

## INFORMATION TO USERS

The most advanced technology has been used to photograph and reproduce this manuscript from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

**The quality of this reproduction is dependent upon the quality of the copy submitted.** Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

# U·M·I

University Microfilms International  
A Bell & Howell Information Company  
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA  
313/761-4700 800/521-0600



**Order Number 9104314**

**Respite for kin caregivers of cognitively impaired and physically  
impaired elders**

**Worcester, Martha Louise Iles, Ph.D.**

**University of Washington, 1990**

**Copyright ©1990 by Worcester, Martha Louise Iles. All rights reserved.**

**U·M·I**  
300 N. Zeeb Rd.  
Ann Arbor, MI 48106



Respite for Kin Caregivers  
of Cognitively Impaired and Physically Impaired Elders

by

Martha Louise Iles Worcester

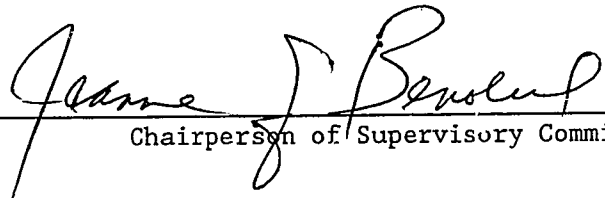
A dissertation submitted in partial fulfillment  
of the requirements for the degree of

Doctor of Philosophy

University of Washington

1990

Approved by



Chairperson of Supervisory Committee

Program Authorized  
to Offer Degree

School of Nursing

Date

15 May 1990

© Copyright by  
MARTHA LOUISE ILES WORCESTER  
1990

In presenting this dissertation in partial fulfillment of the requirements for the Doctoral degree at the University of Washington, I agree that the Library shall make its copies freely available for inspection. I further agree that extensive copying of this dissertation is allowable only for scholarly purposes, consistent with "fair use" as prescribed in the U.S. Copyright Law. Requests for copying or reproduction of this dissertation may be referred to University Microfilms, 300 North Zeeb Road, Ann Arbor, Michigan 48106, to whom the author has granted "the right to reproduce and sell (1) copies of the manuscript in microform and/or (b) printed copies of the manuscript made from microform."

Signature

*Martha L. West*

Date

*May 22, 1990*

University of Washington

Abstract

RESPITE FOR KIN CAREGIVERS  
OF COGNITIVELY IMPAIRED AND PHYSICALLY IMPAIRED ELDERS

by Martha Louise Iles Worcester

Supervisory Committee Chairperson: Professor Jeanne Q. Benoliel  
School of Nursing

A qualitative grounded theory approach was used to examine factors that facilitate or inhibit the use of respite by family caregivers. Thirty caregivers (15 caring for cognitively impaired and 15 caring for physically impaired elders) were interviewed three times over a six month period. Caregivers were spouses, adult children, or siblings who lived with the recipient. An open-ended interview was conducted in the caregiver's home and addressed questions about the ease or difficulty of obtaining respite from both informal and formal sources. Responses were analyzed using constant comparative analysis. Measures of physical, social, and psychological health also were administered at each of the three interview occasions. Comparisons between the two caregiver groups were conducted.

The core category for the grounded theory, Processes in Utilizing Respite, was identified as Conservation of Resources and Energy. The salient processes used by the caregivers for identifying factors that inhibited or facilitated respite were Knowing, Imposing, and Matching. Conservation of Energy and Resources was a screen used by a caregiver to judge whether a respite source was acceptable. Overall, respite was

used infrequently by this sample. There were no significant differences between the two groups on the quantitative measures. Qualitative findings revealed that caregivers of cognitively impaired elders experienced difficulty in using respite in finding a match between the respite source and the recipient-either because helpers could not manage the recipient's behavior or because the recipient became agitated when situations or people were unfamiliar. Caregivers of physically impaired elders experienced difficulty in overcoming the recipient's resistance to being cared for by someone other than the caregiver. Implications of the findings for formal programs and informal sources of respite are provided and the potential usefulness of the Processes of Utilizing Respite theory for nursing and health services are discussed.

## TABLE OF CONTENTS

	Page
Chapter I: Introduction.....	1
Statement of the Problem.....	1
Relevance.....	3
Significance of the Problem.....	5
 Chapter II: Theoretical Perspective and Literature Review.....	 11
Theoretical Perspectives.....	11
Symbolic Interactionism.....	12
Social Networks, Social Support, & Help Seeking.....	16
Summary and Integration of the Concepts.....	22
Review of the Caregiving Literature.....	25
Context of Caregiving.....	25
Socially Constructed Meaning and Caregiving.....	30
Emergent and Negotiated Meanings of Caregiving.....	37
Relationships Among Aspects of Caregiving.....	41
Respite Literature Review.....	44
An Overview of Respite Program Development.....	44
Research and Respite Programs.....	48
In-home Respite.....	49
Adult Day Care.....	50
Institutional Respite.....	50
Combined Types of Respite.....	55
Respite Summary and Symbolic Interactionism.....	60
Statement of Purpose.....	63
Definition of Terms.....	63

TABLE OF CONTENTS (continued)

	Page
Chapter III: Methods.....	64
Study Design .....	64
Sample.....	65
Recruitment of Sample .....	66
Protection of Human Subjects .....	68
Criteria for Sample Selection .....	70
Instruments and Procedures.....	71
The Open-ended Interview .....	72
Receiver Information .....	74
The Mini-Mental State Examination .....	75
The Katz Index of ADL .....	75
Demographic Information .....	76
Caregiver Information .....	76
Demographic Information .....	77
Caregiving Experience .....	77
Caregiver Health Status .....	78
Data Collection Protocol .....	79
First Interview .....	80
Second Interview .....	81
Third Interview .....	82
Procedures for Data Analysis.....	83
Descriptive Data Analysis .....	84
Qualitative Data Analysis .....	84
Constant Comparative Analysis .....	84
Memoing .....	87
Quantifying of Qualitative Results .....	88
Validity and Reliability .....	89
Relationships Among Concepts.....	92
Quantitative Data Analysis .....	92
Triangulation of the Data .....	94

Table of Contents (continued)

	Page
CHAPTER IV: SAMPLE CHARACTERISTICS.....	95
Comparison of Study Sample with National Survey.....	96
Comparison of the CI and PI Caregiver Groups.....	100
The Caregiving Context.....	100
The Nature of Caregiving.....	102
Social Context.....	104
Physical Setting.....	105
Historical Context.....	107
CHAPTER V: RESULTS OF THE QUALITATIVE ANALYSIS.....	109
Processes and Phases of Grounded Theory Development.....	109
Phase I: The Open Coding Process.....	112
Phase II: Development of Major Categories.....	113
Phase III: Selective Coding.....	116
Grounded Theory: Processes in Utilizing Respite (PUR).....	118
Conservation of Energy and Resources.....	119
Knowing: The Central Theme of C-R Interactions.....	121
Imposing: The Central Theme of C-H Interactions.....	134
Matching: The Central Theme of R-H Interactions.....	151
Conservation through Interactional Processes.....	162
Summary and Conclusions.....	175
Validity and Reliability Procedures.....	176
Quantifying the Qualitative Results.....	177
Validity of Themes and Categories.....	178
Reliability Measures.....	180
Results of Quantitative Measures.....	181
Triangulation of the Data.....	183
CHAPTER VI: SUMMARY, DISCUSSION, AND RECOMMENDATIONS.....	186
Summary.....	186
Discussion.....	189
Implications for Nursing and Health Services.....	200
Limitations and Strengths.....	202
Recommendations for Future Research.....	203
References.....	206

Table of Contents (continued)

	Page
Appendix A: University of Washington Consent Form. ....	219
Appendix B: Interview Format.....	224
Appendix C: Genogram.....	227
Appendix D: Themes Scale and Questionnaire.....	228
Appendix E: Mini-Mental State .....	230
Appendix F: Activities of Daily Living .....	231
Appendix G: Demographic Information about Recipient .....	235
Appendix H: Demographic Information about Caregiver .....	238
Appendix I: Caregiving Experience Information .....	241
Appendix J: Caregiver Health Status .....	245
Appendix K: Affect Balance Scale.....	247
Appendix L: Personal Resource Questionnaire.....	248
Appendix M: Coding: Initial Definitions.....	250
Appendix N: Category Analysis .....	249
Appendix O: From Early Codes to Categories to Themes.....	252
Appendix P: Memo Types.....	253
Appendix Q: Example of Ethnograph Coding.....	254

## Tables

	Page
<u>Tables</u>	
Table 1 One Generation Apart Age Proportions.....	7
Table 2 Integration of Symbolic Interactionism with Concepts of Social Network, Social Support, and Help-Seeking.....	23
Table 3 Placement of Variables in Caregiver Studies.....	42
Table 4 Interview Instruments and Time of Administration .....	80
Table 5 Caregiver Study Sample Comparison with National Survey.	97
Table 6 Recipient Study Sample Comparison with National Survey.	99
Table 7 Cognitively Impaired (CI) and Physically Impaired (PI): Group Comparisons.....	101
Table 8 The Nature of Caregiving and the Social Context.....	103
Table 9 Physical Setting and Historical Context of Caregiving.....	106
Table 10 Major Category Definitions at End of Phase II.....	114
Table 11 Knowing: Facilitating and Inhibiting Factors for Respite.....	133
Table 12 Imposing: Facilitating and Inhibiting Factors for Respite.....	150
Table 13 Matching: Facilitating and Inhibiting Factors for Respite.....	161
Table 14 Frequency of Respite Use by Caregivers in One Year.....	178
Table 15 Themes Scale Differences Between Groups.....	179

Figures

Figure 1 Processes in Utilizing Respite..... 119

## ACKNOWLEDGEMENTS

National Research Service Award (1 F31 NU05901-01)  
Division of Nursing, Department of Health and Human  
Services, United States Public Health Services

Health Services Research and Development Field Program,  
Training Stipend, Seattle Veterans Administration Medical Center,  
Seattle, Washington.

Hester McLaws Scholarship Fund,  
School of Nursing, University of Washington.  
Seattle, Washington

## DEDICATION

To my husband John for the quiet reassurance, humor, and freedom that he has given me to pursue my goals;

To my children Belinda, Dan, Jennifer, and Jeff for their love, encouragement, and enjoyment they have added to my life in the course of my studies;

To my parents - Louise and Dwight Iles - for providing the challenges that have reinforced my commitment to caring;

To my friends and especially my doctoral cohort for providing the support I needed during difficult times;

To the clinicians at the Veterans Administration for helping with recruitment; and participants in the study for freely sharing their time and thoughts so others might better care for one another;

To Sandy Eyres for knowing how to care in a way that fostered my growth and sense of self worth; and

To my Dissertation Supervisory Committee, Jeanne Benoliel, Marjorie Batey, Marci Catanzaro, Susan Hedrick, and Edgar Borgatta for their time and effort devoted to enhancing my understanding of the art and science of the nursing profession.

The Ph.D. degree is not an achievement of myself alone but the interdependent work of many along the way. I celebrate the opportunity I have been given and give praise to the mystical driving force that keeps me connected with others and caring about life in all its richness.

## CHAPTER I: INTRODUCTION

### Statement of the Problem

Family caregivers of frail elders provide a protected environment that enables the elder to remain at home. The carer assists with physical care, anticipates needs to protect the recipient of care from feelings of dependency, arranges the physical setting to safeguard against injury, and structures daily activities to accommodate to the recipient's remaining abilities. Such tasks usually are sustained over prolonged periods of time - years rather than months (Bowers, 1987; Houlihan, 1987; Stone, Cafferata, & Sangl, 1987).

Physical and cognitive impairments of the recipient require different kinds of activities on the part of the caregiver. When the recipient has physical disabilities, the caregiver spends energy in assisting with activities of bathing, toileting, standing, and moving. These tasks result in fatigue for the caregiver. Cognitive impairments of recipients require skill in handling unusual behavioral problems and incur stress from having to think for the other individual. When either type of impairment is severe, constant supervision and attentiveness of the caregiver are required (Archbold, 1980; Bowers, 1987; Clark & Rakowski, 1983, Houlihan, 1987).

The impact of caregiving on the carer's health and social life has been well documented in the literature. Effects on the caregiver when compared with non-caregivers in the same age groups have included: (a) reduced levels of morale and positive affect; (b) increased physical and mental exhaustion; (c) increased rates of depression; and (d) greater

disruption of families' daily routines (Fengler & Goodrich, 1979; Gatz, Boyd, & Mellins, 1987; George & Gwyther, 1986; Snyder & Keefe, 1985).

One of the problems most frequently reported by caregivers was loss of personal and social time (Clark & Rakowski, 1983; Crossman, London, & Barry, 1981; Snyder & Keefe, 1985). The loss of personal and social time resulted in reduced contact with family, friends and organizations (informal social networks), and lack of time for the caregiver to restore needed energy. With the worsening of the recipient's chronic illness, caregiving consumed progressively more time resulting in shrinkage of informal social networks at the very time when assistance most was needed. There was some evidence that caregivers of cognitively impaired adults experienced a greater reduction of informal support than caregivers of physically impaired adults (Birkel & Jones, 1989; Burdz, Eaton, & Bond, 1988).

Programs designed to reduce the stress of caregiving and give the caregiver additional social support and time off have been developed only recently. For clinicians in the service professions, the primary purposes of such programs have been to reduce the stress of caregiving and promote better health and quality of life for both the caregiver and recipient. Interested in reducing cost of care, officials responsible for funding government services have viewed the programs as enabling the caregiver to sustain the disabled elder at home for longer periods of time at less cost than would be incurred in an institutional setting (Foundation for Long Term Care [FLTC], 1983; Montgomery, 1989).

Respite - a temporary period of relief - has been coined as the term for programs that provide short-term care for the frail elderly so

the caregiver can have time away from caregiving responsibilities. Despite caregivers' expressed need for personal and social time that respite provides, they have not utilized the programs in the numbers anticipated. The lack of use of respite services has hampered research projects designed to test the effects of such programs on caregiver stress and cost of care. In addition, respite programs frequently have been disbanded because of an inability to obtain or retain adequate numbers for cost-effective operation (Caserta, Lund, Wright, & Redburn, 1987; FLTC, 1983; Lawton, Brody, & Saperstein, 1989).

Although there has been a great deal of exploratory research on the nature and stress of caregiving and some emphasis on the amount of and types of support the elderly get from family, neighbors, and friends, there has been little systematic research on respite as a specific phenomenon. Most programs have been established based on numbers of frail elders or caregivers in the community without obtaining information from caregivers as to types, amounts of respite desired, or the circumstances that might influence respite use (FLTC, 1983; Hildebrandt, 1983).

The focus of this research was the caregiver's perspective on factors that inhibited or facilitated utilization of informal and formal sources of respite. Because there was evidence in the literature that caregivers of the cognitively impaired had different concerns than caregivers of the physically impaired, caregivers of both of these groups were examined. Increased awareness of the factors contributing to obtaining respite was expected to assist in creating programs of

more benefit to caregivers, more appropriately structured to fit with informal sources of respite, and more cost effective than is presently the case.

#### Relevance

The predominant perspective of this research was derived from the discipline of nursing, with additional background stemming from the field of health services research. Caregivers of older veterans served as the population for study.

The discipline and practice of nursing is concerned with the diagnosis and treatment of human responses to actual or potential health problems (American Nurses' Association [ANA], 1980, p.9). Nursing encompasses not only the individual's perspective but the patterning of human behavior in interaction with the environment as it affects the health of the individual, family, or community (Donaldson & Crowley, 1978). The caregiver's interaction with the social environment to obtain needed respite is a legitimate concern of nursing practice and research. Nurses both assess caregivers to determine when caregivers need respite and deliver care to the disabled elder within respite programs. Improved knowledge of factors influencing the caregiver's use of respite can assist the nurse in enhancing the caregiver's ability to obtain respite and provide the background nurses need for developing programs appropriate to both caregivers and recipients of care.

Health service research is an applied multidisciplinary field of endeavor initially established in 1955. Its focus is on (a) the process by which consumers seek health services, (b) the pattern of patient flow through the system, and (c) the cost, quality, and equity of the health

care system (Shortell, 1983). Utilization of respite, its benefits to the caregiver and disabled elder, and its effectiveness in reducing costs to the system are appropriate concerns for health services research. Understanding the balance of informal and formal sources of respite and the caregiver's desires with respect to respite can increase the likelihood that programs once developed are targeted correctly and, therefore, are not wasteful of resources.

Finally, the Veterans' Administration (VA), which has provided a part of the funding for this research, also enabled access to the population from which the sample was drawn. Because the veteran population contains greater proportions of aged than the general population, better and more cost effective ways are being explored by the VA to provide for the aged. The Health Services and Research Development section of the VA has, therefore, created an environment conducive to doing research with aged veterans and their caregivers (Veterans' Administration [VA], 1985).

#### Significance of the Problem

Respite for family caregivers of noninstitutionalized frail elders has become a significant issue in the United States (US). The reasons are several: the changes in numbers and proportions of the aged to other age groups of the US population; the numbers in the older population needing assistance; the time involvement that such assistance demands of other family members; and the inadequacy of the current health delivery system in providing the type of formal support needed.

Numbers and Proportion of Aged

It is common knowledge that the proportion of people over 65 years of age in the United States (US) is increasing and is expected to grow from the current 11% of the population to 30% percent by the year 2030. This figure is based on the present population and is adjusted for current life expectancies (National Center for Health Statistics [NCHS], 1984). Within the veteran population the proportion of elders is even greater than within the general US population. As a result of the widespread participation in World War II, three out of four males in the United States population, aged 60 to 64, are veterans. Currently, the median age of the US population is 31, while for the veteran population it is 53. Because of the movement of World War II veterans into the oldest age categories, the current proportion over 65 is 18% and is projected to reach 30% in the year 2000 and 46% in the year 2015 - 30 years before the peak of 30% expected in the general US population (US Bureau of Census, 1983; VA, 1985, 1986).

Nearly one quarter of persons 65 and over are functionally disabled which means they require assistance with personal care (eating, bathing, dressing, and toileting), mobility (transferring into and out of chairs or beds, going from room to room or outside), instrumental activities (e.g. transportation, shopping, cooking, cleaning); or they need nursing care provided by home care agencies. Only one in five of these persons is in a nursing home setting. The remaining four-fifths live in the community (Doty, 1986). The number of persons residing outside of institutional settings who require help with basic activities of daily living increases with age; between ages 65 to 74, 2% need help;

between ages 75 to 84, 14 % need help; and of those aged 85 and above, 40% need help (Feller, 1983). The fastest growing segment of the population is the over 85 age group, needing the most assistance. The average life expectancy at 85 is 6.7 years (NCHS, section 6, Table 7). Thus the frailest group is not only becoming more numerous but also is living longer with chronic illness because medical care enables even the very frail to be sustained for longer periods of time (U.S. Bureau of Census, 1982).

#### Provision of Assistance by Families

Increased life expectancy and longer life during the age period in which persons experience the frailest health require that more adult children assume a caregiving role and for much longer periods of time than in the past. At the same time the proportion of persons in adult child age groups to those of the next older generation is decreasing. Table 1 is an extrapolation of US census statistics of projected changes in age group proportions. The table contains the proportion in one generation to the next generation assuming generations to be at least 20 years apart. Thus, persons 55 to 64 would be the adult children of those 75 to 84 and persons 65 to 74 would be the adult children of persons 85 or over. As seen in the table the shift in proportion of adult children to elderly parent age group has shown the most dramatic decrease from 1940 to 1980 (from 5:1 to 3:1 in the left hand column for the younger of the elderly and from 17:1 to 7:1 for the older groups). From 1980 to 2040 the projected proportions continue to decrease.

Table 1

One Generation Apart Age Proportions

AGES	55-64	:	75-84	65-74	:	85 +
1900	5	:	1	18	:	1
1940	5	:	1	17	:	1
* 1980	3	:	1	7	:	1
2020	3	:	1	4	:	1
2040	1	:	1	2	:	1

Actual change from the past to 1980 and projected change from 1980 to 2040. "\*" indicates current proportions (US Bureau of Census, 1982).

Because in the past there were greater numbers of persons to assist with care of older relatives, either fewer families actually assumed such care or when care was assumed there were more persons to assist. The newness and intensity of the phenomenon of provision of care for older family members as a normative family experience become evident as one views the table (Brody, 1985; Stone, et al., 1987).

The exact proportion of persons who become involved as caregivers is not known because data commonly are collected as a result of asking older persons whether they need assistance. Difficulties in accurate totals arise because a caregiver might be caring for more than one person and an older disabled person might be receiving care from more than one family member or neighbor. In addition, a cross sectional enumeration of current caregivers does not indicate how many persons have been or will at some time become caregivers (Stone et al., 1987).

Based on an approach of asking disabled older members who assists with their care, two recent national surveys (the 1979 Health Interview Survey - HIS, and the 1982 Long-Term Care Survey -LTC) have provided information on the role of the family in providing long term care to disabled older members who live in the community. Findings of these surveys were that nearly three quarters of the elderly relied solely on family and friends for the assistance they required. Only nine percent of the sample in the HIS survey and five percent in the LTC survey relied totally on the formal care system. The remainder depended on a combination of formal and informal care providers (Doty, 1986; Stone et al., 1987). In 1982 approximately 2.2 million caregivers provided unpaid assistance to 1.2 million noninstitutionalized elderly. Of these persons 44% had provided unpaid assistance from one to four years and 20% had done so for over five years. Eighty percent provided unpaid assistance seven days a week and the average time caregivers spent was four extra hours a day doing caregiving tasks (Stone et al., 1987). Moreover, three quarters of all noninstitutional paid care was privately financed by the elderly themselves and their relatives, with only 26% being government financed (Liu, Manton, & Liu, 1985; Soldo, 1983a, 1983b; US Bureau of the Census, 1983).

#### Formal Services to Elders

The rise in numbers of families affected by caregiving responsibilities and the extended length of time for which that care is needed have coincided with the increased cost of health care and the resultant cut backs in provision of services. Shortened hospital stays have increased the family's involvement in caring for older members

recovering from acute illness. Stricter admission criteria and increased costs for nursing home care have restricted access to nursing home care while at the same time home care agencies have received less funding (Doty, 1986; Fischer & Eustis, 1988; Guterman & Dobson, 1986). Thus, formal supports to the elderly have been cut at the same time that the numbers of persons available for informal support in the population have decreased. However, some new services have been developed. Programs to assist the frail elder have included: (a) chore services that assist with home maintenance; (b) personal care aides for assistance with bathing; and (c) meals on wheels that provide meals delivered to the home (Doty, 1986; Petersen & White, 1989).

Programs for direct relief to family caregivers have been (a) support groups for caregivers to share concerns and obtain information regarding how to care for oneself and the recipient and (b) respite that provides care for the recipient so the caregiving family member can have time off. However, as reported in the literature, many who clearly needed respite services and expressed the need for more personal and social time did not use the respite; this has made planning for effective delivery of respite difficult (Pesznecker & Zahlis, 1986; Petersen & White, 1989).

This study was designed to explore with caregivers of severely disabled elderly the factors that prevented or allowed them to leave the disabled person with someone else. Because it was considered important that formal respite services should not disrupt informal respite sources, factors that facilitated or inhibited the use of both types of respite sources were explored.

## CHAPTER II: THEORETICAL PERSPECTIVE AND LITERATURE REVIEW

This chapter is divided into four sections. In the first section the theoretical and conceptual basis for the study is presented. In the second section the caregiving literature, using the theoretical perspective contained in the first section, is highlighted to identify factors that influence respite use. The third section is a review of the respite literature and the rationale for the chosen approach for the dissertation research. The final section contains the purpose of the research, research questions, and basic definitions of terms.

### Theoretical Perspectives

The highly variable circumstances of caregiving and respite required a perspective that took into account the perceptions of the caregiver, the interactions among the participants (caregiver, recipient, and helper), and the conditions and dynamics in which caregiving and respite occurred. Because symbolic interactionism encompassed all of these factors, it was chosen as the theoretical perspective for this study. In addition, selected aspects of social network, social support, and help-seeking were identified as contributing concepts that aided in defining the availability of sources of respite to the caregiver, the qualities of respite sources, and how transactional processes occurred in acquiring respite.

### Symbolic Interactionism

Symbolic interactionism is a theoretical perspective within sociology and social psychology that illuminates the salient components of interactions between individuals. Central to symbolic interactionism is the viewpoint that the social environment and the individual are inseparable from one another and cannot be understood in isolation from one another (Denzin, 1978; Rock, 1979). Investigators using symbolic interactionism view the social environment and the individual in ongoing transactions. They do not consider persons as products of the environment and focus only on analysis of the social system, nor do they focus solely on the cognitive processes of the individual as dominant over the social environment. The unit of analysis in symbolic interactionism, therefore, is the individual in interaction with the environment (Blumer, 1969; Denzin, 1978). Concepts central to understanding interactions are *context, socially constructed meaning, and the emergent and negotiated nature of interactions.*

#### Context

Context includes all of the conditions that influence a given interaction (Coe & Sarbin, 1977; Goffman, 1959; Rock, 1979). Individual interactants and their characteristics are important, and therefore information about the individual helps define the situation. Interactions occur in settings that can be physically located and described and these settings influence how individuals behave (Goffman, 1959; Denzin, 1978). Context in symbolic interactionism is

inclusive of all the cultural and past experiences the individual brings to the interaction as well as all the features of the setting in which it occurs.

#### Socially Constructed Meaning

The most central concern of scholars of interactionism is how individuals socially construct meaning. Features of the social and physical environment do not by themselves explain how a person behaves because behavior is dependent on how the person interprets the environment. Thus, features in the context that are important to the individual cannot be understood simply by observing the situation or having knowledge of social processes but can be known only by ascertaining the individual's interpretation (Blumer, 1969; Coe & Sarbin, 1977; Rock, 1979).

The person is viewed as both self-reflective and able to take another's viewpoint. These attributes enable individuals to interpret their own actions and those of others through symbols, words, and behaviors (Denzin, 1978; Mead, 1934). Constructing social meaning requires that individuals be in interaction. A fundamental assumption in interactionism is that at birth a person is asocial and thus not human (Burr, Leigh, Day, & Constantine, 1979; Rose, 1962). It is the interaction with others that fosters the ability to be self-reflective and to interpret and take on the role of another. Thus the individual is shaped by interactions with others and, through intrapsychic interpretation of those actions, attaches meaning to prior actions which

in turn shape future behaviors. Because of these capabilities, humans live in a symbolic as well as a physical environment (Burr, et al., 1979; Goffman, 1959)

As individuals interact they come to share many of the same meanings. These shared meanings result in societal norms which are patterns of meaning that link social behavior and situations. When taken together, these norms or rules aid the individual in making the environment more predictable (Parsons, 1967; Rose, 1962). When norms are ascribed to individuals in relationship to one another, meanings vary according to the positions and status of the individuals involved and the context in which the behavior occurs. These positions are called roles (e.g. mother, father, employee) and define what the behavior of a person should be in relation to another person in a given context. All of the roles and norms taken together make up the culture into which a person is born (Biddle & Thomas, 1966; Goode, 1960; Parsons, 1967).

Constructing social meaning, then, is influenced by societal norms and shared meanings about roles as well as the context in which interactions take place. However, because the individual is both self-reflexive and able to take on roles of others, interpretations of roles vary so that some meanings are shared and others are unique. The tension between shared and unique meanings is best illustrated by Mead (1936) in his understanding of the individual. He described self as made up of *me* and *I*. The *me* is the socially defined self that becomes repetitious and habitual and that people come to rely on and can usually predict. Thus the *me* part of self is more influenced by and conforming

to social roles or norms. The I refers to the unpredictable spontaneous part of self that accounts for a role never being played quite the same way by different people. However, neither I nor me is viewed as static, but as dynamic. Conflicting meanings held by different persons are reshaped constantly as interacting individuals construct their own definitions of situations (Blumer, 1969; Bolton, 1981; Denzin, 1978).

#### The Emergent and Negotiated Nature of Interactions

Given the ability to interpret interactions, humans can both guide and respond to the behavior of others in an undetermined and unpredictable number of ways. Each past action is interpreted and utilized within the current interaction and context and is described as an *emergent event*, meaning that the interaction is more than the processes that have led up to it, or more than the sum of its parts (Denzin, 1978; Mead, 1932).

Because interactions always involve two or more people, each person's meanings then must be negotiated. Thus the emergent event contains the negotiated meanings that change as the context changes. In addition, the concept of time takes on new meaning. The past cannot be separated from the present nor can the future, as the individual constantly is reinterpreting the past and future as each present occasion (the social interaction) and its context take on new meanings (Bolton, 1981; Denzin, 1978; Goffman, 1959; Mead, 1932).

The context, socially constructed meaning, and emergent and negotiated nature of interactions together make up the parameters of a given occasion. As each aspect is defined, patterns can be identified that are helpful to understanding a particular type of situation

the caregiving experience). Symbolic interactionism as a perspective does not contain predictions as to how individuals will behave because of the setting, social conditions, or the individual's attitudes. Instead the premise of symbolic interactionism is that a predictive theory about any given situation only can be developed if the researcher becomes part of the experience and examines it from the inside to ascertain the interactant's view of the salient elements (Denzin, 1978; Rock, 1979). Thus interactionism provides the parameters of the situation, and investigators create predictive theories generated within particular kinds of situations. The knowledge gained through this process then must be tempered with an understanding that situations are emergent and that context and interactants change over time.

#### Social Networks, Social Support, and Help-Seeking

The concepts of social network, social support, and help-seeking have not been integrated with symbolic interactionism in prior literature. However, the presence of social contacts or networks may be viewed in interactionism as part of the context; social support as components of socially constructed meaning; and help-seeking as transactional processes that occur as part of the emergent and negotiated nature of interactions. The selected aspects of social networks, social support, and help-seeking described here were chosen because of their applicability to caregiving literature.

Taken together social networks and social support often are called social support networks or social support systems and have been defined as the subset of each person's social contacts which are relied on for

socioemotional aid, instrumental aid, or both (Thoits, 1982). This definition is subdivided commonly into social networks, structural features such as numbers and types of linkages between persons; and social support, the content or functions of social interactions (Cohen & Syme, 1985; House & Kahn, 1985). To enhance conceptual clarity, social networks (SN) and social support (SS) are considered separately.

#### Social Networks (SN)

The social network features discussed here are subdivided into (a) purpose or "action set" (Mayer, 1966; Mitchell, 1987), (b) categories of persons who make up the network, and (c) structure (Dimond & Jones, 1983; Mitchell, 1987). In discussion of caregivers and their use of respite, the purpose is respite acquisition; categories are the types of caregivers (spouse, daughters), types of recipients (impaired elderly), and types of helpers (kin, friends, agency personnel); and network structure refers to the number and types of linkages between the caregiver and helpers. Structural features most commonly examined in caregiving literature are (a) the size of the network or potential network, (b) the proximity, how near network members live to the caregiver, (c) frequency, how frequently the network members are in contact with the caregiver, and (d) duration, how long the caregiver has known network members or been providing care to the recipient.

### Social Support (SS)

The broadest definition of social support is socioemotional and instrumental aid, often subdivided to identify more discrete aspects of each. Components related to socioemotional aid include:

- (1) affect - transactions that include expressions of admiration love and respect (Cobb, 1976; Kahn & Antonucci, 1980).
- (2) attachment - a sense of security and place provided by a dyadic relationship (Weiss, 1974);
- (3) presence of a confidant - a close friend with whom one can share concerns or affective support (Lowenthal & Haven, 1968); and
- (4) affirmation - expressions of agreement or acknowledgement of rightness of some act or statement that what one does is valued (Caplan, 1974; Kahn & Antonucci, 1980).

Instrumental aid has been subdivided into information (e.g. advice, education) and direct assistance such as money, time, or personal care (Cobb, 1976; House & Kahn, 1985). Additional components that do not fit well in either of those categories are nurturance, a relationship in which one takes responsibility for another, and reciprocity, an opportunity for both giving and receiving (Brandt & Weinert, 1981; Mitchell, 1969). Aspects of social support also are examined as to whether the support is: (a) perceived support, the expressed belief that support is available if needed; (b) received support, the actual transfer of information or direct assistance; and (c) appropriateness of support, the match of type and timing of support with a given situation (Jacobson, 1986; Wetherington & Kessler, 1986).

Investigators of social network and social support have addressed network features that contributed to health and to functions of support, fulfilled by different types of relationships (Cohen & Syme, 1985). Examples of research findings utilizing this approach were that larger networks and more frequent contact with persons in the network were associated with less illness and a longer life span (Berkman & Syme, 1979; McFarlane, Norman, Streiner, Roy & Scott, 1986); and that kin most commonly supplied both long-term affective and instrumental support, friends supplied long-term affective support, and neighbors provided short-term instrumental support (Litwak, 1985). Respite within this framework would be a type of instrumental support.

Received versus perceived support differentiates between actual social contacts and the assistance provided, compared to support the person reports as being potentially available. In research of this type, a weak association was found between the received or actual contacts and the person's perception of being supported. In addition, perceived support was found to have a stronger relationship to the person's health and feelings of well-being than received support. Thus it was as important to note whether the caregiver felt that help was forthcoming as it was to observe how much actual help was received (House & Kahn, 1985; Kessler & McLeod, 1985; Wetherington & Kessler, 1989).

Types and timing of support initially were postulated as important by Weiss (1974). Certain types of support were considered more appropriate than others at different phases of crises and for different types of crises. Emotional support was deemed more appropriate during

the initial phases of sudden unexpected crisis, informational support during expected transitions or after an initial time of crisis had passed, and instrumental support (tangible aid and assistance) during long term chronic illnesses (Jacobson, 1986; Weiss 1974, 1976).

Investigators studying SN and SS most commonly show how features of the SN or different types of SS ameliorate the adverse effects of negative life events and thus maintain the person's health and well-being. However, they have not examined how transactions come about that enable and maintain supportive relationships. Components of the help-seeking process serve to illuminate the transactional facets of relationships.

#### The Help-Seeking Process

Writers addressing help-seeking have explored transactional processes that inhibit or facilitate helping relationships. A discussion of the help-seeking process is included here because examination of the process aids in understanding interactions that might occur when a caregiver is seeking a source of respite. Help-seeking is defined as any "communication about a problem or troublesome event which is directed toward obtaining support, advice, or assistance in times of distress" (Gourash, 1978, p. 414). It includes general discussion about the problem, specific appeals for help, and behavioral actions (e.g. looking sad) that might elicit supportive actions (Clark, 1983; Gourash, 1978).

The help-seeking process (HSP) has been conceptualized and defined by Gross and McMullen's (1983). Their model of the process contains three stages: (a) the perception of a problem as amenable to help;

(b) the decision to seek or not seek help; and (c) once help is decided on, the strategies and tactics for seeking help and effective utilization of that help. It is a process approach to examining selected aspects of seeking assistance. Although the process is presented in three stages, Gross and McMullen emphasize that the three stages might not occur in sequence and that all the stages might not occur every time help is sought.

In the first stage, the person must first perceive and acknowledge that a problem exists and that the problem might be resolved if assistance were acquired. Further, how important the problem is relative to other existing problems and how soon the problem must be resolved to prevent harm are considered. An example of findings of a study about this stage was that help considered necessary by the person rather than merely convenient was more likely to be sought (Gross & McMullen, 1982, 1983).

In studies focusing on the second stage of the HSP, deciding to seek or not seek help, investigators found that help that was offered was more likely to be used than help that had to be requested (Piliavin & Gross, 1977). The energy it took to seek or obtain help also was a deciding factor. Energy usually was described as cost and broken down into personal or psychological cost, social cost, economic cost, physical cost, and perceived helper cost. A finding related to cost was that if the help-seeker perceived obtaining help was high in energy cost, the decision to seek help was less likely than if obtaining help

was perceived as low in energy cost (DePaulo & Fisher, 1980; Greenberg & Westcott, 1983; McKinlay, 1972; Piliavin & Piliavin, 1973; Shapiro, 1980; Tessler & Swartz, 1972).

Strategies and tactics for obtaining help and effective utilization of that help comprised the third stage of the HSP. When to ask, how to ask, how much to ask for, and under what circumstance are elements of this stage. Examples of strategies and tactics are (a) stating a problem and waiting to see if help is offered, (b) directly asking individuals for help or information, and (c) not asking too frequently so that when requests are made they are likely to be granted. In the HSP model, the resulting cost and success of the strategies or tactics then are fed back into the factors the person considers when help is needed from that source in the future (Gross & McMullen, 1982, 1983).

#### Summary and Integration of the Concepts

Social networks, social support, and the help-seeking process are integrated with symbolic interactionism as presented in Table 2. Aspects of caregiving are identified in the table to illustrate how they are subsumed within each of the concepts. As shown in the Table, the context of caregiving includes the characteristics of caregivers and recipients, the tasks of caregiving, and the physical and social setting in which caregiving takes place. The social networks make up the social setting with the purpose of the network being to provide support to the

Table 2

Integration of Symbolic Interactionism with Concepts of Social Network,  
Social Support, and Help-Seeking

SYMBOLIC INTERACTIONISM		
<u>Context</u>	<u>Socially Constructed Meaning</u>	<u>Emergent and Negotiated Nature of Interactions</u>
Characteristics of caregivers	Sociocultural norms and caregiving	Influence of past and future on perceptions of caregiver
Characteristics of receivers	Roles and role strain of caregivers	The changing nature of caregiving
Caregiving tasks	Impact of caregiving and perceptions of burden and or satisfaction	<u>Social support</u>
Physical setting		The timing of types of support
<u>Social Network</u>	<u>Social Support</u>	<u>The Help-seeking Process</u>
Categories of helpers	Functions of caregivers support network	Perception of need for assistance
Size of network	Perceived support	Decisions to seek help with caregiving
Proximity of helpers	Appropriateness of support (respite)	Strategies and tactics for obtaining help
Frequency of contact with helpers		Success or failure in obtaining assistance and effect on future requests for help (respite)

caregiver. Characteristics of the network or potential helpers include number, types (informal and formal), proximity, and frequency of contact with the caregiver.

Socially constructed meaning includes the aspects of caregiving that within caregiving literature usually are called the "experience of caregiving" and are the social norms and roles and the caregiver's interpretations of the context. The interpretations are reflected in the roles or behaviors taken on in caregiving (the impact of caregiving on the caregiver's life) and in what is perceived as stressful, burdensome, or satisfying. Social support is considered as part of socially constructed meaning because the caregiver makes interpretations about the roles (or types of support) others provide and derives meaning from the perceived supportiveness or nonsupportiveness of these interactions. Respite is viewed as a form of social support and its availability is a feature of the social network.

Pertinent to the emergent and negotiated nature of interactions is the caregiver's interpretation of how past experiences and future expectations affect caregiving, the changing nature of caregiving, the timing of various types of social support, and factors that constrain or facilitate the HSP or respite-seeking process. The caregiving and respite literature that are reviewed next are placed within the framework of symbolic interactionism.

## Review of the Caregiving Literature

The caregiving literature directing this study was drawn primarily from research specific to caregivers of the frail elderly. In addition, selected literature concerning social support networks and managing chronic or terminal illness in the home were included. The focus of the review was to identify factors that logically might affect the caregiver's need for and use of respite.

### Context of Caregiving

The context of caregiving, as noted in Table 2, includes characteristics of caregivers and recipients, the nature of caregiving tasks, and the physical and social setting in which caregiving occurs. Although context within the framework of symbolic interactionism is inclusive of past and present experiences, for purposes here, context is limited to the objective components of the caregiving environment. Considerations related to past experience and time are presented later in the discussion of the emergent and negotiated nature of caregiving.

### Characteristics of Caregivers and Recipients

Characteristics of caregivers and recipients that have been associated with use of assistance include age, marital status, gender, income, employment status, ethnicity, relationship to the recipient, and health status. In the survey considered most representative of caregivers in the United States (Stone et al., 1987), the mean age of caregiver was 57 with 41% between 25 and 64 years of age, 25% between 56 and 74 years of age, and 10% over 75 years of age. The remainder were

under 44 years of age. Women comprised 72% of caregivers, and men 28%. Twenty-three percent of the women were daughter and daughter-in-law caregivers and 23% were spouse caregivers. When compared with the same age groups in the general population, younger caregivers were more likely to be unmarried and older caregivers were more likely to be married. Caregivers were also less likely to be employed, rated themselves in poorer health, and were more likely to be below the poverty line than the same age groups in the general population. Of the group surveyed, 81% were white and 21% were from ethnic minorities (Stone et al., 1987).

