

RURAL DAUGHTER/DAUGHTER-IN-LAW CAREGIVERS'
INTERACTIONAL PATTERNS

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Abstract

Rural Daughter/Daughter-In-Law Caregivers' Interactional Patterns

Daughters/daughters-in-law who care for a parent with a dementing illness at home are at risk for physical, psychological, and social problems. Also, their parent care recipient runs a higher risk of institutionalization. In order to intervene in this dynamic, a multidimensional, subjective perspective is required. However, literature is sparse regarding a multidimensional subjective perspective of rural daughter/daughter-in-law caregivers' patterns of interaction within the context of caring for a parent with a dementing illness.

The purpose of this research was to identify the multidimensional patterns of person-environment interaction. These patterns emerged from rural daughter/daughter-in-law's descriptions of caring for parents who have Alzheimer's Disease or a related Disorder (ADRD).

Secondary analysis was conducted on sixteen transcribed tape-recorded interviews with rural daughter/daughter-in-law caregivers of parents with ADRD. The nine dimensions of person-environment interaction which organize the NANDA Taxonomy were used as a framework for analysis in conjunction with the method of content analysis described by Miles and Huberman (1994).

Findings indicated that the NANDA dimensions were evident in the data. The dimensions were further synthesized to describe individual daughter/daughter-in-law caregiver person-environment interactional patterns.

Caregiver patterns of person-environment interaction clustered into three common groupings: (a) unconnected caregiver interactional patterns, (b) connected caregiver interactional patterns, and (c) interconnected caregiver interactional patterns.

In the first group of caregiver interactional patterns, daughters/daughters-in-law cared for their parents unconnected to others in their environment and provided no description of caring for themselves. The second group described connecting with others to help with caregiving, but also gave no description of caring for themselves. The third group described caring as a natural, interconnected process in which the family and community participated. The daughters/daughters-in-law indicated they cared for themselves as part of the process.

The findings may help practitioners target interventions to those caregivers who have unconnected patterns of person-environment interaction. These caregivers may exhibit the highest risk for the multidimensional problems associated with caregiving, and the parent care recipient a higher risk of institutionalization.

Table of Contents

	Page
Abstract	i
Acknowledgements	vi
List of Figures and Tables	viii
Chapter I	1
Purpose	4
Research Question and Objectives	4
Definition of Terms	5
Chapter II Review of the Literature	8
Daughter/Daughter-in-law Caregivers	8
Impact of Caregiving	10
Factors Associated with Institutionalization	17
Caregivers' Descriptions of Caregiving	20
Rural Family Caregivers	22
Summary of Caregiver Literature	23
NANDA Framework for Assessment of Interactional Patterns	24
Review of Studies Using the NANDA Framework	28
Summary of the Review	31
Summary of the Literature Review	31

	Page
Chapter III Methodology	33
Original Study from which Data were Obtained	34
Present Study Sample	35
Data Analysis	38
Analysis of One Transcript	43
Criteria for Rigor	60
Protection of Subjects	66
Chapter IV Findings	67
Research Objective One: Individual Patterns	67
Research Objective Two: Common Pattern Groupings	68
Unconnected Caregiver Interactional Patterns	69
Connected Caregiver Interactional Patterns	78
Interconnected Caregiver Interactional Patterns	110
Summary of Findings	120
Chapter V Discussion	122
Interpretation of Findings	122
Implications for Research and Practice	128
Other Relevant Findings	130
References	138
Appendix A Analysis of Jenny's Data	146
Appendix B Auditability Evaluator Forms	153

Appendix C	Fittingness Evaluator Forms	158
Appendix D	Credibility Evaluator Forms	161
Appendix E	Individual Caregiver Interactional Patterns	163
	Barbara's Interactional Pattern	164
	Bernie's Interactional Pattern	165
	Chip's Interactional Pattern	166
	Cynthia's Interactional Pattern	167
	Denise's Interactional Pattern	168
	Joan's Interactional Pattern	169
	Julie's Interactional Pattern	170
	Kathrin's Interactional Pattern	171
	Kathy's Interactional Pattern	172
	Margret's Interactional Pattern	173
	Mary's Interactional Pattern	174
	Patsy's Interactional Pattern	175
	Peggy's Interactional Pattern	176
	Sharie's Interactional Pattern	177
	Susie's Interactional Pattern	178
Appendix F	Initial and Revised Definitions of the Nine Dimensions of Person-Environment	179

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List of Figures and Tables

Figure	Page
1. Parallels of dimensions and diagnostic phenomena	26
2. NANDA framework for assessing a pattern of person-environment interaction	27
3. Process of pattern identification using Miles and Huberman's content analysis with the NANDA framework	42
4. Jenny's pattern of person-environment interaction as displayed on the NUDIST document memo	57
5. Jenny's graphic pattern of person-environment interaction	58
6. Example of three configurations of person-environment interaction	60
7. Bernie's pattern of person-environment interaction	71
8. Peggy's pattern of person-environment interaction	73
9. Susie's pattern of person-environment interaction	76
10. Denise's pattern of person-environment interaction	82
11. Barbara's pattern of person-environment interaction	85
12. Mary's pattern of person-environment interaction	87
13. Kathrin's pattern of person-environment interaction	90
14. Jenny's pattern of person-environment interaction	93
15. Julie's pattern of person-environment interaction	96
16. Joan's pattern of person-environment interaction	99

Figure	Page
17. Kathy's pattern of person-environment interaction	101
18. Margret's pattern of person-environment interaction	105
19. Patsy's pattern of person-environment interaction	107
20. Chip's pattern of person-environment interaction	113
21. Cynthia's pattern of person-environment interaction	115
22. Sharie's pattern of person-environment interaction	118

Table	Page
1. Caregiver characteristics according to three common interactional patterns	124

CHAPTER 1

In the United States, Alzheimer's Disease and Related Disorders (ADRD) causes irreversible cognitive impairment in two to four million adults (National Institute of Health, 1991). The prevalence of ADRD in the noninstitutionalized population over 65 years of age is estimated to be approximately 11%. ADRD affects approximately 4% of those between the ages of 65-74, approximately 20% of those between the ages of 75-84, and approximately 47% of those over 84 years of age (Evans et al., 1989).

Wives and daughters comprise the majority of home caregivers of persons with ADRD (Kuhlman, Wilson, Hutchinson, & Wallhagen, 1991). The caregiving process has a multidimensional impact on the caregiver, causing a high risk of emotional, physical, financial, and social problems (Farran, Keane-Hagerty, Tatorowitz, & Scorze, 1993). Also, the care recipient is more likely to be institutionalized if the home caregiver is a daughter or daughter-in-law (Grant, Patterson, Hauger, & Irwin, 1992). Such a life process event can be considered disruptive to health and is, therefore, suitable for investigation by the nursing discipline (Newman, Sime, & Corcoran-Perry, 1991).

The providers of care and the setting in which care is given best predict the multidimensional impact of caregiving and decisions about institutionalization (George & Gwyther, 1986; Motenko, 1989). If context is an important factor, then it is important to investigate the caregiver's perception

of her activities and her environment. However, there is a lack of research in this area. This study added to the body of contextual research by examining rural daughter/daughter-in-law home caregivers' descriptions of caring for a parent with ADRD.

Newman et al. (1991) declared:

Nursing views the individual as having multiple, interrelated parts in relation to a specific context. To understand a person, the interrelationship of parts and the influence of context must be taken into consideration. Thus, reality is multidimensional and contextual (p. 4).

Previously, researchers asked participants to describe caregiving, but did not use a multidimensional framework to analyze the data. In support of the nursing discipline's viewpoint, this study used a multidimensional framework to analyze rural daughter/daughter-in-law descriptions of caring for their parents with ADRD.

A multidimensional framework for analysis was provided by a group of nursing theorists who identified some common nursing assumptions. The theorists defined health as a fluctuating field of person-environment interaction (Newman, 1984; Roy, 1984). This subjective perspective of health, each person's view of their own pattern of person-environment interaction, became the focus of nursing.

The theorists then developed a framework for assessing patterns in person-environment interaction. They clustered practicing nurses' observations into nine groupings and chose an interactive conceptual label to describe each grouping. These interactive concepts were labeled the nine dimensions (see p. 5). A pattern of person-environment interaction was defined as a synthesis of data relevant to the nine dimensions. Thus, a pattern of person-environment interaction was multidimensional.

Donaldson and Crowley (1978) believed the patternings of humans in interaction with their environment to be an important line of inquiry for the nursing discipline. This study identifies the type of patternings Donaldson and Crowley thought important. It used the multidimensional framework of the nine dimensions to analyze interviews with rural daughter/daughter-in-law caregivers who were caring for a parent with ADRD. This was a secondary analysis of data, which consisted of transcribed interviews with daughter/daughter-in-law caregivers about their perceptions of caregiving. The original data were collected in rural counties in two Midwestern states.

Care for persons with ADRD in the United States costs an estimated \$41 billion for institutionalization and \$13 billion for in-home care (Blume et al., 1992). These figures fail to consider repercussions of ADRD on the caregiver, such as lost wages and the costs of treating problems associated with the multidimensional impact of caregiving. Identification of multidimensional patterns of person-environment interaction within this

subject group will provide valuable information for practitioners. With this information, they can plan interventions which will protect the caregiver from the negative impact of caregiving and help her keep her parent at home as long as it is beneficial for all involved. This is the first step in eventually reducing the costs of institutionalization and treating the multidimensional problems of the caregiver.

Purpose

The purpose of this study was to identify the multidimensional patterns of person-environment interaction in rural daughter/daughter-in-law caregivers, which emerged from their descriptions of caring for parents with ADRD.

Research Question and Objectives

The research question for this study was: What are the patterns of person-environment interaction in rural daughter/daughter-in-law caregivers that are revealed from their descriptions of caring for their parents with ADRD?

The objectives were to: (a) Identify individual patterns of person-environment interaction within the subject group and (b) Identify the common

groupings of patterns among all the individual patterns of person-environment interaction within the subject group.

Definition of Terms

A rural daughter/daughter-in-law home caregiver of a parent with ADRD is defined as a daughter or daughter-in-law who (a) resides in rural counties where 50% of more of the population lives outside an urbanized area, (b) states she is the primary manager of a parent who resides in the same rural community and is diagnosed with an irreversible cognitive impairment, (c) provides four or more hours of supervision and/or care weekly, and (d) is not cognitively impaired herself.

A pattern of person-environment interaction is defined as information that presents a holistic view of the person in the process of connecting with family or significant others, physical surroundings, work, local community, and society. The pattern of person-environment interaction is operationalized through a multidimensional framework which is a synthesis of data relevant to the nine dimensions (Newman, 1984; Roy, 1984).

The nine dimensions of person-environment interaction were initially defined according to Roy (1982 as):

1. Exchanging is defined as the interchange of matter and energy between humans and environment; mutual giving and receiving.

2. **Communicating** is defined as the interchange of information between humans and environment; the sending of messages.
3. **Relating** is defined as connecting with other persons or objects; establishing bonds.
4. **Valuing** is defined as the assigning of relative worth.
5. **Choosing** is defined as the selecting of one or more alternatives.
6. **Moving** is defined as activity within the environment.
7. **Perceiving** is defined as the receiving of information.
8. **Feeling** is defined as the quality of sensation and mood; subjective awareness of information.
9. **Knowing** is defined as meaning associated with a world view or with information.

During data analysis, the definitions presented here for the nine dimensions were refined in the context of daughter/daughter-in-law caregiving. See Appendix F for the initial and refined definitions of the nine dimensions.

According to Roy (1982), these nine dimensions cluster into three general characteristics: interaction, action, and awareness.

1. The **interaction characteristic** is defined as a manifestation of the exchanging, communicating and relating dimensions. This definition is operationalized by synthesizing data relevant to dimensions 1-3.

2. The action characteristic is defined as a manifestation of the valuing, choosing and moving dimensions. This definition is operationalized by synthesizing data relevant to dimension 4-6.

3. The awareness characteristic is defined as a manifestation of the perceiving, feeling and knowing dimensions. This definition is operationalized by synthesizing data relevant to dimensions 7-9.

The synthesis of data relevant to these three characteristics constitute the pattern of person-environment interaction. In this study, the pattern is described in narrative and graphic form.

CHAPTER 2

Review of the Literature

Overview

The review of the literature is organized into three sections. The first section addresses daughter/daughter-in-law caregivers of persons with ADRD and is divided into four sub-sections: (a) the impact of caregiving on family caregivers, (b) the factors associated with institutionalization of the person with ADRD, (c) caregivers' descriptions of what caregiving is like for them, and (d) rural family caregivers. This first section concludes with a summary of the literature related to family caregivers.

The second section addresses the NANDA framework for the assessment of person-environment interaction patterns. It also reviews the literature related to the NANDA assessment framework. The third and final section summarizes the literature review.

Daughter/Daughter-in-law Home Caregivers of Person's with ADRD

Adult children are the largest group of caregivers for the non-institutionalized frail elderly - approximately 37% of all caregivers. The overall ratio of daughters to sons is 3:1, 4:1 among the very ill elderly (Stone, Cafferata, & Sangl, 1987). Brody (1981) coined the term "woman in the

middle" to describe a daughter, daughter-in-law, or granddaughter caring for her parents or grandparents (p. 472).

At least 1.8 million "women in the middle" are caring for their own children while providing support to an elderly relative. Half of these caregivers are members of the paid labor force, and one in five has a parent living in her home (Brakeman, 1994).

The burden of caring for persons with ADRD usually falls on family home caregivers because only a small percentage of those over age sixty-five are in institutions (Kuhlman, Wilson, Hutchinson, & Wallhagen, 1991). The family home caregiver is defined as a member of the person's informal support system (family/friend) who accepts the duty of management at home and is not paid for that service (Wilson, 1989a, 1989b). Most caregivers are wives and daughters of the person with ADRD (Kuhlman et al., 1991).

Caregiving is socially disruptive to the caregiver. The relative with ADRD loses mental and physical capacities and eventually requires twenty-four hour management. The caregiver becomes the "hidden patient" because their caregiving role puts them at a high risk of emotional, physical, financial, and social consequences. In fact, institutionalization of the person with ADRD may be the result of these multidimensional consequences rather than the downward progression of the care recipient's condition (Blume, Persily, Mintzer, 1992; Given, Colins, & Given, 1988; Grant, Patterson, Hauger, & Irwin, 1992). Colerick and George (1986) found that the care recipient was at

a higher risk of institutionalization if the caregiver was a daughter or daughter-in-law.

Impact of Caregiving on the Caregiver

Studies delineating the consequences of ADRD caregiving for the caregiver focused on spouses or a mixture of caregivers, i.e. spouses, adult children, other relatives, and friends. Research related to daughter/daughter-in-law caregivers targeted care recipients who suffered from a multitude of impairments, which may or may not have included ADRD. For this study, the literature review encompassed family caregiver research which included adult children caregivers and ADRD care recipients.

Family caregiving was associated with caregiver burden, caregiver well-being, or role stress/strain in the studies presented. Caregiver burden or well-being was conceptualized as multidimensional as compared to role strain/stress which was a unidimensional concept.

Caregiver burden.

Zarit and Zarit (1983) defined burden as the physiological, emotional, social, and financial problems that are reported by family members caring for impaired older adults. They developed a multidimensional Burden Interview instrument in which caregivers responded to items regarding (a) relationship difficulties between the caregiver and the care recipient, (b) the general negative physical, emotional, and social impact of caregiving on the caregiver's life, and (c) feelings of satisfaction related to caregiving.

Farran, Keane-Hagerty, Tatarowicz, & Scorza (1993) studied 140 family caregivers (58% spouses and 31% adult children) of persons with dementia using the Burden Interview. They found that total caregiver burden increased as the frequency of the impaired person's disruptive behaviors increased. The authors did not differentiate between spouse and adult children caregiver burden scores.

Thompson, Futterman, Gallagher-Thompson, Rose, and Lovett, (1993) used the Burden Interview with a sample of 217 family caregivers (71 daughters) of care recipients who were cognitively impaired (58%) or physically impaired (42%). Caregivers who took part in social interaction for fun and recreation presented lower scores on the Burden Interview.

Daughters and daughters-in-law (n=159) caring for parents with AD/DRD (40%) and other impairments (60%) responded to the Caregiver Reaction Survey (Pohl, Given, Collins, & Given, 1994). The survey explicated a multi-dimensional description of burden through sub-scales for (a) negative reaction, (b) family abandonment, (c) impact on health, and (d) impact on schedule. Survey results indicated no difference in mean scores between the caregivers of parents with AD/DRD and the caregivers of parents with other disabilities. In the study by Pohl et al. (1994), those caregivers who quit their jobs compared to those who did not responded that they felt more impact of caregiving on their health and schedules, had less social support, less income, and were more involved in care.

For all caregivers in this study, as social support increased, negative reactions decreased, feelings of family abandonment decreased, impact on health decreased, and impact on schedule decreased. As caregiver health declined, negative reactions increased; and as income increased, negative reactions increased.

Caregiver well-being.

George and Gwyther (1986) defined the concept of well-being as physical, mental, financial, and social health (George & Gwyther, 1986). They utilized multiple instruments to assess the four dimensions of well-being in order to compare a sample of family caregivers for persons with dementia with randomly sampled middle-aged/elderly people. George and Gwyther also used their assessment to investigate the correlation between caregiver well-being and the caregiver/care recipient relationship, caregiver/care recipient living arrangements, and care recipient illness characteristics.

The participants that completed the well-being instruments consisted of 510 family caregivers (275 spouses, 163 adult children, 72 other family members) for persons with dementia. As compared to the community sample, this survey group experienced burden in the mental health and social participation dimensions of well-being. Caregivers did not differ from the community sample in the physical health or financial security dimensions.

Spouse caregivers showed lower levels of well-being across all four dimensions than the adult children caregivers or other relative caregivers.

Adult children reported fewer visits with family and friends and less time spent relaxing than spouses or other caregiving relatives. Spouses as well as adult children, presented significantly lower statistical means for satisfaction with social activity.

Caregiver coresidence with the care recipient produced lower dimension scores for mental health, social participation, and financial resources. None of the dimensions of caregiver well-being were significantly related to care recipient illness characteristics such as duration of the illness and severity of the symptoms.

Quayhagen & Quayhagen (1988), measured well-being by a composite score from (a) a life satisfaction index, and (b) a global self rating scale for perceived mental and physical health. Husband (n=17), wife (n=26), and daughter caregivers (n=15) participated in the study. The groups differed in their associations between well-being and specific coping strategies. Lower use of fantasy was associated with well-being in both daughters and spouses. Problem-solving and help-seeking were positively associated with well-being for the spouses but not the daughters. The daughters' well-being was positively related to respite time.

Franks & Stephens (1992) studied well-being in relation to caregiver role stress, mother role stress, and wife role stress. Their study consisted of daughter (n=75), daughter-in-law (n=21), granddaughter, niece, and sister (n=10) caregivers of persons with cognitive and physical impairments. Well-

being was operationalized by a self assessed rating of current health status and positive and negative affect. Stress in the mother role and caregiver role was associated with positive and negative affect. Additionally, role adequacy, or perceived feelings of mastery within each role of caregiver and wife, mediated the effects of role stress on caregiver affective indices of well-being.

Deimling & Bass (1986) asked spouse (n=309) and daughter (n=277) caregivers for their perceptions of their dependents' cognitive impairment and the effects on their well-being. Disruptive behaviors and impaired social functioning of the care recipient related to impaired elder, caregiver, and family relationships. Impairment in care recipient activities of daily living (ADL) related to activity restrictions for the caregiver. Those who provided high levels of physical and instrumental care to a cognitively impaired elder were more likely to report changes in their physical health. Finally, care recipient ADL limitations, impaired social functioning, and disruptive behaviors all significantly related to caregiver depression. Authors did not report differences in caregiver outcomes as related to caregiver/care recipient relationships.

Caregiver role stress/strain.

Some studies presented the impact of caregiving as a as a unidimensional concept, such as role strain. Mui (1992) defined role strain as the emotional cost of caregiving in relation to role demand overload and role conflict. Mui studied black (n=117) and white (n=464) daughters caring for

cognitively impaired and physically impaired parents. All daughters experienced role strain, though black daughters reporting less strain. The author did not cite differences between daughters caring for cognitively impaired or physically impaired parents.

Family caregivers (spouses, adult children, other relatives and friends) for persons with cognitive impairments (n=17) as well as physical impairments (n=61), and their care recipients were surveyed to find if mutuality and preparedness were related to role strain (Archbold, Stewart, Greenlick, & Harvath, 1990). This study defined role strain as the caregiver's perception of their own difficulty in executing the caregiver role. Mutuality was defined as the caregiver's "ability to (a) find gratification in the relationship with the impaired person, (b) find meaning in the caregiving situation, and perceive the impaired person as reciprocating by virtue of his/her existence" (Archbold et al., 1990, p. 376). Preparedness for caregiving was defined as caregivers' confidence in their ability to manage their family member's physical, psychological, and social resource needs. Dyads responded to the Family Caregiving Inventory, one for the caregiver and one for the care receiver. The authors did not identify the differences between the two interviews or how the care recipient interview contributed to the research question. The question concerning role strain, mutuality, and preparedness was addressed to caregivers and involved their own perceptions, not those of the care recipient.

The results of the Archbold et al. (1990) study indicated that higher levels of mutuality and preparedness were associated with lower levels of role strain in relation to direct care, increased tension, and global strain. However, mutuality and preparedness were not associated with role strain related to economic burden, worry, or lack of resources.

Skaff and Pearlin (1992) examined "loss of self" in a sample of spouses (n=325) and adult children (n=232) caring for a relative with Alzheimer's disease. Loss of self was defined as "loss of identity that comes about as a result of engulfment in the caregiver role" (p. 656). This definition was operationalized by asking caregivers to what extent they had lost (a) a sense of who they were and (b) an important part of themselves. Care recipient problem behaviors were the most powerful predictors of "loss of self" for both spouse and adult children caregivers. Additionally, the greater the number of outside roles adult children caregivers occupied, the less likely they are to experience a "loss of self".

Parks and Pilsuk (1991) compared female and male adult children caregivers of parents with Alzheimer's disease using the anxiety and depression sub-scales of the Hopkins Symptoms Checklist. They found no difference between the daughters and sons on depression or anxiety. Daughters reported higher levels of caregiving stress and were more likely to cope by the use of fantasy, while men used withdrawal.

Summary of the impact of caregiving on the caregiver.

Prior research revealed that caregiving was associated with caregiver burden, or changes in caregiver well-being, or caregiver role stress/strain. The studies also indicated that the multidimensional effects of caregiving on family caregivers could be balanced by (a) social support, (b) caregivers' positive perception of their health, (c) respite from caregiving, (d) caregivers' perception of mastery of/preparedness for the caregiver role, (e) feelings of mutuality in the caregiver/care recipient relationship, and (f) employment.

Factors Associated with Institutionalization of the Care Recipient

Several characteristics of the caregiver and caregiving environment emerged as reliable predictors of institutionalization in a study by Colerick and George (1986). The sample consisted of 209 cognitively impaired elderly and their caregivers. Within one year, 63 care recipients were institutionalized. Elderly, unemployed spouses who had restricted leisure time, as well as physical and financial burdens were more likely to keep the care recipient at home. In contrast, employed daughter caregivers who reported high levels of stress and increased use of community services were more likely to institutionalize their parents.

Lieberman and Kramer (1991) studied 322 cognitively impaired elderly. At the end of one year, 72 subjects were placed in long term care institutions. No care recipient characteristics emerged as significant predictors of

institutionalization. Instead, predictive characteristics belonged to the caregiver and the environment. Lone spouse caregivers rated lowest in the institutionalization of their elder spouse. A spouse, in combination with his or her son or daughter had higher rates of institutionalization of their elder relative. A spouse, in combination with his or her son or daughter, rated the next highest. A son or daughter, either together or alone or with friends, rated highest in the institutionalization of their elder parent. Financial problems and caregiver psychological problems were reported significantly more often in families that institutionalized the care recipient.

In a study by Cohen, Gold, Shulman, Wortley, McDonald, and Wargon (1993), 196 caregivers of demented relatives were followed for eighteen months. At the end of that time, 37 care recipients were at home, 100 were living in institutions, 19 died at home, 12 had moved, and 22 declined further participation. During the initial baseline assessment, caregivers who had placed the care recipient in an institution reported worse overall health, higher levels of burden as assessed by the Zarit Burden Interview, and more frequent use of community services than those caregivers whose relatives were at home. The institutionalized care recipient scored lower on the Mini Mental Status Exam and exhibited more troublesome behaviors at baseline. In contrast to the previous two studies, caregiver/care recipient relationship were not predictive of actual placement and caregiver characteristics were predictive of institutionalization.

Summary of factors associated with institutionalization.

In all three studies, either the psychological, emotional or physical status of the caregiver was a significant predictor of institutionalization of the care recipient. Being a daughter caregiver and using community services proved to be significant predictors in two of the studies. Caregiver financial problems, caregiver employment, and care recipient characteristics were significant predictors in one study. Review of the literature indicated that the context of the caregiving situation (i.e., the who, what, where, why, and how of the caregiving situation) determined the risk of institutionalization for the care recipient .

In their review of the literature on stress among families caring for relatives, Given, Collins, and Given (1988) stated:

It is difficult to quantify how the sense of responsibility an adult child feels toward a parent interacts with the historical and current environment to color the duration or the amount of burden that adult children are willing and able to endure as a parent's level of dependence increases (p. 71).

To better understand the multidimensional impact of caregiving and the subsequent needs of the caregiver, daughter/daughter-in-law caregivers must provide subjective perceptions of their interaction with the environment. The next section of the literature review concentrates on the qualitative approach in

studying the subjective nature of caregivers' interaction with their environment. In this approach, caregivers are asked to describe what caregiving is like for them.

