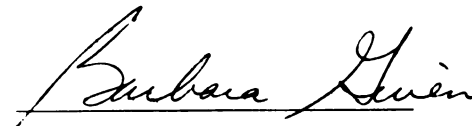




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THE RELATIONSHIP BETWEEN PERCEIVED SOCIAL ISOLATION
AND UTILIZATION OF RESOURCES IN ELDERLY WIVES
CARING FOR DISABLED HUSBANDS

By

Debra D. Berry

A THESIS

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

MASTER OF SCIENCE IN NURSING

1990

ABSTRACT

THE RELATIONSHIP BETWEEN PERCEIVED SOCIAL ISOLATION AND UTILIZATION OF RESOURCES IN ELDERLY WIVES CARING FOR DISABLED HUSBANDS

By

Debra Berry

An exploratory descriptive study of elderly wives was conducted to identify the relationship between wives' perception of social isolation and utilization of resources to assist wives in caring for disabled husbands.

Data were collected by means of home interviews and self-administered questionnaires from 61 elderly wives aged 65 to 80 years. Data were analyzed using descriptive statistics and Pearson-product moment correlations.

Significant relationships were found between Reliable Alliance, Attachment, Social Integration, and Guidance, subscales used to measure part of the affective support dimension of perceived social isolation, and Family Help and Friend Help, subscales used to measure the informal support systems, a dimension of resources. Additionally, a significant relationship was found between Feelings of Family Abandonment, an additional subscale used to measure affective support, and Family Help. Finally, a significant relationship was found between Social Resources, a scale used to measure the tangible support dimension of perceived social isolation, and Family Help.

Nurses should assess social isolation as a factor which may influence wives ability to continue home care.

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1990

DEDICATION

This thesis is dedicated to all women
who care for a disabled spouse.

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

-- Golodetz et al., 1969.

ACKNOWLEDGMENTS

Traditionally, words such as progress, advance, develop, and growth have been used to define the word process. To these traditional definitions I would like to add; patience, perseverance, confidence, and love. The completion of this thesis has truly taught me the meaning of the word process.

I am most grateful to my committee chairperson, Dr. Barbara Given. Without her unending patience, support, and confidence in me, the completion of this thesis would not have been. Barbara has been an exemplary mentor throughout my journey and preparation for advanced nursing practice.

I am also grateful to my committee members, Dr. Sharon King, who taught me not to worry until it was time, and to Dr. Rachel Schiffman and Brigid Warren for their time, support, and advice.

I also wish to acknowledge and thank Dr. Charles W. Given and Dr. Barbara Given for allowing me to use data from their study of family caregivers to elderly relatives.

I am also indebted to my friends and colleagues, Deanna Klaasse, Linda Keilman, Susan Jensen, Rebecca Cole and Carol Goffnett for their support, reassurance, and love. I am truly blessed by the friendship of these special women.

I would also like to acknowledge my sisters, brothers, and parents. They believed in me, supported me, and showed me they cared throughout this process. To Becky especially, I owe much love and thanks for her special faith in me.

And finally and most lovingly, I wish to express my love and gratitude to Carter, my husband and friend, and my beautiful children, Stephanie and Matthew. They always believed in me and what I could accomplish, even when I was unsure. They stayed by me, supported me, and loved me throughout this process. They each gave of themselves, so that I could realize my dream.

TABLE OF CONTENTS

	<u>Page</u>
LIST OF TABLES	ix
LIST OF FIGURES	xi
CHAPTER I	
Overview of the Problem	1
Purpose of the Study	4
Research Question	4
Definition of Concepts	4
Social Isolation	4
Elderly Wives	4
Caregiving Situation	5
Disabled Husbands	5
Utilization of Resources	5
Assumption of the Study	6
Limitation of the Study	6
Overview of the Study	7
CHAPTER II	
Conceptual Framework	9
Overview	9
Theoretical Framework	9
Definition of Pertinent Concepts	16
Social Isolation	16
Caregiving Situation	20
Utilization of Resources	21
Summary	24
CHAPTER III	
Literature Review	25
Overview	25
Social Isolation	25
Caregiver Burden	28
Perceived Social Isolation in the Caregiving Situation	29
Utilization of Resources	36
Formal Support Service Use	36
Informal Support Systems Utilization	43
Summary	49

CHAPTER IV

Method	51
Overview	51
Sample	51
The Longitudinal Study	52
The Present Study	53
Data Collection Procedure	54
The Longitudinal Study	54
The Present Study	55
Protection of Human Subjects	55
The Longitudinal Study	55
The Present Study	56
Operationalization of Study Variables	57
Social Isolation	57
Utilization of Resources	61
Informal Support Systems	61
Formal Support Services	62
Research Question	63
Reliability and Validity of the Instruments	63
Scoring of Instruments	67
Statistical Analysis	68
Summary	69

CHAPTER V

Data Presentation and Analysis	70
Overview	70
Sociodemographic Characteristics of the Study Sample	70
Age of Elderly Wives and Disabled Husbands	70
Race of Elderly Wives and Disabled Husbands	71
Education of the Elderly Wives	72
Income	73
Others Living in the Household	73
Health Insurance Coverage	74
Duration of Caregiving	74
Health Status of Elderly Wife	76
Summary of Sociodemographic Characteristics of Study	76
Analysis of the Data	77
Characteristics of the Sample	77
Statistical Analyses	79
Interpretation of the Research Question	84
Affective Support	85
Tangible Support	89
Summary	90

CHAPTER VI

Recommendations and Implications	91
Overview	91
Limitations of the Study	91
Study Design	91
Social Isolation Instrument	92
Study Sample	92
Intervening Variables	93
Recommendations for Further Research	93
Theoretical Model	96
Implications for Advance Nursing Practice	97
Implications for Nursing Education	103
Summary	105

APPENDICIES

Appendix A	107
UCRIHS Approval	108
Appendix B	110
Consent Forms	111
Appendix C	113
Affective Support Subscales	114
Appendix D	121
Tangible Support Scale	122
Appendix E	124
Informal Support Systems Subscales	125
Appendix F	127
Formal Support Services Subscales	128

REFERENCES	133
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LIST OF TABLES

<u>Table</u>	<u>Page</u>
4.1 Social Isolation and Utilization of Resources Instruments, Number of Items, Number of Subjects, and Reliabilities of Each Subscale	66
5.1 Age Distribution of Elderly Wives and Disabled Husbands	71
5.2 Race Distribution of Elderly Wives and Disabled Husbands	72
5.3 Distribution of Educational Levels of Elderly Wives	72
5.4 Distribution Combined Household Annual Income for 1986 (RS)	73
5.5 Distribution of Others Living in Household with Couples	74
5.6 Distribution of Type of Health Insurance Coverage	75
5.7 Distribution of Duration of Caregiving	75
5.8 Distribution of Elderly Wives Health Status	76
5.10 Distribution of Scores, Possible Range, Actual Range, Mean, and Standard Deviation of Subscales	82
5.11 Distribution of Formal Support Service Use for Wives and Husbands	83
5.12 Distribution of Individual Formal Support Service Use by Wives and Husbands	84
5.13 Correlations of Study Variables	85

LIST OF FIGURES

<u>Figure</u>		<u>Page</u>
1	Dynamic Interacting Systems	13
2	Dynamic Interacting Systems Applied to a Situation with Social Isolation	15
3	A Conceptual Framework for Studying Perceived Affective, Tangible, and Instrumental Support of Family and Friends and the Influence on Formal Support Services	98
4	King's Model of Human Interaction Adapted to Illustrate CNS and Elderly Wife Interaction	100

CHAPTER I

Introduction

Overview of the Problem

The increasing body of scientific knowledge and the technological advancements of our society are functioning to prolong life. Non-biomedical factors, such as changes in health behaviors and habits, coupled with high technological biomedical interventions, such as cardiac pacemakers, hemodialysis, and coronary artery surgery, have contributed to the prolongation of life (Avorn, 1986). As the generation of "Baby Boomers" reach their "Golden Years", in the year 2020, the population age 65 years and over is expected to reach 45 million in the United States (Botwinick, 1984). Seriously debilitating diseases associated with aging, such as heart disease and cancer, are predominate over much of the latter half of life (Fales, 1980). Therefore, we can expect to see an increase in chronic diseases and disabling illnesses in this population.

Chronic illness has been described as the major health problem of this generation (Brody, 1973). About 30% of the total population, 65 years and older, now need some amount of help to deal with these illnesses (Brody, 1985). According to Goldstein, Regnery, and Wellen (1981), the most frequent

care setting for persons with chronic impairments is the home. The majority of care the disabled person receives is provided not by health personnel, but by family members (Brody, 1985). It is the aging population that will require increasing amounts of home care by their family for chronic diseases and disabling illnesses or impairment. In addition, the health care in this country is a fragmented, free enterprise system, unconscionably expensive, and geared toward acute rather than chronic care (Coleman, 1984). The current prospective reimbursement system, in an effort to curtail health care spending, encourages decreased acute care admissions and shorter lengths of stay in the acute care setting. This has resulted in increasing numbers of acutely ill people being cared for in their homes, most likely, at the expense of their family.

The home is traditionally viewed as being under the domain of a woman. Nightingale (1860) acknowledged the role women play in caregiving when she implied that every woman is a nurse. Women have historically served in the role of caregiver, learning their nurturing roles as daughters, wives, and mothers (Coleman, 1984). Wives especially are expected to respond to the need for care and take responsibility for the care of their disabled spouses (Fengler & Goodrich, 1979). It is estimated that at least 80% or more of the primary caregivers of older family members are women (Sommers, 1985). It is, therefore, important to examine the role women play in providing care at home to a disabled family member.

The dimensions of family caregiving are multiple and complex. Because the life expectancy for women is higher than for men (Botwinick, 1984), many women will find themselves caring for a disabled husband. These wives are a particularly high risk group of individuals that Fengler and Goodrich (1979) call the "hidden victims", because many of these wives need as much help and support as their disabled husbands do.

Elderly wives exert efforts in caring for disabled husbands, but their capabilities are contingent on their own energy and strength which may be reduced, and age related ailments. Therefore, these wives may require attention to their own needs for health care, respite, concrete helping services, and emotional support (Brody, 1985). This help may be elicited from a variety of resources, such as the informal support systems of family, friends, and neighbors, or from formal support services, such as private or publicly subsidized organizations, particularly those emphasizing health care.

There is a paucity of research studies on caregiving investigating the effects family caregiving has on elderly wives caring for disabled husbands. In particular, little research exists addressing elderly wives' perceptions of social isolation and their relationship between social isolation and the use of resources to assist these wives in caring for their disabled husbands. Social isolation is a phenomenon experienced by many elderly wives caring for disabled husbands (Coleman, 1984; Crossman, London, & Barry,

1981; Fengler & Goodrich, 1979; Thompson & Haran, 1985). Therefore, it is important to understand how social isolation may influence elderly wives caring for disabled husbands and their use of resources to assist them in caregiving.

Purpose of the Study

The purpose of this descriptive exploratory study is to examine the relationship between perceived social isolation by elderly wives caring for disabled husbands and the resources utilized by these wives to assist in caregiving.

Research Question

Is there a relationship between perceived social isolation in elderly wives caring for disabled husbands and the resources utilized to assist these wives in caregiving?

Definition of Concepts

For the purpose of this study, the concepts within the research question are defined as follows:

Social Isolation

For the purpose of this study, social isolation is defined as low levels of social interaction.

Elderly Wives

The concept elderly is abstract. Webster (1986) defines elderly as: rather old, being past middle age, relating to or characteristic of later life or elderly persons. Elderly groups have been described in terms of subcultures and status. For the purpose of this study, elderly wives are defined as women 65 years of age and older and currently married.

Caregiving Situation

In this study, the caregiving situation is defined as an elderly wife who is providing care at home for her disabled husband. Additionally, the following factors contribute to the caregiving situation: the duration of caregiving, the living arrangement and the financial status of the elderly wife and her disabled husband, the elderly wife's perception of affective and tangible support, the utilization of resources by both the elderly wife and the disabled husband, and the elderly wife's age, education, and health status.

Disabled Husbands

In general, disability is defined in terms of functional and/or cognitive impairment (Bowers, 1987; Coleman, 1984; Haley, Levine, Brown, Berry, & Hughes, 1987; Thompson & Haran, 1985). Fengler and Goodrich (1979) refer to the disabled husband as a man who has been inactive for an extended period of time because of disability. In this study, disabled husbands are defined as men age 64 years of age and older who are currently married and dependent on their wives to provide assistance in at least two activities of daily living (ADL) and/or instrumental activities of daily living (IADL).

Utilization of Resources

Resources are defined in this study as the informal support systems, such as family, friends, and neighbors, and formal support services, such as services provided by agencies, used in behalf of both the elderly wives and/or their disabled husbands to assist these wives in caregiving.

Assumptions of the Study

1. The concept of social isolation is a real and a measurable phenomenon.
2. Social isolation may not be voluntary.
3. The instruments used in this study are sensitive enough to measure the concept of social isolation and utilization of resources.
4. Social isolation of elderly wives caring for disabled husbands inhibits the opportunity/ability of wives to interact with others.

Limitations of the Study

1. There is no control for other variables which could influence social isolation, such as previous patterns of social interaction, personality type, life-style, health status, environmental influences, morale, age changes, and major life transitions.
2. The subjects who agreed to participate in this study may be different from those who refused. Socially isolated subjects may not have participated. Therefore, this sample may not be representative of all wives who provide care for disabled husbands.
3. No determination is made if the wives in any way foster their husbands' dependency on them, thus contributing to an inability to interact with others.
4. It is not known if an anticipated disability (such as Parkinson's disease) versus an unanticipated disability (such as the effects of a stroke) alters the experience

of social isolation.

5. This is a one time measure. Participants in this study have been in the caregiving role for a varied period of time. Perceptions of social isolation may differ at different points and time. Veteran caregivers may perceive less social isolation than new caregivers.
6. This study utilizes measures from a previous study (Given & Given, 1987-89) which were not originally designed to measure social isolation.
7. Wives may answer according to social mores, rather than how they feel. The potential for the effects of bias due to social desirability exists in measures for social isolation and utilization of resources.

Overview of Study

This thesis contains six chapters. In Chapter I the background and purpose of the study, research question, definition of concepts, and the assumptions and limitations of the study are presented. The conceptual framework of the study is described in Chapter II and includes the concepts of social isolation, caregiving situation, and utilization of resources. The relationship among these concepts is explored, and a conceptual model for the study, based on King's (1981) theory of nursing is presented. In Chapter III, a review of the literature pertinent to the research problem is presented. A description of the research methodology and design utilized are discussed in Chapter IV. Study findings and interpretations are presented in Chapter V. Finally, in

Chapter VI implications for advanced nursing practice, education, and future research is suggested.

CHAPTER II
Conceptual Framework
Overview

The focus of this descriptive study is to explore the relationship between social isolation perceived by elderly wives caring for disabled husbands and the resources they utilize to assist them in caregiving. In this chapter, the theoretical model for this study, based on King's (1981) theory of nursing is presented. The concepts pertinent to the conceptual framework are defined. The relationship among the concepts are explored. A model is also presented to depict the relationship among the concepts.

Theoretical Framework

The conceptual framework for this study is based on King's (1981) theory of open systems and her model of human interaction. King utilizes an interactional systems approach to explain and study human beings interacting with their environment. King's theory provides a framework for studying perceived social isolation and its relationship to utilization of resources by elderly wives caring for disabled husbands.

The goal of family caregiving is to maintain and provide care for a relative in the home. Achieving that goal may be dependent on the resources available and utilized to assist

family caregivers and/or their relatives in providing care. Therefore, it is important to understand what barriers exist that prevent a family caregiver, such as an elderly wife who cares for her disabled husband in the home, from interacting with the resources needed to successfully provide care.

King (1981) defines interactions as the acts of two or more persons in mutual presence (p. 85). According to King; when two systems come together for a purpose they are each perceiving the other and the situation, making judgments, taking mental action, or making a decision to act. The perception of the situation, as it relates to elderly wives caring for disabled husbands, is discussed in this chapter. The judgments, actions, and reactions of the interaction will be discussed in a later chapter.

The central focus of King's (1981) theory is the individual interacting with other individuals and with his/her environment. In this study, it is the elderly wife's ability/inability to interact with her environment in order to procure resources to assist in caregiving that is of concern.

King (1981) describes environment as three dynamic interacting systems, the personal system, the interpersonal system, and the social system. Each of these systems permits the exchange of matter, energy, and information. The permeability of the three systems identified by King is depicted in Figure 1 by the broken lines.

Individuals make up the personal system. Individuals are viewed by King (1981) as reacting, time-oriented, social beings with the ability to perceive, think, feel, choose, set goals, and make decisions. In this study, the elderly wife represents a personal system. Several concepts are described by King that will help understand the elderly wife and her ability to interact as an open system: perception, self, space, and time.

According to King (1981), human beings react to events in terms of their perceptions. A perception is each human being's reality, and an awareness of his/her object and events (p. 20). Perceptions are unique for each person because of his/her individualized past experiences, concepts of self, socioeconomic group, biological inheritance, and educational background (p. 20). It is the individual's perception that becomes the basic data for human interactions. Elderly wives' perception of their situation, as primary caregiver of their disabled husbands, influences their experience of social isolation.

The self is a dynamic, open system, perceived in relation to another person or object in the environment (King, 1981). Interactions with relevant others gives an individual a sense of self. The self is goal-oriented. King states that each person has acquired a system of values, needs, and goals that gives him/her an awareness of personal separateness; yet each person's value system recognizes the influence of significant others and their reaction to the self. When interference in

self occurs, such as may happen when elderly wives care for disabled husbands, an inability/opportunity to interact with others may occur, thus preventing the acquisition of needed/desired resources to assist in caregiving.

According to King (1981) space is universal and situational. Space has no boundaries or spatial distance and can be expanded or contracted depending on the nature of the relationship in each situation. Space is also transactional. A person's use of space is based on his/her perception of a situation. Space determines the transactions between an individual and his/her environment. Hence, caregiving elderly wives may experience a contraction of space available to them, both physically and socially, because of their limited interaction with others.

Time is defined by King (1981) as a sequence of events moving onward to the future. It implies change, a past, and a future (p. 148). When an individual perceives a succession of events, there is order and duration implied. Either lengthening or shortening the order and duration of time determines how one perceives the succession of events in the environment (p. 43). The duration of caregiving for a disabled husband may contribute to an elderly wife's ability/opportunity to interact with others in the environment.