Older caregivers were usually spouses and provided more care and were less likely to seek assistance either from informal or formal social networks than were younger caregivers who were usually daughters (Cantor, 1983). Caregivers who were sons usually called on their wives to provide the physical care and had more assistance from others than did women (Horowitz, 1985; Seelbach, 1977).

Married, widowed, and single adult children of recipients had greater numbers of informal helpers nearby and used them more frequently than did spouse caregivers. Caregivers with lower income were more likely to be in poor health, lived nearer to their children, and provided more of the personal care than did caregivers with higher incomes. Higher income caregivers had more visits and telephone calls from friends than did lower income caregivers (Chappell, 1985; Stone et al., 1987). Investigators postulating that some ethnic groups such as black

and hispanic provided more informal assistance with care than whites, found that when income was held constant, there were no differences. (Mindel, Wright, & Starrett, 1986; Rosenthal, 1986).

The mean age of recipients of care was 78 years. Their health status was described either in terms of the number of activity of daily living (ADL) deficits or diagnostic impairments. The six ADL deficits assessed were eating, bathing, toileting, transferring, dressing, and indoor mobility. Of recipients being cared for at home 36% had one to two ADL deficits, 23% had three to four ADL deficits, and 42% had five to six deficits (Stone et al., 1987). Few investigators have related specific characteristics of recipients to the amount of assistance used by caregivers. The findings of one study of this kind was that caregivers of cognitively impaired individuals had significantly smaller networks and used less formal care than caregivers of persons who only had physical impairments (Birkel & Jones, 1989).

#### The Nature of Caregiving Tasks

Caregivers described the nature of caregiving tasks as management of the recipient's physical care, behavior, and environment. Managing the recipient's physical care needs included monitoring symptoms, learning about the illness, and assisting with ADL deficits. Behavioral management included preventing the recipient from becoming depressed or gaining the recipient's cooperation in caregiving tasks. When caring for cognitively impaired elderly, some of the tasks described were being constantly watchful and thinking for the recipient (Archbold, Stewart, Harvath, Lucas, 1987; Bowers, 1987; Fengler & Goodrich, 1979; Wilson, 1989).

Environmental management, though usually invisible to others, included tasks such as monitoring the social environment of the recipient so that visitors who disturbed the recipient would not intrude, contacting and maintaining relationships with kin and helpers, setting up situations in advance so they would go smoothly, and arranging the physical environment so that it would be safe for the recipient. These tasks were reported by caregivers as very time consuming (Archbold, 1982; Bowers, 1987; Clark & Rakowski, 1983).

Researchers consistently have found that the tasks of caregiving need to be considered in light of their social meaning and the caregiver's perception of the tasks. Discussion of the relationship of caregiving tasks to caregiver perceptions and use of assistance, therefore, is considered later within the framework of socially constructed meaning.

#### The Social and Physical Setting

Social network size, proximity, and type of helper (informal or formal) were the characteristics most often studied of the social network, while type of living arrangement was the descriptor most often used for the physical setting. In Stone et al's. (1987) report on the ICS survey, 57% of the caregivers reported that they received assistance from at least one other person in the informal network. However, the issue was complex. In other studies, a decreasing social network size was noted as age advances and as caregiving consumes more time (Branch & Jette, 1982 & 1983; Chappell, 1985; Litwak, 1985). In still other

studies, it was reported that among older persons with chronic illness the size of social network expanded early in the illness or during crisis and then shrank over time (Archbold, 1980; Strauss, 1975).

In a large study of caregivers who lived with the recipient, 50% consisted of the recipient living with a caregiver who was not a spouse; 39% of a spouse caregiver and recipient; and 10% of a frail couple living with another family member or members (Soldo & Myllyluoma, 1983). Assistance with caregiving was most likely to be provided if helpers (usually kin) lived in the same residence with the caregiving dyad. However, most spouse caregivers lived only with the recipient and decreased their contact with others and became more isolated as caregiving demands increased (Branch & Jette, 1982; Fengler & Goodrich, 1979; Silliman, Fletcher, Earp, & Wagner; 1986). Several investigators have found that when informal helpers did provide daily or weekly assistance they rarely lived more than 30 minutes away (Kivett, 1985; Litwak, 1985; Scott & Roberto, 1985).

In Branch and Jette's (1983) report on a national survey of noninstitutionalized elderly, the kind of care needed was associated with the type of support network used. Differentiating between informal networks and formal networks for caregiving tasks, the family and other informal groups most often provided all of the basic care needs (e.g. assistance with bathing, dressing, eating, and grooming), while formal networks were used for instrumental needs (e.g. assistance with housekeeping, transportation, and grocery shopping). Another investigator found that caregivers who used informal networks for assistance used formal services as frequently as those who had little

contact with their informal networks (Chappell, 1985). Most caregivers, however, utilized only the informal network. Of those who used the formal network, only 10% used a combination of the informal and formal (Stone et al., 1987).

The discussion of the context of the caregiving situation has summarized the way in which characteristics of the caregivers and recipients, the tasks of caregiving, and the physical and social setting in which caregiving takes place are related to the caregiver's use of assistance. However, researchers found in many studies that caregivers having similar characteristics, caregiving tasks, and social network characteristics did not report similar amounts of stress, need for, or use of assistance. Caregiving also needed to take into account other than objective context considerations.

#### Socially Constructed Meaning and Caregiving

Investigators explored with caregivers what aspects of caregiving were most difficult and stressful and how caregiving had altered their lives. Measures were developed to determine degrees of difficulty, stress, and burden imposed by the various aspects of caregiving. Role concepts and cultural norms were used to explain why certain aspects of caregiving might be perceived as more difficult by some types of caregivers than others. Most recently, investigators have explored the satisfactions of caregiving and their relationship to perceived social support. All of these factors have been examined because of the possibility that caregivers who experience more stress might be more likely to use respite than those who perceived less stress.

### Perceived Difficulties, Stresses, and Burdens of Caregiving

Physical care tasks reported as most troublesome by caregivers were those that required the caregiver to be present most of the time such as helping the recipient to walk or to go to the toilet. Heavy physical care routines were described as fatiguing rather than stressful. Behavioral management problems such as recipients who interrupted the caregiver frequently, wandered at night, and were depressed were described commonly as upsetting or emotionally draining (Archbold & Stewart, 1987; Clark & Rakowski, 1983; Sanford, 1975). The most frequently reported complaint and most highly rated on distress scales was that of social isolation. When caregiving tasks required a lot of time, spouse caregivers were unable to get away or to maintain social relationships. Adult child caregivers who were employed found that time outside of work became limited. Dealing with health and social service agencies also was rated as one of the more stressful aspects of caregiving though not as often as social isolation (Clark & Rakowski; 1983).

Caregivers frequently reported that it was difficult to deal with their own feelings of resentment, being overwhelmed, anger, embarrassment, and fatigue. Resentment most commonly was directed toward other family members who did not help or toward the recipient because of having to give up career mobility and advancement in order to provide care (Archbold et al., 1987; Clark & Rakowski, 1983; Thompson & Doll, 1982). Feelings of anger and embarrassment were related to the recipient's inadequacies. Embarrassment was related to the recipient doing things that were socially unacceptable, an event that happened

more often if the recipient was cognitively impaired than when the recipient was not (Liptzin, Grob, & Eisen, 1988; Zarit, Reever, & Bach-Peterson, 1980). Despite commonalities of feelings among caregivers, investigators frequently found that tasks which provoked negative feelings and stress varied markedly from one caregiver to another (Montgomery, Stull, & Borgatta, 1985). To explain these differences required inspection of types of caregivers and their social relationships.

#### Social Norms and Role Concepts Related to Perceived Difficulties

Social norms and roles concepts were explored in relationship to: gender of the caregiver, the caregiver's kin relationship to the recipient (spouse, adult child); the amount of time caregiving tasks consumed; the degree of mutuality of role expectations among caregivers, recipients, and others; and the extent of competing roles that caregivers assumed.

Gender differences in caregiving roles were researched by Horowitz (1985), Robinson and Thurnher (1979), and Seelbach (1977). These investigators found that the woman's role of health care supervision was considered the norm. Commonly assumed responsibilities in caregiving differed for the man and the woman. A woman viewed her responsibilities as those of personal care and making the parent happy, while a man maintained more emotional distance from the recipient and assisted with finances or transportation rather than personal care. Therefore, women caregivers experienced feelings of guilt if the parent was unhappy while men caregivers did not feel responsible for the mood of the recipient. The finding that adult daughter caregivers experienced caregiving as

more stressful than spouse caregivers was explained by the societal norm that spouses care for one another "till death do us part" whereas the adult daughter's role in caregiving was not necessarily prescribed, particularly if the daughter also had role obligations to a spouse (Zarit et al., 1980).

Role strain was defined as stress resulting from too many tasks within a single role that created difficulties for persons. In caregiving literature role overload and role expectations were viewed as contributing to role strain. Stress was rated higher by caregivers when tasks for the recipient were so time consuming and fatiguing that there was little time and energy left for other activities, especially if sleep was curtailed. When too many activities were assumed within the role of caregiver, role overload occurred (Archbold, 1980, 1982).

Role expectations added to increased feelings of burden or dissatisfaction with caregiving when (a) role expectations of the caregiver and receiver did not match (e.g. the receiver demanded more than the caregiver thought was needed), (b) the caregivers gave too much of themselves; (c) care of a parent was demanded of a retired couple who both were expecting increased personal time and leisure, and (d) family members disagreed as to the amount of care other family members should give to the impaired elder. In addition, because there were few who observed others caring for spouses or parents for such long periods, there were few role models (Archbold, 1980; Archbold & Stewart, 1987; Cantor, 1983; Strauss, 1975).

Role reversal was used to explain why caregiver's who had similar amounts and types of caregiving tasks differed in their ratings on amounts of stress, burden, and strain scales. Among spouse caregivers stress was greater when tasks performed now had been part of the role of the other partner. Thus, husband caregivers rated personal care (bathing and feeding) or housekeeping as most stressful, while wife caregivers rated making financial decisions, keeping up the car, and home maintenance as more stressful. Role reversal also was used as an explanation for the finding that when caregiving demands were similar adult-child caregivers experienced greater stress than spouse caregivers due to the reversal of the child and parent role. Whenever caring roles were reversed from the past, the caregiver and recipient had difficulty in meeting mutual expectations; both had to learn new roles to which they were unaccustomed (Archbold, et al., 1987).

Encroachment on competing roles of the caregiver (e.g. spouse, mother, employee) created role conflict. Stress or difficulty was reflected in lower scores on morale measures or self-reports of physical health. More stress was reported by working caregivers than those who did not work (Robinson, 1983). For women who cared for parents and whose marriages had been disrupted, work assumed an even more important role; less time was devoted to caregiving tasks than among women whose marriages had not been disrupted. Stress also was experienced because caregiving restricted career mobility and leisure time activities (Archbold, 1982, 1983; Cicirelli, 1983).

A focus on the negative or problematic aspects of caregiving was the predominant approach in studies of caregiving. Knowing the problems was expected to serve as a basis for interventions that would alleviate stress and thus prolong the ability of the caregiver to provide care. With increased attention to caregiving measures, researchers noted that caregivers often expressed satisfaction with positive aspects of caregiving as well as reporting negative aspects. In addition, satisfaction and high morale often were associated with the caregiver's feeling supported by others whether or not actual assistance was provided.

#### Satisfactions of Caregiving and Perceived Social Support

Caregiving satisfaction at first was addressed globally by asking caregivers how satisfied they were with the situation (Worcester & Quayhagen, 1983). As more perceptions of caregivers were elicited in open-ended questions, the positive meanings of caregiving were identified as pride in being able to things well, a chance to teach the next generation how to be helpful, an opportunity to repay past kindnesses of the recipient, and an opportunity for growth (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Quayhagen & Quayhagen, 1988). These perceptions provided a different dimension to the meaning of caregiving.

Aspects of social support in caregiving literature usually were discussed in relationship to informal or formal categories of support. Informal and formal networks were examined to determine the types of social support networks provided. Investigators consistently validated that caregivers primarily used the primary and informal network rather

than the formal network (Branch & Jette, 1983; Stoller & Earl, 1983). Spouses and daughters who lived with the recipient tended to provide all aspects of social support more often than other kin (Stoller & Earl, 1983). The existence of a primary network, however, did not always mean that the network was socially supportive to caregivers. Evidence in several studies demonstrated that primary networks added to the stress of caregiving if family members were in conflict over what care was needed. Good relationships among the caregiver, siblings, and other family members were associated with higher morale of the caregiver whereas conflict among the family over how care was to be given was associated with low morale (Archbold, 1983; Johnson & Catalano, 1983).

Informal support from churches provided assistance with instrumental tasks during crisis; but unless a formal program was organized as part of the church structure, the support was of short duration. Churches usually supplied emotional support and served as a setting for building friendships (Springer & Brubaker, 1984).

The formal network when present supplied various types of support. Caregiver support groups provided social and emotional support through opportunities for sharing and developing contacts with group members outside the support groups meeting times. Support groups also usually had an instrumental component of support (e.g. information about caregiving skills and other aspects of the caregiving role). Other types of instrumental support provided by formal services included: home health services for nursing care; chore services for assistance with

housekeeping or home maintenance tasks; social services for coordination of services and reimbursement mechanisms; and respite for short periods of relief from caregiving.

Research methods used to evaluate formal program effectiveness included applying measures of burden or stress, testing knowledge before and after programs, and asking caregivers what they gained from the programs (received support). In an analysis of twelve support programs for family caregivers, the caregivers reported that the programs provided education, problem solving skills, mutual peer support, and reduction of negative feelings associated with caregiving (Clark & Rakowski, 1983). In another review of formal programs, it was reported that some caregivers perceived mutual help groups as unpleasant experiences because they felt their problems were not like the problems of other group members or advice from other members was not helpful (Gallagher, 1985). In both of these reviews of formal services, the authors concluded that objectives for programs rarely were stated and outcomes measured were limited so it was difficult to determine what facets of the programs had been most effective for reducing stresses of caregiving.

A major limitation in the findings just reported was the failure to take into account the extent of change occurring in the life of the caregiver and recipient, and among informal and formal support networks over time, as well as the meaning of those changes to the caregiver. The emergent and the negotiated nature of meaning of caregiving discussed next encompasses such changes.

### Emergent and Negotiated Meanings of Caregiving

Brody (1985) called caregiving uneven, recurring, and unpredictable as to the time of occurrence. She explained that the recipient of care needed more help at one time than another, that several persons might be cared for in the course of a caregiver's life span, and that caregiving did not come at a predictable developmental phase of one's life but occurred at very different ages and stages of a person's life. To understand how time and ongoing processes affected caregiver's need for or use of assistance required knowledge about: (a) the caregiver's past experience; (b) the effect of caregiving on the caregiver's perceptions of the future; (c) the changing nature of the recipient's disabilities; (d) changes occurring in the life of the caregiver and the caregiver's social network; and (e) the ongoing processes of seeking support.

#### Perceptions of the Past and Future

There was limited linkage of past experiences of caregiving with the present caregiving experience. One study of elders being discharged from the hospital showed that in 70% of the cases, families volunteered to care for the patient in the community; however, when the same patients were admitted a second time, only 38% of the families agreed to care for them at home. The researchers concluded that commitment to caregiving diminished over time (Eggert, Granger, Morris, & Pendleton, 1977). Another researcher reported that caregivers who had a prior

positive experience with caregiving linked it with their willingness to take on caregiving a second time (Archbold,1982). These types of findings were isolated and as yet have not been confirmed by others.

In relationship to caregiver's perspective of the future, Goldfarb (1965) reflected that caring for an infant entailed the expectation of increasing independence from the child while caring for the older adult indicated a future of increasing dependency of the recipient on the caregiver. Investigators reported that caregivers felt a restricted sense of future and had difficulty thinking about or planning for the future. This was reflected in statements like "I just take it a day at a time." The inability of the caregiver to plan ahead was reported as due to the need to accommodate to the constant and changing needs of the recipient (Rakowski & Clark, 1983).

#### Changes in the Recipient

Depending on the variability or trajectory of the chronic illness caregivers were affected differently. With illnesses of slow onset more caregivers took on the care providing role, whereas for illnesses with an acute onset caregivers more often became managers (hired others do the care). Some illnesses had a slow down hill trajectory, while others were punctuated with remissions and exacerbations. Others experienced sudden deficits, such as those resulting from a stroke, and required a great deal of care (Archbold, 1982; Corbin & Strauss, 1988; Strauss, 1975).

### Changes in the Life of the Caregiver

Changes in the caregiver's life included changes in health, contacts with family and friends, and perceptions about caregiving (Barusch, 1988; Gilhooly, 1984; Johnson & Catalano, 1983; Wilson, 1989). In Barusch's study 42% of the caregivers reported negative changes in their health since care had begun, 13% had been hospitalized; 32% rated their health as fair to poor; and 21% had begun taking prescription drugs. Social network contact consistently was reported as decreasing over time by persons caring for the chronically ill whether young or old (Johnson & Catalano, 1983; Minkler, 1985; Strauss, 1975). Disruption in an adult child caregiver's life resulted in decreased amount of time spent providing care. Frequent occurrences were adult child caregiver's loss of spouse and divorces or illnesses of the caregiver's children in the course of caring for the parent. Despite such events, several researchers found an association between a longer duration of care and improved caregiver morale (Cicirelli, 1983; Johnson & Catalano, 1983).

A qualitative approach to changes in caregiver perceptions over time was reported by Wilson (1989). In twenty in depth interviews of caregivers of recipients with Alzheimer's disease, she found three stages of caregiving. The first stage, taking it on, was described as spent in dialogue with self, seeking solace from others, and unburdening. In the second phase, going-through-it, the caregiver described activities of taking care of business, selecting resources, and protecting the recipient. The third and final stage, turning it over, was described as coming to terms with the illness, giving up

control, and entrusting the care to others. These types of findings would be expected to affect the changing meaning of caregiving over time and the type of support needed or sought.

#### The Help-seeking Process

How caregivers sought help and maintained their helping networks was the least researched area in the caregiving literature. Barusch (1988) identified help-seeking as one of the coping strategies and found that 49% of caregivers reported that they had asked for help from family and friends. Weber (1977) found that the family served as a conduit for formal services, but the caregiver reported feeling betrayed by family when referred to an agency and in turn, the kin who referred the caregiver reported feeling guilty for not doing more and being concerned about whether the referral had been the best thing to do.

Ory et al. (1985) found in their review of literature on caregivers of Alzheimer recipients that caregivers expressed a reluctance to ask for help. Further, when asked for the reasons, they stated that various helpers had different ideas about what should be done and the ideas differed with what the caregiver already was doing.

In Wilson's (1989) research she noted that caregivers utilized different types of support at different stages of their caregiving experience. In the early phases caregivers sought emotional support from peers; later they sought information about the illness and resources; and as the illness progressed, assistance was sought with direct care; and finally, assistance with institutionalization was sought.

Relationships Among Aspects of Caregiving

The most common way in which the associations among the various aspects of caregiving were researched are presented in Table 3. As seen in the table, characteristics of the caregiver and recipient were viewed as influencing the amount of objective and subjective burden. Programs that provided social support were considered as interventions (or intervening variables) for reducing the adverse affects of the burden, improving the caregiver's perceived health status and well-being, or reducing the need for more costly formal services.

Table 3

Placement of Variables in Caregiver Studies

	<u>Preintervention measures</u>	<u>Interventions</u>	<u>Outcome measures</u>
Caregiver (C) characteristics	Objective burden	C support groups	Nursing Home placement of R
Receiver (R) characteristics	Subjective burden	Chore service	R & C visits to physician & hospitalizations
		Respite	
		Social services	Subjective burden
	Perceived SS		Perceived SS
	C satisfaction		C satisfaction
	C health status		C health status

---

C=Caregiver: R=Recipient of care: SS=Social Support

---

Findings illustrative of using this arrangement of variables include: (a) use of formal services increased with age (Branch & Jette, 1983); (b) the living arrangement of the care-recipient was much more influential on whether institutionalization was necessary than was the presence of a home health aide; (c) caregivers who lived with recipient cared for recipients at home for longer periods of time than caregivers who lived in a separate residence from recipients (Brody, Poulshock, & Masciocchi, 1978); and (d) levels of stress were not significantly different for a group of caregivers who had chore service than for a group of caregivers who had chore service discontinued (Hooyman, Gonyea, & Montgomery, 1985). As yet few intervention studies have validated positive outcomes for caregivers on quantitative measures. The usual explanations for lack of effects has been that too few caregivers use support services and for too limited amounts of time and that each type of support cannot produce an effect by itself (Hooyman, et al., 1985).

Although much of the information about caregiving just presented may seem tangential to the issue of respite, the rich description of the caregiving experience enhances understanding of the reasons that caregivers express a need for time away and some of benefits experienced with use of assistance of various kinds. Explanations were discussed for not using formal services in general but not respite specifically.

Social isolation consistently was reported by caregivers as an adverse effect of caregiving, and feelings of social isolation were not remedied by additional assistance with care that did not include respite (time away) for the caregiver. Despite reports of satisfaction with

respite when used and respite being the most frequently desired formal service, use of respite was infrequent. Investigators of caregiving have established firmly the need for respite but have not examined closely the reasons for lack of use of respite when offered. The review of the respite literature was done to examine specific issues related to respite use.

### Respite Literature Review

To provide a background for the discussion of research related to respite, an overview of the history and development of types of respite programs is warranted. The salient research findings most relevant to factors that inhibit or facilitate the use of respite are then reported followed by a summary of the research literature using the theoretical perspective of symbolic interactionism. The final portion of this section includes the purpose, research questions, and definitions of terms for the dissertation research.

#### An Overview of Respite Program Development

The first respite programs in the United States followed deinstitutionalization, a social policy of the 1960s that mandated movement of the disabled (primarily mentally retarded children and developmentally disabled adults) residing in institutions, into the family home. Institutional placement subsequently became restricted. The stated goal of the movement was to make life and conditions for the disabled as close to normal as possible. Parents (particularly mothers) quickly realized that the burden of care was very great. The amount of

care needed restricted the mother's life and disrupted the daily life of the entire family. In addition, like care of the elderly, there was no predictable end of care (Cohen, 1982; Warren & Cohen, 1985).

The impetus for respite programs came from the parents and supporting social agencies who banded together to foster legislation for provision of selected services and time off from caregiving through in-home or out-of-home services. Initially, state and federal respite funds were designated only for developmentally disabled or mentally retarded persons. By 1975 most states had some programs in effect with a wide variation in the range of services and eligibility criteria (Meltzer, 1982).

In the late 1970s and early 1980s, research on the burdens and stress of caregiving for frail elders at home and the escalating cost of health care formed the dual motivations for development of respite and other types of support programs for caregivers of frail elders. By 1985, sixteen states had enacted legislation authorizing respite care for families of the elderly (National Council on Aging, 1985).

As with prior respite services for the younger disabled, there was little program uniformity among communities and states. Montgomery (1989) presented a useful format for discussion of program variations when she described respite by the setting in which it occurred, the level of care or tasks provided, and the duration and frequency of services. A description of each of these aspects of respite as well as reimbursement mechanisms is basic to understanding the complexities involved when research to assess program effectiveness was attempted.

### Settings for Respite

There was a wide variation in types of respite settings. Respite programs were located at the caregiver's home, the care recipient's home, or another facility. Out-of-home facilities included foster home-like settings, adult day care facilities (located in churches, community buildings, or nursing homes), and 24-hour care in nursing homes and hospitals. All types of respite were available at some sites while in other programs each type of service was located at a different site. Some cities had extensive respite services while others were limited or nonexistent. Transportation was provided in some cases and not in others.

### Levels of Service

The basic service of respite was for someone to stay with the recipient in the caregiver's absence. The level of in-home care ranged from a volunteer companion to sit with the disabled elder while the family was out to a person who at the same time did chores, provided personal care, or (if a nurse) did nursing care. It was common for in-home respite programs to specify what a helper could or could not do while in the home (e.g. an untrained companion was not allowed to do any lifting; the nurse only could do skilled care but not respite).

Out-of-home programs also varied in the level of care provided. Adult day care facilities that were called social day care served only clients who could manage walking and toileting independently. Medical day cares were open to clients who needed medical or nursing care during the day and were wheelchair bound. The amount and types of social and medical or rehabilitation programs varied among the facilities. Some

programs were only for persons with dementia, while others accommodated many types of clients. Some respite programs provided services for the caregiver such as support groups, coordination with other health and social services, and educational sessions about caregiving issues. There were programs in which a single agency providing respite was part of a wide range of other home care or social services so that only one screening process was necessary for all services. In other situations the different types of respite and other services were acquired through separate agencies, each with their own eligibility requirements (Gallagher, 1985; Montgomery, 1989).

#### Duration and Frequency of Respite Care

The amount of time respite was provided also varied. Services by a single agency ranged from as little as two or four hours once a month (usually an in-home volunteer companion) to six weeks a year in an institutional setting. In-home respite was either intermittent at the request of the caregiver or provided at regular planned times. Adult day care programs, as the name suggests, offered only day time hours and, depending on the program, were open from one to five days a week. Institutional programs that offered 24-hour care most often required at least a week's stay and limited the client to a specified number of weeks per year. Some allowed emergency admissions and others required advance planning and reservations (FLTC, 1983; Gallagher, 1985; Montgomery, 1989).

#### Funding and Fees for Service

A final aspect of respite, not included in Montgomery's review, was the proportion of reimbursement provided by governmental or

insurance agencies and the amount that the client had to pay out-of-pocket. There were volunteer and grant sponsored programs at no cost to participants. Some government funded programs were paid for fully by the administrative agency for those who met the criteria (e.g. VA programs for veterans only). Others had a sliding fee scale with fees set according to income categories. Some programs set low fees for all clients, and others were more expensive and available only to those who could afford to pay the full fee (Scharlach & Frenzel, 1986; Worcester, 1989).

#### Research and Respite Programs

Respite programs were developed in such a variety of forms and at such a rapid rate that there was minimal coordination of effort in the types of programs planned or in methods for evaluation. Studies rarely took into account the larger framework of caregiving literature. Few reports existed in which systematic research methods were used; thus, the literature reviewed includes both studies in which rigorous research methods were used and anecdotal program reports.

The purpose of the literature review is to identify factors that were influential in the caregivers' use of respite. The literature is organized by the setting in which respite occurred. The in-home setting is presented first, adult day care second, in-patient residential treatment third, and finally programs that provided a combination of types of respite and services. This approach serves to distinguish problems unique to each type of setting and to enhance understanding of the context. Aspects of respite that are pertinent to other aspects of

symbolic interactionism are not considered separately as in the previous discussion of caregiving literature so that entire studies can be presented intact. The way in which the studies relate to symbolic interactionism is part of in the final summary of respite literature.

#### In-home Respite

The only comprehensive study that was focused solely on in-home respite as an intervention was reported by Montgomery and Borgatta (1985). Primary caregivers (N-306) were recruited to participate in a quasi-experimental longitudinal study. Caregivers were assigned to education only, education and respite, respite only, and control groups. The respite intervention consisted of in-home volunteers or a monetary allowance was given to the caregiver to hire a respite worker.

Any differences found on measures applied to determine the effects of the respite intervention were discounted because too few of the caregivers (45 of 171 assigned to respite) used respite. In addition, 68 of those who requested respite could not be accommodated because of inability to recruit enough volunteers for the requests to be met or because many recipients were too disabled for the level of care the volunteers could provide during the caregiver's absence. Coordinating time schedules of volunteers with the times care was requested was problematic. Of the 45 who did use the respite, 25 used it only one time. Those given money to pay for respite only used eight hours a month.

Despite the minimal use of respite of the 171 assigned to respite, 86% said they would have used it more if there had been more types available. Reasons given for not using respite included not wanting to

have a stranger in the house, not wanting the volunteer to do difficult personal care, and the recipient being too sick. When the total group of 306 was asked about what type of respite was preferred, the responses were: in home, 66%; in-home overnight, 49%; adult day care 31%; and institutional care 30%. These figures do not sum to 100% because caregivers were allowed to select more than one type of respite.

#### Adult Day Care

A descriptive article by Sands and Suzuki (1983) was representative of articles on adult day care. In this report 58 caregivers used an average of 48 hours of respite in one year. The respite service was structured for persons with Alzheimer's disease but also allowed admission for recipients without dementia. It was located in a closed middle school, was open six hours a day, and provided social activities only. The program also sponsored a monthly family support group. Caregivers reported that because of the program they had experienced a sense of relief, the recipient had improved, and nursing home placement for the recipient had been delayed.

#### Institutional Respite

There were more reports and studies on in-patient respite than any other type. The Foundation for Long Term Care (FLTC) study in New York State (1983), a demonstration project, was the most frequently mentioned report in the respite literature. Respite was provided to 134 caregivers with recipients placed in six nursing homes throughout the state over an 18-month period. Caregivers used the respite time for taking a vacation (38%), for relief (24%), to extend a recipient's hospitalization (22%), and for their own hospital stay (6%).

A similar project (Field, Moore, & Tallman, 1989) was done in Alaska (n=21). Caregivers used the respite time for vacations and caregiver medical treatment, education, moving, and seeking employment. Stays for the recipient were 3 to 21 days. Twenty-one additional caregivers inquired about respite but did not use it because they did not meet the eligibility requirements or were not close enough to a facility (a common problem in rural Alaska). A comparison was made of responses of caregivers on a symptomatic stress scale given on the day of the recipient's admission and one day and seven days after discharge. Compared with the day of admission, there was a 43% reduction in stress symptoms one day after discharge and a 41% reduction reported seven days after discharge.

Scharlach and Frenzel (1986) gave an anecdotal report on reactions of caregivers (n=150) and recipients to a nursing home unit reserved for respite clients. The length of stay ranged from 3 to 28 days. Because care was in an unlocked unit, recipients could not be wanderers or abusive, and both the recipient and caregiver had to be accepting of the care. Reasons caregivers gave for using respite included rest (81%), visiting (55%), solitude (34%), chores (17%), and recreation (12%). After respite, caregivers reported their health as improved (72%), and most caregivers attributed the improvement to the opportunity to catch up on needed rest. Caregivers reported that their relationship with the recipient was improved (56%), worse (38%), and the same (6%). Improvement was attributed most often to the caregiver feeling less resentment toward the recipient. Worsening of the relationship was attributed to the recipient's expressed resentment at having been forced

to leave his own home. Satisfaction was reported by 90% of the caregivers. The 10% who reported dissatisfaction stated that the nursing home setting was depressing or that the recipients complained about being around persons worse off than themselves.

The following three studies also involved institutional settings and attended to problems of cognitively impaired recipients and their caregivers. As there was controversy over whether short-term in-patient stays for persons with cognitive impairment increased confusion and thereby increased difficulties for caregivers on the recipient's return home (British Medical Journal, 1986; Mace & Rabins, 1981), programs serving the cognitively impaired contained evaluations as to whether the stay had adverse affects on the recipient as well as benefits to caregivers.

Burdz, Eaton, and Bond (1988) compared a group of 27 cognitively impaired and 28 physically impaired persons in order to study the difference between responses of the two types of recipients. Using a quasi-experimental design, a group of recipients admitted for respite were compared with those on the waiting list to the respite program. Of the patients admitted, 15 had cognitive impairment and 20 were without cognitive impairment. Of patients on the waiting list, 12 had cognitive impairment and 8 did not. Measures to detect difficulties were administered two to seven days before admission of the client and 14 to 21 days after discharge. The waiting-list-caregivers received the same measures 5 weeks apart.

Caregivers of the nondementia group reported lower levels of burden and fewer problem behaviors of recipients at beginning and end points than did those caring for persons with dementia. When the respite group and the waiting-list group were compared, recipients who were admitted were rated by caregivers as improved while those who were not were rated as worse. No significant difference were found on any of the measures between the respite groups of dementia and nondementia patients. A dementia diagnosis was associated with perceptions of a worsening relationship with the caregiver over time, but there was no significant difference between the caregivers of the waiting-list groups and caregivers of patients who were admitted. The hypothesis that respite caused increased burden for the caregiver and increased memory and behavior problems in the recipient was not confirmed. This was the only study in an extensive literature review that specifically evaluated the difference in responses to respite of cognitively impaired and noncognitively impairment adults.

A seven day in-patient respite program at a VA ten-bed unit for respite clients had admitted 850 clients since the program's inception in 1979 (Berman, Delaney, Gallagher, Atkins, & Graeber, 1987). The three most common diagnoses were cerebrovascular accident, dementia, and chronic obstructive lung disease. Caregivers were asked what were the important services received from the VA staff. Three types of services were described: (a) personal care of oneself; (b) direct care of the patient; and (c) developing informal and formal support systems.

Caregivers described personal care of oneself as encouragement from staff to take time out. They reported that respite allowed them to rest, take care of medical problems, go to self-help groups, maintain their contacts with organizations and friends, and do home maintenance that could not be done when the spouse was home. Direct care of the patient was the caregiver training provided so they could do the recipient's care more easily at home such as managing external drains or incontinence. In addition, the guidance they received in assisting the recipient to be more independent was cited as helpful. Developing formal and informal support systems was described as assistance in how to plan with friends and kin to assist with caregiving tasks, how much to expect from family and neighbors, and how to recruit formal agencies.

The third study (n=37) was conducted in a VA hospital respite program for recipients with Alzheimer's disease (Seltzer et al., 1988). The setting was a locked Alzheimer's unit. A series of tests of cognitive function, behavioral adjustment, and performance of ADLs were administered just prior to admission (time one) and at discharge, 14 days later (time two). When tested for significance there were no differences from time one to time two. Using the rationale that a difference in the severity of the dementia might influence the reaction to respite, the data were reanalyzed using the severity of dementia on admission as a covariate. Patients with highest scores on dementia severity were compared with those with the lowest scores. This analysis revealed significant changes on two of the tests. Those with less severe dementia on admission showed worsening on the measures and those with more severe dementia on admission showed improvement. The changes,

however, were small and largely restricted to ADL changes. No significant cognitive changes were found. Generalization of results was cautioned against because the number of patients in the high and low categories that were compared (number not reported) was small and measurements were repeated only at discharge. The majority of clients remained stable.

#### Combined Types of Respite

Four articles on combined types of respite are reviewed in this segment. Two are research oriented (Caserta et al., 1987; Lawton, Brody, et al., 1989) and two are anecdotal program reports (Hildebrandt, 1983; Crossman, et al., 1981). Caserta et al. reported on a survey (n=597) sent to persons in caregiver support groups in 16 states. The most commonly needed service reported was respite (71%) and the most utilized service was also respite (63%). Respite was defined as any type of service in-home or out-of-home that provided care for the recipient to relieve the caregiver. Users of respite service were compared to nonusers of respite. Users and nonusers were similar in the duration of caregiving and how long the recipient had been diagnosed.

Reasons for not using respite services were that the caregiver did not yet feel the need for it (43%), the caregiver did not want to leave the recipient with a stranger (16%), the recipient presented too many behavioral problems (7%), and the services available were too expensive (5%). Those reporting no need for respite had significantly lower burden scores, higher levels of social support, and the recipients were

not as functionally impaired. Social network size did not differ between those who reported a need for respite and those who did not. Household income was not related to respite utilization.

The study reported by Lawton, Brody et al. (1989) was targeted for caregivers (n= 642) of persons with dementia. Using an experimental design, participants in the project were assigned randomly to a respite-treatment group or a control group. The definition of respite included any of the formal respite offered by the project, formal respite sources the participant used that were not offered by the project, and any unpaid informal sources (including kin). Types of data collected were sources of respite, other types of assistance used, the recipient's illness severity and longevity, and measures of caregiver well-being.

The formal respite program was embedded in a case management approach which involved a social worker who assessed needs and aided in procuring services. The control group received the same case management approach but respite was not part of the services offered. The project provided any type of respite that was not already available in the community so that the treatment group had access to all types of formal respite inclusive of intermittent, regularly planned, and emergency types of respite. A strict accounting of all types of informal and formal respite was maintained for the year-long study. No significant differences were found between the treatment and control groups on any of the measures and, in fact, the control group actually used both informal and formal respite significantly more than the treatment group. Participants in both groups asked for respite more than any other

service. However, the amount of respite used was not of a magnitude that a treatment effect could be established. Because the heaviest recruitment was done through Alzheimer's support groups, lack of differences between groups was attributed to the respondents being more knowledgeable about respite services and more tied to both formal and informal resources initially than the general population.

Case managers reported that caregivers who expressed a desire for respite needed considerable encouragement to use the service, and then caregivers usually waited until late in the caregiving process or when a crisis developed to request respite. The researchers concluded that even though no changes were detected on measures of well being for those who used more respite, the high satisfaction and relief expressed when respite was used and the requests for more respite justified continuation of respite programs.

Combined in-home respite and access to a foster-home respite facility was reported by Hildebrandt (1983). The number who used the program was not reported. The program provided initial assessment by a nurse practitioner who went into the home and worked out a plan of care. Trained respite workers were paid directly by the caregiver, and the nurse practitioner was available as a professional back up for the respite worker. The in-home helper could spend as little as 2 hours or as many as 72 hours at a time in the caregivers home. At first caregivers were reluctant to have a stranger in the home, and the number of clients the first year of services was only one sixth what was anticipated. By the second year the number had tripled. Staff believed that telling the caregivers that they needed and deserved personal time

and that they would give better care if they took time to nurture themselves enabled the caregivers get over the initial embarrassment of needing help and facilitated their use of respite.

Crossman et al.'s (1981) the most quoted article on respite is reported last. Although a research design was not employed, a rich description was provided of the various aspects of the respite program and the way in which it met the needs of the caregivers and their spouses and encouraged respite use. The total number who used the two-year program was not reported. Older women caring for disabled spouses were the caregivers.

The program was tailored to the caregivers' ideas of the types of respite and support needed. Under one program administration, services included: (a) an adult day care, (b) a home-like six-bed in-patient facility for one or four days of care (Thursday through Monday morning), (c) an in-home respite staffed by nurses (one nurse for every 15 families), and (d) a monthly support group for wives that met at the same place and time as the adult day care. Approaches by wives in the group to recruit other wives for the support group were met initially with resistance and statements by potential new members that their lives were already too stressed to deal with anything more. The wives concluded that respite needed to be offered first because until the caregiver obtained needed rest, she might be unable to think about going out to a support group. New support group members were brought to the group by older members to reduce the difficulty of integrating into a new group.

The different components of the programs shared staff so nurses who came into the home were familiar to the caregivers from the adult day care or the overnight setting. Nurses were requested by the wives in their formulation of the program for in-home care because caregivers felt the level of care was beyond what most other types of health workers or an untrained worker could provide. The nurse did not confine her role to aiding the recipient but also did the other necessary tasks of house cleaning and cooking to eliminate the need of having several workers in the home for different tasks.

All of the wives who used the four-day weekend respite reported that it had been 3 years since they had had any vacation from care. Most wives used the time "just to have some peace and quiet." Wives whose husbands used the in-patient respite reported that their husband was in better spirits on returning home and that the change did him good. The home-like atmosphere of the weekend respite facility was considered especially important.

The fact that adult day care was part of the program did not exclude the need for in-home care as well. Adult day care did not provide personal care and some men were too disabled or frail to tolerate the amount of activities or the all day program. Although the number who received care and reported positive effects was not reported, the program description provided prototype of respite program well integrated with other services.

### Respite Summary and Symbolic Interactionism

Limited use of respite was reported in all the most rigorous studies (Montgomery & Borgatta, 1985; Burdz, Eaton, & Bond, 1988; Seltzer et al., 1988; Caserta et al., 1987; Lawton, Brody, et al., 1989). There was no systematic method of studying factors that influenced the use or lack of use of respite, but rigorous studies and program reports usually listed anecdotally the reasons caregivers gave or observations made by respite staff that contributed to respite use.

