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Alzheimer's disease: Perceptions of husband caregivers

Doran, Florence Louise Wright, M.S.N.

The University of Arizona, 1992

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**ALZHEIMER'S DISEASE:
PERCEPTIONS OF HUSBAND CAREGIVERS**

by
Florence Louise Wright Doran

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A Thesis Submitted to the Faculty of the
COLLEGE OF NURSING
In Partial Fulfillment of the Requirements
For the Degree of
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In the Graduate College
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ABSTRACT

This exploratory study was designed to describe, analyze and understand from the perspective of a primary caregiver husband, what it is like to care for a wife with middle stage Alzheimer's Disease. Using the ethnographic approach, three spouses with wives suffering from Alzheimer's Disease were interviewed and two spouses were observed in their home during one dinnertime period. Analysis of data yielded five domains of meaning: lifestyle change concerns, helplessness/powerlessness, care for own, concerns for future and coping. Two cultural themes emerged as "alone" and "hopeless."

Implications for nursing practice include increasing the awareness and understanding among health care professionals of the desperate nature of the caregiver's burden. Additionally, the caregiver's coping skills need to be maintained and enhanced as they "care for their own" and attempt to keep themselves mentally and physically healthy.

CHAPTER 1

INTRODUCTION

Health care and the aging population is a major national public health issue since most older people have at least one chronic illness and many have multiple chronic conditions (Dimond, 1989). One such chronic condition is Alzheimer's Disease (AD) which was first identified by a German neurologist, Alois Alzheimer, in 1907. The cause and cure of this devastating disease are unknown (Wilson, 1990); however, current research is attempting to explore several hypothesized causes: (1) genetic predisposition; (2) biochemical abnormalities in the brain; (3) plaques and tangles in the brain which may impede the flow of oxygen; (4) decreased levels of oxygen resulting from sleep apnea; and (5) additional causes may include environmental toxins, infectious agents, dietary habits and immune system defects. With so many possible causes, the condition may be different diseases but with similar symptoms (Kuhlman, Wilson, Hutchinson & Wallhagen, 1991)

A positive diagnosis of the disease can only be made after death upon autopsy of the brain. To help standardize the diagnosis of Alzheimer's Disease, the U.S. Department of Health and Human Services, has established the following clinical criteria for probable diagnosis: progressive memory

loss and other cognition, dementia confirmed by two neurologic testings, onset of signs and symptoms between ages 40 and 90, and all other neurologic and systemic diseases ruled out. The following selected supporting criteria strengthen a suspected diagnosis: aphasia, depression, inability to perform activities of daily living, family history of the disease, seizures and normal findings on laboratory tests.

The probable diagnosis of Alzheimer's Disease has caused such psychological pain, that some victims in the early stage have committed suicide or requested a medically assisted death rather than suffer the ravages of the disease. There are reported incidents of euthanasia by caregivers who could no longer watch the deterioration of a loved one. This has issued a moral and ethical challenge among those in the legal, medical and theological disciplines (Honey, 1991).

The economic impact to the family and the nation is enormous. The cost of caring for a victim at home ranges from \$5,000 per year for the mild to moderate demented to \$18,000 for advanced dementia. Nursing home costs average \$18,500 to \$22,500 per year (Overman and Stoudemire, 1988). Alzheimer's Disease has increased the national medical expenditures by approximately \$13.4 billion in 1983 (Hay & Ernst, 1987).

Approximately 4 million older persons in the United States are affected and the number is expected to reach 14 million by the year 2050 if no cure can be found (Alzheimer's Disease Association, Inc., 1991). These figures are worthy of attention, but when one considers the caregivers of AD sufferers, the actual numbers of "victims" reaches epidemic proportions.

To understand the stress and pressure on family caregivers, it is necessary to examine the disease's characteristics. AD is a terminal neurologic disease which tends to follow a progressive course as the nerve cells in the cerebral cortex slowly degenerate. Frequently it starts with memory loss, disorientation to time and place, depression, personality change and inability to perform routine tasks. The second stage includes difficulty with verbal communication and repetitive actions (perseveration). During the final stage symptoms include incontinence, twitching, seizing, aversion to eating or forgetting to eat, no longer recognizing family members, withdrawing from all communication, becoming feeble and bedridden. Death usually results from pneumonia or some other infection (Pluckham, 1986). There is no geographic, ethnic, racial nor gender association with the disease. There is an age related prevalence with incidence rising with age: five to seven

percent of persons at 65 and up to 20 percent in the over 80 age group (Kuhlman, et al., 1991).

Approximately seventy percent of the caring of demented elderly is done by the family in the home (Gonzalez-Lima & Gonzalez-Lima, 1987). Typically, when one member of a family becomes permanently disabled, other members of the system experience significant change. AD victims who live at home often place stress and pressure on family members who care for them (Lipkin & Faude, 1987).

Contemporary studies have focused on family caregivers as an aggregate rather than separating them as male or female spouses, daughter, son, grandchild or in-laws; likewise, the victim has been grouped without consideration to the stage of the illness. Very little research has been conducted comparing like samples of caregivers with AD victims in the same stage of illness (Pallett, 1990).

What is the experience of being a caregiver of an AD sufferer? Admittedly, the experience will not be identical for any two caregivers since a multiplicity of factors contribute to how each person deals with challenges. However, questions remain concerning the similar experiences among like caregivers of victims in the same stage of illness. What is it like to care for a person with Alzheimer's Disease? How do you cope in caring for person with Alzheimer's Disease? A qualitative research approach

to studying nursing phenomena provides a means of examining commonalities among caregiver responses. Data from ethnography may provide a thorough understanding of the experience from the caregiver point of view.

