were occurring.
-

(table continues)

D. Loss

(a) Social Life

1. His social activities and personal time are restricted.
2. Maintaining contact with friends is difficult.
3. There is no time for social activities when you are the primary caregiver.

(b) Personal Life

1. Quit his job to become a full time caregiver.
2. Wishes she had some privacy so she and a date could be alone for dinner.
3. There is no personal time for both she and her husband to be together.

(c) Freedom

1. Feels a loss of her freedom because of duty to her mother.
2. I could not go anywhere without him and had to watch him constantly.
3. There is little time for anything other than caregiving.
4. People are afraid to sit with an older person.

(d) Relationships

1. The relationship that once existed is gone, and the wife he used to have is gone, and he is now living her life and his life, and it is not easy.
2. His inability to remember is a loss to her.

(table continues)

3. Struggling with the loss of the person that she knew as her mother.
 4. Becoming a parent to a parent is hard.
-

E. Emotions

(a) Loneliness

1. Has no confidant and is lonely, so finds comfort in talking to her cat.
2. Visits from brother would have been appreciated.
3. Phone calls from friends helped.
4. Giving up social activities results in loneliness.
5. It is good to have someone concerned about the caregiver.

(b) Guilt

1. Feels guilty about taking him to day care.
2. Caregivers feel guilty about some comments to parents.
3. Lack of resources limited what caregiver could do and she feels guilty.
4. Feels guilty that her mother got sick while she was gone.

(c) Stress

1. Thankful that her mother does not complain, but worries that Mother will not tell her something that is important which then creates more for her to do.
2. He does not feel he can provide her everything she needs and is hoping to find someone to help because he is stressed.

(table continues)

3. Family members are not prepared for the role of caregiver.
4. Well-meaning family can also cause additional stress.
5. There are more and more demands.

(d) Anxiety

1. Concerned about own health.
2. Worries about the effects of her Dad's behavior on daughter.
3. He worried when she was home alone.
4. As his condition declined, the greater her concern about his care.
5. I let someone else care for him and they did not know he left, which is scary.

(e) Sadness

1. Sad that they are unable to travel as they planned.
2. It is very sad and painful to see his wife as her condition deteriorates.
3. It is difficult to watch a loved one suffer.

(f) Frustration

1. The doctor does not recognize when older persons are not rational.
2. Perceived knowledge deficit in the medical community about geriatric care.
3. Sometimes it is not worth the hassle to use day care.
4. Frustrated with others who don't understand.

(table continues)

(g) Anger

1. He wants to be recognized for his hard work, not criticized.
2. Angry at doctors that husband did not live as long as he was told.
3. The caregiver is angry that her life is controlled by caregiving.
4. She is very angry at some family members for not visiting.

(h) Uncertainty

1. Worries about future and loss of independence if can't continue providing care.
2. Hesitant to accept help from volunteers who may not understand Dad's behavior.
3. Worries about the future as there is a limit as to what she can ask of her family.
4. Uncertainty is a part of each day.
5. The caregiver needs confirmation from someone that is also a caregiver.

Exhaustive Descriptions of Family Caregivers of Dependent
Older Persons' Lived Experiences of Social Support

The following exhaustive descriptions of the lived experiences of social support of family caregivers of dependent older persons were generated from the (a) theme categories, (b) theme clusters, and (c) the corresponding sub-themes.

Social Support

All study participants addressed some aspect of social support as being critical to their caregiving role. Formal and informal sources of social support were identified. Formal sources were (a) the healthcare system, (b) support groups, and (c) the church. Family members, friends, and neighbors were informal sources of social support. Social support was perceived to be in the form of assistance, guidance, and emotional aspects. Social support was discussed in terms of both positive and negative aspects.

Assistance

Assistance was provided with demands of care which included physical and psychological demands. Physical demands included (a) basic and instrumental activities of daily living; (b) medical responsibilities, such as medication administration and wound care; and (c) transporting to doctor appointments. Psychological demands included (a) scheduling appointments, (b) monitoring the care recipients' conditions, (c) decision-making, and (d) dealing with behavior problems and personalities.

Demands of Care

Multiple physical and psychological demands were placed upon the caregivers. According to caregivers, these demands increased as the care recipients' condition deteriorated.

Physical demands. The loss of the care recipients' abilities to safely perform activities, such as driving, cooking, and managing money, and a decline in self-care

activities, lead to a loss of independence and greater dependence on the caregivers.

Caregivers found themselves overwhelmed with responsibilities, such as (a) personal care, (b) paying bills, (c) cooking, (d) cleaning, (e) laundry, and (f) shopping. One spouse caregiver said, "Gradually she became less active in controlling her behavior and I had to take over." Another caregiver commented, "The doctor helped us receive help through Medicare and Blue Cross by sending a nurse for a while twice a day, and a lady to help with bathing and so forth three times a week. Before this happened, I had to do everything." A parent caregiver said, "Caregiving can be hard, can be very stressful." Complex and time consuming tasks were required of the caregivers.

Transporting to doctor's visits, and medical responsibilities, such as (a) managing and administering medications, (b) wound care, and (c) managing oxygen therapy and a respirator, added to the already relentless demands. One caregiver commented, "When I came home I did the laundry and cooked and cleaned and everything else."

Performing tasks was difficult for some because of physical ailments. In one case, the caregiver stated, "I had this back surgery and I have a rod in my back, so taking care of him was really quite a chore." Others were unable to continue as primary caregivers. One caregiver commented, "She was beyond any care that I could give her at that point."

Psychological demands. Psychological demands discussed by caregivers were (a) dealing with the care recipients' personalities and behavior problems, (b) arranging

appointments, (c) finding help for medical treatment and personal care, (d) decision-making which included medical needs and alternate care options, and (e) entertaining the care recipient. Having to deal with personalities was stressful and demanding. Comments were, "At times, she's like I am, she's non-cooperative. To tell you the truth, I get aggravated;" "I just thought it was pure stubbornness, because along with everything else, she's a stubborn lady;" and "She is so sweet natured, always has been. You know some people get nasty with dementia; she's sweet. She will drive you crazy asking if she can help."

Arranging doctor appointments was difficult. Appointments had to be coordinated with other activities. An example given was, "I had a terrible time coordinating the baby-sitting and a ride for myself and an appointment at the doctor. You had to get an appointment for all three to even go right up here at the clinic. It was really hard to do."

In monitoring medical needs, a caregiver stated, "I have to worry is the thing healing or is it not healing, or do I need to call somebody. Is it okay? Can it go a little longer, or is it getting infected?" One caregiver said, "It's mostly the mental that makes you the caregiver crazier than the physical."

Another caregiver talked about billing errors saying, "The other hardest thing now, Heaven help me, is if there is one care providing service that could keep track of its billing so I wouldn't have to, I would love it. At least every other bill that comes

in this house, there's something wrong with it and I get frustrated spending my time hanging on the phone dealing with it which is frustrating."

Occupying the time of the care recipient was another demand for the caregiver. One caregiver expressed guilt about not having enough time to play cards with her mother.

Guidance

Guidance is the supportive behavior directed at improving the caregivers' abilities to care for their loved ones and themselves. Guidance encompasses commitment and coping.

Commitment

Spouse and parent caregivers indicated that caring for a loved one was a personal commitment. Reasons for assuming the caregiver role varied from one caregiver to another, but for most, there was a deep sense of commitment. Care was rendered out of a sense of obligation or duty and responsibility.

Obligation. Eight (73%) of the 11 participants expressed the importance of caring for a family member and considered it their duty. Spouses considered their role as caregiver to be their obligation and in keeping with their marriage vows. One stated, "I made a pact 47 years ago, so I'm going to live with it." Caring for one's parents was described as a duty and obligation. Spouse and parent caregivers discussed their obligation to be caregivers because their loved ones had cared for or

would care for them if the situations were reversed. A caregiver, who had cared for both dependent older parents at the same time, stated emphatically, "They raised me, so now I'll raise them."

Responsibility. All caregivers indicated a sense of responsibility to care for their loved one. Parent caregivers considered it their responsibility to provide care for their parents as long as they were able to do so. Caregivers reported that they were never free of caregiving responsibilities regardless of where they were or who was caring for their loved ones. Responsibility was ongoing for caregivers, even when the care receiver was institutionalized. Responsibilities shifted but the caregiver role continued. A comment from one caregiver was, "Even with her in a nursing home, I'm still the caregiver."

Some caregivers were concerned that family members or others could or would not be able to provide the same level of care so they did not ask for or accept offers of help. A caregiver whose husband was institutionalized talked about visiting her husband, "I'd just make sure he was being cared for." Caregivers discussed how their responsibilities increased over time and the magnitude of their role. Six (55%) of the 11 caregivers reported 24-hour responsibility 7 days a week for care resulting in sleep disturbances and fatigue. For instance, a comment was, "I just had to be with him all the time. I mean there was no way of getting out of it."

Coping

Different coping strategies were used as the care recipients' physical and cognitive abilities worsened and behavioral problems increased. Problem solving, seeking information/advice, getting away from the situation, and writing were approaches used. Most caregivers used more than one approach.

Problem-solving. All caregivers attempted to find solutions to problems as they arose. Special locks were placed on doors to protect those who wandered and to maintain some privacy for the caregivers and their families. Caregivers were creative in preventing "bathroom accidents" that would cause more work for them. One caregiver described his solution as, "She, during the night, she'd get up to go to the bathroom, but she often didn't make it in time. I'd spread newspapers and when I'd hear those newspapers rattle, I knew to run to help her." Caregivers utilized community services such as Meals on Wheels, public transportation, and respite services to alleviate some of their duties and stress. Two caregivers institutionalized the care receiver when they could no longer mentally or physically cope. One of these caregivers reported contacting her State Senator for assistance when she met with resistance from the healthcare system in getting her husband institutionalized. Obtaining a healthcare power of attorney empowered one caregiver to seek other care options.

Seeking information/advice. Caregivers lacked knowledge about caregiving and the physical and emotional demands of the role. Advice, information, and feedback

from professionals and other caregivers increased understanding of problems and actions to take. Caregivers sought advice from healthcare professionals about treatment regimes that were not effective. In one instance, a caregiver stated, "It had been recommended to us that we go to the hospital daily and take the whirlpool and do whirlpool baths to her legs. We did this for approximately 10 months, 7 days a week, we went to the hospital and her legs got some better but never, was never able to completely cure her legs. At this time, we, I contacted a doctor . . . , a wound doctor, to get help in trying to cure her legs." Information about other care options was requested when caregivers could no longer cope. Caregivers described difficulties in accessing information which often caused frustration and anger toward the healthcare system. Some caregivers described support groups as good sources for information about handling behavioral problems. One caregiver used the Internet to communicate with other caregivers about their experiences and to seek reassurance.

Getting away. Taking breaks from the situation was reported as a way of coping with the hard work of caregiving. Having friends and paid help stay with the care recipient allowed time for the caregiver to get away. Healthcare professionals recommended day care and respite as means of getting away. One caregiver described respite weekends as a "Godsend." Another caregiver stated that her work was her only way of getting away. She said, "I was working full-time and that, I think, was a life-saver for me. If I had not been able to go to work and get away from the situation, I am not sure what would have happened. It was a release for me and you

have to have, otherwise you would not be able to stand it.” One caregiver said “She can dump on me all she wants and I’m not going to desert her. What I’ve learned to do when she really gets on my nerves is well, I’ll come back and see you tomorrow.”

Writing. One caregiver wrote about his wife’s illness and made copious notes on the changes in her (a) physical abilities, (b) appearance, (c) behavior, and (d) cognitive abilities. He commented that this was his way of learning about her illness. A poem he wrote was shared with the researcher during the interview to relate his experiences as he watched his loved one transformed from her former self. The poem reflects the need for social support as his wife’s illness progressed: (a) assistance with the physical and psychological care demands, (b) guidance about commitment and coping, and (c) the emotional aspects to deal with loss and emotions. Permission was granted by the caregiver to use his poem titled “Dorothea” which follows:

Dorothea

Head thrust forward on a scrawny neck.
 Bowed back and sagging shoulders
 Crusty, tissue-thin skin, dry, wrinkled, blotchy
 Mask-like face with hollow vacant eyes
 Hoarse whispery voice filtered through slitted lips
 Trembling hands hung from limp, flaccid arms
 A skeleton laced up with stringy muscles and tendons

Memories hide, fade, or assume capricious shapes
 Goals and plans crumble and like dust whirl away

Thoughts become murky, tangled, snarls
 Words lie buried or tumble out in scattered heaps
 Feelings erode, emotions flatten and dry up
 Only misshapen islands of an earlier self
 Lie submerged in the miasmic sea of a mind in decay

I gaze at the poor remnants of my dear love
 My loving companion for nearly a half a century
 The person with whom I had shared
 Hopes, dreams, triumphs, troubles, and pain
 I yet remember her endearing youthful ardor
 Her lifelong courage and steadfastness
 Her unflagging encouragement and support
 Her enduring faithfulness and devotion.

This ruin no longer my dear love
 Instead her person lives only in memory
 In memory of myself and caring others
 My duty to her is to first remember her
 To remember her as she truly was before
 Beyond that I must faithfully care
 For her poor body and enfeebled mind
 And try to be the person whom she loved.

Emotional Aspects

Family caregivers had an enormous emotional burden placed on them.

Caregivers experienced complex emotional issues which included (a) loss of social

lives, personal lives, freedom, and relationships, and (b) emotions of loneliness, guilt, stress, anxiety, sadness, frustration, anger, and uncertainty.

Loss

Loss was considered to be a consequence of caregiving. Valued aspects of caregivers' lives identified as primary losses were (a) social life, (b) personal life, (c) freedom, and (d) relationships.

Social life. All caregivers sacrificed most or all of their social activities to provide care. Social interactions decreased or ceased as maintaining contact with friends and remaining active in social activities was difficult because of time constraints. One caregiver explained, "It has kept us from doing a lot of things that we loved to do. We don't go to church. We don't go to senior citizens. We spend a lot of time at home. I would probably go and do things but I don't want to leave her. I mean I can't go do things." Another caregiver said, "You have to give up a lot of your activities that you were doing and so you lose a lot of your friends; you just lose that contact." One caregiver described her situation as, "I really didn't have anybody that I could talk too. They'd listen for about two minutes and you could see their attention wandering and you'd say oh, forget it, I'll just go home and talk to my cat. My Siamese was a great listener."

Personal life. Personal lives were also affected in a negative direction. Aspects of their personal lives that caregivers cited as changing were (a) personal time,

(b) privacy, (c) jobs, (d) travel plans, and (e) control of their daily schedules. One caregiver described her situation as, "There is no lifestyle when you're a caregiver. You, you do what fits into your schedule or their schedule and if there's any time in between, that's, well, your time and there's very little of that." Another stated, "I would go to work, cause I had to work, and then come home and start taking care of his needs and that really leaves no time for you." Caregivers discussed having no personal time with spouses. One commented, "The only time my husband and I had together after I retired, and he retired quite a while before I did, was the two months she went to M. and it was in the summertime. And we had those 2 months together in our retirement and that was it." One caregiver discussed her lack of privacy as, "Sometimes I think it would be so nice to make a meal and invite someone over, just the two of us, but there's always Mother you know." Five (71%) of seven employed caregivers resigned from their jobs to be caregivers.

Freedom. Meeting care recipients' needs was time consuming. Some care recipients required constant care and supervision so they would not wander off or get hurt. Chores and other responsibilities and duties also limited the time available for socializing or the opportunity to participate in activities outside the home. Examples of comments were: "I can't go anywhere much." "I am limited where I can go." "I knew that I couldn't go out and leave her even for a couple of hours." As a result, isolation, loneliness, and confinement became a part of the caregivers' lives.

Availability and cost to have someone sit were concerns. The perception that people were afraid to sit with older, demented individuals limited the opportunities for respite.

Relationships. Substantial changes in relationships occurred and caregivers disclosed their feelings of loss as cognitive and behavioral changes occurred. The caregivers experienced the loss of the care receiver as a companion as their role became primarily that of caregiver. One caregiver stated, "Oh, I got these two beautiful cats, kittens, during D.'s illness and their companionship was helpful to me I think and I still enjoy them."