In Figure 1, the elderly wife and the disabled husband are illustrated as two distinct personal systems by enclosing each in a separate circle. The dotted lines of each system

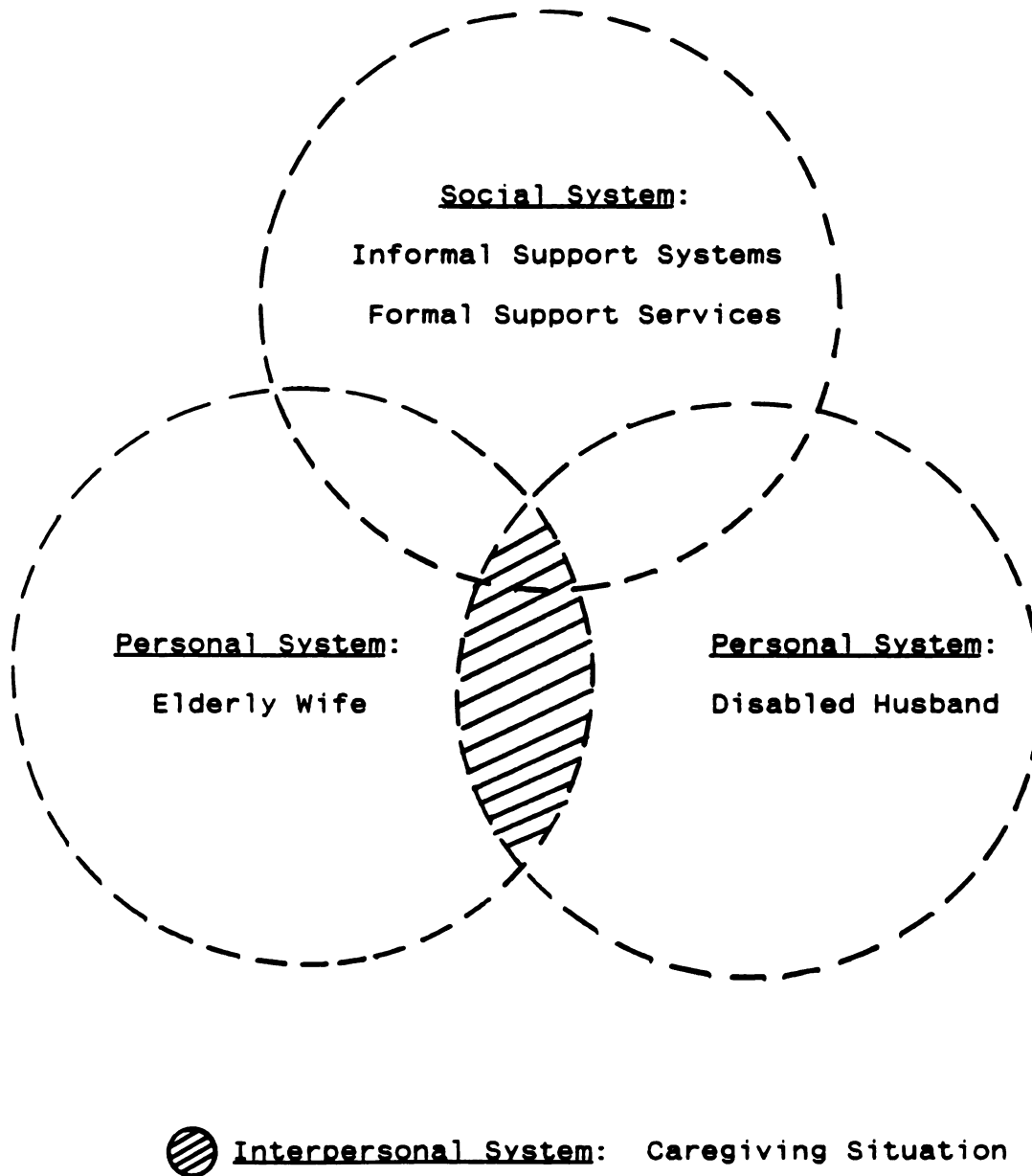


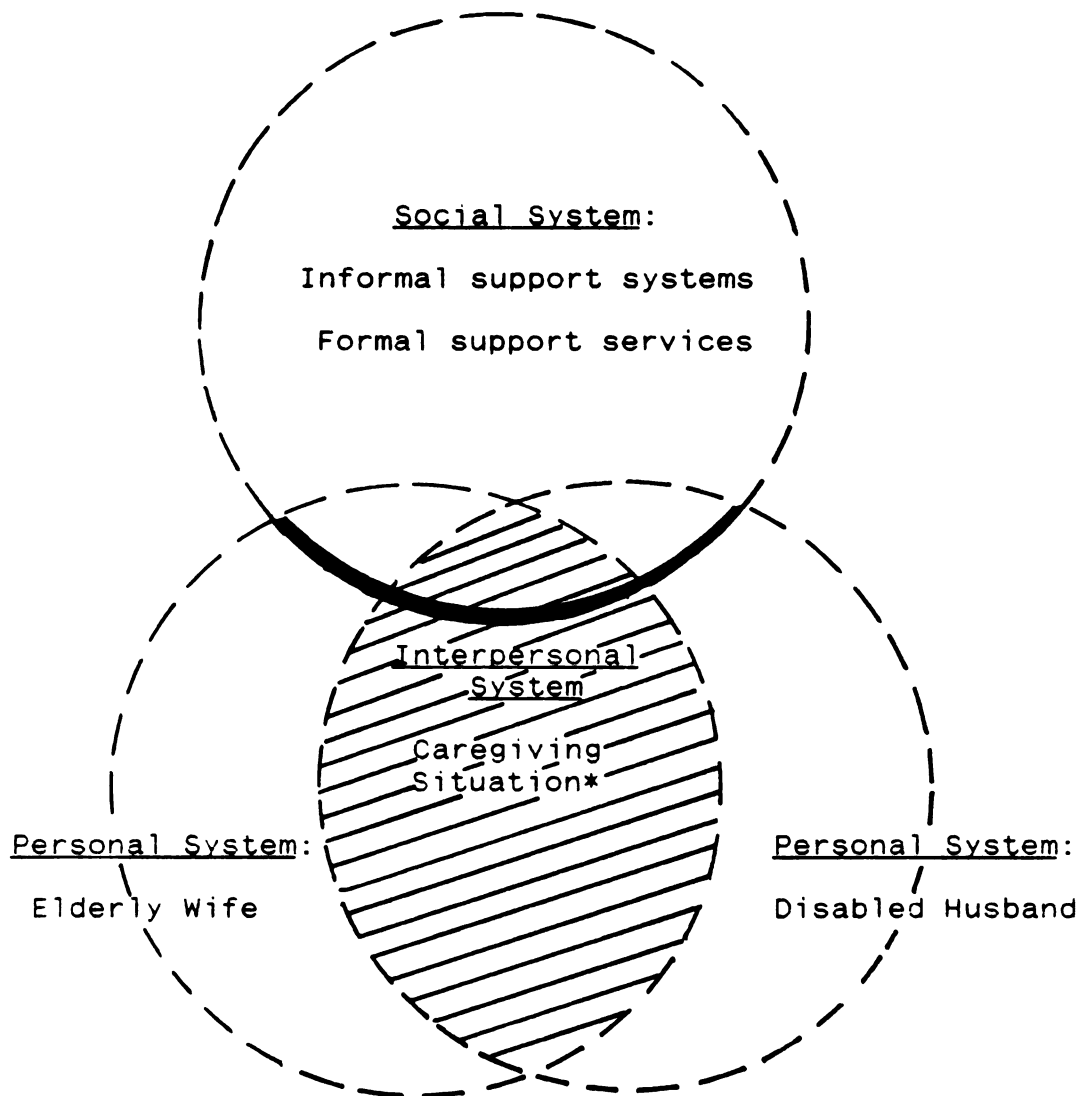
Figure 1: Dynamic Interacting Systems. (Adapted from: King, I. (1981) A Theory for Nursing, New York: John Wiley & Son).

represents the permeability of their boundaries and the ability of each system to interact with the environment.

The interpersonal system is defined by King (1981) as two or more individuals interacting in a given situation. In this study, the interpersonal system is composed of the elderly wife and her disabled husband in a caregiving situation. Again, in Figure 1 the interpersonal system is enclosed as a separate system with the dotted line representing the permeability of its boundaries and thus, the ability of this system to interact with the other systems.

Structural elements such as, informal support systems and formal support services, constitute social systems. In this study, the social system is comprised of informal support systems and formal support services that may be utilized by the elderly wife to assist both herself and her disabled husband in the caregiving situation. Figure 1 depicts the social system enclosed as a separate system with the dotted lines representing its permeable boundaries and its ability to interact with the other systems.

Elderly wives caring for disabled husbands may experience less opportunity for interaction with informal support systems and formal support services and less permeable boundaries within their environment because of their perceptions of being socially isolated, thus limiting the exchange described by King (1981). This is illustrated in Figure 2 by the solid lines.



*Additional Situational Descriptors:
Financial Status
Perceived Affective Support
Perceived Tangible Support
Coverage by Health Insurance
Age, Education, Health Status

Figure 2: Dynamic Interacting Systems Applied to a Situation With Social Isolation.

In summary, King's (1981) theory of open systems and her model of human interaction is presented as a framework for studying the perception of social isolation in elderly wives caring for disabled husbands and the relationship between their utilization of resources to assist both themselves and their disabled husbands in caregiving. Figure 1 is an illustration depicting the ability of the personal, the interpersonal, and the social systems to Figure 1 interact. Figure 2 represents how the perception of social isolation blocks the ability of the elderly wife caring for her disabled husband to interact with informal support systems and formal support services. In the next section the concepts pertinent to this study; social isolation, caregiving situation, and utilization of resources are defined and the relationships among them explored.

Definition of Pertinent Concepts

Social Isolation

Social isolation is the absence of specific role relationships which are generally activated and sustained through direct personal face-to-face interaction (Bennett, 1981). According to Whalen (1980), social isolation is a loss of social roles, social support, and environmental contact which is varied, stimulating, and fulfilling. The basis of Whalen's definition is decreased social interaction.

Goldstein et al. (1981) contend that role constriction occurs when virtually all of an individual's activities center around a single role, such as caregiving, and interpersonal

transactions and opportunities to obtain role relief become minimal. The most frequently mentioned and most severe effects for over half of the caregivers Goldstein et al. studied was confinement within the home and restriction of their activities outside of it. Goldstein et al. noted the more physically and psychologically taxing the caregiving role, the greater the likelihood that virtually all other roles and activities will be sacrificed to the demands of caregiving. Goldstein et al. reported when there is only one caregiver, such as an elderly wife, she becomes almost house bound as the functions and demands related to caregiving increase and the time for self and energy of the wife decrease.

Cole (1984) states confinement and restriction of activities, due to caregiving, is a frequently mentioned problem. Others have also reported that elderly wives caring for disabled husbands often experience role constriction and decreased interaction with their environment (Crossman, London, & Barry, 1981; Fengler & Goodrich, 1979; Goldstein et al., 1981; Thompson & Haren, 1985).

Ravish (1985) defines social isolation as disengagement/self-engagement gone wrong. In the aging theory of disengagement, Cumming and Henry (1961) imply disengagement is the result of mutual decreased interaction between the aging individual and others in the social system to which he/she belongs.

Bennett (1981) states social isolation is either voluntary or involuntary. As a voluntary process, the individual disengages him/herself from society as his/her energy level diminishes. Involuntary disengagement is withdrawal from social roles which occurs as the result of external forces or influences that limit and/or prevent social interaction (Bennett, 1981).

The caregiving situation may inhibit elderly wives caring for disabled husbands from initiating independent social activities that contribute to their well-being because of role constriction and role fatigue (Goldstein et al., 1981). The constriction of interaction with others because of caregiving is a form of involuntary disengagement because of its external nature.

Elderly wives' perception of their situation, as primary caregivers for their disabled husbands, influences their experience of social isolation. A variety of factors may contribute to the perception of social isolation for these wives, such as: the duration of caregiving, financial status, living arrangements, their age, educational background, and health status. Additionally, other factors contributing to elderly wives perception of social isolation include their perception of affective and tangible support. Others probably contributing, but not being analyzed for the purpose of this study include: previous patterns of social interaction, level of caregiving involvement, husband's level of dependency, environmental influences, and whether the role of caregiver

was taken on voluntarily or involuntarily.

Weiss (1973, 1974) identified components of social relationships or provisions which describe perceived affective support elderly wives receive through their interactions with others; attachment, social integration, reliable alliance, and guidance. Attachment represents a close, intimate relationship with another person, such as a confidant. Social integration involves being enmeshed in a social network, where an individual can share common interests and engage in social activities. Reliable alliance is provided by relationships where the individual can count on assistance under any circumstance. And finally, Guidance is provided by relationships with trustworthy and authoritative others who can provide advice. These concepts are pertinent to understanding the type of affective support elderly wives caring for disabled husbands may need or desire to assist them in caring for their husbands. In a caregiving situation, an elderly wife who perceives herself to be socially isolated, may be constrained from interacting with others who may provide her with these types of affective support.

Given, Given, Stommel, Collins and King (1988) describe the reaction to caregiving from the dimensions of Feelings of Family Abandonment and Impact of Caregiving on Daily Schedule. The perception of affective support in elderly wives caring for a disabled husband may be effected by feelings of abandonment by the elderly wife's family and by the impact caregiving has on the elderly wife's schedule. Family

abandonment is the caregiver's feelings of how much other family members have left them to provide care for their relative. Impact on daily schedule is the influence of caregiving upon important aspects of the caregiver's life. Both of these dimensions are important in understanding how perceived social isolation of an elderly wife in a caregiving situation may effect her ability to interact with the informal support systems and the formal support services needed or desired to assist her in the caregiving situation.

Finally, perceived tangible support consist of the number of contacts an elderly wife has with friends and relatives. These may be either face to face, via telephone, or in writing.

In summary, perceived social isolation of an elderly wife caring for her disabled husband occurs as decreased interaction and contact with her environment develops. This decrease in interaction may prohibit an elderly wife from utilizing resources, provided by informal support services and formal support systems, to assist her in the caregiving situation.

Caregiving Situation

In previous research, family caregiving has been studied from the perspective of the caregiver's involvement and/or burden. Archbold (1982) states that these caregiving activities may include the daily management of problems such as incontinence, diarrhea, constipation, rest, feeding, planning a well-balanced diet, bathing, lifting, transferring

from bed to chair, and/or from a chair to the bathroom. Caregiver involvement is defined by Given, King, Collins, and Given (1988) as the activities that caregivers engage in to maintain a patient at home. Given et al. also suggest caregiver burden is the beliefs regarding how caregiving has an impact on different dimensions of the caregiver's life.

Bowers (1987) examined caregiving from the caregiver's perspective, allowing for both task and perception of caregiving to be considered. Bowers describes caregiving as primarily invisible, and as the meaning or purpose a caregiver attributes to the behavior itself. This enables any process engaged in by the caregiver in providing care to be examined.

In this study, the caregiving situation is not concerned with either the involvement or burden of caregiving, but rather the caregiver's perception of being socially isolated. Consequently, in a caregiving situation in which the caregiver perceives his/herself to be socially isolated, the ability to access and utilize resources to assist in caregiving may be obstructed.

Utilization of Resources

Little is known about the barriers which may affect the ability of family caregivers to access needed or desired resources to assist them in caregiving. This researcher believes social isolation is one variable that may influence a family caregiver's ability to access and utilize resources to assist them in caregiving.

Coulton and Frost (1982) suggest the socially isolated elderly may have weak ties to community agencies, such as social and health services, which may provide information about formal support services. Thus, the socially isolated may be unaware, as well as unable to access these services. Access to information about formal support services becomes critical for an elderly wife caring for her dependent husband in order to obtain needed and/or desired assistance for both herself and her disabled husband.

In the summary of findings from the National Survey of Caregivers (1988), conducted for the American Association of Retired Persons, lack of awareness of available formal support services is cited as the second most frequent reason for non-utilization of formal support services by caregivers. Two potential sources of assistance utilized by caregivers to assist them in caregiving have been identified; informal support systems and formal support services (Chappell & Havens, 1985; Given & Given, 1987-1989; Greene, 1983). Specifically, these authors define informal support systems and providers as the networks of family, friends, and neighbors who supply supportive care to the patient and the caregiver; and formal support services as those agencies who make up the large scale systems of formally organized private and public subsidized agencies.

Informal support systems encompass the tangible assistance with personal care and household management. Elderly wives caring for disabled husbands who perceive

themselves to be socially isolated may not be receiving the tangible assistance or the affective support needed or desired because of their impaired interaction with family, friends, and/or neighbors.

Formal support services are comprised of private and public agencies and organizations which provide entitlements to housing, education, safety, transportation, and health and social services. If elderly wives caring for disabled husbands are to become aware of such services and to successfully access these services, they must be able to interact with the organizations and/or agencies which supply these services.

Caserta, Lind, Wright, and Redburn (1987) identified respite, day care or in-home care as being the most commonly utilized services by family caregivers. The common goal of these services according to Caserta et al. (1987) is to provide necessary care to the patient while allowing the primary caregiver, such as an elderly wife, needed time away from the caregiving role. Time away, or free time, from the caregiving situation permits the caregiver to engage in interaction with the informal support systems and formal support services, and thus pursue potential resources to assist him/her in caregiving. Additionally, informal support systems and formal support services also provide the opportunity for caregivers to do what is needed, such as tending to legal and business needs, and shopping for equipment, supplies, and food.

In summary, a caregiver's ability to utilize resources which may provide tangible assistance and affective support to assist them in caregiving, may be limited as a result of the caregiver's perception of being socially isolated.

Summary

In this chapter, King's (1981) theory of open systems and model of interaction was used as a framework for studying the relationship between perceived social isolation in elderly wives caring for disabled husbands and the wives use of resources to assist them in caregiving. A conceptual model was presented to depict the relationship between social isolation in elderly wives caring for disabled husbands and their use of resources to assist them in caregiving. Each of the concepts pertinent to the study was delineated and the relationship among them explored.

A review of current literature pertinent to social isolation, caregiving, and utilization of resources will be provided in Chapter III. Additionally, the strengths and limitations of previous research will be described to establish the relevance of and need for this study.

CHAPTER III
Literature Review
Overview

In this study, the relationship of social isolation and the utilization of resources in the elderly wives caring for the disabled husbands is explored. Research studies and scholarly writings, from nursing and the social sciences are presented and critiqued in this chapter, in order to establish the rationale for this research. This literature review focuses on perceived social isolation and utilization of resources by caregivers to assist in caregiving. The implications of the studies reviewed and the direction of the present research conclude the chapter.

Social Isolation

Social isolation in this study was defined as low levels of social interaction. A research study by Levine (1969) is presented first to support the concept of decreased interaction in elderly persons, followed by a brief discussion of the burdens of caregiving. And finally, research studies and scholarly writings by Crossman et al. (1981), Fengler and Goodrich (1979), Haley et al. (1987), Sexton and Munro (1985), and Thompson and Haren (1985) related to perceived social isolation will be reviewed in this section.

Levine (1969) studied the decrease in older individuals' interaction with their environment by investigating the relationship between the decline in life's central roles and disengagement. Nineteen subjects, age 50 years and older were chosen from a population of individuals residing in a low-income neighborhood housing project on the upper west side of New York City. An attempt was made to choose an equal number of men and women to provide heterogeneity in regard to gender.

Subjects were interviewed in their homes and information obtained was based primarily on retrospective data supplied by the interviewee in response to precoded short-answer questions that followed a prescribed sequence. Questions were designed to discover the respondents' perception of their present interaction rate as compared with that of their past life. Other questions were designed to yield comparisons among amounts of different kinds of interaction.

Levine (1969) defined life's central roles as work for men and unmarried women, and marriage and family for previously married women. Disengagement was said to be in evidence if the number of social roles was five or less and the interaction index was below three on a five point scale. Description of scoring of the interaction index is not discussed.