Statement of Purpose

The purpose of the study was to explore the question "What is it like to care for an AD victim?" The study was designed to describe and analyze the perceptions of the caregiver and attempt to identify the caregiver's coping strategies. These findings will enable the nurse to plan supportive care which will strengthen and maintain the caregiver's coping strategies.

Significance of Study

The term, "caregiver", describes one small facet of the family relationship, and it has come into vogue only within the last ten years. The most common caregivers for the elderly are spouses and adult children. There are no laws requiring this care, but there is a strong social imperative in American society that dictates that families assume responsibility for elders and the families in this country respond without equivocation (Phillips, 1989).

Families appear to prefer home-based care and will go to great lengths to avoid institutionalization of their loved one (Bergmann, Foster, Justice & Mathews, 1977; Kahan, Kemp, Staples & Brummel-Smith, 1985; Schoor, 1980). In addition to financial considerations of institutionalization, families often feel guilt and concern over the adequacy of their care when placing a family member elsewhere (Pearlin, Turner & Semple, 1989).

Caring for the demented person in the home may represent a substantial stress for the identified caregiver, and the term "caregiver burden" has been used to refer to the physical, psychological, social, and financial problems experienced by these family members (George & Gwyther, 1986). In order to focus on the concerns of the caregiver of an AD victim, the nurse needs to have a base of understanding of this group of health care consumers.

The purpose of this study was to conduct a qualitative investigation using ethnographic methodology to explore caregivers' perceptions of caring for an AD victim.

Summary

Very little is known about the perceptions/needs of like-type caregivers of AD persons in the same stage of the disease. Scientifically grounded studies are needed in

order to explore what kinds of information, education, support and treatment would best reinforce or increase the coping abilities of families with Alzheimer's disease members.

CHAPTER 2

LITERATURE REVIEW

The review of literature focused on the family caregiver and used the following criteria: characteristics of the cognitively impaired wife, demographic characteristics of the primary caregiver husband, characteristics of the dyadic relationship, and social support resources of the primary caregiver husband.

Pallett (1990) suggested that there is a preponderance of studies done on caregivers of AD victims but there is a need to know how the variables in the four domains of caregiving influence caregiver stress and well-being. The domains of influence found in Figure 1 are as follows: characteristics of the cognitively impaired relative; characteristics of the primary family caregiver; characteristics of the dyadic relationship; social support resources of the primary caregiver. Additionally, the conceptual framework in Figure 2 (Pallett, 1990) will serve as a guide to investigating the caregiving burden since it outlines determinants and effects of family caregiver burden in Alzheimer's-type dementia.

Characteristics of Cognitively Impaired Relative	Characteristics of Primary Family Caregiver	Characteristics of Dyadic Relationship	Social Support Resources of Primary Caregiver
-Level of cognitive impairment	-Age	-Type of relationship	-Size of support network
-Behavior problems	-Gender	-Quality of relationship prior to dementia	-Type of informal supports available
-Functional status	-Marital status	-Quality of current relationship	-Type of formal supports available
-Type and amount of care and supervision needed	-Health status		-Ease of contact with available supports
	-Social roles		-Perceived supportiveness of social ties in network
	-Management ability		

Figure 1. Variables within four domains that influence family caregiver stress and well-being in dementia.

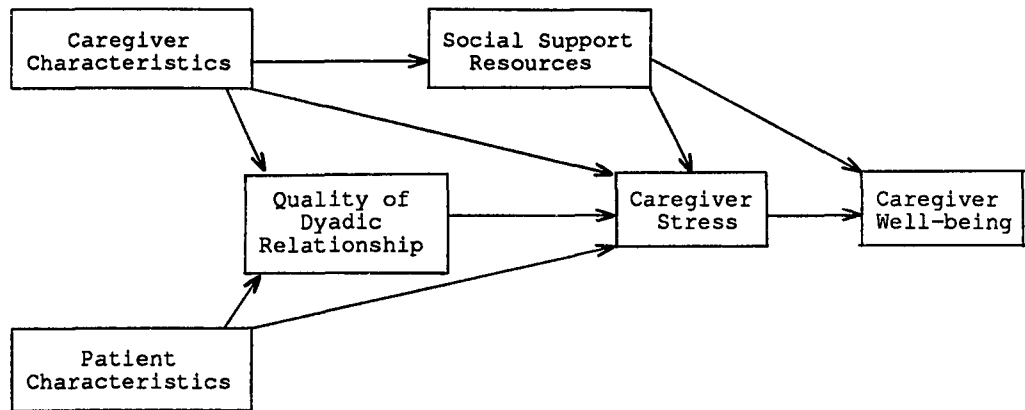


Figure 2. Conceptual framework outlining determinants and effects of family caregiver burden in Alzheimer's-type dementia.

Characteristics of the Cognitively Impaired Relative

The Global Deterioration Scale for Age-Associated Cognitive Decline and Alzheimer's Disease (Reisberg, Ferris, deLeon & Crook, 1982) mentioned seven stages of deterioration which an AD victim might experience (see Appendix A). Pallett (1990) stated the variables in the characteristics of the AD victim domain include cognitive impairment, behavioral problems, functional status and type and amount of care required.

Caregivers described caring for a confused person as extremely taxing and exhausting because of the increased workload of physical care and constant supervision (Beck & Phillips, 1983; Chenoweth & Spencer, 1986). Also a major difficulty and source of burden and strain is the pervasive sense of not knowing what behavior to expect next and how to interpret what is happening (Wilson, 1989). As the demented person deteriorates, the caregiver experiences a sense of loss -- time, money and of love (of loving and not being loved in return). Caring for an AD victim brings on other emotional caregiver responses such as anger, denial, guilt, self-pity and depression (Oliver & Bock, 1985). This study focused on wives with the probable diagnosis of middle stage AD.