Family Caregivers' Descriptions of Caring for a Relative with ADRD

Studies using a qualitative approach with caregivers of person's with ADRD included subject groups with mixtures of family members (Cartwright, Archbold, Stewart, & Limandri, 1994; Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991; Lynch-Sauer, 1990; Wilson, 1989a, 1989b;), spouses (Lindgren, 1993; Harris, 1993), adult children (Bowers, 1987) and an adolescent (Beach, 1994). No researchers specifically explored the experience of daughter/daughter-in-law caregivers, though studies that included this group were reviewed.

Adult children caregivers (31 daughters and 2 sons) described what it was like to be a caregiver for one's parent (Bowers, 1987). A dimensional analysis of the data revealed five categories of care: (a) anticipatory, (b) preventive, (c) supervisory, (d) instrumental, and (e) protective. Caregivers cited protective care as the most difficult and most important type of care. Under this category, caregivers attempted to protect the parent's self image as well as the parent's physical safety.

Wilson (1989a; 1989b) interviewed family caregivers to explore their perceptions of caring for a family member with dementia. Analysis of the

qualitative data resulted in formation of the three stages of family caregiving:

(a) taking it on, (b) going through it, and (c) turning it over.

Ninety-four family caregivers composed of spouses (64%), daughters (24%), sons (3%) and other family members (6%) responded to open-ended questions such as what is difficult/ pleasant/ hopeful/ good about your life? (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991). Four major themes emerged from the analysis: (a) loss and powerlessness, (b) values, choices, and provisional and ultimate meaning, (c) caregiving resources, and (d) responsibilities of caregiving.

Lynch-Sauer (1990) read seven published works about the experience of caring for a family member with Alzheimer' disease. The authors included two spouses (one wife, one husband), four children (two daughters and two sons), and one daughter-in-law. The researcher used phenomenological analysis to discover the following themes in the data: (a) the unending attempt to put care recipients in touch with their surroundings, (b) the progressive experience of asynchrony with the care recipient, (c) the experience of loss of mutuality with the care recipient, (d) a progressive diminishment of diversity in the relationship to the care recipient, others, and the environment, (e) an attempt to attribute meaning to the care recipient's illness, and (f) an ever-present search for personal connectedness with the care recipient.

Nineteen family caregivers of persons with cognitive impairment (n=9) and physical impairments (n=11) were encouraged to talk at length about their

situation (Cartwright, Archbold, Stewart, Limandri, 1994). The sample included daughters (n=6), wives (n=5), husbands (n=4), and other relatives (n=5). A grounded theory of enrichment emerged from the data. The process of enrichment involved the interaction of the caregiver with the care recipient within an environmental context in which a joint activity held meaning for both and had been adapted for the care recipient's impairment. The activity produced enrichment because it was comforting and/or stimulating for both care recipient and caregiver.

Summary of family caregivers' descriptions of caring for a relative with

ADRD.

Researchers studying the context of caregiving from the perspective of the caregiver identified the (a) purposes of caregiving, (b) caregiving stages, (c) caregiver losses, and (d) caregiver themes of searching for meaning and searching for personal connectedness with the care recipient. The studies did not explicate a multidimensional perspective of the caregivers in interaction with their environment.

Rural Family Caregivers of Persons with ADRD

The rural elderly as compared to the urban elderly have less access to formal support services (Buckwalter, Kelly, Hall, & Sime, 1992). Also, a study by Scott and Roberto (1985) showed minimal use of formal services in a

sample of 571 rural elderly adults. Since ADRD is an illness primarily affecting the elderly, the needs of the caregivers for this rural elderly population must be considered in order to develop a complete picture of the daughter/daughter-in-law caregiver experience. The reviewed studies did not specifically sample rural caregivers.

Summary of the Literature Review of Caregivers of Persons with ADRD

Daughter/daughter-in-law caregivers made up a significant proportion of the family caregivers for the non-institutionalized elderly, however there was a lack of research focusing on the rural daughter/daughter-in-law caregiver. A review of the quantitative studies indicated a multidimensional negative impact of caregiving on family caregivers. The parent recipient of daughter/daughter-in-law caregivers proved to be the most at risk for institutionalization. These quantitative studies indicated that the caregiving context provided the best predictors and the probabilities of the care recipient's institutionalization.

The review of the qualitative studies in which caregivers described what caregiving was like for them provided an understanding of caregiving from the perspective of the caregiver. However, a multidimensional perspective of the caregiver in interaction with their environment did not emerge from the data.

A multidimensional perspective is consistent with the quantitative studies that indicated physical, psychological, and social effects of caregiving. This perspective lays the foundation for planning interventions that prevent (a) negative multidimensional impact on daughter/daughter-in-law caregivers and (b) premature institutionalization of their parent care recipient.

NANDA Framework for Assessment of a Pattern of Person-Environment Interaction

The National Group for the Classification of Nursing Diagnoses assembled in 1972 to answer the question: what are the phenomena of concern for nursing? (Gebbie & Lavin, 1975). This group became the North American Nursing Diagnosis Association (NANDA). NANDA developed a taxonomy of nurses' phenomena of concern based on judgments and observations emanating from their own practice. They used an inductive approach to identify 33 pathophysiological and biopsychosocial labels which were representations of phenomena of concern to nursing. Examples of the phenomena are listed in Figure 1.

Nursing theorists working in the NANDA group articulated a theoretical perspective to serve as an organizing framework for the nursing phenomena consistent with nursing's holistic perspective. Members of this group were: Sister Callista Roy, chairperson, Andrea U. Bircher, Rosemary

Ellis, Joyce J. Fitzpatrick, Marjory Gordon, Margaret Hardy, Imogene King, Rose McKay, Margaret A. Newman, Dorothea Orem, Rose Marie Parse, Martha Rogers, Mary Jane Smith, and Gertrude Torres. This theorist group came to consensus on the following assumptions about nursing:

1. The human being is an open energy system, characterized by pattern and constantly interacting with a universe of open systems.
2. The purpose of nursing is to facilitate the health of people.
3. Nurses help people facilitate health by use of self with a body of nursing knowledge.
4. Nursing views the health of a person as a whole.
5. Health is a fluctuating field of person-environment interactions.
6. The motivation for change must come about because the person perceives their own pattern as unsatisfactory. (Newman, 1984; Roy, 1984)

The theorists then examined individual diagnostic phenomena collected by the practicing nurses. They clustered the individual phenomena into groups and chose conceptual labels to describe these clusters, concepts which described dimensions of person-environment interactions (Newman, 1984). As a result, nine dimensions of person-environment interaction were identified (see Figure 1).

The nine dimensions were clustered into three groupings: interaction, action, and awareness. Interaction contained the dimensions of exchanging, communicating, and relating. Valuing, choosing, and moving characterized

action. Perceiving, feeling, and knowing made up the sub-group of awareness (Roy, 1982).

Dimension	Definition	Phenomena
1. Interaction Characteristics		
Exchanging	Mutual giving & receiving.	Nutrition, elimination, oxygenation, circulation, physical regulation, physical integrity.
Communicating	Sending messages.	Communication.
Relating	Establishing bonds.	Role, socialization, family sexuality patterns.
2. Action Characteristics		
Valuing	Assigning of relative worth.	Spirituality.
Choosing	Selection of alternatives.	Coping, participating, judgment, health-seeking.
Moving	Activity.	Activity, rest, recreation, activities of daily living, self-care, growth and development, relocation.
3. Awareness Characteristics		
Perceiving	Reception of information.	Sensory perception, self concept, meaningfulness.
Feeling	Subjective awareness of information.	Comfort, emotional integrity, emotional state.
Knowing	Meaning associated with a world view or with information.	Knowledge, thought processes.

Figure 1. Parallels of dimensions and diagnostic phenomena. (Adapted from Roy, 1984, p. 29-33, England, 1989, p. 353, & Taxonomy I - Revised (1992), Carroll-Johnson & Paquette, 1994, p. 481-483.

These nine dimensions of person-environment interaction provided a holistic framework for assessment which was consistent with the holistic assumptions outlined by the nurse theorist group (Newman, 1984). The nurse theorists stipulated that synthesis of data relevant to the nine dimensions described a pattern of person-environment interaction (Roy, 1984, p. 31). See Figure 2 for the NANDA assessment framework.

Dimensions of Person-Environment Interaction

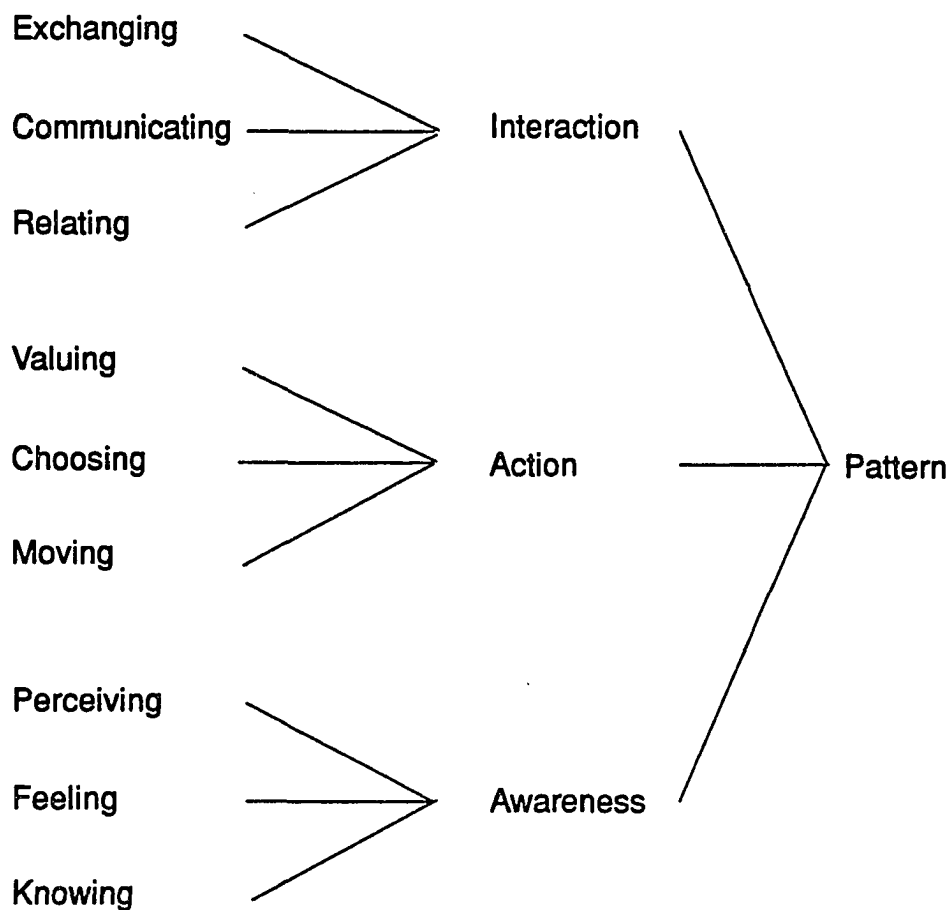


Figure 2. NANDA framework for assessing a pattern of person-environment interaction.

Review of the Literature on Person-Environment Interactional Patterns

Newman (1984, 1986, 1987) proposed that the NANDA assessment framework be used as a method of pattern identification. As reported at the national conferences for the classification of nursing diagnoses between 1982 and 1987, review of the research revealed no evidence of investigators using the NANDA assessment framework to explicate patterns of person-environment interaction (England, 1989). Ridgeway (1992) reviewed the research presented at the national conferences from 1984 through 1991, along with the research articles presented in the Nursing Diagnosis Journal from 1990 to 1992 and found one report by Loomis and Conco (1991) that related the dimensions of person-environment interaction to health.

Loomis and Conco (1991) asked persons with a chronic illness to describe their experience of being healthy and to pick out specific diagnostic phenomena related to nursing care needs. Analysis of the interviews indicated that this subject group viewed "health as the ability to perform functions and (that) they evaluated health in relation to past performance" (Loomis & Conco, 1991, pg. 168). The nursing diagnoses picked by the subjects fell under all nine dimensions of person-environment interaction, however "moving and perceiving" received the most diagnoses. The moving dimension encompassed activities of daily living and recreation, while the perceiving dimension encompassed body image. This was consistent with the subjects' definition of health as the ability to perform functions.

Jones, (1994) used the nine dimensions to organize assessment data and found an "irregular pattern of relating because of poor self-concept or fear of not being accepted". The author went on to suggest that "this statement may describe a diagnosis that reflects a life theme and its potential impact on the total person-environment interaction" (Jones, 1994, p. 110).

Several researchers have used the NANDA assessment framework as a method for pattern identification. For example, Jonsdottir (1988) asked persons with chronic obstructive pulmonary disease (COPD) to describe the most meaningful person or events in their life. The NANDA framework was used as a method of pattern identification; the interview data clustered according to each of the dimensions. The researcher synthesized data in each of the dimensions and formulated a pattern description for each subject according to a developmental sequence. Each subject received a pattern description for childhood/adolescence, early, middle, and late adulthood.

A common theme emerged from the patterns. Limited energy exchange, consistent with COPD, appeared in the relating and feeling dimensions, resulting in isolation and repressed feelings. In these subjects with COPD, patterns of person-environment interaction were similar to the characteristics of their disease. This was consistent with Newman's (1986) theory of health as expanding consciousness.

Moch (1988) used the NANDA assessment framework as a method to explicate the view of health in illness. Women with breast cancer described

their perceptions of living with cancer. Researchers clustered the interview data according to each of the nine dimension statements, and further synthesized the statements into a pattern description for each woman.

Commonalities among patterns emerged from the womens' concept of health within the experience of breast cancer. Common patterning descriptions included:

1. Discussing relatedness often and experiencing and showing relatedness more through cancer
2. Having a busy, "doing for others" moving pattern and slowing down and focusing on self through cancer
3. Identifying perceiving experiences to a greater extent through the cancer experience
4. Discussing knowing about self and life more through increasing time spent reflecting about life and coming to know what is meaningful (Moch, 1988, p. 141).

The common patterning descriptions reflected an increase in person-environment connectedness which was consistent with Newman's (1986) theory of health as expanding consciousness.

In another study, Winn (1990) used the NANDA assessment framework to identify patterns of sexuality in middle aged children. The researcher asked children to describe their experience of being a boy or a girl. Researchers categorized the interview data using the NANDA framework, clustering

specific dimensions into domains: physical (exchanging, perceiving, moving), behavioral (choosing, communicating, relating), and inner experience (valuing, feeling, knowing). Meaningful segments of data were categorized according to the three domains. An emerging developmental progression of sexuality became apparent. Younger children's experiences clustered in the moving dimension, with a shift toward the relating dimension for the older children, and finally an emphasis on the feeling dimension for the oldest of the children.

Summary of literature related to person-environment interactional patterns.

Several researchers tested the NANDA framework with different populations. Two of these researchers identified patterns of person-environment interaction from the interview data of adults experiencing a chronic illness. One of the researchers used interview data from children to identify patterns of sexuality.

Summary of the Literature Review

Review of the literature on family caregivers for persons with ADRD provided evidence of caregiving's negative multidimensional consequences on the caregiver. Additionally, the parent care recipients of the daughter/daughter-in-law caregivers proved most at risk for

institutionalization. There were no studies that addressed only rural daughter/daughter-in-law caregivers for a parent with ADRD.

The negative consequences of caregiving and the institutionalization of the care recipient was associated with the caregiving context. Qualitative studies addressed the caregiving context from the perspective of the family caregiver. These studies provided information about stages of caregiving, the purposes of caregiving, and caregiver losses but did not provide a multidimensional perspective of the caregivers in interaction with their environment.

Studies using the NANDA framework identified patterns of person-environment interaction from subjective interview data. Two of the studies identified multidimensional patterns of person-environment interaction.

CHAPTER 3

Methodology

Overview

The "abduction" approach was used in this research. In this approach, the researcher valued the textual representation of personal experience and believed that "no data, whether verbal or numeric symbols, are independent of theory" (Reed, 1995, p. 74). Tape recorded, transcribed interviews of rural daughter/daughter-in-law caregivers' descriptions of caring for a parent with ADRD were examined using the NANDA framework. Data were analyzed according to the nine dimensions, then synthesized according to the three broader characteristics and, finally, synthesized into a description of the subject's pattern of person-environment interaction. This secondary analysis of data drew from pre-existing interviews with daughter and daughter-in-law caregivers.

This chapter is divided into six sections. The first section describes the original study from which the data for this study were obtained. The second section explains the sampling procedure and the characteristics of the sample for this study. The third section describes the data analysis method used. The fourth section illustrates the analysis of one transcript. The fifth section

reports the procedure for ensuring rigor in the qualitative data analysis. The final section presents the procedure for protecting the subjects' privacy.

Original Study From Which Data Were Obtained

The original study tested two teaching interventions developed to help family home caregivers manage behavioral problems of the care recipient with ADRD (Buckwalter, Kelly, Hall, & Sime, 1992). The original data were collected in rural settings in two Midwestern states. The investigators targeted rural counties because of a lack of knowledge about the needs of rural caregivers of persons with ADRD.

In one of the sites, 2% of the population over 65 had a medically diagnosed dementia (Kokmen, Beard & Offord, 1988). About 7% of elderly in the other site suffered from a dementing illness with 80% cared for in the home (Statewide Geriatric Healthcare Issues, 1992).

Researchers collected quantitative measures of caregiver burden, mood, social support, as well as caregiver perception of care recipient problematic behaviors. These measurements were collected at baseline and then after the intervention at three months, six months, and twelve months. In addition, the caregivers were asked at baseline, six months, and twelve months to describe what caregiving was like for them. The interviewer asked questions for the purpose of clarifying or expanding the description, but not to direct the

interview. The caregivers presented their stories in their own words. The interviews were tape-recorded and transcribed verbatim.

To be included in the original study, caregivers met the following criteria:

1. Informal caregivers (either family members or friends).
2. Caring for an individual who has been diagnosed by a physician as having Alzheimer's disease, multi-infarct dementia, or mixed type dementia, and who is living in the community; or for whom caregiver reports memory impairment.
3. Providing four or more hours of supervision and/or care weekly.
4. Not cognitively impaired themselves.

The caregivers were recruited from support groups affiliated with local Alzheimer's Associations, mental health centers, neurology clinics, hospitals, church groups, and by placing advertisements in Alzheimer's Association newsletters.

Present Study

Investigators using data collected in another study must be explicit in assuring a fit between the original data set and data collection process and their own research question (Thorne, 1994). In the original study, caregivers were asked to describe what caregiving was like for them. This was the only prompt that researchers used to begin the interview. As the interview

progressed, the caregiver expanded upon what was most salient to them in relation to caring for their family member. The researchers listened and asked for clarification or expansion but did not lead the interview.

The research question for the study reported here was: What are the patterns of person-environment interaction for rural daughter/daughter-in-law caregivers that are revealed from their descriptions about caring for their parents who have ADRD? Patterns of person-environment interaction were operationalized through the NANDA framework. Caregivers' descriptions of their own interaction with the environment in the context of caregiving comprise the interviews from the original study. Therefore, the original interviews answered the research question for this present study.

Sample

Sampling Procedure

The investigator purposively sampled from the setting, subjects, and data of the original study to obtain interview transcripts for the present study. Rural counties in two Midwestern states provided the setting, with rural defined as 50% or more of the county's population living outside an urbanized area.

This study sampled daughters/daughters-in-law from the rural family caregivers participating in the original study, using their transcribed baseline interviews. This study used only baseline interviews because the subsequent

interviews were obtained after intervention and may have differed according to treatment groups.

Investigators from the two Midwestern sites collected all baseline daughter or daughter-in-law interviews when they were transcribed. The investigators sent these anonymous interviews to this researcher.

Final sample size consisted of sixteen consecutive interviews and was determined when data saturation occurred, or no new patterns of person-environment interaction occurred. Review of the literature with similar studies of caregivers indicated a similar sampling to meet the criterion of data saturation (Harris, 1993; Wilson, 1989a, 1989b; Lindgren, 1993).

Characteristics of the Sample

The sample consisted of sixteen Caucasian women, fourteen daughters and two daughters-in-law. Their ages were: 39 (n=1), between 40 and 49 (n=4), between 50 and 59 (n=5), and between 60 and 69 (n=6).

Their years of completed education were: 10 years (n=1), 12 years (n=4), between 13 and 16 years (n=6), and between 17 and 21 years (n=4).

There was no report of the educational status of one daughter-in-law.

Subjects either lived in a city in a rural county (n=9) or outside of the city in a rural county (n=7). Eleven subjects co-resided with their parent.

Hours of daily care provided by the daughters/daughters-in-law were: 1-3 hours (n=5), 6-15 hours (n=3), and 18-24 hours (n=8).

Hours of additional informal or professional help per week ranged from no additional help (n=8), 2 to 10 hours (n=5), 36 to 44 hours (n=2), to one caregiver who had 12 hours of professional help per day.

Care recipients were either mothers/mothers-in-law (n=14) or fathers (n=2) of the caregivers. The parent care recipients ranged in age from 73 to 97; between 70 and 79 (n=4), 80 and 89 (n=9), and between 91 and 97 (n=3).

The parents were diagnosed with: irreversible dementia (n=10), Alzheimer's disease (n=3), and multiple infarct dementia (n=3).

Daughters/daughters-in-law reported symptoms of memory impairment in their parents for: 1-2 years (n=9), 5 years (n=1), and 8-11 years (n=6).

Severity of the dementia was assessed using the Global Deterioration Scale (GDS) described by Reisberg, Ferris, De Leon, and Crook (1982). Numeric scores indicated cognitive decline: 1 = none; 2 = very mild; 3 = mild; 4 = moderate; 5 = moderately severe; 6 = severe; and 7 = very severe or late dementia. According to the GDS, parents had: mild cognitive decline (n=2), moderate cognitive decline (n=5), moderately severe cognitive decline (n=6), and severe cognitive decline (n=3).

Data analysis

Content analysis as described by Miles and Huberman (1994) was consistent with a research approach using an explicit framework to code qualitative data. The analysis involved data reduction, data display, and

conclusion drawing/verification as an iterative process. First the conceptual framework was made explicit. Then the data were reduced according to this framework in an organized and observable manner so that conclusion drawing/verification followed. The process continued until the research question was answered.

A qualitative software program, NUDIST (Richards & Richards, 1991) provided a tool for data reduction and data display. The researcher used NUDIST to code the individual transcribed interviews and to retrieve data for easy viewing during both the analysis and auditing processes.

The NUDIST program conceptualized codes as "nodes". The process of coding indexed data at specific nodes. The researcher created a node for each of the nine dimensions of person-environment interaction. Then, each interview was entered into the program and labeled with a pseudonym representing the caregiver.

Overview of the Content Analysis

Each daughter/daughter-in-law caregiver interview was analyzed using the NANDA dimensions of person-environment interaction and Miles and Huberman's (1994) iterative process of content analysis. The researcher used the NUDIST program to index data at nodes labeled for each dimension, retrieve data for viewing and analysis, and display the results of the analysis.

The steps in the content analysis proceeded according to the two research objectives for the study.

Research objective #1.

Identify the individual patterns of person-environment interaction of rural daughter/daughter-in-law caregivers that are revealed from their descriptions of caring for their parents who have ADRD. The steps involved in identifying the individual patterns were:

1. Data reduction. Segments of all interview data for one caregiver were indexed by the researcher in the dimension-labeled nodes within the NUDIST program.

2. Data display, data reduction, and conclusion drawing. All of the data indexed to one dimension node were printed, then synthesized by the researcher into dimension description statement/s.

3. Data display, further data reduction and conclusion drawing. A NUDIST document memo for each caregiver interview displayed the nine dimension description statements for that individual. The exchanging, communicating, and relating dimension statements were synthesized (reduced) into an interaction characteristic statement. Valuing, choosing, and moving dimension statements were synthesized (reduced) into an action characteristic statement. Perceiving, feeling, and knowing dimension statements were synthesized (reduced) into an awareness characteristic statement. These characteristic statements were also displayed on the document memo. Finally,

the characteristic statements were synthesized into a description of the caregiver's pattern of person-environment interaction. The pattern description also appeared on the caregiver's document memo.

4. Data reduction and data display. The researcher reduced the textual description of the caregiver's pattern of person-environment interaction to a graphic depiction.

The researcher used this process to analyze the sixteen caregiver interviews. The sixteen narrative and graphic individual patterns of person-environment interaction met research objective number one. See Figure 3 for the process of individual pattern identification using the NANDA assessment framework.