Another caregiver commented, "You know in the former relationship, I lived my life and she lived hers, and we lived ours together, but now I have to live both of them." Role reversal occurred as the care recipient's condition progressed. Three of the caregivers were daughters who became parents to their parents. Role reversal was described as, "That was the hardest thing to take, was the role reversal, that you have become the parent." Caregivers of those with significant cognitive impairments described the loss they felt because loved ones no longer recognized them or confused them with someone else. Comments from two spouse caregivers were, "Sometimes she didn't know who I was." "Sometimes she thinks I'm her brother." A parent caregiver said of her father, "He doesn't remember my mother that much. Sometimes we wonder if he doesn't have my sister and I confused."

Emotions

Caregiving was described as an emotionally loaded task with a wide range of emotions. Emotions were individualistic, and were described as occurring simultaneously and in varying degrees. Most of the emotions discussed by the caregivers were negative. Caregivers described feelings of (a) loneliness, (b) guilt, (c) stress, (d) anxiety, (e) sadness, (f) anger, (g) frustration, and (h) uncertainty.

Loneliness. The loss of companionship and diminished social contacts lead to feelings of sadness and loneliness. Caregivers appreciated the concern of health professionals about their physical and mental health and the help extended to them which gave them a feeling of being cared about. Pets were company and “someone” to talk to, alleviating some of the loneliness.

Guilt. Guilt was expressed by caregivers who wanted to do more but could not because of limited resources and time. Seeking other care options, such as other family members, day care, or nursing home placement, were also sources of guilt. A caregiver who took her husband to day care commented, “I’d get to feeling bad that I’d taken him over there.” Doubts about decisions, not enough time to spend with the care recipient, and responding to care recipients in a negative tone, caused feelings of guilt. One caregiver was overwhelmed with guilt because her mother became ill during her absence and while in the care of her sister. She shared her feelings as, “You didn’t know what to do. You didn’t know whether to leave her. Of course, I had the guilt trip because I was gone when she got sick, and I think that’s one of the

biggest problems when you're taking care of somebody old, is the guilt that you have cause you are not doing the things that you'd really like to do because you either don't have the time or the money or the experience or what ever it takes and then you feel guilty. I know with me, that's part of my problem, the guilt." She also doubted that the doctor had made the correct diagnosis which she felt she would have been able to rectify had she been available. The caregiver became very emotional and said, "I just know she didn't have a sore throat even though that is what the doctor was treating her for." Another caregiver discussed feeling guilty that her mother became very ill while in her care and wondered if the illness could have been avoided had she monitored the situation better. Criticisms from others about placing a loved one in a nursing home evoked guilt feelings.

Stress. Caregivers experienced extreme emotional stress from being overwhelmed by the role and demands that are involved. Stress resulted from a combination of circumstances, resources, and responses. Stress was associated with the duties and responsibilities of caregiving and with the uncertainty of caregiving outcomes. Trying to balance caregiving with work and other activities created feelings of stress. The dependency demands of care recipients caused caregivers to feel stressed and comments made precipitated guilt feelings. Two caregivers found families to be a source of support and stress. While family visits were enjoyed, they caused additional stress and duties for the caregivers. The caregivers' physical ailments also contributed to the stress related to caregiving. Fatigue and confinement

were additional stresses. Caregivers reported that the mental stress of caregiving was the most difficult part of caregiving for them.

Anxiety. Caregivers indicated high anxiety levels and uncertainty and expressed the need to be reassured that the decisions they made were correct, and that the care recipient's behavioral responses were normal. Feelings of inadequacy added to the anxiety as situations worsened. A comment from one caregiver was, "I was very much concerned with my wife not getting bed sores. Oh, I had gotten a mattress, a special mattress, a rubber mattress with air in it. I thought that that would help and it did, I'm sure."

Leaving care recipients alone caused anxiety. One caregiver using day care was anxious because the loved one wandered away from the facility on several occasions without being noticed. In another instance, a caregiver was anxious about having her daughter at home because of the care recipient's behavioral problems. She said, "Our daughter was here and I was kinda relieved when she went off to college. Several times he's come out and taken his clothes off or you find him wandering around part dressed."

A spouse caregiver talked about how he worried when his wife attended social functions that she would soil herself and it would be embarrassing to her. Caregivers were anxious about their own health problems and the impact of caregiving on their health.

Sadness. Sadness resulted from the loss of their loved one's former self and the loss of the person with whom they had shared a relationship. Witnessing the progressive deterioration and suffering of their loved ones was a traumatic experience that brought much sadness. One parent caregiver said, "My main thing is watching her suffer. That's tough; that's difficult. Not being able to interact with the care recipient and fulfill dreams, such as traveling together, was sad.

Anger. Expressing anger was a way of coping. Caregivers became angry at the care recipients' lack of cooperation. Anger was directed toward family members and friends whom the caregiver perceived to be inattentive to the care recipient, such as not visiting or calling. Comments from one caregiver were, "She needed more people to visit her which she didn't have and that's something you don't do. You don't call up and ask people to come visit which I would like to have but I'm afraid if I had of, I'd been ugly with them, especially her children." Criticism from others with limited understanding of the problems associated with caregiving evoked an angry response. Anger and frustration were directed toward the healthcare system about (a) receiving inadequate answers and care, and (b) the perceived lack of knowledge and skills of staff and physicians.

Frustration. Trying to work through the healthcare system was frustrating. Staff at day care facilities were perceived as lacking knowledge and skills to work with clients with cognitive impairments. Caregivers expressed concern that physicians lacked important knowledge about caring for geriatric patients. One concern of

caregivers was the medications ordered. One commented, "They, half of them don't have any idea about the medication. My mother only weighs 92 pounds. They give her the same amount of pill as they give somebody at 150, and then I get a reaction of 'oh, well'." Another caregiver discussed problems with her Dad's medication. She said "He was stumbling and everything. Got him to Dr. H. the next day. He looked at the medication he was on and said 'whoa, no wonder he's stumbling.' They had him over-medicated." Other caregivers expressed difficulty in receiving a correct diagnosis of dementia/Alzheimer's disease until the illness had progressed for a long period of time.

Acquiring help and the right kind of help was a problem for caregivers. The delineation of jobs caused confusion as to what tasks staff could perform. Frustration was expressed in statements such as, "It was so time consuming and so frustrating for me as a caregiver to find all of these avenues. Some of the things were the home care and reliable home care. And my frustration with the service was they would come in and they would say oh well, I'm a nurse's aide and I don't cook meals or I don't scrub floors, or I don't dust the house. I would say okay, send me a homemaker. Well, the homemaker would come in and they would say I can't change a diaper, I don't turn people over, I don't do this stuff. I had these really delineated job descriptions. The frustration of the people that do this--pool of employees is so unreliable. That is a terrible frustration."

Other frustrations were identified by caregivers: (a) agency staff did not meet the established schedules which interfered with the caregiver's time; (b) trying to coordinate schedules with doctor appointments was time consuming and frustrating; (c) care recipients' behavior was upsetting; (d) expending extra energy to convince the care recipient to go to day care was stressful and frustrating; and (e) trying to get care recipients to appointments. One caregiver said, "Having to get out to doctors--my Dad was so much care to get into a wheelchair to take for his doctor appointments. I began looking around in the system to see who could come here. Looking for these kind of people who would come to you instead of you having to go to them. It was just frustrating for me and for any caregiver."

Uncertainty. Caregivers described uncertainty as a part of each day. Caregivers looked to healthcare professionals and other caregivers for reassurance and confirmation that what they were doing was okay. Caregivers also reported that they did not receive answers to questions or help from some physicians, nurses, or clergy. Caregivers described the healthcare system as a positive and negative source of support. While the caregivers expressed appreciation for the support they received, they also perceived that there was a lack of or inadequate information. One comment was, "You don't know where to go to get the information on what to do or how to do it or why."

There were concerns that schedules might be interrupted with unscheduled events. Caregivers worried about the future. One spouse caregiver commented, "We

don't know how long this will have to go on, and we don't know how long we will be able to keep going as we are. We hope the time don't come when we have to separate, or we have to go to a nursing home and depend on a nursing home for care."

Caregivers were apprehensive about the effects of caregiving on their families. A parent caregiver stated, "I don't know if he starts acting like he did when he was back with my sister, there's going to come a time that we would not, he would have to get a place somewhere, because we just can't have that."

Other caregivers were unsure about their decisions for care for their loved ones at other sites. One parent caregiver who placed her mother in a nursing home said, "We went through this whole thing, maybe we should try assisted living, you know. That would give her more independence. And then I would try to watch and analyze what she was doing, and we went back and forth." A concern for a caregiver whose spouse expired was that he would become a caregiver to his daughter, who was disabled, and to her husband, who had recently become very ill.

Affirmation about thoughts and actions was an important issue with some caregivers. Spousal support and recognition of efforts were important. Through support groups, caregivers were able to (a) exchange information, (b) share feelings, and (c) benefit from knowing there were others in similar situations.

Fundamental Structure

From the exhaustive descriptions of social support, the essential structure was developed. Assistance, guidance, and emotional aspects emerged as the major components of social support.

Assistance involves direct or indirect help with a wide range of demands of care which include physical and psychological demands. Physical demands are from basic and instrumental activities of daily living, and medical responsibilities, such as (a) managing wound care, oxygen therapy, and a respirator; (b) medication administration; and (c) transporting to appointments. Psychological demands are the "mental activities" which include dealing with (a) care recipients' personalities, (b) behavior problems, (c) arranging appointments, (d) correcting medical bills, (e) finding help for medical treatment and personal care, (f) decision-making about medical conditions and appropriateness of alternate care options, and (g) entertaining the care recipient.

Guidance encompasses commitment and coping. Caregivers are committed to their role as caregiver out of obligation and responsibility. Caregivers feel obligated to provide care because their loved ones have cared or would care for them if the situation was reversed. The sense of responsibility for caring was ongoing regardless of who was providing care or where the care was received. Coping with the demands of caregiving entails the use of one or more approaches which includes (a) problem-solving to decrease the demands of care, (b) seeking information/advice about what to

do and how to do, (c) getting away from the situation, and (d) writing about experiences.

Emotional aspects are caring connections from supportive others to help the caregiver deal with the negative consequences of caregiving which are (a) loss and (b) negative emotions. Loss includes social and personal lives, freedom, and relationships. Social activities are sacrificed to provide care. Maintaining contact with friends is difficult due to a lack of time. Personal time, privacy, work, travel plans, and control over daily schedules are areas in which the caregivers' personal lives are affected. Freedom is restricted when care recipients cannot stay alone and there is no one to stay with them, or the caregiver is afraid to let someone else care for them. Relationships change as the spouse or child becomes the primary caregiver.

Emotions experienced are (a) loneliness, (b) guilt, (c) stress, (d) anxiety, (e) sadness, (f) frustration, (g) anger, and (h) uncertainty. Loneliness occurs as caregivers lose contact with friends and the companionship of their loved one. Guilt results from seeking alternate care options, not meeting perceived care needs, and comments made to the care recipients. Stress is associated with care demands, responsibilities, and uncertainty. Anxiety develops from (a) feelings of inadequacy, (b) behavioral problems, and (c) concerns over their own health. Sadness comes from the loss of relationships and seeing a loved one suffer. Frustration develops from the perception that professionals do not have adequate knowledge and skills to provide effective care and attempting to get the appropriate help for individual situations.

Coordinating means of transporting care recipients and appointments is a source of frustration. Anger is expressed when care recipients are uncooperative and when family and friends are perceived to be inattentive. Criticism from others who are perceived to have a limited understanding of the problems of caregiving elicits anger. Uncertainty results from concerns about decisions regarding care options and future outcomes.

CHAPTER V

SUMMARY OF THE STUDY

A summary of the study is included in this final chapter. Following the summary is a discussion of the findings. Conclusions and implications and recommendations for future studies complete the chapter.

Summary

The domain of the study was stated as: What are the lived experiences of social support for a family caregiver who cares for a dependent older person in the home? The purposive sample for the study consisted of five men and six women who could relate their lived experiences of social support as a caregiver. The phenomenological approach used for this study allowed access to the lived experiences of social support and to the individual meanings and representations caregivers gave to their experiences.

This study revealed that the needs of caregivers include assistance with accessing and receiving formal and informal supports that fit the caregivers' needs. Caregivers' stressed the physical and psychological demands of providing care to a dependent older person. The accounts of their subjective experiences revealed that caregiving is a demanding, overwhelming role which points out the importance of

adequate and appropriate support services. Hours of care ranged from 3 to 24 per day, 7 days a week.

All caregivers, at some point in their caregiving experience, needed one or more of the three types of social support identified in the study: (a) assistance with the physical and psychological demands of care, (b) guidance on commitment and coping, (c) and emotional aspects to deal with loss and emotions. Each caregiver's experiences differed, so the type of social support identified as a need was caregiver specific. The types of social support needed changed as the caregiving situation changed.

Assistance with physical and psychological demands was provided by formal support systems, informal support systems, or both. Formal support systems included the healthcare system, clergy, and support groups. Informal systems consisted of family, neighbors, and friends. Healthcare professionals provided services or were helpful in assisting caregivers to obtain the services needed to care for their loved ones at home. Caregivers described receiving assistance with medical responsibilities and personal care. Staff from home health agencies were perceived to be one of the most valued sources of support, providing in home services which relieved caregivers of some of the demands. Family members were helpful to some caregivers by assisting with personal care and providing transportation; others received little or no assistance. Daughters were considered a major source of support while sons could not accept or did not understand their loved ones illness which limited the family support.

Neighbors and friends were sources of support for some caregivers. Caregivers' concerns about having others provide care for fear they had no clear understanding of the problem limited the support that caregivers could receive. One caregiver received financial assistance from the State for home health aides.

Guidance was the supportive behaviors of others directed at improving the caregivers' abilities to care for themselves as well as the care recipient. Guidance encompassed commitment and coping. Obligation and responsibility prevented caregivers from feeling okay with choosing alternate care options. Strategies used to cope with the demands of care consisted of (a) problem solving, (b) seeking information and advice, (c) getting away from the situation, and (d) writing about experiences.

Emotional aspects were identified as a form of social support needed to deal with the loss and emotions experienced by caregivers. Social and personal lives, freedom, and relationships were valued aspects of caregivers' lives identified as primary losses. Caregivers were confined and isolated as they were not able to leave the care recipient alone or had no one to stay with them. Personal lives were impacted as time with families was affected, and caregivers gave up their jobs or added the demands of care to their already busy schedules. Freedom was restricted because of the time commitment to meet the demands of the caregiving role. The change in relationships with spouses or parents was considered to be a major loss and a source of stress and sadness.

Caregivers identified negative emotions resulting from the caregiving situation. Emotions experienced were (a) loneliness, (b) guilt, (c) stress, (d) anxiety, (e) sadness, (f) frustration, (g) anger, and (h) uncertainty. Loneliness resulted from caregivers losing contact with friends and the companionship of their loved one. Caregivers spoke of their pets and how they were a source of strength, comfort, and support. Caregivers said they missed the companionship of their loved ones and pets filled this void. Guilt feelings developed from seeking alternate care options, not meeting perceived care needs, and comments made to the care recipients out of anger and frustration. Stress was associated with care demands, responsibilities, and uncertainty. Anxiety was the result of feelings of inadequacy, behavioral problems, and concerns over own health. Sadness came from the loss of relationships and seeing a loved one suffer. Frustration resulted from the perceptions that professionals did not have adequate knowledge and skills to provide effective care and attempts to get appropriate help for individual situations. Coordinating transportation and appointments was a source of frustration. Anger was expressed when care recipients were uncooperative and family and friends did not visit or call. Criticism from others who were perceived to have a limited understanding of the problems of caregiving elicited anger. Uncertainty resulted from concerns about decisions regarding care options and future outcomes. Reassurance that their decisions and actions were appropriate was important to caregivers.

Recognition of the individual support needs of family caregivers of dependent older persons will enable nurses to plan interventions that best support the caregiving situation. Important to providing appropriate and effective support to caregivers is the initial assessment of the caregiver situation and ongoing monitoring to determine appropriate and acceptable interventions. Understanding caregiver issues from the caregiver's perspective will assist nurses to develop effective ways to support caregivers. Appropriate and acceptable interventions to enable the caregiver to better manage the care of the care recipient and their own care will help to prevent the caregiver from becoming physically and mentally exhausted.

Discussion of Findings

The discussion of findings centers around the 3 theme categories, 5 theme clusters, and 20 sub-themes: (a) assistance with demands of care, both physical and psychological demands; (b) guidance on commitment to caregiving from a sense of obligation and responsibility and coping by problem-solving, seeking information/advice, getting away, and writing; and (c) emotional aspects for loss of social lives, personal lives, freedom, and relationships and for emotions of loneliness, guilt, stress, anxiety, sadness, frustration, anger, and uncertainty.