Characteristics of the Primary Family Caregiver

The variables in the characteristics of the primary caregiver domain include age, gender, marital status, additional social roles and management ability. Although the sociodemographic variable affect caregiver stress, relationships among them appear complex (Pallett, 1990).

Women are predominately the caregivers, particularly wives and daughters, and they have been socialized from birth as family nurturer. Their expectations of themselves often are not nor cannot be achieved, and, thus, they experience a disparity between expectations and reality which exacerbates their emotional strain and leads to guilt (Brody, 1985). Husbands make up 50 percent of the spouse caregivers and Horwitz (1982) found that married men who care for their elderly frail parents suffer less stress than do married women caring for their elderly parents. This has led some to believe that marriage for men confers some protection from stresses of caring, but marriage for women did not hold that same protection.

Compromised health such as mental and physical illness of the caregiver, exacerbates the stress of caregiving (Isaacs, Livingston & Neville, 1972) and is associated with higher levels of depression (Prucho & Resch, 1989). Also there is some indication that healthy, active caregivers

find the confinement of caregiving more stressful than do less robust caregivers (Hirschfeld, 1979).

Management ability involves the use of problem-solving skills necessary in meeting the cognitively impaired person's needs, making good use of support resources, and adopting a caregiving approach that lessens stress (Cohen, Kennedy & Eisdorfer, 1983; Levine, Dastoor & Gendron, 1983; Reeve, Kepfer, Klein & Nagele, 1983). This study focused on husbands, who are approximately seventy years old, who have a middle income, are in good health and have been retired from white collar jobs for approximately eight years.

Characteristics of the Dyadic Caregiving Relationship

The variables in the dyadic relationship include the type of relationship and the quality of the relationship now and before the onset of the dementia. Family caregiving takes place within an historical context since bonds of affection and reciprocity that sustain caregiving took root in past relationships. Both the recipient and caregiver bring a history of interactions that may enhance or complicate the caregiving process (Pallett, 1979).

Premorbid relationships marked by ambivalence, dislike, resentment or conflict hold little promise for emotional satisfaction. The carryover of negative feelings is likely

to aggravate the stresses of caregiving while bonds of affection mediate the primary caregiver's stress (Horwitz & Shindelman, 1981). This study focused on couples who have been married at least 48 years and whose relationship was described by the husband as happy prior to the onset of the disease.

Social Support of Primary Caregiver

Variables included in the domain of social support resources consist of the size of support network, types of informal and formal support, ease of contact and caregiver's perceived supportiveness of social ties in the network (Pallett, 1989). Social support is defined by Thoits (1982) as the degree to which one's basic social needs for affection, esteem or approval, belonging, identity, and security are met. Two types of support reflect the manner in which these needs are met: socioemotional aid (sympathy, understanding) and instrumental aid (advice, information).

The caregiver's perception of social support may have an important impact on the stresses of providing care to a relative with dementia (Hirschfeld, 1979; Zarit, Reever & Bach-Peterson, 1980). Increasing involvement with the AD victim's deteriorating behavior, to the exclusion of other interests, tend to undermine supportive relationships with friends and neighbors thus increasing the isolation of the

caregiver (Johnson & Johnson, 1983). However, the willingness to accept the brunt of caregiving often elicits support from unexpected sources. Examples of such support are monetary gifts to offset respite costs, or emotional support from those too geographically distant or overburdened with other responsibilities for involvement in day-to-day care (Pallett, 1989).

Some caregivers seek formal support systems such as day care centers, which offer periodic respite from caregiving responsibilities, and/or organized family support groups which act to strengthen morale. Reassurance from these systems and groups provides a source of validation for personal strength (Pallett, 1989).

This study focused on caregivers who receive minimal or no "hands on" support from family, friends or paid employees; however, each caregiver has two children who offer emotional support. Two participants have sons who live locally and daughters who live away. The other participant has two sons who both live away. Each participant perceives their family as supportive.

In summary, the literature review substantiated the need for research on the burden of caregiving on like samples of caregivers and their AD victims, and especially husband caregivers. The next chapter presents the methodology of the research study.

CHAPTER 3

METHODOLOGY

The purpose of this study was to describe, analyze and understand from the perspective of a primary caregiver husband, what it is like to care for a wife with middle stage Alzheimer's Disease. Pallett (1990) has suggested that comparing like samples of caregivers and their AD victims is one of the things missing in the literature. The research method chosen for the study was an ethnography, which is a qualitative method used to systematically describe life experiences from the caregiver's viewpoint (Burns & Grove, 1987). Because an interview is useful in uncovering the lived experience of the caregiver, it was chosen as the research strategy in this study.

Research Design

An ethnographic approach was used to understand the way of life of a caregiver of a person with Alzheimer's Disease. The essential core of this method is to understand another way of life as it is lived by the person experiencing it. Rather than "studying people", the ethnographic approach means "learning from people" (Spradley, 1979).