Within the framework of symbolic interactionism factors identified in the literature that facilitated or inhibited respite use can be summarized as they related to context, socially constructed meaning, and the emergent nature of interactions. Contextual factors that restricted the use of respite by caregivers were: the program did not have the type of helper needed to care for the recipient, program criteria excluded the recipient, the recipient was too ill to be moved to an out-of-home setting, transportation was not available, and program was either too costly or too far away.

Factors relating to socially constructed meaning that inhibited respite use included: the caregiver's or recipient's perception of the setting as depressing, and the reluctance to admit a stranger to the home. Factors contributing to respite use were: beliefs of the caregiver that going out was good for the recipient, familiarity of the staff to caregiver and recipient, and the out-of-home setting being perceived as home-like.

Emergent and negotiated meanings that detracted from or contributed to the use of respite were the effects resulting from use of respite, the ability of the respite program to accommodate to the needs of the caregiver, and the type of support given to the caregiver in the process of obtaining respite. Past experiences that discouraged the caregiver from further respite use were resentment expressed by the recipient toward the caregiver as a result of having left him with someone else, and a perception by the caregiver that the recipient's condition had worsened (e.g. increased confusion) because of respite use. Results of respite for the caregiver that encouraged use were reduction of negative feelings toward the recipient, and an ability to engage in activities other than caregiving (e.g. rest, recreation, education, and employment). Respite also was used when the times it was available coincided with crises or emergencies in the life of the caregiver (e.g. hospitalization or death of a loved one).

Helpers (respite agency staff) believed that the type of support the caregiver received in her efforts to access respite was important. Helpers felt that caregivers were embarrassed to ask for help and needed encouragement. Interactions viewed as increasing the likelihood that the caregiver would use respite were telling the caregiver that caring for herself improved her ability to give better care to the recipient and offering respite rather than waiting for the caregiver to ask.

The summary of factors that inhibited or facilitated respite use form a beginning knowledge of some of the issues. However, the most consistent finding among all the research studies was that even when conditions for respite were optimal caregivers continued to use respite

very little despite their stated need for more time away and feelings of social isolation. The reports of reasons for lack of use did not explain these contradictory findings adequately. In addition, the way in which care was described differently for persons with cognitive impairment and those with only physical impairments indicated that further exploration was needed as to how such differences might affect the way caregivers perceived respite.

The anecdotal way in which reasons for or against respite use were presented in the literature was not conducive to understanding the interaction between the caregiver and respite environments because factors identified were isolated from the caregivers who reported them. The literature lacked sufficient evidence for a thorough understanding of factors that facilitated or inhibited caregivers from using respite. Though classifying the various factors into the conceptual components of symbolic interactionism was helpful, it did not convey how the components came together in the perceptions of individual caregivers as they interacted with others in attributing meaning to respite within the context of their changing environment. To gain such an understanding of the caregiver's perspective required use of the grounded theory approach. The statement of purpose and definition of terms that follow contain the questions addressed and the definition of terms for the dissertation research.

### Statement of Purpose

The purpose of this research was to develop a grounded theory about the use of respite by caregivers. Research questions addressed for development of the theory were:

- (a) How do family caregivers make decisions about using available respite?
- (b) What factors inhibit or facilitate the use of respite?
- (c) Do explanations for respite use vary for the family who cares for a cognitively impaired older member and the family who cares for a physically impaired older member?

### Definition of Terms

<u>Respite</u>	Any situation in which the caregiver leaves the recipient in the care of a helper. Respite may be provided in any location.
<u>Caregiver</u> (C).	The informal unpaid person who has primary responsibility for caring for a chronically ill elderly person in the home setting.
<u>Recipient</u> (R).	The person who needs the assistance of the caregiver to continue to live in the community.
<u>Helper</u> (H).	Any person or agency who stays with the recipient in absence of the caregiver respite.
<u>Informal Helper</u> .	Includes kin, family members, friends, neighbors, and voluntary organizations such as churches.
<u>Formal Helper</u> .	Any person paid privately or any organization that provides respite services.

## CHAPTER III: METHODS

This chapter contains the methods used in completing the study. There are five sections. The first describes the study design. The second section describes the process of sample recruitment, the procedures for protection of the participants, and criteria for participant selection. Instrument development and selection of the standard instruments used in the study comprise the third section. The data collection protocol and the data analysis methods are contained in the fourth and fifth sections respectively.

### Study Design

To obtain the caregiver's perspective on respite, grounded theory was chosen as the qualitative approach because of its usefulness in generating data descriptive of social processes (Munhall & Oiler, 1986). This method was consistent with the central assumption of symbolic interactionism that theory cannot be generated from the outside looking in but must be derived from the participants' perspective of interactions (Denzin, 1978; Goffman, 1959).

An open-ended interview using ethnographic techniques was the central procedure for information gathering. Participant observation was also a part of the method of data collection because the interview took place in the caregiver's home where direct observation of the setting and interactions between the caregiver and receiver could be made (Spradley, 1979, 1980).

The study was both retrospective and longitudinal. Questions were asked about the prior six months at the first interview, and interviews were conducted three times over a six-month period with data gathered about respite use during the intervening months.

#### Sample

The sample for the study was purposive. Thirty caregivers were recruited; 15 were caregivers of cognitively impaired adults and 15 of physically impaired adults. In qualitative research the exact number to be interviewed is determined by whether or not new information is being acquired in each successive interview. When no new information is recovered, "saturation" is said to have occurred (Strauss, 1988). Although the sample size necessary for saturation is difficult to predict in advance, to achieve saturation "it is usual to find that a dozen or so interviews if properly selected will exhaust most available information; to include as many as twenty will surely reach beyond redundancy" (Lincoln and Guba, 1985, p. 234). Thus 15 in each group were chosen in case of loss of subjects. Because quantitative analysis also was planned, equal sized groups of 15 were chosen to facilitate useful statistical comparisons. Although larger groups would have been ideal (e.g. 30 in each group) for the quantitative measures, the smaller number was more appropriate for qualitative analysis.

The variability among the types of caregivers sought was: (a) the receiver's relationship to the caregiver, spouse and adult children; (b) gender; (c) ethnicity; (d) living situation, in residence and out-of-residence caregivers, and (e) geographic location, rural and urban.

Maximum information about the caregivers' experiences was the goal rather than having the numbers and types of caregivers representative of the proportion of each type found in the population.

#### Recruitment of Sample

The entire sample was recruited through an ambulatory geriatric clinic at a veteran's medical center in an urban setting. A preliminary survey was conducted to assure that there would be a sufficient number of subjects to meet the criteria in the time allotted. Some advantages and disadvantages in choosing one site for selection were anticipated. Advantages were the ease of access and the fact that all participants had access to the same services for formal respite. Respite was reimbursed, and the settings and conditions under which formal respite could be obtained were more constant for this group than for other segments of the population. This factor increased the likelihood of formal respite use compared to nonveteran groups.

The veteran's facility used served both the urban and surrounding rural areas so that participants of both types of geographic locations could be contacted through one clinic. In addition, the clinic served both the cognitively and physically impaired, and the comprehensive nature of assessments at the clinic meant that cognitive impairments were likely to have been diagnosed.

Disadvantages in using this type of sample were that it was harder to find male caregivers because most veteran recipients of care are male, and that more respite was available to veterans than to the general population. Therefore, application of the findings to other types of caregiving situations was limited. To allow for these

conditions, explicit description of the sample and a comparison to the national sample was done, as well as validation of findings with caregivers outside the veteran sample.

Participants were recruited through eight physicians and one social worker. Initial contact with participants was through the clinician intermediaries in the clinic. The investigator met with the nine clinicians and provided a copy of the criteria for client selection to each of them. As the clinic staff only met one morning a week and recruitment was to occur over a four-month period, a summary of criteria was placed as a reminder in the offices where the clinicians saw clients on clinic days.

The physicians and social worker were provided with a brief explanation of the research to hand to clients who expressed interest in participating. The investigator was present at the clinic, and participants were referred directly to the researcher for further explanation of the study and an initial screening interview. This face-to-face contact with potential subjects was considered important by the researcher because of past clinical experiences in which caregivers were reluctant to have strangers in their homes.

The participant was told that the investigator would call within the next few weeks to set up an appointment time. The researcher gave the caregiver a card with information about herself in addition to a brief explanation of the research. The rationale for waiting to set the

interview time was that the hurried environment of the clinic was not conducive to focusing on dates and the clients already were being asked to schedule several other appointments that day.

The participant was telephoned to set up an appointment. As had been discovered in the pilot study, participants were reluctant to set a date until they were assured that the researcher would call to verify the appointment 24 hours in advance. Thus, if things came up (e.g. the caregiver was too tired or the receiver was ill), they could cancel and an alternative date could be set. This practice was found to be very important as it was not infrequent that the caregiver needed to change the appointment time. Sufficient recruitment was achieved during the researcher's four months of attendance at the clinic (March through June 1988).

#### Protection of Human Subjects

The research proposal was reviewed by the appropriate human subject review boards of the Veterans' Administration Medical Center and the University of Washington. Both the standard consent form of the Veterans' Administration and the form submitted by the researcher to the University of Washington (Appendix A) were required. Separate forms were obtained for the recipient and caregiver.

The consent forms explained the research and assured the participants that their participation in the study was voluntary and that they could withdraw at any time and were free not to answer any questions that were asked. The consent form for the recipient was only

for consent to administer the test to assess mental status and for answering demographic questions if able. If the recipient was impaired cognitively, the caregiver signed for the recipient.

The consent form for the caregiver included permission for the interview and for tape recording the interview. Confidentiality was assured by the taped interviews being identified only by number and being destroyed after transcription. Names were not on any written or transcribed materials. Information identifying participants was kept in locked files. It was explained that no risks to the caregivers or recipients were anticipated but that the questions asked might be emotionally laden and difficult to talk about. They were instructed that if they became tired (caregiver fatigue is common) during the interview and wished to rest or discontinue the interview, they should feel free to do so. Because recipients were in frail health, it was anticipated that there might be a medical emergency during an interview. Procedures were reviewed with the Veterans' Administration as to the usual mechanisms for handling emergencies so that the interviewer could facilitate the caregiver getting assistance should it be needed during the interview.

Benefits of participating were identified for participants as a chance to talk about their concerns, and an opportunity to contribute information that might be helpful to other caregivers. In addition, caregivers were told that a report of the results of the research would be sent to them on their request at the conclusion of the study.

Consent forms were explained verbally and were presented in writing at the first in-home interview. Participants were encouraged to feel free to withdraw at any time, and they were given an opportunity to ask questions about the study prior to starting the interview. At the last interview, opportunity was given to participants for debriefing by asking them what they thought of the interviews and if they had any questions about the research. They also were asked if they wished a brief report of the study. Persons expressing a desire for a report received a written summary of the project and information as to where they could find the dissertation.

#### Criteria for Sample Selection

The criteria for sample selection were that: (a) the caregiver had provided care for at least six months to the recipient; (b) the recipient had two deficits in activities of daily living and either was physically impaired, with a mobility problem and no cognitive problem, or cognitively impaired and ambulatory; (c) the caregiver spoke English; and (c) the care recipient was a Veteran and lived within a 60-mile radius of the ambulatory clinic.

Activity of daily living deficits (ADLs) were defined by the Katz Index of ADL (Katz, Ford, Moskowitz, Jackson, & Jaffee, 1963). Cognitive impairment was determined by a score of 15 or below on the Mini-Mental State Examination (MMS) (Folstein, Folstein, & McHugh, 1975) or by physician diagnosis. The criteria for types of recipients were chosen to distinguish between the physically heavy care tasks that would be needed by nonambulatory persons and the behavioral management needed by cognitively impaired ambulatory persons.

This decision was expected to increase the likelihood that each group would present a different set of factors that inhibited or facilitated the caregiver's acquiring assistance for respite. The severity of disability criterion was chosen on an assumption that caregivers would likely feel a need for respite.

Caregiver variability was sought among each of the two groups as explained previously. This was to ensure variance on characteristics used in previous studies so the widest range of factors influencing respite might be discovered. This was considered a "critical case" approach to qualitative study in that classic types of caregivers were sought and in depth information was acquired from each type (Yin, 1984).

Persons with diagnosed mental problems (either caregiver or recipient) were excluded as were caregivers of terminally ill patients whose prognosis was six months or less.. These persons were excluded because these conditions would make it difficult to differentiate between the cognitive and physical components as factors influencing respite.

#### Instruments and Procedures

Initial procedures included developing and testing the open-ended interview and selecting closed-ended questionnaires that described the sample and measured dimensions of the caregiver's health. Quantitative instruments were selected in part for their brevity since most of the interview time was needed for collection of the qualitative data. Instruments were chosen that had good reliability and that had been used with older populations or caregivers so the results could be compared

with other groups of caregivers. The entire interview (both open-ended questions and other instruments) was used in a pilot test with five caregivers prior to finalization of the interview protocol and adjustments were made based on the results of these findings. The open-ended interview took an average of one hour. The Mini-Mental Status Exam (MMS) took 10 minutes, and the total time needed for all other instruments was 20 minutes.

#### The Open-Ended Interview

The open-ended interview was performed using an ethnographic interview approach. It began with broad questions, and subsequent questions were based on subjects discussed during the evolving interaction between respondent and interviewer. Questions were directed toward explaining the reasons for respite, choices of helpers, understanding the circumstances in which respite was used, and strategies for obtaining and maintaining the sources of respite. In the process of interviewing, open-ended questions such as "tell me about the last time you had someone stay with your husband..." were asked. This type of approach is considered an excellent strategy for discovering grounded theory because it formulates questions that help participants describe and explore the subject of interest without leading them toward the framework of the investigator's biases (Spradley, 1979).

As the interview proceeded, repeated explanations of situations were requested. Restatements were made by the interviewer and clarification was sought by restating in another way what the participant said asking if the perception was correct. The same words used by the participant were used by the interviewer so that rapport was

built and vocabulary was adjusted to that of the participant.

Exploration and description required the asking of "how" questions to discover processes as opposed to "why" and "what do you mean" types of questions that often put a person on the defensive.

The open-ended questions and the prompts that were used were developed by discussing them with a panel of five colleagues who were experts in qualitative interviewing and then with three caregiver support groups not connected with the Veterans' Administration (see the final format in Appendix B).

The investigator began with "Tell me about the last time someone stayed with your husband or took your husband out?" With this approach the caregiver was able to recall many more experiences and was able to describe the context and social situations from which respite resulted or was not considered possible. The interview progressed by asking "How the situation came about?" and what prevented the caregiver from asking a certain person or agency to stay with the recipient. Then the interview proceeded from situation to situation asking if there was another experience the caregiver could describe until no other situations were forthcoming. In the first interview information was requested about all experiences with respite that had occurred in the prior six months. The subsequent two interviews were focused on any experiences with respite that had occurred in the time between interviews.

The genogram (see Appendix C) was helpful after the second interview in obtaining information about which family members were able to provide respite and the reasons each relative might or might not be

available for respite. Relationships of three to four generations were traced along with the distance they lived from the caregiver and notes were made as to their potential for respite. This procedure led to rich data about past and present experiences with family members that influenced respite as well as the way caregivers thought about inclusion or exclusion of same generation and younger generations as sources of respite.

An instrument called "Themes" (Appendix D) was developed by the investigator between the second and third interview as a method for validation of the seven main categories or concepts that had been identified at that time. The instrument contained a 5-point rating scale for caregivers to validate the extent to which the theme was not true (rated 1) or true (rated 5) for them. The development of the themes is described in more detail in data analysis and in the results chapter.

#### Recipient Information

The only instrument administered consistently to recipients was the MMS. The Katz Index of Activities of Daily Living (ADL) that measured the recipient's ability to perform activities of daily living was filled out by the caregiver. The demographic questions about the recipient also were completed by the caregiver except in two cases. In the latter two cases the recipients were in the physically impaired groups and the caregiver preferred that the recipient provide the information. All data regarding the recipient were collected in order to compare the cognitively impaired group with the physically impaired group and the entire sample with other dependent elderly samples.

### The Mini-Mental State Examination (MMS)

The MMS tests cognitive function and takes only 5 to 10 minutes to complete. It tests orientation to time, place and person, short-term recall, attention, calculation, language, ability to follow a three-stage command, writing, and motor function. The MMS is easy to learn to administer, and test retest reliability on past use has ranged from .83 to .99. It has been used extensively to screen for cognitive impairment (Folstein, et al., 1975; Kane & Kane, 1981). The instrument has a total possible score of 30. In the dissertation research, cognitive impairment was determined by a score of 15 or below on the MMS and "without cognitive impairment" by a score of at least 25. These parameters were chosen based on clinical standards of the originators of the instrument (Folstein, et al., 1975) and on the way in which the instrument was used by clinicians at the geriatric clinic (Appendix E).

### The Katz Index of ADL

The Katz Index of ADL (Appendix F) was selected to ensure that the recipient had at least two ADL deficits and also to evaluate the severity of functional impairment. The Katz Index is a dichotomous scale of six ADL functions (Katz, et al., 1963). One point is given for each item of dependency. Sherwood, Morris, Mor, and Gutkin (1977) reported a coefficient of reproducibility of .948 when used in their study. The six functional areas were dressing, bathing, eating, toileting, continence, and ability to transfer from bed to chair. In the dissertation research a seventh item of ability to ambulate (walk independently) was added. This addition has been common in other studies according to Branch and Jette (1982). The Katz Index was suited

particularly to the study's purpose because it had been used previously with both physically and cognitively impaired persons (Katz et al., 1963).

In the study, to be part of the physically impaired group the recipient must have needed assistance with walking and at least 2 of the deficits in ADL function. Those with cognitive impairment needed to be able to walk unassisted but also be limited in performing at least two ADLs of the Katz Index.

#### Demographic Information

The demographic information included the basic survey information of age, gender, ethnic origin, occupation prior to retirement, education, income, marital status, current living situation (persons recipient lives with), housing situation, and relationship to the caregiver (Appendix G).

#### Caregiver Information

Information acquired from the caregiver included demographics, aspects of the caregiving experience, and measures of the caregiver's physical, emotional, and social health. These data were collected for comparison between the two groups within the study and for comparing the entire sample with national samples of caregivers. The demographic information and caregiving experience information were chosen based on common items derived from other studies to facilitate comparative analysis (Archbold et al., 1987; Stone et al., 1987). The caregiver health instruments also were used to compare the sample groups at each interview time and to note changes across time.

### Demographic Information

The demographic information collected from the caregiver was the same as that of the recipient except that the length of time the caregiver had known or was married to the recipient also was requested (Appendix H).

### Caregiving Experience

The Caregiving Experience survey instrument contained sections related to recipient difficulties other than ADL deficits, caregiving responsibilities, and the environment in which caregiving took place (Appendix I). The questions contained in each of the sections were developed from the literature review. The items were those that had been reported as influencing caregiving and were viewed by the investigator as factors that also might influence the ease or difficulty with which respite might be obtained.

Recipient Difficulties (Appendix I, Section A) questions were about the recipient's ability to communicate, the recipient's tendency to interrupt the caregiver, how often the caregiver needed to check on the recipient during the day and night, the recipient's hearing, the caregiver's ability to take the recipient out of the home, and the stability of the recipient's health. Caregiving Responsibilities questions were about the duration of the caregiving experience, how much help the caregiver received, how much time the caregiver was able to get away during a week, how long the recipient could be left alone, past caregiving responsibilities, and current responsibilities for other elderly persons (see Appendix I, Section B). The Caregiving Environment questions were about Caregiving Experience (Appendix I, Section C)

features of the living space, the neighborhood, neighbors, transportation, and frequency with which the recipient left the dwelling.

#### Caregiver Health Status

The caregiver health status questionnaire contained three components for assessment: physical health, emotional health, and social health.

Physical health. The caregiver's physical health was assessed through use of a scale for physical health status in which excellent = 4, good = 3, fair = 2, and poor = 1 (Appendix J: Section A). This scale was a subindex of the Philadelphia Geriatric Multilevel Assessment Instrument (Lawton, Moss, Fulcomer, & Kleban, 1982) and the most frequently used measure in large geriatric and caregiver studies (Archbold et al., 1987; George & Gwyther, 1986; Cornoni-Huntley et al., 1986).

Emotional health. Emotional health was measured by the Affect Balance Scale (ABS) (Bradburn, 1969). The ABS (Appendix K) has shown test retest reliabilities ranging from .86 to .96 on positive affect and from .90 to .97 on negative affect components of the questionnaire. Its internal consistency using Cronbach's alpha was reported by Bradburn as .83 for positive affect and .86 for negative affect.

Social health. The social health questionnaire contained an objective component and two subjective components. The purpose of the objective component was to measure contact with the social network. The subjective component was measured by perceived social support. Social contact was measured by a single question pertaining to the number of

visitors the caregiver was in contact with each week (Appendix J). This question was selected as it had been used in other studies and served to compare the sample in this study with samples from other studies (Archbold et al., 1987; Gaitz & Scott, 1972; George & Gwyther, 1986).

Perceived social support was measured by the Personal Resource Questionnaire (Appendix L). This instrument contains a 25-item Likert scale developed by Brandt and Weinert (1981). Estimates of reliability for the scale have ranged from .85 to .93. The scale measures perceived social support on dimensions of intimacy, social integration, nurturance, worth, and assistance. It has been used with young adult through older adult age groups (Weinert & Brandt, 1987).

#### Data Collection Protocol

Data were collected in three interviews spaced approximately two months apart. All of the interviews were conducted between April 1988 and March 1989. Each interview appointment was made two weeks in advance with a promise to call the caregiver 24 hours in advance to confirm that the time was still all right. Information also was elicited at the first and second interview about possible times the caregiver or recipient might be away or company was expected that might interfere with the next appointment. This information was essential to planning and insured that unnecessary trips were not made.

Each interview lasted from 45 minutes to two hours with the majority being an hour and a half in length. The instruments administered are listed in Table 6, and the interview at which they were

administered is shown. A brief description follows of the way each interview was conducted.

Table 4

Interview Instruments and Time of Administration

	<u>Time One</u>	<u>Time Two</u>	<u>Time</u>
<u>Three</u>			
1. Screening Instrument	X		
2. MMS	X		
3. Katz Index of ADL	X		
4. Receiver Demographic Data	X		
5. Caregiver Demographic Data	X		
6. Caregiving Experience	X		
7. Open-ended Interview	X	X	X
Genogram		X	X
8. Caregiver's Health			
Physical Health Status	X	X	X
ABS	X	X	X
Social Health Objective	X	X	X
Personal Resource Questionnaire	X	X	X
9. Themes			X

---

ABS = Affect Balance Scale

---

First Interview

The first interview began with an explanation of the project and opportunities for questions. It was emphasized that being in the study was totally voluntary and that declining to participate would not affect the care received at the clinic. Confidentiality was stressed. After the caregiver gave verbal consent, consent forms were presented and explained verbally. The tape recording was explained and the caregiver was told when it would be used. Time was allowed to read the consent forms and to ask questions before formal signatures were obtained. Next

the MMS was administered to the recipient. The caregiver had been told on the phone prior to the interview that the recipient only needed to be present for the MMS and that privacy would be needed for the remainder of the conversation. This protocol worked well and resulted in the recipient being out of hearing range when the interview was conducted. The caregiver then was asked the ADL questions. The tape recorder was turned on at the beginning of the open-ended interview which followed the ADL questions. The rest of the questionnaires were administered in the order listed in Table 6 after the tape recorder was turned off. Time was allowed at the end for questions and discussions about the next interview time. If relevant material was discussed at this time, the tape recorder was turned on again to capture the conversation.

Between the first and second occasions, the interview was transcribed and analyzed by the researcher. Unclear aspects were underlined, and questions placed in the right margin for discussion and clarification at the second interview. In addition, as questions arose from interviews that were thought important to discuss with all participants, the questions were added to the next interview. A calendar was developed to trace important incidents that had been reported in the interview as well as occurrences of respite.

#### Second Interview

The second interview began by asking what changes had taken place since the prior interview. If not reported, the caregiver was asked specifically about changes in the recipient's health, doctors appointments, caregiver's health, and changes in the caregiver's or recipient's social network (e.g. visitors, trips, or losses of friends

or family through moving, death or illness). Next the caregiver was asked to report on any occasions in which respite had occurred since the last visit.

The interviewer brought the transcript of the prior interview to the appointment and reviewed selected portions of the transcript with the caregiver to clarify events and asked for elaboration on events that were unclear. Questions were asked of all caregivers that had been determined as important from analysis of the first interviews. The calendar of events that had been developed was shared with the caregiver; dates and times at which events occurred were validated. A genogram was done that had been partially completed based on the first interview. This first portion of the interview was tape recorded. The quantitative measures were administered next with time for questions at the conclusion.

Between the second and third interview, the second interview was transcribed and read. Analysis of the qualitative data was well under way and a series of categories had been developed that seemed most salient to the caregiver's feelings about respite issues. These categories were developed into a "Themes Scale" for validating whether the caregiver agreed with the researcher's analysis.

#### Third Interview

The third and final interview began in the same way as the second interview process. Any major questions that needed clarifying from the second interview were asked. The Themes Scale then was administered. After the scale was administered, caregivers were asked for their reflections about the themes and if they had other names for the themes

than those used by the investigator. Comments made during this portion of the interview were tape recorded. The quantitative measures were administered last.

At the end of the interview the caregiver was thanked for her time and willingness to share. She was asked to sign to indicate whether or not she desired a written summary of the project. Questions were asked by the investigator about the caregiver's reactions to participating in the study, and time was allowed for the participant to comment or ask any final questions.

#### Procedures for Data Analysis

Descriptive statistics were used for analysis of the demographic data and characteristics of recipients and caregivers. Constant comparative analysis was the method used for the qualitative data. Selected inferential statistics were used to compute differences between cognitively and physically impaired groups, to compare measurements of the dimensions of caregiver health over time, and to correlate the various dimensions of health. The Statistical Package for the Social Sciences. Personal Computer (SPSS.PC) program was used for all quantitative data analysis (SPSS.PC, 1985). Triangulation of data was accomplished through comparison of qualitative and quantitative results. Each of these modes of analyses is described more fully in the sections that follow.

### Descriptive Data Analysis

Analysis of the demographic data, Katz Index of ADL, MMS, and Caregiver Experience survey used measures of frequency, central tendency, and variability. Data on the caregiver and recipients were compared with national surveys of dependent elders and caregivers so that similarities and differences could be noted. Differences between the two groups of caregivers were computed using nonparametric procedures for small samples (the Mann-Whitney U-Test from Allen and Yen, 1979 and Bruning and Kintz, 1977).

### Qualitative Data Analysis

The qualitative data analysis involved development of a grounded theory. This was done through the processes of: (a) constant comparative analysis; (b) memoing; (c) checking reliability and validity; (d) quantifying the categories and respite use, and (e) establishing relationships among concepts.

#### Constant Comparative Analysis

Constant comparative analysis (Glaser & Strauss, 1967; Strauss, 1988) was the predominant mode of analyzing the content of the interviews. The Ethnograph, a computer software program (Seidel, Kjolseth, & Seymour, 1988), was used to aid in data analysis and manage the text. This program numbered the text lines, sorted coded words and phrases, and aided in putting together ideas that were repeated throughout the interviews.

Analysis of the interviews was restricted to conversation most directly related to reasons for the caregiver using or not using sources of respite. After the interviews were transcribed and text lines

numbered using The Ethnograph program, the investigator read through each interview and selected key words and ideas (codes). Each of the codes then was placed on a 4 by 6 card, a definition was written, and the text that surrounded the key idea was cited on the card (see Appendix M). This process in content analysis is called "coding" the data.

The inductive approach involved using the participant's own terms and words whenever possible, whereas the deductive approach is performed using concepts derived from current literature as codes (e.g. role conflict) with the participant's words subsumed under concepts with the closest fit (Woods & Catanzaro, 1988; Strauss, 1988). As coding proceeded the use of terminology derived from other known theoretical frameworks (e.g. social support, role theory) was discontinued as it became clear that the names and content of identified themes were valid representations of the participant's viewpoints. The inductive coding of information was continued at increasing levels of abstraction while maintaining coherence with the data. Examples of inductive codes were: transportation difficulty, inconvenient timing of respite, personal conflict with helper, and recipient resistance to help. As analysis continued, and connections between codes were identified, the codes were grouped into categories. When new data seemed to contradict a category, the investigator returned to the original data to determine whether original codes or data had been forced into inappropriate categories.

The early stages of coding data were done by hand. Only when more inclusive categories, containing several codes, began to be identified were the codes labeled using the computer. This step enabled a process

of shifting codes among the categories and led to smaller numbers of categories for reorganization as major themes were established.

The researcher constantly referred back to the passage of the text material and the context of the interview from which the codes were derived. This method of data analysis was designed to generate categories and the properties of those categories, so that categories would be integrated, consistent, and plausible (Glaser & Strauss, 1967). Analysis of each segment of data was compared with other incidents in the same category as categories were constructed.

A full range of possibilities for each category was considered including: the dimensions of the category, the conditions under which the category was most or least evident, and its relationship to other categories. For example, each time the respondent mentioned the topic of being afraid of imposing on others, the coder would review every other time that imposing related concerns had been coded. This step determined whether the current passage of text was consistent with previous discussions of the meaning of impose.

To add structure to the analysis, selected steps in Strauss' (1988) approach to qualitative analysis were followed. The steps included identifying: (a) the conditions under which this category or code emerged, (b) the interactions that occurred among the actors regarding the code -caregiver, receiver, or helper; (c) the strategies that were used that related to the code; and (d) the consequences that resulted. At later stages of the analysis this structure was helpful in judging how each code or category facilitated or did not facilitate the acquisition of respite (see Appendix N).

Examples of the early coding, larger categories, and then main themes are illustrated in three of the phases of data analysis in Appendix O. Although these are presented in the appendix on a single sheet for each phase, the process of category development was enhanced by the use of the 4 by 6 inch cards. These cards could be reshuffled easily and reorganized until the closest fit with the chosen themes could be found.

As themes were identified, a deductive approach to theory development was performed through continuing use of the major themes to organize the data, but only if the data closely approximated the definitions of the themes. Whereas the first codes (substantive) were words directly derived from the data, themes (theoretical codes) were used to explain interrelationships among the substantive codes. Theoretical codes were concepts that related variables to one another at higher analytical levels (Glasser & Strauss, 1967).

#### Memoing

Methodological, observational, and theoretical memos were used to assist in exercising maximum control over the data. Methodological memos reflected the operational plan for accomplishing the study and included concerns about the tactics used to collect data and reminders to the investigator about further data collection. Observational memos were recorded events that seemed important in terms of the who, what, when, where, and how of the activities observed. The field notes recorded by the researcher were included in the observational memos.

Theoretical memos were self-conscious attempts to derive meaning from data (Schatzman & Strauss, 1973). According to Glaser (1978), the goals of theoretical memoing are to develop ideas and raise them to a conceptual or theoretical level. This meant that memos often contained thoughts about possible categories or themes, or relationships among themes. Theoretical memos became a sortable fund of information which added to the substance of the study. Memos were made at times ideas occurred to the researcher and were dated with a note attached to the circumstances under which the idea occurred. Examples of each type of memo are illustrated in Appendix P. Memoing was not a process separated from the comparative analysis but was continuous and led directly into the reorganization of categories, emergence of the dominant themes, and eventually to the core category.

#### Quantifying of Qualitative Results

A method of quantifying main themes was developed between the second and third interview. The number of times the code reoccurred throughout the first two interviews was counted. The count was accomplished easily by using the ethnographic program. The number of occurrences of each theme was totalled and measures of frequency and central tendency were computed on the entire sample and then on the two groups within the sample. Differences between the groups were computed using the t-test for independent samples (Allen & Yen, 1979). A method of quantifying respite also was developed, and similar statistical tests were conducted. A description and rationale for the way in which respite was quantified are presented in the chapter on results (Chapter V).

### Validity and Reliability

Validity and reliability are defined somewhat differently in qualitative than in quantitative research. The following discussion provides qualitative definitions of validity and reliability and the way they were applied in this research.

#### Validity

In quantitative research external validity is the extent to which the results can be generalized to other groups. As random selection is not the usual mode of sample selection in the grounded theory method, external validity depends on being accurate in describing the sample studied and the context (Cook & Reichardt, 1979; Goodwin & Goodwin, 1984). The demographic survey and caregiver experience questionnaires were used for this purpose. This information was used to compare and contrast the sample with national samples and to delineate the circumstances under which the generated theory might be applicable.

To determine whether the grounded theory could be applied to other groups of caregivers, the Themes Scale (Appendix D) was taken to three caregiver support groups, consisting of caregivers very unlike those in the study. Demographics of the caregivers in the support groups were obtained along with the group members' responses to the Themes Scales. The groups also were asked if any components were omitted from the Themes Scale that they thought contributed to decisions about respite. The demographic data and responses to the Themes Scale of the support groups were compared with those of the sample. This analysis was performed to determine how well the generated theory applied to other types of caregivers.

In qualitative research, internal validity is the extent to which the data represents what is true for the participant in a naturalistic setting (LeCompte, & Goetz, 1982; Goodwin & Goodwin, 1984). Conducting the interview in the participant's home provided the natural context and allowed the researcher to make observations about the influence of the setting on responses. Processes for assuring that the data represented what was true for the participant at the second interview included: reviewing the transcript and clarifying unclear points with the caregiver, checking on the chronology of events, and using the genogram to verify kin sources of respite. These processes aided in reducing researcher bias by working systematically to remain as close to the participant's reality as possible.

Validation at the third interview consisted of sharing the major themes generated by the researcher with the participant and then administering the Themes Scale to determine whether or not there was agreement with the themes. These external and internal validity checks were the processes by which validity was taken systematically into account in this research.

#### Reliability

In quantitative studies, external reliability is the extent to which another person can replicate the study, and internal reliability is the extent to which others within the same study can acquire the same results. Since exact replication of the study is not possible in a highly unstructured interview, the alternative in qualitative research is to make explicit every step of the process and the analytical techniques involved (Glaser & Strauss, 1967; Lincoln & Guba, 1985;

Strauss, 1988). This was done through the explanations that were a part of the comparative analysis and memoing already described. In addition, discussions with clinical and academic professionals familiar with caregiver issues served to critique the researcher's analysis for logical construction and coherence with the investigator's experience.

Internal reliability in qualitative research was applied at several points in the research process. During beginning phases of categorization and theme development, the themes were shared with experts in qualitative analysis. These discussions aided the researcher in establishing whether others might be able to understand the reasoning by which the categories were derived. On completion of the coding process and derivation of the final themes, a coding book was written which included the definition of each major theme and illustrations taken from interviews. Interrater reliability was established first through consensus in which two raters discussed the codes and arrived at consensus as to which text fit with which themes. This process sharpened definitions and allowed for definitive quantitative reliability measures to be performed.

Intrarater reliability was conducted by the researcher coding the same interview two weeks apart and calculating the percentage agreement. Interrater reliability then was conducted by having two researchers study the code book, ask questions, and then code ten percent of the interviews randomly selected from the total. Rate of agreement, rate of disagreement, and the Kappa methods were used as each gives a different way of interpreting the reliability for nominal data. These are the methods of establishing reliability for qualitative research comparable

to measures of internal consistency and test/re-test that are used in quantitative research (Kirk & Miller, 1986; Krippendorff, 1980; Topf, 1986).

#### Relationships Among Concepts

Relationships among concepts or themes initially were examined using data from all the interviews. Because the central purpose of the research was to determine factors that facilitated or inhibited respite, the themes were chosen according to how they contributed to the process of respite. The second major emphasis of the study was to discover whether there were different issues for caregivers of cognitively impaired persons compared to caregivers of physically impaired persons. The data again were reviewed for how factors differed between the two groups. A matrix of four sections was constructed by placing texts within one of the four sections of the matrix: (a) factors facilitating respite for the cognitively impaired; (b) factors inhibiting respite for the cognitively impaired; (c) factors facilitating respite for the physically impaired; or (d) factors inhibiting respite for the physically impaired. Examples of the matrix and content are contained in Chapter V in Tables, 11, 12, and 13. By using this procedure to analyze data, hypotheses pertaining to one group or both groups of caregivers could be generated.

#### Quantitative Data Analysis

Differences between groups of recipients who were cognitively impaired and physically impaired were computed on demographic characteristics, caregiver experiences, caregiver health instruments, and frequencies of theme occurrences to determine if any of the factors

might contribute to understanding the use of respite. The nonparametric statistic to test the ordinal data for difference between rank order (Mann-Whitney U) was used for group comparison.

Because it was anticipated that the caregiver's health might become worse over the six-month period, paired t-tests were computed to compare time one with time two interviews, time two with time three interviews, and time one with time three interviews on all the measures on health. If significant differences were found that reflected a change, a one way analysis of variance would be computed to rule out that differences among the paired t-tests had occurred by chance. It was expected that the caregiver's health might worsen over time due to the heavy demands of caregiving.

Correlation coefficients of the total participant group were computed to determine relationships among measures of health to determine if the measures behaved similarly to findings in other research. Three correlation matrices were constructed, one for each interview time. More rigorous statistical tests (multiple regression analyses) were planned if correlation coefficients yielded significant correlations of ample magnitude to warrant further testing.

Validity and reliability of the measures were examined. Validity was examined by looking at the quantitative test results in light of the context and analysis of the qualitative interviews (e.g. did the ABS scale capture the observed mood of the caregiver). External reliability was determined by comparing the test results with other studies of caregivers reported in the literature. Internal reliability was tested

by computing internal consistency of each measure and comparing it with other investigators' results to determine if the measures approximated those in other studies.

#### Triangulation of Data

Triangulation of data was accomplished by asking three questions of the quantitative and qualitative data: (a) were the differences between the groups found in the qualitative data also reflected in the quantitative data? (b) were the changes over time found in quantitative measures (e.g. social support measures) able to be explained by the qualitative data? and (c) did quantitative data as a whole support or not support the qualitative data? Discussions and conclusions were drawn from answers to these questions.

#### CHAPTER IV: SAMPLE CHARACTERISTICS

A diverse sample was selected to obtain examples representative of the types of caregivers identified in the research literature (e.g. by sex, race, and caregiver's relationship to the recipient). Because the sample recruited were all caregivers of United States Veterans, it was not expected that all categories of caregivers could be represented.

All persons who were contacted to participate in the study consented. An equal number of persons who were caregivers of persons with cognitive impairments (the CI group) and who were caregivers of persons with physical impairments (the PI group) was recruited. One caregiver dropped out after the first interview citing the reason as "the questions asked were too personal." Another caregiver was recruited as a replacement. However, data available from the first interview with the caregiver who dropped out were included for analysis. The difference between 31 (15 in the CI group and 16 in the PI group) and 30 totals in some of the subsequent analysis are due to this circumstance.

The demographic profile and context of the sample provide the background against which caregivers considered respite. The chapter includes: (a) comparisons of the study sample with a national sample of caregivers; (b) comparisons within the study sample of the CI group and the PI group; and (c) descriptions of the context in which caregiving took place. Data were derived from the Demographic questionnaires in Appendix G and H and the Caregiving Experience questionnaire in Appendix I. Caregiving context descriptions were supplemented with data from the open-ended interviews and from direct observations.

Throughout the report on the results, characteristics of participants and descriptions of situations are altered to the degree needed to protect the identity of individuals while at the same time being careful that the factors altered protect integrity of the data.

#### Comparison of Study Sample with National Survey

Tables 5 and 6 contain comparisons of the caregivers and the recipients respectively with the 1982 National Long Term Care Survey/Informal Caregivers Study (LTCS) as reported by Stone, Cafferata, and Sangl (1987). The national sample consisted of 1,924 caregivers determined to be representative of 2.2 million persons caring for 1.6 million disabled elders in the United States.

Because the LTCS included both primary and secondary caregivers in some parts of the analysis and this study involved only primary caregivers, these differences were noted in Tables 8 and 9. Comparing caregivers in the research sample to the LTCS (see Table 8), the caregiver research sample: was older (mean age of 68 as compared 65 in the LTCS); contained more females (94% compared to 60% in the LTCS); had more wives as caregivers (71% versus 23% in the LTCS); and had been caring for the recipient for a longer period of time (39% > 5 years compared to 20% > 5 years in the LTCS).