All caregivers described circumstances in which they perceived they had received social support. Findings indicated that the kinds of social support needed and the sources of social support were similar among caregivers regardless of care

recipients' diagnoses. The types of social support were needed singularly or simultaneously depending on the circumstances.

Most caregivers wanted and needed more social support from formal and informal systems. As in previous studies (Rose, 1997), caregivers were able to identify supportive and non-supportive behaviors by (a) healthcare professionals, (b) clergy, (c) support groups, (d) family members, (e) neighbors, and (f) friends. Caregivers, as Rose also found, were appreciative of the professional support from physicians and nurses, but in keeping with previous studies (Holicky, 1996), caregivers perceived a lack of professional support when seeking answers and assistance with diagnoses and other health issues. Nine (82%) of the 11 caregivers reported asking physicians for assistance and 6 (67%) discussed negative experiences.

Eight (73%) of the caregivers had received home health services and 7 (88%) of those reported home health agencies to be a major source of assistance with personal care and medical responsibilities. Four (50%) of the caregivers using home health services reported having some type of difficulty with the staff. One caregiver reported being frustrated when staff did not meet agreed upon schedules, because her daily routines were interrupted. She did not see that some of the staff really helped but did appreciate the nurse taking time to talk with her Mother. Accessing the right kind of help from agencies was difficult and frustrating for two caregivers because of the delineation of duties which was confusing and frustrating. Perceived dishonesty

among helpers was stressful for one caregiver. Another caregiver was upset that he was criticized for leaving his wife unattended for a short period of time.

The caregivers' faith, also reported by Rose (1997), was identified as a source of support. Church members and the clergy were perceived as being supportive emotionally to the care recipients which was a support to the caregivers; one caregiver reported her clergy to be disinterested and non-supportive when asked for assistance in obtaining home care services.

In keeping with previous studies (Whitlatch et al., 1991), support groups were perceived as helpful to some of the caregivers but not to others. As in the present study, Winslow (1997) also found that those who benefited from attending support groups identified with other caregivers with similar problems. Caregivers, exposed to situations more challenging than their own, realized their situation could be worse. While seven of the eight caregivers in this study who attended support groups found them beneficial, the ability to attend for some was limited by the availability of staff to provide care during support group meetings. Consistent with other studies (Worchester & Hedrick, 1997), some caregivers stated that efforts to take the care recipient to day care or respite were too tiring and stressful. Finding a sitter was difficult and usually expensive.

Family members provided support in varying degrees. Of the three caregivers who had daughters and sons, the daughters were reported to be the most supportive, providing assistance and emotional support. Chou et al. (1999) also found daughters

to have a higher filial obligation than sons. Caregivers said that they received little or no support from their sons. Only one of the four parent caregivers had siblings nearby and reported that her sister was a tremendous support, but that her brother never visited. In the study, parent caregivers considered their spouses to be supportive of them in their caregiver role and provided (a) assistance, (b) guidance, and (c) showed caring and concern. Guberman (1999) reported joint sharing of responsibilities of caregiving in some couples. Ten (91%) of the caregivers cited instances in which friends and neighbors offered assistance or were willing to help when asked.

Caregivers discussed assistance with the many demands of care which were both physical and psychological. Physical demands involved tasks that were complex, demanding, tiring, and confining. Personal care, medical responsibilities, and other tasks, such as transporting care recipients to the doctor or to day care, were difficult and time consuming. Physical demands left little or no time for caregivers to socialize or have time to themselves, or private time with their families.

One caregiver said that mental stress was the most difficult. Psychological demands included (a) dealing with care recipients' personalities and behaviors, (b) coordinating schedules with doctor appointments, (c) locating the right kinds of help, (d) correcting medical bills, (e) decision-making, and (f) monitoring medical needs of the care recipient. A caregiver talked about the need for someone to play cards with her mother. Hawkins (1996) identified recreational/diversional activities as an area of help most wanted by caregivers.

Guidance was identified as a form of social support to caregivers. As described in other studies (Beach, 1993; Boland & Sims, 1996; Chou et al., 1999; Globerman, 1996; Guberman, 1999), findings revealed that caregivers feel a personal commitment to care for a loved one. Caregivers expressed a commitment to their role as caregivers out of obligation or duty and responsibility. Caring for spouses or parents was considered by the caregivers to be their duty or obligation. Boland and Sims (1996) found that participants' commitment to caregiving was absolute despite the reality of burden. In the present study and in the study by Boland and Sims (1996), caregivers did not think that others could or would share in the care or be able to render the same quality of care. Caregivers expressed a sense of responsibility to provide care for their loved ones as long as they were able to do so. In keeping with the findings reported by Wykle (1994), the needs of the caregivers were a second priority to their perceived responsibilities to the care recipients. As described in other studies (Bar-David, 1999; Paoletti, 1999), responsibility as a caregiver was considered to be ongoing regardless of where and from whom the care recipient was receiving care. Responsibilities shifted but the caregiver continued in the role. Even when the care recipient was institutionalized, caregivers indicated an obligation to visit often to "check on the care recipient."

Caregivers needed guidance about effective means of coping. As in other studies, coping strategies used by caregivers were reported as (a) problem-solving

(Beach, 1993), (b) seeking information/advice (Almberg et al., 1997; Rose, 1997; Winslow, 1997), and (c) getting away.

Problem-solving was used as a means to protect the care recipient and to maintain privacy for the caregiver. Locks were placed on doors to prevent wandering inside and outside the house. Problem-solving was used to maintain some control over the physical demands of care, such as wetting the bed or on the floor, and asking for assistance with tasks or information.

Seeking information/advice was used to gain information or get advice about (a) the caregiver role; (b) the care recipient's illness; (c) confirmation about actions taken; and (d) alternate options for care, such as day care, respite, and institutionalization. One caregiver discussed the use of the Internet to communicate with other caregivers and gather information. Other researchers (Strawn et al., 1998; Bass et al., 1998; Colantonio et al., 1998) reported that caregivers, who used the telephone, computer, or both as sources of social support, found caregiving less burdensome.

Wilkins et al. (1999) speculated that a high rating of a psychoeducational intervention by caregivers could be attributed to caregivers' relief at having time away from the burden of caring for their spouses. Having time away from the situation was a way of coping for most of the 11 caregivers. Daycare and respite were used by three of the caregivers but all three reported some area of dissatisfaction with the services. Two of the caregivers talked about the frustrations with behavioral problems

in trying to get the care recipients to day care and respite. Even with the difficulties, one caregiver still considered respite a "Godsend." Worchester and Hedrick (1997) reported that the process of utilizing respite was perceived as more stress producing than beneficial. Some caregivers found it difficult to get away because they were hesitant to ask someone to sit or accept offers to sit with the care recipient. The perception was that people were afraid to sit with individuals with Alzheimer's disease, and that some were not aware of the complexities of care. Boland and Sims (1996) reported the same findings in their study. In a study by Robinson and Clemons (1999), volunteer caregivers verbalized fear of patients with Alzheimer's disease and concerns that they might not be able to deal with the behaviors. Nine (82%) of the caregivers discussed the need for more in home sitting services so they could get away.

Writing was discussed as a method of coping by one caregiver in this study. The caregiver reported that he kept copious notes on changes in his wife's condition, recording the changes in her (a) physical and cognitive abilities, (b) behavioral changes, and (c) physical appearance as her illness progressed. No other studies were found in a literature review that reported writing as a way of coping for caregivers.

Findings indicated that emotional aspects were the caring connections of others to help caregivers deal with loss and negative emotions. Loss of valued aspects of caregivers' lives were reported as a result of caregiving: (a) social lives, (b) personal lives, (c) freedom, and (d) relationships. Due to the demands and time constraints,

caregivers did not have the time for a social or personal life. Caregivers reported losing contacts with friends and leaving their jobs to provide care. Beach (1993) also reported that caregivers stopped working or made significant changes in their work schedules. Loss of freedom was reported by study participants. Freedom was limited because the care recipient could not be left alone and no one was available to sit with them. Caregivers were also hesitant to accept help from others which limited their freedom. Loss of relationships was described by caregivers. The loss of the relationships they once shared and the loss of their loved one as a spouse or a parent was painful and sad.

As in other studies (Bar-David, 1999; Chenier, 1997; Holicky, 1996; Miller & Montgomery, 1990; Winslow, 1997), negative emotions in response to the care recipient or the caregiving situation were reported. Holicky (1996) found emotions commonly reported by caregivers to be (a) anger, (b) fear, (c) loneliness, (d) resentment, (e) isolation, and (f) guilt. The most frequently occurring emotions reported in this study were (a) loneliness, (b) guilt, (c) stress, (d) sadness, (e) anger, (f) anxiety, (g) frustration, and (h) uncertainty. Loneliness occurred when contacts with friends and family were limited. Caregivers experienced guilt and anxiety when leaving their loved ones in the care of others. Reacting to the care recipient in what was later felt to be an unkind manner caused caregivers to feel guilty. Families and friends were reported to be sources of emotional support, and sources of frustration and stress as reported in other studies (Fiore et al., 1983). A perceived lack of support

from immediate family and close friends provoked anger among caregivers. Morgan and Zimmerman (1990) and Holicky (1996) also found that when family and friends did not visit as often as the caregiver thought they should or cut off contact altogether, caregivers reported being angry and hurt. Visits from family that were contingent upon reciprocity were reported by one caregiver which made her sad, angry, and frustrated. Interactions with the care recipients were often described as frustrating. While visits from family living out of town were appreciated, two caregivers reported that the visits were stressful. Another caregiver found visits from out-of-town friends to be very supportive. Caregivers expressed sadness about the losses they experienced. Uncertainty was a part of the caregivers' day. Caregivers worried about the future. Lack of confidence in others to provide adequate care caused the caregiver concern.

An intriguing finding of this study was the caregivers' perception of pets as a major source of support, providing companionship and "someone" to talk to. Six (55%) of the caregivers reported that pets filled the void left with the loss of the individual with whom the caregiver shared a relationship. One caregiver talked about how she was comfortable leaving the loved one home alone with her dogs for short periods of time. Another talked about how she could share anything with her cats and be heard. The perception was that people really didn't want to hear about problems, so talking to pets was a comfort. No studies were found pertaining to pets as support for caregivers.

Other researchers (Boland & Sims, 1996) reported financial burdens for family caregivers, but finances was not reported to be a major concern among the study participants. One caregiver was receiving financial aid; another caregiver talked about the cost of someone to sit; one caregiver specifically said finances was not an issue for him.

Findings from the present study support the major roles of social support to the caregiver and the major importance of viewing each caregiving situation as unique. Interventions should include social support that is appropriate and acceptable to the individual caregiver. Findings indicated that:

1. Some type of social support is needed by caregivers.
2. The type of social support needed is contingent on the caregiver and the caregiver situation.
3. Sources of social support differ among caregivers.
4. Social support can be a negative or positive experience.
5. Caregivers desire more family support.
6. Home care services are one of the most valued sources of assistance to caregivers of the dependent older person in the home setting.
7. Daughters are the main caregivers.
8. Pets are an important source of support.
9. Healthcare personnel continue to be a disappointment and may be negligent.

10. Writing as a coping technique and pets as a source of support were findings specific to the study and not located in any other study of caregivers.

Conclusions and Implications

The research reported here studied the lived experiences of social support for a family caregiver who cares for a dependent older person in the home. The conclusions and implications are presented as follows:

1. Caregivers deserve more attention to their problems and concerns because they play a major role in providing care to older dependent persons living in the community. The willingness of the caregivers in the study to discuss their lived experiences of social support, sharing the demands of their role and the intensity of their emotions, is indicative of their need for support in their role. Nurses should become actively involved in lobbying legislative issues that focus on the care of the family caregiver, and communicate and work with community leaders and policy makers to gain support for appropriate interventions that meet the social support needs of caregivers.

2. Sources from formal and informal support systems play a crucial role in providing support to caregivers of the dependent older person. Healthcare professionals play an important role in effectively identifying and responding to caregiving issues which means they must be aware of caregivers' feelings and needs. An understanding of the significance of social support to family caregivers will

contribute to health professionals' ability to assess the needs of family caregivers and find support and resources appropriate and acceptable to the individual situation. Caregivers have needs that should be addressed separately from those of the care recipient. Knowledge of the needs and concerns of caregivers enable support systems to be better prepared to address these needs and concerns before caregivers become mentally and physically exhausted. Addressing caregivers' needs will help ensure that care recipients receive better care in the home and decrease the risk of caregivers developing physical and emotional problems themselves. Nursing education and continuing education programs should (a) focus on the role of the professional as a source of support for the caregiver, (b) support the development of knowledge and skills for assessing and monitoring caregivers' needs for providing effective care in the home, and (c) emphasize the importance of appropriate interventions to support caregivers in meeting their own needs during the caregiving process.

3. Assessment of individual caregiver issues is essential as each caregiver situation is different. Nursing interventions can be designed to increase effective methods of supporting the caregiver through identified needs for support.

Individualizing interventions to the needs of the caregiver is important as interventions that provide beneficial outcomes for some caregivers may not do so for others.

Caregivers can be directed to learn about techniques to help cope with the demands placed upon them and deal effectively with their emotional responses to those demands. Reassurance is needed that negative feelings are normal reactions.

Encouraging caregivers not to lose contact with family and friends is essential to avoid becoming isolated and alone. Caregivers need encouragement to ask for assistance and to request the assistance before becoming overwhelmed and fatigued. Nurses need to develop and implement interventions that include access to caregivers by experienced family caregivers and volunteers who can assess needs at the start of the caregiving process and on an ongoing basis as the caregiving situation changes.

4. There is a need for educational programs for caregivers and formal and informal support systems to increase knowledge and understanding of the dementing process. Provisions for care of the older dependent person during programs would be helpful to the caregivers. A community registry should be established whereby the name of the care recipient is entered at the time of a diagnosis and a professional is assigned who can begin family counseling and education. Specialized training and support for healthcare professionals working directly with family caregivers in community settings is very important in order to help caregivers develop understanding and skills. Knowledge of the aging process and behavioral changes associated with diseases/illnesses will enable caregivers to provide care and cope with the demands of their role effectively. There is also a need for specialized programs about how to manage behavioral problems for volunteers in home sitting, thus increasing the confidence of caregivers in asking for help.

5. The three components of social support from the study sample, assistance, guidance, and emotional aspects, are viewed as fitting into the three concepts of

Kahn's (1979) theory on social support: (a) aid (assistance), (b) affirmation (guidance), and (c) affect (emotional aspects). Kahn (1979) defined social support as,

interpersonal transactions that include one or more of the following: the expression of positive affect of one person toward another; the affirmation or endorsement of another person's behaviors, perceptions, or expressed views; the giving of symbolic or material aid to another. (p. 85)

The concept of affective transactions (emotional aspects) is described as (a) expressions of liking, (b) admiration, (c) respect, or (d) love. Emotional aspects, as a component of social support in the study, are caring connections from supportive others within formal and informal support systems.

Transactions of affirmation (guidance) are expressions of agreement, or acknowledgment that a statement or act of another person is appropriate. As a form of social support in the study, guidance is the supportive behaviors directed at improving the caregivers' abilities. Guidance is from others who give information about what the caregiver can expect, suggest alternate care options, and provide direction on accessing available resources and services. Guidance comes primarily from formal support systems.

Finally, included as social support are transactions of aid (assistance) which refers to direct aid or assistance that is given, such as money, time, and information (Kahn, 1979). In the study, the concept of assistance as social support involves direct or indirect help from formal and informal support systems with demands of care, such as medical responsibilities and the basic and instrumental activities of daily living.

Knowledge of the kinds of social support perceived as useful to family caregivers has major implications for nursing practice. Without knowing the kinds of social support that are needed from the caregiver's perspective, adequate and appropriate interventions are unlikely.

While Kahn's (1979) theory of social support was adequate as an orientation for the study, the present research provides social support mechanisms specific to the family caregiver. Nurses and other healthcare professionals now have concepts of social support to assist in the assessment, diagnosis, planning, intervention, and evaluation of the nursing/healthcare of caregivers of dependent older persons.