Method

The purpose of the ethnographic interview is to get people to talk about what they know (Spradley, 1979). Ethnography is defined as examining a culture from the insider's or native's viewpoint (emic perspective) rather than an outsider's view (etic perspective) regarding behavior patterns, customs, and a peoples' ways of life. These rules, behaviors and norms tell us how people get through life, their lived experiences. The use of selected questions to guide the interview and a participant-observation experience distinguishes it from the phenomenologic approach which describes phenomena. It differs from the analytic hypothesis-based grounded theory approach since ethnography uses no previous knowledge or hypothesis of the topic. Culture is defined as the acquired knowledge that people use to interpret an experience and generate social behavior (norms, mores and beliefs) (Spradley, 1979). The descriptive data obtained were analyzed, compared, and organized into categories, themes and patterns. The concepts that emerge will be evaluated for informational adequacy, credibility, usefulness and centrality (Marshall & Rossman, 1989).

Setting

Data were collected through a prearranged, semi-structured, audio-taped interview. The goal of using open-ended questions was to guide the interview in an environment free from distractions and to allow sufficient time to obtain a complete description. The participants were asked to think about the questions ahead of time, so they would be in touch with as many of their own thoughts, feelings and circumstances as possible.

The two hour dinnertime participant-observation experience in the home, provided the researcher an opportunity to observe a normal daily event in the caregiving setting. Only the researcher's astute ability to observe was used to collect such data as, the interaction between the AD victim and others and the setting of the house; this was accomplished by sitting at the table with the family. The researcher did a self-debriefing (put down data in the form of two pages of notes within one hour after leaving each participant's home). Other data collection tools, such as, tape recorder or note taking would have been too distracting.

Sample

Spradley (1979) identified five minimum requirements for selecting a good-study participant as follows: thorough

enculturation, current involvement, interviewer unfamiliar with participant's cultural scene, adequate time, and a non-analytic focus. After securing Human Subject's approval, three English-speaking husband caregivers with like characteristics, which closely met the criteria, were selected from an adult day care center. Criteria included similarity in the following areas: age, length and quality of the marital relationship, perceived social support and health status, economic level and the stage of cognitive impairment of the AD victim. The specific caregiver characteristics included husbands approximately seventy years of age, married either 48 or 49 years, in good health, middle income, and retired from white collar jobs approximately 8 years (Table 1).

The person with Alzheimer's Disease, whom the caregiver takes care of, also had similar characteristics, such as: the middle level of cognitive impairment, similar behavior and functional problems and required the same amount of care and supervision. Additionally, the dyadic relationship consisted of a happy marriage for 48 plus years. The social support resources were perceived as good by the caregiver. Specifically two out of three mentioned their church as a support and continue to attend regularly because they felt accepted there. The other participant no longer attends

Table 1. Demographic data of subjects.

Description of Cognitively Impaired Wives					
Subject	Age (years)	Marriage length (years)	Christian religion	Level of dementia	Children (living)
A	69	48	Protestant	middle	2
B	71	49	Protestant	middle	2
C	69	48	Protestant	middle	2

Description of Primary Caregiver - Husband					
Subject	Age (approximate years)	Christian religion	Occupation	Health status	Income level
A	70	Protestant	Retired manager	Good	Middle
B	70	Protestant	Retired salesman	Good	Middle
C	70	Protestant	Retired banker	Good	Middle

because his wife's behavior is embarrassing to him. Please see Figure 1.

Data Collection

The participants were recruited from an adult day care center. Protection of the rights of human subjects was accomplished by an explanation of the research question and the purpose of the study; they were also informed that the study has been approved by the Human Subjects Committee. The time commitment (approximately four hours), the involvement of the participant and the option to withdraw at any time were explained. Confidentiality and anonymity was assured since the audio tapes were erased after transcription and data were grouped without identifiers (see Appendix B).

The three types of data-generating questions were: descriptive, structural and contrast (each with several subtypes) (Spradley, 1979) (See Appendix C). The descriptive grand-tour question which encouraged participants to talk about their experience was:

"What is it like to care for a person with Alzheimer's Disease?"

This question was used alternately with structural questions, such as: "What concerns do you have for yourself?" and "How have you coped with these concerns?"

Both types of questions permit identification of domains in the participant's terms rather than in analytic categories and they also explore the organization of the participant's own knowledge of cultural rules and norms (Spradley, 1979).

A contrast question was used to confirm differences and similarities in the experience (Spradley, 1979). The contrast question used was: "Tell me about your life now compared with before your loved one became ill with Alzheimer's Disease."

The researcher obtained the opinion of a recognized expert in the field of ethnographic research regarding the soundness of the questions. As the study unfolded, triangulation of data was accomplished by validating pieces of information derived from at least one other perspective (Lincoln & Guba, 1985). Triangulation sources in this study included non-verbal communication both during the interview and the home participant-observation experience during mealtime.

Data Analysis

Within two days after each ethnographic audio-taped interview was completed, transcribed, checked for accuracy, and field notes concerning non-verbal communication were added, the descriptive data were analyzed, compared, and organized into categories, themes and patterns. Data were

examined for themes related to the variables and each of these sessions lasted approximately three hours. The emergent concepts were evaluated for informational adequacy, creditability, usefulness and centrality (Marshall & Rossman, 1989). This task was accomplished under supervision of the thesis advisor in two sessions lasting ninety minutes each. The first debriefing occurred after two interviews and one participant - observation experience. The expert ethnographer and the researcher agreed on categories, themes and patterns. Notes of debriefing sessions were kept as data. The literature supported what it is like to care for a person with Alzheimer's Disease and validated the analysis. Data collection following the interviews and participant-observation experience ended after three interviews and two participant-observation experiences when no new information was brought forward (Lincoln & Guba, 1985); the researcher accepted a 96 percent category saturation level as calculated and found in Appendix D.