Table 5

Caregiver Study Sample Comparison with National Survey

		STUDY NUMBER	STUDY PERCENT	NATIONAL PERCENT
AGE	14-44	1	3%	7%
	45-64	9	29%	31%
	65 +	21	68%	59%
	(65-74)	(15)	(49%)	
	(75-84)	( 6)	(19%)	
Mean age		68		65
Range		37-83		
SEX	Male	2	6%	40%
	Female	29	94%	60%
RACE	White	24	77%	80% a
	Other	7	23%	20% a
RELATIONSHIP TO RECIPIENT				
	Husband	1	3%	13% a
	Wife	22	71%	23% a
	Daughter (d) & d-in-law	4	13%	37% a
	Other	4	13%	27% a
MARITAL STATUS				
	Married	29	94%	78%
	Widowed	1	6%	8%
	Divorced	0	-	7%
	Never Married	1	3%	7%
INCOME				
	Poor/near poor	14	45%	35%
	Middle income	13	42%	58%
	High income	0	0%	7%
	missing	4	13%	
EDUCATION				
	College degree	17	55%	
	High School > 10th grade	11	35%	
	Less than 10th	3	10%	
HEALTH OF CAREGIVER				
	Excellent	5	16%	20%
	Good	16	52%	38%
	Fair/Poor	10	32%	42%
DURATION OF CAREGIVING				
	< 1 year	1	3%	18% a
	1-4 years	18	58%	44% a
	5 + years	12	39%	20% a
	stopped providing care	-	-	18% a
	range	<1-29yrs		>1-43yrs

Note: "a" after the national percentages indicates that both primary and secondary caregivers were included. The study sample contained only primary caregivers so the comparison is not exact. National survey data from Stone, Cafferata, Sangl (1987). Caregivers frail elderly: A national profile. *Gerontologist*, 27, 616-626.

The recipient research sample differed from those in the LTCS (see Table 9) in that there was: a greater proportion of males (90% versus 60% in the LTCS); more married and less widowed; and more severely disabled (52% had 3 to 4 ADL deficits compared with 19% in the LTCS). These differences were expected in that the Veteran population is predominantly male and the criteria for admission to the two studies differed. The LTCS included persons with as little as one ADL deficit and included both primary and secondary caregivers, while this research required that the individual have at least two ADL deficits and included only primary caregivers. It was interesting to note that despite these differences, the ages of the recipients in this study were not dissimilar to those in the LTCS. One large group of caregivers not represented in this research nor identified in the LTCS is widowed daughters and their widowed mothers.

The 31 caregiver participants are described best as predominantly spouses (22) and female (29). Only two of the caregivers were not married (22 to the recipient and 7 to persons other than the recipient). Only one caregiver did not live with the recipient. There was an almost equal split between middle income and the poor/near-poor classification.

Table 6

Recipient Study Sample Comparison with National Survey

		STUDY NUMBER	STUDY PERCENT	NATIONAL PERCENT
AGE	65-74	12	39%	43% a
	75-84	11	35%	36% a
	85 +	7	23%	21% a
Mean age		77		78 a
SEX	Male	28	90%	60% a
	Female	3	10%	40% a
MARITAL STATUS				
	Married	24	78%	51% a
	Widowed	2	6%	41% a
	Divorced	2	6%	4% a
	Never Married	3	10%	3% a
INCOME				
	Poor/near poor	17	55%	33%
	Middle	12	39%	62%
	High	1	3%	5%
	Missing	1	3%	
RECIPIENT IMPAIRMENTS				
	Cognitive	15	48%	NA
	Physical	16	52%	NA
	ADL Deficits			
	0	NA		7%
	1-2	2	6%	42%
	3-4	16	52%	19%
	5-6	13	42%	32%
	Mean number	4		3

Note: "a" after the national percentages indicates that both primary and secondary caregivers were included. The study sample contained only primary caregivers so the comparison is not exact. National survey data from Stone, Cafferata, Sangl (1987). Caregivers frail elderly: A national profile. Gerontologist, 27, 616-626.

### Comparison of the CI and PI Caregiver Groups

When comparing the caregivers of the CI to the PI group within the study, few differences were found (see Table 7). Using the Mann-Whitney U-Test, there were no significant differences between the CI and PI group in age of the caregivers, gender, race, marital status, income, education, duration of care, or the relationship of caregiver to recipient. In addition, there was no significant difference in the number of recipient ADL impairments, nor the amount of time the recipient could be left alone. The only significant difference found was the mean age of the recipients (CI=73: PI=80). However, when looking at the range of ages in each of the groups (see Table 7), there are recipients represented in each age range for both CI and PI groups.

### The Caregiving Context

The context of caregiving was highly diverse as was intended by the purposive method of sampling. As can be seen in Tables 8 and 9, circumstances varied as to the nature of caregiving role, social context, physical setting, and historical circumstances. How the factors listed in the tables blend together for a single caregiver is examined in the qualitative analysis portion of this chapter. However, an overview of each aspect of the context assists in understanding the frameworks in which caregiving took place.

Table 7

Cognitively Impaired (CI) and Physically Impaired (PI) Group Comparisons

	<u>CI (n=15)</u>		<u>PI (n=16)</u>		p
	X	sd	X	sd	
Age recipient	73	8.67	80	8.61	.018*
Age caregiver	66	9.84	70	7.67	.305
Recipient Mental Status	16	10.64	27	3.27	.000*
ADL (Activities of Daily Living)	3.39	1.16	4.67	1.59	.150
Can be left alone (hours)	3.2	3.1	2.5	1.7	.784
-----					
	<u>CI</u>		<u>PI</u>		
<u>Caregiver Age Ranges</u>					
< 60	2		1		
60-69	8		8		
70-79	5		5		
80 +	0		2		
<u>Recipient Age Ranges</u>					
60-69	7		3		
70-79	5		5		
80-89	2		5		
90 +	1		3		

---

\* = significant differences with  $p < .05$

### The Nature of Caregiving

As noted in Table 8, the recipients were severely disabled. The cognitively impaired group contained the five recipients with two to three deficits and were those having the least severe dementia. They could dress, ambulate, feed themselves and use the bathroom independently but lacked judgement in hygiene and choice of clothing and no longer fulfilled many of the marital roles such as home maintenance and participation in day-to-day decision making. Their daily schedules had to be planned and directed by their caregivers. Three had physical conditions other than the dementia that caused concern (two had Parkinson's, and one, severe diabetes). Only three of the fifteen cognitively impaired could communicate sufficiently to be understood by persons other than the caregiver.

The primary diagnoses of the fifteen recipients in the physically impaired group were eight with cerebral vascular accidents (CVA), two with chronic obstructive pulmonary disease (COPD), two with arthritis, one with heart failure, one with Parkinson's, and one with cancer. All of these persons could communicate well, although for two, there were times when speech became difficult. As specified in the selection criteria, none of the physically impaired could ambulate independently.

All of the caregivers were the primary persons responsible for the recipient's care. Of the two who hired help for eight hours a day, one worked full time and the other was the only caregiver who did not live with the recipient. Two caregivers took the recipients with them if they left the house and never left the recipient alone in the house.

Table 8

The Nature of Caregiving and the Social Context (n=30)

NATURE OF CAREGIVING			SOCIAL CONTEXT		
1. Receiver's Assistance Needs			1. Other Responsibilities		
	n	%		n	%
ADLs*			Cares for Other		
2-3.....	5	17%	Frail Elders....	15	50%
4-5.....	15	50%	Has Children @ Home	5	17%
6-7.....	10	33%	Employed.....	6	20%
2. Caregiving Role			2. Assistance From Others		
	n	%		n	%
Assumes all of care	28	93%	<u>Kin</u> - at least 2		
Has daily assistance	2	7%	hours weekly	15	50%
			- <2 hours/week	5	17%
			- no help.....	10	33%
3. Amount of Time Receiver Can be Left Alone			<u>Neighbors</u>		
	n	%			
<1 - 1 hour.....	12	40%	- some help....	6	20%
2 hours.....	7	23%	- no help.....	24	80%
3 - 4 hours.....	8	27%			
>4 hours.....	3	10%	<u>Paid or Volunteers</u>		
			- 8 hours/day..	2	7%
5. Amount of Time/Week Caregiver Away From Recipient			- 4 hours/day..	1	3%
	n	%	- 2 hours/day..	1	3%
3 hours.....	11	37%	- no paid help.	16	53%
4 hours.....	10	33%			
5 hours.....	6	20%			
>5 hours.....	3	10%			

---

\*ADL = Activities of Daily Living (bathing, dressing, eating, toileting, continence, transferring, ambulating).

---

These two recipients had the severest cognitive impairment of the group. The recipients would be left in the car briefly while the caregiver made quick trips into the store. Half of the caregivers could leave the recipient alone for two hours or less. Usually these times were chosen very carefully to coincide with times of the day that the recipient was either sleeping or was least likely to cause problems.

In answer to the question "On the average, how many hours a week do you spend away from the caregiver?" the total amounts were usually broken into several short times away (see Table 8). These included times that the recipient was left alone as well as times when others were present to "keep an eye out". Rarely was the time away for any reason other than necessary shopping or taking care of business. Of the three who had more than five hours away, all but one had someone else stay with the recipient.

#### Social Context

Many caregivers had major responsibilities for the care of others in addition to the recipient (see Table 8). Of the fifteen who were caring for other elderly persons, four of the other persons receiving care (two parents, one husband, and one sister) resided in the caregiver's home in addition to the recipient. The other eleven caregivers had responsibility for another older adult who was living in another residence. Of these, six had at least weekly caregiving responsibilities for the other older family member. Six caregivers were employed, two full-time and four part-time. For twelve spouse caregivers, caring for the recipient was their sole responsibility.

"Assistance From Others" in Table 8 is divided into kin, neighbor, and paid or volunteer assistance. All of the assistance refers to that provided by kin in the home. Two hours per week was the most common amount of time provided. However, the inconsistency and variability of that time differed markedly. Common types of assistance provided by kin included running errands, transportation, house maintenance, shopping,

and yard care. Provision of respite was not as common and assistance with personal care of the recipient was provided by kin only two times (once each for two different caregivers) over a year's period of time.

As noted in Table 8, the types of assistance provided by neighbors consisted of watching the house, transportation and, in two cases, respite. The paid help of eight hours a day was for the two caregivers who worked full time (one of whom did not live with the recipient). The four hours of assistance was with a bath once a week. The two hours a week was for a chore worker to stay while the caregiver went shopping.

#### The Physical Setting

Table 9 contains the types of physical settings and historical context in which caregiving took place. In this study, urban was defined as a city with a population of greater than 50,000. The urban area in this study was the city of Seattle, Washington. The rural areas were in surrounding towns outside of the suburban areas of Seattle. In the urban areas, despite long lengths of residence (mean of 17 years), only four out of twenty considered their neighbors as friends. Frequently the neighborhood had changed over time, and friends in the vicinity had moved.

In the rural setting two out of the ten caregivers had several children and their families as neighbors, and two others considered neighbors as close friends. The remaining six rural residents did not classify neighbors as friends. Of all the thirty caregivers, only six counted neighbors as friends.

Table 9

Physical Setting and Historical Context of Caregiving (n=30)

PHYSICAL SETTING				HISTORICAL CONTEXT			
1. Location				1. Past History of Providing Care to Elders			
	n	%			n	%	
Urban.....	20	67%		Never.....	14	47%	
Rural.....	10	33%		One time.....	11	37%	
				More than once...	5	17%	
2. Type of Dwelling				2. Length of Time Lived in the Same Place			
	n	%		Range .....	0 - 41 years		
Single house.....	24	80%		Mean time.....	17 years		
Mobile unit.....	3	10%					
Apartment.....	3	10%					
3. Living Arrangement				3. Effect of caregiving on employment			
	n	%			n	%	
Lives with R* only...	18	60%		0 - 5 years.....	8	27%	
Lives with R and others..	11	37%		6 - 10 years.....	5	17%	
Does not live with R.....	1	3%		11 - 20 years.....	4	13%	
				> 20 years.....	13	43%	
4. Kin Proximity							
	n	%		Quit work.....	9	30%	
Lives with kin (other than R)..	12	40%		Reduced time.....	3	10%	
Kin in Town....	10	33%		No Reduced time.....	2	7%	
Kin not in Town	8	27%		Increased time.....	1	3%	
				Were not working.....	15	50%	

---

"R" = recipient of care. All percentages are rounded to the nearest whole number.

---

The type of housing varied a great deal. Of the single dwellings, six were over 2,000 square feet and were in good repair. Eight were between 1,000 and 1,900 square feet and ten were less than 1,000 square feet; half of these were in very poor repair. The mobile unit and apartments were less than 1,000 square feet. The larger sized dwellings added to the caregiver's work while smaller residences made it hard for the caregiver to find space away from the recipient when needed.

The living arrangements of caregivers and kin proximity were important factors in consideration of whether persons were immediately available if respite was needed.

#### Historical Context

Factors selected for the historical context were: (a) the ability to give care (such as past experience); (b) the knowledge of resources in the immediate setting (e.g. length of time in the same residence); the way in which caregiving affected the caregiver's income (e.g. employment); and how the caregiving relationship developed.

"Past Experiences of Providing Care to Elders" in the family (Table 9) included 16 parents or parents-in-law, three sisters, two aunts, and a grandparent as the recipients of past care. Four caregivers also had cared for disabled adult children for extended periods of time. Only those experiences of having cared for another elderly relative were included under "Past History of Providing Care to Elders".

Of persons who were working at the time caregiving began, 40% had either quit or reduced their working time because of caregiving responsibilities. One caregiver had taken early retirement at age 52 which resulted in a reduction of \$200 per month in retirement benefits, a fact that was lamented because of the reduced ability to pay for assistance or to put away for her own future needs. However, one caregiver went to work ("to maintain my sanity") after her husband became severely cognitively impaired. The type of work she did paid only a small fraction over what was necessary to hire someone to be with the recipient in her absence.

The manner in which the caregiving role developed for spouses was in all instances a result of having been married to the person. Illness occurred and the spouse assumed the role as part of the marital responsibilities. Of the eight caregivers who were not spouses, six had brought the recipient to their homes from a long distance away. They had been providing care at long distances prior to that time with several long trips to the recipients home over a period of years. Often periods of six weeks to six months at a time were spent in the recipient's distant home trying to find services so the recipient could stay in his own residence. Finally, when trips became too frequent or too expensive, the recipient was moved into the caregiver's home. Three of these caregivers still had the recipient's home to sell at the distant location. Of the two remaining situations, one recipient lived in the same town and came to stay after a brief hospitalization for a medical illness; subsequently he developed cognitive impairment and never returned to his own residence. The other grew out of a voluntary relationship in providing assistance, which developed into the relationship of primary caregiver for managing the recipient's care.

This summary of the demographics, characteristics, and context of caregiving provides only a small window to understanding the larger number of factors that influenced the caregiver's choices concerning respite. The relevance of the data just reviewed becomes more apparent when reading the subsequent analysis of the qualitative data.

## CHAPTER V: RESULTS OF THE QUALITATIVE ANALYSIS

Analysis of the qualitative data is presented in three parts. The first is an explanation of the process and phases of developing the core category and themes. The second part contains the salient portion of the results. Core categories and themes are described with illustrations of the ways in which they interact to generate grounded theory. The final section contains the methods of quantifying the qualitative data and the methods used to ensure validity and reliability of the findings. The strength of the theory and conditions under which the theory is applicable are discussed.

### Processes and Phases of Grounded Theory Development

In analyzing the data, the primary focus was on the caregiver's perspective of interactions related to respite. In the first round of interviews, however, limiting the interview questions only to interactional processes would have been confusing to the participant because it was not immediately apparent how much information was needed to draw relevant interpretations. Caregivers talked about why they did or did not feel the need for respite, their usual patterns of dealing with stress, and situations outside of caregiving responsibilities that affected their lives. Philosophical positions of the caregivers about their lives as a whole, about the history and future of their family relationships, and viewpoints about the ways in which the larger health care system worked or did not work for them became integral parts of the interviews as each caregiver sought to answer the questions about leaving the recipient in the care of another person. As interviews

progressed from the first through the thirtieth participant, the interviewer was able to aid caregivers in discussing experiences that were most relevant to respite-related interactions compared to experiences that were tangential.

The second interview was conducted only after a thorough analysis of the first interview with that participant. Questions were asked to clarify elements of the first interview and to ascertain how respite was either rejected or accepted in any given set of circumstances. This process led to a clearer delineation of the type of information needed for adequate understanding of the factors influencing respite. To limit the discussion, the interviewer viewed attitudes toward caregiving as "micro" issues. Thus attitudes were explored with caregivers only when caregivers described how their attitudes affected interactions with others about respite. Discussions of larger concerns, such as the organization of the health care system or other past or present experiences outside of caregiving, the interviewer viewed as "macro" issues. Macro issues were given limited attention in the analysis unless the caregiver emphasized them as directly related to a particular respite consideration. The central issues were the ways in which the recipient, caregiver, and helpers influenced one another as to how or if respite was utilized.

The purpose of the research was to discover the factors that inhibited or facilitated the use of respite. This question became focused further in the discovery that there were two dimensions to the question. One dimension centered on personally oriented answers to questions in which caregivers reflected about whether or not they felt

the need for respite. The other dimension pertained to reflections that occurred when caregivers clearly felt the need for respite and were thinking about whether or not they would seek or accept respite. In the analysis, less attention was given to whether or not the caregiver felt the need for respite and more attention was given to situations in which the caregiver tried to obtain respite. It was recognized that the former was important; however, a conscious choice was made to limit the research to situations in which the caregiver tried to obtain respite because the considerations caregivers voiced about feeling a need for respite were more personalized and had less to do with the interactions between people. However, when such considerations were tied directly to interactions around trying to obtain respite, they were included in the analysis.

Throughout the study, segments of the interviews and memos subjected to intensive analysis were: (a) descriptions of how respite came about or was decided against; (b) changes in factors influencing respite over the six months preceding the study and the six months encompassing the time of the interviews; (c) factors that facilitated or inhibited the use of respite; and (d) differences between a, b, and c among CI and PI groups.

Developing the grounded theory approximated Strauss' (1988) description of the three phases of open coding, axial coding, and selective coding. The first phase involved coding small segments of data and defining the codes. In the second phase, codes were combined into larger categories. Axial coding of the major categories involved describing the conditions, interactions, strategies, and consequences

attendant to each of the major categories. In the third phase (selective coding), theoretical sampling was used to saturate the major categories. The result of this phase was derivation of the core category, the three central themes, and explanations of the relationships among them.

The subsequent discussion describes each of the phases more fully. To facilitate identification of the persons involved and types of respite settings, the following abbreviations are used occasionally throughout the discussion:

C = Caregiver (the primary caregiver)  
 R = Recipient (the recipient of care)  
 H = Helper (any source of respite)  
 CI = Cognitively Impaired  
 PI = Physically Impaired  
 RIH = Respite-in-home (R cared for at home)  
 ROH = Respite-out-of-home (R cared for other than at own home.)

Because there were only two male caregivers and two female recipients, caregivers are referred to as she and recipients as he unless otherwise noted.

#### Phase I: The Open Coding Process

Interviews were transcribed, line numbered, and hand coded (see Appendix Q). Early in the coding process it was recognized that there were three ways in which a single segment of data needed to be coded. If a caregiver was talking about a reason for using or not using a particular source of respite, the reason was coded, the type of helper (informal or formal), and the setting for the recipient (RIH or ROH).

Interview Segment	Codes
The <u>times</u> I want to go to my Garden Club is not the time she (H) can come to be with him (R).	Timing Informal (Kin) ROH

The method of organization of codes initially was alphabetical because so many were generated. The next step was grouping these codes into organizing factors such as health factors, strategies for asking helpers, and environmental factors. Each new code name was written on the interview transcript and a four by six card also was made to record the name of the code, the date, the segment of data in which it was identified, and a definition. In addition, notes were made that tied codes to one another or aided the researcher in grouping them into larger categories (see Appendix M). The code cards first were arranged alphabetically and then rearranged into larger categories as the analysis progressed.

Memos were made throughout the coding process at any time a relevant thought occurred. The three types of memos have been described previously. Examples of the three types are found in Appendix P. Some of the questions memos addressed at this phase were: How do each of the codes relate to one another? In which interactions are they important? Does one interactional process precede another? How much context does this code need to make sense? This phase came to an end when a limited number of categories were identified under which most of the codes could be subsumed.

#### Phase II: Development of the Major Categories

The beginning of the second phase was marked by the organization of the codes into eight major categories (see Table 10). Five of the categories (knowing, imposing, only if necessary, timing, and easier not to) were taken from the original words used by the caregivers to describe their thoughts about leaving the recipient with someone else.

Table 10

Major Category Definitions at the End of Phase II

<u>Category</u>	<u>Definition</u>	<u>Examples</u>
Knowing -	The caregiver's (C) integration of past and present experiences with the recipient (R) that are used in providing effective care that works best for both C and R.	Daily routines Ways to talk to R to gain cooperation. Personal care.
Imposing -	Conditions that C describes when speaking about a particular respite source (H) that relate to not wanting to be an inconvenience to someone else or not wanting them to interfere with the way in which she (C) gives care.	Hs had their own problems.  Things done by H in the past that were bothersome to C.
Only if Necessary -	Reasons C cites that she would leave R with someone else.	Only in an emergency. If C got sick.
Matching - (Noticing)	Observations of how R and H get along when together and the comfort of each while they are together; behaviors and conversations about one another after being together.	H looks upset by things that R says or does. R resist H's care.
Environment -	Physical features of the environment that C cites as presenting problems or making it easy to acquire respite.	Distance from H. House too small.
Strategies -	Things either C, R, or H does to initiate or respond to opportunities for respite.	Directly asks H. Accepts an offer. Rejects an offer.
Timing -	Any type of situation in which C mentions that time or timing is a consideration in the use of respite.	How much time can leave H alone. If H is available at time C needs.
Easier not to -	What C cites as alleviating or creating difficulties in the process of obtaining respite.	Too much planning required. Takes too much energy to get R ready to go.

---

C=Caregiver: R=Recipient: H=Helper (source of respite).

Relationships among the categories were not yet clear nor how they might be used in a coherent theory. Category definitions were still quite superficial.

At this point the eight categories were entered on the ethnograph computer program as well as codes for identifying the type of helper and setting of caregiving (see Appendix Q). This procedure placed together all segments of interviews in which a given category or code occurred and for beginning the axial coding. Axial coding proceeded by using the segment of coding, a descriptive profile of C and R, and (when necessary) the entire interview to specify the conditions, interactions, strategies, and consequences relevant to the category. It was during this process that it became clear that three of the codes were most salient to interactions between only two of the actors (C-R, C-H, or R-H). The code *knowing* was relevant to interactions occurring between C and R; *imposing* was the key theme of interactions between C and H; and *matching* related to observations C made about interactions between R and H.

At this time in the analysis the third round of interviews was about to begin. Because the eight categories all seemed important, an instrument was developed to use in the third round to validate seven of the eight categories with caregivers and to serve as a method of theoretical sampling (see Appendix D). Caregivers were asked to rate six of the eight categories (*knowing*, *imposing*, *only if necessary*, *matching*, *timing*, and *easier not to*) as to how true it was for them on a 5 point scale (1 being "not true for me" and 5 being "true for me"). The seventh category (*environment*) was divided into "respite-in-home"

and "respite out-of-home" and the caregiver was asked to state her preference. The eighth category *strategy* was validated by the interviewer clarifying the caregiver's reasons for choosing certain strategies in specific situations.

After the caregiver rated the scale, she was asked if she had a better word for the category and the reasons she rated the scale as she did. When the caregiver indicated her preference for RIH or ROH as a setting, the caregiver was asked about reasons for her choice. The process of questioning led to accumulation of very dense data about each of the eight categories and saturation of the categories (discovery of no new data) was achieved.

#### Phase III: Selective Coding

The validation of categories and axial coding aided the researcher in relating the categories to one another in determining their influence on utilizing sources of respite. The *only if necessary* category was subsumed under the *imposing* category when it became clear that it was one of the conditions under which it was all right to impose on someone to stay with the recipient. The categories of *environment*, *timing*, and *strategies* were re-examined and each segment of interview was coded under one of these categories and reassigned to one of the major themes (knowing, imposing, or matching) based on which interaction (C-R, C-H, or R-H) was being affected. *Environment* fit well as one of the conditions of each major theme. *Timing* was interwoven with the interactions, strategies, and consequences of each theme. *Strategies* were integrated with each of the themes as the intentional

interactions to acquire or reject respite. The exact way in which the integration was achieved becomes clearer in the subsequent discussion of each major theme.

The *easier not to* category was the last to be analyzed as to its fit with the other components. It could not be separated as easily into one or the other of the themes. When axial coding was done, it was found that most often the situation involved interactions among more than just C and R, C and H, or R and H. It became apparent that the caregiver was weighing all of the interactions in the process of making a decision and "easier not to" or "it was easy" constituted the extremes of a continuum on which use of respite was decided.

On further examination the ease of obtaining respite was only a part of what was being weighed by the caregiver. Sometimes it was not easy to obtain respite, but other considerations outweighed the difficulties and the caregiver persisted until respite was acquired. The term conservation then was chosen as a concept that best represented the components of caregivers' decisions about respite. Convenience or ease was a major part but, even more important, was the consideration given to maintaining and protecting the energies and resources of those currently involved as well as of persons who might provide respite in the future.

Conservation then became the core category that unified the three themes and allowed for theoretical relationships to be developed. This process from initial coding of minute segments to major themes and core category was tedious but exciting. When things did not fit, the researcher could feel the tension among conflicting components and

ideas. When ideas seemed to fall into place, it was highly exhilarating. The final identification of the core category was tested and retested with each of the major themes and interviews being reexamined to gain assurance that the core category fit various caregiving situations. Validation of the core category and major themes with outside sources also was done during this phase and is presented in the section on validity and reliability.

A final analysis of all situations in which respite was considered was completed by again using the axial coding method. This approach was especially helpful in determining whether "conservation of energy and resources" was the underlying consideration given to respite choices. The resulting grounded theory and an explanation of its component parts are presented next using examples from the interviews to capture the flavor and feeling tones of caregivers as they talked about caregiving and respite considerations.

#### Grounded Theory: Processes in Utilizing Respite (PUR)

In Figure 1 the grounded theory of Processes in Utilizing Respite (PUR) shows the arrows between the actors (C, R, & H) pointing both ways to indicate that the three major themes (knowing, imposing, and matching) are considered two-way processes in which both participants interact. Conservation is presented in the figure as the final screen through which the caregiver (by means of the knowing, imposing, and matching processes) determines whether respite should or should not be accessed.

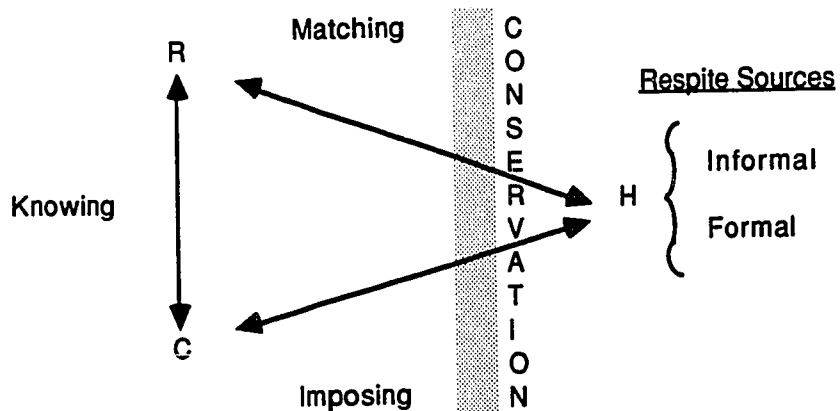


Figure 1: Processes in Utilizing Respite. C = caregiver, R = recipient, H = helper (source of respite).

In the following section, conservation is described first and again after knowing, imposing, and matching are considered separately. The initial description of conservation is used to provide the background against which each of the themes is played. Conservation in the concluding discussion is used to integrate the themes and propose theoretical relationships among them.

#### Conservation of Energy and Resources

Conservation is defined in Webster's dictionary (1973) by the phrases "careful preservation and protection to prevent exploitation and destruction"; "to keep in a safe and sound state and avoid wasteful or destructive use of resources"; and "to remain constant during a process of change" (p.241). These phrases clearly describe the ways in which caregivers thought about the pros and cons of respite. Caregivers were acutely aware of their own limited energy and of their need to conserve

as much as possible for caregiving tasks. Recipients of care were viewed by caregivers as frail or vulnerable and in need of protection in order to maintain their physical and emotional health or to minimize confusion. When respite was considered, the caregiver talked about the energy it took regarding:

- (a) anticipation of the feelings and actions involved (e.g. feelings about independence and privacy, how to get R ready, and deciding on the best time leave R alone);
- (b) actions needed prior to leaving R, such as getting R physically ready, and obtaining cooperation from both R and H about the time and place for respite.
- (c) worry and concerns about R and H in her absence.
- (d) dealing with the consequences of leaving R (e.g. difficulty getting R back on schedule or putting up with R's or H's adverse reactions to what went on in her absence); and
- (e) worry about depleting H resources that might be needed at a future date (e.g. money for paid help, having a friend or relative quit visiting to avoid being asked to stay with R).

As noted in the preceding list, conservation of resources included protecting the physical and emotional energy of self and others, maintaining relationships with informal and formal helpers, and using financial resources sparingly that might be needed even more at a future date. The following example from one caregiver illustrates several of these components:

I would really like to go out to lunch with my friends but first I have to argue with Frank (R) about needing to go and then call around to see who will stay with him. Then I worry about him and whether he's giving my son (H) a bad time all the time I'm gone. After I get back I have to put up with him (R) asking me a hundred times why I didn't take him with me. It's just not worth it. It's easier just to stay home.

Conservation is the essential thread that ties together the before, during, and after concern of leaving the recipient with someone else as well as the core that ties the themes together.

In the next sections, knowing, imposing, and matching are described from the point of view of the caregiver as she reflects on her own and the other participants' parts in the interactions. Each theme is defined and described first. The facilitating and inhibiting factors are presented next and include elements that caregivers anticipate in deciding about respite (conditions and interactions), actions they perform to acquire respite (strategies), and the results of having taken time for respite (consequences). The final portion of the discussion of each theme contains a summary of similarities and differences among CI and PI groups.

#### Knowing: The Central Theme of C-R Interactions

*Knowing is the caregiver's perception, valuing, and use of shared past and ongoing experiences with the recipient as the basis for how she provides care.*

The caregiver's perceptions of past experiences aided her in being able to provide physical care for the recipient and interact in ways that enhanced his cooperation in performing daily routines. The valuing was the importance the caregiver attached to her own way of doing things because of her commitment to the recipient. These ways of doing things were highly specific to each C-R partnership and were considered crucial to having a day go smoothly compared to one that required a great deal of energy expenditure on the part of both recipient and caregiver.

Identification of knowing as the central theme of interactions between the caregiver and recipient was a result of the almost universal initial response of caregivers when asked to describe the last time the recipient stayed with someone else so they could get away. Instead of beginning by describing a particular situation or experience with respite, caregivers began by describing what they had to do for the recipient and how the recipient reacted to their leaving. At first it appeared that caregivers were not attending to the question, but it soon became apparent that they were attempting to explain their reluctance to leave the recipient with anyone who would not be able to understand and interact in the same way as they.

The sentiments and importance of knowing were expressed clearly by these four caregivers:

He can't have anyone else caring for him. Not as close as me. They don't know him.

I think you have to be with people a long time to kind of know what they like and don't like. I mean - like I can always anticipate when he has to have a BM... He wouldn't tell a person I know. I know what food he likes..

He hates loud noises. If I speak quietly and slowly he doesn't get upset. Once he gets upset he's hard to quiet down.

I don't want to go (for respite) because I don't like to leave him. I think he's more secure with me.

#### Factors Facilitating and Inhibiting Respite in C-R Interactions

As can be noted in the illustrations just cited, caregivers were aware of their own discomfort as well as that of the recipient when leaving him with someone else. Therefore the caregiver's knowledge of

the conditions, interactions, strategies, and consequences related to respite reflected how respite would affect the way each felt and acted in relationship to one another.

C-R conditions and interactions. In anticipating whether or not she should consider respite, the caregiver reflected on what she knew about her own and the recipient's health, their daily life preferences, and their physical environment. In addition, she thought about interactions with the recipient about staying with someone else and what she would need to do in preparation that would make it easiest on the recipient and herself.

The caregiver's knowledge of her own health and abilities often precluded her being away from home without assistance for herself as well as for the recipient. Ten caregivers had either chronic or periodic health problems that limited their energy and abilities to spend time away from home. Three caregivers had poor vision (one was legally blind); three had arthritis; and one became easily fatigued or dizzy. Additionally, during the six months in which interviews occurred, three caregivers had surgeries; one caregiver was in a major auto accident; one caregiver was beaten and robbed; and one caregiver had a severe attack of gouty arthritis.

Caregivers managed their own health and energy by developing daily or weekly routines to sustain them. Many talked about quiet times in the morning before the recipient awoke or evening telephone conversations with a close friend. Thus the way in which the caregiver had learned to care for herself was part of the way she structured the times and activities of caregiving.

Knowledge of the recipient's health, functional abilities, communication patterns, preferences for interaction with others, and reactions to a variety of environmental settings were the conditions that caregivers considered carefully in judging as to whether another person could be trusted or able to provide adequate care. Knowing the severity and variability of the recipient's physical condition allowed the caregiver to know what the recipient could and would do for himself and what she needed to do for him. Some things were done because the recipient could not do them for himself. Other things were done for the recipient because the caregiver had learned that to insist that the recipient do them was more difficult than to do them herself. Patterns of care had developed as the caregiver learned the recipient's preferences and abilities. Through experience she had learned to anticipate what needed to be done so that both she and he felt the least tension and stress in the caregiving process and so she had time to herself that would not be disrupted by the recipient's requests, anger, or agitation. The "anticipation of needs" was an important component of the knowing, which the caregiver felt was essential to maintaining the morale of the recipient so he did not feel a burden to her.

The two examples that follow illustrate the intricate detail that was involved in the knowing process.

[C says of her husband (R) who has severe Parkinson's]... he likes to eat at a certain time and he doesn't want too much milk in his glass or too much food on his plate. He likes a certain bowl for this and that.... he likes to be home. He does the same things everyday, watches the same programs. He wouldn't like me taking him somewhere else to be looked after... not few hours or half a day... he wouldn't like it. I know that. I think he would rather try to be alone than have me bring somebody in....

[C says of her husband who has a cognitive impairment]....  
...he gets up at the same time every morning and I do the same thing. I help him get dressed and I take him in the bathroom.... I say here's your comb and he combs his hair. I'll say drop your pants and then he knows he should go to the bathroom. Then he's ready for breakfast. Then he'll say - I'll make the coffee and he does - that's one thing he can still do and it makes him feel good. Then he goes out for a little walk. We've lived here 26 years so he doesn't get lost. He just goes down to the end of the block and comes right back. It's the same thing everyday... and this is what I think keeps things going smoothly. And if you changed anything it would really mess him up...It's a lot of little steps. If I go anywhere, I go in the morning and take him with me.

By anticipating the recipient's needs or modifying the way she responded to him, future problems or adverse reactions could be avoided. When thinking about the "knowing" in relationship to leaving the recipient in the care of someone else, it became problematic as to whether it would be more difficult to leave the recipient or to translate what was needed to a helper. In addition, the caregiver had to weigh her own comfort level in leaving the recipient and to determine whether she would worry too much while she was not with the recipient based on his current behavior patterns and her own daily strength.

Patterns of care frequently changed from day-to-day or over short periods of time so that decisions about leaving the recipient alone or with someone else had to be made on a daily basis rather than planned in advance. Often leaving the recipient alone carried less of a risk than the amount of effort needed to arrange care. The caregiver had an acute sense of how long she could leave the recipient alone safely, at what

time of day his being alone carried the least risk, if she could trust him not to do something unsafe, and under which conditions she could take him with her.

Another part of knowing was the awareness of the caregiver's own reactions to the recipient and the interdependence of her own feelings with how well he was responding to the care she provided. This was reflected in the caregiver's responses to the question "what are the best things about caring for R?". The most common answers were "knowing I'm doing a good job" or "when he's happy, I'm happy" or:

the best part is when I go to bed at night and I've had a day that I haven't gotten angry with him or said anything that hurt him or made him feel bad... and I can go to bed and not have that on my conscience.

These caregivers were talking about conserving a relationship they cared about and the knowing how to do it was very important to their own sense of importance. If respite circumstances interfered with their sense of doing a good job or resulted in increasing the recipient's stress, then respite was usually foregone.

For most caregivers the amount of structure needed in daily routines, the importance of anticipating the recipient's needs, and his preference for being at home with her as the sole caregiver served as strong inhibitions to using respite. However, the most common reasons caregivers wanted respite were for additional rest and getting housework done. Both of these reasons meant that the recipient needed to be out of the house, and in all but three of the thirty situations, the caregiver knew from past experience that the recipient was either resistive to going out or became confused in unfamiliar settings.

Instances were rare in which the caregivers' knowledge of themselves and the recipient interacted to facilitate respite use. Optimal conditions were those in which the caregiver was feeling good, could easily get out by herself, and the recipient willingly went to a respite setting outside the home. Two caregivers, however, used respite despite the less than optimal conditions. Both considered it important to their own health. One used the time the recipient was at the adult day center for rest from the fatigue of having to be watchful constantly. The other caregiver worked full time and hired help while she was at work. She explained she needed to work "for my own sanity". The recipient in this case, despite severe cognitive impairments and an inability to hold a conversation, was not agitated easily by unfamiliar people or settings.

R-C strategies and consequences. When a caregiver decided that respite was appropriate, approaches to the recipient about arrangements were tailored to the way in which the caregiver thought the recipient would respond. These approaches were continuously in flux based on the recipients latest reactions to her leaving. Several caregivers said they would mention to the recipient that they wanted to go somewhere or needed a rest and then would wait to see how he reacted. If there was an argument about it or his confusion increased, respite as a possibility usually was dropped and no further steps were taken.

One caregiver said she told the recipient two days in advance of when she intended to be gone and then reminded him several times each day. She had learned if she did that he did not spend hours asking her why she had not taken him with her after she returned. Another

caregiver said she told the recipient just before leaving or else he repeatedly asked about when she was leaving and got very agitated.

Most often when the caregiver arranged for RIH, she would plan to be gone for short periods at times when the recipient needed the least care so there would be little interaction between R and H. Meals and toileting were particular concerns. If the caregiver had to leave the recipient during a meal time, before she left she would set everything out just the way he liked it. If she was concerned about him being embarrassed by the personal care involved in toileting, she would be sure he went to the bathroom prior to her leaving and tried to return prior to when he might need to use the toilet again. These strategies minimized the resistance of the recipient to the caregiver's leaving and reduced the possibility of problems on her return. Another frequent concern was trying to conceal from the recipient the fact that he needed someone to care for him or be there in her absence. Most recipients who could communicate well would insist they be left at home alone. They were very vocal and highly resistant to others caring for them. For the caregivers who had other family members living with them who could be there and who knew the recipient well, leaving was less problematic. Yet again, being away was timed so there would be little interaction of R with H so the recipient would be unaware that the caregiver left only when someone else was there.

For ROH there was usually more resistance by the recipient than for RIH. Two caregivers who used adult day care for the longest period felt they had to trick the recipient into going. To get one recipient (who was female) to go the caregiver told the recipient, "you are going

to help care for some people at a senior center." The recipient's confusion was such that this was accepted as an explanation. The other (also cognitively impaired) thought he was going to work, and the caregiver did not correct his misperception. In three situations in which in-patient respite was acquired, the caregiver asked the recipient if it was all right for her to go and he agreed; but in two of these cases the recipient was angry enough to berate the caregiver for weeks after about having left him, and both caregivers said they would not use the in-patient setting for respite a second time.