42

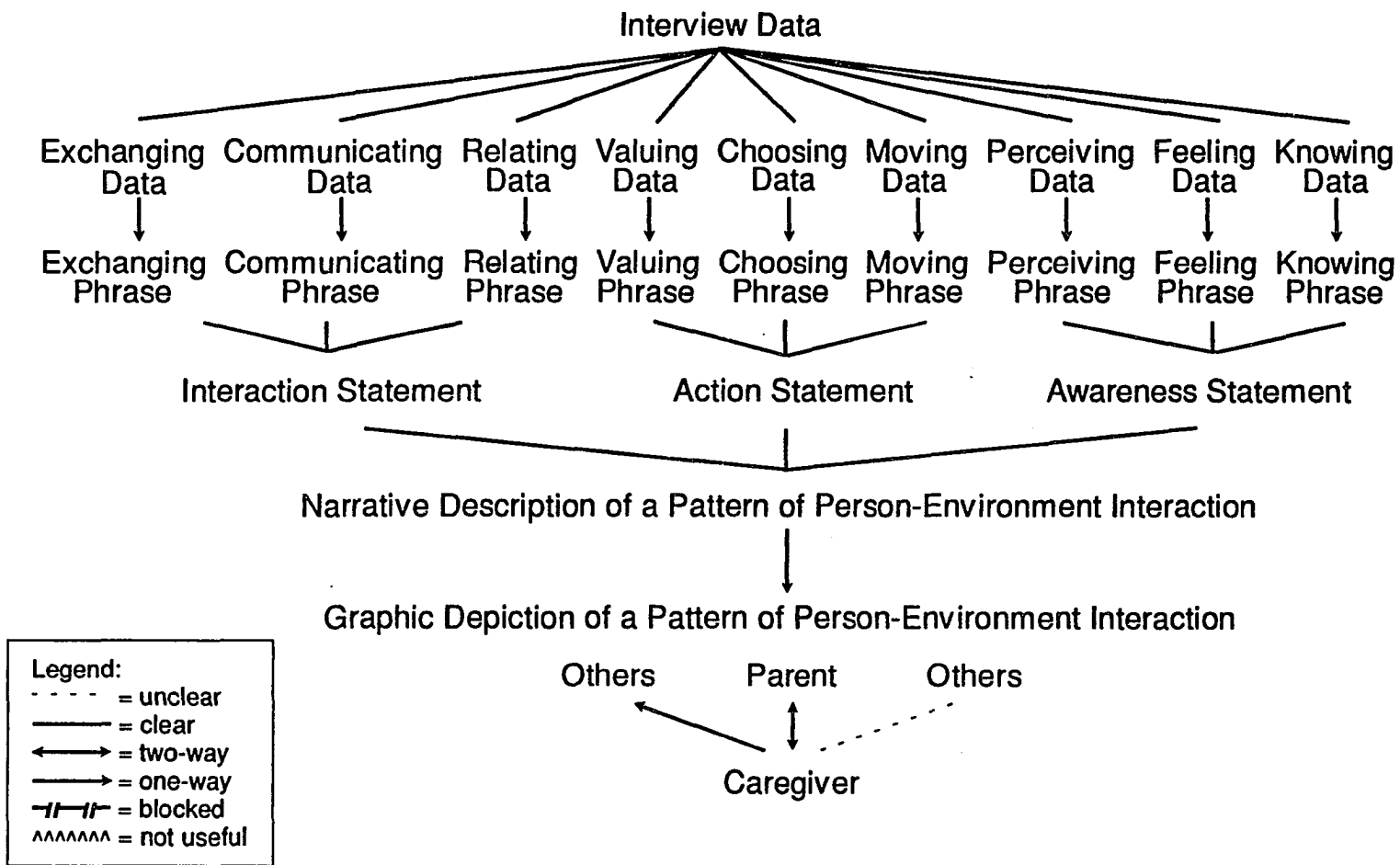


Figure 3. Process of pattern identification using Miles & Huberman's content analysis with the NANDA framework.

Research objective # 2.

Identify the common groupings of patterns among all the rural daughter/daughter-in-law individual patterns of person-environment interaction. The steps involved in identifying the common groupings were:

5. Data display, conclusion drawing. The researcher placed all sixteen graphic depictions of caregiver patterns of person-environment interaction side by side. Commonalities in patterns were identified.

6. Further data display, conclusion drawing. The narrative depictions of all sixteen interviews were reviewed for commonalities. The process of reviewing the graphic and narrative representations continued until common groupings among the individual patterns of person-environment interaction were identified. The identification of common groupings met research objective number two.

Detailed Analysis of One Transcript

The first interview transcript the researcher received was that of a daughter, identified in this study as Jenny (pseudonym), caring for her mother. This interview was used to determine the feasibility of the data analysis procedure. By using the proposed procedure, the researcher identified Jenny's pattern of person-environment interaction from her description of caring for her mother.

While the first analysis process succeeded, some issues evolved from the analysis of Jenny's interview data. The NANDA dimensions were not mutually exclusive. Also, some of the dimension definitions could not be applied to this study's process.

It became apparent that data fit under more than one dimension. For example, Jenny stated in her interview: "It (caregiving) has brought my mother and me closer together than we had ever been in our whole lives as far as I was concerned". This sentence was indexed according to the exchanging dimension as a positive benefit in reciprocation for caregiving. The same sentence was also indexed according to the valuing dimension as a statement assigning worth to the process of caregiving.

Nurse theorists acknowledged that the dimensions were not mutually exclusive. They believed interactions between persons and their environment were indicative of the whole, therefore, reflections of other dimensions would be found within each dimension (Newman, 1984; Roy, 1984). The analysis of Jenny's interview data revealed the relative unimportance of clustering the data within the "correct dimension". What became important was the ability to identify the various dimension reflections in Jenny's person-environment interactions and to resolve those reflections into her pattern of interaction as a whole.

The second issue raised by the first analysis, was that some of the dimension definitions were inappropriate for indexing this study's data. For

example, the exchanging dimension had been defined as the interchange of matter and energy between humans and environment, or mutual giving and receiving. NANDA theorists clustered the concepts of circulation, oxygenation, nutrition, and elimination within this dimension. Under their definition, interchange of matter and energy referred to the cellular level of exchanging.

Jenny's data redefined exchanging as a process of giving and receiving between the caregiver and her parent rather than a cellular process. Furthermore, as the researcher analyzed additional interviews, receiving included a variety of caregiver benefits which did or did not come specifically from the care recipient. For this reason, the exchanging dimension was defined simply as mutual giving and receiving.

In this way, the process of analysis became iterative. Used as a starting point, the dimensions helped identify a multidimensional pattern of person-environment interaction. As patterns emerged, the researcher clarified the dimension definitions within the context of daughter/daughter-in-law caregiving. With dimensions redefined to fit the context of the present study, the data were reexamined and appropriately modified. For that reason, the final analysis of Jenny's interview differed from the first analysis.

The final analysis of Jenny's interview follows. Each dimension is discussed in relation to the data indexed under it. The initial definition of the dimension is presented along with the clarifying definition which emerged

through the iterative process. The steps in the analysis are delineated according to Miles and Huberman's (1994) iterative process of content analysis and the two objectives of the research study.

Research Objective # 1

The first objective of this research study was to identify the individual patterns of person-environment interaction of rural daughter/daughter-in-law caregivers that are revealed from their descriptions of caring for their parents who have ADRD. The steps in the analysis of Jenny's interview were:

1. Data reduction.

Data reduction involved indexing segments of Jenny's interview data in dimension labeled nodes on the NUDIST program. All interview data were indexed. The following excerpt from Jenny's interview is an example of how the segments of data within her interview were labeled according to specific dimensions before they were indexed into the NUDIST program.

First of all I would like to say that I came (choosing, moving) to take care of my mother (relating). I took myself out of my familiar surroundings (choosing, moving) --job, home, family, church, all of those things that you're familiar with (relating) --and took myself 200 miles away (choosing, moving) to take care of my mother (relating, moving).

It was a very stressful situation (feeling) since I had to put myself into a totally new community (choosing, moving), where I didn't know anyone and didn't know people very well except that I remembered as a child (relating, knowing).

The first paragraph of this excerpt was indexed under the NUDIST dimension nodes of relating , choosing , and moving. The second paragraph was indexed under the dimension nodes of relating , choosing , moving , feeling, and knowing. Jenny's entire interview was indexed in this way.

2. Data display, conclusion drawing, and further data reduction.

The next stage of analysis consisted of printing the contents of a dimension node, then synthesizing the segments of data comprising the node into a dimension description.

The process is illustrated below. Each dimension is presented with a sample of the data segments assigned to it. (See Appendix A for all of the data indexed in each of the dimensions for Jenny.) Opposite the data segments is the dimension description statement. A discussion regarding that particular dimension follows each dimension and dimension description. The discussion includes the initial definition, the emergent definition, and a description of the types of data from all the caregivers which corresponded to that particular dimension.

Exchanging Dimension

It has not been difficult to take care of my mother.

It has brought my mother & me closer together than we had ever been in our whole lives as far as I was concerned.

Dimension Description

Mutuality in her relationship with her mother.

Discussion: In the case of Jenny, exchanging was the giving of care and the receiving of gratification from the closeness of her relationship with her mother.

Initially, exchanging was defined as the interchange of matter and energy between humans and environment, or mutual giving and receiving. As the analysis of the data proceeded, exchanging came to mean that the daughters gave care and in turn received benefits. The benefits included (a) gratification from or meaning in their relationship with their parent care recipient, (b) vicarious gratification because they would be repaid in the future by being cared for in a similar manner, or the care they provided helped their parent remain at home, or (c) a present in the form of help with their caregiving from other people in their social network. Therefore, the definition of exchanging was changed to mutual giving and receiving.

Communicating Dimension

I have tried to make it a learning experience.
I have tried to teach others about what it is like to be a caregiver.

Dimension Description

Receiving messages about how to care and sending the messages back to other caregivers.

Discussion: Jenny described receiving messages by learning about caregiving and sending messages to others by teaching. This data also represented Jenny's knowing, perceiving, or valuing dimensions. This illustrates the nine dimensions' lack of mutual exclusivity, data in one dimension, reflecting other dimensions of person-environment interaction.

Initially, communicating was defined as the interchange of information between humans and environment, or the sending of messages. Through the interviews, communicating came to mean (a) a typical pattern of sending and receiving messages, (b) difficulty sending or receiving messages because of cognitive impairment, (c) sending messages, or (d) receiving messages.

Because the communicating dimension did not emerge from all the interview data as two way messages, the definition of communicating was changed to the sending and/or receiving of messages.

Relating Dimension

I have now become a farmer and a caregiver.
I've tried to teach others about what it's like to be a caregiver.
I took myself out of job, home, family, and church.

Dimension Description

Connecting with others through caregiving, teaching, farming.
Experienced blocked connections with others due to her move.

Discussion: Jenny talked about her connection to her mother through caregiving and her connection to others through the roles of teaching and farming. She also explained that her connections to others in her previous place of residence were blocked.

Initially, relating was defined as connecting with other persons or objects, or establishing bonds. Through the analysis of all the interviews, relating came to mean (a) connecting to the care recipient only, (b) connecting to the care recipient and other people in the environment, and (c) blocked

connections. Therefore, the initial definition of relating was helpful in indexing data.

Valuing Dimension

It is in turn difficult for me because remembering what my mother was like and what she is now is a very difficult transition, but I will never regret it because it brought my mother and me closer together than we had ever been in our whole lives as far as I was concerned.

Dimension Description

Even though her mother has changed, she values the experience of caregiving because it brought them closer together.

Discussion: Jenny assigned worth to caring for her mother because it brought them closer together. This data indicated a positive benefit of caregiving and therefore was categorized according to exchanging as well.

Initially the definition of valuing was the assigning of relative worth. From the analysis of all the interviews, valuing came to mean the caregivers assigned worth to the (a) imperative that they care for others as they would have others care for themselves, (b) relationship with their parent, (c) ability of their parent to remain in their own home and be happy and comfortable, (d) help of others with caregiving, and (e) certainty in their everyday activities. Therefore, valuing in this study was defined as the assigning of relative worth to people, imperatives, and predictability of circumstances.

Choosing Dimension

First of all I would like to say I came to take care of my mother. I took myself out of my familiar surroundings and took myself 200 miles away to take care of my mothers.

Dimension Description

Chose to be a caregiver and to relocate to do so.

Discussion: Jenny elected to relocate to take care of her mother, thereby allowing her mother to remain in her own surroundings. Choice was implicit in the interview rather than an explicit statement of choice by Jenny.

Initially, choosing was defined as the selecting of one or more alternatives. In the analysis of all the interviews, the selection of alternatives was implicit. Caregivers chose to (a) care for their parent, (b) take time off to rest, and (c) use alternative care so they could enjoy other activities. In this study, choosing was defined as the implicit selecting of one or more alternatives.

Moving Dimension

I took myself out of my familiar surroundings jobs, home, family, and church, all of those that you're familiar with--took myself 200 miles away to take care of my mother. It has been difficult taking myself out of my totally familiar surroundings and putting myself into a totally strange one. It has not been difficult to take care of my mother.

Dimension Description

Most activity directed to relocation rather than caregiving.

Discussion: Jenny directed her activity toward moving and adjusting to the move. Once more, some of this data also reflected Jenny's choosing and relating dimensions.

Initially moving was defined as activity within the environment.

Through the analysis of the interviews, moving came to mean the daughters/daughters-in-law directed their activity toward the (a) provision of physical and supervisory care, (b) location of appropriate resources such as housing, (c) provision of activities which maintained self esteem in their parent in spite of cognitive impairment, and (d) relocation of themselves or their parent and adjusting to the move. The initial definition of moving was helpful for indexing the data.

Perceiving Dimension

It (moving) has been difficult as I said, but I tried to make it a learning experience. It has brought my mother and me closer together...

Dimension Description

Perceives caregiving is meaningful because it is a learning experience and it brought her and her mother closer together. Also perceives relocation as difficult.

Discussion: Jenny interpreted the caregiving situation as meaningful.

Additionally, she interpreted the relocation as difficult. Again, the same data were descriptive of Jenny's communicating, valuing and exchanging dimensions.

Initially, perceiving was defined as the receiving of information.

Through the analysis of the interviews, perceiving came to mean that daughters/daughters-in-law interpreted their parents' types of (a) needs, (b) cognitive losses, and (c) feelings. Additionally, daughters/daughters-in-law

interpreted the acts of their parents to mean (a) the parent had improved with their care and (b) the situation was not so bad or that it was difficult. Finally, daughters/daughters-in-law interpreted caregiving as meaningful. For this reason, the definition of the perceiving dimension was changed to receiving and interpreting information which was consistent with Newman's (1986) revised definition of the perceiving dimension.

Feeling Dimension

It was a very stressful situation, since I had to put myself into a totally new community. It is in turn difficult for me, because remembering what my mother was like and what she is now is a very difficult transition.

Dimension Description

Feeling stress & grief.

Discussion: Jenny expressed feelings of grief related to her mother's illness. She also acknowledged the stress of adjusting to a new community.

Initially, feeling was defined as the quality of sensation and mood or subjective awareness of information. Through the analysis of the interviews, feeling came to mean that the daughters/daughters-in-law had sensations of (a) grief or loss in response to their parent's cognitive impairment, (b) comfort about how caregiving was proceeding, (c) exhaustion from high levels of physical and/or supervisory care, and (d) stress from adjusting to caregiving. The initial definition of the feeling dimension was consistent with the data from the interviews.

Knowing Dimension

I've tried to help them (other caregivers) find places & people & things that would be helpful to them in caregiving. I've tried to use my teaching abilities in that way. She (Mother) seems to understand what is happening to her.

Dimension Description

Knows about resources available in caregiving.
Knows teaching skills.
Knows her mother still has insight.

Discussion: Jenny was informed about resources useful for caregivers and shared that information with them. Jenny understood her mother still had insight about her cognitive impairment.

Initially, knowing was defined as meaning associated with a world view or with information, which was similar to the definition of perceiving.

Through the analysis of the interviews, knowing came to mean that daughters/daughters-in-law understood (a) their parents through the lens of cognitive impairment, (b) how to care for themselves within the context of caring for someone with cognitive impairment, and (c) when they needed more information about caring for someone with cognitive impairment. For this study, the definition of knowing was changed to personal recognizing of self and world, which was consistent with Newman's (1986) revised definition of the knowing dimension.

Summary. A sample of Jenny's data was presented to illustrate the first data reduction and display process. The dimensions were not mutually exclusive, so Jenny's data grouped under more than one dimension. The dimension statements from all the caregivers helped to clarify the meaning of

the dimension for the researcher, therefore some of the definitions of the dimensions were changed.

3. Data display and further data reduction and conclusion drawing.

This process was accomplished by displaying Jenny's individual dimension descriptions on her individual NUDIST program document memo. The exchanging, communicating, and relating dimension descriptions were integrated into an interaction characteristic statement and displayed on Jenny's document memo (see Figure 4). Jenny's interaction characteristic statement was:

Mutuality in relationships with Mother. Connecting with others through her farming and teaching. Blocked connections with job, family, home, and church in her previous community.

The valuing, choosing, and moving dimension descriptions were integrated into an action characteristic statement (see Figure 4). Jenny's action characteristic statement was:

Activity focused on relocation and roles other than caregiving. Values closeness in relationship with Mother as a result of caregiving.

The perceiving, feeling, and knowing dimension descriptions were integrated into an awareness characteristic statement (see Figure 4). Jenny's awareness characteristic statement was:

Finds meaning in caregiving. Acknowledges the stress of moving and the grief in adjusting to the changes in her mother.

Finally, interaction, action, and awareness characteristic statements were synthesized into a pattern description for Jenny and displayed on her individual document memo (see Figure 4). Jenny's pattern of person-environment interaction was:

Jenny's activity is focused on relocating away from her previous job, family, home, and church and adjusting to new roles of caregiver, farmer, and teacher in her new community. Energized by the closeness of the caregiving relationship and by teaching others about caregiving. No specific description of caring for herself.

See Figure 4 for an example of Jenny's pattern of person-environment interaction as it was displayed on her NUDIST document memo.

4. Data display.

Once the narrative representation of Jenny's pattern of person-environment interaction was complete, a graphic representation, as described by Newman (1987) was created. The sketches represented another way of visualizing Jenny's pattern of person-environment interaction. This example of data display is presented in Figure 5.

Dimension	Dimension Description	Characteristic Synthesis Statement
Exchanging	Mutuality apparent in that she is giving care and receiving from Mother - feeling "closer to her than ever before."	Interaction: Mutuality in relationship with Mother. Connecting with others through her farming & teaching. Blocked connections with previous job, family, church, & home.
Communicating	Receiving messages about how to care & sharing message with other caregivers - "teaching others about caregiving."	
Relating	Connecting by caregiving, farming, teaching. Blocked connections to previous family church, home, & job.	
Valuing	Even though her mother has changed, she values the caregiving because it brought them closer together.	Action: Activity focused on relocation and roles other than caregiving. Values looseness in relationship with Mother as a result of caregiving.
Choosing	Chose to be a caregiver and to relocate to do so.	
Moving	Most activity focused on relocation rather than caregiving.	
Perceiving	Perceives caregiving is meaningful because it is a learning experience & it brought her and her mother closer together than we have ever been. Perceives relocation as difficult.	Awareness: Finds meaning in caregiving. Acknowledges stress in moving and adjusting to changes in her mother.
Feeling	Feeling stress and grief.	
Knowing	Knows about resources helpful in caregiving. Knows teaching skills. Knows her mother still has insight.	

JENNY'S PATTERN DESCRIPTION: Jenny's activity is focused on relocating from previous job, family, home, and church and connecting with others in new roles as caregiver, farmer, and teacher in her new community. Energized by the closeness of the caregiving relationship and by teaching others about caregiving. No specific description of caring for herself.

Figure 4. Jenny's pattern of person-environment interaction as displayed on the NUDIST document memo.

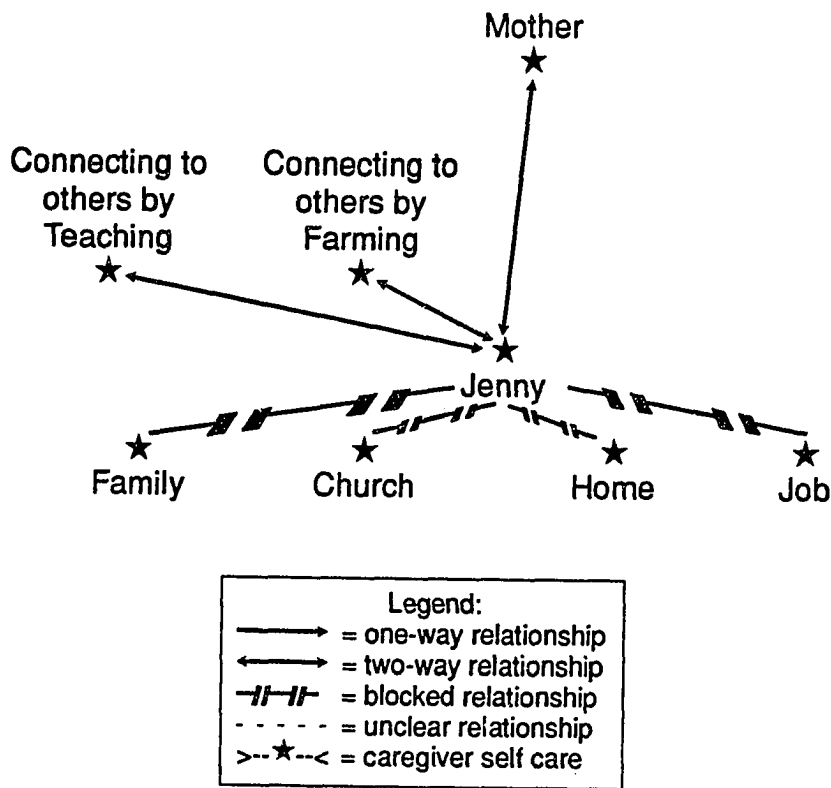


Figure 5. Jenny's graphic pattern of person-environment interaction.

After displaying Jenny's pattern of person-environment interaction, the researcher analyzed the other fifteen daughter/daughter-in-law caregiver interviews. The researcher followed the steps of the analysis as outlined until all of the sixteen caregivers' individual patterns of person-environment interaction were identified both narratively and graphically. The process continued to be iterative. As interviews were analyzed, the researcher went

back to refine and clarify earlier analyses. At this point, research objective number one was met.

Research Objective # 2

The second objective of this research study was to identify the common groupings of patterns among all the rural daughter/daughter-in-law individual patterns of person-environment interaction. The final steps in this analysis process are presented using Miles and Huberman's (1994) iterative process of content analysis.

5. Date display and conclusion drawing.

At this point in the analysis process, the researcher examined all of the graphic depictions of individual patterns of person-environment interaction. Common groupings were apparent.

6. Further data display, conclusion drawing, data reduction, and data display.

The iterative process of analysis continued as the researcher reviewed all of the narrative representations of the individual person-environment interaction patterns in relation to the common groupings of the graphic depictions. This process of going back and forth between the narrative and graphic depictions continued until common groupings were identified. At this point, research objective number two was met. See Figure 6 for examples of different configurations of person-environment interaction.

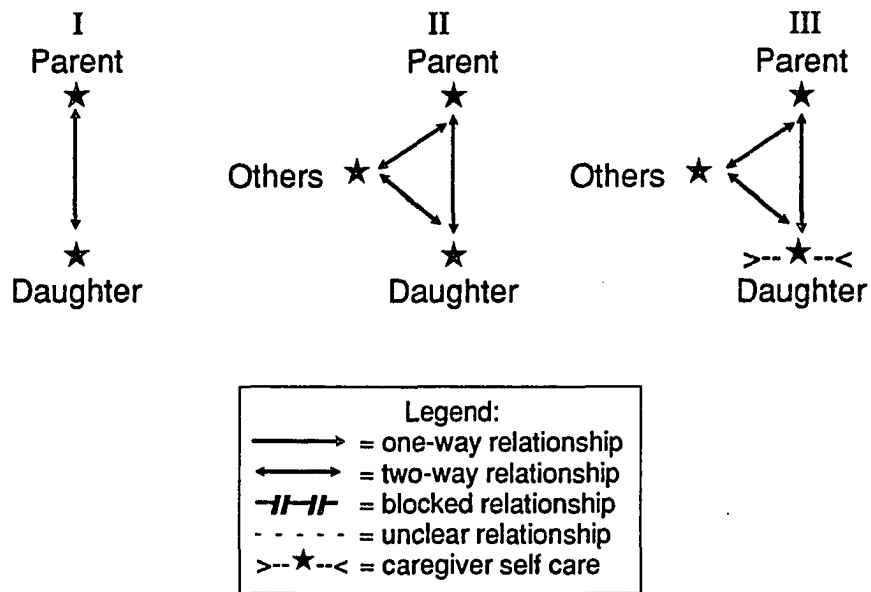


Figure 6. Examples of three configurations of person-environment interaction.

Criteria for Rigor

Sandelowski (1986) proposed the criteria of auditability, fittingness, and credibility for analysis of qualitative data. Each criterion is defined and compared to the traditional criterion for evaluating quantitative data. The approach for achieving rigor consistent with each criterion is described.

Auditability

Auditability was defined as the ability of another researcher to clearly follow the decision trail in the analysis process. Reliability is the comparable criterion for evaluating quantitative data analysis.

To test the auditability of this study, one nurse researcher who used qualitative methodology in her own research, examined five randomly selected interviews. She checked whether she could (a) clearly follow the "decision trail" and (b) arrive at the same or comparable but not contradictory conclusions given the researcher's data, perspective, and situation.

The researcher was given (a) the NANDA dimensions and definitions, (b) a description of the method, (c) the five transcribed caregiver interviews, (d) the NUDIST data analysis computer print outs for those five caregiver interviews, and (e) an Auditability Evaluator Report Form. The Auditability Evaluator Report Form allowed spaces for evaluator comments regarding the indexing of data under specific dimensions, synthesizing data into dimension description statements, synthesizing dimension descriptions into characteristic statements, synthesizing characteristic statements into a pattern description, and fitting the pattern to one of the three common pattern groupings (See Appendix B for a copy of the Auditability Evaluator Form).

The evaluator suggested adding data to three dimension nodes and thought four lines of data should be deleted from one dimension node. Additional suggestions for clarifying dimension description statements were incorporated throughout the analysis. The evaluator came to the same conclusion as the researcher that the dimensions were not mutually exclusive and that data fit with more than one dimension. The evaluator concurred with

all final descriptions of the person-environment interaction patterns, and agreed they were reflective of the data as a whole.

Another researcher, who was familiar with qualitative methodology but used quantitative data in her own research, examined an interview which was randomly selected from the five interviews previously audited. She disagreed with one dimension description statement and also suggested additional wording to make the synthesis statements more clear and more consistent with the original data. She also commented that it was difficult to consider the caregiver in interaction with her environment when the caregiver focused on tasks rather than on herself. She agreed with the general nature of the one pattern description, but suggested wording changes for clarification as well as consistency with the original data.

Suggestions from both evaluators were incorporated into the synthesis statements by adding to or clarifying the language so that the statements more closely reflected the original data. The cumulative evaluation of the two reviewers indicated they both followed the decision trail and did arrive at comparable conclusions. The criterion of auditability was achieved.

Fittingness

According to Sandelowski (1986), the criterion of fittingness means that "findings fit into contexts outside the study situation because the audience

views finding as meaningful from their own experience" (p. 32). Fittingness is comparable to external validity in quantitative research.