Trustworthiness and Creditability of Data

The basic issue related to trustworthiness is how can the researcher persuade the reader that the findings are worthy of attention (Lincoln & Guba, 1985). One way to minimize error is to create an audit trail which includes a

compilation of data collection and analysis in the order of occurrence. The audit trail leaves a path for future researchers to verify the work. Triangulation, validating data with other sources, was done to verify and give substance to the findings. Neutrality was maintained since the convenience sample of participants was randomly selected and unknown to the researcher. Debriefing of transcribed data with field notes added, was done by the researcher, within three days following each interview. Data bits were copied on cards and then hand-sorted into categories themes and patterns. Creditability was first established by use of an expert ethnographer debriefer (thesis advisor) and later supported with similar findings in the literature.

Limitations

Trustworthiness of research is often limited by circumstances. For instance, in this study, the sample size is small but in spite of this limitation a 96 percent saturation level of the categories was obtained; however, there may be limited understanding of their culture, since short-term involvement may not be long enough for them to take off their socially accepted mask. Additionally, time prevented "prolonged engagement" with the participants which is another deterrent to achieving total saturation. Lastly, due to the sensitivity of the subject and the emotional pain

suffered by some caregivers, perhaps total disclosure did not take place.

Human Subjects

Data collection was done in accordance with the protection of human subjects. Participants were given verbal and written instruction regarding the nature of the study, how data would be collected and confidentiality would be maintained, the absence of risk and the freedom not to participate. A written disclaimer to describe the purpose of the study and data collection was given to each participant (Appendix B).

Summary

This chapter included the description of the research design, setting and sample, as well as, the method of data collection and analysis. The next chapter will present the data analysis.

CHAPTER 4

ANALYSIS AND PRESENTATION OF DATA

This chapter presents the analysis of data which purpose was to explore the male spouses' perceptions of what it is like to care for a mate with Alzheimer's Disease; interviews ceased when it became apparent that data became redundant (categories were 96 percent saturated) (Lincoln & Guba, 1985). An ethnographic method was used to gain the viewpoint of men with wives who had Alzheimer's Disease. The five domains of meaning that emerged from the content analysis of the ethnographic interviews are discussed in this chapter. Cultural themes derived from analysis of interviews with the spouses are also presented.

Participants

Participants in this study were three males of wives who have Alzheimer's Disease. All couples were Caucasian and of Protestant faith. The victims' ages ranged from sixty-nine to seventy-one years while the caregivers' ages were approximately seventy years. They all had been married forty-eight plus years and each couple has two living children. All victims were in the middle stage of the disease exhibiting such symptoms as the following: severe cognitive loss, incontinence, wandering,

sundowning (confused or disoriented at the end of the day) and combativeness.

All three victims lived at home and were cared for by their retired husbands. All attended the same day care center for four hours, two or three times a week. The caregivers were of the middle-income class and each described his health as good, although one had a heart attack two years ago.

Interviews were conducted in the researcher's home. The length of the interviews ranged from sixty to ninety minutes. Two of the three caregivers permitted a participant-observation experience (lasting ninety minutes) that took place in the couple's home at dinnertime. Informants are identified in this study with alphabetic letters in order to protect their identity (Table 1).

Participant A

The wife is a native of Great Britain and came to the United States in 1947 as an "English War Bride", a program which united spouses who were married overseas during World War II. The couple moved to the husband's native Tucson upon retirement seven years ago after living in southern California for several years. Their daughter lives two hundred miles away while their son lives locally two miles away. Both children have families and offer minimal hands-

on assistance to their parents but are sympathetically supportive of them.

The onset of Alzheimer's symptoms started seven years ago and was first noticed when she could not balance the checkbook. Four years ago when she failed mental tests and laboratory tests showed no physiologic etiology, a neurologist suggested the problem might be Alzheimer's Disease.

During the dinnertime, participant-observation experience, the victim was treated as if she were invisible by her two adult grandsons who were invited for dinner. Neither grandson greeted her, looked at her, nor acknowledged her presence verbally. The spouse introduced his wife to the researcher and then invited the researcher to join the couple as they walked in the back yard. Other interactions included: lighting her cigarette, asking if she was hungry, serving her dinner and cutting her meat. The wife fed herself.

The victim's verbal interactions were minimal and included asking her husband for a cigarette three times (and then he lit one for her) and telling the researcher, "he is a nice man, but so is my husband" and "I don't live here". The victim no longer knows her husband nor where she lives.

The home environment showed no signs of adaptation to a cognitively disabled person except that smoking materials

(cigarette, matches, lighter) were hidden for safety reasons. There were no memory aid reminders on the walls nor special locks on the doors. Fragile items, magazines, memorabilia and pictures appointed the home. The caregiver pays a neighbor to clean and do the laundry once a week. The dinner menu was prepared by the caregiver and included: grilled steak, salad, rolls, broccoli, potatoes au gratin and pie. Data obtained from the interview regarding "constant watching", "she doesn't know me", and "I do everything" were validated during the home participant-observation experience when the researcher observed how the caregiver prepared dinner, carefully watched the wife's lighted smoking materials and the AD victim indicated to the researcher that "that man is not my husband".

Participant B

The couple moved to Tucson four years ago from southern California because of the climate and medical facilities. The wife had already been diagnosed with Alzheimer's Disease. They have a daughter one hundred miles away and a son living locally. Both children have families and offer minimal hands-on assistance to their parents but are sympathetically supportive of them.