#### CI and PI Similarities and Differences in C-R Interactions

Knowing, the major theme of C-R interactions, was the important theme of the interviews with caregivers about the recipient. Factors particular to the C-R partnerships that facilitated or inhibited use of respite varied considerably based on the particular conditions and interactions of each situation. Difficulties in gaining the recipient's cooperation in using respite and the aftermath of respite on C-R interactions more often inhibited the use of respite than facilitated it. Protecting and maintaining the recipient's care in the way the caregiver knew he liked it to be done was paramount. These broad similarities were true for both the CI and PI groups. However, the particular types of activities required were quite different.

For the recipients in the CI group, understanding communication, being able to gain cooperation, and calming agitation were the main aspects of care that caregivers felt they knew best and would be

difficult for others to duplicate. The following examples of caregivers talking about recipients illustrate the knowing aspect regarding communication for the CI group:

He has a problem of getting the right word out and he will say something that happened yesterday or the day before or what's coming up... and just the way he says it you know... and I can tell what he's talking about...

.....she (R) has all kinds of strange names for things that aren't even close. I can translate...even when it's completely out of context just because I know her.

...he (R) can't say it plain, but when your with him all the time you know their grunts, their motions and their whatever....

... and bowel movements. Of course he can't tell anyone but I've been around him so long I kind of know so I can get him to go to the commode - keep him from soiling himself.

Preventing agitation required knowing how to respond to these garbled communications or taking action in a situation that the caregiver knew was upsetting the recipient such as helping him dress when he was having difficulty. Calming agitation required knowing the reasons for agitation and the actions to take once agitation occurred. One caregiver reported that the three-month check up required by the doctor for the recipient was the worst event of all. She stated that the recipient could not tolerate being asked questions. The result was that it took two weeks after these visits for the recipient to be calm enough so she could get him to put his arm in his shirt to get dressed.

One of the most common actions taken to reduce agitation was taking the recipient for a ride in the car. Others mentioned fixing the recipient something he liked to eat, or just ignoring the agitation.

Still others found that a simple direct statement was needed before the recipient "settled down". One said she asked the recipient to "just sit down". She had observed that if she said this to him, he would walk around inside the house in a big circle about three times and then sit down rather than just keep getting more and more excited. The exact phrase that worked differed for each recipient. The phrases used had been discovered by a long process of trial and error. Some examples of phrases used were "don't do that it's not good for you" or "just straighten up and behave yourself." It was not just what was said but the way it was said that was important. For some they stressed that talking quietly, calmly, and slowly was important, while others stressed that you had to be firm and repeat a phrase loudly several times before the recipient responded.

Caregivers in the CI group frequently felt that the way they interacted with the recipient was not easily transferable to others, because there were so many unique ways of managing the recipient's behavior. These had been built up over a long period of knowing the recipient and were important for not increasing his stress and thereby making care difficult.

For caregivers in the PI group, the types of knowing had more to do with physical care routines and anticipating recipient's needs so he would not have to make requests of her. For recipients with physical impairments, knowing meant that the caregiver was able to assist them with activities of daily living in ways they preferred. Recipients were

able to tell the caregiver exactly what they wanted and were vocal about having things done the way they liked or the environment arranged in ways that were most helpful to them. The caregivers in this study were very familiar with the recipients' habits because they had cared for them a long time and could anticipate what was wanted. They knew how to hide from the recipient the amount of care provided by simply arranging the environment so he could do things for himself or by meeting his needs without being asked. Caregivers said that these abilities contributed to the recipient's sense of well being by preventing him from feeling a burden to the caregiver. Having a helper come or taking the recipient out to be cared for was viewed as making the recipient more aware of his inadequacies which usually resulted in strained feelings between the caregiver and the recipient when the caregiver returned.

Neither the CI or PI groups seemed any more willing to turn the care over to others except for short periods when caretaking activities were minimal. The CI talked longer and more adamantly about the difficulties in leaving the recipient. The similarities and differences are summarized in Table 11. In reviewing the table it is striking that factors that facilitated respite were those that also made caregiving easier, while factors that inhibited respite were most often those that made caregiving more difficult and thus created a greater desire for respite.

Table 11

Knowing: Facilitating and Inhibiting Factors for Respite

	Facilitating Factors	Inhibiting Factors
	<u>Recipient (R) Factors</u>	<u>Recipient (R) Factors</u>
Cognitively Impaired (CI)	Able to communicate Does not wander Is not confused by strangers Early morning or mid day better Uses "tricking" R to get him to respite	Unable to communicate Hard to control wandering Confused by strangers Evening the worst time R's bizarre or socially unacceptable behaviors Agitated behavior after hard to get back on schedule.
Physically Impaired (PI)	Requires physical care that takes minimal assistance Physical care times can be adjusted without adverse affects Physical health status stable	Complex care tasks (oxygen, insulin) Physical care requires a rigid daily schedule to maintain stability Physical health status unstable Appears unhappy or verbally berates caregiver after a respite episode.
	C's health is stable C enjoys socializing C feels she needs to get out for her own health	C is easily fatigued C prefers privacy C feels she does not need time away
Both CI & PI	R accepts strangers R encourages C to get out R accepts that he cannot be left alone	R is upset by having others provide care R does not want C to leave R believes he can care for himself

---

C=Caregiver: R=Recipient: H=Helper (source of respite).

### Imposing: The Central Theme of C-H Interactions

*Imposing is the sense the caregiver has of boundaries between herself and sources of respite. Intrusion of helpers on caregiver's routines or privacy results in caregivers feeling imposed upon by helpers. Caregivers in turn consider that asking or accepting assistance from others is an imposition to helpers whenever it disrupts the helpers usual commitments or routines.*

Imposing carried with it a sense of boundaries between self and others. Boundaries were more or less rigid depending on the type of helper being considered for respite. Kin relationship to the caregiver, friends, neighbors, informal organizations, paid help, and agencies were differentiated in caregivers' conversations about what types of assistance were warranted and whether they might provide respite. The caregiver's expectations of each type of helper formed the conditions and interactions between caregiver and helper. The strategies used and resulting consequences reflected the way caregivers understood their own responsibilities and those of a particular helper.

### Factors Facilitating and Inhibiting Respite in C-H Interactions

Caregivers did not talk explicitly about "social roles," but the way in which they talked about interacting with helpers or potential helpers consistently specified what behaviors were expected from different types of helpers. Helpers were classified by the researcher as *informal* (kin, friends, neighbors, and informal organizations) or *formal* (paid help, or social or health service agencies). With informal helpers, the usual attitude expressed was that respite only should be requested if it was absolutely necessary. Spouse caregivers defined necessary as emergencies, caregiver illness, important business, and

shopping that could not be done at a time when the recipient could be left alone. Occasionally attendance at a funeral or wedding of a very close friend or relative was included as an acceptable reason. Caregivers other than spouses (daughters, siblings, and friends) also included as necessary some activities with their spouses. If respite was used for other than necessary reasons, it needed to be at the convenience of the helper. The most predominant attitude was expressed by this caregiver:

..... I know she (H) would come if it was convenient for her. If she wasn't working or something. I'm a true believer in not imposing my problems on other people.

If there was a reason the caregiver wanted respite when it was convenient for her, then she felt she should pay for it even if was a family member. In the case of using formal services, most caregivers still felt it should be used only when necessary but they expanded the necessary to include needs for rest and seeing other relatives who were ill. The most consistent viewpoint regarding respite from either formal or informal sources was that respite for purposes other than those just mentioned was not necessary though "it would be nice."

One caregiver whose garden and greenhouse were overgrown could not take care of it because she was afraid her husband would fall while she was out in the garden. She said:

...well it doesn't seem important enough to have somebody take their time to come and sit here. In other words, if somebody came and sat here, that would be taking their time. To do that so I could go out, and should I say play (laughs). But I sure do like gardening.

Use of social or monetary resources should be reserved for unusual circumstances. More detailed descriptions of the usual circumstances with variations and exceptions are considered next.

C-H conditions and interactions. The informal relationships of caregivers included kin, friends, neighbors, and persons in organizations of which they were members. All of the caregiving partnerships had some contact with kin within the year encompassed by questions in the interview. Although ten of the caregivers did not receive any direct assistance from their relatives, there were phone calls and an occasional drop in visit. However, respite was not commonly expected or requested from kin.

Several conditions influenced the extent and frequency of the caregiver's use of kin for respite. Kin living in the same household or near by, or who came by frequently, presented more opportunities for respite than when they lived far away or visited infrequently. However, even when kin lived with the caregiver or close by, respite was used sparingly. On the other hand several episodes of respite were provided by kin living long distances away who would arrive during vacations or summer and stay with the recipient while the caregiver was away.

In-home helpers included husbands and children of the caregiver. Of the husband helpers, three of the five had serious illnesses during the six-month period that interviews were taking place and one husband had died in the prior six months. Wives of ill husbands had some caregiving obligations for the husbands as well as the person identified as the recipient in the study. In these cases respite was considered acceptable for getting away with their husbands.

Adult children were considered for respite if they did not have other obligations (e.g. family, jobs) and if they visited frequently. If there were several adult children who could be asked rather than just one, respite was considered more often. However, most caregivers stated that their relatives provided other types of assistance such as help with housework, transportation, and shopping which allowed the caregiver not to be away from the recipient. To ask for respite in addition was considered an imposition. For most, leaving the recipient with a relative caused equal if not greater concern than leaving him alone. Caregivers then worried about the helper as well as the recipient. Caregivers explained that their adult children "already had a full schedule of activities".

Friends of caregivers were excluded almost universally. Caregivers stated "that's not what friends are for" and "if I want to do something, I want to do it with my friend." In two instances that a friend did stay, it happened only once in a year's period. The only other instances were two in which the friend was also a neighbor and caring for a person with a condition similar to the recipient's. The friend could, therefore, watch both persons needing care at the same time, and the caregiver could reciprocate when her friend was away.

Except in the two cases just mentioned, neighbors were not considered as respite sources. However, they often played a role in how safe the caregiver felt in leaving the recipient alone. Two caregivers said they would tell the neighbor if they were going to be gone a short time and be leaving the recipient alone; they would explain to the neighbor that checking on the recipient was not necessary and that if

the neighbor needed to go out while the caregiver was gone to do so. Most caregivers explained that even to tell neighbors that they were leaving the recipient alone was an imposition to the neighbor because it implied that the neighbor should have some responsibility for recipient and this was "just not right". These same caregivers, however, had told the neighbors about the recipient's condition "in case anything should go wrong."

Neighborhood informal gatherings provided respite for two caregivers. One was a long standing morning coffee group at a local rural restaurant. The recipient, though cognitively impaired, was able to find his way there because he had been going there prior to his difficulties. He continued to go each morning and the caregiver said that it really made a difference in getting her day off to a good start without him bothering her. Another caregiver was able to leave the recipient in a restaurant attached to the grocery store where she shopped because one of the waiters had told her "he would keep an eye on him."

Informal organizations such as churches and veterans' clubs were occasional sources of respite. In three situations informal organizations provided respite on a monthly basis; the recipient had belonged to the organization prior to becoming ill. Members took him to organizational meetings or, in one case, to a monthly luncheon. One caregiver could leave the recipient at his church on Sundays and go on to her own church because the members would look after him because they had known him so long.

A major consideration in using any informal source of respite, including kin, was whether or not personal care needed to be done. Bathing, toileting, feeding, and meal preparation were viewed by the caregiver as tasks that were her responsibility and should not be imposed on others. When speaking about personal care the caregivers explained:

.. if they were hired to do it, but I couldn't ask a friend to come in and do the things I do... like wiping his butt... No, I wouldn't ask a friend to give him a bath, I know I wouldn't.. or take his teeth out, wash them, and put them back in.

...he (R) lost control of himself (meaning urine). Other people might take care of it, but I'd rather not impose that on them. I'd rather have somebody to come in and sit with him and talk to him. I wouldn't expect anyone but nurses to clean him up or give him a bath.

Formal sources of respite were privately hired helpers, chore services, agency health aides, adult day care, and in-patient respite at the Veterans' Medical Center. Private helpers were hired due to the higher cost of agency-supervised help. The one agency person was hired for only four hours a week because that was the most the caregiver could afford. Adult day care and in-patient respite were new services provided under Veterans' benefits without cost.

Even when a formal service was without cost, the amount of effort required by the caregivers to access the services was a barrier to the use of the service. Convincing the recipient to go out or have someone in was difficult. Adult day care (ADC) was used by six of the caregivers over a year's time, but for four of these it was a one-time experience because they could not get the recipient to return. Only two of the caregivers used ADC more than a month and no caregivers were

using it by the end of the study. Seven caregivers had used the in-patient setting at the Veterans' Medical Center; one caregiver had used it more than once. Five of the recipients refused to return a second time.

Circumstances that magnified the difficulties and increased caregiver's feelings of imposition on others was the need to coordinate both informal contacts and formal sources of respite or two informal types of assistance because the caregiver needed a person to be with her as well as someone to be with the recipient. If a daughter was asked to stay with the recipient, it meant this had to occur at the same time that someone was available to do something with the caregiver. Fitting together the best time for the recipient, times for two helpers and a time when the caregiver felt able and wanted to be out usually was more than caregivers cared to organize. As one caregiver stated:

It's just that if the opportunity comes at times, why I might take advantage of it, but I don't ask for it. I don't look for it.

This might be called a "non-strategy" way of thinking about respite.

With formal care in particular, caregivers stated they did not like to plan ahead because it often did not work out and it also made them worry too much about the future. It was better to take one day at a time.

C-H strategies and consequences. A wide range of strategies existed for acquiring respite. In the case of informal helpers (usually kin), the underlying concern was acquiring respite in a way that caused the least imposition for helpers and created the least intrusion on the life of the caregiver. Strategies were shared by caregivers in response to the question "how did it (respite) come about?" This

approach was necessary because caregivers' least common way of obtaining respite was by direct request. "Working around others schedules" was the way caregivers talked about times when kin might provide respite. "If I know it's an inconvenient time for my daughter, I don't even ask" and "they're busy, you can't ask very often." Thus when a request was made as well as how often was important.

Most often respite occurred as a result of several conversations between the helper and caregiver in which the caregiver made a statement about needing to get away to do something. Then she would wait for the helper to offer a solution. The caregiver thought that this approach caused less of an imposition because then the helper easily could ignore the statement.

When the helper did accept or offer to provide respite, caregivers worked to reduce the difficulties for helpers. The most common ways of reducing helper difficulties included: being gone for the minimum amount of time needed (usually a 2 hour maximum); timing being gone so that the recipient would require the least amount of care; preparing a meal in advance so it could be heated or set on the table; and making sure that the recipient had used the toilet just prior to her leaving. Reducing the difficulties for the helper also reduced the caregiver's feelings that she was an imposition to the helper.

If there were several helpers with few responsibilities to call on for assistance, caregivers felt least like they were imposing. The most optimal situation was one in which the caregiver had four adult children living near-by, not one of them was married and they all had offered to stay when needed. She could call one of the four and tell them when she

wanted to be away and ask that one to consult with the others. The caregiver said she always would be surprised which one came. The caregiver said she would not have asked her adult children for help if they had families to consider.

Building in reciprocity was considered an important strategy in the case of the two neighbors who also were friends, and they used strategies of "asking the other person if they were busy" before considering if they would impose on their time. They felt strongly that they should not take advantage of one another. In the case of daughters as helpers, spouse caregivers would take care of the daughter's children to reduce the caregivers feeling of being an imposition. One male caregiver took his wife (R) along with him to a son's house and helped with home repairs. During this time the caregiver felt he could suggest an occasional game of golf. He said he just had to mention golfing and the family would arrange for someone to stay with his wife. However, it had been over a year since the project at his son's house was finished. He had not played golf since or mentioned it because he now felt that to expect respite would be an imposition. Instead he waited for his adult children to visit. He had several children and most every weekend one or the other would come for a day. However, he did not know what day they would come or for how long. They came at their convenience and he never knew when until they called just before coming. He said when they did come, he rarely left his wife alone with them. His wife had gotten worse in the past year so he felt staying

with her was more of an imposition; and he no longer tried to suggest when it would be best for them to come but always let them determine when to come.

There was a clear distinction made between having family members stay at their convenience and at times that were most convenient for the caregiver. Caregivers said if they wanted respite on their own terms they felt they should pay for it.

Caregivers also had strategies for limiting helpers from coming when they felt that the helper would take over or make it harder for them. Unsolicited advice giving by helpers (especially family) was viewed by caregivers as an intrusion. Solutions helpers offered to problems of care or respite were often the cues that caregivers used in determining if a helper's offer should be accepted. As one caregiver stated "I can't accept the solutions she (H) offers so I just don't even mention that I need to get away anymore when she's around". If the helper was bossy or nervous, the caregiver simply ignored the offers for help. When with the undesired helper, the caregiver would refrain from mentioning problems with caregiving so as not to evoke an offer for help.

Caregivers often requested respite from family members once or twice or for a period of time in the past, but the outcome or changes in the helper's life or recipient's health resulted in kin no longer being asked to help. Opportunities for respite constantly were changing. Daughter helpers got married and moved away; work schedules of helpers changed so they were no longer available; and household members came to live and then left. Of the twelve who had other people at home to help,

six of these helpers moved into the home during the course of the six months and four of those had moved out again by the end of the six months.

Characteristic of family respite was its fluctuating, intermittent, and infrequent use. Long distant family members and friends frequently arrived in the summer and allowed some brief respite. For some this was a welcome relief, and for others it created more stress from which they felt they had to recover because of disrupted caregiving routines.

Caregivers recalled past experiences with kin who repeatedly had offered to stay with the recipient and then, once taken up on the offer, never offered again and subsequently reduced visits and contacts with the caregiver. The reduction in contact signaled to the caregiver that the experience had been difficult for the helper. In addition it caused the caregiver to restrict asking or accepting offers of respite from other potential helpers for fear that they too might avoid her.

Families rarely offered a regular time the caregiver could count on to be away from the recipient. For the caregiver to make such a request was considered an imposition. Rather, respite times accommodated to the helper; and if that was not possible, the caregiver respite was not requested.

Respite that accommodated most to the caregiver needs was that in which family members were in and out of the home, aware of each others needs, and through several encounters would work out a solution that accommodated to the needs of both. Only two situations met these criteria. More often, even if there was a lot of contact, the caregiver

did not make her needs known either because she felt she was imposing or family members would be too intrusive and cause more difficulties. Arrangements were usually informal, and the ebb and flow of contact and respite opportunities occurred more by chance than design. Most caregivers felt they could count on their families in emergencies, but respite was a luxury that should not be expected.

Formal agencies posed a somewhat different picture. Paid help and agency sources of respite were accompanied by difficulties in access and finding a source that fit the caregiver's needs without costing too much. Typical of situations was that described by this caregiver in trying to get a chore worker to come at a time that coordinated with her needs:

Well I would like to go play cards at the senior center but I have to be there at 12:30 and I have to put him (R) down for his nap then. I tried to get the chore worker to come earlier but there was no way because the buses can't get him (H) here in time. So I just gave up that idea.

For caregivers who initiated obtaining formal agency help in the home, there were frequently long stories about the time involved in discovering what agency to access and actually achieving a time that fit with the caregiver's needs. Initially the caregiver asked informal contacts about what they knew about sources, which led to several phone calls and months and in some cases years of time passing before a source actually was used.

Occasionally agency staff made the initial offer. One physician required the caregiver to use agency help or he would not discharge the recipient from a nursing home to her care. This was the only case of paid agency in-home help that had been used for longer than a month.

The paid help had changed from twice a week for eight hours to four hours once a week over the course of three months because the caregiver felt she could not afford the cost. The eight hours of care was \$64 dollars a day which, when used twice a week, amounted to \$254 a month. The four hours a day was costing her \$128 a month. This type of help she explained was not covered by insurance.

Adult day care (ADC) and in-patient respite were suggested either by formal helpers when the caregiver and recipient were attending the geriatric clinic or requested by the caregiver as a result of information acquired through caregiver support groups. In approaching formal agency staff about respite, the most common strategy was to make a statement to the physician or social worker about tiredness or wanting to get away and waiting for the clinician to offer. Both ADC and in-patient respite were covered under veterans' benefits so cost was not a factor. However, the varied living situations of caregivers and types of adult day care available made ADC inaccessible to most caregivers. The most optimal situation was that in which ADC provided transportation, met several times a week, and was close by. This was the experience of only two of the caregivers. Five caregivers who did not access ADC, though they would have liked to, lived in rural settings and the ADC available there did not offer transportation. For the blind caregiver who lived in a rural setting, transporting the recipient to the ADC was an impossibility. For the other caregivers, the thought of talking the recipient into going and getting him to stay presented too many difficulties. Several went one time and could not get the

recipient to return. Helpers did not anticipate these circumstances and had not offered any suggestions for circumventing the problems of access.

Another caregiver who used ADC said the time the recipient was gone allowed her just enough time to get housecleaning done that she could not do while the recipient was home due to his agitation when she cleaned. One afternoon while he was gone, she tried to visit friends but had to rush so much that she came home too tired and said she would not try to visit friends again while he was at ADC. This type of occurrence was common. Respite might be enough to get the "necessary" tasks accomplished but rarely was enough to accommodate to relaxation or social visiting.

In-patient respite was accessed the most easily. The caregivers reported that the clinician arranged respite when it was desired. The veterans' hospital was familiar to both the caregiver and recipient. In two cases in-patient worked out well and caregivers used it more than one time. For four other cases, the recipient refused to return a second time, and in one instance staff at the in-patient setting called the caregiver to bring the recipient home early because they could not manage his behavior. The caregiver had planned her time carefully so she could get all her work done the first week the recipient was gone and get some rest and do some visiting the second week. The staff called at the end of the first week so that the caregiver never got her rest or visiting accomplished.

In most cases when respite was desired, caregivers needed to coordinate more than one source of informal and/or formal assistance. If there was in-patient respite and the caregiver wanted to be away, someone had to take care of the house. If the caregiver did not drive, she also needed transportation for herself. Often the caregiver wanted the recipient out of the home setting so she could clean and take care of repairs but needed assistance herself because she did not have the energy to accomplish the tasks alone.

Steps in acquiring a formal source of respite required asking about many sources before the right one was found. Usually the caregiver was advised first by a family member or friend. Then she asked specific questions about the source by phoning other people she knew. If she belonged to an organization, she would ask several people when she attended meetings. Then she would check on sources such as asking a potential helper to come by to determine whether her own and the helper's schedules would fit together or finding out what kind of criteria were needed in order to qualify for a respite source.

The best opportunities for respite described by caregivers were those in which potential helpers made repeated offers to care for the recipient and a friend, at the same time, was inviting the caregiver to go out. These simultaneous conditions made it easier to find a time that both the helper and friend might be available for the caregiver. If the caregiver had things she wanted to do by herself, repeated offers by the helper were necessary to coordinate a time.

Respite by formal agencies (particularly in-patient respite) was facilitated by the helper offering and then accommodating with the time the caregiver wanted to be away. The ADC that was most accommodating was offered by the agency without the caregiver requesting it and provided transportation. Caregivers described situations in which respite worked well as "things just fell into place."

Both informal and formal sources of respite most often were rejected at the point of anticipating what was involved in making arrangements. There was enough to be concerned about in meeting daily needs without trying to arrange several person's schedules and dealing with the attendant feelings of imposition. The times caregivers reported respite being used because of their own extreme fatigue was accomplished by the helpers "taking over" and making all the arrangements for the caregiver.

There were no situations in which caregivers used either informal or formal sources of respite for regular weekly times that had lasted for more than a two-month period during the year encompassing this study. The two-month period of regular respite time was used only by two of the thirty caregivers. In one case a formal agency provided the respite, and in the other a paid helper provided respite.

CI and PI similarities and differences. Factors that facilitated interactions between the caregiver and helper for successful respite outcomes are summarized in Table 12. No differentiation is made in the table between CI and PI groups as these are more relevant to the R-H interactions discussed in the section on matching.

Table 12

Imposing: Facilitating and Inhibiting Factors for Respite

	Facilitating Factors	Inhibiting Factors
Informal Respite	H has no family responsibilities Opportunity for C & H reciprocity H-C schedules match H lives close or in household H visits frequently H familiar with R so H needs few directions H makes repeated offers	H married and working H gives too much advice H already helping in other ways R personal care needed in C's absence H complains about own busy schedule H lives too far away
Formal Respite	Cost is minimal or no charge Transportation provided for ROH Setting familiar to H H offers and makes arrangements H time matches needs of C	C must make many phone to arrange H No transportation if ROH H does not fit with reasons C needs No effort made by H to help C arrange respite

---

C = Caregiver: R = Recipient: H=Helper (respite source): ROH = Respite out of home: RIH = Respite-in-home.

---

Imposing was the major theme that characterized the thinking around sources of help. In informal helper contacts, being an imposition to helpers was often the concern. In formal helping situations, impositions were those of the agency on the caregiver. The caregiver's concern centered on the requirements imposed by an

agency for accessing the agency and meeting the agency's selection criteria and time frame. When coordination of several persons was required to effect respite, difficulties in scheduling became compounded and respite was less likely to be used than when only one person's schedule had to be taken into account. For caregivers of both CI and PI groups the tension involved in being imposed on and imposing on others usually resulted in inhibiting the use of respite and taking the chance of leaving the recipient alone at carefully selected times.

Matching: The Central Theme of R-H Interactions

*Matching is the process of the caregiver's taking into account the past and present interactions between potential helpers and the recipient and using that information in judging whether or not leaving the recipient in the helper's care will be a positive experience for both.*

Matching was mentioned most often by the caregiver in the context of describing an unusually positive or negative reaction of others to the recipient. Positive experiences were those in which she noticed that both the potential helper and the recipient enjoyed the interaction. A typical example was one in which the caregiver explained:

...and this is why he (R) doesn't mind being with my sister and brother-in-law (Hs). They (Hs) might not understand about everything but they don't make anything of it.. like they don't even make any fuss by looking at him, whereas somebody else gets a shocked look on their face.

Negative reactions consisted of comments by potential helpers like "how can you stand him (R)" or one caregiver said of R's son, "he (the son) really looks uncomfortable when he's around him (R), he won't hardly

even look at him (R)". Caregivers had vivid, detailed, and animated recall of these types of interactions. Each caregiver talked about several such experiences and kept them in a mental file for judging whether or not to use a particular source of respite.

Matching in some ways overlapped with imposing in that the caregiver would feel that it was more of an imposition to the helper if the helper expressed negative reactions to the recipient. However, in imposing the caregiver's concern was to maintain socially expected boundaries between individuals and protect against too much intrusion. By contrast, the caregiver's concern in matching was to take notice of persons who could cross the usual boundaries and be sensitive to the physical and emotional needs of the recipient and to avoid contact (or set up rigid boundaries) between the recipient and helper when they were not responsive to one another's needs.

The central focus for matching was the recipient and helper and noticing situations that were exceptional. Caregivers often expressed surprise at the interaction between the helper and recipient as though it went beyond what could be expected of most people in the situation. If positive, the caregiver felt comfortable in having the helper stay with the recipient; and if negative, the caregiver made a particular effort to exclude that person from contact with the recipient.

#### Factors Facilitating and Inhibiting Respite in R-H Interactions

The caregiver saw her job as protecting the recipient from harmful or degrading interactions as well as not exposing the helper to situations that caused distress. The more salient of the two was

protection of the recipient. From experience, she recognized that paying attention to this matching component also influenced the ease or difficulty of her own interactions with the recipient and the helper both before and after respite.

R-H conditions and interactions. Situations in which a positive match occurred with informal sources of respite were characterized by the helper having had a history of contact with the recipient and having seen him (R) change with the illness. Behaviors of family members that were taken as cues to positive reactions were continuing to visit and taking time to interact with the recipient. If kin initiated assisting the recipient with toileting and the recipient cooperated, the action was of particular note because it meant that caregiver could leave the recipient with the helper for longer periods than she could if she was worrying about returning in time to avoid inconveniencing the helper. Even when the caregiver and recipient were able to get along well, this personal type of care was rare among informal caregivers. As one caregiver stated:

When I took him (R) out shopping with me last time my brother was with me. They seemed to enjoy each other even though he (R) can't make much sense when he talks. My brother even took him to the bathroom and they both came out looking like it was no big deal.. So I know that they'd get along just fine.

This caregiver subsequently asked her brother to stay with the recipient and did not worry about them while she was gone.

Caregivers also noted negative reactions to the recipient by informal helpers which included avoiding contact with the recipient when they visited, and comments to the caregiver such as "I don't know how

you do it". Common statements by potential helpers were "I think you should put him (R) in a nursing home" or "you should get some help so you could get out." Although the caregiver said she knew that the potential helper was expressing concern for the heavy care being done, the caregiver also interpreted these comments to mean the person who made them would not be willing to stay with the recipient.

Neighborhood groups or informal organizations that the recipient continued to attend throughout his progressing illness often accommodated to the recipient's changes. Caregivers noted group members' willingness to continue to have the recipient in the group. One caregiver continued to take the recipient to his church which she had never attended. She noticed that the congregation helped the recipient around to classes as his condition deteriorated and "looked out for him" without any making negative comments to her.

Matching activities also involved noticing the settings in which the recipient was most comfortable. Some helpers only could provide respite in the recipient's home while others required the recipient to come to their setting (e.g. churches and informal groups). The setting usually needed to be one familiar to the recipient. Car rides frequently were reported by caregivers as resulting in positive reactions from the recipient because he could be out without being exposed to people who might react negatively. Several caregivers said they wished they could ask people to just take the recipient on a ride so she could have some rest, but such offers were rare.

Time was a major component which needed matching when leaving the recipient with informal helpers. Usually these had to be short periods

of time during which physical care was not required. The time that the helper was available had to match the times that the recipient was at his best because some periods of the day were more confusing for the CI group, or more tiring for the PI group.

Gender was a major consideration in informal care situations if helpers were other than family. Several caregivers felt that it would be strange to have a woman in the house with the recipient and that the recipient would feel uncomfortable. In the case of formal care a nurse in the home did not have to be the same gender, but if the recipient went to an adult day center or in-patient respite, how many men were there was a frequent concern. The Veterans' Medical Center was considered desirable because of the predominance of men.

In formal respite out-of-home settings (ROH), like ADC and in-patient settings, caregivers looked for activities for the recipient and his willingness to go to or return to the setting. Caregivers felt that recipients needed social interaction as well as physical care so looked to see if social opportunities were available.

R-H caregiver strategies and consequences. Caregivers used several strategies to effect a match. They talked about "keeping their ears open" for persons who had cared for someone exactly like the recipient and then asking questions of that person about where help might be obtained. Caregivers were alert to offers by others and noted whether what the person who offered indicated awareness of the difficulties involved. When someone offered to help, it was not taken at face value by caregivers. Caregivers often said "I know they couldn't manage it" or "they wouldn't know what they were getting into".

Sometimes offers of respite were accepted and the caregiver judged on the basis of the first experience whether she would have a particular helper stay again. This was sometimes the case when the caregiver had few choices and wanted to go somewhere for an overnight stay. A daughter or son would be asked to stay and based on what happened, the caregiver would decide whether to ask that person another time. Most often after the first time, a second request was not made because personal care such as hygiene was neglected or done in a way that left the recipient uncomfortable or else the caregiver noticed that the helper's nonverbal behavior indicated dissatisfaction whether or not anything was verbalized.

Caregivers explained that a helper just could not get the recipient to cooperate or that she (C) found the recipient's clothes unchanged or smelling bad. Bathing the recipient always presented problems for family members. Even in a family in which the recipient had been ill since the children were young, the only time the children had participated in bathing the recipient was a time when he had been in a coma.

Respite offered in the helper's home was less common than having the informal helper come to the caregiver's home. When the family helpers took the recipient to their own home, the caregiver reported that the helper had not realized until then what the care involved or how ill the recipient had become. Although it worked out well for the

recipient, the caregiver noticed that it was hard on the helper.

A typical type of comment by caregivers was:

It was really hard on her (H). I mean she didn't actually come out and say it... I could just tell. It was difficult for her to see somebody that was very, very strong and independent decline the way she (R) has.

In addition, this helper (the recipient's sister) no longer called the caregiver as frequently or visited her sister (R) after the respite episode. This was a common type of experience for caregivers and caused caregivers to curtail offers for help.

Informal arrangements that were working out well for the recipient were checked on often by caregivers to make sure that the recipient was not causing the helper problems. Checking was done through the caregiver's friends who would ask discretely how things were going and if the recipient was creating any problems for the helpers. Caregivers did not ask the helpers directly if there were problems because they (Cs) felt the helpers would not be truthful in order to protect the caregiver's feelings.

Strategies of helpers such as veterans' clubs and men's clubs accommodated to the recipient, and helpers would pick him up and take him to regular meetings. These situations were especially helpful to caregivers because they did not have to arrange them and the recipient interacted directly with the helper. In fact, the helper may not have recognized that respite was being provided for the caregiver. These situations of a continuing relationship between the recipient and the organization were particularly helpful to the caregiver because she could count on respite to occur at regular intervals. However,

arrangements between recipient and helper that resulted in respite were exclusive to the PI groups because the CI recipient could not initiate such interactions.

With formal helpers, caregivers often checked out the situation in advance to ensure that it might be one that the recipient would enjoy. There were several steps to the process of checking in advance. They would ask friends or people at informal organizations they belonged to about sources of respite and then try to narrow it down to situations for persons like their husbands. The best sources were considered those people who were taking care of someone "just like my husband". In addition, the caregiver would stay with the recipient the first few times to facilitate the adjustment of recipient and helper to one another. She would coach the helper and would leave only after she felt a match had occurred. This worked well in some cases, and in others it prevented the caregiver from using the source more than once because of adverse reactions of the recipient. Five caregivers explained that they had taken the recipient to adult day care centers and the recipient refused to return or would not let her leave him there. Confused recipients in two cases grabbed the caregiver's arm and would not let go until they were back in the car. In the case of three recipients with physically impairments, recipients told the caregiver that the setting was depressing and there were no interesting activities.

Caregivers were reluctant to initiate conversations with the recipient about in-patient respite. When caregivers expressed such reluctance to clinicians at the in-patient setting, the clinician would take the initiative and talk with recipient about the caregiver needing

a rest which helped smooth the process. This strategy worked well in several cases and enlisted the cooperation of the recipient with the helping agency. Two recipients used the in-patient respite situation twice in the year's time. In the five other cases it worked one time but not a second time. In one case the recipient refused to return and berated the caregiver for several weeks after for having left him. In another case, the staff at the in-patient respite unit the told the caregiver they could not handle the recipient again because he repeatedly asked to go home and became too confused.

Arrangements for respite always were subject to change based on the changing health of the recipient and the availability of helpers. The situations in which the recipients went to a neighborhood coffee shop lasted for several months. Then the recipient started coming home earlier or refused to go again. These recipients were cognitively impaired, and both caregivers surmised that the recipients were unable to answer questions which made them reluctant to return. In another case a recipient with PI who was attending an informal organization complained about not being able to hear and refused to return.

#### CI and PI Similarities and Differences in R-H Interactions

A good match between recipient and helper were more common among the PI group than the CI group because the recipient could act independently in calling old friends without having to involve the caregiver. Recipients in the PI group who always had been reclusive created poor matches because they denied needing anyone with them unless the helper went for a week or two vacation. More unstable physical illnesses resulted in hospitalizations which often interrupted

previously well matched R-H conditions. Helpers were more likely to be uncomfortable if they thought the recipient's condition might worsen while the caregiver was gone. As one caregiver noted "I just don't want to upset her (H). It bothers her when her Dad's (R) breathing real heavy like that.. I can tell."

In the CI groups, though matching occurred on a few occasions, it was more difficult to achieve. The ability to interpret garbled communication and nonverbal behavior required a lot of familiarity with the recipient. The one situation in which it worked the best was still very tenuous. The caregiver's families lived close by, visited weekly and had Sunday dinners together, but the recipient's reactions to family members changed from day to day. On one day a family member could take the recipient to her house, and the next time she (H) could not get him out of the car and would have to bring him back home. Caregivers felt the need to check up on the recipient and helper before returning home by phoning home; such checking was not as true for the PI group because the recipient could be counted on to communicate what might be needed.

The key differences between CI and PI groups are summarized in Table 16. Some of the same factors apply as did for C-H interactions. Persons with more serious cognitive impairments were harder to match with a helper than those with milder cognitive deficits. For the physically impaired it was not so much the degree of impairment as the willingness of recipient to be cared for by others. Thus, in both the CI and PI cases, those caregivers who were more likely to be in need of time away were also those caregivers who found it most difficult to achieve a match between helper and recipient.

Table 13

Matching: Facilitating and Inhibiting Factors for Respite

	Facilitating Factors	Inhibiting Factors
Cognitively Impaired (CI)	R not upset by H R not confused by change of environment for ROH H talks quietly with R H does not ask questions H has worked with person like R in the past	R becomes agitated by H R behaviors cause H discomfort H not available when R can best tolerate H H complains about R's behavior to C H not able to direct R's behavior
Physically Impaired (PI)	R willing to have H do personal care H knows how to do treatments for R R willing to make requests of H R-H friends prior to illness	H omits physical care needed by R H bothered by physical symptoms or appearance of R R doesn't like settings in which too many CI or too many women
CI & PI	H and R appear comfortable with each H initiates interactions with R without C's encouragement R looks happy after being with H H as "helping" hidden from R H's gender matches R for informal Hs H does activities that R enjoys C takes time to facilitates C-H match H familiar with R prior to illness and during illness	H shows discomfort in presence of R R resists care by H H abilities do not match R's needs H not comfortable doing physical care Formal H criteria do not match R needs R's behavior is disruptive after being with H H does not repeat offer to stay with R H reduces number of visits to R H unable to be in setting in which R comfortable

C=caregiver; R= recipient; H=helper; ROH=Respite-out-of-home

### Conservation Through Interactional Processes

As the caregiver thought and interacted through the processes of knowing, imposing, and matching, she interwove the elements of conservation as she made judgments about obtaining respite. To illustrate how these judgments were made, scenarios of five respite situations are provided and each is followed by an analysis based on the themes and core category. Two spouse caregivers from the CI group, two spouse caregivers from the PI group, and a daughter caregiver are presented respectively. They were selected for their ability to represent the range of factors that influenced caregivers' respite choices. After each scenario the theoretical relationships among the themes are analyzed and application to respite services is discussed.

#### Scenario #1

Over the course of the four years, Mrs. Wheeler's husband had undergone several surgeries and hospitalizations. Two years ago he was diagnosed as cognitively impaired. Mrs. Wheeler said she was exhausted from running back and forth to hospitals, caring for her husband in between surgeries, and dealing with his behavior changes.

She called many agencies to find in-home respite because her husband refused to be cared for in any other setting. She finally hired a man to stay with her husband but said the man seemed afraid of her husband, so she stopped having him come. In the last month her husband's condition had stabilized enough so that he could go to church with her. He was able to dress himself but not always appropriately.

The members of the church noticed "I was just down and out" she said. The minister of the church called her son who lived 300 miles away and told him that his mother really needed a rest. Her son then called her and said she was to get on the train and come to see him right away. "He wouldn't take no for an answer." The minister had told her that the church members would take care of her husband while she was gone.

She said "I didn't have to do anything. They (the church members) just took over and I got my train ticket and left. My son had to come about 60 miles to the train station to get me so when I got there I was really tired. I have all these bowel problems so it was real hard being there. I know I was in the way. I came back more tired than when I left. I know I won't do that again." She said her greatest need was for some time alone at home just to relax.

Analysis of scenario #1. Mrs. Wheeler had no relatives in town. She had tried formal respite services care after a lengthy search and could not achieve a match between the helper and her husband. Church members had known her and her husband long enough to sense when help was needed and to know what family members to call for assistance. They initiated the plan. The church members needed little instruction regarding Mr. Wheeler's care because they were aware of his changed behavior. The caregiver knew that her own energy was depleted and she needed the rest. Her husband's condition was stable enough so that if the church members brought in meals he would be all right. The "knowing" process did not inhibit her from leaving because the church members knew her husband well enough for positive "matching" to occur.