6. In determining strategies for theory development, Oiler (1985) suggested phenomenology as a method. From this phenomenological study, concepts were identified which have implications for a beginning level of theory construction. Concepts are the labels, categories, or selected properties of (a) objects, (b) events, or (c) entities to be studied. Concepts constitute the building blocks and are the bricks from which theories are constructed (Beard, 1997; Bush, 1979; Hardy, 1974). Concepts are the dimensional aspects or attributes of reality (Beard, 1997). The dimensions of the concepts of assistance, guidance, and emotional aspects can be determined. The reality sought is the lived experiences of social support of family caregivers of dependent older persons.

Hardy (1985) defined Level 1 theory development as the stage of conceptualization. Level 1 is narrowing the conceptual focus, that is, refining the

concepts. The focus is on developing the details of selected workable ideas and terms. Terms selected are those emerging in the conceptualization phase which have potential for inclusion in an empirically testable theory. Attention is then on (a) concept formation, (b) differentiation of concepts, (c) definition, and (d) measurement. The scientific work then becomes one of creativity in selection and development of meaningful conceptualizations followed by meticulous work in developing conceptual and operational definitions. The general aim here is to develop measurable concepts which can be linked in testable statements into a theoretical formulation, thus generating knowledge unique to nursing.

Recommendations for Future Studies

There is a need for further research to explore the:

1. Meaning of social support to caregivers in the home.
2. Perception of effectiveness of support as needs for support change over time.
3. Perceived usefulness of social support to individual situations.
4. Perception of social support and interactions with health professionals and their effect on coping. Factors include physicians' and nurses' lack of knowledge and skills in care of ill aging persons as evidenced in their inadequate care and inadequate answers to questions. Additionally, there continues to be a lack of nursing/healthcare training of home care personnel.

5. Factors that inhibit caregivers from asking for or accepting assistance.
6. Caregivers' feelings of obligation and responsibility to continue in the caregiver role despite the negative consequences.
7. Development and assessment of (a) interventions, (b) programs, and (c) resources to determine the most effective measures to sustain caregivers in their roles.
8. Development of a theory of social support for family caregivers of dependent older persons.
9. Roles of pets as a source of support to family caregivers.
10. Role that writing or journalizing may play in the caregivers' coping.

REFERENCES

- Almberg, G., Grafstrom, M., & Winblad, B. (1997). Major strain and coping strategies as reported by family members who care for aged demented relatives. Journal of Advanced Nursing, 26, 683-691.
- Anderson, J. (1991). The phenomenological perspective. In J. M. Morse (Ed.), Qualitative nursing research: A contemporary dialogue (pp. 25-38). Newbury Park, CA: Sage.
- Aneshensel, C., Pearlin, L., Mullan, J., Zarit, S., & Whitlatch, C. (1995). Profiles in caregiving: The unexpected career. San Diego, CA: Academic Press.
- Bar-David, G. (1999). Three phase development of caring capacity in primary caregivers for relatives with Alzheimer's disease. Journal of Aging Studies, 13(2), 177-197.
- Bass, D., McClendon, M., Brennan, P., & McCarthy, C. (1998). The buffering effect of a computer support network on caregiver strain. Journal of Aging & Health, 10(1), 20-43.
- Baum, E., & Rutecki, G. (1998). The demographic imperative and geriatric education in transition: Assessing needs. Annals of Long-Term Care, 6, 267-273.
- Beach, D. (1993). Gerontological caregiving: Analysis of family experience. Journal of Gerontological Nursing, 19(12), 35-41.
- Beard, M. (1997). Concepts and theory generation. The Journal of Theory Construction and Testing, 1(2), 33-34.
- Boland, D., & Sims, S. (1996). Family care giving at home as a solitary journey. Image: Journal of Nursing Scholarship, 28(1), 55-58.
- Braddock, D. (1999). Aging and developmental disabilities: Demographic and policy issues affecting American families. Mental Retardation, 37(2), 155-161.

Brandriet, L. (1994). Gerontological nursing: Application of ethnography and grounded theory. Journal of Gerontological Nursing, 20(7), 33-40.

Burns, N., & Grove, S. (1993). The practice of nursing research: Conduct, critique and utilization. Philadelphia: Saunders.

Bush, H. (1979). Models for nursing. Advances in Nursing Science, 1(2), 13-21.

Chang, B. (1999). Cognitive-behavioral intervention for homebound caregivers of persons with dementia. Nursing Research, 48(3), 173-182.

Chenier, M. (1997). Review and analysis of caregiver burden and nursing home placement. Geriatric Nursing, 18(3), 121-126.

Chou, K., LaMontagne, L., & Hepworth, J. (1999). Burden experienced by caregivers of relatives with dementia in Taiwan. Nursing Research, 48(4), 206-214.

Cobb, S. (1976). Social support as a moderator of life stress. Psychosomatic Medicine, 38(5), 300-314.

Colaizzi, P. (1978). Psychological research as the phenomenologist views it. In R. Valle & M. King (Eds.), Existential-phenomenological alternatives for psychology (pp. 48-71). New York: Oxford University Press.

Colantonio, A., Cohen, C., & Corlett, S. (1998). Support needs of elderly caregivers of persons with dementia. Canadian Journal on Aging, 17(3), 330-345.

Creswell, J. (1994). Research design: Qualitative and quantitative approaches. Thousand Oaks, CA: Sage.

Davis, A. (1978). The phenomenological approach in nursing research. In N. L. Chaska (Ed.), The nursing profession: Views through the mist (pp. 186-197). New York: McGraw-Hill.

Delong, M. (1995, March). Caring for the elderly, Part 1: Elder abuse. Nurseweek, 8-9.

England, M. (1997). Self-coherence, emotional arousal and perceived health of adult children caring for a brain-impaired parent. Journal of Advanced Nursing, 26, 672-682.

Erlandson, D., Harris, E., Skipper, B., & Allen, S. (1993). Doing naturalistic inquiry: A guide to methods. Newbury Park, CA: Sage.

Evans, J. (1998). Geriatric medicine: The education imperative. Annals of Long-Term Care, 6, 291-294.

Fiore, J., Becker, J., & Coppel, D. (1983). Social network interactions: A buffer or a stress. American Journal of Community Psychology, 11(4), 423-439.

Gallant, M., & Connell, C. (1998). The stress process among dementia spouse caregivers. Research on Aging, 20(3), 267-297.

Garity, J. (1999). Gender differences in learning style of Alzheimer family caregivers. Home Healthcare Nurse, 17(1), 37-44.

Gaynor, S. (1990). The long haul: The effects of home care on caregivers. Image: Journal of Nursing Scholarship, 22(4), 208-212.

Globerman, J. (1996). Motivations to care: Daughters- and sons-in-law caring for relatives with Alzheimer's disease. Family Relations, 45, 37-45.

Goode, K., Haley, W., Roth, D., & Ford, G. (1998). Predicting longitudinal changes in caregiver physical and mental health: A stress process model. Health Psychology, 17(2), 190-198.

Guberman, N. (1999). Daughters-in-laws as caregivers: How and why do they come to care? Journal of Women & Aging, 11(1), 85-102.

Habel, M. (1998, July 20). The oldest old: A new gerontological challenge. HealthWeek, p. 26.

Haley, W. (1997). The family caregiver's role in Alzheimer's disease. Neurology 48(5, Supplement 6), S25-S29.

Hardy, M. (1974). Theories: Components development, evaluation. Nursing Research, 23(2), 100-107.

Hardy, M. (1985, March 21-22). Strategy for theory development: Stages of theory development. Proceedings of the Second Annual Nursing Science Colloquium. Strategies for Theory Development in Nursing: II (pp. 35-65). Boston: Boston University.

Hawkins, B. (1996). Daughters and caregiving: Taking care of your own. AAOHN Journal, 44(9), 433-437.

Heidegger, M. (1962). Being and time. New York: Harper & Row.

Hellinghausen, M. (1997, November 3). Not alone: Support is the key for family caregivers. NurseWeek, 6.

Holicky, R. (1996). Caring for the caregivers: The hidden victims of illness and disability. Rehabilitation Nursing, 21(5), 247-252.

Husserl, E. (1962). General introduction to pure phenomenology. New York: Collier.

Husserl, E. (1964). The phenomenology of internal time-consciousness. Bloomington, IN: Indiana University Press.

Kahn, R. (1979). Aging and social support. In M. W. Riley (Ed.), Aging from birth to death: Interdisciplinary perspectives (pp. 77-91). Boulder, CO: Westview.

Kamer, T. (1998). Professional caring: Homecare workers as fictive kin. Journal of Aging Studies, 12(1), 69-82.

Kleffel, D. (1998). Lives on hold. Home Healthcare Nurse, 16, 465-472.

Knaack, P. (1984). Phenomenological research. Western Journal of Nursing Research, 6, 107-114.

Larsen, L. (1998). Effectiveness of a counseling intervention to assist family caregivers of chronically ill relatives. Journal of Psychosocial Nursing, 36(8), 26-32.

Lin, N., Ensel, W., Simeone, R., & Kuo, W. (1979). Social support, stressful life events, and illness: A model and an empirical test. Journal of Health and Social Behavior, 20, 108-119.

Lincoln, Y., & Guba, E. (1985). Naturalistic inquiry. Beverly Hills, CA: Sage.

Lindgren, C., (1993). The caregiver career. Image: Journal of Nursing Scholarship, 25(3), 214-219.

Mac Rae, H. (1998). Managing feelings: Caregiving as emotion work. Research on Aging, 20(1), 137-160.

Marshall, C., & Rossman, G. (1995). Designing qualitative research. Thousands Oaks, CA: Sage.

McCabe, B., Sand, B., Yeaworth, R., & Nieveen, J. (1995). Availability and utilization of services by Alzheimer's Disease caregivers. Journal of Gerontological Nursing, 21(1), 14-22.

Miller, B., & Montgomery, A. (1990). Family caregivers and limitations in social activities. Research on Aging, 12(1), 72-93.

Mitchell, G., & Cody, W. (1993). The role of theory in qualitative research. Nursing Science Quarterly, 6(4), 170-178.

Morgan, A., & Zimmerman, M. (1990). Easing the transition to nursing homes: Identifying the need of spousal caregivers at the time of institutionalization. Clinical Gerontologist, 9(3-4), 1-17.

Morse, J. (1991). Approaches to qualitative-quantitative methodological triangulation. Nursing Research, 40(1), 120-123.

Oiler, C. (1982). The phenomenological approach in nursing research. Nursing Research, 31(3), 178-181.

Oiler, C. (1985, March 21-22). Strategy for theory development: Phenomenology. Proceedings of the Second Annual Nursing Science Colloquium. Strategies for Theory Development in Nursing: II (pp. 85-99). Boston: Boston University.

Oiler, C. (1986). Phenomenology: The method. In P. L. Munhall & C. J. Oiler (Eds.), Nursing research: A qualitative perspective (pp. 69-83). New York: Appleton-Century-Crofts.

Omery, A. (1993). Phenomenology: A method for nursing research. Advances in Nursing Science, 5(2), 49-63.

Paoletti, I. (1999). A half life: Women caregivers of older disabled relatives. Journal of Women & Aging, 11(1), 53-67.

Pearlin, L., Mullan, J., Semple, S., & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist, 35(5), 583-591.

Reed, J. (1994). Phenomenology without phenomena: A discussion of the use of phenomenology to examine expertise in long-term care of elderly patients. Journal of Advanced Nursing, 19, 336-341.

Roberts, J., Browne, G., Milne, C., Spooner, L., Gafni, A., Drummond-Young, M., LeGris, J., Watt, S., LeClair, K., Beaumont, L., & Roberts, J. (1999). Problem-solving counseling for caregivers of the cognitively impaired: Effective for whom? Nursing Research, 48(3), 162-172.

Robinson, K. (1997a). Family caregiving: Who provides the care, and at what cost? Nursing Economic\$, 15(5), 243-247.

Robinson, K. (1997b). The family's role in long-term care. Journal of Gerontological Nursing, 23(9), 7-11.

Robinson, K. (1988). A social skills training program for adult caregivers. Advances in Nursing Science, 10(2), 59-72.

Robinson, K., & Clemons, J. (1999) Respite care--volunteers as providers. Journal of Psychosocial Nursing, 37(1), 30-35.

Robinson, K., & Steele, D. (1995). The relationship between health and social support in caregiving wives as perceived by significant others. Journal of Advanced Nursing, 21, 88-94.

Rose, L. (1997). Caring for caregivers. Perceptions of social support. Journal of Psychosocial Nursing, 35(2), 17-24.

Sayles-Cross, S. (1993). Perceptions of familial caregivers of elder adults. Image: Journal of Nursing Scholarship, 25(2), 88-91.

Song, L., Biegel, D., & Milligan, S. (1997). Predictors of depressive symptomatology among lower social class caregivers of persons with chronic mental illness. Community Mental Health Journal, 33(4), 269-286.

Strawbridge, W., Wallhagen, M., Shema, S., & Kaplan, G. (1997). New burdens or more of the same? Comparing grandparent, spouse, and adult-child caregivers. The Gerontologist, 37(4), 505-510.

Strawn, B., Hester, S., & Brown, W. (1998). Telecare: A social support intervention for family caregivers of dementia victims. Clinical Gerontologist, 18(3), 66-69.

Szabo, V., & Strang, V. (1999). Experiencing control in caregiving. Image: Journal of Nursing Scholarship, 31(1), 71-75.

U.S. Bureau of the Census. (1996, April). Current population reports. Special studies (P23-190). Washington, DC: U.S. Government Printing Office.

U.S. Department of Health and Human Services. (1990). Healthy people 2000: National health promotion and disease prevention objectives (Summary Report). Washington, DC: U.S. Government Printing Office.

Valle, R., & King, M. (1978). Existential-phenomenological alternatives for psychology. New York: Oxford University Press.

Ward, D., & Carney, P. (1994). Caregiving women and the U.S. welfare state: The case of elder kin care by low-income women. Holistic Nursing Practice, 8(4), 44-58.

Whitlatch, C., Zarit, S., & von Eye, A. (1991). Efficacy of interventions with caregivers: A reanalysis. The Gerontologist, 31(1), 9-14.

Wilkins, S., Castle, S., Heck, H., Tanzy, K., & Fahey, J. (1999). Immune function, mood, and perceived burden among caregivers participating in a psychoeducational intervention. Psychiatric Services, 50(6), 747-749.

Winslow, B. (1998). Family caregiving and the use of formal community support services: A qualitative case study. Issues in Mental Health Nursing, 19(1), 11-27.

Winston, M. (1994, August). Dealing with depression & anger: Reactions of family caregivers. Caring, 52-59.

Worcester, M., & Hedrick, S. (1997). Dilemmas in using respite for family caregivers of frail elders. Family Community Health, 19(4), 31-48.

Wright, L., Bennet, G., & Gramling, L. (1998). Telecommunication interventions for caregivers of elders with dementia. Advances in Nursing Science, 20(3), 76-88.

Wykle, M. (1994). The physical and mental health of women caregivers of older adults. Journal of Psychosocial Nursing, 32(3), 41-42.

APPENDIX A

Human Subjects Review Committee Permission

TEXAS WOMAN'S
UNIVERSITY
DENTON/DALLAS/HOUSTON

HUMAN SUBJECTS
REVIEW COMMITTEE
P.O. Box 425619
Denton, TX 76204-5619
Phone: 940/898-3377
Fax: 940/898-3416

May 14, 1998

Ms. Mary Gilliland
2101 Rigsbee Drive
Plano, TX 75074

Dear Ms. Gilliland:

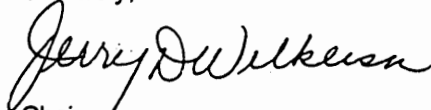
Social Security # 427-94-9994

Your study entitled "Lived Experiences of Social Support for Family Caregivers of Dependent Older Persons" has been reviewed by a committee of the Human Subjects Review Committee and appears to meet our requirements in regard to protection of individuals' rights.

If applicable, agency approval letters obtained should be submitted to the HSRC upon receipt. **The signed consent forms and an annual/final report (attached) are to be filed with the Human Subjects Review Committee at the completion of the study.**

This approval is valid one year from the date of this letter. Furthermore, according to HHS regulations, another review by the Committee is required if your project changes. If you have any questions, please feel free to call the Human Subjects Review Committee at the phone number listed above.