Levine (1969) found 70% of the subjects exhibited scores of either one or two on a five-point interactions index, 16% of the subjects were engaged in six or more roles, and 84% exhibited some evidence of decreased interaction. Thus, data

derived from the role count, and the interaction index indicated that the sample population had decreased their interactions and were consequently classified as either disengaged or in the process of becoming disengaged.

By including subjects of mixed ethnicity and low socioeconomic status, and by examining how the loss of life's central roles contributes to altered interaction of individuals with their social system, Levine's (1969) work affords a better understanding of the change in interactions of elderly persons previously described by Cumming and Henry (1961). However, the small sample size reduces the generalizations that can be made.

In summary, Levine's (1969) study demonstrates that aging individuals see fewer people, less often, and for shorter periods of time than they did at earlier ages. Levine suggest the loss of one's central roles in life is related to the decreased rate of interaction with others. However, Levine's (1969) explanation does not allow for possibility of the decrease in interactions occurring as a result of the aging individual's living situation. Although elderly wives caring for disabled husbands may experience decreased interactions due to either functional reasons or loss of central roles, the caregiving situation may also alter these wives level of interaction and generate feelings of social isolation. In the next section the concept of burden as it relates to perception of social isolation in the caregiving situation is discussed.

Caregiver Burden

The burdens of caregiving are well documented in the literature (Fitting, Rabins, Lucas, & Eastham 1986; George & Gwyther, 1984; Montgomery, Gonyea, & Hooyman, 1985; and Zarit, Reever, & Bach-Peterson, 1980). Zarit et al. (1980) first reported finding that the extent of burden reported by family caregivers was associated with the social supports available. Montgomery et al. (1985) distinguished the concrete events, happenings, and activities of caregiving from the feelings, attitudes, and emotions expressed about the caregiving experience. Thus, Montgomery et al. defined burden as having both an objective and a subjective component. Objective burden was defined as the extent of disruptions or changes in various aspects of the caregivers' life and household, and subjective burden as the caregivers' attitudes toward or emotional reactions to the caregiving experience.

Montgomery et al. (1985) contend that different factors predict each type of burden, that is, subjective burden is related to characteristics of the caregiver, while in contrast, objective burden is related to the type of caregiving tasks performed. What is of significance is that burden, whether objective or subjective in nature, contributes to social isolation as the task of caregiving confines the caregiver in terms of interactions with others. This decrease in an elderly individual's interactions may lead to their perception of social isolation, and thus inhibit them from accessing needed or desired resources and lead to caregiver

burden.

Perceived Social Isolation in the Caregiving Situation

Contrary to an acute illness, chronic disabling illness often involves the need for long term care. The impact of caring for a spouse with a chronic disabling illness was examined by Sexton and Munro (1985). Subjects were 46 wives of men who had a diagnosis of Chronic Obstructive Pulmonary Disease (COPD) and 30 wives whose husbands did not have a chronic disease. Questions were designed by the investigators and focused on: a) the activity level of the wife, such as recreation and diversion, b) who the wife relies on for help, c) with whom the wife discusses problems, and d) activities relinquished. Data were collected by mailed questionnaires.

Sexton and Munro (1985) found only about one-third of the wives of husbands with COPD indicated that they talked over problems with either a child, friend, or their husbands, while nearly one-half of the wives of husbands with no chronic illness, indicated that they talked over problems with either a child, friend, or their husbands. All of the wives indicated when in need of help, they relied comparably on children, physicians, and neighbors. Wives of husbands with COPD relied on friends for help only 37% of the time, while wives of husbands with no chronic illness, relied on friends 73.3% of the time for help. Additionally, Sexton and Munro found almost one-third of the wives of husbands with COPD reported they had given up social activities because of their husband's illness, while only 13.3% of the wives of husbands

with no chronic illness indicated that they were involved in fewer business related activities.

The Sexton and Munro (1985) findings must be considered with caution. They did not make any attempt to match the wives according to age, socioeconomic status, or other sociodemographic variables which may influence the caregiving wives ability to interact with others. However, their work does provide some information about the perception of affective support by wives who care for a husband with a chronic disabling illness.

Thompson and Haran (1985) found social isolation was a major problem, which increased over time, for elderly wives caring for disabled husbands. Their subjects consisted of 109 British caregivers, 82% of them women, mostly wives caring for husbands with an amputation, and more than one-third of the sample were aged 65 years and older. Thompson and Haran divided their sample into two groups. The Early Group (n=61) were caring for amputees starting prosthetic rehabilitation and the Established Group (n=48) were caring for amputees who had worn prostheses for one to two years. Thompson and Haran postulated that caregivers of amputees who had gone through the rehabilitation process and had worn prosthesis for one to two years might be less isolated. Data were collected via a semi-structured interview with subjects predominantly in their own homes. A social isolation scale devised by Townsend (1974) was utilized to measure social isolation in the sample.

Thompson and Haran (1985) found 47% of the total subjects studied were socially isolated. Subjects reported feeling themselves subjected to "house arrest". Further, they found the difference between social isolation in the Early Group and in the Established Group was statistically significant, with 36% of the Early Group and 58% of the Established Group judged to be socially isolated. Thus, it appeared that social isolation had become formidable with the passage of time. Additionally, Thompson and Haran reported that increase in social isolation was associated with the caregivers diminished capacity to express needs.

Fengler and Goodrich (1979) suggested, that for an elderly wife caring for a disabled husband, the increased demands and the increased time spent caregiving leads to a greater sense of isolation and to less time spent engaging in meaningful activities as well as less time spent with other significant confidants.

Fengler and Goodrich's (1979) study emerged from an evaluation of a volunteer workshop in a setting for older handicapped males in a northern New England city. The sample consisted of 15 wives, ranging in age from 58 to 81 years old who were caring for husbands who had been inactive for an extended period of time because of their disabilities.

Senior year nursing students interviewed subjects at three different times approximately two months apart. No information about the type or content of the interview is reported by Fengler and Goodrich (1979), nor do they report

any statistical analysis of their findings. Fengler and Goodrich also acknowledge the sense of isolation found in their sample is probably heightened by New England winters which keeps people indoors more, and thus hinders social interactions.

Fengler and Goodrich's (1979) study did not consider how the level of the husbands' disability, nor how the duration of caregiving effected the wives' sense of isolation. They did however, attempt to look at the elderly wives' situation over a longer period of time. Fengler and Goodrich's study findings must also be considered with much caution because of their small sample (n=15).

Crossman et al. (1981) reported on the effect of a multi-service support program for older women caring for disabled husbands at home. The majority of the wives participating in the group were caring for husbands who were brain-injured to some degree, either from a stroke or organic brain disease. At the time the article was written, a total of 101 wives had participated in the group since its inception. Attendance at the meetings averaged 15 to 20 wives. Crossman et al. state, "the issues raised within the group meetings corroborate the findings from other studies. There is a prevailing sense of isolation, both social and emotional" (p. 466). Crossman et al. cite an example given by one wife, "We were prisoners in our own homes." (p. 466).

Crossman et al. (1981) state that the participation in support group did reduce the social and emotional isolation

experienced by wives. Although Crossman et al.'s conclusions are not based on empirical methods, they do support the premise of perceived social isolation by elderly wives caring for disabled husbands.

Haley et al. (1987) studied the social consequences of caring for a relative with senile dementia by comparing a group of caregivers with a matched control group. Subjects in the caregiver group were screened to assure that they had daily responsibility for a community-dwelling relative who was over 60 years of age, and who had at least a six-month history of cognitive and functional impairment suggestive of dementia. Subjects were matched as closely as possible for age, sex, race, and marital status. Subjects in the caregivers group were visited in their homes by a research assistant who administered the Mini-Mental State (MMS) to the relative identified as demented. If the subject's relative scored less than 24 on the MMS they were given a structured interview and a number of questionnaires.

Social support and activity measures were measured using the Health and Daily Living Form (HDLF), which includes measures that provide information concerning the frequency of interactions with others, such as; the number of friends and close relationships, network contacts, activities with family, and church attendance. In addition, a scale developed by Haley et al. (1987) to measure satisfaction with network size and activity was administered along with a question asking subjects whether they had had a vacation in the past six

months, and whether they planned a vacation in the next six months.

Preliminary analysis were made comparing the caregivers and controls on basic demographic information. In the control group the mean age of subjects was 53.4 years, 77% were female, and 64% were married. In the caregivers group the mean age of the caregiver was 58 years, 80% were female, and 70% were married. Caregivers and controls did not differ significantly on these or other demographic variables, such as race, education, and income which had been purposely matched.

Caregivers showed no differences from controls on measures of social network size, such as number of friends and close relationships. Both groups also had similar numbers of social network contacts and activities with families. Despite these similarities in actual network size Haley et al. (1987) reported caregivers were significantly less satisfied with their network than controls. Caregivers were also reported to have been clearly hampered in their activities. Significant decrement in activities with friends, current and planned vacation, and church attendance was observed.

The strength of Haley et al.'s (1987) research lies in their attempt to control for variables which may effect how caregiving impacts caregivers socially through use of a control group. While attempting to control for more variables, the total number in each study remained relatively small (n=44) in each group. Haley et al. acknowledge some of

the requirements for participation in their study appeared to exclude a subsample of caregivers with even fewer social supports and poorer health, who cited those problems as their reason for not participating in the study.

The findings in the Haley et al. (1987) study should be considered and applied cautiously to elderly wives caring for disabled husbands. Caregiving wives accounted for only 18% of the caregivers (n=8), while caregiving daughters comprised the majority of the caregivers studied (n=22). No comparisons were made of the relationship of caregiver to the care recipient. However, these results do provide supportive evidence that family caregivers experience major changes in their social functioning which may contribute to a sense of social isolation.

In summary, the studies in this section were presented to show that elderly wives' caring for disabled husbands interactions with others decreased and thus, contributed to a sense of social isolation. Research studies in the early 1970's sought to determine a better understanding of the change in people's interaction with their environment. Few studies have been done since related to decreasing interaction in the elderly. Research studies involving the types and frequencies of interaction in elderly wives caring for disabled husbands are especially limited. At this time evidence does support the presence of perceived social isolation in this population. In the next section the utilization of resources will be discussed.

Utilization of Resources

Resources are conceptualized in this study as being composed of informal support systems, such as family, friends, and neighbors, and formal support services such as those provided by agencies. The amount of assistance and support received from family members (Baillie, Norbeck & Barnes, 1988; George & Gwyther, 1986; and Scott, Roberto & Hutton, 1986) and the social support available from others and community services are factors within the caregiving situation that enables caregiving to be continued in the home (Given, Given, Stommel, Collins & King, 1990). Little is known about the utilization patterns of caregivers. In this section, a review of the literature which considers factors that influence the utilization for formal support services is presented, followed by a review of the literature on informal support systems utilization in elderly wives caring for disabled husbands.

Formal Support Service Use

Studies by Branch, Jette, Evashwick, Polansky, Rowe and Diehr (1981), Coulton & Frost (1982), Evashwick, Rowe, Diehr & Branch (1984), and Wolinsky, Coe, Miller, Prendergasat, Crell, & Chavez (1983) will be reviewed, all of which utilize Anderson and Newman's (1973) behavioral framework to examine formal service utilization.

Anderson and Newman (1973) developed a popular behavioral framework for studying the factors which inhibit or facilitate individuals' use of health services. They conceptualize utilization behavior as a consequence of characteristics of

the health delivery system and characteristics of the population at risk. Only the characteristics of the population at risk are pertinent to this study and will be discussed.

The population at risk, in this study elderly wives caring for disabled husbands, is characterized as having Predisposing, Enabling, and Need characteristics. Predisposing variables are those which are mutable or immutable, such as the individual's sex or ethnicity, or their level of education or social support. The Enabling component describes the means an individual has available which may either hinder or facilitate use of services, such as their financial status and insurance coverage or their awareness and access to services. Need may consist of either that perceived by the individual or evaluation by members of the delivery system.

Branch et al. (1981) attempted to provide a greater understanding of the factors which inhibited or facilitated elders' use of health services. Their data for analysis came from a state wide survey initiated in 1974 by the Massachusetts Department of Public Health and conducted by the Center for Survey Research. Interviews were completed with a sample of 1,625 noninstitutionalized elders aged 65 years or older.

Twenty independent variables based on Anderson and Newman's (1973) framework were selected for analysis. Utilization of five categories of formal support services

served as the dependent variables. Multiple regression was used to examine the relative contribution of each independent variable in explaining the variance in utilization of formal support services.

Branch et al.'s (1981) findings indicated level of education was the only predisposing characteristic which achieved a consistent significant effect on utilization of formal support services, however no measure of social support was included as a predisposing factor. Additionally, few enabling characteristics were reported to have an independent influence on formal support services utilization, and the variance in need variables were reported between a high of over 20% to a low of 2%.

Branch et al.'s (1981) work was among the first to contribute to the understanding of factors which inhibit or facilitate elders' use of formal support services by examining a variety of variables, utilizing Anderson and Newman's (1973) behavioral framework, in explaining the variance in formal support services utilization. However, limitations do exist in Branch et al.'s (1981) work.

Branch et al.'s (1981) focus was on the individual's use of services. Thus, Branch et al.'s (1981) findings cannot be generalized to an individual who is using formal support services, not only for him/her, but also to assist the individual in the care of someone else, such as an elderly wife who is caring for a disabled husband. Additionally, the independent variables identified by Branch et al. focused

primarily on socioeconomic factors and health status. No measures were included to ascertain psychosocial factors which may influence the use of formal support services. For example, an individual who is socially isolated may be unable to engage in interactions necessary to either elicit information about or access to formal support services.

Evashwick, Rowe, Diehr, and Branch (1984) reinterviewed 1,317 of the subjects whose utilization of health services was previously studied by Branch et al. (1981) after a fifteen month interval. Using multivariate analyses, Evashwick et al. found no single demographic characteristic which was consistently a statistically significant prediction or utilization of service.

As with the two previous studies reviewed, Coulton and Frost (1982) utilized the Anderson and Newman (1973) behavioral model as their conceptual framework to examine factors which influence utilization of formal support services. However, Coulton and Frost (1982) add social support as a variable which the others had not included. Coulton and Frost (1982) contend that social support is an important predisposing factor affecting the utilization of formal support services, therefore, it is expected to have some impact on an individual's predisposition to seek assistance.

One-thousand eight-hundred and thirty-four noninstitutionalized persons residing in Cleveland, over the age of 65 years, were interviewed in 1975, and 1,519 of them

were interviewed again one year later. Approximately sixty-five percent of the sample were female. Data were obtained from interviews administered in the home. Utilization of formal support services was measured using the Older Americans Research and Service Instrument (OARS). Need was measured using data from the initial interview, before any individual use of formal support services, which included the individual's perception of need for formal support services and a measure of the level of impairment. Enabling factors were measured by reported income and a health insurance index, in addition to educational level. Sex, age, race, and social isolation were all considered to be predisposing factors. Social isolation was measured by an index of social contacts.

Coulton and Frost (1982), like Branch et al. (1981) and Evashwick et al. (1984), reported once need was taken into account, enabling and predisposing factors explained little variance in any of the services. However, Coulton and Frost suggest that although predisposing factors do not make a large contribution to the explained variance, they do produce some noteworthy effects. For example, a slightly higher proportion of women were found to use both mental health and recreational services, indicating the influence in sex differences.

In summary, Branch et al. (1981), Coulton and Frost (1982), and Evashwick et al. (1984) all found the variance in use of formal support services among the elderly is largely attributable to need factors, with little additional variance explained by enabling and predisposing factors. However, all

three studies considered formal support service use only by the individual using the service. Neither of the three studies attempted to explain formal support service use by individual's on behalf of his/herself, and the formal support services he/she utilizes to assist him/her in the care of another individual. However, Coulton and Frost suggest that the socially isolated elderly may have minimal ties to community agencies, and that these individuals may occupy generally sparse social networks in which the available resources are few.

Wolinsky et al. (1983), modified Anderson and Newman's (1973) behavioral model to study the utilization of formal support services by the elderly, by introducing the concept of informal health services and by adding more comprehensive sets of measures of the predisposing, enabling, and need characteristics.

Data used in Wolinsky et al.'s (1983) study were taken from a survey of 401 persons age 65 or older residing in Metropolitan St. Louis. All interviews were conducted in the respondent's home. Informal health services use was measured by determining the number of days in the last month that the respondent was unable to do everything he or she usually did because of a health problem and how many days the respondent had to stay in bed all day because of a health problem.

The attempt to distinguish the difference in utilization of informal and formal service utilization is important in understanding individuals' need and preference for assistance.

Wolinsky et al. (1983) did not clearly define informal services, but suggest that the first stage in the consumption of health services represents an informal or nonprofessional level. Their measure of informal use of health services leads to the assumption that assistance is required from someone to assist the elderly individual in some way.

Wolinsky et al. (1983) measured utilization of formal health services by determining if the respondent had contact with a dentist or physician for preventive purposes, number of physician visits, number of visits to an emergency room, and number of nights spent in a hospital. Wolinsky et al. found need characteristics accounted for at least 50 percent of the variance in informal health service utilization. Additionally, Wolinsky et al. found predisposing characteristics never added more than 3% to the overall explained variance for any measure of health services utilization. Need characteristics, often determined by an individual's level of disability, were found to be the most powerful predictor of the use of health services, consistent with the previous studies cited (Branch, 1981; Coulton & Frost, 1982; and Evashwick et al. 1984).

Like Branch et al. (1981), Coulton and Frost (1982), and Evashwick et al. (1984), Wolinsky et al. (1983) conceptualized formal health services as those services which are made up of physician services, hospital services, ambulatory care services, and home care services, and did not include community or social services, but rather the more traditional

medical services.

In conclusion, four studies were reviewed in this section which utilized Anderson and Newman's (1973) behavioral model to assess factors influencing service utilization in the elderly. The findings from these studies contend that, at least for formal support services, need is the major predictor of service utilization in the elderly population. These studies contribute a great deal to our understanding of formal service use by elderly individuals. Additionally, these findings are useful in planning and developing services for older adults, and to those involved in forming institutional and public policies. Still, what remains is lack of understanding of why individuals do not or cannot use existing services. A better understanding of how the elderly access formal services is still needed. A dearth of information exist about barriers which may inhibit formal support service use on behalf of the elderly individual and/or a disabled family member for whom he/she provides care. In the next section the use of informal support systems will be reviewed.

Informal Support Systems Utilization

The National Survey of Caregiver Summary of Findings (1988) found assistance received by caregivers, who care for an individual age 50 or older, is reported to most likely come from community agencies, followed by friends and family. In contrast, Brody (1985) and Coe, Wolinsky, Miller, and Prendergrast (1988) contend family support networks provide for the majority of the care elderly members in the community

receive. Ward, Sherman, and LaGory (1984) assert that although informal networks may serve as lay referral to formal services, they may also reduce awareness for formal services by substituting for them. In this section, studies by Barusch and Spaid (1989), Caserta, Lind, Wright, and Redburn (1987), and Scott, Roberto, and Hutton (1986) are reviewed.

Caserta et al. (1987) studied 587 caregivers who were caring for community residing individuals. Subjects were predominantly married women who averaged 60 years of age, 57% of the sample were spouses.