Helpers initiated the idea of respite and "took over" making it easy for the Mrs. Wheeler to leave. The son's offer for her to come to his home was specific and clear, thus alleviating her fear of imposing. However, when she got to her son's home and had a chance to reflect, she reported that her son's family had "gone out of their way" and it had been a lot of inconvenience for them. She also did not see that the respite had restored her own energy. Mrs. Wheeler had engaged in the processes exemplified in each of the themes. She also had been

influenced throughout by conservation as she recognized the need to maintain her own health and provide a protected home environment for Mr. Wheeler.

Aspects of the knowing and matching processes facilitated her taking advantage of the respite which required coordination of both kin and members of an informal organization. Imposing acted retrospectively to inhibit her from repeating the experience as did her feeling that her fatigue was not relieved by having had the time away. She was appreciative of the churches intent to help her, but Mrs. Wheeler reflected "that kind of help is a one time thing for a church group. They can't be expected to do that again." She still felt she needed more time to rest at home, but the strategies she had tried to get Mr. Wheeler to use ROH had been unsuccessful. Her prior experiences with making many calls to obtain a helper and then achieving a poor match prevented her from attempting to acquire in-home respite again.

Applications to respite services. Applying the theoretical model to analysis of the situation allows for the conditions and interactions to become evident. Mrs. Wheeler currently wants respite so she can have some time alone at home to rest. There are adult day centers in the area, but she does not know how to get Mr. Wheeler to go. Agency personnel, by identifying these conditions and interactions, could assist Mrs. Wheeler in developing alternative strategies to get Mr. Wheeler to attend an adult day center. Persistence and follow through would be needed for a match to occur between the formal helpers and the recipient.

Mrs. Wheeler has strong informal support in her son's family and local church. Her son's family, though a long distance away, visits several times a year. With some assistance from agency personnel, the family visits could be opportunities for respite rather than an exhausting time because of the family's lack of knowledge about how best to make the situation easier for all involved. The church group really wanted to help and their acceptance by the recipient as caregivers could allow additional opportunities for respite, though not on a regular basis. Mrs. Wheeler's feelings of being an imposition could be reduced by educating church members regarding ways to offer periodic respite.

Assessment of the situation must involve acquiring the information regarding what Mrs. Wheeler knows about her own and Mr. Wheeler's needs, her feelings about imposing on her informal contacts, and her attempts to match her husband with an appropriate helper. Being aware of these factors could allow formulation of a plan that conserves Mrs. Wheeler's energy, social relationships, and resources. A plan that incorporates sensitivity to conservation anticipates in advance whether informal and formal services will bring the desired result. Periodic assessment would be needed as Mr. Wheeler's health changes over time.

#### Scenario #2

Mrs. Martin lives in a rural area with her husband who has severe dementia. She has been caring for him for 2 years. He cannot independently accomplish any of the activities of daily living other than ambulating. He cannot be understood by others and is agitated easily by the presence of other people and noise. He cannot be left alone, but he loves to ride in the car and cannot get out of the seat belt. She does her grocery shopping by running into the store for 15 minutes at a time, "because if you leave him longer than that he'll really get upset." She reports that whenever he gets too upset "I can't get him to put his arm in his sleeve for over a week."

Mrs. Martin has a daughter who lives just across the road and two other daughters within two miles all of whom have families with children. "The family is very close knit," she says. "We have dinner here every Sunday." She says "I can ask the oldest and middle girl to stay, but not the youngest because she's got 4 kids." However, she rarely asks them, because she cannot predict how her husband will behave with them. She states, "if I do leave him with one of them, I have to trick him and go when he's not looking or he'll get out the door. Once my daughter tried to take him to her house so I could get some rest but she couldn't get him to get out of the car so she just had to bring him back home."

Mrs. Martin is unwilling to use the in-patient respite because she knows her husband will just get more confused. She also believes "once you start using welfare, they just tell you what to do and they want to know all your business." She considers the in-patient respite as welfare because it does not cost anything.

Analysis of scenario #2. The predominant theme that inhibits Mrs. Martin from obtaining respite is the "knowing" aspect. She knows how to interact with her husband and that he becomes confused in any other setting than the home. Her children are willing to stay with him and she does not feel it is imposing to ask them, but there is also an inability to match her husband with anyone (either informal or formal) who she feels can take care of him in the way that he needs it. The proximity of her daughters and their repeated offers to stay with her husband, however, facilitate occasional short (no more than one hour) episodes of respite. She feels, on the other hand, that formal agencies impose on her by wanting too much information and giving out unwanted advice. Conservation is the primary screen, however, that bears the most weight in her respite considerations. She wishes to maintain her husband in the least agitated state of mind by keeping him in a protected environment. If he is not upset, she is able to gain his

cooperation in dressing and thereby is able to conserve her own energy. In this situation, it is evident that most elements of the themes and of conservation work together to inhibit the use of respite.

Applications to respite services. An evaluation of the knowing elements with Mrs. Martin would reveal that Mr. Martin is least disturbed when he is out riding in a car or at home. As long as people do not ask him questions he is rather content. Mrs. Martin's expressed needs for respite are for getting out shopping and for working out in the garden. There are no formal sources of respite in the rural community in which she lives. Her informal sources of help are eager to help, and she does not feel she is imposing on them but has not developed a strategy for matching the helper and setting with the recipient.

Instruction and work with the family that takes these conditions and interactions into account would strengthen their ability to provide respite occasions. Taking Mr. Wheeler for long rides might be one option that would give Mrs. Wheeler time for her self at home or for shopping. Formal services that provide such instruction to the family may be all that is needed in this situation and could facilitate the family feeling like they were more helpful to one another.

### Scenario #3

Mrs. Burwell has cared for her husband since his stroke five years ago. He did not sustain any cognitive impairment but due to his physical condition, he needs assistance with all of the activities of daily living. Six months prior to the first interview, Mr. Burwell had to go to the hospital for minor surgery. When Mrs. Burwell's daughter heard about it, the daughter offered to take Mrs. Burwell to the Bahamas (her daughter gets free tickets from her work) while Mr. Burwell was in the hospital. Her daughter's husband offered to stay at the house and take care of the house and the dog.

Mrs. Burwell said she had a great time and she really needed the rest, but when she returned her husband was very angry. He claimed she had deserted him. She said she would never have gone if she had known how much difficulty he would create for her on her return. She said "he also resents anyone coming in (the home)."

Mrs. Burwell has arthritis that causes her a lot of pain especially in the mornings and is currently feeling exhausted and overwhelmed by the care demands of her husband. Her only daughter travels a lot so is rarely at home. The daughter is married and works full time and she considers asking the daughter to help would be an imposition. She states "they say as we get older we become a burden to other people and use up younger peoples resources. Well that's one thing I'll never be (meaning a burden)."

The only other respite Mrs. Burwell had was when Mr. Burwell's old club members took him to lunch once a month. During the six months of interviews, he decided that he didn't want to go anymore because of his fear of falling.

Analysis of scenario #3. Respite was facilitated in the first instance because Mrs. Burwell was in regular phone contact with her daughter so there was an opportunity for the daughter to offer. The fact that the trip was offered and that it was free of charge to her daughter decreased Mrs. Burwell's usual feeling of being an imposition. The son-in-law's offer to care for the house and dog resolved any further difficulties. She also felt "I really needed the rest," a recognition of a need to restore her energy for caregiving.

The consequences, however, prevented her from using respite again. Knowing the problems it created for her with her husband made her unwilling to accept respite a second time. Her strong sense of imposition on others extended to both informal and formal sources of respite. She protected her husband from being upset by complying with

his wishes but was not as protective of her own need for rest. She wanted to maintain a good relationship with her daughter so she did not request assistance unless "absolutely necessary," which was explained as meaning, "only if I am too ill to take care of him myself."

Application to respite services. Analysis of the conditions and interactions of Mr. and Mrs. Burwell would bring to light the physical exhaustion of Mrs. Burwell as well as the strong desire by Mr. Burwell to remain in the home setting. The resistance to imposing on her only daughter and Mrs. Burwell's lack of other social connections leave formal respite as the most feasible option.

Because Mr. Burwell is not cognitively impaired, direct interaction with a clinician to encourage his acceptance of outside assistance and some joint counseling with both Mr. and Mrs. Burwell might be necessary before any respite would be accepted. Because Mrs. Burwell never makes a direct request for help, the offer would need to be initiated by a clinician with a step-by-step plan for working toward an acceptable solution. Mrs. Burwell already was feeling too overwhelmed to organize a plan. Suggestions that the daughter might be involved would need to be avoided. Respite services need to build in ways of assisting caregivers in the process of accessing and interacting with recipients who are resistive to care rather than just offering a setting or helper.

#### Scenario #4

Mrs. Doran's husband had a stroke 3 years prior to the study. Although she described him as "depressed at times," he was not cognitively impaired. She had brought him home from the nursing home after the first stroke, cared for him two years and then he had a second stroke. At the time of the first interview she had been caring for him for six

months after a second discharge from a nursing home. She had to bring him home because insurance would no longer pay for his care. She was aware that if he stayed in the nursing home, Medicaid would be necessary. Mrs. Doran felt her husband was not active enough at home and aggressively sought further therapy and respite despite his resistance. She said he needed opportunities that "would help him keep active". She also felt the need to maintain her own social activities "to keep my own health and sanity." She was living in an apartment when first interviewed but subsequently moved to a house which her son arranged for her. Her son stayed with her for a little while but she reported he was afraid to help with her husband's care. She was never sure when her son would be home. Her other daughters lived out of state. They would call and tell her to come and visit, but Mrs. Doran said "who would stay with my husband?"

Mrs. Doran had a friend, Mrs. Arnold, who encouraged her to access agencies and be persistent until she found the one that would work for her. Mrs. Arnold told Mrs. Doran it would be a lot of work but it would be worth it for both herself and her husband. Mrs. Arnold could not provide any respite but gave her information on how to call agencies.

Mrs. Doran followed through on suggestions and made many phone calls over a three month period before she was able to find a chore worker who would sit with her husband 2 hours a week. She said, "the chore worker was not allowed to help her husband get up or down." This meant that she worried while she was gone as to whether her husband might need to get up to the bathroom since he had a hard time controlling his urine.

After her husband received rehabilitation, he progressed from being only able to stand to walking 20 feet with a walker. At that time, Mrs. Doran visited three adult day centers before she found one that she thought matched her husband's needs and that her husband was willing to attend. Her husband attended there 6 hours a week.

Analysis of scenario #4. Mrs. Doran's situation was one in which conservation of her husband's abilities was the primary focus. She knew what her husband had been able to do before the stroke, valued those abilities, and fought against further deterioration. She talked about not pushing him beyond his capabilities but having him evaluated so she

could judge how much she needed to do for him and how much he should be able to do for himself. Knowing to her did not mean accommodating to all her husband's stated preferences as in the case of some caregivers but meant knowing what he was capable of and working to sustain it, with or without his stated approval. Mr. Doran responded to his wife's admonitions that, if he could do more things, it would be easier for her to care for him. She knew this approach would work and used the same approach to overcome his resistance to going to an adult day care center. Thus her knowing what strategy to use with her husband facilitated the use of formal respite care. Her friend, Mrs. Arnold, also provided the encouragement she needed to persist.

Mrs. Doran did not ask her son to stay with Mr. Doran even though he lived with her. She had implied from her son's negative comments about Mr. Doran that they were not a good match. Because her son worked and did not let her know his schedule, she concluded that it would be an imposition to ask him to provide respite. She also thought that physical care of her husband was too much to expect from her son. Because she wanted any respite for her husband to be on her own terms, she thought she should seek a formal agency for services and actively sought a situation that would maintain her husband's abilities and be timed to conserve her own energy for caregiving.

Application to respite services. Mrs. Doran is well and has a lot of energy for coordinating her own services. She drives and is able to take Mr. Doran with her to church and to manage his walker and wheelchair. She has a friend who assists her in how to access services and is able to use strategies that convince Mr. Doran of her need for

time away and his need to be able to do what he can for himself. She does not have family that assists her and does not feel they could provide a match with Mr. Doran in his care.

Mrs. Doran had a clear idea of what type of care she desired and was able to work out 2 hours of RIH as well as 6 hours of ROH at an adult day center. Clinicians at the adult day center, being aware of Mrs. Doran's supporting friend and Mrs. Doran's persistence, would not need to assist with coordination and would only need to encourage Mrs. Doran to check with them if there were changes or other alternatives were needed. Knowing that Mr. Doran is motivated by being able to reduce the burden of care for Mrs. Doran, the staff at the adult day center could use the same strategies to encourage his attendance and activities at the center.

Awareness of Mrs. Doran's experience and energy would allow agency staff to spend less time encouraging Mrs. Doran to use respite. Utilization of appropriate strategies in work with Mr. Doran would increase the likelihood that he would remain cooperative in provision of respite time for Mrs. Doran.

#### Scenario #5

Mrs. Pollan lived in an urban setting with her husband. She was caring for her parents, her father (Mr. George) was the study recipient who was cognitively impaired and his wife was very frail and could not manage his care. Mrs. Pollan and her husband had brought Mr. and Mrs. George to live with them after several years of traveling back and forth from New Mexico and trying to arrange household help. Mr. Pollan had a heart attack during the six months interview period and was hospitalized for a short time and came home with the news that he would need to take early retirement.

Mrs. Pollan felt she and her husband needed to get away for a week and asked her 2 adult daughters who lived nearby to stay with her parents. While Mr. and Mrs. Pollan were gone,

Mr. George locked himself in the bathroom and they had a hard time getting him out. Mrs. George refused to take a bath. When Mrs. Pollan returned both her father and mother smelled terrible and she really had a job cleaning up the bathroom. She said she could tell her son-in-law did not like her daughter staying there to provide care and that the daughters gave a detailed account of the difficulties they experienced.

Mrs. George said, "they (the daughters) just didn't know how to tell my father what to do. You have to be very firm and he'll (R) give you a dirty look but he'll do what you say. The kids (daughters) just won't talk to him that way."

Mrs. Pollen also did not like to leave her parents with her husband because her husband would get so angry and tense that she was afraid he might have another heart attack.

Mr. George roamed the house at night and made it difficult for Mr. and Mrs. Pollan to have any privacy. She knew her parents had never socialized well with other people and could not imagine that they would stay willingly at an adult day center. When her daughters visited, they suggested she put him in a nursing home or find an adult day center. She said she knew their suggestions meant that they would not want to care for them again, so she no longer asked them for respite or mentioned her difficulties when they visited.

Mrs. Pollen said that even with the reserves she had from selling her parents home; she knew that the money would not last more than a couple of years if they were in a nursing home so she needed to hold off as long as she could. When asked about using agencies for respite, she said "you know, I'm busy as I can be... to go get help there's so much red tape. They (agency staff) say would you come to my office and we'll meet at two o'clock on January 3rd. I don't know what I'm going to be doing on January 3rd. I don't like to schedule things. And, you know every time you go up there (to the agency) it's hours of waiting .... And, I sit and get so frustrated and so tired.... they suggest all these different programs and things.... But I don't have time to get involved in that. I'm too busy scrubbing up pee...to put it bluntly!"

Mrs. Pollan explained that the main reason she wanted respite was for a chance to relax at home to "just put my feet up and enjoy."

Analysis of scenario #5. Scenario #5 was chosen because fifteen (50%) of the caregivers also were involved in caring for another older adult in addition to the recipient. All but one of the caregivers who were siblings or daughters of the recipient had husbands to consider as well. Although most husbands did offer and provide occasional respite, responsibilities for other older family members increased the complexity and scheduling problems for acquiring and accessing both informal and formal sources of respite. Having several adult children nearby did not result automatically in respite opportunities.

For Mrs. Pollen, knowing that her parents did not like to be with strangers inhibited respite from being used. She usually felt that she should not impose on her daughters, but her need to be with her husband over rode that concern on one occasion. After the daughters stayed with her parents, she considered them a poor match because of the difficulties with bathing and the daughter's suggestions about using formal respite. Mrs. Pollen's son-in-law told her daughter that he did not like the situation so Mrs. Pollen interpreted that to mean that she (C) was being an imposition.

In anticipating the use of formal services, Mrs. Pollen thought about the time it took and all the forms and judged that the application process would deplete her energy and probably not result in a workable situation. Scheduling ahead was difficult because of all the arrangements that had to be made with her family if she were to have her parents cared for in her absence. The daily care of Mr. George was exhausting enough without having to think about other alternatives.

Applications for respite services. In evaluating Mrs. Pollen's situation, clinicians would need to sort out the complexities of strategies for working with her parents to accomplish a match between the recipients and a helping agency. A case worker would need to be flexible in making appointments in the caregiver's home. Despite the need for ROH, initially a worker in the home probably would be needed to get to know both recipients and develop a strategy for having them accept a period of out-of-home respite.

Because family lived close by and visited frequently, there may be possibilities for a clinician to meet with family members and devise ways to allow for some intermittent respite that would be the least imposing on family schedules. The need for a clinician to schedule an appointment in the caregiver's home would be imperative as a beginning point. Currently services are rare that provide both in-home and out-of-home respite. Separate agencies and services make it difficult for caregivers who already are overwhelmed to access the services and then to change from one type of setting to another as recipients adjust to accepting assistance.

#### Summary and Conclusions

Although each situation has a different interweaving of the themes with concerns about conservation, in each instance there are both facilitating and inhibiting factors for the use of respite. Each caregiver puts these factors together differently; and with ensuing needs for respite, past experiences and the reason for respite shape the type of respite source that the caregiver will be open to considering. The grounded theory of Processes in Utilizing Respite incorporates

knowing, imposing, and matching as the basic concepts needed to expose the factors relevant to caregivers in thinking about respite. Whether the respite offered is sensitive to the caregiver's need to conserve energy, social relationships, and resources is the screen the caregiver uses to judge if a respite source is acceptable. Understanding the Processes in Utilizing Respite and the particular elements salient for caregivers of CI and PI recipients can strengthen the nurse's ability to assist caregivers and recipients in using respite solutions that protect the energy, social relationships, and resources of all concerned. In delivery of health services, accurate assessment of salient processes used by caregivers can assure that formal respite programs have features that prevent underutilization among groups of caregivers who desire them.

#### Validity and Reliability Procedures

To supplement the preceding qualitative analysis, categories were quantified and analysis was conducted of the Themes Scale and Questionnaire (see Appendix D). Validity procedures were conducted by administering the Themes Scale to the study group, comparing results of CI and PI groups, and comparing the study group results with a group of nonveteran caregivers. Reliability procedures consisted of computing interrater reliabilities for the major categories and consulting with experts to arrive at consensus on the major themes and core category. Standardized instruments were administered for measuring emotional, social, and physical health and results were analyzed for the entire group. The CI and PI group results were compared on the same measures.

The total sample results also were compared with results from other caregiving studies. The way in which the triangulation of the qualitative and quantitative data contributed to understanding caregivers and their needs for respite was evaluated.

#### Quantifying the Qualitative Results

Segments of coded data in each category were counted. The counting was done at the end of the second interviews because the first two interviews were structured more by the respondent while the third interview was structured by the interviewer. The number of times knowing, imposing, matching, easier not to, strategy, timing, and respite was coded was summed and t-tests (Allen and Yen, 1979) were conducted to examine the differences between the CI and PI groups. The only statistically significant difference between the groups was the knowing category ( $p \leq .001$ ). The knowing category was coded over twice as frequently in the CI as the PI group (107 times to 41 times). For the CI group the researcher found that not only did knowing occur more frequently but also the segments of data that were coded were longer. Explanations of the behaviors of the cognitively impaired required elaboration about the variety of unusual behaviors of the recipient and explanations of how the caregiver had to adapt her care to accommodate to the behaviors.

Besides quantifying respite according to the number of times it was discussed, a scale was developed to quantify the amount of respite incidents reported by caregivers during a one-year period. The respite category definitions were difficult to construct because of the sporadic

and intermittent way in which respite was used. The six-month recall requested from the caregiver for the period prior to the first interview was only a gross representation of the amount of respite used.

The scale with frequencies and percentages of respite use is presented in Table 14. There were no significant differences between the CI and PI groups when respite was scaled in this way.

Table 14

Frequency of Respite Use by Caregivers in One Year

Scale	<u>0</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
Frequency	2	6	13	5	2	2
Percentage	7	20	43	17	7	7

0 = No respite: 1 = 2 hours or less per week: 2 = 2 to 4 hours per week: 3 = 5 hours per week including paid help and adult day care: 4 = 1 to 2 week block of respite or regular paid help: 5 = 1 week block of respite and weekly paid help.

Validity of Themes and Categories

The process of establishing validity in qualitative research is to be certain that the conclusions drawn are consistent with the participants' viewpoints. A scale, therefore, was constructed to determine how well caregivers agreed with the researcher's themes. Each major category or theme was given a name and a statement was attached to the name that best represented the researcher's understanding of what caregivers had conveyed (see Appendix D). The caregivers were asked to rate each theme as to how true it was for them (0 being not true and 5 being true for me). To strengthen the validity of the themes, CI and PI participants' responses were compared; in addition, the total group response was compared with 3 support groups of caregivers of

nonveterans. There were no significant differences in mean scores of the CI and PI groups which was interpreted as meaning that the categories were equally applicable to the two groups in the study. However, in comparing the total study group (SG) sample with the caregiver support groups (CSG), with the necessary and imposing categories (in later analysis combined into imposing) and the ease category (later to become the core category of conservation) there were significant differences in the mean scores (see Table 15).

Table 15

Themes Scale Differences Between Groups.

THEME	COMPARISON BY TYPE OF RECEIVER GROUP			COMPARISON OF STUDY GROUP (SG) AND CAREGIVER SUPPORT GROUP (CSG)		
	CI (n=15)	PI (n=15)	p	SG (n=31)	CSG (n=27)	p
	$\bar{x}$	$\bar{x}$		$\bar{x}$	$\bar{x}$	
Knowing	4.2	3.9	.56	4.1	3.7	.253
Necessary	3.6	4.1	.31	3.8	2.9	.024*
Imposing	4.4	4.3	.96	4.3	3.3	.015*
Matching	4.0	4.0	1.00	4.0	4.1	.897
Timing	4.1	3.7	.41	3.9	3.6	.346
Easier not to	4.4	4.7	.17	4.1	3.2	.042*

CI = Cognitively impaired group; PI = Physically impaired group;  
\* indicates p value of .05 or less.

The caregiver support groups (CSG) were also significantly different than the study group (SG) on demographic variables. The mean age of the CSG was younger than the SG, 61 years and 68 respectively,

had more men as caregivers (7 of 26 compared to 2 of 30), had more daughters (15 of 26 compared to 4 of 30), and more did not live with the recipient (10 out of 26 in the CSG group and 1 out 30 in the SG). Only selected demographic variables were requested from the CSG group so variables such as the recipient's type of impairment, the functional ability of recipients, and whether the caregivers were primary or secondary were not known.

There were several group members within each CSG who told the researcher that they still were coming to the group even though the recipient had died or was now in a nursing home. The fact that there were more caregiver daughters in the CSG may have accounted for fewer feelings of imposing on others; even within the SG, caregiver daughters often requested assistance from husbands and children, while spouse caregivers did not have those options. The easier not to category might be different because those who attend caregiver support groups already have made considerable effort to gain assistance and are being encouraged by group facilitators to persist in acquiring respite. The knowing and matching categories remained salient (as indicated by the lack of statistical significance) for the CSG group despite demographic differences with the SG.

#### Reliability Measures

Interrater reliability measures were used to protect against researcher bias in attaching codes to segments of the transcribed interviews. After developing a code book and definitions of each of the categories listed in Table 15, six interviews (10%) were chosen randomly and coded independently by two coders. Total percentage agreement,

percentage of nonoccurrence, and kappa measures were computed. Total percentage agreement ranged between 80% and 84% among the categories. In qualitative research 70% is considered acceptable. Kappa ranged between .48 and .57. Kappa protects against naming a category by chance and figures close to .50 are considered the most acceptable (Topf, 1986).

When the three themes and one core category were developed, a panel of three experts knowledgeable about the caregiving literature and experienced in work with caregiving families were consulted. Through discussion and consensus building, the choice and logic of the themes and core category were examined and found to be congruent with the experience and knowledge of the experts.

#### Results of the Quantitative Analysis

The scales used to evaluate the health of respondents were (a) the Subindex for Physical Health (PH) of the Philadelphia Geriatric Multilevel Assessment Instrument (Lawton, Moss, Fulconer, & Kleban, 1982); (b) the Affect Balance Scale - ABS (Bradburn, 1969) for emotional health; (c) a single item rating scale for the frequency of visitors - (FV), and (d) Part II of the Personal Resources Questionnaire - PRQ (Brandt & Weinert, 1981) to assess social health of the respondents. On all of these scales more of the attribute is indicated by higher scores on the scale.

The scales were administered to caregivers at each of the interview times (three times at two-month intervals over a six-month period). Internal consistency using Cronbach's alpha was computed on

each of the ABS and PRQ scales for each of the interview times and compared with those achieved by the originators of the scales.

The Cronbach's alpha for the ABS scale ranged from .59 to .67 on the study sample compared to .83 to .86 in Bradburn's (1969) research and .80 to .90 in Mariwaki's study (1974). Bradburn's research consisted of testing the scale on five samples with mean ages of 21 to 59 years. In Mariwaki's study the sample mean age was 68, the same as the sample in this research. The lower reliabilities for the current research sample needs examination. On the PRQ Scale, Cronbach's alpha for internal consistency was comparable to Brandt and Weinert's (1981) work (alphas of .81 to .91 for older adults). Means and ranges on the ABS and PRQ scales were comparable to those reported for other studies of caregivers and older adults.

The Mann Whitney U test was computed on each of the four scales (PH, ABS, FV, and PRQ) for each of the three interview times, and no significant differences were found between the CI and PI groups. Because one third of the study participants were in a nursing home by the end of third interview, the Mann Whitney U test also was computed on the final interview to determine if there were significant differences in the four measures between those who were admitted to the nursing home and those who were not. No significant differences were found.

Paired t-tests were calculated to compare interviews 1 and 2, 2 and 3, and 1 and 3 for the total group. The results did not indicate a pattern of change over time. The means and ranges of scores for the PH

scale, the PRQ, and the ABS were comparable to those found in other studies of caregivers and older adults (Brandt & Weinert, 1981; Gwyther & George, 1986; Lawton, Brody, & Saperstein, 1989).

Pearson correlation coefficients were computed for the PH, ABS, FV, PRQ, Activities of Daily Living (ADL), Mini Mental Status Exam (MMS), and the Respite Scale (RESP) for the total group (n=30) at each of the three interview times. At interview 1 there was a significant positive correlation ( $r = .58$ ,  $p \leq .0001$ ) between positive affect (ABS) and perceived social support (PRQ) and a significant negative correlation ( $r = -.47$ ,  $p \leq .03$ ) between ADL and FV (more ADL deficits were associated with fewer visitors). The same correlations were not significant at times 2 and 3.

At time 2 and 3 interviews there were significant positive correlations between physical health and positive affect (time 2,  $r = .43$ ,  $p \leq .03$ ; time 3,  $r = .41$ ,  $p \leq .04$ ). There were also significant positive correlations between FV and PRQ (time 2,  $r = .46$ ,  $p \leq .02$ ; time 3,  $r = .39$ ,  $p \leq .05$ ). All significant correlations were in the expected direction.

#### Triangulation of the Data

Triangulation of the data consisted of comparing the qualitative data results with those of the quantitative measures. The standard quantitative measures utilized did not detect any differences between the CI and PI groups. Quantification of the qualitative data gave evidence that knowing was significantly different in the number of times it was used by CI caregiver group. The CI discussed knowing more and for longer periods of time. The analysis of the qualitative data

revealed a difference in content in that the CI group's explanations of the intricacies of interpreting nonverbal behavior was not a part of the PI group concerns.

In the quantitative analysis of changes over time on standard measures there were no significant trends in a positive or negative direction on any of the measures. However, in the qualitative data there were many dramatic changes. Recipients as well as caregivers had acute episodes of care in the hospital, and one third of the recipient sample were admitted to nursing homes by the end of the study. Even when examining the data case by case, changes in the caregivers' and recipients' lives were not reflected, as anticipated, in the scores (e.g. when important helpers moved away the perceived social support did not change; when recipients were admitted to nursing homes the Affect Balance Scale did not show more or less negative or positive affect).

The quantitative data did not detect the types of differences and changes that were found in the qualitative data. The qualitative data were not specific enough to quantify some of the factors that might indicate significant changes. Neither the quantitative data nor the qualitative data are sufficient by themselves. Each adds a different perspective. The lack of association of the quantitative data with the qualitative findings, however, does indicate that other quantitative measures need to be examined for use in future studies of caregivers.

The lack of change in the quantitative measures in relationship to changes in the lives of the caregivers indicates that quantitative measures chosen to use in conjunction with longitudinal studies need to be those that have proven to be able to detect changes over time.

Prior use of the scales in this study had been in cross sectional designs only. The lack of changes in these results suggests that the scales in this sample may be measures of traits more so than states or that the sample size was too small to detect changes. However, more plausible interpretations are that (a) social desirability influenced the caregiver's responses, (b) six months was too short of a time to capture change, or (c) all of the caregivers were in the later phase of caregiving (already having adjusted emotionally and socially to the time consuming nature of caregiving) and were not in a transition phase in which changes in scores would have been likely. The last of the interpretations is the most plausible interpretation from the investigator's point of view.

## CHAPTER VI: SUMMARY, DISCUSSION, AND RECOMMENDATIONS

The purpose of the study was to explore the facilitating and inhibiting factors in the use of respite by caregivers of frail elders. This chapter contains a summary of the research, a discussion of the findings, implications for nursing and health services, limitations and strengths of the research, and recommendations for future research.

### Summary

The theory of Processes in Utilizing Respite, was an empirically grounded analysis of the ways caregivers thought about respite. The knowing, imposing, and matching processes captured the ways by which they thought about any given opportunity for respite. Conserving energy and resources was the core meaning that guided caregivers in considering the potential effects of accessing or using respite.

Knowing considerations arose out of past shared experiences of the caregiver and recipient that were not apparent to others unless time was taken to invite the caregiver to share her concerns about what she knew and considered important. The caregivers' anticipation of needs of recipients with physical impairments and interpretation of the nonverbal behavior of recipients with cognitive impairments were central concerns in the knowing process.

In requesting or accepting respite from persons in their informal networks, caregivers carefully weighed how such experiences affected future relationships. Social norms were applied as to what was expected

of themselves, their families, friends, neighbors, and informal organizations. Imposing was the word most often used to identify when social boundaries were crossed in either direction. The caregiver considered requesting respite as an imposition when it did not qualify as necessary. If respite was offered and accepted, physical care of the recipient was not expected. By the same token, the caregiver considered it an imposition for her family and friends to give her unsolicited advice about managing the recipient's care. She viewed caregiving as her domain.

Caregivers considered formal agencies as legitimate sources of respite and provision of personal care. However, clinicians were unfamiliar with the difficulties of utilization for the caregiver (e.g. talking the recipient into coming, rural access, and dealing with recipient's behavior after the respite episode). Because agency personnel offered minimal solutions to problems in utilization, caregivers considered themselves an imposition if they could not access formal respite without assistance particularly when the service was offered without cost. Experiences with in-home nonagency paid personnel often were reported as negative because of poor matches with the recipient and helper behaviors that imposed on the caregiver and recipient's privacy.

Matching the recipient with a helper took place outside the normal social expectations of informal and formal agencies. Caregivers looked for persons who were exceptional in their ability to perceive what was needed without an explanation. Positive matching occurred on a few occasions with informal helpers because caregivers had consistent

contact with a particular helper. Just being able to do the physical care tasks did not suffice as a match. The social and emotional component of interactions also needed to match for the caregiver to accept the helper. Use of formal agencies took consistent effort on the part of the caregiver in acquisition and monitoring services. In addition, skill was required in developing strategies to effect a match (e.g. coaching agency personnel and the recipient in adjusting to one another).

Maintaining and protecting her own energy and that of the recipient were primary to the caregiver. By so doing she was able to meet the day-to-day demands of care and gain the cooperation of the recipient. In addition, sustaining social and economic resources were paramount to survival. If social relationships were imposed upon, she feared that they might not be available at a future time when the need may be even greater.

Despite the many barriers to respite, caregivers in the study remained alert to respite opportunities that did not involve the work of planning ahead and imposing on others. All caregivers were able to name at least one example of respite that occurred in which little effort was expended, impositions on others were at a minimum, and a caregiver and helper match were achieved. Using the processes in utilizing respite to examine both successful and unsuccessful respite occurrences aided in identifying the essential elements common to caregivers.

Ideally, the purpose of respite is to provide the caregiver with opportunities for restoring her energy and maintaining her social network, conditions that are supportive to physical and psychological

health. Yet in reality, both informal and formal opportunities for respite usually required more energy to acquire and maintain than the caregiver normally would expend in the usual process of caregiving. The force of social constraints that inhibited the caregiver from acquiring adequate respite, requires an integration of the findings within the perspective of symbolic interactionism and prior caregiving literature.

### Discussion

Symbolic interactionism takes into account the entire social environment and the interplay of factors that are common to society and those unique to the individual. It encompasses factors currently existent as well as the meanings that are reconstructed within ongoing interactions. The concepts of context, socially constructed meaning, and the emergent and negotiated nature of interactions are used to expand and compare the ways in which the themes of knowing, imposing, matching, and conservation of resources and energy are related to the caregiving and respite literature.

#### Context of Family Caregiving

In prior literature the consensus has been that assistance from the informal system is more likely in rural settings than in urban settings and that assistance is more likely when helpers are in closer proximity to the caregiver (Froland et al., 1981; Scott & Roberto, 1985). In this study, respite was not analogous to other types of assistance. Respite was used rarely and when used occurred in a different manner than other types of assistance.

Although sources of respite needed to be present for a possibility of respite to exist, the rural or urban nature of the setting was only important in that rural settings did not have formal respite services in place. The one occasion in which there was a formal program, there was no transportation provided and it was not used. Respite was not more available from informal sources.

Proximity as a factor influencing respite use occurred only in conjunction with defined circumstances. Persons in close proximity who were most likely to be sources of respite (kin) were already being used for the necessary assistance such as shopping, transportation, and home maintenance. Even when the helper lived in the same residence, the caregiver was reluctant to leave, except for short periods to run necessary errands. The most optimal situations were ones in which the helper: (a) lived next door so, while still at home, could see the residence of the recipient and watch from a distance, (b) knew the recipient well, and (c) was caring for someone with a similar impairment, and the caregiver could reciprocate. These circumstances only occurred twice, one in a rural setting and the other in an urban setting.

Another type of respite occurrences was when relatives or friends came to visit from a long distance. In four cases more than one visitor came so that the caregiver could go out with one while others remained at the house with the recipient. In addition, three of the caregivers traveled out of state with the recipient to provide respite to other family members involved in caregiving. In these types of respite, proximity was clearly not a factor.

### Social Constructed Meaning of Family Caregiving

While types of assistance other than respite were frequent among the study participants, respite was a rarity. One cannot make sense of the reason for lack of use of respite except through examination of socially constructed meanings related to respite. The caregiver's viewpoint that asking for respite was imposing grew out of the meaning of social roles and social boundaries within the fabric of the larger society. The social norm of independence, the relegation of personal care to women, the social roles of spouse and daughter caregivers, and the complexity and multiplicity of tasks related to respite worked together to inhibit caregivers from seeking respite or utilizing sources of respite available.

### The Social Norm of Independence

The social norm of independence was expressed by caregivers as not wanting to impose on, inconvenience, or be a burden to others. The strong constraining force to seeking assistance from others could not have occurred in a societal context in which interdependence was the expected social norm. The high value attached to independence and individualism had a pronounced effect on the interactions between the caregiver and recipient as well as the caregiver and helper. The efforts taken by the caregiver not to let the recipient know that he was dependent on her for care was considered necessary to protect the recipient from feeling ashamed for needing assistance. Such behavior reflects a social norm of protecting the other person from unpleasant

realities and fostering an image that nothing has changed. In Strauss' (1975) words, the caregivers used normalization behaviors to minimize the appearance of social dependency.

The norm of independence was enforced by recipients with physically impairments who refused to let persons other than the caregiver see how dependent they were and, in the case of recipient's with cognitive impairments, was enforced by the caregiver so that others would not see how dependent the recipient had become. Assistance with care was more acceptable if the caregiver was present because she could monitor helpers and prevent the recipient from experiencing too much embarrassment. The intimate nature of caregiving requirements was a strong inhibitor of seeking respite, but equally important was the social norm of not being a burden to those outside the caregiving relationship. Family members might be considered only if respite did not inconvenience them, but neighbors or friends were not within the realm of socially acceptable avenues for respite. If the caregiver was not aware of this type of social norm, it was quickly brought to her attention by nonverbal and verbal communication by others about the unacceptability of the dependence of the recipient to the potential helpers.

#### The Specificity of Gender Roles

More constraining than the societal expectation of independence, is the specificity of the roles and tasks assigned to women within society. Caregiving literature is replete with illustrations of how caregiving is assigned primarily to women (Finch & Groves, 1983;

Seelbach, 1977; Ward, 1987; Zarit & Zarit, 1986). Moreover, respite as regular planned time off for rest and relaxation is not part of the family role expectation for women caregivers of family members. Twenty-four hours a day and seven days a week are the norms. In the larger society employment outside the home carries with it expected days off and vacation times for purposes other than work-related activities. For women in family caregiving, no such societal expectation exists. The pervasiveness of the belief that as family caregivers women are expected to be always available was shown consistently in these data. Not a single caregiver expected relief from caregiving on a regular basis. Except for the purpose of carrying out specific and delimited activities related to caregiving, respite was considered a luxury. These findings provide strong support for Graham's (1983) contention that the caregiving role expected of women has four seminal characteristics: (a) heavy focus on concerns and needs of the another person, (b) labor-intensive activity covering a 24-hour day, (c) stressful and demanding of the caregiver's time and energy, and (d) invisible, devalued, and privatized.

The other major societal barrier to respite was the task assignment of personal care to women, especially the touching involved with toileting and hygiene. Although past caregiving literature has noted that there were a significant number of men who did the personal care as part of a spousal caregiving relationship, there was always a great deal of sympathy expressed for the men because this is not their usual role. In addition, there were many more offers for assistance with such roles both from informal and formal sources because

such roles were not expected of men (Froland et al., 1981; Seelbach, 1977; Wright, 1983). For women personal care was expected both in wife and daughter roles. The exclusivity of personal care as the role of the caregivers, required that respite from informal sources be short enough periods to avoid personal care being given by the helper. The anxiety experienced by caregivers in transgressing these social norms was pronounced as expressed both in the importance of knowing the recipient and not imposing on others.

If the caregiver's own discomfort with assigning her role responsibilities to someone else were not enough, potential helpers made clear their own discomfort with taking on personal care. Nonverbal behaviors of potential helpers (e.g. avoiding personal contact with and averting their from the recipient) conveyed to caregivers that helpers viewed personal care as distasteful and repulsive. The caregiver was frequently admonished by potential helpers to obtain help from the formal system if she could not manage rather than to inconvenience them. These messages were conveyed as frequently by kin as by friends or neighbors. The intimate and difficult nature of personal caregiving makes the acquisition of respite almost an impossibility given the established societal norms.

#### Differences and Similarities in Wife and Daughter Roles

Specificity of societal roles for wives and daughters as caregivers has been well delineated in the caregiving literature (Archbold, 1980; Barush, 1988; Brody, 1981, 1985; Cantor, 1983). Investigators found that wives invoked the phrase "in sickness and health" as the societal expectation for care of their spouse, whereas

there was more societal permission to forego caregiving by daughter caregivers particularly if the daughter was married. Investigators have also explored the role issues of caregivers in spousal and daughter caregivers.