The onset of Alzheimer's Disease started ten years ago when the wife, as the husband explained, had five to ten minute periods on being "out-of-it" and talked of things

that never existed. Finally after many medical doctors and laboratory tests, the probable diagnosis was made five years ago. However, during the five years prior to diagnosis, the husband said he hid her cognitive decline from the family and friends by answering questions for her. He did this because she had made him promise not to let her embarrass herself. The wife has not been told she has the disease. She was informed by her husband that the problem is "over-medication" which will hopefully "boil out of her system" and she will get better. The husband's reasoning for not informing his wife is that Alzheimer's Disease diagnosis offers no hope, and it is wrong to take away a person's hope. However, presently he doubts there is much cognitive ability left, so it does not matter anymore what the problem is called.

At dinnertime, participant-observation experience was arranged, but one week later, the caregiver reneged the invitation explaining that it would not be helpful to the researcher, rather the researcher should go to the day care center to watch his wife eat. During the course of the cordial interview, the husband said things which may or may not have influenced his decision to withdraw the invitation, such as: (1) "I promised her I'd never let her embarrass herself"; (2) "I lost weight because when we ate together (she slops her food), I lost my appetite"; (3) "when I fix

dinner, I fix two plates then feed her and when she is through I microwave mine and eat afterwards"; and (4) "I am a terrible cook...can't even boil water without scorching it".

Participant C

Nine years ago the couple selected Tucson as a retirement location after living in many locations throughout the United States and the world. Her sister lived here at that time but soon moved out of state. Their two sons live in the Midwest and eastern United States, offering minimal hands-on assistance to their parents but are sympathetically supportive of them.

The onset of Alzheimer's Disease began five years ago when the victim had trouble balancing the checkbook and did not object when the husband took over. According to her husband, not objecting was totally out of character since ordinarily she would have been insulted. A medical doctor internist sent them to a neurologist who did exhaustive tests and concluded the problem was dementia. One year later, a second neurologist performed more laboratory tests, could find no physiologic etiology, and then diagnosed the problem as Alzheimer's Disease.

During the dinnertime, participant-observation experience, the victim was treated with loving acceptance,

as she talked almost constantly (articulated well but conversation was not on topic nor made sense). When interrupted the caregiver would stop talking and wait to resume when the victim had finished speaking. He never showed verbal nor non verbal irritation, and two times he showed affection by patting her hand. If she said erroneous things about the topic at hand, he would gently correct her; however, when she rambled nonsensically, nothing was said.

The husband introduced his wife to the researcher and assisted both the researcher and the victim with their dining chairs. He served his wife's food and asked if she wanted more when that food was eaten. The menu included Hamburger Helper, corn, dinner roll, ice cream and wine. The victim fed herself and told the researcher "this man does everything, he is wonderful". The victim does not know who her spouse is anymore.

The home environment showed no signs of adaptation to a cognitively disabled person, such as memory aid signs and special locks. The home had the appearance of normalcy with books, magazines, pictures and memorabilia displayed. When the victim displayed affection toward their cat, the caregiver remarked, "my wife knows the cat belongs to us but gets other relationships mixed up, for instance, who I am, and to whom our sons and grandchildren belong". Interview data regarding "I took over the cooking", and non-verbal

expressions of sadness on the caregiver's face, as his wife talked non-sensically, were validated during the home participant-observation experience. The half dozen library mystery books on the table confirmed the husband's assertion that he read a great deal after his wife went to sleep -- a time which he referred to as "my time".

Interview Data

Five domains of meaning emerged from content analysis of the interviews with husbands whose wives had Alzheimer's Disease (Table 2). Domains of meaning included concerns regarding: (1) lifestyle change, (2) helplessness and powerlessness, (3) care for own, (4) future, and (5) coping. A narrative of the meaning of the domains is the focus of this section. Participant's statements pertaining to the domains are in quotation marks.

Lifestyle Change Concerns

The domain of lifestyle change was derived during the initial interviews with participants. This domain included responses to the descriptive question, "What is it like to care for someone with Alzheimer's Disease?", and, "Tell me about how your life is now compared with before the onset of your wife's illness?" The answers to both questions were similar, thus confirming the domain. Participants

Table 2. Domains of meaning of the experience of caring for an Alzheimer's Disease victim

Lifestyle change

Helplessness and powerlessness

Care for own

Concerns for the future

Coping

responded, "It's the pits"; "It's pure hell"; and "It means constant watching". The categories of lifestyle change that emerged were provider, caregiver, and social isolation (Table 3). Participants felt their life had drastically changed for the worse and continued with such statements as follows: "We don't travel anymore"; "I don't have alone time -- even to go to the bathroom"; "You don't have normal relations"; and, "I can't do anything that requires concentration".

Provider

One participant responded, "I had to learn to cook... and I hate it" while another mentioned, "I took over all the cooking, the washing, and just about everything she used to do". The third participant mentioned, "I get a neighbor to come in once a week to clean and launder but I do the rest."

Caregiver

One participant said, "You get 'em up, dress 'em, prepare the breakfast, take care of the dirty dishes, clean the house and entertain them." Another explained, "Depending on her mood, it's a chore getting her ready." The third participant commented, "I completely take care of her...bathe once a day and sometimes two or three times if she has an accident."

Table 3. Domain of meaning: lifestyle change

What is it like to care for an Alzheimer Disease Victim?

<u>Caregiver</u>	Bathe, dress her Clean her if accident
<u>Provider</u>	Cook, wash Do everything Entertain her
<u>Social Isolation</u>	Not many people come around Crawled into four walls Stuck, never get out

Social isolation

This category included responses: "Not too many people come around anymore because they can't handle it"; "I crawled into four walls, so to speak, and in time that will drive you up the wall"; and, "I'm stuck and never able to get out."