Thorne (1994) suggested that in secondary analysis of data, when the researcher is not able to go back to the subjects, clinical experts may be called upon to evaluate the study according to this criterion. In this study the researcher could not go back to the subjects. Therefore, a master's prepared nurse who works with caregivers of persons with ADRD reviewed the findings of the study for evidence of implications for practice.

She examined the introductory chapter, the methodological chapter, the chapter with the report of the findings, and a Fittingness Evaluator Report Form. The report form provided spaces for the reviewer to document implications for practice for the individual patterns of person-environment interaction, as well as for the common groupings of patterns (See Appendix C for the Fittingness Report Form).

The reviewer reported the following:

1. "It is important to understand individual patterns in order to support people's own individual coping mechanisms and to assist in the growth process".
2. "First it is important to understand what the unconnected caregiver values, then to affirm it and also to assist in broadening the ability of the caregiver to see her own needs in a way she can hear.

3. "Again, it is important to affirm the connected caregiver in her understanding of her role as a caregiver, provide information to support her in learning about the disease process and going further in caring for herself".

4. "In relation to the interconnected caregiver, it is important to support all family members as well as caregivers in the process, to assist caregiver in her role, and then to promote growth".

This clinical expert determined that each of the three common groupings of daughter/daughter-in-law patterns of person-environment interaction indicated pattern specific interventions. The findings were consistent with her philosophy of nursing practice which was to support caregivers' individual coping mechanisms. Based on the report of this clinical expert, the findings did have implications for practice and the criterion of fittingness was met.

Credibility

Credibility was defined as verification of individual patterns by the individual from whom the data were collected (Sandelowski, 1986). Credibility is comparable to internal validity in quantitative research.

The traditional method of achieving credibility in a qualitative study is to go back to the subjects themselves for verification of patterns. The researcher could not go back to the original subjects because this study was a secondary analysis of data. Thorne (1994) suggests that in the case of

secondary analysis, a researcher from the original study may testify to the credibility of the findings.

A nurse researcher who collected caregiver interviews for the original study reviewed the patterns of person-environment interaction in this study's final report. She examined a description of the framework for analysis, a report of the findings, and a Credibility Evaluator Report Form. The Credibility Report Form provided space for the reviewer to document if she recognized the unconnected patterns, the connected patterns, and the interconnected patterns of person-environment interaction in the population of caregivers whom she interviewed. (See Appendix D for the Credibility Report Form).

The reviewer reported the following:

1. "Yes, an example of one unconnected caregiver comes to mind. Her interviews usually consisted of descriptions of care recipient behaviors or caregiver symptoms, with no evidence of taking care of herself emotionally".
2. "The connected patterns of person-environment interaction were recognizable in numerous interviews".
3. "An example of one interconnected caregiver interview comes to mind. This caregiver includes her children in helping with the care recipient. This caregiver has a strong commitment to caring for the care recipient and prepares every meal and supervises his bathing and dressing, etc. However, she continues volunteer work with a senior home and takes part in community activities".

This nurse researcher could identify examples of unconnected, connected, and interconnected caregivers from her interviews with caregivers at other sites. The examples were testimony to the credibility of these research findings. The criterion of credibility was met.

Protection of Subjects

The principal investigators from the two sites were supportive of the proposed study. They gave permission to use the interview data with no subject identification. All of the data were coded by number, no other identifiers were used.

Human Subjects Approval

This study was approved by the University of Minnesota IRB.

CHAPTER 4

Findings

The findings are presented according to the two research objectives of the study. The first section describes the findings for the first research objective, and the second section describes the findings for the second research objective. A summary of the findings concludes this chapter.

Research Objective One

The first research objective for this study was to identify the individual patterns of person-environment interaction of rural daughter/daughter-in-law caregivers that are revealed from their descriptions of caring for their parents who have ADRD. An individual pattern of person-environment interaction was identified for each rural daughter/daughter-in-law caregiver using the NANDA framework. The process of analysis and the emergent pattern for one daughter (Jenny) was illustrated in Chapter 3. The indexing of all of Jenny's interview data according to the dimensions as well as her document memo is in Appendix A.

The (a) dimension descriptions, (b) characteristic synthesis statements, and (c) individual pattern of person-environment interaction are presented in

Appendix E for the remaining fifteen daughters/daughters-in-law. The individual pattern of person-environment interaction for each subject is presented in the following section.

Research Objective Two

The second research objective for this study was to identify the common groupings of patterns among all the rural daughter/daughter-in-law individual person-environment interaction patterns.

The individual narrative patterns were depicted in graphic form. The investigator inspected all of the graphic depictions and noted commonalities in the patterns of person-environment interaction. Next, the researcher examined the multidimensional view of the caregivers denoted by the individual dimension descriptions. Finally, the narrative representations of the individual patterns were reviewed and three groupings of patterns of person-environment interaction emerged from the data: (a) unconnected caregiver patterns of person-environment interaction, (b) connected caregiver patterns of person-environment interaction, and (c) interconnected caregiver patterns of person-environment interaction.

The first group pattern of person-environment interaction was one in which the daughters/daughters-in-law described caring for their parents with no descriptions within the interviews of connections to others or of caring for themselves. The second group pattern was one in which the

daughters/daughters-in-law described connecting with others for help in caregiving, but also gave no description of caring for themselves. In the third group pattern, the daughters/daughters-in-law described caring as a natural interconnected process in which their family and community participated. The daughters/daughters-in-law in this group indicated they were caring for themselves as part of the process of caregiving.

Under these common groupings, individual daughter/daughter-in-law person-environment patterns are presented. The caregiver's pseudonym is followed by (a) demographic data, (b) narrative description containing examples of dimension specific words/phrases/sentences, and (c) interaction, action, and awareness characteristic synthesis statements. The words in bold print are the actual words of the caregiver. Each caregiver's narrative is followed by the graphic depiction of her pattern and the pattern description. A summary discussion concludes each common grouping section.

Unconnected caregiver patterns of person-environment interaction

Three daughter caregivers (19%) showed similar patterns of relating. The connection to their parent care recipient was the only relationship described in the interview. For two of these caregivers, the demographic data indicated that they were utilizing outside help in their caregiving, but in their interviews, they referred to caregiving as if they were alone in this endeavor.

Bernie. Bernie is a 58 year old daughter caregiver who has completed 16 years of education. She has lived with her 88 year old mother for one year since her mother was diagnosed with multiple infarct dementia. Her mother has moderate cognitive impairment. Bernie provides 23 hours of care per week for her mother and uses six hours of professional help per week. See Appendix E for Bernie's individual analysis.

Bernie's interview. Bernie explains there have been quite a few adjustments for both of us (exchanging) now that my mother is living with me (relating). She hears her mother's message that her mother blames me a little bit for the move (communicating).

INTERACTION: Experiencing mutuality in adjusting. No other relationships described except the caregiving/care receiving relationship.

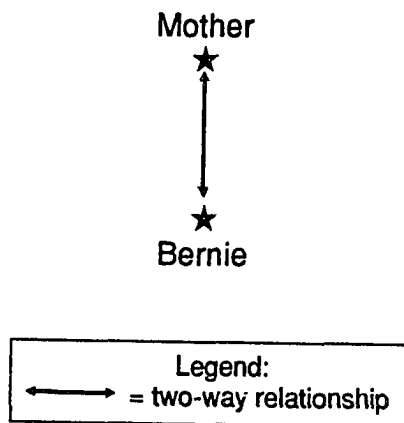
Making her mother happy and comfortable is what is important for Bernie right now (valuing) since she has elected to move her from Montana here (choosing). Bernie's activity is directed toward adjusting to each other and making her (Mother) happy and comfortable (moving).

ACTION: Focusing on having Mother happy and comfortable in her home.

Bernie interprets that her mother misses her previous friends and home, and blames her for the move (perceiving). She senses there are good days and some days are difficult (feeling). Bernie recognizes that her mother

understands the move and that her life would have changed even if she hadn't moved (knowing).

AWARENESS: Aware of her mother's feelings of loss and blame and of her own feelings that there are good times and difficult times. Figure 7 depicts Bernie's pattern of person-environment interaction.



BERNIE'S PATTERN DESCRIPTION: Experienced give and take with Mother which was sometimes good and sometimes difficult. Activity directed toward adjusting to the caregiving relationship and making her mother happy and comfortable. No other activities or relationships articulated or how she cared for Mother and herself in relation to the difficult days.

Figure 7. Bernie's pattern of person-environment interaction.

Peggy. Peggy is a 68 year old daughter caregiver who has completed 12 years of education. She has lived with her 97 year old mother for 20 years. Her mother has been diagnosed with irreversible dementia for eight years and

has moderately severe cognitive impairment. Peggy provides 24 hours of care per day for her mother and has no help. See Appendix E for Peggy's individual analysis.

Peggy's interview. Peggy states that taking care of my mother is very **uncertain (relating)**. Peggy's interview did not provide data consistent with the exchanging or communicating dimensions. The interaction statement was a restatement of the data within the relating dimension.

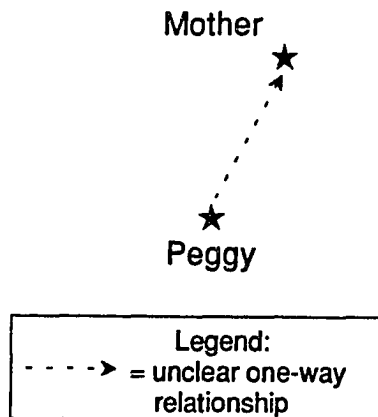
INTERACTION: Experiencing uncertainty because of the caregiving relationship.

I've been used to in the past doing something and sticking with the one thing until it was finished (valuing) and you can't do that (choosing) Peggy explains. **Additionally, you have to spend a lot of time checking on her (moving).**

ACTION: Values an uninterrupted work schedule. Caregiving involves constant interruptions, and therefore more energy expenditure.

Peggy interprets that it's hard to plan (perceiving) which makes it difficult (feeling). She doesn't know whether she'll (mother) get up later, and **I think that depends on the activities (Knowing).**

AWARENESS: Aware that the nature of the illness makes life uncertain and therefore more difficult. See Figure 8 for Peggy's pattern description.



PEGGY'S PATTERN DESCRIPTION: No pattern of communication or mutuality described. Focusing on how the caregiving experience is a major loss of certainty resulting in an increase in expenditure of energy. No other relationships described or how she cares for her mother and herself in relation to this uncertainty.

Figure 8. Peggy's pattern of person-environment interaction.

Susie. Susie is a 44 year old daughter caregiver who completed 18 years of education. She lives with her 84 year old father who was diagnosed a year ago with an irreversible dementia. Her father has severe cognitive impairment. Susie provides 18 hours of care per day for her father and receives 6 hours of professional and informal help per day. See Appendix E for Susie's individual analysis.

Susie's interview. Susie is hearing the confusion in her father's messages when he asks her: "Did you know you tied me in bed last night? I had one heck of a time getting out of that!" and sharing the humor in the confusion with the interviewer by telling her: "you'll love my posey (restraint) story" (communicating). Susie illustrates that her relationship with her father is one of intensive caregiving: He is up all night and wandering and he'd fall. He'd pull out the catheter. We didn't know if we were going to make it the first couple of weeks (relating). Susie did not talk about receiving any benefits for the intensive caregiving she is providing, therefore no data were indexed according to the exchanging dimension.

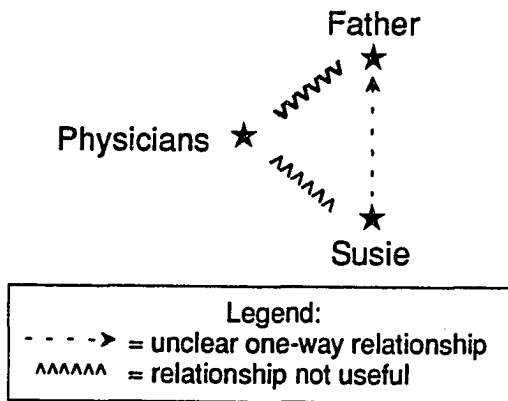
INTERACTION: Focusing on caregiving with no evidence of mutuality in the relationship or description of other relationships.

Susie assigns worth to the (a) humor in the situation when she exclaims : Oh, you'll love my posey story and (b) ability to rest because as we started getting sleep at night we could handle more of what he presented (valuing). Even though it was really bad, Susie is still caring for her father at home (choosing). She is up at two, three, or four o'clock in the morning because he has days and nights totally mixed up. He pulls out his catheter. We take him to Dr ----- to try to help him (moving).

ACTION: Focusing on keeping her father safe resulting in intensive caregiving activity.

Interpreting that physician's help is not useful because Dr gave us some medication to give him at night, the pill did nothing. Then he told us we needed to see a psychiatrist who prescribed some more medication that made him weak. So we haven't been giving him anything and he started sleeping nights (perceiving). Susie senses that caregiving has been nerve racking , exhausting, and that it was really bad (feeling). Additionally, we have not known what to do at times, we didn't know if we were going to make it at times, but as we started getting sleep at night we could handle more of what he presented (knowing).

AWARENESS: Aware that her caregiving activities are resulting in a more tolerable situation. No evidence of her awareness of what she needs to do for herself to maintain her ability to give such intensive care. See Figure 9 for Susie's pattern of person-environment interaction.



SUSIE'S PATTERN DESCRIPTION: Intensive one-way expenditure of energy in caring for her father with no helpful interventions from physicians. No description of mutuality in other relationships in her life, or awareness of how to care for herself. Is aware that her interventions are effective.

Figure 9. Susie's pattern of person-environment interaction.

Discussion of unconnected patterns of person-environment

interaction.

The caregiving relationship was the only relationship illustrated in the pattern descriptions. Susie had a relationship with her father's physicians which was perceived as not useful. Susie and Bernie both utilized outside help with caregiving but their descriptions of what caregiving was like for them indicated they were unconnected to others in their environment. Relating was also described in the interviews as connecting to the parent through caregiving

rather than as interacting with the parent in diverse ways such as recreation or socialization.

Susie's and Peggy's patterns of interaction reflected a one-way interaction with their parent. They gave to their parents through caregiving without describing what positive benefits they received in return. In contrast, Bernie described good days during this adjustment period, which indicated she was receiving some positive feedback from her mother.

Peggy conceptualized caregiving as inconsistent with her value of being able to plan ahead and then to finish her activities. Susie provided intensive care, especially in relation to her father's problem behaviors. All three caregivers chose home care despite their illustrations of the difficulties encountered and the energy expended.

The caregivers' perceptions centered on the needs of their parents. Susie and Peggy were aware of their parents' need for protection while Bernie was aware that her mother needed to grieve the loss of her friends and home.

All three daughters described negative feelings about the experience. They presented no understanding of how to care for themselves and their parent in relation to these negative feelings.

Summary.

Bernie, Peggy, and Susie were in the process of "going through it" as described in Wilson's (1989) stages of caregiving. Their descriptions were multidimensional in that physical, emotional, and social characteristics of their interaction with their environment were apparent. The lack of mutuality in two of the caregiving relationships, the absence of other relationships, the feelings of difficulty, exhaustion, frustration, and the physical expenditure of energy testified to the impact of caregiving on these daughters.

In contrast to these testimonials of the impact of caregiving on their lives, there was no indication in the data that they were ready to "turn it over" (Wilson, 1989). Each pattern presented the same lack of description of others in their environment, and the caregiver's awareness of how to care for themselves and their parent. Each pattern differed in relation to the perceiving, feeling, moving, valuing, communicating, and choosing dimensions.

Connected caregiver patterns of person-environment interaction

Ten (60%) of the daughter/daughter-in-law patterns contained common characteristics which differed from the unconnected patterns and the interconnected patterns. These daughter/daughter-in-law caregivers described connecting to others in their environments in addition to their

parents. Additionally, all of these daughter/daughter-in-law interviews evidenced some form of mutuality in the context of caregiving. The daughters/daughters-in law gave care and received (a) gratification in the relationship with their care recipient; (b) vicarious gratification by hoping that they would be cared for similarly in the future, or that the care they provided helped their parent to remain at home; and (c) a present in the form of help/support from others in the environment.

The individual daughter/daughter-in-law patterns of person-environment interaction are illustrated within the mutuality groupings. First, the five caregivers who described gratification from the care recipient relationship are presented, then the three caregivers who illustrated the vicarious reception of benefits. Lastly, the two caregivers are presented whose receiving took the form of help/support from others.

Gratification.

The following five caregivers displayed unique individual patterns of person-environment interaction as well as some common characteristics. These daughters/daughters-in-law, in contrast to the unconnected group of caregivers, described connecting with others in their environment within the context of caregiving. They also talked about receiving gratification through their relationship with their parent. Each of the five daughter/daughter-in-

law patterns of person-environment interaction are presented followed by a summary discussion of the five patterns.

Denise. Denise is a 60 year old daughter caregiver who completed 14 years of education. She has lived with her 88 year old mother for two years. Her mother was diagnosed with Alzheimer's disease five years ago and has mild cognitive impairment. Denise provides 22 hours of care per day for her mother and has no professional or informal help. See Appendix E for Denise's individual analysis.

Denise's Interview: Denise is giving as a caregiver but also receiving from Mother: **we laugh together**, (exchanging). She is able to give and receive messages from Mother because **we play games together** (communicating). Denise and her mother are connecting with others when **they visit people together** (relating).

INTERACTION: Experiencing mutuality in the relationship with her mother. Relating to others in the environment with her mother.

Denise assigns worth to her mother now and as she was prior to the illness: **she has been a very caring mother to our family and for a lady who is 90 years old now, I think she is quite remarkable** (valuing). She states: **her ability to reason and think normally are diminishing, and she lives with**

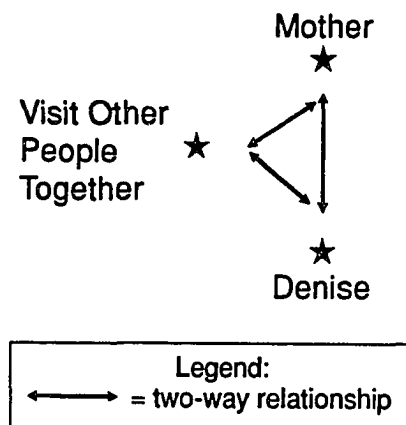
me now because of this (choosing). My mother is not demanding and pretty much cares for herself , therefore Denise is involved in little physical care at this point (moving).

ACTION: Minimal energy to care for her mother and she values her mother as she was and as she is now.

Denise interprets that she trusts me to care for her so far (perceiving).

Denise has a sense of comfort in her relationship with her mother because for a lady who is 90 years old, I think she is quite remarkable (feeling). She understands the problems inherent in this stage of the illness: I do cook the meals because I don't want her to hurt herself on the stove (knowing).

AWARENESS: Aware that illness is mild and Mother trusts her and enjoys her company. No awareness of caring for herself or Mother in progressive stages of the illness. Figure 10 depicts Denise's pattern of person-environment interaction.



DENISE'S PATTERN DESCRIPTION: Activity focusing on caregiving in a mutual relationship with Mother which includes other people. Values Mother as she was and as she is now. No awareness of how to care for herself or her mother in progressive stages of the illness.

Figure 10. Denise's pattern of person-environment interaction.

Barbara. Barbara is a 54 year old daughter caregiver who completed 16 years of education. She has lived with her 87 year old mother for less than a year. Her mother was diagnosed with irreversible dementia eight years ago and has moderate cognitive impairment. Barbara provides 14 hours of care per day for her mother and uses five hours per day of professional help. See Appendix E for Barbara's individual analysis.

Barbara's interview: Barbara is giving in the form of caregiving and receiving gratification because it's neat having her here. I've been planning and plotting for this day for years (exchanging). She is sending

messages to her mother in ways that help her mother live with cognitive impairment : **Everything we take pictures of so we can talk about it with her (communicating). Barbara is connecting with others and her mother through caregiving: We had two brothers and sisters out for the weekend and my husband I took her (Mother) out to the movies (relating).**

INTERACTION: Mutuality apparent in the daughter/mother relationship. Connecting with husband and siblings within the context of caregiving.

Barbara places importance on focusing on the more positive rather than dwelling with her mother on the **negative impact** of cognitive impairment (valuing). She is electing to be her mother's primary caregiver as well as to help others understand the illness: **We hired a 12 hour companion before she moved in with me and we helped them, we counseled them, to reduce the stimulation around her (choosing).** Barbara's activities focus on understanding and acting through the lens of cognitive impairment: **I have a full photograph album of Myron's funeral, from his deathbed in the hospital all the way through the funeral and afterwards, because I was worried that she would get suspicious that we did away with him and she wouldn't have any record of it. So we did up this book and took pictures every step of the way. It has, I think been really helpful for her (moving).**

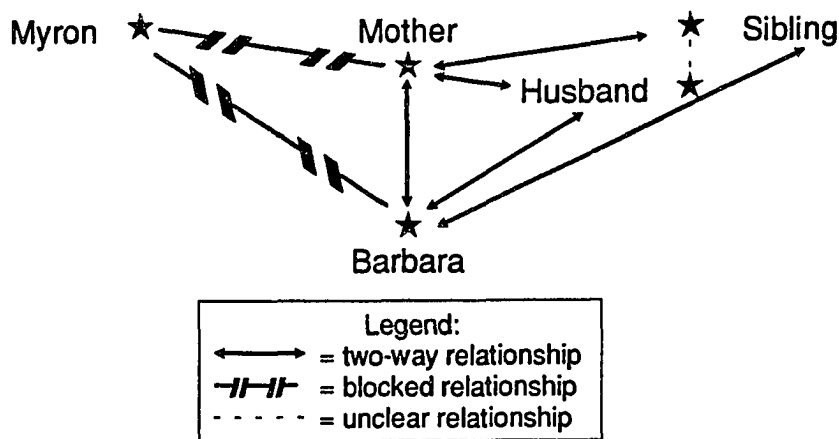
ACTION: Expending energy by choosing to care for mother through activities that are supportive in the context of cognitive impairment such as helping Mother remember Myron's death through the use of pictures. No recreational or self care activities outside of caregiving described.

Barbara is trying to interpret the world through her mother's eyes:

When my brother and sisters were here for the weekend, she (Mother) woke up totally surprised - it was a brand new experience for her every day!

(perceiving). She is sensitive to her negative and positive feelings about caring for her mother: **It's great to do things that give her pleasure and hell when she's not going to remember (feeling).** Understands mother's way of being at this point in time is a result of cognitive impairment: **This is a major memory loss for her and I have to get involved in a big way in helping her (knowing).**

AWARENESS: Aware of her positive and negative feeling towards her mother's cognitive impairment and relates to her mother by understanding the illness. No evidence of awareness of how to care for herself. See Figure 11 for Barbara's pattern of person-environment interaction.



BARBARA'S PATTERN DESCRIPTION: Expending energy caring for her mother but energized by a caregiving relationship she values. Relating, recreating, socializing in the context of caregiving. Perceives her mother's reactions are related to the illness, and bases her caregiving on this knowledge such as helping Mother remember Myron's death through pictures. No evidence of awareness of caring for herself.

Figure 11. Barbara's pattern of person-environment interaction.

Mary. Mary is a 49 year old daughter-in-law caregiver who has been caring for her 81 year old mother-in-law for two years since she was diagnosed with irreversible dementia. Mary's mother-in-law lives by herself and has moderately severe cognitive impairment. Mary provides eight hours of care per week for her mother-in-law and uses ten hours per week of professional help. See Appendix E for Mary's individual analysis.

Mary's interview: Mary experienced some benefit from caring for her mother-in-law: Some days I really feel she wants to open up some feelings for me and it is a delight to have her... we were without grandparents in

our area for about 25 years...it is a delight for our children (exchanging). She is having difficulty receiving messages from her mother-in-law: it is almost impossible to get her to communicate verbally (communicating). Mary is connecting to both mother-in-law and her aunt as a caregiver. She is also trying to connect with her mother-in-law in relation to her pre illness pattern: **My mother-in-law used manipulatory sense throughout her lifetime and it's still apparent in relationship to my husband and myself caretaking for her (relating).**

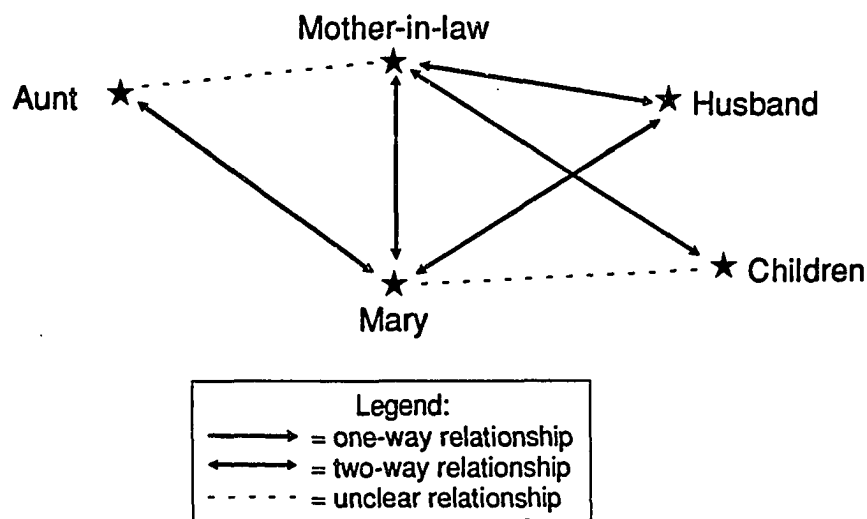
INTERACTION: There is mutuality in the interaction with her mother-in-law. She described her relationships to her mother-in-law, her aunt, her husband, and her children within the context of caregiving.

Mary assigns worth to (a) having her mother-in-law in the area, (b) having her mother-in-law just enjoy life and not doing anything, and (c) sharing her time with both care recipients: I tell her there is her son, myself, my aunt, and her and whatever time I have I spend with both of them. She is electing to share her time between two care recipients (choosing) and Mary's activity is directed toward caring for both of them (moving).

ACTION: Description focuses on caregiving activities and the value she places on caregiving.