Subjects were identified through mailing lists of various local support groups in 16 different states. Data were collected through self-report questionnaires completed by the caregivers. To obtain information about community services, subjects were asked to identify services they knew were available in the area and, also, which services they had utilized and how frequently they had utilized them. The dimensions of informal support systems were measured by network size, as operationalized by the number of people the caregiver reported were available to give assistance in caregiving activities, and the ease and frequency of contact with network members. In addition, demographic data on both the caregivers and the patients were collected.

Caserta et al. (1987) reported subject's scores varied greatly in levels of informal support systems. However some type of respite, daycare, or in-home care accounted for 71.3% of the service needs reported. Other needs mentioned included

companionship, education, financial assistance, legal assistance, chores and household help, mental health counseling, and nutritional assistance.

Those who claimed that they were not yet ready for services reported significantly lower burden and higher levels of social support than those who were utilizing services. Network size did not differ between the groups of utilizers and those not yet ready to utilize resources. Among those who reported that they were not yet ready to utilize services, 70.5% were spouses. In comparison, spouses comprised 51.5% of those who were currently utilizing services.

Forty-three percent of the sample responding indicated they were aware of available formal community services. Twenty-one percent indicated they had no knowledge of such services available and 36% replied that they did not know whether services were available or not.

Caserta et al. (1987) concluded from their findings that although there was an association, it was apparent that knowledge and access do not always lead to utilization. Caserta et al. speculated that one reason why some caregivers felt they were not yet ready to utilize services was because caregivers were able to draw upon others to fill in for them in their caregiving duties. Thus, for some caregivers who are not utilizers of formal services, the presence of informal support ameliorates the burden associated with caregiving.

Instrumental and social-emotional support provided by families to caregivers was examined by Scott et al. (1986).

The sample consisted of 23 caregivers, of which 65% were women with a mean age of 64.4 years. Scott et al. indicate caregivers participated in open-ended in-depth interviews which allowed, "a first hand glimpse of the dynamics of family interaction and support while coping with a chronic illness." (p. 350). In addition, a burden scale and a behavioral coping index were completed by the caregivers.

Instrumental assistance was defined as "concrete" forms of help, such as physical care of the care recipient. Scott et al. (1986) found some type of respite from the caregiving situation was the most appreciated type of instrumental assistance, followed by assistance with the care-recipient's physical care.

Social-emotional support was conceptualized by Scott et al. (1986) as having both a positive and negative affective quality. Five support styles were identified: 1) cohesive, inferring a high positive and low negative affective support; 2) intense, suggesting high positive and high negative support; 3) detached, implying low positive and low negative support; 4) divided, indicating other combination of negative and positive levels of support; and 5) conflicted, which was not described. Scott et al. found the majority (66.7%) of the sample expressed a cohesive style of support from family members, followed by a divided support style (28.5%).

In addition, when Scott et al. (1986) rated caregivers on the total amount of support, instrumental and social-emotional, they found that 81% of the caregivers perceived

themselves as receiving either enough or more than enough support. The remainder of the caregivers perceived themselves as not receiving enough support. Caregivers who did not perceive enough support reported infrequent visits by family members, a lack of willingness to help out with housework, or sitting with the care-recipient as some of the areas where support was lacking.

Scott et al. (1986) anticipated that the more adequate the support provided by the family, the less sense of burden the caregiver would experience. No statistical inferences were reported. However, Scott et al. contend that caregivers who did not receive enough support were the most burdened, which is comparable to Caserta et al.'s (1987) findings.

In addition, Scott et al. (1986) report an unanticipated finding, in which the group receiving the greatest amount of support was the next most burdened. Scott et al. suggest that perhaps caregivers in this group received increased support from family because they were most at risk of dysfunction. However it is unclear what type of support is increased. The assumption is made that instrumental support is increased, but probably at the same time social-emotional support takes on a negative connotation. This may result when a caregiver requires increased assistance from family members due to; the care-recipient becoming increasingly disabled or decreased formal support services due to loss in financial support. a study by Barusch and Spaid (1989) supports the assumption of negative affective support.

Barusch and Spaid (1989) explored gender differences related to caregiver burden. Findings related to women's use of informal support systems and formal support services as related to this study are reported. Use of informal support system and formal support service use in 90 wives, ranging in age from 55 to 89 years, caring for a husband requiring assistance with ADLs is presented.

Use of formal support services was measured by Barusch and Spaid (1989) providing caregivers with a list of nine traditional community services, such as; home-delivered meals, visiting nurse, and transportation. Barusch and Spaid (1989) indicated that caregivers were asked to indicate how many times they had used each service in the preceding six months. However, it is unclear whether the services were used for only the caregiver, the care-recipient only, or both. The greatest formal support used by wives was a visiting nurse (20%), followed by a home aide (14%), social activities (14%), and transportation and congregate meals (each 10%). The remaining formal support services accounted for less than 8% use.

A social support inventory, and two additive scales which measured aversive social contacts and positive social contacts, was used to assess informal support systems. Again, it is unclear if use of the informal support system is by the caregiver only, the care-recipient only, or both. The primary source of social contact, both pleasant and aversive, was neighbors and friends.

Barusch and Spaid (1989) report that formal support services did not increase burden. However, adverse social contact was determined to be a contributing factor which served to increase burden in this group of wives.

In summary, in this section three studies were presented to show the effect of informal support systems on caregiver burden. Additionally, these studies introduced the assumption that informal support systems influence the need for or use of formal support services.

Summary

In this chapter, one dimension of the literature review presented studies to support that elderly wives caring for disabled husbands often experience a sense of burden. An elderly wife's experience of burden, whether subjective or objective in nature, contributes to social isolation as the task of caregiving inhibits her from interaction with her environment. In the later part of this chapter, literature was presented to demonstrate how social isolation may be a barrier, thus inhibiting wives from access to resources either needed and/or desired to assist wives in their caregiving role.

Implications for research from this review follow. First, past research has not specifically examined if there is a relationship between a caregiver's social interaction and the caregiver's ability to procure assistance with caregiving. Secondly, there has been a lack of conceptual clarity regarding what constitutes formal and informal resources, as

well as how interactions should be defined and operationalized. Finally, without special efforts to reach them, elderly wives caring for disabled husbands may be at high risk for deterioration and institutionalization (Coulton & Frost, 1982).

In Chapter IV, the research design and methodology for this study is presented. Sample selection, the data collection procedure, protection of human rights, and operational definitions of the variable are delineated. In addition, data analysis methods, instruments and scoring, and the research question will be presented.

CHAPTER IV

Method

Overview

This exploratory study is based on a cross-sectional design. The purpose of the study is to investigate the relationship between perceived social isolation of elderly wives caring for disabled husbands and the wives use of resources to assist them in caregiving.

In this chapter the research methodology and design are discussed. Sample selection, procedures for data collection, and protection of human subjects are delineated. Operational definitions of the variables and the instruments used to measure them are described. The research question is presented, as well as a discussion of the reliability and validity of the scales, the scoring, and the statistical analysis used.

Sample

The sample for this study was drawn from a federally funded longitudinal research project, "Caregiver Responses to Managing Elderly Patients at Home," Grant #R01 AG06524-03, B. Given and C.W. Given, Co-principal Investigators. The longitudinal project was funded by the National Institute of Aging, Department of Health and Human Services. A description

of how the longitudinal sample was derived will be presented first, followed by a discussion of how the sample for this study was procured.

The Longitudinal Study

To secure an adequate subject pool for the longitudinal study, family members providing home care for persons over the age of sixty were identified via community agencies, through informal support groups, churches and voluntary organizations and asked to participate in this research. To maintain confidentiality, family caregivers were presented with a description of the project and a stamped postcard which they returned if they wished to participate. Those persons returning a card were contacted via telephone by project members and screened to determine if they met eligibility criteria.

A total of 815 patient/caregiver dyads were contacted via telephone and asked to respond to a screening questionnaire. Criteria for inclusion into the study were:

1. The care recipient is 64 years of age or older.
2. The care recipient is dependent in two or more activities of daily living or instrumental activities of daily living.
3. The caregiver is a family member.
4. The caregiver is the primary caregiver (i.e. providing most of the care).

Four-hundred ninety-three patient/caregiver dyads met the screening criteria. Upon recontact for entry into the

longitudinal phase of the study, 307 caregivers completed wave one of the longitudinal study. The remainder did not participate due to either death or institutionalization of the care recipient, death of the caregiver, refusals, or because the caregiver lived in an isolated location that was not accessible to interviewers.

The Present Study

A sub-sample of elderly wives caring for their disabled husbands at home was selected from the longitudinal study for the purposes of this study. Criteria for inclusion into the present study included;

1. The caregiver/care recipient dyad is composed of a wife and husband who are currently married.
2. The caregiver is a wife, 65 years of age or older, who is the primary caregiver (i.e. providing most of the care) for her disabled husband.
3. The care recipient, the disabled husband, is 64 years of age or older.
4. The care recipient, the disabled husband, is dependent in two or more activities of daily living or instrumental activities of daily living.

There were sixty-one wife/husband dyads from the longitudinal study who met the criteria for the present study. No attempt was made to randomize the subject selection or to limit the sample based on duration of care, severity of the husbands' disability, or previous utilization of resources.

Data Collection Procedure

A description of the data collection procedure for the longitudinal study is presented next, followed by a discussion of the data collection procedure for the present study.

The Longitudinal Study

Data for the longitudinal study were collected over the course of one year (1987-1988), using voluntary participants who responded to both in-home interviews and to self-administered questionnaires. Family caregivers were interviewed five times during a year long period (1987 - 1988). Two of these interviews were conducted in the caregiver's home and lasted approximately one and one-half hours. One interview was an intensive phone interview and lasted approximately one hour. At these three data collections points, respondents were also asked to fill out a questionnaire which was mailed back to the interviewer. During these intensive interviews, respondents provided information about patient and caregiver characteristics and formal support services and informal support systems. In addition, two brief phone calls were interspersed between the interviews to obtain information about health service utilization of patients and caregivers. The caregivers were the exclusive source of information about themselves and their care recipients.

The home interviews were conducted by Registered Nurses who were enrolled in the Clinical Nurse Specialist program in the College of Nursing at Michigan State University and were

specially trained for collecting data for this study. The method of training interviewers has been described in detail elsewhere (Collins, Given, Given, & King, 1988).

The Present Study

Data for this study are based on the final wave of interviews, 12 months after intake, from the longitudinal study previously described. Data collection at this wave consisted of a home interview, which lasted approximately one and one-half hours. During the home interview subjects provided information about their use of formal and informal resources. Additionally, respondents were asked to fill out a self-administered questionnaire containing questions about their perception of persons available and helpful to them and questions regarding the frequency and type of contact with others. The questionnaires were mailed back by the subjects when completed.

Protection of Human Subjects

In this section, the protection of subjects in the longitudinal study is presented first, followed by a discussion of the protection of subjects in the present study.

The Longitudinal Study

The right of the respondents were protected through adherence to established standard criteria set forth by Michigan State University's Committee on Research Including Human Subjects (UCRIHS). See Appendix A for the approval letter from UCRIHS. Informed consent was obtained from all participants before enrolling into the longitudinal study.

When an interviewer initiated phone contact with a subject who returned a postcard the longitudinal study was again described to the potential subject, questions were answered, and if the person indicated a willingness to participate, an appointment time was arranged to meet with the interviewer, usually in the subject's home.

At the time the interviewer met with the subject, he/she again described the longitudinal study and told the subject he/she had a right to withdraw from the study at anytime without consequences. Upon eliciting the subject's consent to participate in the longitudinal study, the interviewer explained again what would be involved in participating in the longitudinal study. the subject wa asked to sign the consent form before proceeding with the interview. The consent form was subsequently returned to the principal investigators. The consent form provided an explanation of the research, the purpose, utilization of results, and assurance of anonymity and confidentiality. See Appendix B for the consent procedure and letter of consent.

The Present Study

This researchers also received approval from the UCRIHS to conduct further analysis of data from the longitudinal study related to the relationship between perceived social isolation of elderly wives caring for disabled husbands and their use of resources to assist them in caregiving. See Appendix A for the approval letter from UCRIHS.

This researcher was a data-collector for the longitudinal study. Insofar as the data collected from the longitudinal study had been coded and entered into the computer before initiation of the present research, the data could not be traced. This researcher had access to the data in coded form only. No further risks to the subjects were identified from the present study.

Operationalization of Study Variables

Social Isolation

Perceived social isolation was conceptualized as being composed of an affective support dimension and a tangible support dimension. Affective support was measured using four subscales from the Social Provisions Scale (Russell, Altmaier, & Van Velze, 1984) and two subscales from the Caregiver's Reactions Inventory (Given, et al. 1990). Tangible support was measured by the Social Resources Scale developed by Donald an Ware (1982) and modified by Given and Given (1986). A discussion of each subscale utilized follows, along with an example from each.

The Social Provisions Scale consists of six subscales, with four items each. Four of the six subscales; Attachment, Social Integration, Reliable Alliance, and Guidance were selected to measure the degree to which elderly wives perceive that there are people who are available and helpful to them. The remaining two subscales, Reassurance of Worth and Opportunity for Nurturance, were not utilized because these subscales appeared to measure individuals' perceptions that

others find them competent in skills and depended on by others, dimensions of affective support deemed not applicable to the present study. Elderly wives responded on a four point Likert scale ranging from strongly disagree to strongly agree to items in statement form. Below, each subscale is defined followed by a sample statement from the subscale:

Attachment represents a close, intimate relationship with another person, such as a confident.

I feel a strong emotional bond with at least one person. (Item 17)

strongly disagree	disagree	agree	strongly agree
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Social Integration involves being enmeshed in a social network, where an individual can share common interests and engage in social activities.

I feel part of a group of people who share my attitudes and beliefs. (Item 8)

strongly disagree	disagree	agree	strongly agree
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Reliable Alliance describes the relationships where an individual can count on assistance under any circumstances.

There are people I can depend on to help me if I really need it. (Item 1)

strongly disagree	disagree	agree	strongly agree
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Guidance describes the relationships with trustworthy and authoritative others who can provide advice.

There is someone I could talk to about important decisions in my life. (Item 12)

strongly disagree	disagree	agree	strongly agree
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Appendix C contains the complete subscales.

The Caregiver's Reaction Inventory is composed of six subscales. Two of these subscales Feeling of Family Abandonment and Impact of Caregiving on Daily Schedule, were used in the present study to measure affective support. The remaining four subscales; Financial Impact of Caregiving, Impact of Caregiving on Health, Negative Reaction to Caregiving, and Role Responsibility, were not utilized to measure affective support, as these subscales measured perceived financial and health status, and psychological and belief responses, concepts believed not appropriate to this study. Subjects were asked to respond on a five point Likert scale ranging from strongly disagree to strongly agree to items in statement form. Below each subscale is described and a sample statement from the scale is included.

The Feelings of Family Abandonment subscale is composed of six items designed to elicit caregivers' feelings that other family members have not helped them to care for their patient.

Sample statement:

It is very difficult to get help from my family in taking care of _____. (Item 13)

strongly
disagree

disagree

agree

strongly
agree

Appendix C contains the complete subscale.

The Impact of Caregiving on Daily Schedule subscale contains five items designed to measure the degree to which caregiving alters the caregiver's normal routine.

Sample statement:

I visit family and friends less since I have been caring for _____. (Item 25)

strongly
disagree

disagree

agree

strongly
agree

Appendix C contains the complete subscale.

Six items form the modified Social Resource Scale was used to measure perceived tangible support, such as the number of contacts with friends and relatives. The response categories for these items were as follows; everyday, several days a week, about once a week, two or three times in past month, once in past month, and not at all in past month. While Donald and Ware (1982) did not attempt to score these items, Given and Given (1986) placed six of the items in a response format suitable for scaling. A sample question follows:

Over a months time, how often do you get together with friends or relatives, like going out together or visiting in each other's homes? (Item 1)

every day	several days a week	about once a month	two or three times a month	once in past month	not at all in past month
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Appendix D contains the complete scale. Additionally, Table 4.1 identifies each dimension of social isolation, the subscales used to measure each dimension, and the number of items in each subscale.

Utilization of Resources

Utilization of resources was conceptualized as being composed of the informal support systems and the formal support services used by the elderly wife, either for herself or for her husband, to assist the wife with caregiving. A discussion of each dimension of utilization of resources follows, along with an example from each.

Informal Support Systems

Utilization of informal support systems was derived from the Family Help and Friend Help subscales developed by Given and Given (1986), to measure the perception of assistance family and friends or neighbors provide in performing either the tasks of caregiving or in providing respite from the caregiving situation for caregivers.

In the Family Help and Friend Help subscales, elderly wives were asked to respond to the frequency in which family and friends or neighbors assisted them in caring for their disabled husband over the past three months. Elderly wives selected one of four categories, rarely or none of the time, some of the time, most of the time, or almost all of the time.

Family Help and Friend Help subscales each contained the same nine items. Sample questions are listed below:

How often, over the past three months, has anyone given you assistance in the following ways?

Helped with physical care (Item 1a)

Stayed with your relative so you can take a vacation (for a weekend or longer). (Item 1d)

rarely or none of the time	some of the time	most of the time	almost all of the time
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Appendix E contains the complete subscales for Family Help and Friend Help.

Formal Support Services

Formal support services, provided to both the elderly wife and the wife's disabled husband, was measured via the Utilization of Services section of the Older Americans Research and Service Center Instrument (OARS) developed by Pfeffer (1975), and modified by Given and Given (1986). For the purposes of this study, formal support services consist of following six services provided to either the elderly wife or her disabled husband: Visiting/Public Health Nurse; Meals on Wheels; Transportation Services; Counseling of Emotional Problems; Chore or Housekeeping Services; and Family Support Groups. Additionally, the following formal support services provided to the disabled husband only were considered: the use of a home companion or home health aide during the day; the use of a home companion or home health aide at night; and adult day care. Respondents answered with a dichotomous yes

or no, as to whether either the wife or the husband had used formal support services in the past three months.

Sample questions are listed below:

Visiting Nurse or Public Health Nurse (Item 11a and b)

a. Have you used this service in the past three months
for yourself?

yes no

b. Have you used this service in the past three months
for your relative?

yes no

Appendix F contains the subscales for formal support services. Additionally, Table 4.1 depicts the subscales used to measure the utilization of resources and the number of items in each measure.

Research Question

The purpose of this study was to answer the following research question:

Is there a relationship between perceived social isolation in elderly wives caring for disabled husbands and the resources utilized to assist them in caregiving?

Reliability and Validity of the Instruments

Reliability refers to the degree of consistency with which an instrument measures the underlying attribute it is designed to measure. One measure of reliability of an instrument is its internal consistency (Woods & Catanzaro, 1988). Internal consistency refers to the homogeneity of the measuring instrument. The greater the reliability coefficient

reflecting internal consistency, the greater the likelihood that the scale measures the attribute of interest and nothing else (Woods & Catanzaro, 1988, p. 249).

Russell et al. (1984), reported the internal consistency of the Social Provisions subscale as follows: Attachment .80; Social Integration .80; Reliable Alliance .80; and Guidance .84. Given et al. (1988) also reported the following coefficients alphas; for Feelings of Family Abandonment .85 and for Impact of Caregiving on Daily Schedule .81. However, Given and Given (1989) report a coefficient alpha of only .42 on four items of the Social Resources scale. At the present time Given and Given have not reported any findings related to the reliability of the Family Help or Friend Help subscales.