Some antisocial behavior which was said to contribute to social isolation included: "We don't eat out because she slops her food and I don't want to ruin other people's dinner"; "She gets belligerent"; and, "She talks nonsensically." The caregivers shared their feelings about the social isolation they were experiencing which included: "I miss going out"; and, "The thing I miss most is talking to people who can carry on a conversation".

Helplessness/Powerlessness

The domain of helplessness/powerlessness emerged from the descriptive question, "What is it like to care for a person with Alzheimer's Disease?" Each informant mentioned the hopeless aspect of the terminal disease and stated, "I realize it is totally hopeless"; and, "the doctor tells me that I will go through this to the best of my ability and lose her in the end anyway". The three categories that emerged from the helplessness/powerless domain were: sadness, anger, and frustration (Table 4).

Table 4. Domain of meaning: helplessness/powerlessness

What is it like to care for an Alzheimer's Disease victim?

Sadness

See her deteriorate
Lose her anyway
Feel sorry

Anger

Nothing pleases her
I cause everything
Chews on me
Kiss her or kill her

Frustration

Would go anywhere
Remember when it was not this way

Sadness

One participant revealed, "My wife was brilliant, to see her deteriorate, kills me"; while another lamented, "They talk about a cure being ten years away...it won't do us any good." The third mentioned, "I feel so sorry for her...if it were me I'd rather be dead."

Anger

One participant said, "Nothing pleases her; I cause everything...she chews on me all the time." Another explained, "I get so annoyed that I can't take it anymore and sleep in the other bedroom"; while the third said, "I don't know whether to kiss her or kill her."

Frustration

The category included responses of "everything they do is frustrating, because you can remember when it wasn't the case." Another disclosed, "I would go anywhere to get something that anybody thought might work"; while a third asserted, "If a person has a disease that is going to kill them, then for God's sake give them something...if nothing else you are giving them hope."

Care For Own

The domain of care for own emerged from the structural question, "What concerns do you have for yourself?" Most primary caregiver participants responded: "As long as I can manage, I'll do it"; and, "I want her taken care of and will do that to the best of my ability." Two categories that emerged from this domain were: self-responsibility and self-reliant (Table 5).

Self-responsibility

"I'm not making their mother a burden on them"; "It's not their responsibility, it's mine"; and, "... don't want them to feel they're obligated to us" are examples of responses in the domain of caring for own. One participant said, "It's my responsibility. I paid two and a half dollars for that privilege years ago (referring to the cost of their marriage icense)."

Self-reliant

"I know her well...when what I'm trying doesn't work, then I approach her from another angle and get in"; and, "I try not to bother the rest of the family too much" are illustrations of responses in the domain of caring for own.

Table 5. Domain of meaning: care for own

What is it like to care for an Alzheimer's Disease victim?

<u>Self-responsibility</u>	Not making a burden Others not obligated My responsibility
<u>Self-reliant</u>	Approach from another angle Not bother family I'll do it

A third respondent divulged, "Kids wanted me to place her in a home a long time ago and I said, 'I'd do it as long as I could (referring to caring for wife at home)'."

Concerns For The Future

This domain emerged from the structural question, "What concerns do you have for yourself?" The participants responded: "... don't know how much longer I can keep going like this (referring to the caregiving burden)." Two categories of concern for the future were: money and keeping healthy (Table 6).

Money

Samples of responses included: "... being dragged down financially"; "A nursing home will be the end of me financially"; and, "I haven't been able to get her any long term care (insurance)." Another mentioned, "I'd like to be gainfully employed because it's costing us and I might as well start replenishing (money)."

Keeping healthy

One participant said, "I have no concerns for myself... as long as I don't have too many highballs (referring to a type of alcoholic beverage)"; while another stated, "I need

Table 6. Domain of meaning: concerns for the future

What is it like to care for an Alzheimer's Disease victim?

<u>Money</u>	Dragged down financially Costing us End of me financially
<u>Keeping healthy</u>	Too many highballs Not getting sleep Feeling down

to get enough sleep." The third participant mentioned, "I'm all right if I don't get too tired and feel down."

Coping

This domain emerged from the structural question asked of the participants, "Tell me how you have coped with these concerns?" One participant expressed the difficulty of caregiving and the resourcefulness needed when he said, "Old age isn't for sissies," referring to the physical stamina, mental cleverness, and the perseverance needed to withstand the caregiving burden. Others said: "... little by little you learn to cope"; "I know you can't restrain her, it only makes things worse"; and, "Yelling back at her just makes things worse, so I keep myself under control and tell her I love her and know it isn't her that's talking." The categories within the coping domain included: attitude, activity and respite (Table 7).

Attitude

"You have to be thick-skinned" (meaning the victim's verbal responses could hurt your feelings); and, "... it's part of the game, so we take it" were expressions of attitude about coping. Each respondent had a late evening time each called, "my time," and one participant stated, "When she infringes on that, it drives me up the wall."

Table 7. Domain of meaning: coping

What is it like to care for an Alzheimer's Disease victim?

Attitude

Have thick skin
Part of the game

Action

Car ride
TV
Give her pills
Couple of drinks

Respite

Day care
Get her to nap

Actions

Two participants mentioned, "... take her for a car ride", as a means to calm their wives; while all expressed, "TV is a good way to entertain them." All used medication sparingly; one participant stated, "After benadryl she is so disoriented...I'd rather deal with a little anger"; while another said, "When she is really bad, you can't get the pills down her"; and, the third remarked, "I'm not so sure the pills work." One participant mentioned alcohol use for himself and stated, "After she goes to bed I kinda fall apart...have a couple of drinks to relax...and depending on the day might even have a third, and I don't like that many...but you gotta do something."