Mary is interpreting that because I am the person involved with her on a daily basis then her problematic behaviors have subsided to a certain degree (perceiving). Mary feels the demands she (mother-in-law) puts on a person (feeling) and understands that behaviors are a result of the illness: I feel she doesn't have provision for understanding...so I kind of use that to help me cope (knowing).

AWARENESS: Aware that behaviors are a result of the illness and this is helping her to cope with the demands of caregiving. No description of her own awareness of how to take care of herself. See Figure 12 for Mary's pattern of person-environment interaction.



MARY'S PATTERN DESCRIPTION: Focusing on caregiving for her mother-in-law and her aunt with description of mutuality in the relationship with her mother-in-law. Connecting with husband, aunt, mother-in-law, & children in relation to caregiving. Aware that the behavior of her mother-in-law is related to cognitive impairment with no description of her own awareness of how to care for herself.

Figure 12. Mary's pattern of person-environment interaction.

Kathrin. Kathrin is a 53 year old daughter caregiver who completed 19 years of education. She has lived with her 79 year old mother for six months. Her mother was diagnosed with multiple infarct dementia nine years ago and has moderate cognitive impairment. Kathrin provides 25 hours of care per week for her mother and uses three hours per week of professional help. See Appendix E for Kathrin's individual analysis.

Kathrin's interview: Kathrin is giving care to her mother and receiving in return because she believes I'm dealing with one of the most precious people in my life (exchanging). She is receiving messages from her mother and sending messages back to her: Mother what are the tears about? She says I just can't remember. I say, you're feeling bad aren't you? And she says, well sure, wouldn't you? (communicating). Kathrin is connecting with others in her life within the context of caregiving: A neighbor came over with cupcakes and visited with her (mother); when I have guests for dinnerI make sure the dishes she (mother) washed are clean; my cousin called and mother tried to explain what she said about her father breaking his hip (relating).

INTERACTION: Experiencing mutuality in the caregiving relationship. Is connecting with guests, neighbors, and family within the context of caregiving.

Kathrin sees worth in her mother as a person and her mother's need to feel useful in her role in the family: **The dishes (mother washes) aren't clean but if it's just a little it can't hurt. I'm dealing with one of the most precious people in my life. If I drink a little poison, so to speak, so that her feelings aren't hurt, I'll survive (valuing, choosing) and in that way is electing to provide an environment for her mother that allows her to use her remaining skills . Kathrin is directing her activity to provide an environment that decreases her mother's frustrations: Mostly she just misplaces things. I have gotten careful to put away anything of significance. It's very frustrating for her (moving).**

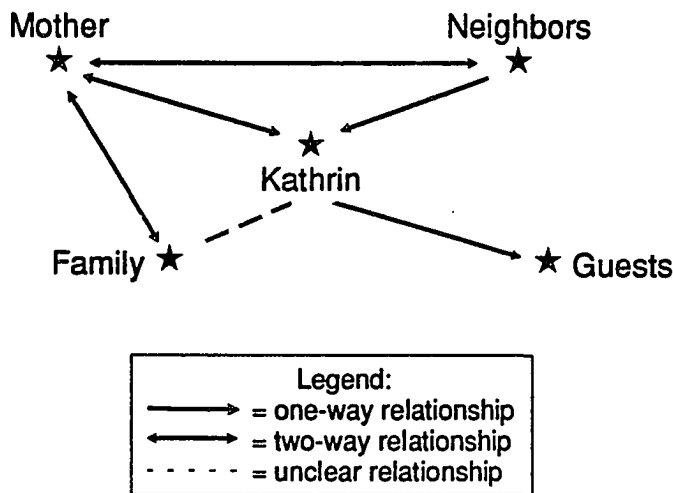
ACTION: Values her mother's ability to maintain her self-esteem and is therefore choosing to direct her own energy to provide an environment that allows her mother to maintain her roles. No activity directed toward care of self.

Kathrin interprets her mother's behavior as meaningful and therefore useful in helping to care appropriately for her: **In the house where she doesn't have to have the burden of responsibility, she's felt useless. I have dreamed up various things for her to do (perceiving). She acknowledges her own grief in seeing her mother deal with the illness: The grief of this situation is that she perceives that she cannot remember (feeling). Kathrin**

understands her mother' behavior through the lens of cognitive impairment: She's not capable of seeing the bathroom needs cleaning and just doing it (knowing).

AWARENESS: Acknowledges her own grief. Synthesizing information about the illness with her mother's own pattern so as to facilitate her mother's sense of self worth.

See Figure 13 for Kathrin's pattern of person-environment interaction.



KATHRIN'S PATTERN DESCRIPTION: Experiencing mutuality in the caregiver/care recipient relationship. Facilitating mother's self worth through understanding of cognitive impairment. Interacts with neighbors, guests, and family in relation to the caregiving role. No description of awareness of how to care for herself.

Figure 13. Kathrin's pattern of person-environment interaction.

Jenny. Jenny is a 58 year old daughter caregiver who completed 21 years of education. She has cared for her 88 year old mother for one year. She lives with her mother who was diagnosed with irreversible dementia one year ago and has mild cognitive impairment. She provides 24 hours of care per day for her mother and does not use professional or informal help. See Appendix A for Jenny's individual analysis.

Jenny's interview: Jenny is giving care to her mother and receiving from Mother: **It has brought my mother and me closer together than we had ever been before (exchanging).** She is learning about caregiving and then **teaching others about what it's like to be a caregiver (communicating).** Jenny is connecting with others through teaching and farming: **I have now become a farmer and I try to do the teaching part** She is experiencing blocked relationships due to her move to take care of her mother: **I took myself away from job, home, family, church.....(relating)**

INTERACTION: Mutuality in her relationship with her mother. Connecting with others through her job and by teaching about caregiving. Blocked connections with job, family, home, and church in her previous community.

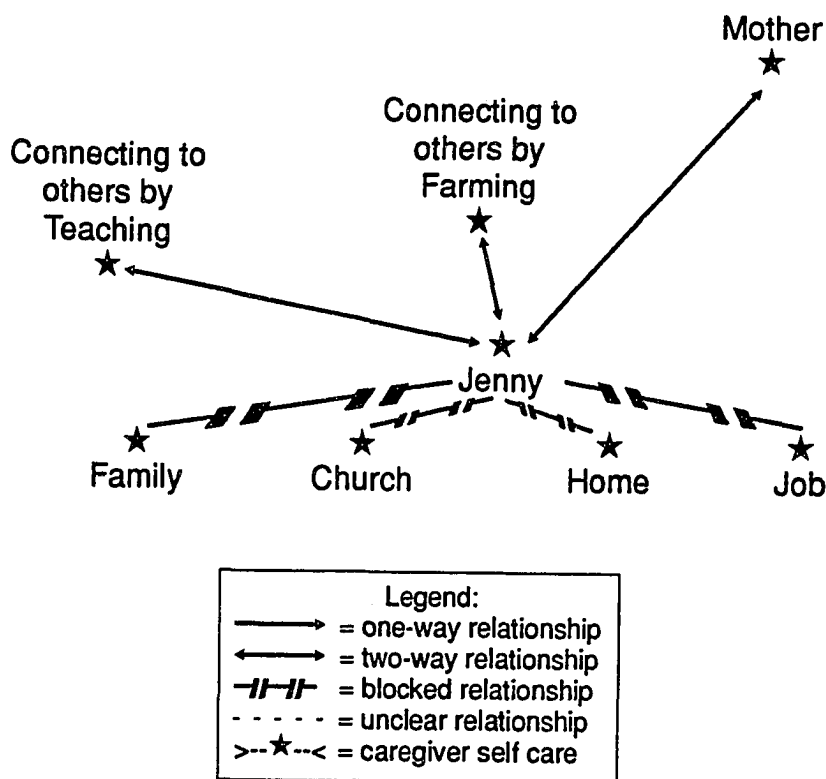
Jenny assigns worth to the relationship with her mother: **I will never regret it because it brought my mother and me closer together(valuing).** She elected to take myself 200 miles away to take care of my mother

(choosing). Jenny's activity is directed toward **taking myself out of familiar surroundings and putting myself into a totally strange one it has not been difficult taking care of my mother (moving).**

ACTION: Activity focuses on relocation rather than caregiving. Values closeness in the relationship with her mother that came about because of caregiving.

Jenny interprets that there is meaning in the caregiving because I have tried to make it a learning experience and it has brought us closer together than we have ever been (perceiving). She senses that it is a **difficult transition (for herself) in what my mother was and what she is now.** She is also experiencing stress since I had to put myself in a totally new community (feeling). Jenny understands about **people, places, and things that are helpful in caregiving (knowing).**

AWARENESS: Finds meaning in caregiving. Acknowledges stress in moving and the grief in adjusting to changes in her mother. See Figure 14 for Jenny's pattern description.



JENNY'S PATTERN DESCRIPTION: Jenny's activity is focused on relocating from her previous job, family, home, and church and adjusting to new roles of caregiver, farmer, and teacher in her new community. Energized by the closeness of the caregiving relationship and by teaching others about caregiving. No specific description of caring for herself.

Figure 14. Jenny's pattern of person-environment interaction.

Summary. Denise, Barbara, Mary, Kathrin, and Jenny were all connecting with others in their environment in addition to their care recipients. They each expressed some form of gratification from their relationship with their mother or mother-in-law. Each caregiver expressed feelings about the emotional impact of the caregiving with no indication of what they were doing

to care for themselves in relation to this impact. Thus, the caregiver patterns were similar in aspects of the exchanging, relating, and knowing dimensions. The patterns were also unique in other aspects of knowing, feeling, perceiving, moving, choosing, valuing, and communicating.

Vicarious Benefits.

The following three caregivers were connecting with others in their environment as well as with their care recipient parent. Furthermore, they received vicarious benefits such as (a) hoping they would be cared for similarly in the future or (b) having their parent remain at home. A summary discussion follows the presentation of this group of daughter/daughter-in-law patterns of person-environment interaction.

Julie. Julie is a 66 year old daughter caregiver who completed 10 years of education. Her mother lives alone and was diagnosed with irreversible dementia two years ago. Julie's mother has moderately severe cognitive impairment. Julie provides 15 hours of care per day for her mother and receives no outside help. See Appendix E for Julie's individual analysis.

Julie's interview: Julie is caring for her mother because she wants to receive the same care when she is in need (exchanging). She is communicating her wishes to her mother but understands when she doesn't

remember them: **everything that happens, it's because she forgets**

(communicating). Jenny's description of her connection to her sister is only

through caregiving: **When she goes to my sister in -----(relating).**

INTERACTION: Caregiving relationship is primary relationship. Mutuality in caregiving because Julie hopes to receive similar care if she is in need.

Connecting with her sister when her mother goes to visit.

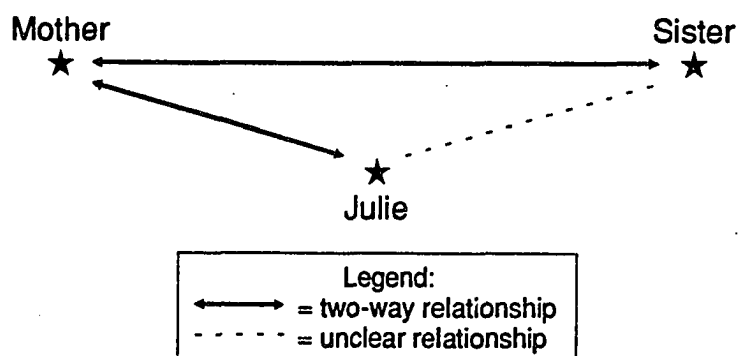
Julie believes it is a **duty to care for her mother and that one should treat others the way they would like to be treated (valuing)**. Julie is electing to care for her mother because **I'm not bursting with energy to get out and live another life because of my health problems (choosing)**. Julie's activity is directed toward physical care: **The last three years I've done all the cooking. It's just been this last year that I've had to keep her apartment up as well, and her laundry, and do her hair (moving)**.

ACTION: Expending more and more energy on a caregiving relationship which she values.

Julie construes that her mother is **improved and it's not bad at all (perceiving)**. She has sensations of **sympathy for her mother because I've had a lot of health problems myself. Julie feels caregiving is a problem only when I don't get enough rest (feeling)**. She is reading about the illness so she

can understand the behavior: **I have been reading the literature and I really appreciate that chapter on bathing (knowing).**

AWARENESS: Aware that her mother's behavior is a result of the illness and that she (caregiver) needs to get enough rest. She is not making other arrangements for rest. See Figure 15 for Julie's pattern of person-environment interaction.



JULIE'S PATTERN DESCRIPTION: Experiencing vicarious mutuality in the relationship with her mother. Connecting with her sister because her mother visits her. Has a decrease in energy due to health problems and therefore chooses to expend that energy on caregiving. Feels caregiving is not so bad if she gets her rest. No description of her awareness of how to care for herself in relation to her needed rest.

Figure 15. Julie's pattern of person-environment interaction.

Joan. Joan is a 59 year old daughter caregiver who completed 12 years of education. She has been caring for her mother since her mother was

diagnosed with multiple infarct dementia 11 years ago. Her mother lives alone and has moderate cognitive impairment. Joan provides six hours of care per day for her mother and uses no professional help. See Appendix E for Joan's individual analysis.

Joan's interview: Joan is exchanging full time caregiving for having her mother remain at home and function at a higher level: **If we took her out of her home I think she would be completely lost (exchanging).** Joan and her mother are sending and receiving messages by using their previous patterns of **bantering back and forth (communicating).** Connecting with her mother as a caregiver with participation of her husband. Is not including brothers: **I take care of making sure she is clean, there are meals...My husband helps with the yard work...I have a bible study every week at her house--I have two brothers but boys are just not the ones to do anything (relating).**

INTERACTION: Connecting with her husband and bible study friends within the context of caregiving. The connection with her brothers is blocked. Receiving some benefit from the energy she expends in caregiving by having her mother remain at home.

Joan sees worth in (a) caring for her mother so she can stay in her own home: **I am afraid she would die if we took her out of her own home and (b) taking time to provide meaningful activities for her mother: We try to take**

her out once a dayand once a week we have a bible meeting at her house (valuing). Joan is electing to provide care for her mother without the help of her brothers: If we took her out of her home she would be completely lost, so by doing that I have everything to do (choosing).

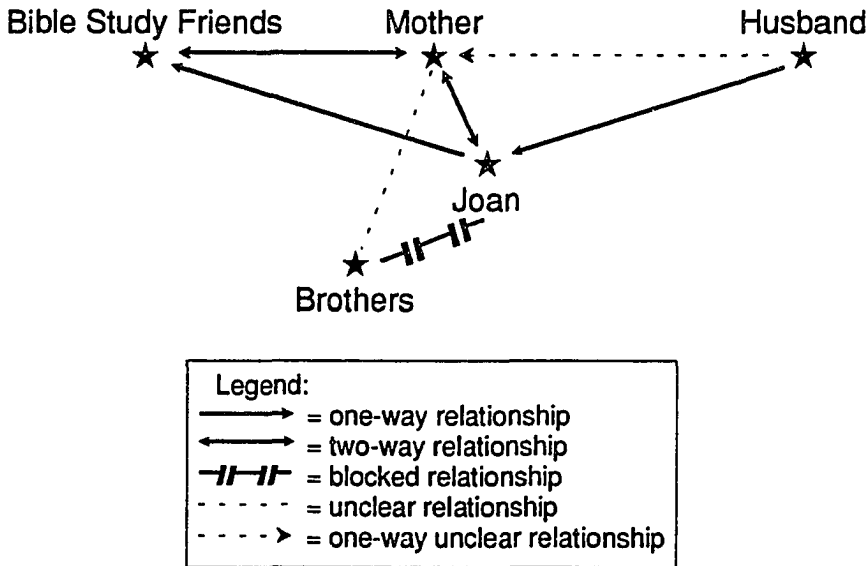
Description of activity focuses on caregiving tasks which are numerous: I get everything ready because she can't do it anymore (moving).

ACTION: Activity directed toward intensive caregiving which she values for the benefits her mother is receiving by living in her own home.

Joan construes that (a) I am the only one to help, (b) if I do not take her out of her routine, she is just fine, and (c) her mother is experiencing depression because of her losses (perceiving). She has sensations of anger when her mother is depressed and tells her (Joan) to go home (feeling). Joan understands her patterns of interaction with her mother: But we have kind of been at each others throats all of our lives. It doesn't sound too good in front of other people, and that routines are important to maintain for people with cognitive impairment (knowing).at each others throats all of our lives. It doesn't sound too good in front of other people, and that routines are important to maintain for people with cognitive impairment (knowing).

AWARENESS: Aware of important strategies for caring for someone with cognitive impairment but no description of awareness of caring for herself and

her mother in relation to the stresses experienced in their relationship. See Figure 16 for Joan's pattern of person-environment interaction.



JOAN'S PATTERN DESCRIPTION: Receiving benefit from caregiving by having her mother remain in her home. Connecting to her husband and bible study friends in the context of caregiving; blocked connections with her brothers. Awareness and action are focused on caregiving to the exclusion of being aware of and acting on care of herself .

Figure 16. Joan's pattern of person-environment interaction.

Kathy. Kathy is a 39 year old daughter caregiver who completed 14 years of education. She is caring for her 74 year old father who has been diagnosed with irreversible dementia for one year. Her father lives at home with his spouse and has moderately severe cognitive decline. Kathy provides

eight hours of care per week for her father and uses 12 hours per day of professional help. See Appendix E for Kathy's individual analysis.

Kathy's interview: Kathy is realizing benefits in caring for her father because when his medical status is in control then her father is able to help her mother and everything just clicks along (exchanging). She is telling her father: you have to take your pills and the only way mother can stay home is if you look after her (communicating). Kathy is connecting to her father and others through caregiving: and between my brother and sister-in-law and myself, there is someone there every day to look in on him (relating).

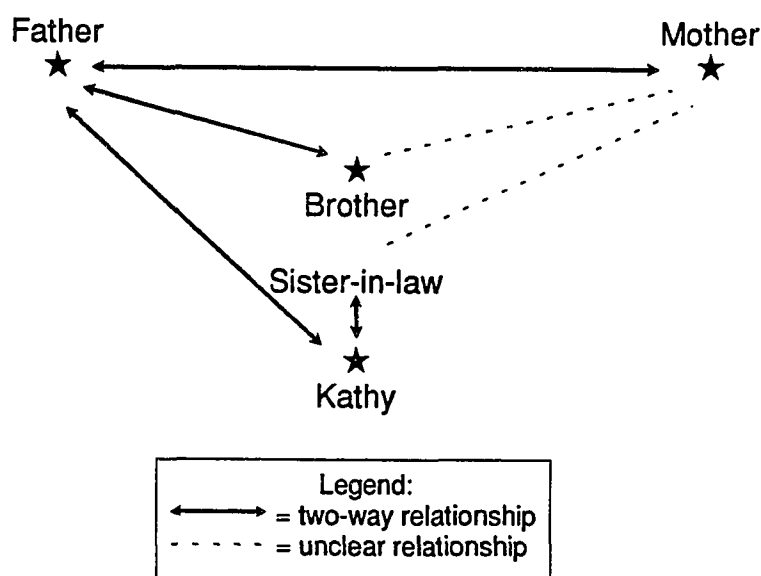
INTERACTION: Kathy, her brother and his wife are participating in caring for their father by managing his medical needs. In return, the mother and father are able to live in their own home.

Kathy believes it is worthwhile to have her mother stay at home (valuing) and participates with her family in keeping her father's diabetes under control so she may stay at home (choosing). Kathy's caregiving activities focus on setting out his medication for him, reminding him to take his pills and his insulin (moving).

ACTION: Activity focuses on participatory caregiving in relation to medical needs of care recipient so that he is able to be a partial caregiver for his wife.

Kathy construes that it is like he has forgotten he has to take insulin for the rest of his life (perceiving). She senses "things are clicking along" now that they are taking care of their father (feeling). Kathy understands how her father is doing in relation to his medical needs: we kind of have his diabetes under control right now (knowing).

AWARENESS: Aware only of her father's medical needs. No description of how cognitive deterioration will affect the ability to "click along". See Figure 17 for Kathy's pattern of person-environment interaction.



KATHY'S PATTERN DESCRIPTION: Participatory caregiving with brother and sister-in-law focusing on father's medical needs which has resulted in the benefit of having father help mother to stay at home. No mention of other relationships outside of caregiving and what will happen as father's cognitive abilities deteriorate. No description of her own awareness of how to care for herself.

Figure 17. Kathy's pattern of person-environment interaction.

Summary. Julie, Joan, and Kathy all connected with others in their environment as well as their parent care recipient. In addition, they benefitted vicariously from caregiving.

Julie was caring for her mother because she hoped for similar care if she was in her mother's situation. Julie was connected to one sister.

Joan benefitted by having her mother remain in her own home. She was afraid that her mother would deteriorate rapidly if she were institutionalized. Joan's spouse was helping with the caregiving while her brothers were not participating.

Kathy benefitted from caring for her father because when his medical problems were under control he could help care for his wife. This allowed the wife to remain at home. Kathy recounted a participatory caregiving relationship in which her brother and sister-in-law were secondary caregivers.

These three caregivers received benefits outside of the caregiver/care recipient relationship. They all connected with the care recipient as well as others in the environment. Additionally, the three caregivers did not articulate an awareness of how to care for themselves.

The individual patterns of person-environment interaction of Julie, Joan, and Kathy demonstrated commonalities in the exchanging, relating, and knowing dimensions. Their patterns were unique in the communicating, valuing, choosing, moving, perceiving, and feeling dimensions.

Help/support from others.

Two caregivers with connected patterns of person-environment interaction experienced reciprocity in the form of help or support of others in their environment. The two caregiver patterns which exemplified this conception of mutuality are presented. A summary discussion follows.

Margret. Margret is a 67 year old daughter caregiver who completed 12 years of education. She lives with her 95 year old mother who has been diagnosed with irreversible dementia for 9 months. Margret's mother has moderate cognitive impairment. Margret provides 24 hours of care per day for her mother and uses two hours of informal help per week. See Appendix E for Margret's individual analysis.

Margret's interview: Margret is giving care and receiving help from her sister: My sister came every day because it took the two of us to stand her up (exchanging). She is receiving a message from her mother that she (Mother) gets upset because she's alone in the evening when I do dishes (communicating). Margret is connecting with her sister only through caregiving (relating).

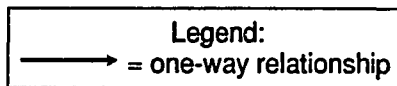
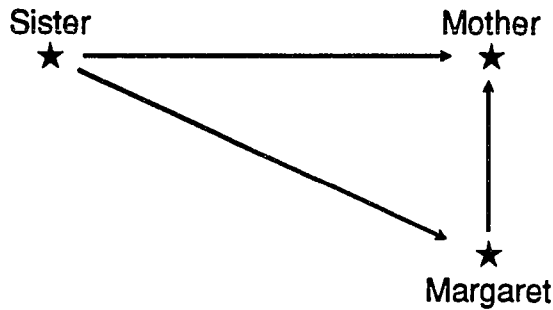
INTERACTION: No mutuality in interactions with mother. Experiencing benefits in the form of help from her sister.

Margret attaches worth to good physical care for her mother: **We used to exercise every day (valuing). She is electing to provide intensive care for her mother: I help my mother get up, fix breakfast, help her exercise, fix lunch, fix supper, help her get ready for bed (choosing, moving).**

ACTION: Activity directed totally to physical activities of caregiving.

Margret interprets that her mother is upset when she is left alone: **She gets upset when she's alone in the evenings(perceiving). She senses "that the afternoons just sort of roll along" when she's caring for her mother (feeling). Margret understands how to provide physical care: Then it got so I could walk her alone with a belt on. Then it got so I could walk her without the belt on. Now I just kind of let her walk by herself, but stay within shouting distance (knowing).**

AWARENESS: Aware of mother's physical needs and feels "afternoons roll along" as she provides for those needs. No description of providing for her own needs. See Figure 18 for Margret's pattern of person-environment interaction.



MARGRET'S PATTERN DESCRIPTION: Very much alone except for the help of her sister in provision of intensive capable physical care with no description of her awareness of how to care for herself.

Figure 18. Margret's pattern of person-environment interaction.

Patsy. Patsy is a 44 year old daughter caregiver who completed 21 years of education. She is caring for her 77 year old mother who has been diagnosed with irreversible dementia for 6 months. Patsy's mother lives alone and has moderately severe cognitive impairment. Patsy provides 10 hours of care per week for her mother and uses no outside help. See Appendix E for Patsy's individual analysis.

Patsy's interview: Patsy is giving care and receiving help from the physician: He wrote on a prescription pad that she can't drive - she wouldn't have quit driving if any of her children had told her. Also receiving help from social services: They sent a list of residential facilities ... (exchanging).

She is sending verbal messages to her mother: **I would like you to live in a situation where you have friends around you (communicating).** Patsy is connecting with her mother and others through concerns about her **mother's driving, living situation, problems with locks. (relating).**

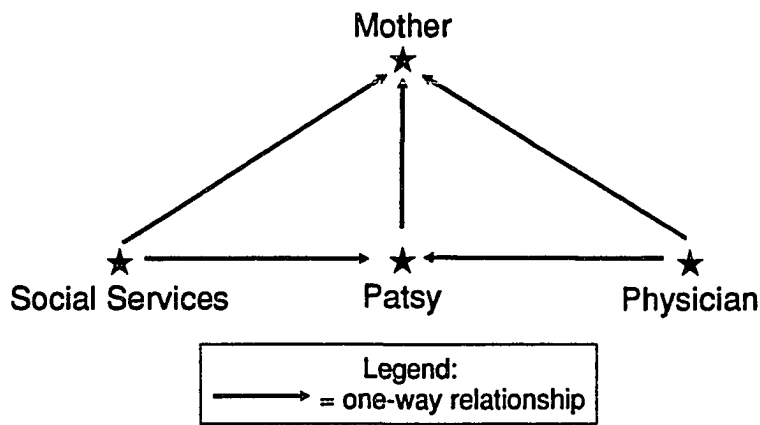
INTERACTION: Descriptions of her interactions focus entirely on caring for her mother. She is receiving help from health care providers.