Sincerely,



Chair
Human Subjects Review Committee

cc. Graduate School
Dr. Margaret Beard, College of Nursing
Dr. Carolyn Gunning, College of Nursing

TEXAS WOMAN'S
UNIVERSITY
DENTON/DALLAS/HOUSTON

HUMAN SUBJECTS
REVIEW COMMITTEE
P.O. Box 425619
Denton, TX 76204-5619
Phone: 940/898-3377
Fax: 940/898-3416

June 14, 1999

Ms. Mary Gilliland
2101 Rigsbee Drive
Plano, TX 75074

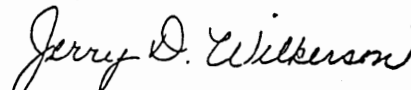
Dear Ms. Gilliland:

The request for an extension of the approval for your study entitled "Family Caregivers of Older Persons Lived Experiences of Social Support" has been reviewed by a committee of the Human Subjects Review Committee and appears to meet our requirements in regard to protection of individuals' rights.

Be reminded that both the University and the Department of Health and Human Services (HHS) regulations typically require that agency approval letters and signatures indicating informed consent be obtained from all human subjects in your study. **These consent forms, agency approval letters, and an annual/final report are to be filed with the Human Subjects Review Committee at the completion of the study.**

This approval is valid one year from May 14, 1999. Furthermore, according to HHS regulations, another review by the Committee is required if your project changes. If you have any questions, please feel free to call the Human Subjects Review Committee at the phone number listed above.

Sincerely,



Chair
Human Subjects Review Committee

cc. Graduate School
Dr. Margaret Beard, College of Nursing
Dr. Carolyn Gunning, College of Nursing

APPENDIX B

Graduate School Letter of Permission

TEXAS WOMAN'S
UNIVERSITY
DENTON/DALLAS/HOUSTON

THE GRADUATE SCHOOL
P.O. Box 425649
Denton, TX 76204-5649
Phone: 940/898-3400
Fax: 940/898-3412

January 26, 1999

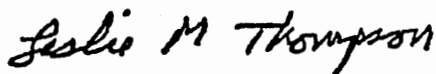
Mrs. Mary Palmore Gilliland
2101 Rigsbee Dr.
Plano, Tx 75074

Dear Mrs. Gilliland:

I have received and approved the prospectus entitled "Lived Experiences of Social Support for Family Caregivers of Dependent Older Persons" for your *Dissertation* research project.

Best wishes to you in the research and writing of your project.

Sincerely yours,



Leslie M. Thompson
Associate Vice President for Research and
Dean of the Graduate School

LMT/sgm

cc Dr. Margaret T. Beard, Nursing
Dr. Carolyn Gunning, Nursing

APPENDIX C

Verbal Explanation of Study

VERBAL EXPLANATION OF STUDY

My name is Mary Gilliland, and I am a graduate nursing student at Texas Woman's University. I am conducting a research study to examine the lived experiences of social support for family caregivers of dependent older persons living in the home. It is expected that this research study will benefit nursing practice by providing an understanding of the caregiver's experiences of social support, which will enable healthcare professionals and policymakers in identifying methods of social support to support caregivers in their role.

Your participation in the research study is requested because you have been the primary caregiver in the home to a dependent person for three months or longer. If you volunteer to participate in the research study, you will be asked to complete a personal information questionnaire. This will take about 5 minutes. An interview will be scheduled for one hour and during this time, you will be asked to describe what social support is like for you as a caregiver caring for an older dependent person in the home. Your response will be audio-tape recorded with your permission.

There are some potential benefits and some potential risks from participating in this research study. Potential benefits are that sharing your experiences as a caregiver may relieve anxiety and provide some comfort. Reading the results of the study may provide awareness that experiences of caregivers may be similar. You may gain knowledge about yourself by sharing your experiences. Potential risks are

the loss of time, fear of loss of privacy, and emotional distress. To minimize the risk of loss of time, the questionnaire you will be asked to complete is short, easy to read, and easy to use, and interviews will last no longer than one hour. Your participation in this research study will be kept confidential to decrease the fear of loss of privacy. Only the investigator has access to the information provided by you on the questionnaire and during the audio-taped interview. The information will be coded so your name will not appear on any documents. The data will be stored in a locked drawer in the investigator's office for five years. The tapes will be erased and the questionnaires shredded at the end of five years. The following steps will be taken to decrease the risk for emotional distress. You may end the interview at anytime; a relaxation exercise may be used, and/or you may contact a psychologist whose name and number will be given to you by the researcher.

You may ask questions about the research or about your rights as a participant at any time before and after the interview. Your participation in this study is voluntary. You may withdraw from the study at any time and for any reason without penalty.

As a participant of this study, you may receive the results of the study by writing your address on the 3 x 5 index card provided by the researcher. The results will be mailed to you.

Do you have any questions? Are you willing to participate?

APPENDIX D
Consent to Participate

TEXAS WOMAN'S UNIVERSITY
SUBJECT CONSENT TO PARTICIPATE IN RESEARCH

Title: Lived Experiences of Social Support for Family Caregivers of Dependent Older Persons

Investigator's Name: Mary Gilliland, MS, RN
Office Phone Number: 972-727-9293

Research Advisor's Name: Margaret Beard, Ph.D., RN
Office Phone Number: 940-898-2401

I agree to participate in a research study that has been designed for the purpose of gaining a better understanding of the lived experiences of social support of family caregivers providing care to a dependent older person living in the home. I understand that the study involves research. As a participant in this research study, I will be asked to complete a demographic data questionnaire which will take approximately 5 minutes. I will also be asked to describe my experiences of social support as a caregiver during an interview scheduled for one hour.

I do understand that my responses will be audio-tape recorded and later transcribed verbatim. I understand that the material recorded today may be made available for research purposes and the tapes will be heard by the researcher and the transcriptionist. I understand that the questionnaire and tapes will not be labeled with my name, but will be coded so my identity is known only to the researcher in order to clarify information with me. It is my understanding that the tapes and questionnaires will be stored in a locked drawer in the investigator's office at Texas Woman's University for five years. I understand that the tapes will be erased and the questionnaires shredded at the end of five years.

I have received an oral description of this study, including any associated risks and discomforts and potential benefits. I understand that the questionnaire is short, easy to read and easy to use to decrease the risk of loss of time as well as a time limited interview of one hour. To alleviate any risks of fear of loss of privacy, I understand that all information is confidential and is coded and not labeled with my name, and will be stored in a locked drawer. I understand that the tapes will be erased and questionnaires shredded at the end of five years. I understand the following steps will be taken to decrease the risk for emotional distress: I may end the interview at anytime; I can participate in a relaxation exercise; and/or contact a psychologist whose name and number the researcher will make available to me. As a participant in this research, I understand that the potential benefits are that sharing my

experiences as a caregiver may relieve anxiety and provide some comfort; reading the results of the study may provide awareness that experiences of caregivers may be similar which may provide some comfort; and I may gain knowledge about myself.

The researchers will try to prevent any problem that could happen because of this research. I should let the researchers know at once if there is a problem and they will help me. I understand, however, that TWU does not provide medical services or financial assistance for injuries that might happen because I am taking part in this research.

If I have any questions about the research or about my rights as a participant, I should ask the researcher: her phone number is at the top of this form. If I have questions later, or wish to report a problem, I may call the Research Advisor or the Office of Research & Grants Administration at 940-898-3377.

I understand that participation in this study is voluntary and that I am free to withdraw from the study at any time without any penalty. I further understand that I am free to ask questions before and after the interview. I have been given a copy of the dated and signed consent form to keep.

Signature of Participant

Date

The above consent form was read, discussed, and signed in my presence. In my opinion, the person signing said consent form did so freely and with full knowledge and understanding of the contents.

Representative of Texas Woman's University

Date

APPENDIX E

Demographic Data Questionnaire

DEMOGRAPHIC DATA QUESTIONNAIRE

1. Age: _____

2. Gender: _____ Male _____ Female

3. Marital Status: _____ Married
_____ Widowed
_____ Single
_____ Divorced
_____ Other (specify) _____

4. Race: _____ White
_____ Black
_____ Hispanic
_____ Asian
_____ Native American
_____ Other (specify) _____

5. Education: _____ 6th Grade or Less
_____ Up to 9th Grade
_____ Partial High School
_____ High School
_____ Bachelor's Degree
_____ Degree(s) beyond Bachelor's

6. How long have you been a caregiver?
_____ Months
_____ Years

7. As a caregiver, you provide:
_____ Hours of care per day _____ Days per week

8. Income: _____ Less than \$15,999
_____ Between \$16,000-\$25,999
_____ Between \$26,000-\$32,999
_____ Between \$33,000-\$40,999
_____ Between \$41,000-\$59,999
_____ Over \$60,000

9. Are you employed now? _____ No _____ Yes
If yes, _____ Part-time _____ Full-time

10. I am a caregiver to my:
_____ Husband
_____ Wife
_____ Child
_____ Relative
_____ Friend
_____ Other (specify) _____

11. I provide the following care:
_____ Bathing
_____ Feeding
_____ Cooking
_____ Laundry
_____ Dressing
_____ Transporting to doctor
_____ Other(specify) _____

12. What is the care recipient's diagnosis?

APPENDIX F

Cue Words

CUE WORDS

1. Feelings
2. Problems
3. Changes
4. Assistance

APPENDIX G

Complete List of Significant Statements

COMPLETE LIST OF SIGNIFICANT STATEMENTS

Participant 1

It had been recommended that we go to the hospital daily and do whirlpool baths to her legs. We did this for approximately ten months, seven days a week.

I contacted a wound doctor to get help in trying to cure her legs.

The doctor helped us receive help through Medicare and Blue Cross by sending a nurse for a while twice a day, and a lady to help with bathing and so forth three times a week. Before this happened, I had to do everything.

At my age, it is hard for me to get up and down. I've had back trouble and had been treated for my back and for that reason, I was having no trouble making the bed because I could do that, but my trouble was bathing the patient, getting down on my knees to wash her feet and to be real careful in washing her legs.

She's taking nine different medications from the doctors and that includes three drops that had to go in her eyes four times daily which has been pretty hard on me.

I've always worked up until I needed to be home to take care of her, and I quit work. And, since that time, I've devoted practically my whole life to looking after her.

We don't know how long this will have to go on, and we don't know how long we will be able to keep going as we are. We hope that the time don't come when we have to separate or we have to go to a nursing home and depend on a nursing home for care.

The thing that helps most is having this nurse come once a day to do her legs, also to fill these syringes with insulin.

I feel like it's the love I have for her, and it's my duty.

I know that if I, if I, needed her if it was me and and she'd do the same for me.

It would be awfully hard for me to get along without her.

It has kept us from doing a lot of things that we loved to do. We don't go to church. We don't go to senior citizens. We spend a lot of time at home. I would probably go and do things but I don't want to leave her. I mean I can't go do things.

It takes a lot of my time just to buy groceries to bring home.

It's changed her life and changed my life too, because we liked to see things and go places after we retired.

She paid all the bills and now I have all of that to do and plus I do a major portion of the cooking, two meals a day. We do have Meals on Wheels bring one meal a day five days a week.

I just hope I can stay able to do it.

We thought three or four times that her legs were healed but it just keeps coming back. Personally, I don't think they'll ever be healed.

We enjoy being together. A lot of times we talk about old times.

Our son visits us almost every day. Our daughter-in-law doesn't visit very often but we talk to her on the phone and they take us out to eat about, about once a month.

She takes R. and me to our doctor appointments that are out of town where I can't drive. We use the CART sometimes too.

One of neighbors that we've known for many, for many years checks on us and brings us something that he has cooked. He has taken us to a few doctors appointments when C. and M. couldn't. We see some of our neighbors when we are out and talk to them.

R.'s brothers and sisters were just here a few weeks ago. We really enjoyed their visit. Sometimes it makes it hard on me trying to get everything ready for them. The girl that cleans makes up the beds.

Participant 2

We bought a home we could all live in, and I proceeded to start taking care of my dad.

A lot of my problems was with getting help and getting the right help. It ended up to be a major, major problem because they stole from us.

It was a nightmare, understandable, and I was not working, I was not going to school, I was not doing anything but taking care of my dad at that time.

He had progressed to where he was totally incontinent, totally needed to be fed, and could not speak any longer. So, finally, it reached the point where he had to go live with someone else, and I went back to college, so I did have some relief in that interim.

He died and my mother became paralyzed just from the death kinda, so I immediately began taking care of her the day my dad died.

I've been taking over more and more.

However, I am still going to school full time, so I am managing to have a life.

Now she doesn't drive, so I take her to all her appointments. She used to help me when I first went back to college, she cooked some of the meals, share things but now I do all the meals, and so I've just gradually taken over everything.

We are in a crisis right now because she has CHF, and so its the business with the phones, the doctors, the nurses, and they're not there and then I'm in class and that goes round and round.

Most of the time I don't mind. We have a real symbiotic relationship here. I could not be going to college if she weren't putting a roof over my head and food on the table.

I shouldn't say I feel it's my duty, but because I would do this anyway, you know. I would care for her rather I was being, this is her way of reimbursing me.

There hasn't been a crisis thing that has interfered with my nursing, but as for as feelings, that is in the back of my mind and I do try to keep some kind of shifting contingency plan if I get up one day and something drastic has happened.

The woman that took care of my Dad is a home health nurse, case manager, I could go to her in a minute you know. She is a major support. I also have a significant relationship so he is also a support to me.

She is a wonderful support to me. She's somebody at home when I come home and I've had a bad day.

I made a cover for her and she didn't have it on the other day and hit her leg and has torn it wide open and when that happened, I was so angry.

I could see from having taken care of the other one, it's time consuming. Everyday I have to change the dressing, I have to worry is the thing healing or is it not healing, or do I need to call somebody, is it okay, can it go a little longer, or is it getting infected. But there's the daily keeping it sterile and doing a sterile dressing change which some days I just don't want to put forth the effort. I just don't have time.

I'm blessed that she is not a complainer. In fact, to the opposite extreme. I have to drag it out of her and try not to let her get into a crisis about something before I can find out the real problem. She also doesn't tell me when she plays with her medicine some of the time. When she gets herself in trouble that's how I find out.

Sometimes in the dating situation, the privacy. Sometimes I think it would be so nice to make a meal and invite someone over, just the two of us, but there's always Mother.

I wear a beeper all the time, everywhere I go, and so I'm tethered in a sense.

When I was single and living alone, I went and did anytime, anywhere that I wanted to and now I have to think about, make sure I have a meal for her planned or something she can get for herself, so I would say my freedom is a little bit constrained. But it's not overbearing or overwhelming.

I have done support groups so I know what other people are going through as far as the caring and the hours and the freedom and the never getting out, and trying to find somebody for them for a day. My dad could not be left alone ever at all for a moment and so if somebody called off that I counted on that day then I had no choice but to sit here and care for him and that was very constraining, very, very.

Faith, I have strong faith it will work out. God will get me through whatever does come up that I can't handle on my own.

My main thing is watching her suffer. That's tough; that's difficult.

Other support is people that take me out to dinner and movies, is definitely a support and friends to do things with and students at school. There've been times when some things would come up and I would go talk to an instructor.

The frustration of trying to find people in the medical community that are really aware of the geriatric needs of our patients makes me crazy. They, half of them don't have any idea about the medication. My mother only weighs 92 pounds and they give her the same amount of pill as they give somebody at 150.

It was so time consuming and so frustrating for me as a caregiver to find all of these avenues. Some of the things were the home care and reliable home care and my frustration with the service was they would come in and they would say "Oh well, I'm a nurses aide and I don't cook meals or I don't scrub floors, or I don't dust the house." I would say "Okay, send me a homemaker." Well, the homemaker would come in and they would say "I can't change a diaper. I don't turn people over. I don't do this stuff." I had these really delineated job descriptions. The frustration of the people that do this--pool of employees is so unreliable. That is a terrible frustration.

Having to get out to doctors--my Dad was so much care to get into a wheelchair to take for his doctor appointments. I began looking around in the system to see who could come here. Looking for these kind of people who would come to you instead of you having to go to them. It was just so frustrating for me and for any caregiver.

I don't have a lot of family resources down here. Some people maybe have a couple of brothers and sisters that live around, they can trade off or do that kind of thing, but I don't.

Participant 3

My wife had a very strong supportive network of friends in Illinois. Never made any here. Really, she agreed to come, but really didn't like it.

All along we've fooled with, is her problem that she doesn't like it here or is there something else?