Stress was reported to be greater for daughter caregivers because they had competing roles, while wives did not have so many roles (Cantor, 1983). Roles, respite, and imposing took on additional meaning as wife and daughter differences were considered. Daughter caregivers married to persons other than the recipient all experienced role conflicts (a tension between role of caregiver and other roles). Three of the husbands had major illnesses so that respite was obtained to be with the husband. In addition, in the life of the daughter caregivers, their adult children had events occurring such as major surgery, divorces, or deaths in the family that the daughter caregiver felt needed attention as well as caregiving. Informal helpers were used for respite in all of these cases but caregivers worked hard not to have the informal helpers do personal care. In all instances when personal care was required of kin helpers, the helper expressed discomfort about doing the personal care to the extent that the caregiver was reluctant to ask the relative a second time.

Wife caregivers more often experienced role strain (too much to do within a single role). Despite fatigue and in five cases major illnesses of their own, they did not feel comfortable asking the next generation for respite and rarely did so. However, there was a great deal of overlap with role conflict being of concern with wife caregivers as well as daughter caregivers. Half of the spouse caregivers had role

conflicts equivalent to those of daughter caregivers. These included caring for persons other than the recipient, involvement in their own children's lives, and employment. Thus the supposition in some caregiving literature that spouse caregivers wives have to fulfill only one role was not born out in this study.

#### The Complexity and Multiplicity of Factors

All of the identified factors worked together to make the complexity of obtaining adequate respite particularly difficult. Considering the expectation that women provide personal care and the strong feeling caregivers had of being an imposition, obstacles to respite became exponentially multiplied when more than one factor had to be taken into account. When the spouse caregiver was not strong or did not drive, two helpers were required to effect respite rather than one (one to be with the caregiver, and one with the recipient). If the caregiver wanted to be out with a friend, schedules which fit with the best time for the friend, the time when the caregiver had the energy, and the time that the recipient would be the least trouble to the helper were all taken into account. Having all these factors work together smoothly meant being explicit about what was needed which exposed the caregiver's dependency needs as well as increased feelings of being an imposition.

Formal agency assistance was a socially acceptable choice, particularly if nurses who did formal care were the helpers. However, caregivers believed that when respite was offered, agency personnel were unaware of the number of steps and difficulty involved in arranging a time and getting the recipient to accept it. The coordination of

schedules, health of the caregiver and recipient, getting the recipient to cooperate, and the nuances of what needed to be done while the caregiver was gone were invisible tasks to formal agency personnel. If the person offering assistance did not show sensitivity to these issues, the caregiver felt it was an imposition to ask. Also because, respite was not an expected service, in all but one case that respite was used, the service was offered rather than requested.

Several caregivers viewed seeking formal assistance as an admission to role failure. Most caregivers viewed going to the formal system as being "a burden to society" and cited readings they had done or television programs which had conveyed the message that the elderly were a problematic to society. These messages further strengthened the caregiver's resolve to use the least assistance possible.

Finally, the social construction of formal systems of care was not amenable to providing the type of care that the caregiver deemed necessary. Tasks needing attention if she were not in attendance were divided among several sources, often each with different criteria. Societal relegation of specific types of tasks for each worker meant that for a single block of time, several persons would be required to perform what the caregiver usually did without assistance. In other words, the task division of labor of the formal system did not match with the whole person needs of family caregiving.

#### Emergent and Negotiated Nature of Respite Use

Most relevant to the emergent and negotiated nature of respite use were the processes of knowing and matching. These processes were outside the realm of most people's understanding who were not involved

intimately with the caregiving dyad. The tasks required during respite did not conform to usual social roles. Role making was constantly occurring as a result of the changing dynamics of the caregiving situation. The time involved, day-to-day negotiations, and extent of care was invisible to outsiders. The knowing component meant that familiarity with the recipient was necessary to be sensitive to changes that might indicate a need for more or less assistance. Both knowing and matching distinguished respite from other types of assistance in which the caregiver was present to be an interpreter and coach the helper.

The invisible nature of ongoing care has been delineated clearly by Bowers (1987) as those things done to anticipate needs, negotiate with others in supervision of care, and monitor the needs. The knowing adds yet another dimension because it necessitates a unique knowledge of the recipient. For recipients with cognitive impairment the knowing for caregivers weighed heavily in the use of respite. Difficult as it was to obtain a match between helper and recipient with a physical impairment, it was even more so when nonverbal clues had to be translated and socially unacceptable behaviors had to be tolerated. In either case, for a respite source to be utilized required gaining familiarity with the recipient which required maintaining contact on a regular basis to become acquainted with the variations in behavior and be able to anticipate needs. A role relationship with specified tasks could not be assigned but had to be recreated continually as the recipient's condition changed.

Formal care structures are tailored to provide intermittent acute care. This type of care is short term and fragmented and thus not conducive to the type of knowing needed in the long-term management of severely disabled\* elders. Conditions and health of caregivers, recipients, and informal helpers changed frequently within the year of the study. Because of the absence of both informal and formal structures that accommodate to the dynamic nature of long term caregiving, a consistent ongoing and regularly used source of respite was nonexistent among the caregivers.

Perhaps, caregivers' wisdom in conservation of resources and energy was the best that could be achieved given the current state of social norms and available services. In the larger societal context, however, the longer term effect of lack of respite is relevant to the emergent and negotiated meaning of caregiving. Caregiving spouses and daughters often had yet to accrue enough income for their own retirement. Caregiving meant that opportunities for work or advancement were either limited or foregone due to the increased demands of caregiving. Thus, the consequences of not having the type of respite that could accommodate to their working career meant that conservation that made sense in the short range view, made impossible longer range security that comes with being able to buy needed services in old age. Long term financial consequences for both male and female caregivers has already been well documented (Baldwin & Glendinning, 1983; Rimmer, 1983; Ward, 1987; Wright, 1983) and was also a concern of caregivers in this study. The two male caregivers in this sample had both curtailed their

work due to caregiving and one felt his future financial stability was in serious jeopardy due to the caregiving demanded. It is evident that the processes of utilizing respite resources that are adaptive to immediate survival may not in the long run create optimal conditions for either the caregiver or society.

#### Implications for Nursing and Health Services

Explication of processes in utilizing respite resources within the theoretical perspective of symbolic interactionism contributes to nursing science by adding knowledge of factors that affect the individual in interaction with the environment in response to health and illness. Conservation of resources and energy is the caregiver's adaptation to illness care of the recipient. The processes involved provide direction for an approach to providing care for the caregiver and recipient. Specific elements of each caregiving dyad being highly individualized necessitates a theory that identifies the components of caregiving extant to the caregiver and the underlying drive that organizes the individual components. The processes in utilizing respite take account of the social environment as a powerful influencing force.

The current adaptive pattern of conserving resources and energy frequently works to the detriment of both the caregiver's and recipient's health but presently it is the chosen alternative given the current societal context. Implications for nursing practice extend beyond the usual caregiver considerations when respite is involved. Leaving the person in the care of another and for enough time for the

caregiver to acquire the benefits of social contacts, work endeavors, and rest requires a different type of approach than that of alleviating the caregiver of certain tasks while the caregiver is present.

The findings identify alternative approaches to delivery of health care services. The theory supplies insight into the way the current health care system's deliver of respite is perceived by caregivers and recipients of care. Helpers in the formal system are not yet sensitive enough or accessible enough for caregivers to consistently find them to be of assistance. Knowing the recipient is of equal importance to knowing the caregiver in the initial assessment to determine the difficulties in access and finding ways to ameliorate them. Developing ways of structuring services to be less fragmented, imposing, and exhausting of the caregivers energy and resources are clearly indicated.

Matching recipient to helper and setting is perhaps the biggest challenge. Varied types of respite need to be available that accommodate to the changing circumstances of caregiver and recipient. Programs that provide continuity of contact are needed to for matching to occur and to adjust services to the clients condition and caregiver needs over time. The interdisciplinary nature of health services is conducive to promoting health care practitioners who can accomplish tasks which cross usual work role boundaries and thereby require that fewer providers be in the home setting where privacy and independence is prized.

Economic considerations must go beyond the value of respite being for the purpose of delaying nursing home admissions. Such admissions have probably already been too long delayed. Cost of care must include the accounting of missed work days, reduced amount of work, lack of retirement benefits, and the long term consequences for the caregiver. Current economic losses today mean a greater cost for society in the future accruing from the neglected caregivers, particularly women, who will be tomorrow recipients lacking in funds to maintain themselves and lacking the quality of care they deserve after having given freely of their time to prevent others from being burdened by the care that they gave.

#### Limitations and Strengths

The limitations of this research related primarily to the characteristics of caregivers, and the way in which respite was defined. The research sample contained mostly women, all of whom were married. All except one caregiver was married and lived with the recipient and provided direct care. Although there was one Filipino and four Afro-American caregivers, the research did not address cultural differences. Caregivers were predominately low to middle income women caring for severely disabled recipients. All caregivers were in the late stages of a prolonged caregiving career. The characteristics of the caregivers, their situations, and the stage of caregiving need to be taken into account and may require adjustment in applying the theory to caregivers with different characteristics (e.g. early stage caregivers, single women, and men).

Respite in other caregiving literature is often defined to include types of relief during which the caregiver is present to assist or advise. Because of varying definitions of respite, comparing other studies with this one needs to be done with attention to how respite is defined.

The major strength of the research grew from defining respite as only occurring when the caregiver was not present. Using this definition brought to light the processes that most apply to time off from caregiving in apposition to having help with tasks. Thus, respite was differentiated from other types of activities that relieve the caregiver. The research added to theory development for understanding the interaction between social networks and health service providers that create difficulties for caregivers in acquisition of respite. These understandings may be applicable to a wider range of long-term caregivers including those who care for chronically disabled children.

#### Recommendations for Future Research

Suggestions for future research address the need for stating clearly the purpose and definition of respite, testing of long term respite programs that are well integrated with other types of assistance, and looking at larger and more varied groups of caregivers.

The purpose of respite is to provide time away from caregiving that can be used for rest, leisure activities, time with friends and

family, and work. All of these purposes need to be met when desired for respite to be considered adequate. If caregiving does not constrict any of these activities then enough time away is already occurring and other types of help than respite may be more appropriate. The essential element of the definition is that the recipient is being cared for by someone else without the caregiver being present. Definitions need to be consistent across studies for strengthening the findings.

Long term intervention studies which contain model services of well coordinated on going care need to be developed with qualitative and quantitative components. The processes in utilizing respite theory can form the nucleus of evaluating services qualitatively. Consistent methods of defining and quantifying the amount of respite can assist in comparing studies with one another. Costs need to be monitored for employment time and benefits lost by caregivers, as well as the cost of providing services.

A wide variety of caregivers need to be studied at the same time to determine how services can best be tailored to different groups. Young caregivers who care for disabled children need to be included in the same studies as caregivers of older adults to help dispel the myth that the elderly are the only ones in need long term assistance and to evaluate the true cost to society of all the work of caring that women do over the course of the life span.

The amount of caregiving preformed in the home today is a new and unprecedented phenomenon which has come to our awareness only in the last decade. The numbers receiving extensive care at home has expanded in proportion to the rest of the population due not only to increased

numbers achieving old age, but to infants with severe impairments living into adulthood, shorter stays in the hospital for acute illness, and highly sophisticated chronic illness care being delivered in the home. The difficult nature of the care provided and amount of time consumed providing care is largely invisible to those not directly involved. The extent of care needed for all disabled persons when restricted to the home setting, confines the caregiver as well as the recipient and limits opportunities for both. In addition, society loses important contributions of the persons who must expend much of their time and expenses to caregiving. The current system of health care delivery offers only intermittent relief for long periods of difficult care.

Only by careful descriptive research that makes visible what now goes on behind closed doors, and that quantifies the magnitude of the cost to society beyond health care dollars can attention be brought to the issues. Investment made now in identifying the issues and uniting persons involved in caregiving is imperative as the pool of persons in the age groups providing care decrease in proportion to those needing assistance. Although it is true that the heaviest demands are made upon women, segregating and identifying one gender or age group as needing all the attention obscures the real magnitude of caregiving that is occurring and expanding across the life span of men and women in all age groups. Investigators planning research need coordination of effort to clarify the way in which each group is affected.

## References

- Allen, M., & Yen, W. (1979). Introduction to measurement theory. Monterey, CA: Brooks/Cole Publishing Co.
- American Nurses' Association (1980). Nursing: A social policy statement. Kansas City: American Nurses' Association.
- Archbold, P. (1980). Impact of parent caring on middle-aged offspring. Journal of Gerontological Nursing, 6 (2), 78-85.
- Archbold, P. (1982). An analysis of parentcaring by women. Home Health Services Quarterly, 3(2), 5-25.
- Archbold, P. (1983). Impact of parent-caring on women. Family Relations, 32, 39-43.
- Archbold, P., & Stewart, B. (1987). Preliminary report of caregiver relief study. Presentation at teleconference of northwest regional nursing faculty. Portland, Oregon: Oregon Health Science University.
- Archbold, P., Stewart B., Harvath, T., & Lucas, S. (1987). New measures of concepts central to an understanding of caregiving. Portland, OR: Oregon Health Science University.
- Baldwin, S., & Glendinning, C. (1983). Employment, women and their disabled children. In J. Finch, & D. Groves (Eds.), A labour of love: Women, work and caring (pp. 53-71). Boston: Routledge & Kegan Paul.
- Barusch, A. (1988). Problems and coping strategies of elderly spouse caregivers. Gerontologist, 28, 677-685.
- Berkman, L.F., & Syme L. (1979). Social networks, host resistance, and mortality: A nine-year follow up study of Alameda County. American Journal of Epidemiology, 109 (2), 186-201.
- Berman, S., Delaney, N., Gallagher, D., Atkins, P., & Graeber, M. (1987). Respite care: A partnership between a veterans administration nursing home and families to care for frail elder at home. Gerontologist, 27, 581-584.
- Biddle, B., & Thomas, E. (1966). Role theory: Concepts and research. New York: Wiley.
- Birkel, R., & Jones, C. (1989). A comparison of the caregiving networks of dependent elderly individuals who are lucid and those who are demented. The Gerontologist, 29, 114-119.
- Blumer, H. (1969). Symbolic interactionism: Perspective and method. Englewood Cliffs, NJ: Prentice-Hall.

- Bolton, C. (1981). Some consequences of the Meadian self. Symbolic Interactionism, 5 (2), 245-259.
- Bowers, B. (1987). Intergenerational caregiving: Adult caregivers and their aging parents. Advances in Nursing Science, 9 (2), 20-31.
- Bradburn, N. (1969). The structure of psychological well-being. Chicago, IL: Aldine Publishing Co.
- Branch, L., & Jette, A. (1982). The Farmingham disability study: I. Social disability among the aging. American Journal of Public Health, 71, 1202-1210.
- Branch, L., & Jette, A. (1983). Elders use of informal long-term care assistance. Gerontologist, 23, 51-56.
- Brandt, P., & Weinert, C. (1981). The PRQ - A social support measure. Nursing Research, 30, 277-280.
- \_\_\_\_\_. British Medical Journal (1986). 292, pp. 240 & 481-483 (Short report and letters to the editor).
- Brody, E.M. (1981). Women in the middle and family help to older people. Gerontologist, 21, 471-480.
- Brody, E.M. (1985). Parent care as a normative family stress. Gerontologist, 25, 19-29.
- Brody, S., Poulshock, W., & Masciocchi, C. (1978). The family caring unit: A major consideration in long-term care. Gerontologist, 18, 556-561.
- Bruning, J., & Kintz, B. (1977). Computational handbook of statistics, (2nd edition). Glenview, IL: Scott, Foresman & Company.
- Burdz, M., Eaton, W., & Bond, J. (1988). Effect of respite care on dementia and nondementia patients and their caregivers. Psychology and Aging, 3(1), 38-42.
- Burr, W.R., Leigh, G.K., Day, R.D., & Constantine, J. (1979). Symbolic interaction and the family. In W. Burr, R.Hill, R.I. Nye, & E.L. Reiss. (Eds.), Contemporary theories about the family, Vol II (Chapter 2, pp. 42-107). New York: New Haven Press.
- Cantor, M.H. (1983). Strain among caregivers: A study of experience in the United States. Gerontologist, 32, 597-604.
- Caplan, G. (1974). Support systems and community mental health. New York: Behavioral Publications.

- Caserta, M., Lund, D., Wright, S., & Redburn, D. (1987). Caregivers of dementia patients: The utilization of community services. The Gerontologist, 27, 209-214.
- Chappell, N. (1985). Social support and the receipt of home care services. Gerontologist, 25, 47-54.
- Cicirelli, V. (1983). A comparison of helping behavior to elderly parents of adult children with intact and disrupted marriages. Gerontologist, 23, 619-625.
- Clark, M. (1983). Some implications of close social bonds for help-seeking. In B. DePaulo, A. Nadler, & J. Fisher (Eds.), New directions in helping: Help-seeking (Vol. 2) (pp. 205-232). New York: Academic Press.
- Clark, N., & Rakowski, W. (1983). Family caregivers of older adults. Improving helping skills. Gerontologist, 23, 637-642.
- Cobb, S. (1976). Social support as a moderator of life stress. Psychosomatic Medicine, 38, 300-314.
- Coe, W., & Sarbin, T. (1977). Hypnosis from the standpoint of the contextualist. Annals of the New York Academy of Sciences, 296 (October), 2-13.
- Cohen, S. (1982). Supporting families through respite care. Rehabilitation Literature, 43, 7-11.
- Cohen, S., & Syme, S.L. (Eds.). (1985). Social support and health. New York: Academic Press.
- Cook, T., & Reichardt, C. (1979). Qualitative & quantitative methods in evaluation research. Beverly Hills: Sage Publications.
- Corbin, J.M., & Strauss, A. (1988). Unending work and care. San Francisco: Jossey-Bass Publishers.
- Cornoni-Huntley, J., Borck, D., Ostfeld, A., Taylor, J., Wallace, R. (Eds.). (1986). Established populations for epidemiologic studies of the elderly. U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health, NIH Publication No. 86-2443.
- Crossman, L., London, C., & Barry, C. (1981). Older women caring for disabled spouses: A model for supportive services. Gerontologist, 21, 464-470.
- Denzin, N.K. (1978). The research act: A theoretical introduction to sociological methods (2nd ed.), New York: McGraw-Hill.

- DePaulo, B.M., & Fisher, J. (1980). The costs of asking for help. Basic and Applied Social Psychology, 1, 23-36.
- Dimond, M., & Jones, S. (1983). Social support: A review and theoretical integration. In P. Chinn (Ed.), Advances in nursing theory and development (pp. 235-249). Rockville, MD: Aspen.
- Donaldson, S., & Crowley, D. (1978). The discipline of nursing. Nursing Outlook, 26, 113-120.
- Doty, P. (1986). Family care of the elderly: The role of public policy. Milbank Quarterly, 64 (1), 34-75.
- Eggert, G., Granger, C., Morris, R., & Pendleton, S. (1977). Caring for the patient with long-term disability. Geriatrics, 32 (10), 102-114.
- Feller, B.A. (1983). Need for care among the non institutionalized elderly. Health: United States and Prevention Profile. Md: USDHHS.
- Fengler, A.P., & Goodrich, N. (1979). Wives of elderly disabled men: The hidden patients. Gerontologist, 19 (2), 175 -183.
- Field, M., Moore, L., & Tallman, B. (1989). Bridging the gap: A Demonstration respite care project. Juneau, Alaska: Older Alaskans Commission
- Finch, J., & Groves, D. (Eds). (1983). A labour of love: Women, work and caring. Boston: Routledge & Kegan Paul.
- Fischer, L., & Eustis, N. (1988). DRGs and family care for the elderly: A case study. The Gerontologist, 28, 383-389.
- Folstein, M., Folstein, S. & McHugh, P. (1975). Mini-mental State, A practical method for grading cognitive states of patients for clinicians. Journal of Psychiatric Research, 12, 189-198.
- Foundation for Long Term Care (1983). Respite care for the frail elderly. Albany, New York: The Center for the Study of Aging, Inc.
- Froland, C., Pancoast, D., Chapman, N., & Kimboko, P. (1981). Helping networks and human services. Beverly Hills, CA: Sage Publications.
- Gaitz, C., & Scott, J. (1972). Age and measurement of mental health. Journal of Health and Social Behavior, 13, 55-67.
- Gallagher, D. (1985). Intervention strategies to assist caregivers of frail elders: Current research status and future directions: Annual Review of Gerontology and Geriatrics, 5, 249-282.

- Gatz, M., Boyd, S., & Mellins, C., (1987). Mentally and physically impaired elders: Family consequences. Paper presented at Gerontological Society of American (November, 1987): Washington D.C..
- George, L., & Gwyther, L. (1986). Caregiver well-being: A multidimensional examination of demented adults. Gerontologist, 26, 253-259.
- Gilhooly, M. (1984). The impact of care-giving on care-givers: Factors associated with psychological well-being of people supporting a dementing relative in the community. British Journal of Medical Psychology, 57, 35-44.
- Glaser, B. (1978). Theoretical Sensitivity: Advances in methodology of grounded theory. Mill Valley, CA: Sociology Press.
- Glaser, B., & Strauss, A. (1967). The discovery of grounded theory. New York: Atherton.
- Goffman, E. (1959). The presentation of self in everyday life. Garden City, New York: Doubleday Anchor Books.
- Goldfarb, A.I. (1965). Psychodynamics and the three-generation family. In El Shanas & G. Streib (Eds.). Social structure and the family: Generational relations (pp. 10-45). Englewood Cliffs, NJ: Prentice Hall.
- Goode, W.J. (1960). A theory of role strain. American Sociological Review, 25, 483-496.
- Goodwin L., & Goodwin, W. (1984). Are validity and reliability "relevant" in qualitative evaluation research? Evaluation in the Health Professions, 7, 413-426.
- Gourash, N. (1978). Help seeking: A review of the literature. American Journal of Community Psychology, 6, 413-425.
- Graham, H. (1983). Caring: A labour of love. In J. Finch, & D. Groves (Eds.), A labour of love: Women, work and caring (pp.13-30). Boston: Routledge & Kegan Paul.
- Greenberg, M., & Westcott, D. (1983). Indebtedness as a mediator of reactions to aid. In J. Fisher, A., Nadler, & B. DePaulo (Eds.), New directions in helping: Recipient reactions to aid (Vol. 1). New York: Academic Press.
- Gross, A.E., & McMullen, P. (1982). The help-seeking process. In V. Derlega, & J. Grzelak (Eds.), Cooperation and helping behavior (pp. 305-326). New York: Academic Press, Inc.

- Gross, A.E., & McMullen, P. (1983). Models of the help-seeking process. In B. DePaulo, A., Nadler, & J. Fisher, J. (Eds.). New directions in helping: Help-seeking (Vol. 2) (pp. 47-72). New York: Academic Press.
- Guterman, S., & Dobson, A. (1986). Impact of the medicare prospective payment system for hospitals. Health Care Financing Administration, 7 (3), 97-114.
- Gwyther, L.P., & George, L.K. (1986). Caregivers for dementia patients: Complex determinants of well-being and burden. Gerontologist, 26 (3), 245-247.
- Hildebrandt, E. (1983). Respite care in the home. American Journal of Nursing, 83, 1428-1431.
- Hooyman, N., Gonyea, J., & Montgomery, R. (1985). The impact of in-home services termination on family caregivers. Gerontologist, 25, 141-145.
- Horowitz, A. (1985). Sons and daughters as caregivers to older parents: Differences in role performance and consequences. Gerontologist, 25, 612-617.
- Houlihan, J.P. (1987). Families caring for frail and demented elderly: A review of selected findings. Family Systems Medicine, 5 (3), 344-356.
- House, J., & Kahn, R. (1985). Measures and concepts of social support. In S. Cohen, & S.L. Syme (Eds.), Social support and health (pp. 83-108). New York: Academic Press, Inc.
- Jacobson, D. (1986). Types and timing of social support. Journal of Health and Social Behavior, 27, 250-264.
- Johnson, C., & Catalano, D. (1983). A longitudinal study of family supports to impaired elderly. Gerontologist, 23, 612-618.
- Kahn, R.L., & Antonucci, T.C. (1980). Convoys over the life course: Attachment, roles and social support. Life Span Development and Behavior, 1, 253-286.
- Kane, R.A., & Kane, R.L. (1981). Assessing the elderly: A practical guide to measurement. Lexington, MA: The Rand Corporation.
- Katz, S., Ford, A., Moskowitz, R., Jackson, B. & Jaffee, M. (1963). Studies of illness in the aged. The index of ADL: A standardized measure of biological and psychosocial function. Journal of the American Medical Association, 185, 94+

- Kessler, R. & McLeod, J. (1985). Social support and psychological distress in community surveys. In S. Cohen and S. Syme (Eds.), Social support and health (pp. 19-40). New York: Academic Press.
- Kirk, J. & Miller, M. (1986). Reliability and validity in qualitative research. Beverly Hills: Sage Publications.
- Kivett, V. (1985). Consanguinity and kin level: Their relative importance to the helping network of older adults. Journal of Gerontology, 40 (2), 228-234.
- Krippendorff, K. (1980). Content analysis: An introduction to its methodology. Beverly Hills: Sage Publications.
- Lawton, M., Brody, E., & Saperstein, A. (1989). A controlled study of respite service for caregivers of Alzheimer's Patients. The Gerontologist, 29, 8-16.
- Lawton, M., Kleban, M., Moss, M., Rovine, M. Glicksman, A. (1989). Measuring caregiving appraisal. Journal of Gerontology, 44(3), 61-67.
- Lawton, M., Moss M., Fulcomer, M. & Kleban, M. (1982). A research and service oriented multilevel assessment instrument. Journal of Gerontology. 37, 91-99.
- LeCompte, M., & Goetz, J. (1982). Problems of reliability and validity in ethnographic research. Review of Educational Research, 52, 31-60.
- Lincoln, Y. & Guba, E. (1985). Naturalistic inquiry. Beverly Hills: Sage Publications.
- Litwak, E. (1985). Helping the elderly. New York: Guilford Press.
- Liptzin, B., Grob., M., & Eisen, S. (1988). Family burden of demented and depressed elderly patients. Gerontologist, 28, 397-401.
- Liu, K., Manton, K., & Liu, B. (1985). Home care expenses for disabled elderly. Health Care Financing Review, 7, 51-58.
- Lowenthal, M., & Haven, C. (1968). Interaction and adaptation: Intimacy as a critical variable. In B. Neugarten (Ed.), Middle age and aging (pp. 390-400). Chicago: University of Chicago Press.
- Mace, N. & Rabins, P. (1981). The 36-hour day: A family guide to caring for persons with Alzheimer's disease, related dementing illnesses, and memory loss in later life. Baltimore, MD: John Hopkins University Press.

- Mayer, A. (1966). The significance of quasi-groups in the study of complex societies. In M. Banton (Ed.), The social anthropology of complex societies, A.S.A. Monographs, 4, London: Tavistock Publications.
- McFarlane, A., Norman, G., Streiner, D., Roy, R., & Scott, D. (1986). A longitudinal study of the influence of the psychosocial environment on health status: A preliminary report. Journal of Health and Social Behavior, 21, 124-133.
- McKinlay, J. (1972). Some approaches and problems in the study of use of services: An overview. Journal of Health and Social Behavior, 13, 115-152.
- Mead G. (1932). Time. In A. Strauss (Ed.), (1956). George Hubert Mead: On social psychology (pp. 328-341). Chicago: Phoenix Books, The University of Chicago Press.
- Mead, G. (1934). The self and the organism. In C. W. Morris (Ed.), Mind self and society (pp. 135-226). Chicago: University of Chicago Press.
- Mead, G. (1936). The problem of society - how we become ourselves. In A. Strauss (1956). George Hubert Mead: On social psychology (pp.19-42). Chicago: Phoenix Books, The University of Chicago Press.
- Meltzer, J. (1982). Respite care: An emerging family support service. Washington, D.C.: The Center for the Study of Social Policy.
- Mindel, C., Wright, R., & Starrett, R. (1986). Informal and formal health and social systems of black and white elderly: A comparative cost approach. Gerontologist, 26, 279-285.
- Minkler, M. (1985). Social support and the elderly. In S. Cohen & S.L. Syme, (Eds.), Social support and health (pp. 199-216). New York: Academic Press.
- Mitchell, J.C. (1969). Social networks in urban situations. Manchester: Manchester University Press.
- Mitchell, J.C. (1987). Cities society and social perception. Oxford: Clarendon Press.
- Montgomery, R. (1989). Respite services for family caregivers. In M.D. Petersen & D. White (Eds), Health care of the elderly: An information source book (pp. 382-410). Newbury Park, CA: Sage.
- Montgomery, R., & Borgatta, E. (1985). Family support project: Final report to the administration on aging. Seattle, WA: Institute of aging/Long-Term Care Center, University of Washington.

- Montgomery, R., Gonyea, J., & Hooyman, N. (1985). Caregiving and the experience of subjective and objective burden. Family Relations, 34, 19-26.
- Montgomery, R., Stull, D., & Borgatta, E. (1985). Measurement and analysis of burden. Research on Aging, 7(1), 137-152.
- Moritz, D., Kasl, S., & Berkman, L. (1989). The health impact of living with a cognitively impaired elderly spouse: Depressive symptoms and social functioning. Journal of Gerontology, 44 (1), 517-527.
- Moriwaki, S. (1974). The Affect Balance Scale: A validity study with aged samples. Journal of Gerontology, 29(1), 73-78.
- Munhall, P., & Oiler, C. (1986). Nursing research: A qualitative perspective. Norwalk, Connecticut: Appleton-Century-Crofts.
- National Council on Aging, Inc. (1985). State support for respite care: Report of an exploratory survey. Washington D.C.: Author.
- National Center for Health Statistics (1984). Vital Statistics of the United States: 1979 Volume II - Mortality, Part A. MD: USDHHS.
- Ory, M., Willians, T.F., Emr, M., Lebowitz, B., Rabins, P., Salloway, J., Sluss-Radbaugh, T., Wolff, El, Zarit, S. (1985). Families, informal supports, and Alzheimer's disease: Current research and future agendas. Research on Aging, 7, 623-648.
- Parsons, T. (1967). Sociological theory and modern society. New York: The Free Press.
- Pesznecker, B., & Zahlis, E. (1986). Establishing mutual-help groups for the family-member care givers: A new role for community health nurses. Public Health Nursing, 3 (1), 29-37.
- Petersen, M., & White, D. (Eds.). (1989). Health care of the elderly: An information source book. Newbury Park, CA: Sage.
- Piliavin, I., Gross, A., (1977). The effects of separation of services and income maintenance on AFDC recipients. Social Service Review 389-406.
- Piliavin, J., & Piliavin, I. (1973). The good samaritan: Why does he help? Unpublished manuscript. University of Wisconsin.
- Rakowski, W., & Clark, N. (1985). Future outlook, caregiving, and care-receiving in the family context. Gerontologist, 25, 618-623.

- Rimmer, L. (1983). The economics of work and caring. In J. Finch, & D. Groves (Eds.), A labour of love: Women, work and caring (pp. 131-147). Boston: Routledge & Kegan Paul.
- Robinson, B. (1983). Validation of a caregiver strain index. Journal of Gerontology, 38, 344-348.
- Robinson, B., & Thurnher, M. (1979). Taking care of aged parents: A family cycle transition. Gerontologist, 19 (6), 586-593.
- Rock, P. (1979). The making of symbolic interactionism. London: Macmillan Press.
- Rose, A.M. (1962). A systematic summary of symbolic interactionism theory. In A. Rose (Ed.), Human behavior and social processes (pp. 3-18). Boston: Houghton Mifflin.
- Rosenthal, C. (1986). Family supports in later life: Does ethnicity make a difference. Gerontologist, 26, 19-24.
- Sands, D., & Suzuki, T. (1983). Adult day care for Alzheimer's patients and their families. Gerontologist, 23, 21-23.
- Sanford, J.R. (1975). Tolerance of debility in elderly dependents by supporters at home: Its significance for hospital practice. British Medical Journal, 3, 471-473.
- Scharlach, A., & Frenzel, C. (1986). An evaluation of institution based respite care. Gerontologist, 26, 77-82.
- Schatzman, L., & Strauss, A. (1973). Field research: Strategies for natural sociology. Englewood Cliffs, N.J.: Prentice Hall.
- Scott, J., & Roberto, D. (1985). Use of informal and formal support networks by rural elderly poor. Gerontologist, 25, 624-630.
- Seelbach, W. C. (1977). Gender differences in expectations for filial responsibility. Gerontologist, 17, 421-425.
- Seidel, J., Kjolseth, R., & Seymour, E. (1988). The Ethnograph [Computer program]. Littleton, CO: Qualis Research Associates.
- Seltzer, B., Rheaume, Y., Volicer, I., Fabiszewski, K., Lyon, P., Brown, J., Volicer, B. (1988). The short-term effects of in-hospital respite on the patient with Alzheimer's disease. Gerontologist, 28, 121-124.
- Shapiro, E. (1980). Is seeking help from a friend like seeking help from a stranger? Social Psychology Quarterly, 2, 259-263.

- Sherwood, S., Morris, J., Mor, V., & Gutkin, C. (1977). Compendium of measures for describing and assisting long term care populations. Boston: Hebrew Rehabilitation Center for Aged (Mimeographed).
- Shortell, S. (1983). The contribution and relevance of sociology to health services research. In T. Choi & J Greenberg (Eds.), Social science approaches to health services research (Chapter 2, pp. 23-52). Ann Arbor, MI: Health Administration Press.
- Silliman, R., Fletcher, R., Earp J. & Wagner, E. (1986). Families of elderly stroke patients. Journal of the American Geriatrics Society, 34, 643-648.
- Soldo, B. 1983a. In-home services for the dependent elderly: determinants of current use and implications for future demand. Washington. Urban Institute.
- Soldo, B. 1983b. The home care population: National prevalence rates. Select characteristics and alternative sources of assistance. Urban Institute.
- Soldo, B., & Myllyluoma, J. (1983). Caregivers who live with dependent elderly. Gerontologist, 23 (6), 605-611.
- Snyder, B., & Keefe, K. (1985). The unmet needs of family caregivers for frail and disabled adults. Social Work in Health Care, 10 (3), 1-14.
- Spradley, J. (1979). The ethnographic interview. San Francisco: Holt, Rinehart & Winston.
- Spradley, J. (1980). Participant observation. San Francisco: Holt, Rinehart & Winston.
- Springer, D., & Brubaker, T. (1984). Family caregivers and dependent elderly: Minimizing stress and maximizing independence. Beverly Hills, CA: Sage publications.
- \_\_\_\_\_. (1985). Statistical Package for the Social Sciences. Personal Computer. Chicago: SPSS Inc.
- Stoller, E., & Earl, L. (1983). Help with activities of every day life: Sources for the noninstitutionalized elderly. Gerontologist, 23, 64-70.
- Stone, R., Cafferata, G., & Sangl, J. (1987). Caregivers of the frail elderly.: A national profile. The Gerontologist, 27, 616-626.
- Strauss, A. (1956). George Hubert Mead: On social psychology. Chicago: Phoenix Books, The University of Chicago Press.

- Strauss, A. (1975). Chronic illness and the quality of life. St. Louis, Missouri: C.V. Mosby Co.
- Strauss, A. (1988). Qualitative analysis for social scientist. Melbourne, Australia: Cambridge University Press.
- Tessler, R.C., & Swartz, S. H. (1972). Help-seeking, self-esteem, and achievement motivations: An attributional analysis, Journal of Personality and Social Psychology, 21, 318-326.
- Thoits, P. (1982). Conceptual, methodological, and theoretical problems in studying social support as a buffer against life stress. Journal of Health and Social Behavior, 23, 145-149.
- Thompson, E., & Doll, W. (1982). The burden of families coping with the mentally ill. Family Relations, 31, 279-388.
- Topf, M. (1986). Three estimates of interrater reliability for nominal data. Nursing Research, 35 (4), 253-255.
- U.S. Bureau of Census (October 1982). Decennial censuses of the population, 1900-1980 and Projections of the population of the United States: 1982-2050 (advanced report). Current Population Reports, Series P-25, No. 922.
- U.S. Bureau of Census (1983). America in transition: An aging society. Current Population Reports, special studies, series P-23, no. 128. Washington.
- Veterans Administration (1985). Annual Report 1985. Washington, D.C. Office of Administrator of Veterans Affairs.
- Veterans Administration (1986). New projections of the veteran population: A review of the data. Washington, D.C.: Office of Information Management and Statistics, Statistical Policy and Research Services Research Division (711 IM&S 70-86-7, July).
- Ward, D. (1987). The new old burden: Gender and cost in kin care of disabled elderly. Unpublished doctoral dissertation. Ann Arbor, MI: University Microfilms International.
- Warren, R., & Cohen, S. (1985). Respite care. Rehabilitation Literature, 46 (3-4), 66-71.
- Weber, R. (1977). Evaluative research on community mental health services for the aged. In J.E. O'Brien (Ed.), Evaluative research on social programs for the elderly (pp. 40-50). USGPO, Washington, DC.
- \_\_\_\_\_. (1973). Webster's new collegiate dictionary. Springfield, Massachusetts, G. & C. Merriam Company.

- Weinert, C., & Brandt, P. (1987). Measuring social support with the PRQ. Western Journal of Nursing Research, 9(4), 589-602.
- Weiss, R. (1974). The provisions of social relationships. In S. Rubin (Ed.), Doing unto others (pp.17-26). Englewood Cliffs, N.J.: Prentice Hall.
- Wetherington, E. & Kessler, R. (1986). Perceived support, received support, and adjustment to stressful life events. Journal of Health and Social Behavior, 27, 78-96.
- Wilson, H. (1989). Family caregiving for a relative with Alzheimer's dementia. Nursing Research, 38 (2), 94-98.
- Woods, N., & Catanzaro, M. (1988). Nursing research: Theory and practice. St. Louis, C.V. Mosby Co.
- Worcester, M. (1989). Personal survey of respite services in Seattle, WA.
- Worcester, M., & Quayhagen, M. (1983). Correlates of caregiving satisfaction: Prerequisites to nursing home admission. Research in Nursing and Health, 6, 61-67.
- Wright, F. (1983). Single carers, employment, housework and caring. In J. Finch, & D. Groves (Eds.), A labour of love: Women, work and caring (pp. 89-105). Boston: Routledge & Kegan Paul.
- Yin, R.K. (1984). Case study research: Design and method. Beverly Hills: Sage.
- Zarit, S., Reever, K., & Bach-Peterson, T. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. The Gerontologist, 20, 649-655.
- Zarit, S., Todd, P., & Zarit, J. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. Gerontologist, 20, 649-655.

## APPENDIX A

### UNIVERSITY OF WASHINGTON CONSENT FORM - CAREGIVER

University of Washington  
School of Nursing

Title of Project: Use of Helping Networks

Martha L. Worcester R.N.  
Investigator, Predoctoral Student  
University of Washington SM-24  
Seattle, WA 98195 (206) 543-6950

#### Purpose and Benefits

The purpose of this study is gain information about the experiences family members and friends have in trying to obtain help in caring for a person with physical problems or confusion in the home. The kind of help I am most interested in is someone who will stay with the person who needs care while the care provider is not there. I am a registered nurse who has chosen this study as part of the Doctoral Program at the University of Washington. The results of this study will be placed in the University of Washington Library. Your participation will help plan for the needs of people in similar situations.

#### Procedures

First I will ask some brief question to determine if you are eligible to participate in the study. These questions I can ask while you are at the clinic with the person you care for, or if you do not come to the clinic or it is more convenient for you to have me come to your home, then I will arrange to come to your home. You may or may not be selected based on your answers to these questions. If you are selected, your participation in this study will involve answering some questions about the person you assist and yourself and particularly about your reasons for having or not having someone else stay with the person you assist when you are away. The study will involve three interviews in your home at your convenience over a 6 month period of time. You may feel free refuse to answer any questions that you do not wish to answer. If you live with the person you provide care for and would like someone to sit with them during the interview I will make arrangements for a person to come.

The first interview will last no longer than 2 hours and will involve:

1. Completing some basic information about yourself such as marital status and education; caregiving;
2. Completing information about ways you assist the person for whom you provide care;

## APPENDIX A (continued)

3. Completing information about your health status;
4. Completing information about who you can call on to stay with the person you care for while you are out; and
5. A tape recorded interview so that I may concentrate on what you say, rather than on writing every word down. The taped interview will be about your reasons for having or not having someone stay with the person you care for while you are away. This will involve such questions as:

If you need to leave the person you care for with someone else what things do you have to consider?