This researchers conducted reliability testing for each of the subscale son the population in the present study. An inter-item correlation matrix was computed for each of the six subscales of affective support, for the tangible support scale, and for the subscales of informal support systems. Formal support services are reported in terms of the frequency of use. Therefore, no subscale reliability is reported.

The internal consistency of each measure was evaluated through computation of Cronbach's coefficient alpha. The alpha coefficient for each affective support subscale follows: Attachment .81; Social Integration .64; Reliable Alliance .86; Guidance .83; Feeling of Family Abandonment .84; and Impact of Caregiving on Daily Schedule .85. The measure of tangible

support, the modified Social Resources scale, had an alpha coefficient of .60. Subscales and alphas for the affective support and tangible support dimensions of perceived social isolation are depicted in Table 4.1.

After assessing the inter-item correlation matrix for Family Help and Friend Help, two items from each subscale were deleted from the original subscales due to the two items low correlations with the other items in the subscale. The coefficient alpha for the informal support systems revised subscales follow: Family Help .78 and Friend Help .71. Subscales and alphas for the informal support systems are also presented in Table 4.1.

The validity of an instrument refers to the degree to which the instrument measures what it is intended to measure (Woods & Catanzaro, 1988). Content validity is based on the judgement regarding the sampling adequacy of the content area being measured (Woods & Catanzaro, 1988). In the subscales used to measure social isolation and utilization of resources, content validity was evaluated based on review of pertinent literature by this researcher. Construct validity involves attempting to validate a body of theory underlying the measure and testing hypothesized relationships (Woods & Catanzaro, 1988, p. 253). No attempt was made to either confirm or reject the relationships that would be predicted among the concepts.

Table 4.1: Social Isolation and Utilization of Resources Instruments. Number of Items, Number of Subjects, and Reliabilities of Each Subscale

	No. of Items	Coefficient Alphas of Previous Studies	Coefficient Alphas of Present Study
Social Isolation			
Affective Support		(N = 100)	
Attachment	4	.80	.81 (N=59)
Social Integration	4	.80	.64 (N=58)
Reliable Alliance	4	.80	.86 (N=61)
Guidance	4	.84 (N = 189)	.83 (N=60)
Feelings of Family Abandonment	6	.85	.84 (N=57)
Impact of Caregiving on Daily Schedule	5	.81	.85 (N=60)
Tangible Support		(N = 189)	
Social Resources	6	.42*	.60 (N=53)
Utilization of Resources			
Informal Support Services			
Family Help	9	--	.78 (N=61)
Friend Help	9	--	.71 (N=55)
Formal Support Services			
Elderly Wife	6	--	--
Disabled Husband	9	--	--
*Reflects 4 items reported by Given & Given (1988).			

Scoring of Instruments

For the purpose of this study, and based on a review of the literature, social isolation is conceptualized as being comprised of both affective and tangible support. Six subscales are utilized in this study to depict affective support in an elderly wife caring for a disabled husband. The possible score range for each subscale; Attachment, Social Integration, Reliable Alliance, and Guidance is one to four. A score for each subscale is derived such that a low score indicates the elderly wife is not receiving that provision. The possible score range for Feelings of Family Abandonment is one to five, with a low score indicative of a low degree of feelings of family abandonment. The possible score range for Impact of Caregiving on Daily Schedule is one to five with a low score representative of a low degree on impact of daily schedule.

Tangible support was measured utilizing the modified Social Resources scale. The possible score range for Social Resources is one to six. Allow score is suggestive of a high amount of contacts with friends and family.

For the purpose of this study, utilization of resources was conceptualized as being comprised of an informal support dimension and a formal support dimension. Informal support system use was measured using the Family Help and Friend Help scales. Each had a potential score range of one to nine, with a low score suggestive of a low level of help from either family or friends.

Formal support service use was measured by the modified version of the Utilization of Services scale and was divided into wife's use and husband's use. Wives had a potential score range of zero to six. Husbands had a potential score range of zero to nine. A low score for either is indicative of a low level of formal service use.

Statistical Analysis

Sociodemographic data, which included the elderly wife's age, education, and race; the disabled husband's age and race; household income and whether the income was enough to meet needs; whether any one else was living in the household; coverage by health insurance; the wife's health status; and the duration of caregiving were analyzed using descriptive statistics in order to describe and summarize the sample characteristics. Frequencies, percentages, and measures of central tendency were applied as appropriate.

The most common method of describing the relationship between two variables is through correlation procedures, which identifies to what extent two variables are related to each other (Wood & Catanzaro, 1988). Pearson product-moment correlations were utilized in this study to determine whether a relationship existed between the perception of social isolation and the utilization of resources in elderly wives caring for disabled husbands.

Affective support scores were correlated separately with the informal support systems scores, as well as with the formal support services scores. Additionally, the tangible

support score was correlated separately with the informal support systems scores as well as with the formal services scores. The sign of a correlation, either a plus or a minus, conveys the nature of the relationship. The closer the coefficient is to either +1 or -1, the higher, or stronger, the correlation is, while the closer the coefficient is to 0, the lower, or weaker, the relationship is (Woods & Catanzaro, 1988). For the purpose of this study a level of significance of $p < .05$ is utilized to accept/reject the probability that there is a relation between perceived social isolation in elderly wives caring for disabled husbands and the utilization of resources to assist these wives in caregiving. Results of the data analysis are presented in Chapter V.

Summary

In this chapter, the research methodology and design used in this study is discussed. The study variables, perceived social isolation and utilization of resources, is operationally defined. Development of the instruments used to measure the concepts is described. The research question is presented, and the statistics used to analyze the data is delineated. A description of the sample population and the procedures to protect the rights of human subjects is also included in this chapter.

Next, in Chapter V a description of the sociodemographic characteristics of the sample is presented, along with an analyses and interpretation of the data.

CHAPTER V
Data Presentation and Analysis
Overview

A summary and interpretation of the findings are presented in Chapter V. In this chapter, the following information is presented: 1) a description of the sociodemographic characteristics of the study population; 2) the reliability measures for each of the scales; 3) analysis of the data; and 4) an interpretation of the findings.

Sociodemographic Characteristics of the Study Sample (RS)

The sample for this study consisted of 61 elderly wives who were caring for a disabled husbands at home. Sociodemographic data included both the elderly wife's and the disabled husband's age and race; their household income, health insurance coverage, and others living in their household; the wife's educational level and perception of her health status; and the duration of caregiving. A summary of the sociodemographic characteristics of the study population follows.

Age of Elderly Wives and Disabled Husbands

Study participants, elderly wives, ranged in age from 65 to 80 years. The mean age was 69.92 years, with a standard deviation of 3.95 years. The wives in this study were caring

for disabled husbands who ranged in age from 64 to 88 years. The mean age of the disabled husbands was 74.36 years, with a standard deviation of 6.43 years. The age distribution for elderly wives and disabled husbands is presented in Table 5.1.

Table 5.1: Age Distribution of Elderly Wives and Disabled Husbands.

Wives: \bar{M} = 69.99 years (SD = 3.85)

Husbands: \bar{M} = 74.36 years (SD = 6.43)

Age	No. of Wives (N=61)	%	No. of Husbands (N=61)	%
< 65	0	0.0	1	1.6
65-69	34	55.7	15	24.6
70-74	20	32.8	15	24.5
75-79	6	9.8	19	31.1
80-84	1	1.6	6	9.7
> 85	<u>0</u>		<u>5</u>	
TOTAL	61		61	

Race of Elderly Wives and Disabled Husbands

The majority of wives and husbands in this study were white (96.7%). The remaining wives and husbands were Black (3.3%). Distribution for race of elderly wives and disabled husbands is shown in Table 5.2.

Table 5.2: Race Distribution of Elderly Wives and Disabled Husbands.

Race	No. of Wives (N=61)	%	No. of Husbands (N=61)	%
Caucasian	59	96.7	59	96.7
Black	<u>2</u>	3.3	<u>2</u>	3.3
TOTAL	61		61	

Education of the Elderly Wives

The majority of the elderly wives graduated from high school and had either some college education or technical training. The distribution of elderly wives level of education is summarized in Table 5.3.

Table 5.3: Distribution of Educational Levels of Elderly Wives.

Level of Education	No. of (N=61)	%
Grade School or Less	6	9.8
Some High School	12	19.7
High School Graduate	18	29.5
Some College or Technical Training	20	32.8
College Graduate	1	1.6
Post Bachelors	<u>4</u>	6.6
TOTAL	61	

Income

Income for the elderly wives and their disabled husbands ranged from \$5,500 to over \$40,000, with a mean household income of \$18,500 and a standard deviation of \$9,000 in 1986. The majority (81.5%) of the elderly wives (N=60) reported that their income was enough to meet their needs. A summary of distribution for combined annual income is presented in Table 5.4.

Table 5.4: Distribution of Combined Household Annual Income for 1986.

M = \$18,500 (SD = \$9,000)

Income	No. of Couples (N=58)	%
<hr/>		
< \$10,000	11	18.8
\$10,000 - \$19,000	29	50.0
\$20,000 - \$29,000	12	20.6
\$30,000 - \$39,000	0	0.0
> \$40,000	<u>6</u>	10.3
TOTAL	61	

Others Living in the Household

Eighty-nine percent of the elderly wives (N=57) reported no one else living in their household. The remainder of the wives reported either a child, a sibling, or another person living in their household. Distribution of others living in the household is depicted in Table 5.5.

Table 5.5: Distribution of Others Living in Household with Couples

Relationship	No. (N=57)	%
No one else	51	89.0
Child	1	1.7
Sibling	2	3.5
Other	<u>3</u>	5.3
TOTAL	57	

Health Insurance Coverage

The majority of the elderly wives reported having either Medicare A, Medicare B, or Blue Cross for themselves and their husbands. Distribution of type of health insurance coverage is presented in Table 5.6.

Duration of Caregiving

The range of years of duration of caregiving was from less than one year to 29 years. The mean duration of care was 5.33 years with a standard deviation 6.66 years. The majority, that is forty wives, had been providing care for their husbands less than four years. Distribution for duration of caregiving is presented in Table 5.7.

Table 5.6: Distribution of Type of Health Insurance Coverage

Type of Coverage	No.	%
Medicaid $N = 56$	3	5.4
Medicare A $N = 60$	58	96.7
Medicare B $N = 60$	49	81.7
Blue Cross $N = 60$	41	68.3
Other $N = 60$	23	38.3

Table 5.7: Distribution of Duration of Caregiving

$M = 5.33$ years (SD = 6.66)

Time in Years	No. (N=61)	%
> 1	8	13.1
1 - 3	28	45.9
4 - 6	11	18.0
7 - 9	4	6.5
10 - 12	4	6.5
13 - 15	1	1.6
16 - 18	0	0.0
19 - 21	2	3.3
22 - 24	1	1.6
25 plus	<u>2</u>	3.2
TOTAL	61	

Health Status of Elderly Wife

Wives were asked to rate their overall physical health as; excellent, good, fair, or poor. A total of 29 wives (47.5%) reported their health as either excellent or good, while 32 wives (52.5%) reported their health as either fair or poor. The number and percent of wives reporting in each category of health status is shown in Table 5.8.

Table 5.8: Distribution of Elderly Wives Health Status

Health Status	No. (N=61)	%
Excellent	6	9.8
Good	23	37.7
Fair	28	45.9
Poor	<u>4</u>	6.6
TOTAL	61	

Summary of Sociodemographic Characteristics of Study

The sample for this study is composed of 61 elderly wives who are caring for a disabled husband. Both wives and husbands are predominantly Caucasian (96.7%) with the remaining being Black (3.3%). The majority of wives reported no one else to be living in the household.

Wives ranged in age from 65 to 80 years, with a mean of 69.62 years. Husbands averaged 74.36 years of age with a range of 64 to 88 years. The majority of the wives were at least high school graduates. On the average these wives have

been providing care for their disabled husbands for less than seven years. The majority of wives reported their health status to be either good or fair.

Additionally, the mean annual household income for this population in 1986 was \$18,500, with 81.7% indicating that their income was enough to meet their needs. The majority of sample reported at having some type of insurance coverage.

Analysis of the Data

In this section the characteristics of the study sample are compared with other studies, the statistical analysis is presented and an interpretation of the research question based on the data from this study is provided.

Characteristics of the Sample

The study sample was acquired from predominantly white middle class women living in Michigan who had been providing care to their disabled husbands on average of 5.33 years. The mean age of the wives was 69.92 years, and the mean age of their husbands was 74.36 years.

Only one study (Thompson & Haran, 1985) was found which attempted to differentiate how the duration of caregiving might influence social isolation in elderly women caring for disabled husbands. Although the actual duration of caregiving is not specifically stated by Thompson and Haran, their sample compared caregivers of husbands who were beginning prosthetic rehabilitation with caregivers of husbands who had worn prostheses for one to two years.

Two studies on utilization of resources by caregivers (Caserta et al., 1987 and Snyder & Keefe, 1985) considered duration of care as a variable affecting formal support service use by caregivers. Snyder and Keefe reported over half of the caregivers in their studies had been providing care for more than five years, while Caserta et al. reported caregivers in their study had been providing care an average of 4.3 years.

Snyder and Keefe (1985) assert that the longer caregivers have been providing care the more likely they are receiving assistance from family and friends. In contrast, Gaynor's (1989) findings revealed that by month 33, some of the caregivers in her sample reported receiving no help from family members. A review of the literature related to the utilization of resources in the elderly caregivers generally did not take into account the duration of caregiving.

Seventy percent of the elderly wives in the present study had at least a high school education. Branch et al.'s (1981) findings support educational level as the only demographic variable having a consistently significant effect on the utilization of formal services. This is consistent with Noelker and Bass's (1987) premise that education is a proxy for knowledge of resources.

The mean income of the study sample was \$18,500 with the majority of the sample reporting that their income was enough to meet their needs. Additionally, the majority of the study sample possessed some type of health insurance coverage.

Interestingly, in studies by Coulton and Frost (1982), Evashwick et al. (1984), and Wolinsky et al. (1983), no single demographic characteristics was consistently significant in predicting use of resources. However, these studies looked at formal service use by elders themselves, not elders who were caregivers. In contrast, Bass and Noelker (1987) reported the amount of volume of service use was determined particularly by household income in elders providing caregiving.

Statistical Analysis

A discussion of the possible subscale scores for the affective support and tangible support dimensions of perceived social isolation and the informal support and formal support dimensions of utilization of resources will be presented first, followed by a discussion of the correlational results.

As previously indicated, perceived social isolation was conceptualized as having both an affective and a tangible support dimension. Six scores of affective support were elicited, along with one tangible support score. The affective support scores ranged as follows: 1) Reliable Alliance had a possible score range of one to four, a mean of 1.73 and a standard deviation of .57, indicating wives perceived a low degree of having someone to count on or to assist them under any circumstances; 2) Attachment had a possible score range of one to four, a mean score of 3.12 and a standard deviation of .54, representing wives perceived a high degree of having a close, intimate relationship with

another person, such as a confident; 3) Guidance had a possible score range of one to four, a mean score of 3.18 and a standard deviation .50, suggesting wives perceived a high degree of having relationships with trustworthy and authoritative others who can provide advice; 4) Social Integration had a possible score range of one to four, a mean score of 3.10 and a standard deviation .40, depicting wives perceived a high degree of being enmeshed in a social network where they can share common interests and engage in social activities; 5) Impact of Caregiving on Schedule had a possible score range of one to five, a mean score of 3.95 and a standard deviation .75, indicating wives perceived caregiving to have a high degree of impact on their daily schedule; and 6) Feelings of Family Abandonment had a possible score range of one to five, a mean score of 2.46 and a standard deviation .83, suggesting wives did not perceive themselves to be abandoned by family members.

The tangible support score, Social Resources, had a possible score range of one to six, a mean score of 4.33 and a standard deviation of .91, indicating wives perceived low levels of contact with family and friends. The possible score ranges, means, and standard deviations for the affective and tangible support dimensions of perceived social isolation are depicted in Table 5.

Utilization of resources was conceptualized as informal support systems and formal support services used by both elderly wives and their husbands to assist in caregiving.

Informal support systems was divided into help received from family and help received from friends. The possible score range for Family Help was one to seven, a mean score of 1.76 and a standard deviation .56, indicating wives received little help from family to assist with caregiving. The possible score range for Friend Help was one to seven, a mean score of 1.53 and a standard deviation of .44, suggesting wives received little help from friends to assist with caregiving. The possible score range, mean, and standard deviation of informal support systems is presented in Table 5.10.

Formal support services for elderly wives had a possible score range of zero to six, a mean score of .71 and a standard deviation of .78. Forty-six percent of the wives used no services, while 41% used only one service. The two formal support services used most frequently by wives were housekeeping services followed by support groups. Formal support services used for the disabled husbands had a possible score range from zero to nine, a mean score of 1.38 and a standard deviation of 1.20. Twenty-six percent of the husbands used no services, while 36% used only one service. Visiting Nurses were the formal support service most frequently used, followed by a day companion. The

Table 5.10: Possible Scale Range, Means, and Standard Deviations of Subscales (N=61)

	Possible Scale Range	M	SD
Social Isolation			
Affective Support			
Reliable Alliance	1-4	1.73	.57
Attachment	1-4	3.12	.54
Guidance	1-4	3.18	.50
Social Integration	1-4	3.10	.40
Impact of Caregiving on Daily Schedule	1-5	3.95	.75
Feelings of Family Abandonment	1-6	2.50	.83
Tangible Support			
Social Resources	1-6	4.36	.91
Utilization of Resources			
Informal Support Systems			
Family Help	1-7	1.76	.56
Friend Help	1-7	1.53	.44
Formal Support Services			
Utilized by Wife	0-6	0.71	.78
Utilized by Husband	0-9	1.38	1.20

possible score range mean, and standard deviation of formal support services is depicted in Table 5.10. The distribution of formal support service use by elderly wives and disabled husbands is presented in Table 5.11, followed by the distribution of individual formal support service use by the wives and the husbands in Table 5.12.

Table 5.11: Distribution of Formal Support Service Use for Wives and Husbands.

Wives: $\bar{M} = .70$ $SD = .78$ Husbands: $\bar{M} = 1.38$ $SD = 1.20$

No. of Services	No. of Wives ($N=61$)	%	No. of Husbands ($N=61$)	%
0	28	45.9	16	26.2
1	25	41.0	22	36.1
2	6	9.8	10	16.4
3	2	3.3	11	18.0
4	-	---	1	1.6
5	-	---	1	1.6
TOTAL	61		61	

Table 5.12: Distribution of Individual Formal Support Service Use by Wives and Husbands.

	No. of Wives (N=61)	%	No. of Husbands (N=61)	%
Service				
Visiting Nurses	1	1.6	26	42.6
Meals	1	1.6	1	1.6
Transportation	3	4.9	10	16.4
Counseling	5	8.2	3	4.9
Housekeeping	18	29.5	12	20.0
Support Groups	15	24.6	7	11.5
Day Companion	--	----	23	37.7
Night Companion	--	----	1	1.6
Adult Day Care	--	----	<u>1</u>	1.6
TOTAL	43		84	

Interpretation of the Research Question

The correlations between the study variables is presented next. Pearson Product Moment Correlation were carried out among the study variables in order to answer the research question:

Is there a relationship between perceived social isolation in elderly wives caring for disabled husbands and the resources utilized to assist these wives in caring for their disabled husbands?