We saw a neurologist, social workers, doctors. Looked at depression as a possible source of the problem. Saw a therapist on our own who thought that she was unhappy with being here and this was her way of dealing with it.

This was over the course of three years or so, four years, Doctor, our family doctor finally said well you know there's one thing, we can do we can get a diagnosis.

The diagnosis was a form of dementia. The disease is progressive if that's the right word. It's more like regressive. It's gotten worse, of course. Sometimes she thinks I'm her brother.

She had some bowel trouble which I think we found out was due to the Aricept, so we are dealing with that. That's the thing I worry about the most. I mean I don't mind. It doesn't bother me, but if she's out with somebody, I hate for it to happen. She was asked to a fashion show recently and I said maybe she shouldn't go because of this, and they said no, that's all right so it was okay.

I got her Depends panties for emergencies.

She is so sweet natured, always has been. You know some people get nasty with dementia, she's sweet, will drive you crazy asking if she can help.

Well, you have to live for two people. You know in the former relationship, I lived my life and she lived hers and we lived ours together. But now I have to live both of them.

I can't go anywhere much. I still play golf.

We would go to one church one week and the other church another but we go just to the Anglican church now, and it's harder to travel.

People help. These ladies I was telling you about.

My daughter who lives a mile and a half away, she's good.

Watching her so that I can go somewhere else.

She's gained some weight because she eats a lot, so I cleared the house out of food. We only eat out. A few things we have at home, but I can't have jam or jelly because she'll eat the whole thing.

Well, I've tried just the assisted living. They have an Alzheimer's unit. We were there for one day.

I'm looking forward to this place. That support group is run by P., just built a place nearby, if they strike me as being good people. What would help me is for me to know that she is getting the right kind of attention. I mean, I can't give her all the right I can I I can't give her all the attention she needs, and I can't give her the right

kind. But maybe in a group, maybe people that know what's going on. So I'm looking forward to some day care there. That would help.

Another thing that helped was a neighbor from I. was here a week ago. It was her best friend. It was good to have them here to help out. So those kind of things help.

Participant 4

We simplified his environment. Kinda felt bad about, well he doesn't have his stuff, very much stuff.

We went around and put child locks on all the drawers and stuff. And we put rubber bands on the utility room door, and we got through without him undoing it. We took the locks off his bathroom and his door, and we put locks on the other doors so he can't get into the bedrooms, bathrooms, and or something and we have a monitor that we can hear him.

We had to get him to the bathroom or we weren't going to be able to take care of him much longer. But, through the night, he was calling me to get up and I was following him to the bathroom. He was doing just fine. But then he started calling me every hour and then he started calling before I even got back in the bed. And I finally said don't call me unless it's an emergency and I went back to bed and went to sleep for two hours and he calls me again.

I can see why people put them in some place.

We had to change our lives somewhat. There are some organization things that we've changed.

I haven't figured out how to get dad transferred yet from one place to another and have a smooth transition.

But I've seen them kick somebody out up there that if they even gave them a chance. I mean this place is supposed to be for Alzheimer's and this is the problems that go with dementia. They don't remember what is socially acceptable and you have to be patient with them.

Our daughter was here and I was kinda relieved when she went off to college. Several times he's come out and taken his clothes off or you find him wandering around part dressed.

We've changed his clothes, changed his, you know, he got to the point he couldn't handle his zipper and stuff like that so we got pull on pant. I had to do everything.

I have her some so we can go out so that hasn't been too bad.

I don't know if he starts acting like he did when he was back with my sister, there's going to come a time that we would not, he would have to get a place somewhere, because we just can't have that.

He doesn't really remember my mother that much. Sometimes we wonder if he doesn't have my sister and I confused.

My son stays with him sometimes.

We've had a couple of people, volunteers from different organizations, but I, you know, unless its an emergency, I wouldn't feel comfortable letting, just because he's apt to take his clothes off or something.

I've applied for a few jobs and wanted to see if he could stay with me. I didn't get the job so I don't know if its because of him or if they found someone else that's more qualified.

My husband. We can't go a lot of places together now so he will stay home and baby-sit and then he can go out and I baby-sit.

It would be nice to have a baby-sitting service. If you could get a student nurse or something like that, that would understand or where you could drop them off at day care in the evening and stuff rather, but you have to find someone to pay.

You attend support groups if they allow you to drop them off and have them taken care of at some place else.

Participant 5

I made an appointment at Southwestern Medical Center and yes she received a diagnosis of Alzheimer's in 1989.

We went pretty much with our regular affairs. She still did cooking, housekeeping, drove the car some and went to meetings, University Women's Club that she belonged to.

She had managed the checkbook, bank statements and so on and I had to help her and finally take over that particular chore. She continued to do rather simple cooking but eventually I had to take over that particular role also. I made a point of going with her when she drove and came to the conclusion she was no longer a safe driver.

I was fortunate in that my wife was always very cooperative to the point that she was able to understand things. I didn't have problems of aggression or anything of that kind with her.

So, the gradual process of me taking responsibility for her. I would help her dress and take her to church. Also, I took her to meetings at a so-called nutrition center at one of the churches.

By then, she did little talking, face was sort of mask-like in appearance and she was not, she, she was not very expressive of feelings. It was all very emotional flat as far as I could tell.

During the night, she'd get up to go to the bathroom but she often wouldn't make it in time. I'd spread out newspapers and when I'd hear those newspapers rattle, I knew to run to help her.

Started urinating in bed at night and at first I tried putting out big bath towels and she soaked them and I would laundry them and so on and we managed for a while. I soon discovered it was necessary to use the commercial product, the plastic with absorbent facing, and that helped.

I bought a potty chair for her so that it was right beside the bed but she never did learn to use it herself, so I would have to position her on it and that seemed to work pretty well. Also fed her. At first, she was able to use her knife and spoon and fork and so on but gradually she started using her hand, not using the fork anymore, sometimes using the spoon, and using her hands to pick up food. She developed difficulty in swallowing. Found it necessary to, to puree her food. I guess that's what you call it. In later stages, it was necessary to use a syringe.

I wanted to continue carrying on as many activities as I had been doing.

At first, I was able to leave her at home by herself without worrying about her handling herself, but I became more and more concerned.

Some friends would sometime come in and sit with her while I went to a concert or to a play. I also hired a part-time worker to sit for 16-20 hours a week at about \$7 per

hour. I had no difficulty paying the money and I was always pleased with the help I got. I got wonderful people.

I was very much concerned with my wife not getting bed sores. Oh, I had gotten a mattress, a special mattress, a rubber mattress with air in it. I thought that that would help and it did, I'm sure.

Anyway, she developed this ulcer, and I called my brother who is a medical doctor and he looked at it and he said, well, it's worked its way under the skin and so on. Well I knew that was beyond me to take care of, so that's when I contacted my doctor and the Visiting Nurse Association and finally settled on an organization which at that time was known as Home Care Services. So Medicare paid okay.

Let me say that I, in general, felt very pleased with the level of help I received. I had no complaints. One thing that did happen, however, a social worker appeared on the scene and I, he interviewed me about the care I was giving. When he found out that I sometimes left D. alone in the house, and I'll tell you when I did that. When she reached the point where she was completely bedfast and could not walk. So, he was upset. He said what if there was a fire? When you consider all the care that I'm giving her, its tremendous. That was upsetting. I resented it very much. That was the only really negative experience.

Also went to one of these Alzheimer's support groups and when I listened to the other people and the problems they had, I thought I was fortunate. I always felt much more sorry for D. than for myself. I really had it easy compared with what a lot of people might have had to deal with.

Sometimes she didn't know who I was.

I kept some notes during the time of D.'s illness, and I actually wrote them up. This one is titled "D.'s Talking," and I broke it down by years and indicated roughly the times and its all in dialogue form.

Well, the services which Home Care Services supplied. There were some things I needed to learn.

Oh, I got these two beautiful cat, kittens, during D.'s illness and their companionship was helpful to me I think and I still enjoy them.

I have a brother that lives in town and I wish he'd come over more often to visit and keep up with things, but that's about the only thing I missed.

Participant 6

The only way I could get her out of there was if they, under the conditions that they train me on the respirator and then get help through BMC Home health. The nurse came out a couple of times to help me with some problems.

I am limited where I can go.

I have an intercom here, I, we got one out in the garage and she's got one on her bed. It gets a little tiring.

My son stays with her some and helps when he is here but that's not very often. He's on the road most of the time.

At times, she's like I am, she's non-cooperative. To tell you the truth, I get aggravated.

I made a pact 47 years ago, so I'm going to live with it.

We get the hairdresser, and she comes here and does W.'s hair.

I have a neighbor that would come over anytime, but she's been sick. There are those that call and check on us like J., the nurse who is a friend.

If I had somebody, just somebody to come stay when I need to go somewhere, buy groceries, something like that.

This dog takes me for walks everyday. Gets me out.

Participant 7

Mom came two days later and I had to arrange a physician, home health care, and everything and that's when I talked to C. E. and he says I'm not involved in that and he was on the Board of VNA.

I turned around and called a couple of other nurses that I knew and they referred me to a person who worked at VNA, and by that weekend I had home health care set up.

She was on Meals on Wheels, because I was working during the day and didn't want her fooling around in the kitchen that she was not familiar with.

I remember my sister-in-law coming over to stay with mom.

Within a week I had Dad in Texas, Mom in Texas, and I was caring for both of them.

I called Dr. H. or Dr. S. and they had set up the home health care, the oxygen, the hospital bed, everything within that 24-hour period. Bless their hearts.

Dad was listening on the other line and the look on his face cause he had idolized that man as his favorite son.

But I had an aide coming for Dad during the day, and she did the breakfast for them and the lunch. Meals on Wheels brought lunch and she set everything up for them and when I came home, I did the laundry and cooked and cleaned and everything else.

I've been blessed that every aide I've had has stayed anywhere from 2 to 4 years, and the one that I have now and the one before her were great. And I'd say well can you and they'd go along and help me with Mom.

In the last year, Mom's health has deteriorated so much that I do have to have help getting her out of the car and everything. S. and B. came over and helped me get her out of the car and into the house.

The state pays for her care and Meals on Wheels.

I do have neighbors that look in on her and everywhere that I've lived a neighbor has come in and checked on Mom. And if I needed anything, all I had to do was call them.

Just someone, you know, if Mom, if I came home and Mom's health was good enough and she was alert and oriented, to say do you want to go shopping, do you want to go window shopping and that, and if I needed to go somewhere or that to get away if they could come in and stay at a moment's notice. Usually the aide that I have now will work something out will work something out three or four weeks in advance.

Gave up a social life. I mean when you are interested in a guy and he finds out you're taking care of your mother. Oh, how old is she? Oh, 80 something. You know, they're like oh, I don't want to be saddled with that and off they go.

I was use to taking off after work and going somewhere. I guess now I have to come home and check on Mom, make sure she has something to eat, but to me they are just minor inconveniences. You just have to work around them.

Wouldn't have it any other way. I'm sorry I belong to the old school.

Caregiving can be hard, can be very stressful.

I really didn't have anybody that I could talk too. They'd listen for about two minutes and you could see their attention wandering and you'd say oh, forget it, I'll just go home and talk to my cat. My Siamese was a great listener.

You only have your parents once. And there are good times and bad times.

Participant 8

He would get to feeling a little bit better and it was time for him to go start another treatment and that was hard on him and hard on me.

I am not sure that the doctors are always honest in these situations. He asked them how long he would have because there were some things that he needed to take care of and they told him that he would have about two years. Well that is not what happened. He died in three months, so I don't think that is right. I know that they don't know exactly, but they should be more honest about it with their patients.

I had a nurse and a home health aide that came and took care of him during the day and the aide was really the most help to me.

I was working full-time and that I think was a life-saver for me. If I had not been able to go to work and get away from the situation, I am not sure what would have happened. It was a release for me, and you have to have that, otherwise, you would not be able to stand it.

You have to give up a lot of your activities that you were doing and so you lose a lot of your friends; you just lose that contact.

Friends would call to see if we needed anything and that helped.

I don't have any family that lives near here, so I didn't have them to lean on and that may have been a good thing too because one of my daughters came and stayed for a week, and he was glad when she left and so was I. It was good to have her for a while but.

They did call pretty often to check on us but its not the same as getting out and seeing your friends and doing things. Because you just have to make so many changes and give up most of your social life. Really, it can be very lonesome. We couldn't go and do things like we did before he got sick, so you can feel like you are all alone.

I did attend a support group one time at the church but it wasn't for me and I never went back, and you don't have the time either.

We got this dog and he was a godsend. He was so much company to us when my husband was sick.

My caregiving did not last long but I can tell you that it was hard work and very tiring. I would go to work, cause I had to work, and then come home and start taking care of his needs and that really leaves no time for you. You, you are just on a merry-go-round for a while or that is what it feels like. Just having something to give me a break from that would have helped.

Participant 9

I went to a doctor and said well, there's something wrong. It's more than just a bit of senility.

I had to have special locks put on the doors. That way he couldn't get out and because he'd get up in the middle of the night, maybe roam around.

I just had to be with him all the time. I mean there was no way of getting out of it.

They chatted and when he forgot to call the friend, then the friend didn't call and that was really upsetting. He didn't know the difference, but I knew.

My son was never a lot of support.

We got them to accept him at the W. VA, but I had to get my State Senator to help.

I had taken him down there a couple of times and all they would say is that I was doing such a good job, and he looks wonderful, taking care of him that I needed to continue doing it and, on the other hand, my Internist and my Orthopedic surgeon were telling me I was killing myself and that I couldn't do that.

I'd have to call my daughter to come at 2 a.m. to help me get him in the bed.

I finally realized I had to get up with him all the time.

I'd have to take him with me, and I didn't dare let him out of my sight.

I was always tired after, you know, about a year and a half of being totally confined all the time.

My daughter, who lived a block and a half away, was excellent support.

I mean, he could go to the bathroom 10 times a day and still he'd be wet all the time, so it was a real problem.

At the time all this started, I had had a second mastectomy in '87.

I had this back surgery and I have a rod in my back, so taking care of him was really quite a chore.

I quit my career, and then, I was home with him.

A nurse friend, J. B., recommended that I take him to a day care.

I mean, by the time I got him in, it was time to go back and get him.

I'd get to feeling bad that I'd taken him over there.

They suggested that I get him involved in a DART taxi.

It was helpful for me. I meant, I was finally getting some rest, but I always had so much to do that I tried to get stuff done while he was gone.

One day he escaped. They hadn't missed him and that was scary for me.

This lady has what she calls "respite weekends" for \$100. As far as I can say, it was a Godsend.

I really would have been very ill or I could not have kept him as long as I kept him and that was a big help, a big support.

There were other support groups in town that I could have joined but that one was most convenient because I could take him with me and I wouldn't have to worry about getting someone to stay with him.

My neighbors would always ask, but everybody on my block is almost as old as I am so there was nobody that was really able to come over and say, "You want to go somewhere. I'll stay with him."

I'd just make sure he was being cared for.

I worried about him as he got further along.

It was so sad. I think that was kinda the beginning of the end.

J. B. would come by when she was out this way, come by to check on me and him too. She knew he was getting care. She thought I wasn't cause I was doing so much work.

Participant 10

I'm an only child so we brought Mom back home, and I have been a caregiver ever since.

Living here seemed the best solution. In fact, we have moved across P. to a larger home.

That's how I became a caregiver, and it kind of snuck up on me - the magnitude of it.

I got my doctor to accept her as a patient even though she was Medicare and she wasn't taking them. I'm going help, I'm moving her down here. Dad died. I don't know what's going on. She needs the medication. I don't know where to go to find a good doctor.

What really prompted the change to B., she'd had a problem, she was soiling the bed at night. I made contact with one of the social workers at the BSC here in P. and I called her. I said what do I do?

I had health care power of attorney which I had not known about before.

It turned out to be a kidney infection, but it took all her mental processes with it. I guess I had become lax in monitoring.

It was very easy for me to say okay, she's got to go to the hospital, that's it. You know, rather she wanted to or not, she was beyond any care that B. or I could give her at that point.

We went through this whole thing, now who wants to leave your mother in a nursing home?

I knew that I couldn't go out and leave her even for a couple of hours.

We went through this whole thing, maybe we should try assisted living, you know. That would give her more independence. And then I would try to watch and analyze what she was doing, and we went back and forth.

Our church offered a course on parenting your parents and that had seemed like a good idea to me. Maybe I'd learn something there.

The group, there were four of us, we bonded rather tightly and formed a group at the church.