Patsy attaches worth to having her mother live where there are social opportunities (valuing). Patsy is electing to arrange for her mother's living situation, social activities, and safety (choosing, moving).

ACTION: Activity focuses on planning for her mother's care.

Patsy construes that her mother needs independence: **She's always been very independent.** She also construes that she would find the bus system or whatever very confusing (perceiving). Patsy has a sensation of comfort in the fact that she (Mother) is not driving right now (feeling). Patsy does not understand the extent of cognitive impairment at this point: **When we get a final summary of all the tests it will help us (knowing).**

AWARENESS: Aware of mother's pattern of independence. Plans for caregiving do not include how to allow her mother to feel independent. See Figure 19 for Patsy's pattern of person-environment interaction.



PATSY'S PATTERN DESCRIPTION: Receiving help from health care team with no description of mutuality in caregiver/care recipient relationship or connections to others in her environment. Activity directed to planning for caregiving with lack of awareness of integrating mother's need for an environment that allows feeling of independence with the effects of cognitive impairment. No description of how it has affected her, other relationships in her life, or how she cares for herself.

Figure 19. Patsy's pattern of person-environment interaction.

Summary. Margret and Patsy were both connecting with others in the environment besides their parent care recipient. Neither caregiver experienced mutuality with their parent but did receive the help of others with their caregiving responsibilities.

Margret cared for her mother and received help from her sister daily when her mother could not stand by herself. She continued to provide high levels of physical care for her mother with no explanation of how she cared for herself.

Patsy provided care for her mother and received help from the health care team in preventing her mother from driving and in locating a place for her mother to reside. Her objective was to maintain her mother's independence but she did not communicate a knowledge of how to do that in the context of cognitive impairment. Additionally, there was no indication of how she cared for herself.

These two caregivers were caring for their mothers and receiving the help of others with their caregiving responsibilities. They both connected with the care recipient as well as others in the environment. These caregivers did not describe an understanding of how to care for themselves.

Margret's and Patsy's patterns of person-environment interaction had commonalities in the exchanging, relating, and knowing dimensions. Their patterns were unique within the dimensions of communicating, valuing, choosing, moving, perceiving, and feeling.

Summary of connected caregiver patterns of person-environment interaction.

Ten caregivers displayed patterns of person-environment interaction which contrasted with the unconnected caregiver patterns of person-environment interaction. These daughters/daughters-in-law connected to the

care recipient as well as to others in their environment within the context of caregiving.

Additionally, the ten caregiver interviews depicted three different forms of mutuality. Five of the caregivers experienced benefits from their relationship with their parent care recipient. Three of the caregivers received vicarious benefits, and two caregivers received help in their caregiving activities from family or the health care team.

The daughters and daughters-in-law within this group gave no accounting in their interviews of how they were caring for themselves. All caregivers within this group displayed the following characteristics.

1. Connection to the care recipient as well as to others in the context of caregiving.

2. Perception of reciprocity in one of three forms within the context of caregiving.

3. Provision of care for their parent without providing care for themselves.

All ten caregiver were in the process of "going through it" as described in Wilson's (1989) stages of caregiving. All dimensions of their interaction with their environment appeared in their descriptions, making their interactions multidimensional. Their testimonials to the grief, stress, exhaustion, anger, and demands in their lives provided examples of the impact

of caregiving on them. The connections to others, the reciprocation of benefits with the care recipient or through others, and the instrumental help of others may be balancing factors for the negative impact described.

This group was similar to the unconnected group in their lack of awareness about the need to care for themselves. Furthermore, daughter/daughter-in-law caregivers were similar to the caregivers in the unconnected group because their interviews showed no readiness to "turn it over".

Interconnected caregiver patterns of person-environment interaction

Three caregivers (19%) had patterns of person-environment interaction which were similar to and contrasted with the unconnected and connected caregiver patterns. The caregivers provided care to their parents and were connected with others who were helping them provide the care. They differed from the other two groups in that they were providing care for themselves. In this form, caring for oneself and another are not two separate processes but one interconnected process.

The following caregiver patterns of person-environment interaction are consistent with this definition of caring and are presented individually. A summary discussion follows after the presentation of the patterns.

Chip. Chip is a 42 year old daughter-in-law caregiver who completed 14 years of education. She is living with her 73 year old mother-in-law who was diagnosed with irreversible dementia one year ago. Chip's mother-in-law has moderate cognitive impairment. Chip provides 14 hours of care per week for her mother and uses no outside help. See Appendix E for chip's individual analysis.

Chip's interview: Chip is giving care and receiving by learning things about her son and his family and her mother-in-law that I would have never known. She also expresses that the joy of seeing our son who is 17 has been marvelous, he's very responsive to helping her.....someday he may take care of me in this way (exchanging). She is sending and receiving messages from her family: I felt it was all on my shoulders, it took some discussing and we worked through it very well (communicating). Chip is caring for her husband who is also blind, which means he needs extra care (relating).

INTERACTION: Experiencing mutuality in her caregiving because she is "receiving" in the form of help from her family and knowledge of family history from the care recipient. She is also caring for her husband.

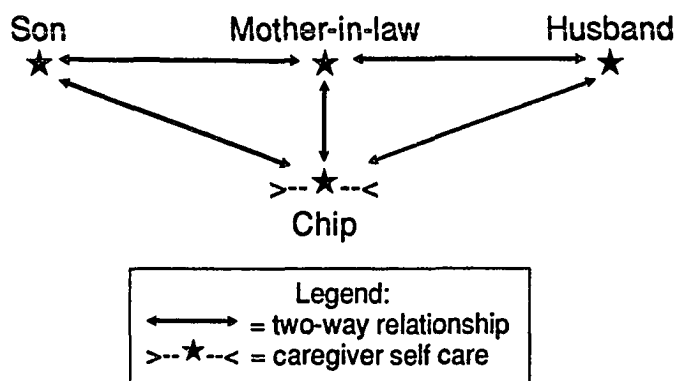
Chip assigns worth to the imperative that " time goes on and you must move forward" in dealing with the problems of caregiving (valuing). She is electing to move her (mother-in-law) in and adjust to what her lifestyle was compared to ours and to take some time off when I get frustrated (choosing).

Chip's activity is directed toward learning face to face with no training (moving).

ACTION: Activity directed toward moving forward as a primary caregiver with a lack of training. Does take time off from caregiving.

Chip construes that this is a major change for the family but the family has worked through it well (perceiving). She states: sometimes I feel it's a burden, sometimes I feel frustrated, and sometimes I feel it's a blessing (feeling). Chip does not know how to handle situations and how to make her feel like this is her home. She does know with the help of my husband to take some time off (knowing).

AWARENESS: Aware of contrasting feelings of caregiving as a burden and a joy and that caregiving without training is more difficult and frustrating. Also aware of the need for taking time off. See Figure 20 for Chip's pattern of person-environment interaction.



CHIP'S PATTERN DESCRIPTION: Focusing on the joy and frustrations of caring for her mother-in-law as she is blending into the family composed of her husband, her son, and herself. Family is participating. Chip is also caring for her husband who is blind. Feeling her lack of training is the cause of her frustration and does take time off.

Figure 20. Chip's pattern of person-environment interaction.

Cynthia Cynthia is a 65 year old daughter caregiver who completed 13 years of education. She is living with her 87 year old mother who has been diagnosed with Alzheimer's disease for 9 years. Cynthia's mother has severe cognitive impairment. Cynthia provides 20 hours of care per day for her mother and uses four hours of professional help per week. See Appendix E for Cynthia's individual analysis.

Cynthia's interview: Cynthia is giving care to her mother and receiving help from family, friend, and neighbors: **The kids are really good about helping. I have a friend who keeps Mother on Wednesdays. I just called the neighbor and they came over (exchanging). She is sending messages**

when she needs help: **I called the neighbors right away and they came** (communicating). Cynthia includes her network of family, friends, and neighbors in helping in her caregiving. She also relates to others outside of caregiving: **I go and have coffee with the girls and I have lunch with my daughter** (relating).

INTERACTION: Uses her familial and social network in her role as caregiver. Interacts with family and friends outside of her caregiving role.

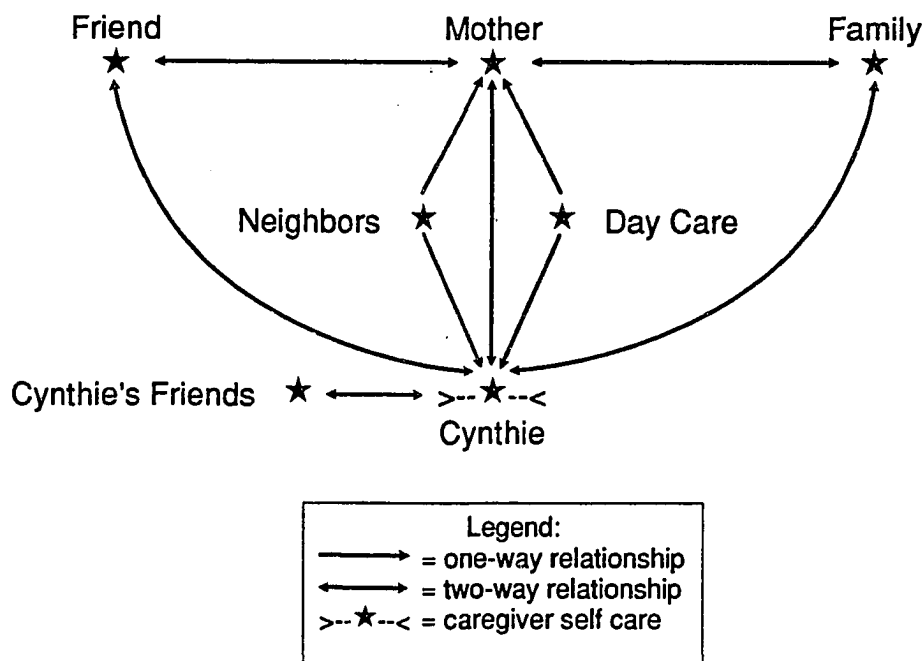
Cynthia considers day care expensive (valuing). Elects to use respite care: **My oldest daughter thought I needed a day off and so I use it once a week** (choosing). Cynthia's activity is directed toward intensive caregiving: **I've taken everything off the walls and out of the drawers in her room because she wants to prowl at night. I give her a bath every other day, give her the pills, fix meals, and help her with toileting** (moving).

ACTIVITY: Expending energy through caregiving but balancing with other activities for her own enjoyment.

Cynthia construes that her friend enjoys her mother. She also construes that her mother is not remembering (perceiving). She has a sensation that caregiving is not too bad (feeling). Cynthia understands how to (a) protect her mother: **I put locks on the doors she couldn't turn by herself;**

(b) care for her physical needs: I give her a bath every other day; and (c) how to provide for her social needs: Right now (mother) she is out to Lenten lunch with her friend (knowing).

AWARENESS: Knows how to care for her mother and she is comfortable helping her mother live with the illness. See Figure 21 for Cynthie's pattern of person-environment interaction.



CYNTHIE'S PATTERN DESCRIPTION: Included her family, friends, neighbor, and community day care resource in the caregiving experience. Valued taking time for herself to be with her friends and family. Knows how to care for her mother and is comfortable helping her mother live with the illness.

Figure 21. Cynthie's pattern of person-environment interaction.

Sharie. Sharie is a 64 year old daughter caregiver who completed 12 years of education. She is living with her 86 year old mother who was diagnosed with Alzheimer's disease ten years ago. Sharie's mother has severe cognitive decline. Sharie is providing 23 hour of care per day for her mother and uses six hour of informal help per week. See Appendix E for Sharie's individual analysis.

Sharie's interview: Sharie is giving care and "receiving" by (a) having her mother remain with her: **They said I couldn't take care of her at home. My doctor said if I want to try it, he'd help me all he could;** (b) seeing her mother enjoy activities such as **eating and playing with the cat;** and (c) accepting help from the doctors and nurses, her grandkids, and her friend: **I can't load her into the car so the doctor and nurses stop up. The grandkids mow the lawn and stuff. My friend has been so good, she comes so I can go to work at the post office.** (exchanging). Sharie states that communicating with her mother is difficult: **She knows there's a connection with me but sometimes she calls me MaMa or Grandma** (communicating). Sharie describes relationships with her grandchildren, health care team, her cat, and her friend in the context of helping her care for her mother (relating).

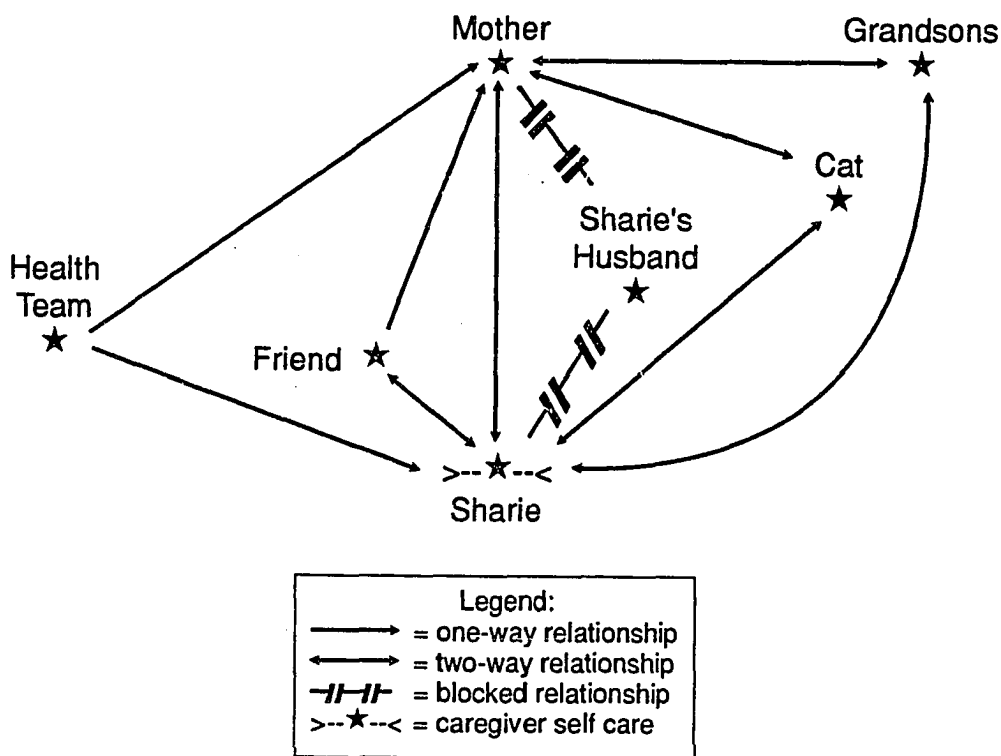
INTERACTION: Interacting as a caregiver with help from her friend, family, and health care team. Maintains her connections at the post office with the help of her friend.

Sharie wants to keep her mother at home: They said I couldn't keep her at home but my doctor, he knows I'm kind of a determined person. She believes that respite care is costly (valuing). Sharie is electing to rest: I make myself quit whatever I'm doing and lie down. She is electing not to use respite care because: it's costly, and electing to use the help of her community to keep her mother at home (choosing). Sharie is using much energy to care for her mother at home: She doesn't sleep all that much and I'm up with her and sometimes she has some agitated days. I lift her up under her arms and walk backwards with her to the bathroom (moving)
ACTION: Intensive caregiving with time out for naps. Allowing others to help her in the caregiving.

Sharie construes that her mother's condition bothers granddaughters and her mother misses her son-in-law, who is dead. Sharie senses that our nights are no good. It's frustrating because there are so many things I'd like to get done; but in the past 2 years time, I cannot think of any time we hadn't been able to work things out (feeling). Sharie understands (a) that animal therapy does work - that cat is so good to her; (b) when her mother's reactions are unusual: One day I was really concerned - she wouldn't respond to me when I got her up; but doesn't understand how to predict the

good nights and the bad nights: I had a couple of good nights but the last two have been just awful – you just never know (knowing).

AWARENESS: Aware that caring for her mother limits what she can do but feels that everything has always worked out. Aware that Mother misses her son-in-law who is dead. See Figure 22 for Sharie's pattern of person-environment interaction.



SHARIE'S PATTERN DESCRIPTION: Working in partnership with the health team, her friend, the cat and her grandsons to keep her mother at home and to keep her job as a postal worker. Providing intensive caretaking especially at night. Taking time to rest without using "expensive" respite care. Aware her mother misses her son-in-law.

Figure 22. Sharie's pattern of person-environment interaction.

Summary of interconnected caregiver patterns of person-environment interaction.

All three daughter/daughter-in-law caregivers were including others in the work of caring. Furthermore, they were caring for themselves in the process.

Chip was caring for her mother-in-law and received the benefit of learning more about her husband and his family in the process. The participation of her son in caregiving was an additional benefit for her.

Chip was caring for her husband who is blind while trying to blend her mother-in-law into the family. Her husband sensed her frustration in not being prepared to deal with the problems of caregiving. In response to her frustrations, he encouraged her to take some time off.

Cynthia was giving care to her mother and receiving help from family, a friend, and neighbors. She took advantage of respite care when her daughter suggested she needed it even though it was expensive. The respite time was used for socialization with family and friends outside of the context of caregiving.

Sharie was giving intensive physical care to her mother and receiving help from the doctor and nurses, her friend, her cat, and her grandsons. This help allowed Sharie to keep her mother with her at home and to continue her employment as a postal worker.

Sharie provided intensive physical care but made herself take naps every day. She chose not to use respite care because it was too expensive.

The three daughters/daughters-in-law within this group were providing high levels of physical and supervisory care to their mothers and mother-in-law. They were clear in their portrayals of their frustration, exhaustion, and disrupted lives, but balancing those descriptions with examples of the joys and comforts in caregiving and the help they received from family and community resources.

The one characteristic of this group that distinguished them from the other groups was their commitment to caring for themselves. They followed through with this commitment despite their intensive caregiving.

Summary of Findings

The first objective of the research was to identify individual patterns of person-environment interaction for rural daughter/daughter-in-law caregivers that were revealed from their descriptions of caring for their parents who have ADRD. Individual patterns of person-environment interaction were revealed for each rural daughter/daughter-in-law using the NANDA framework. The individual dimension descriptions for each caregiver provided a multidimensional view of the caregivers in interaction with their environment.

The second objective of the research was to identify common groupings among all of the individual patterns of person-environment interaction. Review of the graphic and narrative representations of the individual patterns, as well as the multidimensional view of the caregivers provided through the individual dimension descriptions, resulted in the identification of three common groupings of caregiver patterns. The three common groupings were (a) unconnected caregiver patterns of person-environment interaction, (b) connected caregiver patterns of person-environment interaction, and (c) interconnected caregiver patterns of person-environment interaction.

Commonalities related to the caregivers' relationship to other persons in their environment as well as caregiver activity directed toward care of themselves. Those caregivers with the unconnected person-environment interactional patterns described only their relationship with the care recipient and did not describe caring for themselves. Those caregivers with the connected person-environment interactional patterns reported connections to other people beside the parent care recipient and did not report caring for themselves. Those caregivers with the interconnected person-environment interactional patterns included others in the work of caregiving and took care of themselves as well.

CHAPTER 5

Discussion

The discussion of the findings of this study are presented in the following sequence. The first section is the interpretation of findings. The implications for research and practice are presented in the second section, and other relevant findings are presented in the third section.

Interpretation of Findings

The research question for this study was what are the patterns of person-environment interaction of rural daughter/daughter-in-law caregivers that are revealed from their descriptions of caring for their parents who have ADRD? Two types of patterns of person-environment interaction were found in this study: individual rural daughter/daughter-in-law caregiver patterns of person-environment interaction and common groupings among all the individual caregiver patterns of person-environment interaction.

The individual patterns of person-environment interaction were revealed for each rural daughter/daughter-in-law using the NANDA framework. The individual dimension descriptions for each caregiver provided a multidimensional view of the caregivers in interaction with their environment.

Review of the graphic and narrative representations of the individual patterns of person-environment interaction, as well as the multidimensional view of the caregivers provided through the individual dimension

descriptions, resulted in the identification of three common groupings of caregiver patterns of person-environment interaction. The three common groupings were (a) unconnected caregiver patterns of person-environment interaction, (b) connected caregiver patterns of person-environment interaction, and (c) interconnected caregiver patterns of person-environment interaction. Table 1 presents the characteristics for each caregiver/care recipient according to the three common interactional patterns. Upon inspection, there were no relationships evident between the characteristics and the three common patterns.

The findings of these common groupings may be important when considering the impact of caregiving on the caregiver. Daughters/daughters-in-law with the unconnected patterns of person-environment interaction differed from the other caregivers in the dimension of relating. They were not talking about support from others within their environment when they described what caregiving was like for them even though two of these daughters utilized professional help. Two of these three daughters expressed no mutuality in their relationship with their parent which became apparent when viewing their data from the exchanging dimension.

Pattern	Caregiver	Age	Education	Hours of Care	Level of Decline	Length of ADRD
Un-connected	Bernie	58	16	23/day	4	1 yr.
	Peggy	68	12	24/day	5	8 yr.
	Susie	44	18	18/day	6	1 yr.
Connected	Denise	60	14	22/day	3	5 yr.
	Barbara	54	16	14/day	4	8 yr.
	Mary*	49	No Report	8/week	5	2 yr.
	Kathrin	53	19	25/week	4	9 yr.
	Jenny	58	21	24/day	3	1 yr.
	Julie	66	10	15/day	5	2 yr.
	Joan	59	12	6/day	4	11 yr.
	Kathy	39	14	8/week	5	1 yr.
	Margret	67	12	24/day	4	9 mth.
	Patsy	44	21	10/week	5	6 mth.
Inter-connected	Chip*	14	14	14/week	4	1 yr.
	Cynthia	13	13	20/day	6	9 yr.
	Sharie	12	12	23/day	6	10 yr.

Table 1. Caregiver/care recipient characteristics according to three interactional patterns.

* Daughter-in-law

This unconnected pattern of person-environment interaction was consistent with the findings of Lynch-Sauer (1990). She found that a progressive decrease in diversity in caregiver-environment interaction emerged from caregivers' descriptions of their experience of caregiving. In other studies, a decrease in social support was associated with an increase in caregiver negative reactions (Brody, et al., 1987; Pohl, et al., 1994). These three daughter caregivers with unconnected patterns of person-environment interaction may be at risk for the negative consequences of caregiving.

Daughters/daughters-in-law with connected patterns of person-environment interaction differed from the unconnected group in the dimension of relating. They described connections with others in their environment within the context of caring for their parent. Eight of the ten women within this group talked about receiving some form of benefit in relation to giving care to their parent. Archbold, et al., (1990) reported that the more caregivers perceived mutuality in their relationship with the impaired person, the lower their levels of role strain. The benefits of social support and perceptions of mutuality may balance the negative effects of caregiving for these particular daughter/daughter-in-law caregivers.

The two daughters and one daughter-in-law with the interconnected patterns of person-environment interaction talked about (a) connecting with others (relating), (b) experiencing mutuality with their mothers/mother-in-law care recipient (exchanging), and (c) activities of self care (moving). As discussed previously, studies have shown that social support and perceptions of mutuality may balance the negative effects of caregiving. In addition, Thompson, et al., (1993) found that caregivers who took part in social interaction for fun and recreation had lower burden scores.

Daughters/daughters-in-law with interconnected patterns of person-environment interaction may be at a much lower risk for the negative consequences of caregiving.

The findings of this study indicated that the unconnected, connected, and interconnected daughter/daughter-in-law caregiver patterns may be consistent with and build upon the developmental process of caring based on Gilligan's (1982) longitudinal studies of women. Gilligan's (1982) first stage of development was one in which women cared for themselves in isolation from others. The unconnected pattern of daughter/daughter-in-law caregivers paralleled Gilligan's stage one. The difference between the women in Gilligan's stage one and the unconnected group of caregivers was that the daughters/daughters-in-law were not selfishly caring for themselves. Instead, they had reached out to care for their parent, but in seeming isolation from others.

Gilligan's (1982) second stage of development occurred when the women reached out to care for others. Caring for others came out of a sense of responsibility and included self-sacrifice. The group of daughters/daughters-in-law who showed connected patterns of person-environment interaction were reaching out to others within the context of caring for their parent with cognitive impairment. The caregivers reached out to others to help them with the (a) physical care of their parent, (b) socialization of their parent, (c) finding of resources , and (d) protection of their parent's sense of self worth. These daughters/daughters-in-law were exemplifying self-sacrifice because in their

interviews they did not describe any activities in which they cared for themselves.

Gilligan's (1982) third stage in development included a balance between caring for others and caring for oneself. The women she studied recognized the interconnection between oneself and others, so that taking care of one's own needs became integral to caring for others. The daughters/daughter-in-law in this study with interconnected patterns of person-environment interaction cared for their parent, connected with others in the environment, and cared for themselves in the process.

The findings of this study of daughter/daughter-in-law caregivers contrasted with the findings of Harris (1993) who interviewed 15 male spouse caregivers. These male caregivers perceived caregiving as a "job", a labor of love, a sense of duty, and a crossroads.

The daughters/daughters-in-law in this study viewed caregiving as an activity that protected their parents from the insult of cognitive impairment rather than as a "job". The majority of the daughters/daughters-in-law in this study described mutuality in their relationship with their parent in contrast to a one-sided labor of love. Only one of the daughters in this study described her attitude about caregiving as a sense of duty, while a group of the male caregivers in the Harris study took on caregiving because of a sense of duty.

Finally, daughters/daughters-in-law in this study verbalized their frustrations but gave no indication that they were in crisis. In comparison, a group of male caregivers "at the crossroads" were described as being in a crisis because they felt they could not get organized. In summary, this study of daughter/daughter-in-law caregivers as contrasted with the Harris (1993) study suggested there may be differences between male spouse caregivers and daughter/daughter-in-law caregivers.