Table 5.13 depicts correlations of the variables in this study and level of significance for each.

Table 5.13: Correlations of Study Variables N = 61

Social Isolation	Utilization of Resources			
	Formal Service Wife	Formal Service Husband	Family Help	Friend Help
<u>Affective Support</u>				
Reliable Alliance	.1392	-.1893	.3556*	.3594*
Attachment	.1172	.0688	.2624*	.3151*
Guidance	.1657	-.0247	.3177*	.2543*
Social Integration	.1518	-.0562	.2184*	.2733*
Impact of Caregiving on Schedule	.0503	-.0134	.1754	.1130
Feelings of Family Abandonment	.0302	.1302	-.6263**	.0138
<u>Tangible Support</u>				
Social Resources	.0504	-.1987	.0193	.2231*

*p < .05

**p < .001

Affective Support

No statistically significant correlations were found between Reliable Alliance, Attachment, Guidance, and Social Integration, measures of the affective support dimensions of social isolation, and Formal Services used by the wife or for her husband. This suggests and is consistent with Greene's (1983) contention that, formal services probably do not provide affective support, but rather substitutes for instrumental types of assistance that family and friends cannot provide. This is also consistent with eligibility requirements for social services and government subsidized

programs which provide formal services.

Wives scored low on the Family Help and Friend Help subscales, measures of informal support systems, indicating wives received little instrument help from family and friends to assist in caregiving. However, correlations between the affective support measures of Reliable Alliance, Attachment, Guidance, and Society Integration and Family Help and Friend Help, between Attachment and Family Help and Friend Help, were all positively correlated and statistically significant. This suggests that family and friends, while not providing large amount of instrumental help, in terms of providing assistance with caregiving task or providing respite from the caregiving situation, do provide wives with a sense of: having someone they can depend on; sharing a strong emotional bond with another person; a feeling of having someone who is trustworthy and on whom they can elicit advice from; and feeling that they share mutual attitudes and values with others. This finding supports Tennstedt, McKinlay, and Sullivan's (1989) premise that informal support systems, such as family and friends, provide a supplementary pattern of assistance, such as emotional support for the caregiver, rather than substitutive or complementary pattern of care suggested by Greene (1983).

Wives' scores on Impact of Caregiving on Daily Schedule, another measure of an affective support dimension of social isolation, were fairly high indicating a high degree to which caregiving alters the wives normal routine. The correlations between Impact of Caregiving on Daily Schedule, although not

statistically significant and weakly correlated, were positively correlated with Formal Service use for the wives and between Family Help and Friend Help. In contrast, a weak negative correlation existed between Impact of Caregiving on Daily Schedule and Formal Service use for the husbands. This may in part be explained by the wife's need or desire to control the caregiving situation or due to the wife's sense of obligation to provide care for her husband.

Tennstedt et al., (1989) suggest spouse caregivers provide much more care than non-spouse caregivers. This may explain why, for the wives in this study, perceived caregiving was perceived to have such a high degree of impact on their daily schedule. Additionally, wives may perceive assistance, whether from formal services or from family and friends, to create even further disruption in the wives daily routine. Furthermore, Hooyman and Ryan (1987) assert that women, by their own internalized barriers against letting go of caregiving responsibility, set limits on accepting other help. According to Hooyman and Ryan (1987) these barriers are the result of women's belief and/or socialization that they should be able to do everything themselves.

Additionally, the need to control the caregiving situation, by preventing intrusions or preventing embarrassment may be additional ways to explain why wives perceive a caregiving to have a high degree of impact on their normal routine. Ekberg et al. (1986) suggest the issue of embarrassment, due to the care-recipient's behavior,

appearance, or inability to communicate, for both caregiver and others, and may also influence caregivers' use of resources to assist them with caregiving. Given et al. (In Press) also support negative care-recipient behaviors and role obligation as significant predictors of impact on the caregivers' daily schedule.

Wives scores on Feelings of Family Abandonment, another measure of affective support, indicated wives felt somewhat indecisive about whether they had been abandoned by their families to provide care for their husbands. There was a very strong negative correlation, which was statistically significant, between Feelings of Family Abandonment and Family Help. This implies that those wives that feel abandoned by family do not utilize or get family help. As previously discussed, wives scored low on the Family Help subscale, indicating wives received little help from Family members to assist in caregiving. No determination could be made as to any causal relationship between Feeling to Family Abandonment and Family Help. For example, a wife who feels left alone to care for her husband may be less willing to ask family member for help. The unwillingness to ask for help may be a result of the wife's feeling that family members are already doing enough, that family members should be able to see that help is needed without being asked, the wife's sense of role obligation as part o the marital bond, or the wife's feeling that she cannot reciprocate. Additionally, family members may have other role obligations, or may themselves experience role

fatigue and stress related to the caregiving situation. This may contribute to family members ability of lack of willingness to assist caregiving, and thus add to the wives sense of family abandonment.

Tangible Support

Finally, wives scored high on the social resources scale, a measure of tangible support, suggesting a low amount of contact with family and friends. Social Resources correlated positively with Family Help and Friend Help, but was statistically significant only with Friend Help. This supports the assumption that the quality of wives' interactions, rather than the quantity of wives' interactions, may be more influential in wives' perception of social isolation, and thus the ability to continue caregiving. Additionally, the statistical significance of the correlation between Social Resources and Friend Help can be explained by the finding of Tennstedt et al. (1989) that nonrelatives, such as friends, provide assistance in the absence of family members. Baurisch and Spaid (1989) findings suggest that the primary source of interaction, whether positive or negative, for caregivers was no family members, but neighbors and friends.

In summary, in this study, elderly wives caring for disabled husbands did not appear to be entirely isolated socially. Wives in this study appeared to be isolated socially only in terms of tangible support and in one component of affective support, impact on daily schedule.

Findings from this study do support social isolation as being conceptualized as having both an affective support dimension and a tangible support dimension. Additionally, it appears, wives' levels of perceived affective and tangible support may be an important predictor of their use of informal support systems and formal support services.

Summary

In this chapter, data were presented to describe the sociodemographic characteristics of the study sample. An analysis of the data was presented. An interpretation of the findings was included. In Chapter VI, the implication of the findings for nursing practice, nursing education and further research will be presented.

CHAPTER VI

Recommendations and Implications

Overview

In this chapter, limitations of the present study are discussed, recommendations for future research are offered, and implications for advanced nursing practice and nursing education are delineated.

Limitation of the Study

Limitations of the study are discussed in the following section of this chapter. In this study, limitations were found in the following areas: study design, social isolation instrument, study sample, and other intervening variables.

Study Design

This study utilized a correlational analysis in order to assess the extent to which perceived social isolation in elderly wives caring for disabled husbands corresponded to the wives utilization of resources to assist them in caregiving. The main disadvantage of this form of analysis is that cause and effect cannot be determined. Therefore, the information obtained from this study cannot be used to predict if caregiving influences social isolation or whether social isolation existed prior to caregiving.

Social Isolation Instrument

Existing data from a completed study was utilized to further analyze the concept of perceived social isolation. Therefore, subscales that were not originally designed to measure the concept of social isolation were used in order to make some inferences about perceived social isolation in wives caring for disabled husbands. As such, six subscales were used to measure affective support, and one scale was used to measure tangible support. Affective support and tangible support were dimensions used in this study to describe perceived social isolation. No attempt was made to generate a single score for perceived social isolation.

Upon analysis of the data, it appeared that the affective support dimension of perceived social isolation could have been further divided into two dimensions of affective support. For example, the subscales of Reliable Alliance, Attachment, Social Integration, and Guidance appeared to reflect wives' feelings of affective support related to relationships with others. Whereas, Impact on Daily Schedule and Feelings of Family Abandonment appeared to reflect wives' reactions to relationships with others.

Study Sample

The sample for this study was one of convenience. Since the sample came from a predominantly white, middle class area, the results can not be generalized to the rest of the population. Demographic data needs to be expanded to include a better indicator of the wives' social network size. The

availability of the social network, in terms of the size of the family and the family's geographical distance, would also be desirable. In addition, this study should be replicated with a culturally diverse population.

Intervening Variables

Intervening variables were not taken into consideration which may impact on the wives' perception of social isolation or use of resources. Measures were only from the wives' perspective and may differ significantly from other family members' perceptions. Information about the level of the husbands' disability and the wives' level of involvement in the task of caregiving would also provide a better understanding of the wife's perception of social isolation and the utilization of resources. Knowledge about the wives' previous patterns of social interaction would also be of benefit. Whether the caregiving role was taken on voluntarily or involuntarily, or unexpectedly would also be of interest.

Recommendations for Further Research

The present study should be replicated to further test the relationship between perceived social isolation and the use of resources by elderly wives caring for disabled husbands. In further testing, the limitations of the present study should be considered in designing the methodology in order to improve the control.

Studies which contribute to the development of predictive theories related to perceived social isolation and caregiving should be designed. A qualitative approach is suggested which

would contribute to our understanding of the experience of social isolation in elderly wives caring for disabled husbands.

Comparative designs, which examine wives caring for cognitively impaired husbands with wives caring for physically impaired husbands, and the wives' perception of social isolation should also be done. This would provide a better understanding of how the husband's disability, especially in terms of his ability to communicate with his wife, contributes to the perception of the wife's perception of social isolation.

Replication of study with a longitudinal design would also facilitate a more meaningful understanding of the relationship of perceived social isolation and utilization of resources in caregivers if multiple measures were taken over time, rather than a one time measure. This would permit the following hypothesis to be tested: The longer the duration of caregiving, the greater the perception of social isolation. It is conceivable that with longer durations of caregiving, wives adapt to their decreasing interactions. Therefore, a longitudinal design could further delineate whether elderly wives perception of social isolation changes over time. The following research question is suggested: Does the perception of social isolation in elderly wife caring for disabled husbands increase with the duration of caregiving?

There must be further conceptual clarity of the concept of social isolation. In this study, social isolation was

defined as low levels of interaction and conceptualized as having both an affective support and a tangible support dimension. Other instruments should be tested which either support or reject the assumption of social isolation being composed of an affective and a tangible support dimension.

The sample in the present study resided in a predominantly white middle class area. A study including a variety of subjects in higher, middle, and lower socioeconomic classes and of various cultural and ethnic backgrounds would yield conclusions applicable to a broader population. The study could also be replicated to compare sociodemographic characteristics of the sample with the variables being examined.

A replication of the study is also recommended comparing wives caring for cognitively impaired husbands and wives caring for physically impaired husbands. The following research question is suggested: Is there a difference in the perception of social isolation in elderly wives caring for cognitively impaired husbands and elderly wives caring for physically impaired husbands?

A comparison of wives' involvement in caregiving and factors surrounding the inception of caregiving, such as the decision to take on the caregiving role, and period of time between the decision to take on the caregiving role and the actual assumption of the caregiving role should be considered as variables contributing to wives' perception of social isolation. Additionally, depression, role obligation, and

satisfaction with informal support systems and formal support services should be considered as intervening variables affecting perceived social isolation in wives caring for disabled husbands.

Finally, nurse researchers could also design and test interventions which ameliorate wives' perception of social isolation. For example, nursing interventions, such as permission giving or reminiscence, could be tested utilizing a comparative experimental design. Using a pretest-posttest analysis of social isolation, Clinical Nurse Specialist (CNS) practicing in primary care setting could identify a population of elderly wives caring for a disabled husband, randomly assign them to an experimental group and a control group. The CNS would then introduce the intervention to the experimental group of wives, such as giving the wives permission to ask for or accept assistance from family members with caring for the wife's husband. Analysis of the pretest and the posttest would provide information about the effectiveness of the intervention.

Theoretical Model

King's (1981) model of dynamic interacting systems was used as the theoretical base for this study. This framework incorporated the idea that human beings are open systems interacting with the environment. In order for the interaction to occur the boundaries of the interacting systems must be permeable. In this study, the focus of interaction was between the wife's personal system and the social system.

The findings from this study indicate wives appeared to be isolated socially, only in terms of tangible support and in two components of affective support, feelings of family abandonment and impact of caregiving on daily schedule. In this study, the wives' perception of affective support appeared to be the significant factor which influenced the wives' perception of not being entirely socially isolated, and thus allowed her interaction with her environment. Furthermore, based on the data, it appears that for the wives in this study, family and friends provide a supplemental type of care, at least in terms of affective support, rather than a substitutive type of instrumental support previously described in the literature.

A new model is presented in which formal support services and informal support systems each comprise their own system. Separate interpersonal systems are formulated between the elderly wife and formal support services and informal support systems in order to depict a supplementary role verses the traditional substitutive role, each system plays in preventing social isolation in elderly wives caring for disabled husbands. Figure 3 illustrates the new model. It is suggested that King's (1981) conceptual framework and the new model be utilized in the recommended studies to test its application more explicitly.

Implications for Advanced Nursing Practice

The Clinical Nurse Specialist (CNS) is a primary care provider in that the CNS serves the client, in this situation an elderly wife who is providing care for her disabled

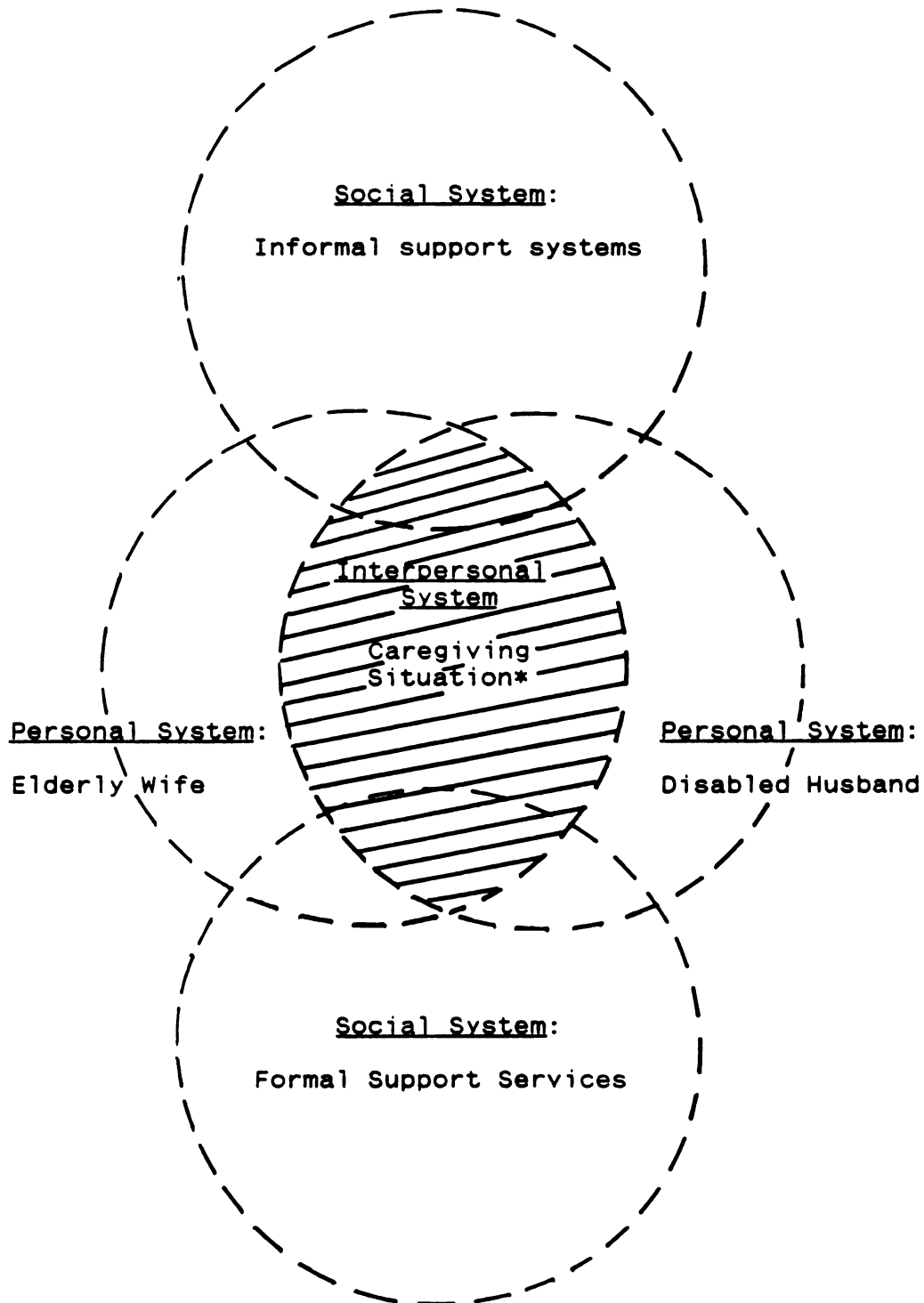


Figure 3: A Conceptual Framework for Studying the Influence of Informal Support Systems and Formal Support Services of Social Isolation in a Caregiving Situation.

husbands, by providing comprehensive, continuous, coordinated, and collaborative care. The implications for advanced nurse practice will be discussed within the context of King's (1981) model of dynamic interacting systems and theory of goal attainment.

King (1981) defines nursing as a process of action, reaction, and interaction whereby nurse and client share information about their perceptions in the nursing situation (p. 2). King's theory of goal attainment was derived from the conceptual framework of the interpersonal system. The basic assumption of King's theory is a nurse and client come together in a nursing situation, share perceptions, communicate information, mutually set goals, and take action to attain goals. (See Figure 4).

In the assessment phase, the nurse and the elderly wife come together forming an interpersonal system. The elderly wife and CNS communicate with each other through verbal and non-verbal language and information is exchanged and interpreted. According to King (1981) communication is an interchange of thoughts and opinions among individuals and the means whereby social interaction takes place. Thus, communication leads for the formation of perceptions.