What makes it difficult to leave the person you care for with some one else?

6. Filling out a 25 item scale about the support you feel from other people.

The audiotape will be put into written form and no one but the person who transcribes them, my project advisor and myself will have access to the tapes. They tapes will be erased within 6 months of when they are made.

During the first interview or prior to it at the medical center, I will be conducting a short interview with the person you care for that includes a short memory test and self care questions.

The second and third interviews I will not be taping. They will last about 45 minutes each. In the second interview I will first be asking if you have had anyone stay with the person you care for since our last interview. Second I will be sharing with you a summary of the information you gave me and asking your help to see if I have interpreted what you said correctly. In the third interview I will be sharing with you a summary of the results of the entire study and asking you what the most important reasons are for asking or not asking others to stay with the person you care for while you are away.

#### Risks

There are no physical risks involved in this study. Your name will not appear on any of the final reports. The information you provide will remain confidential and will be seen only by myself and my research assistant. No one at the Veteran's Administration Medical Center where you are a patient will have access to this information.

## APPENDIX A (continued)

When reports are written only summary information will be reported and it will not be possible to identify any particularly individual. The information gathered in this study will be retained for 5 years.

Your participation in this study is completely voluntary and you are free to withdraw from the study at any time without affecting your care at the Veteran's Medical Center and without penalty or loss of benefits to which you are otherwise entitled.

For veterans eligible for medical care from the Veterans Administration (VA), medical care and treatment for any injury sustained will be provided by the VA. For non-eligible veterans and non-veterans, care and treatment by the VA is available on a humanitarian emergency basis.

---

Signature of Investigator

Date

Participant's Statement  
Care Provider

This study described to me has been explained and I voluntarily consent to participate. I have had an opportunity to ask questions. I understand that future questions I may have about the research or about my rights as a participant will be answered by Ms. Worcester.

I consent to having my answers audio tape recorded.

---

Signature of Participant (care provider) Date

Copies to: Care Provider Participant  
Investigator's File

APPENDIX A (continued)

UNIVERSITY OF WASHINGTON CONSENT FORM - PATIENT

University of Washington  
School of Nursing

Title of Project: Use of Helping Networks

Martha L. Worcester R.N.  
Investigator, Predoctoral Student  
University of Washington SM-24  
Seattle, WA 98195 (206) 543-6950

Purpose and Benefits

The purpose of this study is gain information about the experiences family members and friends have in trying to obtain help in caring for a person with physical problems or confusion in the home. The kind of help I am most interested in is someone who will stay with the person who needs care while the care provider is not there. I am a registered nurse who has chosen this study as part of the Doctoral Program at the University of Washington. The results of this study will be placed in the University of Washington Library. Your participation will help plan for the needs of people in similar situations.

Procedures

Your participation in this study will involve answering some questions about your ability to perform activities independently and your memory and also talking with the persons who assists you in the home. The person who assists you will be asked questions about the type of assistance provided and especially about how she or he obtains help when it is necessary to be away. If the person who helps you with your care wishes me to have a person be with you while the interview is conducted, I will make those arrangements.

Risks

There are no physical risks involved in this study. Your name will not appear on any of the final reports. The information you provide will remain confidential and will be seen only by myself and my research assistant. No one at the Veteran's Administration Medical Center where you are a patient will have access to this information. When reports are written only summary information will be reported and it will not be possible to identify any particularly individual. The information gathered in this study will be retained for 5 years.

## APPENDIX A (continued)

Your participation in this study is completely voluntary and you are free to withdraw from the study at any time without affecting your care at the Veteran's Medical Center and without penalty or loss of benefits to which you are otherwise entitled.

---

 Date

---

 Signature of Investigator

Participant's Statement  
Patient

This study described to me has been explained and I voluntarily consent to participate. I have had an opportunity to ask questions. I understand that future questions I may have about the research or about my rights as a participant will be answered by Ms. Worcester.

---

 Date

---

 Signature of Patient

---

 Signature of Person Representing Patient  
(if necessary).

Copies to: Investigator's File  
Participant or Their Representative

APPENDIX B

INTERVIEW FORMAT

Open-ended Prompts

I. BEGINNING OF INTERVIEW

The rest of the time I will be using the tape recorder so I won't need to take notes.

Tell me what caregiving is like for you.....

II. INTRODUCTION IF CAREGIVER HAS HAD SOMEONE STAY WITH CAREGIVER  
(If caregiver has not had anyone stay with the recipient for the last 6 months skip to the next introduction)

For this part of the interview I will be asking you about your experiences in getting people to stay with R\_\_\_\_\_ in the past 6 months (R=Recipient).

You have been caring for R\_\_\_\_\_ for quite a while. Can you think of the last time you had someone come in while you went out or took him/her out to stay with someone else while you went out?

Tell me about the situation..

Prompts: - ASK ABOUT A. KIN B. FRIENDS/NEIGHBORS C. AGENCIES

III. QUESTIONS SPECIFIC TO RESPITE

1. Think of the last time someone else stayed with R
2. How did it come about?
3. Tell me about what happened..

Prompts:

arrangements you had to make?

instructions you had to plan?

preparation of R for person coming?

length of time you were gone?

what you did with the time?

R's response on your return?

## APPENDIX B (continued)

## III. RESPITE cont...

4. Would you leave R with H again (H=helper, source of respite)?  
(reasons for or against)
5. Some people find it easy some find it difficult to  
get or ask for someone to stay with R  
what is it like for you?
6. What would you do with your time if you were not  
caring for R?
7. POSITIVE EXPERIENCES WITH Hs caring for R
8. NEGATIVE EXPERIENCES WITH Hs caring for R
9. What do you do for R that you feel no one else can  
do?
10. What reasons do you have for providing the care  
versus having someone else do it?

## IV. GENERAL

1. What really helps you be able to keep R at home....
2. How do you find relief when you feel you need it...
3. What do you do that you enjoy?
4. What restores your energy?
5. What keeps you going?
6. What tells you that you need some time away from R?
7. Are there times you feel more in need of getting away than  
others? worst times?
8. What are the best times, when you don't feel the need to get  
away...
9. If I don't get away I will \_\_\_\_\_.
10. If I could leave R alone safely I would have more  
time to \_\_\_\_\_.

## APPENDIX B (continued)

## V. FUTURE

1. How much longer do you think you'll need to provide care for R?...
2. What makes you want to continue caring for R ....
3. What concerns do you have about the future....
4. What have you done to prepare for the future...

VII. CONCLUSION

Thank you for taking the time for sharing this information for this project. I will be contacting you again in about a month's time. I will not be using a tape recorder next time but will be asking you help sort out some of the things you have told me so that the information you have given me can be in a form that will be helpful to other people that are in situations like yours.

In case we have trouble reaching you, is there someone who always knows where you are? What is that person's name, and how can we reach him/her?

NAME: \_\_\_\_\_

PHONE NO: \_\_\_\_\_

Notes for next visit or phone call:

---



---



---



---



---



---



---



---

APPENDIX C

GENOGRAM


Key to the Use of Genogram

A complete genogram includes

1. Names and ages of family members
2. Years of birth, marriage, separations, divorce, death, and other significant in the past year.
3. Places of residence of family members (how far away from the caregiver).
4. When last saw each of the family members. Visits expected during the year of the study.
5. Notations about which ones have provided respite or direct assistance with caregiving.

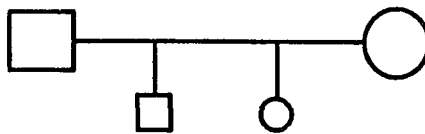
Key to Important symbols:

Male:  Female:  Death:  

Marriage: Husband on left, wife on right 

Children: Listed in order of birth beginning on the left with oldest:

Example: First child (daughter), second child (son)

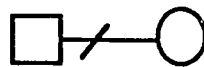


Common variations:

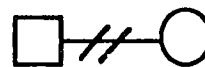
Living together  
in common-law  
relationship



Marital  
separation



Divorce



---

Carter, E., & McGoldrick, M. (1980). The family life cycle: A framework for family therapy. New York: Gardner Press (p. XXIII)

---





APPENDIX E  
MINI-MENTAL STATE

<u>Maximum Score</u>	<u>Client Score</u>	
		<u>ORIENTATION</u>
5	_____	1. What is the (year) (season) (date) (day) (month)?
5	_____	2. Where are we (state) (county) (town) (street) (number)?
		<u>REGISTRATION</u>
3	_____	3. Name three objects: (e.g. cat, ball, rose). Then ask the client to repeat all three after you have said them all. Give 1 point for each correct answer. Then repeat them until he/she has learned all three. Count trials and record number of trials _____.
		<u>ATTENTION AND CALCULATION</u>
5	_____	4. Serial 7's. Ask to subtract 7 from 100 (93, 86, 79, 72, 65). If does not get any of serial 7's right, then ask to spell WORLD backwards (DLROW 0-5) and score it instead. If the person can not understand the WORLD substitute another five letter word.
		<u>RECALL</u>
3	_____	5. Ask for the 3 objects repeated in number 3. Give one point for each correct answer.
		<u>LANGUAGE</u>
2	_____	6. Show the client a pencil and a watch and ask "What is this?" (2 points).
1	_____	7. Ask the client to repeat the following: 'no ifs, ands, or buts" (1 point).
3	_____	8. Following a 3 stage command. "Take a paper in your right hand, fold it in half and put it on the floor." (3 points) Another 3 stage command may be substituted if person unable to do task due to physical impairment.
3	_____	9. Have the client read and obey the following: CLOSE YOUR EYES (1 point) WRITE A SENTENCE (1 point) COPY THE DESIGN (1 point) - Draw a circle, square, and triangle. Ask client to copy them. Tremor or shakiness ignored but all three must be closed figures.
30	_____	TOTAL

---

Folstein, M., & Folstein, S. & McHugh, P. (1975). Mini-mental State, A practical method for grading cognitive states of patients for clinicians. Journal of Psychiatric Research, 12, 189-198.

APPENDIX F

ACTIVITIES OF DAILY LIVING

Preface Statement: During this interview I will be asking you some questions about the person your (INSERT RELATIONSHIP),

Mr., Mrs., Ms., (FAMILY NAME OF CARE RECEIVER - "R" \_\_\_\_\_). When I do so, how would you like me to refer to him/her? would you like me to use his/her first name, family name, or just refer to him/ her as you (INSERT RELATIONSHIP).

These next questions are about assistance that you need to provide for R (person's name) \_\_\_\_\_.

A. The next questions are about DRESSING.

1. In the past week did he/she usually get dressed for the day or did he/she stay in night clothes?  
GOT DRESSED ..... 1  
STAYED IN NIGHT CLOTHES... 2
2. Do you need to help him/her (dress/ change his/her night clothes) or stay in the room in case he/she needs help?  
YES, USUALLY HELPED..... 2  
NO, NOT USUALLY HELPED... 1  
DID NOT CHANGE CLOTHS  
AT ALL..... 3
3. Was the help you gave more than just tying his/her shoes?  
YES..... 2  
NO..... 1

B. The next questions are about BATHING - including turning on the water.

4. During the past week, when he/she had a full bath did he/she usually bathe in a tub or a shower, at a sink or basin, or did you give him/her bedbaths?

IF MULTIPLE METHODS ARE USED PROBE:

Which did you usually use for a full bath?

- IN TUB OR SHOWER..... 1
- IN SINK OR BASIN..... 2
- BEDBATHS/DID NOT HAVE  
FULL BATHS..... 3

## APPENDIX F (continued)

## ACTIVITIES OF DAILY LIVING page 2

5. Did you help him/her in or out of the (tub or shower) or stay in the room in case he/she needed help getting in or out?
- |          |   |
|----------|---|
| YES..... | 2 |
| NO.....  | 1 |

6. During the past week did he/she need help with washing or did you need to stay in the room in case he/she needed help?
- |                           |   |
|---------------------------|---|
| YES, USUALLY HELPED.....  | 2 |
| NO, NOT USUALLY HELPED... | 1 |

7. Did you need to help him/her wash more than his/her back or feet?  
(EXCLUDE HELP WITH SHAMPOOING HAIR)
- |          |   |
|----------|---|
| YES..... | 2 |
| NO.....  | 1 |

## C. Next I will ask you about help you provide with EATING?

8. During the past week, did you usually feed him/her or stay in the room in case he/she needed help with eating?
- |                          |   |
|--------------------------|---|
| YES, USUALLY HELPED..... | 2 |
| NO.....                  | 1 |

9. Did you provide help with more than cutting the meat or buttering bread?
- |          |   |
|----------|---|
| YES..... | 2 |
| NO.....  | 1 |

## D. TOILETING

10. During the past week did you need to help with his/her use of the toilet for either bowel or bladder functions?
- |                      |  |   |
|----------------------|--|---|
| IF NO PROBE:         | YES, TOILET FOR AT LEAST ONE FUNCTION..... | 2 |
| (What did he/she use | NO (BEDPAN, BEDSIDE COMMUNE).....          | 1 |
|                      | NO (CATHETER, COLOSTOMY)                   | 1 |

## APPENDIX F (continued)

## ACTIVITIES OF DAILY LIVING page 3

11. Do you usually have to help him/her get to the bathroom, help him/her on the toilet or stay nearby in case help is needed?
- |                          |   |
|--------------------------|---|
| YES, USUALLY HELP.....   | 2 |
| NO, NOT USUALLY HELPED.. | 1 |
12. Do you usually need to help clean him/her or adjust clothing after toileting?
- |          |   |
|----------|---|
| YES..... | 2 |
| NO.....  | 1 |
13. CODE WITHOUT ASKING IF KNOWN: Does he/she use a device such as a catheter bag or colostomy bag?
- |          |   |
|----------|---|
| YES..... | 2 |
| NO.....  | 1 |
14. Does he/she change (this device) by himself/herself?
- |                     |   |
|---------------------|---|
| SELF CARE.....      | 1 |
| HELP WITH CARE..... | 2 |

## E. INCONTINENCE

15. During the past week, did he/she accidentally wet himself/herself, either day or night?
- |          |   |
|----------|---|
| YES..... | 2 |
| NO.....  | 1 |
16. IF COLOSTOMY SKIP TO QUESTION 6:  
During the past week, did he/she have an accident with his/her bowels, either day or night?
- |          |   |
|----------|---|
| YES..... | 2 |
| NO.....  | 1 |

## F. TRANSFERRING

17. Is he/she able to move in and out of bed and chairs without your assistance? (may use object for support such as cane or walker)
- |                           |   |
|---------------------------|---|
| YES.....                  | 1 |
| NO.....                   | 2 |
| DOESN'T GET OUT OF BED... | 3 |

## APPENDIX F (continued)

## ACTIVITIES OF DAILY LIVING page 4

18. Do you need to lift him/her to get him/her from one place to another (for example out of a chair, or from a bed to a chair?)

YES.....	2
NO.....	1
DOESN'T GET OUT OF BED...	3

## G. AMBULATION

19. Does he/she need assistance with walking (for example need to give him/her your arm or get a walker?)

YES.....	2
NO.....	1
DOESN'T GET OUT OF BED...	3

## TOTAL

20. If a yes in any of the 7 areas above (ABCDEFG) give one point for each. Maximum score = 7.

APPENDIX G

DEMOGRAPHIC INFORMATION ABOUT RECIPIENT (R)

Note: Questions to be asked of caregiver about care-receiver.

1. What is R's \_\_\_\_\_ birthdate \_\_\_\_/\_\_\_\_/\_\_\_\_

2. R's Gender (Record without asking if obvious)?

Male.....1  
Female.....2

3. What is R \_\_\_\_\_ ethnic origin (race)?

White..... 1  
Black..... 2  
Asian..... 3  
Hispanic..... 4  
Native American... 5  
Mixed..... 6

4. What was R's \_\_\_\_\_ occupation (prior to retirement)?

Higher Executive.. 1  
Business Manager.. 2  
Adm. Personnel.... 3  
Clerical Sales.... 4  
Skilled Manual.... 5  
Semi-skilled..... 6  
Unskilled..... 7  
Missing..... 9

5. What is the highest grade in school that R \_\_\_\_\_  
completed?

Graduate degree..... 1  
Standard college..... 2  
Partial college..... 3  
High School graduate..... 4  
Partial high school-at least 10th 5  
Junior high-at least 7th..... 6  
Less than 7th..... 7  
Don't know or missing..... 9

## APPENDIX G (continued)

DEMOGRAPHIC INFORMATION ABOUT RECIPIENT - page 2

6. Here is a list of monthly income categories. Which category best describes the total amount of R' income? This includes total income for all that live in the household?

Under 250 per month.....1  
 \$250 to \$499 per month.....2  
 \$500 to \$832 per month.....3  
 \$833 to \$1249 per month.....4  
 \$1250 to \$2000 per month.....5  
 \$2001 to \$2833 per month.....6  
 \$2844 to \$4165 per month.....7  
 \$4166 and over per month.....8  
 Don't know.....8  
 Preferred not to answer.....9

IF STATES THAT HIS/HER INCOME IS VARIABLE ASK  
 "What was it last month?"

7. What is R's current marital status?

Married.....1  
 Widowed.....2  
 Divorced.....3  
 Separated.....4  
 Never married.....5  
 Living with partner.....6

8. What is R's current living situation?

	NO	YES
Does <u>R</u> live alone?.....	0	1

IF YES SKIP TO QUESTION 13  
 IF NO ASK

- |   |   |   |
|---|---|---|
| 9. Does he/she live with a spouse or partner?   | 0 | 1 |
| 10. Does he/she live with his/her children?.... | 0 | 1 |
| 11. Does he/she live with other relatives?..... | 0 | 1 |
| 12. Does he/she live with non-relatives?.....   | 0 | 1 |



APPENDIX H

DEMOGRAPHIC INFORMATION CAREGIVER (C)

1. What is your birthdate? \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

2. Caregiver's Gender (Record without asking if obvious)

Male.....1  
Female.....2

3. What is your ethnic origin (race)?

White..... 1  
Black..... 2  
Asian..... 3  
Hispanic..... 4  
Native American... 5  
Mixed..... 6

4. What is or was your occupation?

Higher Executive.. 1  
Business Manager.. 2  
Adm. Personnel.... 3  
Clerical Sales.... 4  
Skilled Manual.... 5  
Semi-skilled..... 6  
Unskilled..... 7  
Missing..... 9

5. What is the highest grade in school you completed?

Graduate degree..... 1  
Standard college..... 2  
Partial college..... 3  
High School graduate..... 4  
Partial high school-at least 10th 5  
Junior high-at least 7th..... 6  
Less than 7th..... 7  
Don't know or missing..... 9

## APPENDIX H (continued)

## DEMOGRAPHIC INFORMATION CAREGIVER - page 2

6. Here is a list of annual income categories. Which category best describes the total amount of your household income?

Under 250 per month.....1  
 \$250 to \$499 per month.....2  
 \$500 to \$832 per month.....3  
 \$833 to \$1249 per month.....4  
 \$1250 to \$2000 per month.....5  
 \$2001 to \$2833 per month.....6  
 \$2844 to \$4165 per month.....7  
 \$4166 and over per month.....8  
 Don't know.....8  
 Preferred not to answer.....9

IF STATES THAT HIS/HER INCOME IS VARIABLE ASK  
 "What was it last month?"

7. (Ask only if caregiver does not live with the care receiver  
 "How are away in travel time do you live from R \_\_\_\_\_ ?"  
 (If lives with care-receiver code as 0, next door =.5)  
 Other wise number of miles.
8. What is C \_\_\_\_\_ current marital status?
- Married.....1  
 Widowed.....2  
 Divorced....3  
 Separated.....4  
 Never married.....5  
 Living with partner.....6
9. How long have you known (been married to) R \_\_\_\_\_ ?
10. What is your relationship to R \_\_\_\_\_ ?  
 I am R's \_\_\_\_\_.  
 (If already certain of relationship do not ask.
- Wife..... 1  
 Husband..... 2  
 Daughter..... 3  
 Daughter-in-law..... 4  
 Sister..... 5  
 Brother..... 6  
 Friend..... 7

## APPENDIX H (continued)

## DEMOGRAPHIC INFORMATION CAREGIVER - page 3

11. Do you have a car?
- No... 1  
Yes.. 2
12. Are you able to drive the car?
- No.... 1  
Yes... 2  
NA.... 8
13. Who else lives with you? (Do not ask if lives with R). (Code Number of people)

LIST	INITIALS	RELATIONSHIP	AGE

---



---



---



---

APPENDIX I

CAREGIVING EXPERIENCE INFORMATION

A. RECIPIENT (R) DIFFICULTIES

1. Is R able to communicate his/her needs  
so you can understand him/her?  
No.....2  
Yes..... 1
2. Is R able to communicate his/her needs  
so others besides yourself can understand him/her?  
No.....2  
Yes..... 1
3. Dose R frequently interrupt what you are doing  
with requests or because of agitated behavior?  
No.....1  
Yes..... 2
4. How often do you feel you need to check on R if he/she is  
not within your line of vision?  
nearest number of minutes \_\_\_\_\_
5. Do you have to check on R at night?  
No.....1  
Yes.....2
6. Does R have difficulty hearing?  
No.....1  
Yes.....2
7. Are you able to take R shopping with you?  
No.... 2  
Yes... 1
8. Are you able to take R out to eat?  
No.... 2  
Yes... 1
9. Are you able to take R out to groups (e.g. church, concert)?  
No.... 2  
Yes... 1
10. Are you able to go on trips with R ?  
No.... 2  
Yes... 1
11. How long can R tolerate riding in a car?  
Time in number of minutes \_\_\_\_\_.

## APPENDIX I (continued)

## CAREGIVING EXPERIENCE page 2

## A. R DIFFICULTIES cont...

How would you describe R'S health condition over the last 6 months?

12. Better or Worse

Has improved.....1  
 Stayed the same.....2  
 Is getting worse.....3

13. Stable or Unstable

Stable.....1  
 Somewhat unstable.....2  
 Very unstable..... 3

## B. CAREGIVING RESPONSIBILITIES

1. How long have you been providing care for R \_\_\_\_\_?  
 (closest number of years and months) \_\_\_\_\_  
 Also fill in exact no of months \_\_\_\_\_
2. How long have you been providing as much care as you are now  
 (closest number of years & months) \_\_\_\_\_  
 Fill in total months here. \_\_\_\_\_
3. Which of the following statements best describes  
 the care you provide for R \_\_\_\_\_ ?
 

Do you do it all yourself?.....	4
Do you have days off and that people do it?.....	3
Do you have lots of help from others but feel you are really the one responsible to see that care is done?.....	2
Do you supervise and manage the care that others do?	1
4. On the average how many hours do you spend with R \_\_\_\_\_  
 a day? (closest number of hours) \_\_\_\_\_
5. How much time during a one week period do you go out  
 of the house?
 

not at all.....	1
less than one hour.....	2
1-3 hours.....	3
3-5 hours.....	4
more than 5 hours.....	5

## APPENDIX I (continued)

## CAREGIVING EXPERIENCE page 3

## C. CAREGIVING RESPONSIBILITIES cont...

6. What is longest period of time you have left R\_\_\_\_\_ alone in last 6 months? (In hours)\_\_\_\_\_
7. How long do you feel comfortable leaving R\_\_\_\_\_ alone? (In hours and minutes)\_\_\_\_\_
8. What is longest period of time you have been away from R\_\_\_\_\_ in last 6 months?\_\_\_\_\_
- Days \_\_\_\_\_ Hours \_\_\_\_\_ Minutes \_\_\_\_\_
9. What other chronically ill elder family members have you had to care for at home for a period of longer than 3 months in the past? (code number of people)

<u>INITIALS</u>	<u>RELATIONSHIP</u>	<u>AGE</u>	<u>HOW LONG?</u>
_____	_____	_____	_____
_____	_____	_____	_____

10. Are you helping take care of anyone else besides R now?

<u>INITIALS</u>	<u>RELATIONSHIP</u>	<u>AGE</u>	<u>HOW LONG?</u>
_____	_____	_____	_____
_____	_____	_____	_____

## C. CAREGIVING ENVIRONMENT

Now I am going to ask you a few questions about the place that R\_\_\_\_\_ lives. (If lives with R then ask about place caregiver lives).

1. How many rooms (other than the bathroom) does the residence have? \_\_\_\_\_
2. Does R\_\_\_\_\_ need to go up or down stairs to:  
get to the bathroom? No...1  
Yes...2
3. " " get to his/her bedroom? No...1  
Yes...2

## APPENDIX I (continued)

## CAREGIVING EXPERIENCE page 4

## C. CAREGIVING ENVIRONMENT cont...

4. How long has R \_\_\_\_\_ lived in the same place?  
 Years \_\_\_\_\_ Months \_\_\_\_\_
5. Do you consider R \_\_\_\_\_ neighborhood to be safe?  
 No...1  
 Yes..2
6. ASK ONLY IF CAREGIVER LIVES WITH CARE RECEIVER:  
 Is there bus service close enough for you to use?  
 No...1  
 Yes..2
7. Do you know R \_\_\_\_\_ next door neighbors?  
 No...1  
 Yes..2
8. Are any of R \_\_\_\_\_ neighbors close friends of yourself  
 or R \_\_\_\_\_ ?  
 No...1  
 Yes..2
9. ASK ONLY IF C LIVES WITH R: How often do you have visitors?  
 Daily.....6  
 At least 2 times a week....5  
 Once a week.....4  
 Twice a month.....3  
 Once a month.....2  
 Less than once a month.....1  
 Does not live with R..... 9
10. How often does R \_\_\_\_\_ leave his/her residence?  
 Daily.....6  
 At least 2 times a week....5  
 Once a week.....4  
 Twice a month.....3  
 Once a month.....2  
 Less than once a month.....1  
 Does not live with R.....9
11. When was the last time R \_\_\_\_\_ was out of the house to go  
 somewhere else? \_\_\_\_\_

APPENDIX J

CAREGIVER HEALTH STATUS

Now I would like to ask you a few questions about your health?

A. PHYSICAL HEALTH

1. How would you rate your own health compared to other persons your age?  
Excellent.....4  
Good.....3  
Fair.....2  
Poor.....1
  
2. How does your physical health compare with your health one year ago?  
Much better.....5  
A little better..4  
About the same...3  
A little worse...2  
Much worse.....1

B. SOCIAL HEALTH

1. From discussions with many caregivers, we know that for some people caregiving is very confining, while for others it is not. How much confinement do you feel because of all the caregiving things you have to do for R \_\_\_\_\_? (READ CHOICES)  
  
None at all..... 0  
A little confinement..... 1  
Some confinement..... 2  
A lot of confinement..... 3  
Overwhelming confinement... 4

If respondent does not understand the word confined say "Do you feel restricted in being able to do the things you want to do because of all the caregiving you do for R \_\_\_\_\_?"

2. Do you think caring for R \_\_\_\_\_ has caused you to loose contact with family?  
No.....1  
Yes....2
  
3. Do you think caring for R \_\_\_\_\_ has caused you to loose contact with friends?  
No....1  
Yes...2
  
4. Do you think caring for R \_\_\_\_\_ has caused you to loose organizations you belonged to?  
No....1  
Yes...2

## APPENDIX J (continued)

CAREGIVER HEALTH STATUS page 2

10. ASK ONLY IF C LIVES WITH R: How often do you have visitors?

Daily.....	6
At least 2 times a week.....	5
Once a week.....	4
Twice a month.....	3
Once a month.....	2
Less than once a month.....	1
Does not live with R.....	9



**PLEASE NOTE:**

Copyrighted materials in this document have not been filmed at the request of the author. They are available for consultation, however, in the author's university library.

These consist of pages:

248-249 PERSONAL RESOURCE QUESTIONNAIRE Part II  
(Brandt/Weinert)

**UMI**

APPENDIX M

CODING: INITIAL DEFINITIONS - EXAMPLES OF 4 X 6 CARDS

---

Code: Sentiment  
Date: 10/5/88

Definition: Feelings C & R have for each other  
that makes it ok or not ok to  
leave R with someone else.

Example: Case # 206: Lines 1230-1253

He knows I understand. He can talk freely.  
I don't think he could do that with anyone else.  
He knows he can depend on me. He knows my first  
concern is with him.

Note: Perhaps a better name for this would be  
knowing.

Code: Health C  
Date: 10/4/88

Definition: Any aspect of C's health that  
affects her ability to spend time  
away from R

Example: Case # 108: Lines 436-450

But then there isn't anyplace I could go because  
I'd have to take the bus or walk.. and I get  
tired easily - like in 45 minutes and most  
places I have to go would take a couple hours.

---

Note: C = Caregiver: R = Recipient: Notes were hand written on  
4 x 6 cards rather than typed as illustrated here.

APPENDIX N

CATEGORY ANALYSIS - EXAMPLES

CATEGORIES: Respite & Matching      Date: 3/1/89  
Kin    Case # 116

Conditions: When daughter comes to town (once every one to two months) son-in-law will come and stay with R so C and daughter can go out. [It takes two for respite to occur - one to stay with R and one to go with C.]

Interactions: Matching - " my two other sons won't help or sit with R (they are afraid of him) but my son-law-sits and chats and they have a good time.

Strategy: Sometimes C and daughter plan together for respite. Sometimes daughter just calls and says they'll come and care for R without C having to ask.

Consequences: C goes shopping with daughter once or twice a month without having to worry about R.

CATEGORIES: Respite & Imposing      Date: 2/1/89  
Strategy (Knowing C-R Interaction)      Case # 218 p.13  
Neighbor

Conditions: R needed to go to the doctor and C didn't have energy to drive him.

Interactions: R put up a lot of resistance to C getting some one else. By knowing R, C knew what strategy to use with him. She said "if I'm sick you'll have to ask someone else. So he hushed."

Strategy: Strategy was related to Imposing that was used with H (neighbor). She told the neighbor that traffic made her nervous.

Consequences: C stayed home and rested but said she couldn't ask H anymore because his wife was on oxygen and than would he couldn't leave her (Imposing). Also due to changes in Hs life since last time he was asked.

Note: C=Caregiver: R=Recipient: H=Helper (source of respite).

APPENDIX O

FROM EARLY CODES TO CATEGORIES TO THEMES

<u>Early Codes</u>	<u>Categories</u>	<u>Themes</u>
alone	Knowing	Knowing
attitude	sentiment	environment R-C
at home	humor	strategy R-C
appreciation	health	timing R-C
adult day care	attitude	
cost	appreciation	
changes	time away	
distance		
ease not	Imposing	Imposing
environment	health H	necessary
frequency	friend	environment C-H
future	frequency	strategy C-H
health	life event	timing C-H
health system		
health R	Matching	
health C	man	Matching
humor		environment R-H
informal		strategy R-H
impose	Environment	timing R-H
intervention	respite-in-home	
kin	respite-out-of-home	
knowing	adult day care	
life events	distance	
matching		
man	Easier not to	CONSERVATION
nursing home	cost	easier not to
necessary	stress	
neighbor		
offer	Strategy	
respite	offer	
sentiment	request	
stress	time away	
social network loss		
time away		
timing		
trajectory	Necessary	
tasks	health C	
takeout	life events	
	Timing	
	trajectory	
	time away	

C=Caregiver: R=Recipient: H=Helper. These are examples and are not all inclusive of how codes were classified at each phase.

## APPENDIX P

### MEMO TYPES

Theoretical Memo: 2/5/89 Working on how codes relate to one another. Cs seem to be weighing whether it is easier to make plans to get away from R for some rest or whether the planning process and the effect on R will result in having less rest in the long run. Several seem to be so tired already that any change at all from the automatic routine established is difficult to think about. This is a lot like cost and benefit, but mostly they are just trying to expend the least energy.

Method Memo: 12/5/88 Returning from caregiver number 108 visit. The way in which I asked that last question really got the response I wanted. Just asking how different things came about gets the caregiver to elaborate much better than asking "what." This applies not just to respite but to how things have changed.

Observational Memo: 10/29/88. Returning from visit #102. The caregiver seemed really depressed. I wonder if she's always that way. She seems like someone who would need respite no matter how little there was for her to do. She complained about her house being a mess but it was really clean. There was plenty of room for someone to come in and stay with R and still allow her to have some privacy in another part of the house (1400 square feet). The yard was a lot to care for and a lot of her stress seemed to be anger at R for no longer being able to do yard maintenance because of his confusion because physically he was able to get around easily.

Theoretical Memo: 10/29/88. The preceding memo really relates to role theory in that when roles must be taken on that were previously the role of the other person more stress is experienced.

---

Note: C=Caregiver: R=Recipient

APPENDIX Q

EXAMPLE OF ETHNOGRAPH CODING

(Line Numbered and Hand Coded)

NUMBERED VERSION OF 124 5/20/1990 21:20

Page 1

+24 7/18/88 Monday PI wife

INT: Does your, does any of your family come and give you any assistance at all with, do they stay here so you can get out from time to time?

CG: Um, we have um a daughter and son who live in elsewhere. And the son was over on Saturday, and he washed the car, and occasionally he will help with um, cutting the grass and doing some chores. But not religiously. He's not, he's twenty si--25 and into basketball. So we don't see him very much.

INT: Have you ever asked him to just come and stay so you could somewhere for longer than you would have ordinarily? Come and sit and visit with him or something so you can get out, for a longer period of time?

CG: Actually no. I've not asked him.

INT: Has he ever offered, or done it, or?

CG: He does offer, yes. To come over and stay. When he \*?leaves, call me, if you need me, and this sort of thing.

INT: But you just, you've never really done it?

CG: No, he's not taken the time to come over and just offer to ah, stay. And my daughter is married and ah, it's a recent ah marriage, so she doesn't have the time. And then she's holding down a full time job too.

COM: Someone clears throat loudly.

INT: Has she ever done it, anyway? Has she come over and stayed a while so you can get out? When you needed to?

CG: No.

INT: (pause). Would you feel comfortable asking her to?

CG: If it, if it were necessary, sure.

INT: What kind of things would you call necessary? (laugh).

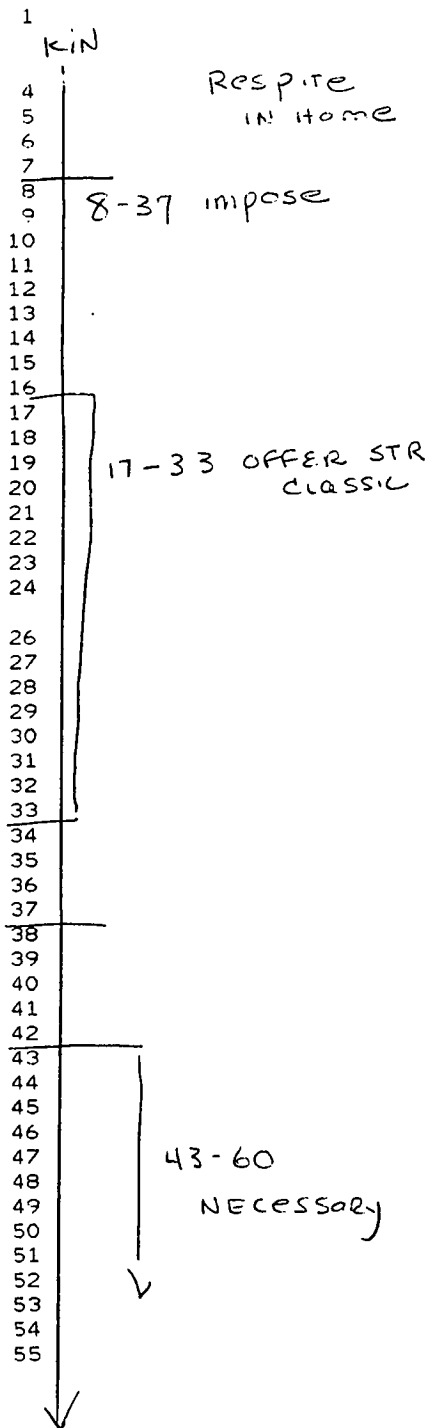
CG: Aah, if he did not feel good.

INT: Uh, huh.

CG: Um, if he felt worse than he does today, for instance. And I needed, absolutely needed to go and do something pen-, you know, pressing.

INT: Uh, huh.

CG: Only under those circumstances. So



## APPENDIX Q (continued)

## EXAMPLE OF ETHNOGRAPH CODING (continued)

(Coded by Ethnograph \*)

INT: Does your, does any of your family	4		
come and give you any assistance at	5		
all with, do they stay here so you	6		
can get out from time to time?	7		
#-AR            #-IMPOSE			
CG: Um, we have um a daughter and son	8	-#	
who live in elsewhere. And the son	9		
was over on Saturday, and he washed	10		
the car, and occasionally he will	11		
help with um, cutting the grass and	12		
doing some chores. But not	13		
religiously. He's not, he's twenty	14		
si--25 and into basketball. So we	15		
don't see him very much.	16		
\$-CLASSIC    \$-OFFER			
INT: Have you ever asked him to just	17	-\$	
come and stay so you could somewhere	18		
for longer than you would have	19		
ordinarily? Come and sit and visit	20		
with him or something so you can get	21		
out, for a longer period of time?	22		
CG: Actually no. I've not asked him.	23		
INT: Has he ever offered, or done it,	24		
or?			
CG: He does offer, yes. To come over	26		
and stay. When he *?leaves, call me,	27		
if you need me, and this sort of	28		
thing.	29		
INT: But you just, you've never really	30		
done it?	31		
%-IMPOSE			
CG: No, he's not taken the time to come	32	-\$	-%
over and just offer to ah, stay. And	33		
my daughter is married and ah, it's a	34		
recent ah marriage, so she doesn't	35		
have the time. And then she's	36		
holding down a full time job too.	37	-#	-%
COM: Someone clears throat loudly.	38		
INT: Has she ever done it, anyway? Has	39		
she come over and stayed a while so	40		
you can get out? When you needed to?	41		
CG: No.	42		
#-NEC			
INT: (pause). Would you feel	43	-#	
comfortable asking her to?	44		
CG: If it, if it were necessary, sure.	45		
INT: What kind of things would you call	46		
necessary? (laugh).	47		
CG: Aah, if he did not feel good.	48		
INT: Uh, huh.	49		
CG: Um, if he felt worse than he does	50		
today, for instance. And I needed,	51		

\* Seidel, J., Kjolseth, R., & Seymour, E. (1988). The ethnograph.  
Littleton, Colorado: Qualis Research Associates.

## BIBLIOGRAPHIC NOTE

AUTHOR: Martha Louise Iles Worcester

DATE OF BIRTH: October 10, 1941

PLACE OF BIRTH: Lafayette, Indiana

### CREDENTIALS

RN Registered Nurse (WA License #258-00)

ARNP Advance Registered Nurse Practitioner

GNP Gerontological Nurse Practitioner, Prescriptive Privileges  
State of WA (License 258-04 & REF # WO-RC-EM-1594PJ)

### ACADEMIC AND PROFESSIONAL EDUCATION

1962 Bachelors of Science in Nursing  
California State University, Chico, California

1964 M.S. Masters of Science in Nursing  
University of California at San Francisco, California

1982 Adult/Gerontology Nurse Practitioner Certification  
University of Colorado Health Science  
Denver, Colorado

1990 Ph.D. University of Washington, Seattle, Washington

### PUBLICATIONS

Worcester, M. (1980). The need for access to nursing specialists in the rural hospital. Pulse, 16 (1&2) pp. 5-6 & p.2 respectively.

Worcester, M. & Quayhagen, M.P. (1983). Correlates of caregiving satisfaction: Prerequisites of elder home care. Research in Nursing and Health, 6, 61-67.

Worcester, M. (1990). Family coping: Giving care to older family members. Health Services Quarterly (In press).

Worcester, M. (1990). Tailoring teaching to the elderly. Health Services Quarterly (In press).

Worcester, M., Pesznecker, B., & Albert, M. (1990). Cancer symptom management in the elderly. Health Services Quarterly (In Press).  
Seattle, WA: Elderly Homecare Project, University of Washington.

Book Reviewer for Journal of Gerontological Nursing 1979-1990.