Implications for Research and Practice

This was a secondary analysis of interviews with Caucasian daughters and daughters-in-law from rural areas, accessed primarily through health care agencies and Alzheimer's Associations. The purpose of this study was to gain some insight regarding the patterns of person-environment interaction of these rural daughters/daughters-in-law who cared for their parents. For this reason, the findings cannot be generalized to other populations. This study provided the beginning point for exploring the stories of daughter/daughter-in-law caregivers in order to determine patterns of person-environment interaction.

The interviews analyzed were short and contained few probes for expansion or clarification. Probes for expansion or clarification may have allowed the caregivers with the unconnected interactional patterns to describe connections to others in relation to caregiving. Similarly, care of self may have

emerged through probes for clarification or expansion of ideas. In the next study, the investigator plans to interview caregivers rather than to use secondary interview transcripts.

The next step in the development of knowledge is to interview a group of daughters at different points in the caregiving process, share their patterns of person-environment interaction with them, and determine if the pattern changes.

A second group of daughter caregivers could be interviewed at the same points in the caregiving process without sharing the pattern with them along the way. The patterns of the two groups could be examined for differences to determine if sharing the pattern with the caregiver may provide her with the insight to change her pattern.

In relation to the implications for practice, women in each of the groupings may be at varying risks for the negative impact of caregiving. Their parent care recipients may also be at varying risks for premature institutionalization. It is important not to stereotype all caregiving as burdensome. Those caregivers with the unconnected interactional patterns described no social support in their interviews. They may be at a higher risk for experiencing the multidimensional effects of burden (George & Gwyther, 1986; Pohl et al., 1994). Two of these caregivers with unconnected interactional patterns did not describe mutuality in their relationship with their parent.

Archbold et al. (1990) found that mutuality in the caregiver/care recipient relationship may mediate the effects of role strain.

Finally, one of the caregivers with the unconnected interactional patterns was coping with her father's night time disruptive behaviors. Care recipient disruptive behaviors were associated with increased caregiver burden (Farran et al., 1993), decreased caregiver well-being (Deimling & Bass, 1986), caregiver feelings of self loss (Skaff & Pearlin, 1992), and increased risk of care recipient institutionalization (Cohen et al., 1993). Research has shown that these three caregivers with the unconnected interactional patterns are at a higher risk for the negative effects of caregiving. They should be targeted for interventions such as education about support groups, respite care, and the importance of self-care.

Other Relevant Findings

Because caregiving has a multidimensional impact on the caregiver, the NANDA dimensions were used to identify a multidimensional pattern of person-environment interaction. This section describes findings related to the nine dimensions of person-environment interaction.

When daughters/daughters-in-law talked about what caregiving was like for them, most conversations reflected all nine dimensions of person-environment interaction. The data from two interviews did not reflect the

exchanging dimension, and the data from one interview did not reflect the communicating dimension.

No interview data for any transcript were unclassified. All of the interview data for each transcript were classified according to at least one dimension.

The following section presents the findings as they relate to each of the nine dimensions of person-environment interaction.

1. Exchanging manifested as mutuality in giving and receiving . Two daughter caregivers did not talk about receiving any benefits from their caregiving, either as (a) gratification or meaning in the caregiver/care recipient relationship, (b) vicarious benefit in the hope of similar care provided for themselves in the future, or in the fact that their parent was able to remain at home, or (c) through a present in the form of help with caregiving.

The remainder of the caregivers addressed one of the three forms of mutuality in their conversations about providing care for their parent.

Archbold, et al., (1990) reported in their study that the more caregivers perceived mutuality in their relationship with the impaired person, the lower their levels of role strain. Caregivers who do not experience mutuality within the context of caregiving may be at risk for negative consequences of caregiving. The experience of mutuality may be a balancing factor for decreasing the risk of the negative consequences of caregiving.

2. Communicating. In most of the caregiver interviews, communicating manifested as the sending and/or receiving of messages. The communicating dimension did not appear in one daughter interview.

One daughter sent and received messages from her mother as they laughed and played games together. Thompson, et al., (1993) found that caregivers who took part in social interaction for fun and recreation had lower burden scores.

3. Relating. Relating manifested as connecting with other persons/objects in all of the caregiver interviews. Three daughters described only the caregiver/parent relationship.

In a previous study, a progressive decrease in the diversity in the relationship to the care recipient, others, and the environment emerged from caregivers' descriptions of their experience (Lynch-Sauer, 1990). Social support was absent in these three daughter interviews. A decrease in social support was associated with an increase in caregiver negative reactions (Brody, et al., 1987; Pohl, et al., 1994). These three daughter caregivers may be at risk for the negative consequences of caregiving.

4. Valuing. In all of the caregiver interviews, valuing appeared as the assigning of relative worth. The findings of this study were consistent with those of Farran, et al. (1991) who found that caregivers' values emerged in their interviews of family caregivers.

5. Choosing. Choosing appeared in all the interviews as the implicit selecting of one or more alternatives. All caregivers were caring for their parent in the community setting. There was no indication in the interviews that any of the daughters/daughters-in-law were choosing to institutionalize their parent care recipient. This was consistent with Brody's (1985) study that found "firm commitment for filial help for the aged" (p. 24).

6. Moving. In all of the caregiver interviews, moving emerged as activity directed to providing care for their parent. Some of the daughters were providing high levels of physical and protective care. In a study by Deimling and Bass (1986), the provision of high levels of physical care was associated with changes in physical health and increased depression. Another daughter's activity was directed to dealing with her father's disruptive behaviors. There was some evidence from previous studies that as the care recipient's disruptive behaviors increased, total burden increased, depression increased, self loss increased, and institutionalization of the care recipient increased (Cohen et al., 1993; Deimling & Bass, 1986; Farran, et al., 1993; Skaff & Pearlin, 1992).

Two daughters and one daughter-in-law described activities directed toward caring for themselves. Caregivers who took part in social interaction for fun and recreation had lower burden scores (Thompson, et al., 1990) and use of respite care by daughter caregivers was positively associated with well-

being (Quayhagen & Quayhagen, 1988). Attention to activities of self care may balance the negative impact of providing high levels of physical and supportive care.

7. Perceiving. Perceiving emerged from all daughter/daughter-in-law conversations as the receiving and interpreting of information. The majority of the caregivers interpreted the care recipient's needs. Caregivers perceived that their parents needed (a) protection, (b) to grieve the losses of friends and home, (c) to feel useful, and (d) to feel independent. In her study of the experience of intergenerational caregivers, Bowers (1987) discovered that the daughters and sons perceived their parents' need to feel useful and independent in the context of cognitive impairment and could tolerate behavior which sometimes seemed unsafe to the health care team. The caregivers suggested that doctors and nurses should be aware of the caregivers' perceptions of their parents' needs to feel useful and independent.

8. Feeling. Feeling manifested as the quality of sensation and mood or the subjective awareness of information in the caregiver interviews. Some caregivers reported feelings of being comfortable with the caregiving situation. Others felt that the caregiving was difficult. Additionally, they shared their feelings of grief, sadness, exhaustion, and stress.

In a study by Franks and Stephens (1992), perceived feelings of mastery within the role of caregiver mediated the effects of role stress on affective

indices of caregiver well-being. Promoting caregivers' feeling of mastery may be an intervention which is protective for the caregiver.

9. Knowing. In all of the caregiver interviews, knowing emerged as personal recognition of self and world (Newman, 1986). Some caregivers knew about cognitive impairment and applied that knowledge in their own caregiving. Two daughters and one daughter-in-law knew how to care for themselves within the context of caring for someone with cognitive impairment. Some of the caregivers said they did not know how to care for their parent. Archbold et al. (1990) found that the caregiver's feeling of preparedness for the caregiving role was associated with lower levels of caregiver role strain.

Though many of the daughters and daughters-in-law expressed feelings of sadness, grief, stress, and exhaustion, they did not voice how to take care of themselves in relation to these feelings. These findings were consistent with the findings of a study of black and white daughter caregivers in which all daughters experienced role strain. These caregivers who were not caring for their own needs may be a risk for the negative effects associated with caregiving. Promoting daughter/daughter-in-law preparedness for the role and her ability to care for herself may balance the burden associated with caregiving.

Discussion

Since the dimensions are not mutually exclusive, one should be able to detect an understanding of other dimensions from the data within one dimension (Moch, 1988; Newman, 1984; Roy, 1984). This was consistent with the data from this study.

Examination of each of the dimensions demonstrated that the physical, social, and emotional impact of caregiving was explicated through the synthesis of data related to each of the dimensions. Similar data was explicated through the use of multiple assessment instruments in previous research studies. The results of this study indicated that the subjective description of the daughter/daughter-in-law provided data which gave a multidimensional picture of that person within her own context rather than from the context of the researcher.

The use of the NANDA framework delineated individual patterns of person-environment interaction which then clustered according to unconnected, connected, and interconnected caring patterns. Brody (1985), in her study of daughter and daughter-in-law caregivers found a firm commitment to caring for their elderly parents. The results of this study provided evidence that these rural daughter/daughter-in-law caregivers' commitment to caring may put them at a higher risk for negative effects depending upon their particular pattern of caring.

In response to this finding, interventions which support women in their caring endeavors are essential. Additionally, the decision to "turn it over", may be a time that women must consider their needs in relation to everyone else in their caring environment. Interventions which support women in the "turning it over" phase are essential, also.

Caring in the human health experience is the focus for the development of knowledge for the discipline of nursing (Newman, Sime, Corcoran-Perry, 1991). The definition of health within the NANDA framework is that health is a fluctuating pattern of person-environment interaction which is operationalized by the synthesis of data relevant to the nine dimensions. The human health experience for these daughters/daughters-in-law is a fluctuating pattern consistent with a caring developmental framework. Therefore, the use of the NANDA framework contributed to the development of nursing knowledge about a "hidden community nursing work force"..

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Appendix A
Analysis of Jenny's Interview Data

Example of the Analysis of Jenny's Interview Using the NANDA Assessment Framework

The following text is Jenny's interview coded according to dimensions with the summary dimension descriptions. The NUDIST document memo for Jenny follows with the dimension descriptions, the characteristic synthesis statements, and Jenny's pattern description.

DIMENSION DATA

Exchanging

It has not been difficult to take care of my mother since she is a very appreciative person and she seems to understand what is happening to her. She realizes her difficulty in remembering and understanding and these sorts of things.

It is in turn difficult for me because remembering what my mother was like and what she is now is a very difficult transition, but I will never regret it because it brought my mother and me closer together than we had ever been in our whole lives as far as I was concerned. I will always remember it for that reason.

Communicating

It has been difficult, as I said, taking myself out of my totally familiar surroundings and putting myself into a totally strange one, but on the other hand I have tried to make it a learning experience.

DIMENSION DESCRIPTION

Exchanging

Mutuality in her relationship with her mother.

Communicating

Receiving messages about how to care and sending the messages back to other caregivers.

I have tried to do the teaching part, which was my profession, and tried to teach others about what it's like to be a caregiver. I've tried to help them to find places and people and things that would be helpful to them in caregiving. I've tried to use my teaching abilities in that way.

Relating

First of all I would like to say that I came to take care of my mother.

I took myself out of my familiar surroundings—job, home, family, church, all of those things that you're familiar with—and took myself 200 miles away to take care of my mother.

It was a very stressful situation since I had to put myself into a totally new community where I didn't know anyone and didn't know people very well except that I remembered as a child.

It has not been difficult to take care of my mother since she is a very appreciate person and she seems to understand what is happening to her. She realizes her difficulty in remembering and understanding and these sorts of things.

But I will never regret it because it brought our whole lives as far as I was concerned. I will always remember it for that reason.

I have now become a farmer and a caregiver. I have tried to do the teaching part, which was my profession, and tried to teach others about what it's like to be a caregiver. I've tried to help them to find places and people and things that would be helpful to them in caregiving. I've tried to use my teaching abilities in that way.

Relating

Connecting with others through caregiving, teaching, farming. Experienced blocked connections with others due to her move.

Valuing

It is in turn difficult for me because because remembering what my mother was like and what she is now is a very difficult transition, but I will never regret it because it brought me mother and me closer together than we had ever been in our whole lives as far as I was concerned.

Choosing

First of all I would like to say that I came to take care of my mother. I took myself out of my familiar surroundings--job, home, family, church, all of those things that you're familiar with--and took myself 200 miles away to take care of my mother.

It was a very stressful situation since I had to pt myself into a totally new community where I didn't know anyone and didn't know people very well except that I remembered as a child.

Moving

First of all I would like to say that I came to take care of my mother. I took myself out of my familiar surroundings--job, home, family, church, all of those things that you're familiar with--and took myself 200 miles away to take care of my

First of all I would like to say that I came to take care of my mother. I took myself out of my familiar

Valuing

Even though her mother has changed, she values the experience of caregiving because it brought them closer together.

Choosing

Chose to be a caregiver and to relocate to do so.

Moving

Most activity directed to relocation rather than caregiving.

surroundings--job, home, family, church, all of those things that you're familiar with--took myself 200 miles away to take care of my mother.

It was a very stressful situation since I had to put myself into a totally new community where I didn't know anyone and didn't know people very well except that I remembered as a child.

It has not been difficult to take care of my mother since she is a very appreciative person and she seems to understand what is happening to her.

It has been difficult, as I said, taking myself out of my totally familiar surroundings and putting myself into a totally strange one, but on the other hand I have tried to make it a learning experience. I have now become a farmer and a caregiver.

Perceiving

It has not been difficult to take care of my mother since she is a very appreciative person and she seems to understand what is happening to her. She realizes her difficulty in remembering and understanding and these sorts of things.

But I will never regret it because it brought my mother and me closer together than we had ever been in our whole lives as far as I was concerned. I will always remember it for that reason.

It has been difficult, as I said, taking myself out of my totally familiar surroundings

Perceiving

Perceives caregiving is meaningful because it is a learning experience and it brought her & her mother closer together. Also perceives relocation as difficult.

and putting myself into a totally strange one, but on the other hand I have tried to make it learning experience.

Feeling

It was a very stressful situation since I had to put myself into a totally new community where I didn't know anyone and didn't know people very well except that I remembered as a child.

It is in turn difficult for me because remembering what my mother was like and what she is now is a very difficult transition.

Knowing

It was a very stressful situation since I had to put myself into a totally new community where I didn't know anyone and didn't know people very well except that I remembered as a child.

She (mother) realizes her difficulty in remembering and understanding and these sorts of things.

It has been difficult, as I said, taking myself out of my totally familiar surroundings and putting myself into a totally strange one, but on the other hand I have tried to make it a learning experience.

I have tried to do the teaching part, which was my profession, and tried to teach others about what it's like to be a caregiver. I've tried to help them to find places and people and things that would be helpful to them in caregiving. I've tried to use my teaching abilities in that way.

Feeling

Feeling stress and grief.

Knowing

Knows about resources available in caregiving. Knows teaching skills. Knows her mother still has insight.

Dimension	Dimension Description	Characteristic Synthesis Statement
Exchanging	Mutuality apparent in that she is giving care and receiving from Mother - feeling "closer to her than ever before."	Interaction: Mutuality in relationship with Mother. Connecting with others through her farming & teaching. Blocked connections with previous job, family, church, & home.
Communicating	Receiving messages about how to care & sharing message with other caregivers - "teaching others about caregiving.	
Relating	Connecting by caregiving, farming, teaching. Blocked connections to previous family church, home, & job.	
Valuing	Even though her mother has changed, she values the caregiving because it brought them closer together.	Action: Activity focused on relocation and roles other than caregiving. Values looseness in relationship with Mother as a result of caregiving.
Choosing	Chose to be a caregiver and to relocate to do so.	
Moving	Most activity focused on relocation rather than caregiving.	
Perceiving	Perceives caregiving is meaningful because it is a learning experience & it brought her and her mother closer together than we have ever been. Perceives relocation as difficult.	Awareness: Finds meaning in caregiving. Acknowledges stress in moving and adjusting to changes in her mother.
Feeling	Feeling stress and grief.	
Knowing	Knows about resources helpful in caregiving. Knows teaching skills. Knows her mother still has insight.	
<p>JENNY'S PATTERN DESCRIPTION: Jenny's activity is focused on relocating from previous job, family, home, and church and connecting with others in new roles as caregiver, farmer, and teacher in her new community. Energized by the closeness of the caregiving relationship and by teaching others about caregiving. No specific description of caring for herself.</p>		

Figure 4. Jenny's pattern of person-environment interaction as displayed on the NUDIST document memo.

Appendix B

Criterion for Rigor in Qualitative Methods:

Auditability Evaluator Form

Criterion for Rigor in Qualitative Methods
Sandelowski, 1986

Concern: Consistency - Another researcher can clearly follow the "decision trail" and could arrive at the same or comparable but not contradictory conclusions given the researcher's data, perspective, and situation.

What are the patterns of person-environment interaction of rural daughter/daughter-in-law caregivers that are revealed from their descriptions of caring for their parents with ADRD?

- a. Identify individual patterns of person-environment interaction in the subject group.
- b. Identify the common groupings of patterns among all the individual patterns of person-environment interaction within the subject group.

Peer Evaluation for Auditability for -----'s Interview

Instructions to evaluator: Review the computer print out with the coding of key phrases/paragraphs according to dimension nodes. On the form below, document whether you agree or disagree with the coding as well as any comments regarding your decision.

1. Exchanging: Peer Auditor's Evaluation Comments:

2. Communicating: Peer Auditor's Evaluation Comments:

3. Relating: Peer Auditor's Evaluation Comments:

4. Valuing: Peer Auditor's Evaluation Comments:

5. Choosing: Peer Auditor's Evaluation Comments:

6. Moving: Peer Auditor's Evaluation Comments:

7. Perceiving: Peer Auditor's Evaluation Comments:

8. Feeling: Peer Auditor's Evaluation Comments:

9. Knowing: Peer Auditor's Evaluation Comments:

Peer Evaluation for Auditability for _____'s Interview

Instructions to evaluator: Review the computer print out of each dimension description statement, each characteristic synthesis statement, and the caregiver's pattern description. On the form below, document whether you agree or disagree with the synthesis statements as well as any comments regarding your decision.

1. Peer evaluator's comments regarding the following synthesis statements:

Exchanging:

Communicating:

Relating:

Interaction Synthesis Statement/s:

2. Peer evaluator's comments regarding the following synthesis statements:

Valuing:

Choosing:

Moving:

Action Synthesis Statement/s:

3. Peer evaluator's comments regarding the following synthesis statements:

Perceiving:

Feeling:

Knowing:

Awareness Synthesis Statement/s:

4. Peer evaluator's comments regarding the following synthesis statements:

PATTERN DESCRIPTION:

Peer Evaluation for Auditability for -----'s Interview

Instructions to evaluator: Review the pattern description for the caregiver. On the form below, document which common pattern grouping is consistent with this caregiver's pattern description and any comments regarding your decision.

1. Daughter cares independently with no evidence that she cares for herself:

2. Daughter cares for her parent in combination with other relationships with no evidence that she cares for herself:

3. Daughter cares for her parent in combination with other relationships and there is evidence that she also cares for herself:

Instructions to evaluator: On the form below, document whether you could arrive at the same or comparable conclusions as the researcher or whether you arrived at conclusions contradictory to the researcher.

1. Could arrive at same or comparable conclusions:

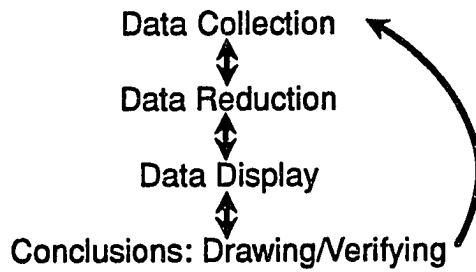
2. Arrived at contradictory conclusions:

Appendix C

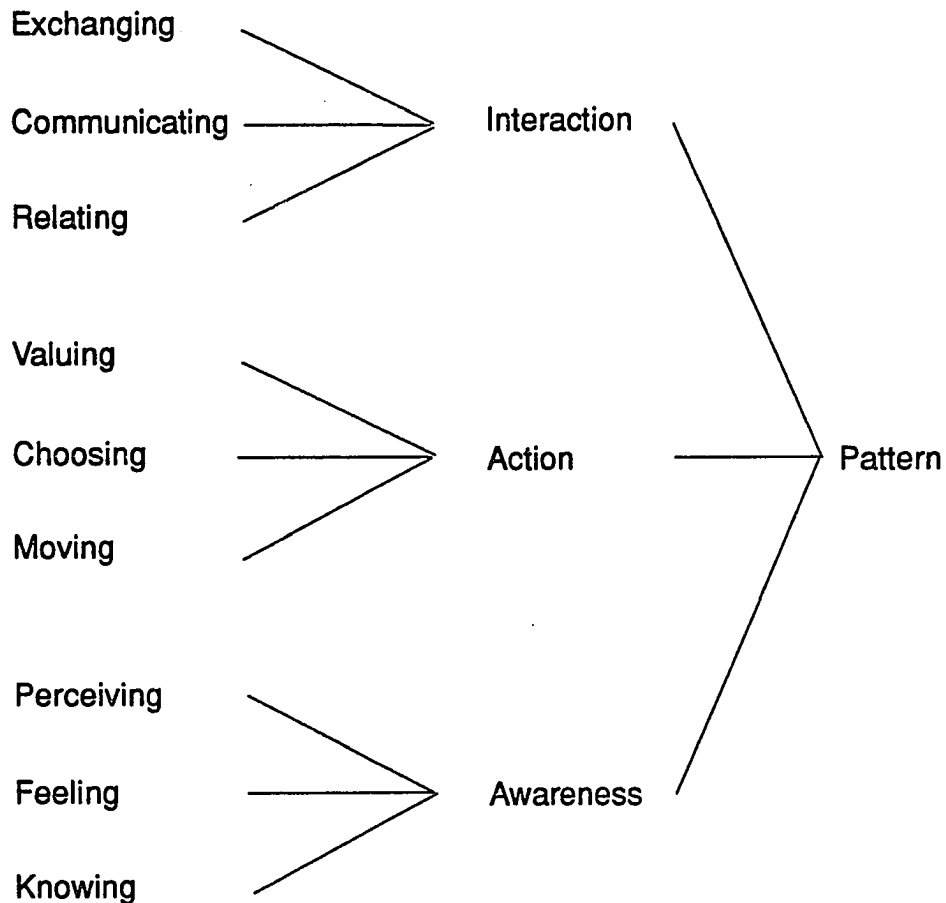
Criterion for Rigor in Qualitative Methods: Fittingness

Evaluator Forms

Analysis
Content analysis per Miles & Huberman (1994)



Conceptual Framework



Criterion for Rigor in Qualitative Methods
Sandelowski, 1986

Criterion: Fittingness - Findings of the study fit into contexts outside the situation because the audience views findings as meaningful from their own experience.

Instructions to the evaluator: In secondary analysis of data, when the researcher is not able to go back to the subjects, clinical experts may be called upon to evaluate the study according to the criterion of fittingness. Please review the introductory chapter, the methodology chapter, and the report of findings chapter. Do the findings of the study have meaningful implications for practice as you have experienced practice in relation to caregivers of persons with ADRD?

1. Do the individual caregiver patterns have implications for practice?

2. Do the groupings of patterns have implications for practice?
 - (a) Interconnected caregiver patterns of person-environment interaction?

 - (b) Connected patterns of person-environment interaction?

 - (c) Interconnected patterns of person-environment interaction?

Appendix D

Criterion for Rigor in Qualitative Methods: Credibility

Evaluator Forms

Criterion for Rigor in Qualitative Methods
Sandelowski, 1986

Criterion: Credibility: - Credibility was defined as verification of individual patterns by the person from whom the data was collected (Sandelowski, 1986). Credibility is comparable to internal validity in quantitative research.

Instructions to the evaluator: The traditional method of achieving credibility in a qualitative study is to go back to the subjects themselves for verification of patterns. Thorne (1994) suggests that in the case of secondary analysis, a researcher from the original study may testify to the credibility of the findings. A nurse researcher from the original study who collected caregiver interviews at another site is asked to review the method and report of the findings chapters.

Document on the form below if these patterns are recognizable in your interviews:

- a. Connected patterns of person-environment interaction?

- b. Unconnected patterns of person-environment interaction?

- c. Interconnected patterns of person-environment interaction.

Appendix E
Individual Patterns of Person-Environment Interaction
for the
Daughter/Daughter-in-law Caregivers
as they
Appear on the NUDIST Document Memo

Barbara's Pattern of Person-Environment Interaction

Dimension	Dimension Description	Characteristic Synthesis Statement
Exchanging	Receiving by having her mother live with her while she is giving in the form of caretaking (It's neat having her here. I've been planning & plotting for this day for years.	Interaction: Connecting with husband and siblings within the context of caregiving. Mutuality apparent in the daughter/mother relationship.
Communicating	Communicating with her mother in ways that help her mother live positively with the cognitive impairment ("Everything we take pictures of so we can talk about it with her"). e.g. Myron's death.	
Relating	Integrates caring for her mother with other relationships with her husband & siblings.	
Valuing	Values what mother values as positive & focuses on that in caretaking ("And yet she's mentally aware now; she knows this is happening. So we focus on the more positive & move on to something else").	Action: Expending energy by choosing to care for mother by understanding the illness as well as mother's values. No recreational or self care activities outside of caregiving described.
Choosing	Choosing to be her mother's primary caregiver & to care for her as well as to help others care for in in a positive way ("We hired a 12 hour companion before she moved in with me. We helped them, we counseled them, to reduce the stimulation around her").	
Moving	Activities focus on understanding & acting through the lens of cognitive impairment. No recreational or self care activities outside of caregiving.	
Perceiving	Trying to perceive world through Mother's lens of cognitive deterioration so she can care for her in supportive ways.	Awareness: Aware of her positive & negative feelings towards her mother's actions & relates to her mother with the understanding of cognitive deterioration. Unaware of need to take care of herself.
Feeling	Acknowledging negative and positive feelings about caring for her mother ("It's great to do things that give her pleasure & hell when she's not going to remember").	
Knowing	Knows mother's way of being at this point in time is a result of cognitive impairment.	