Based on the elderly wife's and CNS's perceptions of one another, a judgement is made about whether the elderly wife and the CNS can help each other achieve the goal, in this study a level of interaction which permits the elderly wife to access resources which facilitate the continuation of home

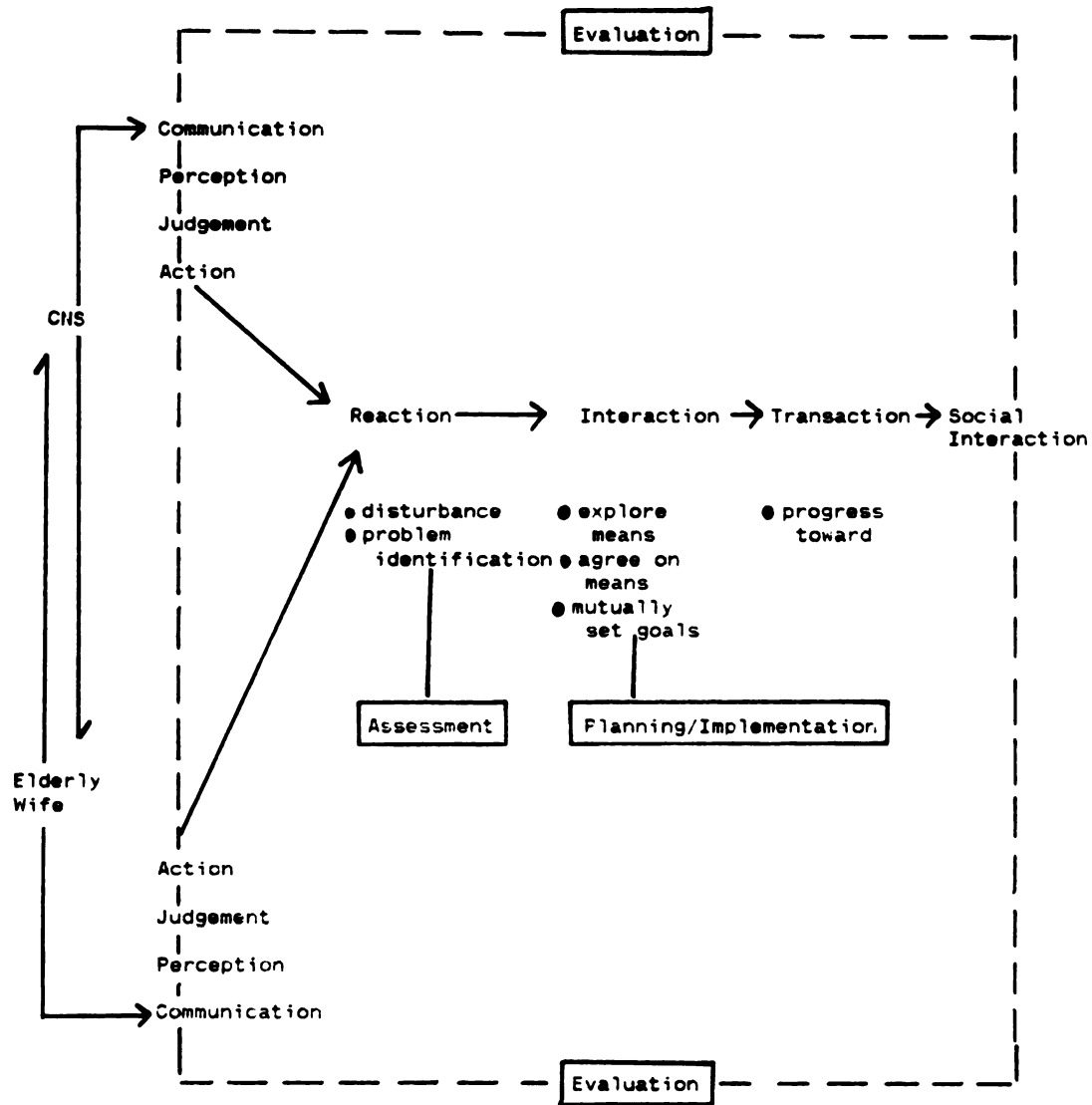


Figure 4: King's Model of Human Interaction Adapted to Illustrate CNS and Elderly Wife Interaction (Adapted from: King, I. (1981). A Theory for Nursing. New York: John Wiley & Son).

care. This is followed by a sequence of behaviors, or actions, which leads to recognition and initiation of activities related to the condition or situation. Reaction results than as the disturbance or problem is identified, in this study perceived social isolation.

In practice, the CNS must be aware of not only the quantity of interaction, but more importantly the quality of interaction between elderly wives caring for disabled husbands and their family and friends. Thus, the CNS must assess barriers which inhibit the elderly wife from engaging in quality interaction with family and friends. An assessment tool could be used for this purpose. The nurse can use this tool to elicit information regarding the wife's past history of help seeking behaviors, the wife's attitudes and values about receiving help from family and friends, as well as the wife's assumption that family and friends already know what kind of help the wife needs.

Also during the assessment phase, it is important for the CNS to help the wife identify what characterizes quality interaction with family and friends. The assumption and values of the CNS regarding what barriers prevent quality interaction may not be true. Accuracy in perception will depend upon verifying the CNS's inferences with the elderly wife. Therefore, it is important to elicit the wife's perception of what barriers inhibit quality interaction with family and friends.

In the planning and implementation phase, the CNS and wife agree on realistic goals to decrease barriers to quality interaction between the wife and her family and friends, explore the means and agree of the means to achieve the goals. The CNS may facilitate goal-setting and the means to achieve the goals by using his/her counseling skills, and his/her understanding of family dynamics. The CNS can also assist by coordinating help from family and friends and formal services support.

Early in the caregiving situation, as well as intermittently throughout the duration of caregiving, the CNS can facilitate family care conferences to provide a forum for open communication between all individuals providing care for the disabled husband. The family conference can also be a time for the CNS to provide anticipatory guidance, helping families to plan for future care needs, as well as providing a time for families to evaluate how things are going.

Besides working with families, the CNS uses his/her counseling skills working with the elderly wife. Through active listening, presence, cognitive restructuring, confrontation, and normalizing feelings, the CNS can help wives dispel guilt related to asking for assistance. The CNS may also teach wives assertiveness techniques to facilitate wives ability to ask for assistance.

In the Evaluation phase of the nursing process, progress toward goal attainment is appraised. In this study, goal attainment is represented by the wife's ability to interact

with her environment in order to access resources that facilitate maintenance and continuation of care for her disabled husband. King (1981) includes feedback in her model of goal attainment, but does not discuss it in detail. Feedback is included in this model to indicate that continuous exchange of quality interaction is necessary to maintain and continue the caregiving situation.

To summarize, the implications for advanced nursing practice were presented based on the findings of this study. The role of the nurse in facilitating interactions that promote access to resources for elderly wives caring for disabled husbands was outlined.

Implications for Nursing Education

The following recommendations for nursing education could be applied to undergraduate, graduate, and continuing education programs for nurses. Nursing education should include a theoretical framework for understanding and predicting interactions of individuals with their environment. Those variables affecting the quality of interaction of caregivers and their environment would be especially important to include in nursing education. The present study has suggested that affective support and the instrumental help of family and friends, have the potential for influencing formal support services.

Nursing diagnosis describing individuals interactions with their environment should also be included in nursing education. Diagnoses related to individuals interactions with

their environment could be included in the role-relationship, coping-stress-tolerance, value-belief patterns of the functional health patterns areas described by Gordon (1987). Diagnoses generated from assessment of the functional patterns listed could assist nurses in planning interventions and identifying desired outcomes.

It is suggested that nursing education also include content related to aging theories, as these theories address the levels of interaction between the elderly individual and his/her environment. Additionally, content on developmental task of aging needs to be included in nursing education, as these developmental task affect interactions in the elderly.

Further, it is recommended that nursing education include content on family caregiving. As the population continues to age and long-term care continues to be provided in the home nurses need to understand the dynamics caregiving has on family systems and in policy planning/decisions.

In summary, the implications for nursing education presented are based on the findings of this study. Implications are applicable to undergraduate, graduate, and continuing education nursing programs. Nursing educators must prepare nurses to meet the demands and challenges of family home care.

In conclusion, implications for advanced nursing practice were presented in relation to King's (1981) theory of goal attainment/model of nursing process. Suggestions for nursing education were discussed, and recommendation for further

research were delineated in this chapter.

Nurses in advanced practice need to accept the responsibility, as well as the challenge, in assisting family caregivers to continue to provide care of a family member at home. Therefore, CNS need to continue to do research, develop and implement interventions, and publish their findings related to perceived social isolation and family caregivers.

Summary

This study has analyzed the relationship between perceived social isolation and the utilization of resources for a sample of 61 elderly wives caring for disabled husbands.

The findings of this study have implications not only for nursing practice, but for other disciplines as well. Nurses and other professionals, such as, social workers, psychologist, and clergy, as well as the family and friends of caregivers, need to be aware of the quality of interactions as they affect elderly wives caring ability to maintain and continue caring for disabled husbands.

APPENDICIES

APPENDIX A
UCRIHS Approval

MICHIGAN STATE UNIVERSITY

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING
HUMAN SUBJECTS (UCRIHS)
206 BERKEY HALL
(517) 353-9738

EAST LANSING • MICHIGAN • 48824-1111

December 5, 1989

IRB# 89-523

Debra Berry
116 W. Pine Street
Carson City, MI 48811

Dear Ms. Berry:

RE: "THE RELATIONSHIP BETWEEN PERCEIVED SOCIAL ISOLATION AMONG
ELDERLY WIVES CARING FOR DISABLED HUSBANDS AND THEIR USE
OF RESOURCES IRB# 89-523"

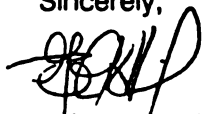
The above project is exempt from full UCRIHS review. I have reviewed the proposed research protocol and find that the rights and welfare of human subjects appear to be protected. You have approval to conduct the research.

You are reminded that UCRIHS approval is valid for one calendar year. If you plan to continue this project beyond one year, please make provisions for obtaining appropriate UCRIHS approval one month prior to December 5, 1990.

Any changes in procedures involving human subjects must be reviewed by UCRIHS prior to initiation of the change. UCRIHS must also be notified promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

Thank you for bringing this project to our attention. If we can be of any future help, please do not hesitate to let us know.

Sincerely,



John K. Hudzik, Ph.D.
Chair, UCRIHS

JKH/sar

cc: B. Given

MICHIGAN STATE UNIVERSITY

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING
HUMAN SUBJECTS (UCRIHS)
294 ADMINISTRATION BUILDING
(517) 355-2186

EAST LANSING • MICHIGAN • 48824-1046

February 3, 1987

Dr. Charles W. Given
Family Practice
B-100 Clinical Center

Dear Dr. Given:

Subject: Revision of Proposal Entitled, "Caregiver Responses to
Managing Elderly Patients at Home"

UCRIHS' review of the above referenced revision has now been completed. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and the Committee, therefore, approved this revision at its meeting on February 2, 1987.

You are reminded that UCRIHS approval is valid for one calendar year. If you plan to continue this project beyond one year, please make provisions for obtaining appropriate UCRIHS approval prior to February 2, 1988.

Any changes in procedures involving human subjects must be reviewed by the UCRIHS prior to initiation of the change. UCRIHS must also be notified promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

Thank you for bringing this project to our attention. If we can be of any future help, please do not hesitate to let us know.

Sincerely,



Henry E. Bredeck, Ph.D.
Chairman, UCRIHS

jms

APPENDIX B
Consent Forms

INFORMED CONSENT PROCEDURE

Before we get started, I would like to take some time to explain what will be involved in taking part in this study and to answer questions you may have about taking part.

Basically, over the course of the year, there will be two home visits which will be arranged at your convenience as well as several telephone calls and mailed questionnaires.

There are some other things that are important for me to let you know about relative to taking part in this study.

One thing is that taking part in the study will not change the health care or services that you are now receiving. The study does not provide any services and cannot arrange for services for you.

Also, if your situation should change during the year so that you are no longer helping your relative, we would still like to maintain contact and ask questions of you.

It is important for you to know that all of your responses during the course of the study are anonymous and confidential. Your name and anything which would identify you personally will be kept separate from the answers you give. Neither your name nor the name of your family member will be given out to anyone else or used in any written reports of the study at any time.

We want you to be aware that taking part in the study is voluntary and you are free to withdraw from the study at any time without consequence.

Do you have any questions about taking part in the study?

I have a written consent form with me that I would like to have you sign. I'll leave one copy of the consent form for you to keep and take one copy to keep with the records of the research study.

IF SUBJECT DOES NOT WISH TO SIGN FORM, LEAVE THEM A COPY AND PROCEED WITH THE INTERVIEW. INCLUDE THIS INFORMATION ON THE INTERVIEWER ASSESSMENT.

2/4/87
jy

MICHIGAN STATE UNIVERSITY
Family Caregiver Study

CONSENT FORM

The study in which we are asking you to participate is designed to learn more about the ways in which caring for an older family member affects the person providing the care.

Over the next year, family caregivers will be interviewed by a member of the Family Caregiver Study research staff three times (at intake, six months, and at one-year). Each interview will take approximately one and one-half hours to complete. Caregivers will be asked to complete written questionnaires and to answer questions asked by the interviewer. They will also be asked to report, each three months during the year, on any health care services used.

If you are willing to participate, please read and sign the following statement:

1. I have freely consented to take part in a study of caregivers and their patients conducted by the College of Nursing and the Department of Family Practice, College of Human Medicine, at Michigan State University.
2. The study has been described and explained to me and I understand what my participation will involve.
3. I understand that participating in this study is voluntary.
4. I understand that I can withdraw from participating at any time.
5. I understand that the results of the study will be treated in strict confidence and, should they be published, my name will remain anonymous. I understand that within these restrictions, results can, upon request, be made available to me.
6. I understand that no immediate benefits will result from taking part in this study, but am aware that my responses may add to the understanding of health care professionals of the experience of being responsible for an older family member.

I, _____, state that I understand what is required of me as a participant and agree to take part in this study.

Signed _____
(signature)

Date _____

12/17/86
jy

APPENDIX C**Affective Support Subscales**

Reliable Alliance:	Survey Items # 1, 10, 18, 23
Attachment:	Survey Items # 1, 11, 17, 21
Guidance:	Survey Items # 1, 12, 16, 19
Social Integration:	Survey Items # 5, 8, 14, 22
Feelings of Family Abandonment:	Survey Items # 1, 4, 7, 13, 16, 23
Impact of Caregiving on Daily Schedule:	Survey Items # 6, 10, 14, 20, 25

WA'E V

ID _ _ _ 1-3
 Card 7 6 4-5
 Date _ _ / _ _ / _ _ 6-11
 INT _ _ 12-13
 INT Code 5 14
 Study 1 15

THE SOCIAL PROVISIONS SCALE

In answering this set of questions think about your current relationships with friends, family members, community members, and church members. PLEASE IDENTIFY HOW MUCH YOU AGREE WITH EACH STATEMENT. For example, if you feel a statement is very true of your current relationships, you should circle STRONGLY AGREE. If you feel a statement clearly does not describe your relationships, you should circle STRONGLY DISAGREE. Circle one response for each statement.

EXAMPLE

I like the color blue.

STRONGLY DISAGREE

DISAGREE

AGREE

STRONGLY AGREE

1. There are people I can depend on to help me if I really need it.

16

STRONGLY DISAGREE

DISAGREE

AGREE

STRONGLY AGREE

2. I feel that I do not have close personal relationships with other people.

17

STRONGLY DISAGREE

DISAGREE

AGREE

STRONGLY AGREE

3. There is no one I can turn to for guidance in times of stress.

18

STRONGLY DISAGREE

DISAGREE

AGREE

STRONGLY AGREE

4. There are people who depend on me for help.

19

STRONGLY DISAGREE

DISAGREE

AGREE

STRONGLY AGREE

5. There are people who enjoy the same social activities I do.

20

STRONGLY DISAGREE

DISAGREE

AGREE

STRONGLY AGREE

6. Other people do not view me as competent.

21

STRONGLY DISAGREE

DISAGREE

AGREE

STRONGLY AGREE

7. I feel personally responsible for the well-being of my relative

22

STRONGLY DISAGREE

DISAGREE

AGREE

STRONGLY AGREE

WAVE V
Social Provisions
Page 2

ID
Card 76

- | | | |
|---|----------|----------------|
| 8. I feel part of a group of people who share my attitudes and beliefs. | | <u>23</u> |
| STRONGLY DISAGREE | DISAGREE | AGREE |
| | | STRONGLY AGREE |
| 9. I do not think other people respect my skills and abilities. | | <u>24</u> |
| STRONGLY DISAGREE | DISAGREE | AGREE |
| | | STRONGLY AGREE |
| 10. If something went wrong, no one would come to my assistance. | | <u>25</u> |
| STRONGLY DISAGREE | DISAGREE | AGREE |
| | | STRONGLY AGREE |
| 11. I have close relationships that provide me with a sense of emotional security and well-being. | | <u>26</u> |
| STRONGLY DISAGREE | DISAGREE | AGREE |
| | | STRONGLY AGREE |
| 12. There is someone I could talk to about important decisions in my life. | | <u>27</u> |
| STRONGLY DISAGREE | DISAGREE | AGREE |
| | | STRONGLY AGREE |
| 13. I have relationships where my competence and skills are recognized. | | <u>28</u> |
| STRONGLY DISAGREE | DISAGREE | AGREE |
| | | STRONGLY AGREE |
| 14. There is no one who shares my interests and concerns. | | <u>29</u> |
| STRONGLY DISAGREE | DISAGREE | AGREE |
| | | STRONGLY AGREE |
| 15. There is no who really relies on me for their well-being. | | <u>30</u> |
| STRONGLY DISAGREE | DISAGREE | AGREE |
| | | STRONGLY AGREE |
| 16. There is a trustworthy person I could turn to for advice if I were having problems. | | <u>31</u> |
| STRONGLY DISAGREE | DISAGREE | AGREE |
| | | STRONGLY AGREE |
| 17. I feel a strong emotional bond with at least one person. | | <u>32</u> |
| STRONGLY DISAGREE | DISAGREE | AGREE |
| | | STRONGLY AGREE |

Wave V
Social Provisions Scale
Page 3

ID
Card 76

- | | |
|--|----|
| 18. There is no one I can depend on for aid if I really need it. | 33 |
| STRONGLY DISAGREE DISAGREE AGREE STRONGLY AGREE | |
| 19. There is no one I feel comfortable talking about my problems with. | 34 |
| STRONGLY DISAGREE DISAGREE AGREE STRONGLY AGREE | |
| 20. There are people who admire my talents and abilities. | 35 |
| STRONGLY DISAGREE DISAGREE AGREE STRONGLY AGREE | |
| 21. I lack a feeling of intimacy with another person. | 36 |
| STRONGLY DISAGREE DISAGREE AGREE STRONGLY AGREE | |
| 22. There is no one who likes to do the things I like to do. | 37 |
| STRONGLY DISAGREE DISAGREE AGREE STRONGLY AGREE | |
| 23. There are people I can count on in an emergency. | 38 |
| STRONGLY DISAGREE DISAGREE AGREE STRONGLY AGREE | |
| 24. No one needs me to care for them. | 39 |
| STRONGLY DISAGREE DISAGREE AGREE STRONGLY AGREE | |

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WAVE V

ID _ _ _ 1-3
 Card 81 4-5
 Date _ _ / _ _ / _ _ 6-11
 INT _ _ 12-13
 INT Code 5 14
 Study 1 15

CAREGIVING INVENTORY

We are trying to understand how providing care for your family member has affected you, your relationships with others, and your social activities and daily routines.

In the questions that follow, please circle the response that most represents how you feel about each statement. The blank line in some statements represents the name of the elderly person for whom you provide care. It may be helpful for you to place the initials of the person on the blank line. Answer all the questions in response to caring for the elderly person. (Circle one response for each statement.)

EXAMPLE

Since I began caring for _____, my day-to-day schedule has changed a lot.