I made the decision even though I kinda kept reevaluating my decision to be sure I was doing it right.

I never worried about her. I left them alone in the house and I knew he'd take care of her. Any strange noises they heard they'd go in and look so they were by backup support. My husband traveled a lot so it often was me and the dogs taking care of Mom.

You don't know where to go to get the information on what to do or how to do it or why.

Two of my supports were a friend in S., now a friend in NJ. In e-mail contact with both of them, e-mailing back and forth with those two. And I was always able to write well, you know, Mom did and I did thus and such. What does this seem like to you?

Okay, so you're going to take your Mom to the doctor, well what's the big deal? Well, there's the getting her up in time because with the arthritis you can only make an appointment after noon because it takes her so long to get moving in the morning.

The diuretic, can't even think of it. It governed my life for two years....We went out to dinner, "Well, when should I take my pill?" "I don't know, if you get up in the morning you can take it then, but we're going out at this time."

At this point she doesn't really grasp, today she doesn't grasp enough to worry about it, tomorrow she might. I don't know.

If someone doesn't have that experience, they don't know that your whole day is gone, from morning until afternoon, you know.

So, I'm required to be home and take her to the appointment.

Until you find someone you can talk to about it, its very difficult and of course now there's the people, "You put your mother in a nursing home!" Her former hairdresser has yet to forgive me, "How can you do that?"

Our minister was by to visit and said something. "Your mother is a very lovely lady." And there was two things that brought me up short. One, I don't see the lovely lady because I'm so busy. I walk in the door and it's "I need." That's what she hits me with, "I need." So I rarely see this lovely lady and yet this is the gracious lady persona that strangers see.

Even the doctor at the hospital thought she was being rational when she wasn't.

I just thought it was pure stubbornness because along with everything else, she's a stubborn lady.

I have a wonderful husband and he's put up with a lot. And what he's put up with, he tells me to, is getting angry when Mother's on my case and he did tell me he was not looking forward to it but she does not treat you well for all you do for her.

I'm an only child. That makes caregiving easy because I don't have to check with anybody else you know. I make the decisions. Its unilateral. That's it. On the other hand, there's no one to check with and say "Well, you know, she's your Mom to, what would you like to do to do with her?"

She can dump on me all she wants and I'm not going to desert her. What I've learned to do when she really gets on my nerves is well, I'll come back and see you tomorrow.

You feel guilty to some degree for saying it, you know.

She's my mother and she isn't. She's not the same person that my mother was.

It would be nice if there was a miracle out there, someone who could come to you and say, "This is normal, you're normal." Finding support is hard.

One of the ministers came, and she was quite pleased as was I, and had kinda of a mini Holy Week service in her room, said the prayers there and everything, and that's been an unexpected source of support for her if not for me.

Just knowing that somebody else actually really relates to it, not just sits there and says I can see you've got a problem or that kind of thing. Really relates to it.

I said if it will not jeopardize your job, get home. I'm going to have a nervous breakdown.

I worked myself into exhaustion, and there has to be a way around it.

When mother was with a doctor in private practice and became ill, I couldn't get her to the doctor. If I call her, she's going to say go to the hospital.

The other hardest thing now, Heaven help me, is if there is one care providing service that could keep track of its billing so I wouldn't have to, I would love it. At least every other bill that comes in this house, there's something wrong with it, and I get frustrated spending my time hanging on the phone dealing with it.

Even with her in a nursing home, I'm still the caregiver.

The good thing about it is the load that is off my shoulders.

Oh, it would be hard to say, well, my mother is in a nursing home.

It was just not possible for us to care for Mom here.

Well, we could get help, but unless it was live-in help and what kind of help, because this one doesn't do this, this one doesn't cook.

The services are there, I've come to the conclusion, it's how to access them.

Accessing the Internet has made it a lot easier to get information. That's been helpful.

When you're the primary caregiver, you are isolated.

Most people don't know what you're, oh, they're beginning to know what you're talking about, but it is not as openly discussed and people don't worry about it. I've talked to some of our Sunday School classes and some of the people who come to our group and they don't worry about it until it happens.

That was the hardest thing to take, was the role reversal, that you have become the parent.

It's mostly the mental that makes you the caregiver crazier than the physical.

I gave up my consulting job because when something happened to mother I had to call my clients and reschedule appointments and that was frustrating to me and the client.

Participant 11

She got to where she couldn't remember anything, so I served as her memory board.

Sometimes, I would get real angry with her.

I did all the cooking and all the cleaning, and she did not have to do anything.

We did not have enough friends to drop in like she wanted them to.

I couldn't play games with her, because I didn't have the time.

We did not get involved in the DART Share Ride. I don't drive, so I did need a ride, but we never got involved in that because I didn't think I could handle her, putting her on a bus and going any place, and I knew that I couldn't handle the wheelchair.

I always had someone to take us where ever we went and generally my sister did. My daughter helped. She lives here too, and she helped a lot, and she would drive us places.

One thing I needed desperately from them or anyone was baby-sitting.

Nobody wants to baby-sit an elderly person. They're, they're scared.

I had a terrible time coordinating the baby-sitting and a ride for myself and an appointment at the doctor. You had to get an appointment for all three to even go right up here at the clinic. It was really hard to do.

We did find a lady from T. that would come out and sit with her but she charged ten dollars a time, an hour to sit. But at ten dollars an hour, you didn't run out whenever you really wanted to.

My neighbor across the street would sit with Mama and I trusted her.

You didn't know whether to leave her. Of course, I had the guilt trip because I was gone when she got sick.

I think that's one of the biggest problems, when you're taking care of somebody old, is the guilt that you have cause you are not doing the thing that you'd really like to do because you either don't have the time or the money or the experience or whatever it takes, and then you feel guilty. I know with me that's part of my problem--the guilt. I just know she didn't have a sore throat even though that is what the doctor was treating her for.

She needed more people to visit her which she didn't have and that's something you don't do. You don't call up and ask people to come visit, which I would like to have, but I'm afraid if I had of, I'd been ugly with them especially her children. I have a brother that lives right here in R. and he would go for years without seeing her. We also have family that will come if you invite them to dinner but they never just drop in or all. I resented that very much.

The people from her church were wonderful.

They told me they could come early or late and do her. That's what I was mostly concerned with. They could not, even though they said they could come early or late. The nurse lived in C. She worked out fine. But the other two, as I say, were more of hindrance than they were a help.

There is no lifestyle when you're a caregiver. You, you do what fits into your schedule or their schedule, and if there's any time in between, that's, well your time, and there's very little of that.

The only time my husband and I had together after I retired, and he retired quite a while before I did, was the two months she went to M. And it was in the summer-time, and we had those two months together in our retirement, and that was it.

The only thing that I'm unhappy about is the guilt that I feel. I just wish that I didn't feel it but I do.

I really needed to dump on someone, and I feel better after talking.

APPENDIX H

Complete List of Formulated Meanings

COMPLETE LIST OF FORMULATED MEANINGS

Participant 1

Making frequent trips to the hospital was tiring and hard.

Recognized prescribed treatment wasn't working and contacted another doctor.

He got assistance through the doctor which lessened his care demands.

Some tasks are difficult for him because of his age and disabilities.

Frequency with which medications must be administered is hard on him.

Quit his job to become a full-time caregiver.

Worries about the future and loss of independence if can't continue providing care.

What helps most is having a nurse do leg dressings and fill syringes with insulin.

Feels an obligation to care for wife because of duty and love for her.

I do this for her because she would do it for me.

It would be hard on him without her.

Experiencing isolation because he had to give up social and personal activities.

Chores, such as grocery shopping, require so much time.

Sad that they are unable to travel as they planned.

Getting Meals on Wheels, but the demands are still great.

Concerned about own health.

Uncertain about the future because wounds continue to develop.

Finds comfort in one another and from sharing memories.

Family visits or calls and takes them out to eat.

Family takes to doctor appointments and public transportation is used as well.

A neighbor checks on them and brings food.

Enjoys visits from out of town relatives but he feels stressed.

Participant 2

Gave up own home to live with parents to care for her dad.

Trying to get the right help is a major problem.

Gave up work and pursuit of further education to care for her dad.

Caring for her dad became so demanding she could no longer cope.

Feels a sense of responsibility for her mother.

There are more and more demands.

Is managing to do some things that she wants to do.

As time passes, she has to assume more responsibility.

Trying to contact doctors and carry on with other things is frustrating.

She is caring for her mother, but her mother, in some respects, is caring for her in return.

Caring for her mother is her duty.

Ever present concern that schedule will be disrupted by an unscheduled event.

There are professionals and personal friends she can turn to for help.

The care recipient is a source of support.

Angry because efforts to prevent injury were for naught.

Worries that care for wound is correct and about the time to care for wound.

Thankful that her mother does not complain, but worries that she will not tell her something important and cause more work.

Wishes she had some privacy so she and a date could be alone for dinner.

Can never get away from the responsibility no matter where she goes.

Feels a loss of her freedom because of her duty to her mother.

Through support groups has learned of other caregiving situations.

Relies on her faith for support.

Seeing her mother suffer makes her sad.

Support is from friends and fellow students who ask her to participate in social activities and from instructors who listen to her.

Perceived knowledge deficit in the medical community about geriatric care.

Working through the system to get the right help is frustrating.

This is a tough job and getting her dad to the doctor is an additional demand.

Seeking outside help is her only option because she has no family to support her.

Participant 3

Feels some guilt that family relocated and wife lost supportive group of friends.

Looking for answers as to why the change in his wife after they moved.

Reaching out for professional help for an answer but not getting it.

Looking for answers to changes in wife, and finally his family doctor helped.

His wife is becoming progressively harder to care for and he is losing her mentally.

His wife's bowel trouble is a worry to him, and he would be embarrassed for her if she soiled herself while out with someone else.

He is doing all he can for her and is trying to deal with each problem as it arises.

He doesn't want to criticize his wife, but some of her behavior upsets him.

The relationship that once existed is gone, and the wife he used to have is gone, and he is now living her life and his life, and it is not easy.

His social activities and personal time are restricted.

It is easier to go her way to help the situation as it is hard to take care of her.

Help from other people gives him some time to himself.

Daughter is a big support to him.

He needs to get away from the situation sometimes.

Concerned about her weight gain so limits the food that is available to her.

He tried an assisted living facility with an Alzheimer's unit but was not satisfied.

He does not feel he can provide her everything she needs and is hoping to find someone that he trusts to help because he is stressed.

Finds strength and support from old friends and he got a break.

Participant 4

The situation is stressful, and she is trying to make the situation less complicated.

Taking desperate measures to maintain some means of control and privacy.

Caring for him day and night is difficult and she cannot get any sleep.

His care can be too much to handle so other arrangements may be necessary.

Has had to rearrange lives and change organizational activities.

Wants to use another day care but worries about the change on she and her dad.

Frustrated with the staff's level of knowledge about Alzheimer's patients.

Worries about the effects of her dad's behavior on daughter.

It is difficult to take care of him so looking for ways to make it easier.

With help of daughter, there is some time for personal activities.

Worries about the future as there is a limit as to what she can ask of her family.

His inability to remember is a loss to her.

Family members help out at times.

Hesitant to accept help from volunteers who may not understand dad's behavior.

Needs assurance of self-worth and some relief but is still obligated to care for her dad.

There is no personal time for both she and her husband to be together.

Needs more convenient services and knowledgeable support people.

Can only participate in support groups if they have staff to care for her dad.

Participant 5

Recognized something was wrong and sought help to determine cause.

Attempting to keep the routines going.

Demands of care increase as he gradually loses her.

Recognizes the situation could be worse.

He is trying to meet her needs.

It is very sad and painful to see his wife as her condition deteriorates.

Fears he won't hear her go to the bathroom and will have to clean up after her.

Problem-solving to cope with the demands of care.

As her condition declines, his responsibility becomes greater.

Trying to hold on to the things in life that are important to him.

He worried when she was home alone.

Found friends and paid help as a means of having time away.

He was doing the best he could.

Recognized that he had to have help and sought professional advice.

Appreciative of the assistance he got.

He wants to be recognized for his hard work, not criticized.

Recognizes that his situation isn't as bad as some others in the support group.

He knows he is losing her mentally.

It helped to document the changes that were occurring.

The healthcare system provided helpful information.

He was lonely without the companionship of his wife, and the cats provided some companionship.

Visits from brother would have been appreciated.

Participant 6

Received support through home health agency with respirator problems.

The freedom to come and go at will is gone.

Uses intercom system to allow some freedom of movement about house.

Son is a source of support when available.

When she is difficult, he has a hard time coping.

Has a duty and responsibility to honor his marriage vows.

Services that are rendered in the home reduce the stress.

Neighbors, friends, and professionals are sources of support.

Needs help to come to his house to give him some time away.

The dog kept him from being so lonely.

Participant 7

Clergy offered no help when approached.

Nurses provided direction to get immediate help.

Meals on Wheels provided relief from some of the demands.

Family members helped a little at first.

Has the responsibility of caring for both parents.

Appreciative of the response from physicians when she asked for help.

Loves her Dad and is angry about treatment from his son.

After working all day, there was still everything to do when getting home.

The aides are dependable and help a lot.

As health deteriorates, it is more difficult to provide care.

The state provides financial aid.

Neighbors are helpful.

Lonely and has lost freedom to socialize at will.

One loses their social and personal life.

Responsibilities restrict freedom.

It is a duty and obligation to care for ones' parents.

Caregiving is not easy.

Has no confidant and is lonely, so finds comfort in talking to her cat.

Feels an obligation to care for parents in good times and bad times.

Participant 8

It is difficult to watch a loved one suffer.

Angry at doctors that husband did not live as long as he was told.

The nurse and aide did the personal care and most of the medical responsibilities.

Work was a way to get away from the situation.

Maintaining contact with friends is difficult.

Phone calls from friends helped.

Well-meaning family can also cause additional stress.

Giving up social activities results in loneliness.

Attending support groups takes time and does not always meet needs.

The dog was company and helped relieve some of the loneliness.

A break is necessary in order to cope with the hard work of caregiving.

Participant 9

There are so many questions and no answers.

Special locks were placed on the doors to protect him.

There was no way to get out of being with him all the time.

His friend abandoned him when he got sicker which hurt.

My son was not a source of support.

Getting help from the system was difficult, so a State Senator helped me.

I was told to continue to care for him, but my doctor said I was killing myself.

My daughter would come help me get him back in bed at 2:00 in the morning.

I had to get up with him all the time which interfered with sleep.

I could not go anywhere without him and had to watch him constantly.

The confinement was difficult and I felt tired.

Daughter was an excellent source of family support.

Caring for him was very difficult with him being wet so often.

I was not physically well myself.

It was difficult taking care of him with an injured back.

I gave up my career and was able to stay home with him.

A nurse suggested day care.

Sometimes it was not worth the hassle to use day care.

Feels guilty about taking him to day care.

People offered suggestions about the use of various services.

Day care gave her time alone which was restful even though she had things to do.

I let someone else care for him and they did not know he left which is scary.

Having respite weekends was a "Godsend."

Without a break, she would become ill and could not continue to care for him.

Attended the support group that was convenient and provided care so she did not have to find someone to stay with him.

The neighbors would offer to help, but she wasn't sure they could care for him.

She still feels the need to watch out for him.

As his condition declined, the greater her concern about his care.

She was sad as she saw him getting worse.

It is good to have someone concerned about the caregiver.

Participant 10

There was no one else to care for her mother.

It was easier to let her mother live with her, and that required a larger home.

Not prepared for the magnitude of the role of caregiver.

The doctor did not accept patients on Medicare but made an exception.

The social worker gave her advise when she asked.

The healthcare power of attorney empowered her to look at other care options.

Feels guilty that her mother's condition deteriorated while in her care.

The care required was too much for the caregiver.

Feels guilty that she put her mother in a nursing home.

Her mother cannot be alone for any period of time, restricting her freedom.

Needs information about parenting her parent.

Those in similar situations form a bond.

Continues to re-evaluate her decision because she feels guilty.

The dogs relieved some of her worry when she had to leave her mother alone.

Did not know where to find caregiving information.

Caregivers need reassurance.

Frustrated with others who don't understand.

The caregiver is angry that her life is controlled by caregiving.

Uncertainty is a part of each day.

Someone has to have been in the situation to understand.

It is a difficult for the caregiver to get her mother to an appointment.

Criticism and lack of understanding adds to the frustration and guilt feelings.