BARBARA'S PATTERN OF PERSON-ENVIRONMENT INTERACTION: Expending energy caring for her mother but energized by a caregiving relationship she values. Relating, recreating, socializing in the context of caregiving. Perceives her mother's reactions as related to the illness, & bases her caregiving on this knowledge such as helping her remember Myron's death. No evidence of self care.

Bernie's Pattern of Person-Environment Interaction

Dimension	Dimension Description	Characteristic Synthesis Statement
Exchanging	Experiencing mutual adjustments for both she and Mother in relation to her mother's move.	Interaction: Experiencing mutuality in adjustment. No relationship described except the caregiver/care recipient relationship.
Communicating	Receiving messages from her mother that she is blaming her for the move.	
Relating	Learning to relate with mother now that she has dementia and is living with her.	
Valuing	Values that eventually Mother feels happy and comfortable with her.	Action: Action focuses on having Mother happy and comfortable in her new home.
Choosing	Chose to mover her mother from Montana to be with her.	
Moving	Directing her activity to adjusting to living with her mother.	
Perceiving	Perceives that Mother misses her previous friends and home and blames her for the move.	Awareness: Aware of her mother's feelings of loss & blame & of her own feelings that there are good & bad days.
Feeling	Feels there are good & bad days.	
Knowing	Knows that her mother understands the reason for the move and that her life would have changed even if she hadn't moved.	

BERNIE'S PATTERN OF PERSON-ENVIRONMENT INTERACTION: Experiencing give and take with Mother which is sometimes good and sometimes difficult. Activity directed toward adjusting to the caregiving relationship and making her mother happy and comfortable.. No other activities or relationships articulated or how she cares for her mother and herself in relation to the difficult days.

Chip's Pattern of Person-Environment Interaction

Dimension	Dimension Description	Characteristic Synthesis Statement
Exchanging	Giving by caregiving but receiving by (1) "learning things about her son & his family & her that I would have never known", (2) joy of seeing "our son who is 17 has been marvelous - he's very responsive to helping her", (3) feeling hopeful that "my son may someday take care of me in this way".	Interaction: Mutuality in her caregiving because she is receiving pay back in the form of help from family and knowledge of family history from care recipient. Is also caring for her husband.
Communicating	Communicating with her family ("I felt at it was all on my shoulders, it took some discussing & we worked through it very well"). Hears her mother-in-law in that "she still does not feel this is her home".	
Relating	She is caring for her mother-in-law, her son, & her husband. "Our family being blended was the hardest part". Caring for her mother-in-law in addition to her husband who "is also blind, which means he needs extra care".	
Valuing	Values are: (1) "time goes on, you must move forward", (2) knowledge of family history, (3) participation of children in care of their grandparents.	Action: Activity directed toward moving forward as a primary caregiver with a lack of training. Does take time off from caregiving.
Choosing	Choosing to (1) "move her (mother-in-law) in & adjusting to what her lifestyle was compared to ours", (2) communicate with other family members about caretaking, & (3) "take some time off".	
Moving	Activity focuses on "learning face to face with no training".	
Perceiving	Perceiving is full of change for the family but the family has worked through it well.	Awareness: Aware (1) of caregiving as both a burden & a joy, (2) caregiving without training is more difficult & frustrating, & (3) of the need for taking time off.
Feeling	"Sometimes I feel it's a burden, sometimes I feel frustrated, sometimes I feel it's a blessing".	
Knowing	Does not "know how to handle situations" & how to "make her feel like this is her home". Does know with the help of her husband to "take some time off".	

CHIP'S PATTERN OF PERSON-ENVIRONMENT INTERACTION: Focusing on the joy & frustrations of caring for her mother-in-law as a blended member of her family. Family is participating. Chip is also caring for her husband & son. Feeling lack of training is cause of her frustration & does take time off.

Cynthia's Pattern of Person-Environment Interaction

Dimension	Dimension Description	Characteristic Synthesis Statement
Exchanging	Giving care to Mother & receiving help from family, friend, & neighbors.	Interaction: Uses her familial & social network in her role as caregiver. Interacts with family & friends outside of her caregiving role.
Communicating	Communicates needs ("I just called the neighbor & they came over").	
Relating	Including others in the caregiving role ("The kids are really good about helping. I have a friend who keeps Mother on Wednesdays"). Socializing with friends & family during respite time ("I go & have coffee with the girls and I have lunch with my daughter").	
Valuing	Considers day care "expensive."	Action: Expending energy in her caregiving role but balancing with other activities for her own enjoyment.
Choosing	Chooses to take advantage of respite care through day care, family, & friends. Chooses to call neighbors when she needs help.	
Moving	Activity directed toward intensive caregiving.	
Perceiving	Perceives caregiving situation as "Not too bad". Perceives that her friend "enjoys her mother". Perceives mother "is not remembering".	Awareness: Knows how to care for her mother & is comfortable helping her mother live with it.
Feeling	Feels "it's not too bad for me".	
Knowing	Understands how to protect her mother, care for her physical needs, & how to provide for her special needs.	

CYNTHIE'S PATTERN OF PERSON-ENVIRONMENT INTERACTION: Including her neighbor, family, friends, and community day care resource in the caregiving experience. Values taking time for herself. Knows how to care for her mother and is comfortable helping her mother live with the illness.

Denise's Pattern of Person-Environment Interaction

Dimension	Dimension Description	Characteristic Synthesis Statement
Exchanging	Giving as a caregiver but also receiving from mother ("we laugh together, we play games together, we visit people").	Interaction: Mutuality in relationship with mother. Connecting with others in the environment with her mother.
Communicating Relating	Able to communicate with mother. Connecting with others when she and her mother visit others together.	
Valuing	Values mother now & how she was prior to illness ("she has been a very caring mother to our family" and "For a lady who is 90 years old, I think she is quite remarkable")	Action: Minimal energy to care for mother & she values mother as she was & as she is now. No description of self care.
Choosing	Chooses to care for mother because of the illness ("Her ability to reason & think normally are diminishing, & she lives with me now because of this").	
Moving	Minimal increase in energy due to mild impairment at this stage ("She is not demanding & pretty much cares for herself").	
Perceiving	Perceives that mother trusts her to caretaker as she experiences this illness ("She knows that her memory is failing, but I feel that she trusts me to care for her so far").	Awareness: Aware of that illness is mild and Mother trusts her & enjoys her company. No awareness of caring for herself or Mother in progressive stages of illness.
Feeling	Feels comfortable with her mother's status so far (For a lady who is 90 years old, I think she is quite remarkable").	
Knowing	Knows problems inherent in this stage of the illness. No reference to upcoming stages ("I do cook the meals because I don't want her to hurt herself on the stove").	

DENISE'S PATTERN OF PERSON-ENVIRONMENT INTERACTION: Activity focused on caregiving in a mutual relationship with Mother which includes other people. Values Mother as she was and is now. No awareness of how to care for herself or Mother in progressive stages of the illness.

Joan's Pattern of Person-Environment Interaction

Dimension	Dimension Description	Characteristic Synthesis Statement
Exchanging	Exchanging full time caregiving for having her mother remain at home & function at a higher level ("If we took her out of her home I think she would be completely lost").	Interaction: Describes connecting with husband & bible study in relation to caregiving. Receiving benefit by having her mother remain at home. The connection with her brothers is blocked.
Communicating	Communicating with mother by "bantering back & forth".	
Relating	Relating to mother as full time caregiver with participation of her husband. Is not including brothers. No mention of any other participants or other relating or socializing activities outside of caregiving.	
Valuing	Values caring for her mother so she can stay in her own home, taking time to provide meaningful activities for her mother ("We try to take her out once a day - and then she is better"), but does not value her brothers' abilities to help in the caregiving ("I have 2 brothers, but boys are not the ones to do anything").	Action: Activity directed toward intensive caregiving which she values for the benefits her mother is receiving by staying at home.
Choosing	Choosing to provide extensive care to mother without the help of her brothers so so her mother may stay in her own home, & to include her husband in the caretaking ("My husband & I take care of the yard").	
Moving	Description of activity focuses on caregiving tasks which are numerous. No mention self care of the caregiver.	
Perceiving	Perceives that she is the only person to help, maintaining her mother's routine helps her to function at a higher level, & her mother is experiencing "depression" because of her losses.	Awareness: Aware of important strategies for caring for cognitive impairment. No awareness of how to care for herself and her mother in relation to the stresses experienced in their relationship.
Feeling	Feels "angry" when her mother is depressed and tells her to go home.	
Knowing	Knows what this illness means to her mom, how being in her own home & keeping her routines help, & her patterns of interacting with her mom.	

JOAN'S PATTERN OF PERSON-ENVIRONMENT INTERACTION: Receiving benefit if Mother remains at home. Describes connecting to her husband & bible study friends in the context of caregiving. Blocked connections with brothers. No description of caring for herself in light of the stresses in her relationship with her mother.

Julie's Pattern of Person-Environment Interaction

Dimension	Dimension Description	Characteristic Synthesis Statement
Exchanging	Giving care to her mother because "she wants to receive the same care". Decrease in energy due to health problems.	Interaction: Caregiving relationship is primary relationship. describes one sister as having mother come for a visit.
Communicating	Communicates her wishes to her mother but understands when she doesn't remember them ("everything that happens, it's because she forgets")	
Relating	She is connected through her sister who has her mother come for a visit.	
Valuing	Believes it is a "duty" to care for her mother & that one "should treat others the way they would like to be treated".	Action: Expending energy on a caregiving relationship which she values. Has difficulty only when she doesn't get her rest. No self care noted.
Choosing	Choosing to care for her mother because it's a duty & she doesn't have energy for other relationships.	
Moving	Spending more & more energy on caregiving. Does need rest periods. No form of recreation described.	
Perceiving	Perceives her mother is "improved" & it's "not bad at all".	Awareness: Aware that mother's behavior is a result of the illness & that she needs to get enough rest. Is not making other arrangements for rest when her mother is awakening her constantly.
Feeling	Feels sympathy for her mother because she has health problems herself. Feels caregiving is a problem only when she doesn't get enough rest. Feels upset when she sees others abuse their parents.	
Knowing	Understands mother acts as she does because of the illness. Reading about the illness so she can understand the behavior ("I have been reading the literature & I really appreciate that chapter on bathing").	

JULIE'S PATTERN OF PERSON-ENVIRONMENT INTERACTION: Experiencing vicarious mutuality in the relationship with mother. Has a decrease in energy due to health problems and chooses to expend that energy on caregiving. Feels caregiving is not so bad if she gets her rest but not making other arrangements when her mother doesn't let her rest. connected with one sister who Mother visits.

Kathrin's Pattern of Person-Environment Interaction

Dimension	Dimension Description	Characteristic Synthesis Statement
Exchanging	Giving care & receiving benefit because "I'm dealing with one of the most precious people in my life.	Interaction: Experiencing mutuality in the caregiving relationship. Is connecting with guests, neighbors family, and guests within the context of caregiving.
Communicating	Is sending & receiving messages: ("Mother what are the tears about?" She says I just can't remember. I say, you're feeling bad aren't you? And she says "Well sure, wouldn't you?").	
Relating	Describes relationships with friends, neighbors only within the context of the caregiving relationship.	
Valuing	Values her mother as a person & her mother's need to useful in her role in the family ("The dishes aren't clean but if it's just a little it can't hurt. I'm dealing with one of the most precious people in my life. If I drink a little poison, so to speak, so that her feelings aren't hurt, I'll survive.	Action: Values her mother's self worth & is choosing to direct her own energy to provide an environment that allows her mother to maintain her roles. No activity directed toward self care.
Choosing	Choosing to provide an environment for her mother that allows her to use her remaining skills.	
Moving	Directing her own activity to provide an environment that allows for her mother's cognitive disabilities but provides for activities that maintain her mother's self esteem. No activity directed toward self care.	
Perceiving	Sees meaning in her mother's behavior as it relates to her former patterns & how she is now with cognitive deterioration.	Awareness: Acknowledges her own grief. Synthesizing information about the illness with her mother's own pattern so as to facilitate her mother's sense of self worth.
Feeling	Acknowledges her own grief in seeing her mother deal with the illness (The grief of this situation is that she perceives that she cannot remember").	
Knowing	Understands her mother's behavior through the lens of cognitive impairment ("She's not capable of seeing the bathroom needs cleaning & just doing it").	

KATHRIN'S PATTERN OF PERSON-ENVIRONMENT INTERACTION:

Experiencing mutuality in the caregiver/care recipient relationship. Facilitation mother's self worth through understanding of cognitive impairment. Interacts with neighbors, guests, and family in relation to the caregiving role. No description of how she cares for herself.

Kathy's Pattern of Person-Environment Interaction

Dimension	Dimension Description	Characteristic Synthesis Statement
Exchanging	Realizing benefits in caring for father in that when medical status is "in control" father help mother & everything "clicks along".	Interaction: Kathy, her brother & his wife are participating in caring for their father by managing his medical needs. In return, the mother & father are living in their own home.
Communicating	Communicating to father (1) he has to take care of his wife & (2) when he has to take his medication.	
Relating	Connecting to her father, brother, & sister-in-law within the context of caregiving.	
Valuing	Values looking after father because both because both parents may stay at home.	Action: Action focuses on participatory caregiving in relation to medical needs of care recipient so that he is able to be a partial caregiver for his wife.
Choosing	Choosing to participate with brother & his wife to help father keep his diabetes & heart problems under control.	
Moving	Activity focuses on father's medical needs. Description does not include rest or recreation for the caregiver.	
Perceiving	Perceives that father needs them to take the responsibility for keeping his diabetes & heart problems under control which then has allowed him to live with his wife & help care for her ("it is like he has forgotten he has to take these (insulin) for the rest of his life" & "yes he is taking care of my mother")	Awareness: Aware only of care recipient's medical needs. No mention of how cognitive deterioration will affect the ability to "click along".
Feeling	Feeling concerned before diagnosis of cognitive impairment. Now feeling he is doing better physically as a result of the caregiving.	
Knowing	Knows how father is doing in relation to diabetes and cardiac status. Knows that keeping those under control by caregiving is helping things "click along". otherwise things "fall apart".	

KATHY'S PATTERN OF PERSON-ENVIRONMENT INTERACTION: Participatory caregiving with brother and sister-in-law focusing on father's medical needs which has resulted in the benefit of having father live at home and to help mother. No mention of other relationships outside of caregiving and what will happen as father's cognitive abilities deteriorate. No description of her own awareness of how to care for herself.

Margret's Pattern of Person-Environment Interaction

Dimension	Dimension Description	Characteristic Synthesis Statement
Exchanging	Receiving help from her sister ("My sister came every day because it took the two of us to stand her up").	Interaction: No mutuality in interactions with mother. Does receive caretaking help from her sister.
Communicating	Receiving message from mother that she gets upset when left alone ("then she gets upset because she's alone in the evening while I do the dishes").	
Relating	Describes relationships only as they relate to caregiving for her mother.	
Valuing	Values good physical care for her mother ("We used to exercise every day - 20 minutes in the morning & 20 minutes in the afternoon, but since she's been walking more we don't exercise that much").	Action: Action directed totally physical activities of caregiving. No other activities related to self care described.
Choosing	Choosing to provide good physical care for her mother with little outside help.	
Moving	Directing activity totally to caregiving. No mention of recreation/socialization of her own.	
Perceiving	Perceives her mother is upset when she is left alone.	Awareness: Aware of mother's physical needs & feels "days roll along" as she provides for those needs. No awareness of self care needs.
Feeling	Feels that day "rolls along".	
Knowing	Understands how to provide physical care.	

MARGRET'S PATTERN OF PERSON-ENVIRONMENT INTERACTION: Very much alone except for the help of her sister in provision of intensive physical care with no mention of caring for herself.

Mary's Pattern of Person-Environment Interaction

Dimension	Dimension Description	Characteristic Synthesis Statement
Exchanging	Experiencing a sense of "receiving" from her "mother-in-law ("some days I really feel she wants to open up some feelings for me" and "it is a delight to have her ... we were without grandparents in our area for about 25 years..it is delightful for our children.	Interaction: There is mutuality in the caregiver/care recipient relationship. She is relating to her mother-in-law, aunt, husband, & children within the context of caregiving.
Communicating	Difficulty communicating with her mother-in-law ("it is almost impossible to get her to communicate verbally").	
Relating	Relating to both mother-in-law & her aunt as a caregiver. Trying to relate with mother-in-law in relation to her pre illness pattern ("my mother-in-law used manipulatory sense throughout her lifetime & are still apparent in relationship to my husband & myself caretaking for her.	
Valuing	Values (1) having her mother-in-law close by, (2) having her mother-in-law just "enjoy life & not doing anything", & sharing her time with both care recipients ("I tell her: there is her son, myself, my aunt, and her & whatever time I have I spend with both of them").	Action: Description focuses only on caregiving activities & the value she places on caregiving.
Choosing	Choosing (1) to take care of her mother-in-law, (2) to understand purpose behind her communication, & (3) to share her time with two care recipients.	
Moving	Activity directed toward caregiving for two. No description of activities of self care.	
Perceiving	Perceiving that her caretaking has resulted in a decrease in problem behaviors.	Awareness: Aware that behaviors are a result of the interaction of the illness with previous patterns of behavior & this is helping her cope. No awareness of self care.
Feeling	Feels the demands care recipient puts on her.	
Knowing	Knowing that behaviors are a result of the illness help her to cope ("I feel she doesn't have provision for understanding so I kind of use that to help me cope").	

MARY'S PATTERN OF PERSON-ENVIRONMENT INTERACTION: Focusing on caregiving with description of some mutuality in the relationship with her mother-in-law. Connecting with husband, aunt, mother-in-law, & children within the context of caregiving. Aware that the behavior of her mother-in-law is related to the cognitive impairment with no description of her awareness of how to care for herself.

Patsy's Pattern of Person-Environment Interaction

Dimension	Dimension Description	Characteristic Synthesis Statement
Exchanging	Giving as a caregiver & receiving from (1) physician: "he wrote it on a prescription pad that she can't drive - she wouldn't have quit driving if any of her children had told her", & (2) social services: "social services sent a list of residential facilities, I've called a lot of them".	Interaction: Descriptions of interactions focused entirely on caring for her mother. She is receiving help from health care providers.
Communicating	Communicating with the health care team. Communicating to mother that "I'd like to have you live in situation where you have friends around you".	
Relating	Relating to Mother as her caretaker while acknowledging that Mother "is very independent & has had to be the person in the family who took care of everything."	
Valuing	Values input from the health care team. Values having her mother live in a place where she can be socially active.	Action: Activity focused on planning for her mother's care. No mention of activities related to caring for herself.
Choosing	Choosing to participate in all aspects of the planning of care for her mother.	
Moving	Focusing caretaking activity on planning for her mother's (1) living arrangements, (2) social activities, & (3) safety.	
Perceiving	Perceives Mother (1) needs independence, (2) is afraid of some situations because of her cognitive impairment ("I think she would find the bus system confusing"), & (3) is not insightful about all of her cognitive losses ("she thinks she's going to get her drivers license back").	Awareness: Aware of mother's pattern of independence. Plans for caregiving do not include how to allow her mother to feel independent.
Feeling	Feeling comfortable with Mother not driving.	
Knowing	Knows Mother's patterns. Does not know extent of disability at this point ("when we get a final summary of all the tests it will help us").	

PATSY'S PATTERN OF PERSON ENVIRONMENT INTERACTION: Receiving help from the health care team with no description of mutuality in the caregiver/care recipient relationship or connection to others in her environment. Activity directed toward planning for caregiving with lack of awareness of mother's need for an environment that allows feeling of independence while still confronting the effects of cognitive impairment. No mention of how it has affected her, other relationships other in her life, or how she cares for herself.

Peggy's Pattern of Person-Environment Interaction

Dimension	Dimension Description	Characteristic Synthesis Statement
Exchanging Communicating Relating	No data indexed for this dimension. No data indexed for this dimension. Relating to her mother as a care recipient who makes her life "uncertain" and therefore difficult.	Interaction: Experiencing uncertainty due to the caregiving relationship. No other relationships described.
Valuing Choosing Moving	Values being able to work without interruptions & complete tasks. The days are so uncertain; she is not able to make meaningful choices. Constant vigilance & watching takes more energy because daily uncertainty of what to expect in the caregiving situation.	Action: Values an uninterrupted work schedule. Caregiving involves constant interruptions & therefore more energy expenditure.
Perceiving Feeling Knowing	Perceives that it's hard to plan. without interruptions. Feels that caring for her mother is difficult. Knows that nature of the illness makes her life as a caregiver uncertain and difficult.	Awareness: Aware that the nature of the illness makes life more uncertain & more difficult.

PEGGY'S PATTERN OF PERSON-ENVIRONMENT INTERACTION: No pattern of communication or mutuality described. Focusing on how the caregiving experience is a major loss of certainty resulting in an increase in expenditure of energy. No other relationships described or how she cares for herself in relation to this uncertainty.

Sharie's Pattern of Person-Environment Interaction

Dimension	Dimension Description	Characteristic Synthesis Statement
Exchanging	Giving in the form of caretaking and receiving by (1) having her mother remain with her ("They said I couldn't take care of her at home. My doctor said if I want to try it, he'd help all he could), (2) seeing her mother enjoy activities such as "eating & playing with the cat", (3) accepting help from the "health care team, grandkids, & her friend".	Interaction: Interacting as a caregiver with help from friends, family, cat & health care team. Maintains her role of postal worker with the help of her friend.
Communicating	Verbal communication with her mother is difficult ("she knows there's a connection (between us) but sometimes she call me Mama or Grandma). Trying to pick up nonverbal cues ("One day she wouldn't respond to me - I called the doc	
Relating	Describing relationships with her cat, grandchildren, doctors, nurses & her friend in the context of caregiving. Is a postal worker.	
Valuing	Values caring for her mother at home & her mother's enjoyment & respite is expensive. ("Mom will hang on to that cat so tight - animal therapy works; and She can feed herself - it's not real pleasant - but I just let her go on - she just loves to eat!"). Values help of the health care team ("I can't load mother into the car myself so the doctor will stop up - the nurse came out to give us our flu shots"); her friends help while she works, and her grandkids mowing the yard.	Action: Intensive caregiving with time out for naps. Allowing others to help her in the caretaking.
Choosing	Choosing to rest ("I make myself quit whatever I'm doing and lie down"). Chooses not to use respite care at night ("It's costly"). Chooses to use help of those around her to keep her mother at home.	
Moving	Using much energy to care for her mother but finding time to rest. No description of recreation for herself.	
Perceiving	Perceives that (1) her mother's condition "bothers granddaughters" & her mother misses her son-in-law who is dead.	Awareness: Aware that caring for her mother limits what she can do but feels that everything has always worked out.
Feeling	Feels (1) "our nights are no good", (2) "it's frustrating - there are so many things I'd like to get done", & (3) "in the 2 years time, I can't think of any time we haven't been able to work things out".	
Knowing	Understands what works, when Mother's reactions are unusual, can't predict good or bad nights.	

SHARIE'S PATTERN OF PERSON-ENVIRONMENT INTERACTION: Working in partnership with the health team, her friend, & her grandkids to keep her mother at home & to keep her job as a postal worker. Providing intensive caretaking especially at night. Taking time to rest.

Susie's Pattern of Person-Environment Interaction

Dimension	Synthesis Statement	Characteristic Synthesis Statement
Exchanging Communicating	No data indexed for this dimension. Hearing Father's confusion in his communication.	Interaction: Focusing on caregiving with no evidence of mutuality in the relationship or description of other relationships.
Relating	Relating to Father as an intensive caregiver.	
Valuing	Values humor in the situation & ability to rest.	Action: Focusing on keeping her father safe resulting in intensive caregiving activity.
Choosing	Choosing to care for her father at home, though it is difficult & time-consuming.	
Moving	Activity focused on keeping her father safe resulting in exhaustion for the caregiver.	
Perceiving	At first perceiving that Father's behavioral problems could be ameliorated with the physician's help but now perceiving that her interventions are effective.	Awareness: Aware that her caregiving activities are resulting in a more tolerable situation. No evidence of her awareness of what she needs to do for herself to maintain her ability to give such intensive care. Aware physicians' interventions aren't helpful.
Feeling	Feeling (1) exhausted, (2) nerve-wracked, (3) frustrated because of the energy required as well as not knowing what to do. Able to appreciate the humor in the situation.	
Knowing	Progressing from not knowing how to handle behavioral problems to finding some strategies which are helping her to cope more effectively because the behavior makes sense in the context of the illness. No evidence of knowing how to integrate caring for herself with the caregiving.	

SUSIE'S PATTERN OF PERSON-ENVIRONMENT INTERACTION: Intensive one-sided expenditure of energy in caring for her father with no helpful interventions from physicians. No description of mutuality in other relationships in her life, or awareness of how she might care for herself. Is aware her own interventions are effective.

Appendix F

Initial and Revised Definitions of the Nine Dimensions of Person-Environment

Interaction

During data analysis the initial definitions for the nine dimensions were revised in the context of daughter/daughter-in-law caregiving. The initial definitions and the revised definitions are presented below:

Dimension	Initial Definition	Revised Definition
Exchanging	Interchange of matter and energy between humans and environment; mutual giving and receiving.	Mutual giving and receiving.
Communicating	Interchange of information between humans and environment; the sending of messages.	The sending and/or receiving of messages.
Relating	Connecting with other persons or objects; establishing bonds.	Same.
Valuing	The assigning of relative worth.	The assigning of relative worth to people, imperatives, and predictability of circumstances.
Choosing	The selecting of one or more alternatives.	The implicit selecting of one or more alternatives.
Moving	Activity within the environment.	Same.
Perceiving	The receiving of information.	The receiving and interpreting of information.
Feeling	Quality of sensation and mood; subjective awareness of information.	Same
Knowing	Meaning associated with a world view or with information.	Personal recognizing of self and world.