**STRONGLY
AGREE**

AGREE

NEITHER AGREE
NOR DISAGREE

DISAGREE

STRONGLY
DISAGREE

1. My family works together at caring for _____. (CIRCLE ONE)

16

STRONGLY
AGREE

AGREE

NEITHER AGREE
NOR DISAGREE

DISAGREE

STRONGLY
DISAGREE

2. My financial resources are adequate to pay for things that are required for caregiving. (CIRCLE ONE)

17

STRONGLY
AGREE

AGREE

NEITHER AGREE
NOR DISAGREE

DISAGREE

STRONGLY
DISAGREE

3. I feel overwhelmed by the problems I have caring for _____. (CIRCLE ONE)

18

STRONGLY
AGREE

AGREE

NEITHER AGREE
NOR DISAGREE

DISAGREE

STRONGLY
DISAGREE

4. I wish the family depended less on me to care for _____. (CIRCLE ONE)

19

STRONGLY
AGREE

AGREE

NEITHER AGREE
NOR DISAGREE

DISAGREE

STRONGLY
DISAGREE

5. Its difficult to pay for _____'s health needs and services. (CIRCLE ONE)

20

STRONGLY
AGREE

AGREE

NEITHER AGREE
NOR DISAGREE

DISAGREE

STRONGLY
DISAGREE

WAVE V
Inventory
Page 2

ID
Card 81

6. My activities are centered around care for _____. (CIRCLE ONE) 21
- | | | | | |
|-------------------|-------|-------------------------------|----------|----------------------|
| STRONGLY
AGREE | AGREE | NEITHER AGREE
NOR DISAGREE | DISAGREE | STRONGLY
DISAGREE |
|-------------------|-------|-------------------------------|----------|----------------------|
7. I am healthy enough to care for _____. (CIRCLE ONE) 22
- | | | | | |
|-------------------|-------|-------------------------------|----------|----------------------|
| STRONGLY
AGREE | AGREE | NEITHER AGREE
NOR DISAGREE | DISAGREE | STRONGLY
DISAGREE |
|-------------------|-------|-------------------------------|----------|----------------------|
8. Since caring for _____, I feel that my family has abandoned me. (CIRCLE ONE) 23
- | | | | | |
|-------------------|-------|-------------------------------|----------|----------------------|
| STRONGLY
AGREE | AGREE | NEITHER AGREE
NOR DISAGREE | DISAGREE | STRONGLY
DISAGREE |
|-------------------|-------|-------------------------------|----------|----------------------|
9. Caring for _____ has put a financial strain on the family. (CIRCLE ONE) 24
- | | | | | |
|-------------------|-------|-------------------------------|----------|----------------------|
| STRONGLY
AGREE | AGREE | NEITHER AGREE
NOR DISAGREE | DISAGREE | STRONGLY
DISAGREE |
|-------------------|-------|-------------------------------|----------|----------------------|
10. I have to stop in the middle of my work or activities to provide care. (CIRCLE ONE) 25
- | | | | | |
|-------------------|-------|-------------------------------|----------|----------------------|
| STRONGLY
AGREE | AGREE | NEITHER AGREE
NOR DISAGREE | DISAGREE | STRONGLY
DISAGREE |
|-------------------|-------|-------------------------------|----------|----------------------|
11. Caring for _____ is important to me. (CIRCLE ONE) 26
- | | | | | |
|-------------------|-------|-------------------------------|----------|----------------------|
| STRONGLY
AGREE | AGREE | NEITHER AGREE
NOR DISAGREE | DISAGREE | STRONGLY
DISAGREE |
|-------------------|-------|-------------------------------|----------|----------------------|
12. I resent having to take care of _____. (CIRCLE ONE) 27
- | | | | | |
|-------------------|-------|-------------------------------|----------|----------------------|
| STRONGLY
AGREE | AGREE | NEITHER AGREE
NOR DISAGREE | DISAGREE | STRONGLY
DISAGREE |
|-------------------|-------|-------------------------------|----------|----------------------|
13. It is very difficult to get help from my family in taking care of _____. (CIRCLE ONE) 28
- | | | | | |
|-------------------|-------|-------------------------------|----------|----------------------|
| STRONGLY
AGREE | AGREE | NEITHER AGREE
NOR DISAGREE | DISAGREE | STRONGLY
DISAGREE |
|-------------------|-------|-------------------------------|----------|----------------------|
14. I have eliminated things from my schedule since caring for _____. (CIRCLE ONE) 29
- | | | | | |
|-------------------|-------|-------------------------------|----------|----------------------|
| STRONGLY
AGREE | AGREE | NEITHER AGREE
NOR DISAGREE | DISAGREE | STRONGLY
DISAGREE |
|-------------------|-------|-------------------------------|----------|----------------------|

15. I enjoy caring for _____. (CIRCLE ONE) 30
- | | | | | |
|-------------------|-------|-------------------------------|----------|----------------------|
| STRONGLY
AGREE | AGREE | NEITHER AGREE
NOR DISAGREE | DISAGREE | STRONGLY
DISAGREE |
|-------------------|-------|-------------------------------|----------|----------------------|
16. Others have dumped caring for _____ on to me. (CIRCLE ONE) 31
- | | | | | |
|-------------------|-------|-------------------------------|----------|----------------------|
| STRONGLY
AGREE | AGREE | NEITHER AGREE
NOR DISAGREE | DISAGREE | STRONGLY
DISAGREE |
|-------------------|-------|-------------------------------|----------|----------------------|
17. I get very discouraged with caring for _____. (CIRCLE ONE) 32
- | | | | | |
|-------------------|-------|-------------------------------|----------|----------------------|
| STRONGLY
AGREE | AGREE | NEITHER AGREE
NOR DISAGREE | DISAGREE | STRONGLY
DISAGREE |
|-------------------|-------|-------------------------------|----------|----------------------|
18. It takes all my physical strength to care for _____. (CIRCLE ONE) 33
- | | | | | |
|-------------------|-------|-------------------------------|----------|----------------------|
| STRONGLY
AGREE | AGREE | NEITHER AGREE
NOR DISAGREE | DISAGREE | STRONGLY
DISAGREE |
|-------------------|-------|-------------------------------|----------|----------------------|
19. If I could afford it, I would find some other way to care for _____.
(CIRCLE ONE) 34
- | | | | | |
|-------------------|-------|-------------------------------|----------|----------------------|
| STRONGLY
AGREE | AGREE | NEITHER AGREE
NOR DISAGREE | DISAGREE | STRONGLY
DISAGREE |
|-------------------|-------|-------------------------------|----------|----------------------|
20. The constant interruptions make it difficult to find time for relaxation.
(CIRCLE ONE) 35
- | | | | | |
|-------------------|-------|-------------------------------|----------|----------------------|
| STRONGLY
AGREE | AGREE | NEITHER AGREE
NOR DISAGREE | DISAGREE | STRONGLY
DISAGREE |
|-------------------|-------|-------------------------------|----------|----------------------|
21. Caring for _____ makes me feel good. (CIRCLE ONE) 36
- | | | | | |
|-------------------|-------|-------------------------------|----------|----------------------|
| STRONGLY
AGREE | AGREE | NEITHER AGREE
NOR DISAGREE | DISAGREE | STRONGLY
DISAGREE |
|-------------------|-------|-------------------------------|----------|----------------------|
22. My health has gotten worse since I've been caring for _____. (CIRCLE ONE) 37
- | | | | | |
|-------------------|-------|-------------------------------|----------|----------------------|
| STRONGLY
AGREE | AGREE | NEITHER AGREE
NOR DISAGREE | DISAGREE | STRONGLY
DISAGREE |
|-------------------|-------|-------------------------------|----------|----------------------|
23. My family (brothers, sister, children) left me alone to care for _____.
(CIRCLE ONE) 38
- | | | | | |
|-------------------|-------|-------------------------------|----------|----------------------|
| STRONGLY
AGREE | AGREE | NEITHER AGREE
NOR DISAGREE | DISAGREE | STRONGLY
DISAGREE |
|-------------------|-------|-------------------------------|----------|----------------------|

WAVE V
Inventory
Page 4

ID
Card 81

24. _____ sometimes disrupts meals or makes them unpleasant. (CIRCLE ONE)

STRONGLY NEITHER AGREE STRONGLY
AGREE AGREE NOR DISAGREE DISAGREE DISAGREE

39

25. I visit family and friends less since I have been caring for _____.
(CIRCLE ONE)

STRONGLY NEITHER AGREE STRONGLY
AGREE AGREE NOR DISAGREE DISAGREE DISAGREE

40

26. Since caring for _____, sometimes I hate the way my life has turned out.
(CIRCLE ONE)

STRONGLY NEITHER AGREE STRONGLY
AGREE AGREE NOR DISAGREE DISAGREE DISAGREE

41

27. I have enough physical strength to care for _____. (CIRCLE ONE)

STRONGLY NEITHER AGREE STRONGLY
AGREE AGREE NOR DISAGREE DISAGREE DISAGREE

42

28. I feel I was forced into caring for _____. (CIRCLE ONE)

STRONGLY NEITHER AGREE STRONGLY
AGREE AGREE NOR DISAGREE DISAGREE DISAGREE

43

29. I feel trapped by my caregiving role. (CIRCLE ONE)

STRONGLY NEITHER AGREE STRONGLY
AGREE AGREE NOR DISAGREE DISAGREE DISAGREE

44

30. Caregiving has worn me out. (CIRCLE ONE)

STRONGLY NEITHER AGREE STRONGLY
AGREE AGREE NOR DISAGREE DISAGREE DISAGREE

45

31. Since caring for _____, it seems like I'm tired all of the time.
(CIRCLE ONE)

STRONGLY NEITHER AGREE STRONGLY
AGREE AGREE NOR DISAGREE DISAGREE DISAGREE

46

32. At this time in my life, I don't think I should have to be caring for _____.
(CIRCLE ONE)

STRONGLY NEITHER AGREE STRONGLY
AGREE AGREE NOR DISAGREE DISAGREE DISAGREE

47

APPENDIX D

Tangible Support Scale

Social Resources	Survey Items # 1, 2, 3, 4, 5, 6
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WAVE V

ID _ _ _ 1-3
 Card 77 4-5
 Date _ _ / _ _ / _ _ 6-11
 INT _ _ 12-13
 INT Code 5 14
 Study 1 15

SOCIAL RESOURCES SCALE

1. Over a months time, about how often do you get together with friends or relatives, like going out together or visiting in each other's homes? (CHECK ONE)

☐ Everyday (1) ☐ About once a month (5)
☐ Several days a week (2) ☐ Five to ten times a year (6)
☐ About once a week (3) ☐ Less than five times a year (7)
☐ Two or three times a month (4)

16

2. During the past month, about how often have you had friends over to your home? (Do not count relatives.) CHECK ONE

☐ Everyday (1) ☐ Two or three times in past month (4)
☐ Several days a week (2) ☐ Once in past month (5)
☐ About once a week (3) ☐ Not at all in past month (6)

17

3. About how often have you visited with friends at their homes during the past month? (Do not count relatives.) (CHECK ONE)

☐ Everyday (1) ☐ Two or three times in past month (4)
☐ Several days a week (2) ☐ Once in past month (5)
☐ About once a week (3) ☐ Not at all in past month (6)

18

4. About how often were you on the telephone with close friends or relatives during the past month? (CHECK ONE)

☐ Everyday (1) ☐ Two or three times in past month (4)
☐ Several days a week (2) ☐ Once in past month (5)
☐ About once a week (3) ☐ Not at all in past month (6)

19

5. About how often did you write a letter to a friend or relative during the last month? (CHECK ONE)

☐ Everyday (1) ☐ Two or three times in past month (4)
☐ Several days a week (2) ☐ Once in past month (5)
☐ About once a week (3) ☐ Not at all in past month (6)

20

Wave V
Social Resources
Page 2

ID
Card 77

6. About how often have you attended a religious service during the past month?
(CHECK ONE)

21

<input type="checkbox"/> Everyday (1)	<input type="checkbox"/> Two or three times in past month (4)
<input type="checkbox"/> Several days a week (2)	<input type="checkbox"/> Once in past month (5)
<input type="checkbox"/> About once a week (3)	<input type="checkbox"/> Not at all in past month (6)

7. How many meetings or social gatherings of voluntary groups or organizations do you actually attend each month (on the average)?

 per month

22 23

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APPENDIX E

Informal Support Systems Subscales

Family Help: Survey Items # 1a, b, c, f, g, h, i, j

Friend Help: Survey Items # 3a, b, c, f, g, h, i, j

WAVE V

ID _ _ _ 1-3
 Card 6 3 4-5
 Date _ _ / _ _ / _ _ 6-11
 INT _ _ 12-13
 INT Code _ _ _ 14
 Study 1 15

ASSISTANCE

The questions that I have just asked are about assistance that you receive through agencies. Now I'm going to ask you questions about the assistance that you receive from other people to care for your relative. By other people, I mean friends or relatives whether you pay them or not.

For the next set of questions, I would like you to pick one of four categories of answers. You can choose from "RARELY OR NONE OF THE TIME," "SOME OF THE TIME," "MOST OF THE TIME" or "ALMOST ALL OF THE TIME."

1. How often, over the past three months, HAS ANYONE IN YOUR FAMILY given you assistance in the following ways?

	(1) RARELY OR NONE OF THE TIME	(2) SOME OF THE TIME	(3) MOST OF THE TIME	(4) ALMOST ALL OF THE TIME	
a) Helped with physical care.					__ 16
b) Spent time keeping your relative company.					__ 17
c) Stayed with your relative so you could do something else for a few hours.					__ 18
d) Stayed with your relative so you can take a vacation (for a weekend or longer).					__ 19
e) Gotten up during the night with your relative.					__ 20
f) Given you emotional support or encouragement.					__ 21
g) Helped with transportation (for either you or your relative).					__ 22
h) Helped you with money or other material goods.					__ 23
i) Checked on you to be sure that you were all right.					__ 24

2. Overall, how satisfied are you with the assistance you are currently receiving from family to care for your relative? Are you...

VERY SOMEWHAT SOMEWHAT VERY
 SATISFIED SATISFIED DISSATISFIED DISSATISFIED

3. How often, over the past three months, have FRIENDS OR NEIGHBORS (not relatives) given you help in the following ways?

	(1) RARELY OR NONE OF THE TIME	(2) SOME OF THE TIME	(3) MOST OF THE TIME	(4) ALMOST ALL OF THE TIME	
a) Helped with physical care.					__ 26
b) Spent time keeping your relative company.					__ 27
c) Stayed with your relative so you could do something else for a few hours.					__ 28
d) Stayed with your relative so you can take a vacation (for a weekend or longer).					__ 29
e) Gotten up during the night with your relative.					__ 30
f) Given you emotional support or encouragement.					__ 31
g) Helped with transportation (for either you or your relative)..					__ 32
h) Helped you with money or other material goods.					__ 33
i) Checked on you to be sure that you were all right.					__ 34

3. Now, I would like to know who it is that helps with your relative's care. To begin with, I need the relationship of this person to you.

INTERVIEWER: LIST PEOPLE. FOR EACH PERSON ASK: "What is this person's relationship to you"? ASK "In the last month how many hours does this person help you"?

	<u>RELATIONSHIP OF PERSON TO CAREGIVER</u>	<u>AVERAGE HOURS PER WEEK HELP</u>	
a)	_____	_____	35 36 37 38
b)	_____	_____	39 40 41 42
c)	_____	_____	43 44 45 46
d)	_____	_____	47 48 49 50
e)	_____	_____	51 52 53 54

APPENDIX F**Formal Support Services Subscales**

Elderly Wife:	Survey Items # 11, 12, 13, 14, 15, 16
Disabled Husband:	Survey Items # 11, 12, 13, 14, 15, 16, 17, 18, 19

WAVE V
Utilization
Page 2

ID
Card 61

"I am going to read you a list of services you may have used for your relative or yourself in the past three months.

11. Visiting Nurse or Public Health Nurse

- a. Have you used this service in the past three months for yourself? 36
- ___ YES (1) —————> How many times have you used this service in the
last three months? (number of times)
- ___ NO (2) 37 38
- b. Have you used this service in the past three months for your relative? 39
- ___ YES (1) —————> How many times in the past three months?
- ___ NO (2) (number of times) 40 41

12. Meals on Wheels

- a. Have you used this service in the past three months for yourself? 42
- ___ YES (1) —————> How many times have you used this service in the
last three months? (number of times)
- ___ NO (2) 43 44
- b. Have you used this service in the past three months for your relative? 45
- ___ YES (1) —————> How many times in the past three months?
- ___ NO (2) (number of times) 46 47

13. Transportation Services

- a. Have you used this service in the past three months for yourself? 48
- ___ YES (1) —————> How many times have you used this service in the
last three months? (number of times)
- ___ NO (2) 49 50
- b. Have you used this service in the past three months for your relative? 51
- ___ YES (1) —————> How many times in the past three months?
- ___ NO (2) (number of times) 52 53

14. Counseling for Emotional Problems

- a. Have you used this service in the past three months for yourself? 54
- ___ YES (1) —————> How many times have you used this service in the
last three months? _____ (number of times) 55 56
- ___ NO (2)
- b. Have you used this service in the past three months for your relative? 57
- ___ YES (1) —————> How many times in the past three months? _____ (number of times) 58 59
- ___ NO (2)

15. Chore or Housekeeping Services

- a. Have you used this service in the past three months for yourself? 60
- ___ YES (1) —————> How many times have you used this service in the
last three months? _____ (number of times) 61 62
- ___ NO (2) 63
- b. Have you used this service in the past three months for your relative? 64 65
- ___ YES (1) —————> How many times in the past three months? _____ (number of times)
- ___ NO (2) 66

16. Family Support Groups

- a. Have you used this service in the past three months for yourself? 66
- ___ YES (1) —————> How many times have you used this service in the
last three months? _____ (number of times)
- ___ NO (2) 67 68
- b. Has your relative used this service in the last three months? 69
- ___ YES (1) —————> How many times in the past three months?
- ___ NO (2) _____ (number of times) 70 71

WAVE V
Utilization
Page 4

End of Card 6 1
Keypunch: ID 6 2 1-3
Card 6 2 4-5
Keypunch: Duplicate columns 6-15

INTERVIEWER: THE NEXT QUESTIONS ARE FOR SERVICE USE BY RELATIVE
ONLY.

17. Home Companion or Home Health Aide During the Day

a. Have you used this service in the past three months for your relative?

 YES (1) —————> How many times in the past three months?

16

 (number of times)

17 18

How many hours have you used this service for your
relative in the past three months?

 (total number of hours)

19 20 21

 NO (2)

18. Home Companion or Home Health Aide at Night

a. Have you used this service in the past three months for your relative?

 YES (1) —————> How many times in the past three months?

22

 (number of times)

23 24

How many hours have you used this service for your
relative in the past three months?

 (total number of hours)

25 26 27

 NO (2)

19. Adult Day Care

a. Have you used this service in the past three months for your relative?

 YES (1) —————> How many times in the past three months?

28

 (number of times)

29 30

How many hours have you used this service for your
relative in the past three months?

 (total number of hours)

31 32 33

 NO (2)

20. Respite Care During the Day

INTERVIEWER: Respite Care refers to services provided by a program titled RESPITE.

This item refers to day time services. Include over-night care under question 28.

a. Have you used this service in the past three months for your relative?

34

___ YES (1) —————> How many times in the past three months?

_____ (number of times)

35 36

How many hours have you used this service for your relative in the past three months?

_____ (total number of hours)

37 38 39

___ NO (2)

21. Temporary Overnight Care (Outside of Home)

a. Have you used this service in the past three months for your relative?

40

___ YES (1) —————> How many times in the past three months?

_____ (number of times)

41 42

How many hours have you used this service for your relative in the past three months?

_____ (total number of hours)

43 44 45

___ NO (2)

22. Are there services that you are not currently receiving that you would be interested in obtaining for your relative?

46

___ YES (1) ___ NO (2)

47 48

↓
If YES, describe:

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