Meeting her mother's needs leaves no time to reflect.

The doctor does not recognize when older persons are not rational.

She needs a lot of care, and her stubbornness just adds to my work.

Spousal support and recognition of efforts are important to the caregiver.

Having another person to share the responsibility would be good.

The caregiver has learned to cope by getting away from the situation.

Caregivers feel guilty about some comments to parents.

Struggling with the loss of the person that she knew as her mother.

The caregiver needs confirmation from someone that is also a caregiver.

Visits by the minister to her mother are good for her also.

Needs to relate to someone who is in a similar situation.

She needs some help, as she can't cope any longer.

The physical demand is too much, and there has to be some relief.

It is difficult to get help from the medical profession, and it is frustrating.

She is overwhelmed and now has billing errors to correct which takes time.

The direct care is over but the responsibility is still there.

The load she had to carry is not as heavy.

It is not socially acceptable to place your parent in a nursing home.

Recognizes her limitations but still feels guilty.

Getting the right kind of help is frustrating.

Clearly defined ways to access services are not available.

The Internet makes access to information easier.

There is no time for social activities when you are the primary caregiver.

Family members are not prepared for the role of caregiver.

Becoming a parent to a parent is hard.

The mental stress of caregiving is difficult.

Quit her job as it was too frustrating to change clients' appointments so frequently.

Participant 11

It was difficult to accept her parent's memory loss.

Inability to cope can result in anger.

The caregiver had all the duties to do herself.

Angry that friends did not visit more often.

Regrets that she could not spend more leisure time with her mother.

Using transportation services was difficult for the caregiver physically.

Family members helped with transportation.

It would be helpful for someone to baby sit.

People are afraid to sit with an older person.

There is no time to meet her own needs.

Availability and cost of baby sitters limit activities.

A neighbor would sit for her.

Feels guilty that her mother got sick while she was gone.

Lack of resources limited what caregiver could do and she feels guilty.

The caregiver did not have confidence in the doctor.

She is very angry at some family members for not visiting.

Church members were very attentive.

The help was a hindrance because they did not come early as they agreed.

There is little time for anything other than caregiving.

She and her husband had little time together alone.

She feels guilty that she could not do more.

I feel better after being able to talk to someone.

APPENDIX I

Complete List of Theme Clusters and Sub-themes

COMPLETE LIST OF THEMES CLUSTERS AND SUB-THEMES

A. Demands of Carea. Physical Demands

Making frequent trips to the hospital was tiring and hard.

Getting Meals on Wheels but the demands are still great.

Meals on Wheels provided relief from some of the demands.

Frequency with which medications must be administered is hard on him.

Some tasks are difficult for him because of his age and disabilities.

Chores, such as grocery shopping, require so much time.

This is a tough job and getting her dad to the doctor is an additional demand.

Caring for him day and night is difficult and she cannot get any sleep.

He was doing the best he could.

The physical demand is too much, and there has to be some relief.

As health deteriorates, it is more difficult to provide care.

My daughter would come help me get him back in bed at 2:00 in the morning.

After working all day, there is still everything to do when getting home.

Caring for him was very difficult with him being wet so often.

It was difficult taking care of him with an injured back.

I had to get up with him all the time which interfered with sleep.

What helps most is having a nurse do leg dressings and fill syringes with insulin.

Family takes to doctor appointments and public transportation is used as well.

Using transportation services was difficult for the caregiver physically.

It is difficult for the caregiver to get her mother to an appointment.

Appreciative of the assistance he got.

b. Psychological Demands

Daughter is a big support to him.

He doesn't want to criticize his wife, but some of her behavior upsets him.

Trying to get the right help is a major problem.

Working through the system to get the right help is frustrating.

Trying to contact doctors and carry on with other things is frustrating.

Recognized prescribed treatment wasn't working and contacted another doctor.

Worries that care for wound is correct and about the time to care for wound.

Wants to use another day care but worries about the change on she and her dad.

Visits by minister to her mother are good for her also.

Needs more convenient services and knowledgeable support people.

Received support through home health agency with respirator problems.

He tried an assisted living facility with an Alzheimer's unit but was not satisfied.

Services rendered in the home reduce the stress.

Can only participate in support groups if they have staff to care for her dad.

Church members were very attentive.

Regrets that she could not spend more leisure time with her mother.

Son is a source of support when available.

The aides are dependable and help a lot.

Appreciative of the response from physicians when she asked for help.

The mental stress of caregiving is difficult.

Neighbors are helpful.

The state provides financial aid.

The nurse and aide did the personal care and most of the medical responsibilities.

Daughter was an excellent source of social support.

The doctor did not accept patients on Medicare but made an exception.

It is difficult to get help from the medical profession, and it is frustrating.

She is overwhelmed and now has billing errors to correct which takes time.

She needs a lot of care, and her stubbornness just adds to my work.

When she is difficult, he has a hard time coping.

Having another person to share the responsibility would be good.

Attended the support group that was convenient and provided care so she did not have to find someone to stay with him.

Seeking outside help is her only option because she has no family to support her.

The caregiver did not have confidence in the doctor.

There was no one else to care for her mother.

Reaching out for professional help for an answer but not getting it.

Looking for answers to changes in wife and finally his family doctor helped.

Getting the right kind of help is frustrating.

B. Commitment

a. Obligation

I do this for her because she would do it for me.

Feels an obligation to care for wife because of duty and love for her.

Caring for her mother is her duty.

Has a duty and responsibility to honor his marriage vows.

It is a duty and obligation to care for one's parents.

Feels an obligation to care for parents.

Needs assurance of self-worth and some relief but obligated to care for her dad.

b. Responsibility

The neighbors would offer to help, but she wasn't sure they could care for him.

Can never get away from the responsibility no matter where she goes.

As time passes, she has to assume more responsibility.

Feels a sense of responsibility for mother.

As her condition declines, his responsibility becomes greater.

Has the responsibility of caring for both parents.

The direct care is over but the responsibility is still there.

She still feels the need to watch out for him.

The load she had to carry is not as heavy.

C. Coping

a. Problem-solving

Getting help from the system was difficult, so a State Senator helped me.

He got assistance through the doctor which lessened his care demands.

He is doing all he can for her, and is trying to deal with each problem as it arises.

It is easier to go her way to help the situation, as it is hard to take care of her.

The situation is stressful, and she is trying to make the situation less complicated.

It is difficult to take care of him so looking for ways to make it easier.

Problem-solving to cope with the demands of care.

Fears he won't hear her go to the bathroom and will have to clean up after her.

He is trying to meet her needs.

Special locks were placed on the doors to protect him.

Taking desperate measures to maintain some means of control and privacy.

Relies on her faith for support.

Trying to hold on to the things in life that are important to him.

The healthcare power of attorney empowered her to look at other care options.

b. Seeking Information/advice

Those in similar situations form a bond.

There are professionals and personal friends she can turn to for help.

Recognized that he had to have help and sought professional advice.

She needs some help, as she can't cope any longer.

I was told to continue to care for him, but my doctor said I was killing myself.

Through support groups has learned of other caregiving situations.

Support group provided information about alternate place for respite.

Nurses provided direction to get immediate help.

Clergy offered no help when approached.

Someone has to have been in the situation to understand.

People offered suggestions about the use of various services.

There are so many questions and no answers.

Clearly defined ways to access services are not available.

Did not know where to find caregiving information.

Needs information about parenting her parent.

The healthcare system provided helpful information.

The social worker gave her advise when she asked.

The Internet makes access to information easier.

c. Getting Away

Having respite weekends was a "Godsend."

Needs help to come to his house to give him some time away.

Help from other people gives him some time to himself.

Finds strength and support from old friends and he got a break.

The caregiver has learned to cope by getting away from the situation.

Found friends and paid help as a means of having time away.

Is managing to do some things that she wants to do.

A break is necessary in order to cope with the hard work of caregiving.

Caring for her dad became so demanding she could no longer cope.

Without a break, she would become ill and could not continue to care for him.

Day care gave her time alone which was restful even though she had things to do.

He needs to get away from the situation sometimes.

Work was a way to get away from the situation.

A nurse suggested day care.

A neighbor would sit for her.

d. Writing

It helped to document the changes that were occurring.

D. Loss

a. Social Life

Experiencing isolation because he had to give up social and personal activities.

His social activities and personal time are restricted.

One loses their social and personal life.

Maintaining contact with friends is difficult.

There is no time for social activities when you are the primary caregiver.

b. Personal Life

Quit his job to become a full time caregiver.

Gave up work and pursuit of further education to care for her dad.

Gave up own home to live with parents to care for her dad.

Wishes she had some privacy so she and a date could be alone for dinner.

There is no personal time for both she and her husband to be together.

I gave up my career and was able to stay home with him.

Quit her job as it was too frustrating to change client appointments so frequently.

She and her husband had little time together alone.

c. Freedom

Feels a loss of her freedom because of duty to her mother.

The freedom to come and go at will is gone.

Uses intercom system to allow some freedom of movement about the house.

Lonely and has lost freedom to socialize at will.

Responsibilities restrict freedom.

There was no way to get out of being with him all the time.

I could not go anywhere without him and had to watch him constantly.

The confinement was difficult and I was tired.

Meeting her mother's needs leaves no time to reflect.

Her mother cannot be alone for any period of time, restricting her freedom.

There is little time for anything other than caregiving.

Attending support groups takes time and does not always meet needs.

There is no time to meet own needs.

Availability of baby sitters and the cost restrict activities.

It would be helpful for someone to baby sit.

People are afraid to sit with an elderly person.

d. Relationships

It would be hard on him without her.

The relationship that once existed is gone, and the wife he used to have is gone, and he is now living her life and his life and it is not easy.

His inability to remember is a loss to her.

He knows he is losing her mentally.

Struggling with the loss of the person that she knew as her mother.

Becoming a parent to a parent is hard.

It was difficult to accept her parent's memory loss.

E. Emotions

a. Loneliness

Has no confidant and is lonely, so finds comfort in talking to her cat.

He was lonely without the companionship of his wife, and the cats provided some companionship.

The dog was company and helped relieve some of the loneliness.

The dog kept him from being so lonely.

Visits from brother would have been appreciated.

Phone calls from friends helped.

Family visits or call and takes them out to eat.

Giving up social activities results in loneliness.

Finds comfort in one another and from sharing memories.

It is good to have someone concerned about the caregiver.

b. Guilt

Feels guilty about taking him to day care.

Feels guilty that she put her mother in a nursing home.

Continues to reevaluate her decision because she feels guilty.

Recognizes her limitations but still feels guilty.

Criticism and lack of understanding adds to the frustration and guilt feelings.

Caregivers feel guilty about some comments to parents.

Lack of resources limited what caregiver could do and she feels guilty.

Feels guilt that her mother's condition deteriorated while in her care.

Feels guilty that her mother got sick while she was gone.

I feel better after being able to talk to someone.

She feels guilty that she could not do more.

c. Stress

Thankful that her mother does not complain, but worries that mother will not tell her something that is important which then creates more for her to do.

Enjoys visits from out-of-town relatives but he feels stressed.

He does not feel he can provide her everything she needs, and is hoping to find someone to help because he is stressed.

Family members are not prepared for the role of caregiver.

Well-meaning family can also cause additional stress.

Spousal support and recognition of efforts are important to the caregiver.

Caregiving is not easy.

There are more and more demands.

d. Anxiety

Concerned about own health.

Worries about the effects of her dad's behavior on daughter.

He worried when she was home alone.

As his condition declined, the greater her concern about his care.

I was not physically well myself.

I let someone else care for him and they did not know he left which is scary.

The dogs relieved some of the worry when she had to leave her mother alone.

e. Sadness

Sad that they are unable to travel as they planned.

Seeing her mother suffer makes her sad.

It is very sad and painful to see his wife as her condition deteriorates.

It is difficult to watch a loved one suffer.

She was sad as he got worse.

f. Frustration

The doctor does not recognize when older persons are not rational.

Perceived knowledge deficit in the medical community about geriatric care.

Frustrated with the staff's lack of knowledge about Alzheimer's patients.

Sometimes it is not worth the hassle to use day care.

The help were a hindrance as they did not come early as they agreed.

Frustrated with others who don't understand.

g. Anger

Angry because efforts to prevent injury were for naught.

He wants to be recognized for his hard work, not criticized.

Loves her dad and is angry about treatment from his son.

Angry at doctors that husband did not live as long as he was told.

The caregiver is angry that her life is controlled by caregiving.

She is very angry at some family members for not visiting.

Angry that friends did not visit more often.

His friend abandoned him when he got sicker which hurt.

My son was not a source of support.

Inability to cope can result in anger.

h. Uncertainty

Uncertain about the future because wounds continue to develop.

Worries about future and loss of independence if can't continue providing care.

Ever present concern that schedule will be disrupted by an unscheduled event.

Hesitant to accept help from volunteers who may not understand dad's behavior.

His care can be too much to handle so other arrangements may be necessary.

Worries about the future as there is a limit as to what she can ask of her family.

Uncertainty is a part of each day.

Wondering if assisted living would be better for her mother.

Needs to relate to someone who is in a similar situation.

Caregivers need reassurance.

The caregiver needs confirmation from someone that is also a caregiver.

APPENDIX J

Sample of Transcribed Interview

SAMPLE OF TRANSCRIBED INTERVIEW

My husband had open heart surgery and was in the hospital for several days at which time I would go to work during the day and then go to the hospital and spend the night with him because he was not happy with the nursing care he was getting nor was I, so I stayed with him. That was very tiring for me. Shortly after he came home, he was then diagnosed with cancer of the throat, and, at first, he decided that he was not going to have chemotherapy. The doctors, he was told he would live about 4 months if he didn't have it but after talking with our minister he decided to go ahead with it. The minister pointed out to him that it would be too late if he changed his mind in 3 months to start treatments so he decided it would be the smart thing to do. He had to stay in the hospital for his treatments and then he would come home and stay for a few weeks and just as he would get to feeling a little bit better it was time for him to go start another treatment and that was hard on him and hard on me. The doctors, I am not sure that the doctors are always honest in these situations because he asked them how long he would have because there were some things that he needed to take care of and they told him that he would have about 2 years. Well, that is not what happened. He died in 3 months, so I don't think that is right. I know that they don't know exactly, but they should be more honest about it with their patients.

I had a nurse and a home health aide, as a matter of fact from I. Home Health, that came and took care of him during the day and the aide was really the most help to

me. The nurse was helpful because he had to have antibiotics along the way and she gave those to him so that helped but with the aide that was the most help. I was working full-time and that I think was a life-saver for me. If I had not been able to go to work and get away from the situation, I am not sure what would have happened. It was a release for me and you have to have that otherwise you would not be able to stand it.

You have to give up a lot of your activities that you were doing and so you lose a lot of your friends, you just lose that contact. We used to go play bridge every week and would have friends over here often to play bridge but, after he got sick, he wasn't able to go like we used to and also being around people for a long period of time would just tire him out. People would come visit him in the hospital and after he came home and I would finally have to tell them that he was too tired to visit anymore. It has made me be more careful when I visit to keep it under 15 minutes. Friends would call to see if we needed anything and that helped. I don't have any family that lives near here, so I didn't have them to lean on and that may have been a good thing too because one of my daughter came and stayed for a week, and he was glad when she left and so was I. It was good to have her for a while but. They did call pretty often to check on us but its not the same as getting out and seeing your friends and doing things.

Because you just have to make so many changes and give up most of your social life, really it can be very lonesome. We couldn't go and do things like we did

before he got sick, so you can feel like you are all alone. I did attend a support group one time at the church, but it wasn't for me, and I never went back and you don't have the time either. I know some of the hospitals have support groups for cancer patients but we never went to any of them. I did find one support group that helped after he died and went to, well it was a six weeks class on how to grieve and that helped. We got this dog as a result of a couple breaking up and needing someone to take the dog and he was a Godsend. He was so much company to us when my husband was sick and he continues to be a lot of company to me and I guess that is why I have spoiled him so much. Animals can really help you. There is that unconditional love.

My caregiving did not last long, but I can tell you that it was hard work and very tiring. I would go to work, cause I had to work, and then come home and start taking care of his needs and that really leaves no time for you. You, you are just on a merry-go-round for a while or that is what it feels like. Just having something to give me a break from that would have helped. I hope what I have told you has been helpful to you and can be used to help someone else. If I can answer any of your questions later, I will be happy to talk to you.