Respite

Aside from adult day care which they all praised and one participant called it, "a Godsend"; there was minimal respite from the caregiving tasks. One participant said, "I hesitate to ask anyone to stay with her. I just couldn't put that off on somebody." Others shared, "I leave her for an hour or so once a week and go to the library"; and, "If I can get her to take a nap in the afternoon, that's a break." Regarding support groups, one of the participants said, "I'd go if there was one near me...you need all the help you can get." Another participant described support groups as,

"It's a waste of everybody's time to go and listen to all their troubles...and I'm sure not going to bother them with mine." The third participant disclosed, "They aren't all that helpful but you get to talk to people. I really miss talking to people who make sense and can respond back sensibly."

Cultural Themes

Cultural themes are norms and patterns of recurring messages, from the researcher's point of view, that represent the organizing principles in the cultural system under study (Morse, 1989). The cultural themes that emerged from the domains were "alone" and "hopeless" (Table 8).

Alone

This cultural theme was declared by the participants and is present in many domains. "Alone" seems to include the absence of family and friends who as one participant said, "... don't come around too much...they just can't handle it." This illustrates the need of the caregiver to have others understand their need for emotional and respite support.

Within the Lifestyle Change domain, in the Social Isolation category are illustrations of the cultural themes, such as: "I miss going out"; "The thing I miss most is

Table 8. Cultural themes: alone and hopeless

<u>Alone</u>	
<u>Family</u>	Don't come around Not their responsibility Not bother family
<u>Friends</u>	Miss talking to people Others not obligated Hesitate to ask

<u>Hopeless</u>	
<u>Alzheimer's Disease</u>	Go anywhere for something Cure ten years away
<u>Caregiver feelings</u>	Nothing pleases her Will lose her

talking to people who can carry on a conversation"; "I crawled into four walls"; and, "I'm stuck and can't get out." The Care For Own domain, in the Self-responsibility and Self-reliant categories, there are additional supportive statements, such as: "It's not their responsibility, it's mine"; "... don't want others to feel obligated to us"; and, "I try not to bother the rest of the family too much." In the domain of Coping, within the Respite category, another illustration existed, "I hesitate to ask anyone to stay with her. I just couldn't put that off on somebody."

Hopeless

This cultural theme was present in the Helpless/Powerless domain, and the word "hopeless" was mentioned by each participant when he referred to feelings regarding their spouses' illness and their caregiving role. This theme emphasizes the need for health care professionals to be sensitive to the feelings of devastation experienced by loved ones when they learn of the diagnosis and when they are burdened with caregiving. There is a need for supportive listening, education regarding the disease, and for local and national resources to help.

Within the sadness category of Helplessness/Powerless domain, respondents commented: "I'll go all through this and lose her in the end anyway"; "By then I realized it was

hopeless"; and, "They talk about a cure being ten years away...it won't do us any good." Within the frustration category of the same domain, another spouse remarked, "It's kind of hopeless...I'd go anywhere to get something that anybody thought might work." In the same domain, the category anger had the supportive statement, "Nothing I do pleases her." Within the Lifestyle Change domain (provider category), participants stated, "I don't know how much longer I can go on like this."

Summary

The participants for this study were three males who are at-home primary caregivers for their wives who suffer from Alzheimer's Disease. Participants were selected according to their similar characteristics regarding: gender, age, income, social support (religion), length of marriage, number of children, occupation, health status, income and the level of impairment of the Alzheimer's Disease victim.

The five domains of meaning which emerged were: (1) lifestyle change (categories: caregiver, provider, social isolation); (2) helplessness and hopelessness (categories: sadness, anger, frustration); (3) care for own (categories: money, keeping healthy); (4) concerns for the

future (categories: money; keeping healthy); and (5) coping (categories: attitude, actions, respite).

The cultural themes that emerged were: alone and hopeless. To minimize error, data were confirmed with findings reported in the literature and discussed with expert ethnographer (thesis advisor).

CHAPTER 5

DISCUSSION AND CONCLUSIONS

This research was designed to learn from male spouses what it is like to care for a mate with Alzheimer's Disease. The conclusions of this research project are divided into the following sections: conceptual orientation; literature review; summary; recommendations for nursing practice; significance of the study; recommendations for further study; and conclusions.

Conceptual Orientation

The participants of this study include wives with Alzheimer's Disease and their primary caregiver husbands. It is said that the disease has two victims - the first victim is the one with the disease and the second is the "hidden victim," the primary caregiver (Zarit, Orr & Zarit, 1985). The severe cognitive and physical losses experienced by the victim create alterations in the couple's relationship. The caregivers' responses to the illness are manifested in concerns in the following areas: lifestyle change; feelings of helplessness and powerlessness; the reality of caring for one's own; the future; and coping strategies. Health care for the Alzheimer's victim means palliative care since the illness is terminal with no known

cure. Health care for the caregiver can be defined in terms of facilitating coping strategies. This conceptual orientation has various linkages but does not imply any association nor cause-effect relationship (Figure 3).

The concerns of the spouse caregivers are, in part, due to lifestyle change because of the cognitive decline of their wives. The mutuality of the marital relationship, as they knew it, has disappeared. The husband moved from a partnership position to the new role of caregiver and protector. Included in the lifestyle change is social isolation which resulted from the victim's behavior, and the time-consuming nature of the caregiving burden. Another concern which emerged is helplessness and powerlessness, as the caregiver deals with a terminal illness of a family member. Furthermore, there is a strong cultural message to care for one's own, which is sometimes done to the caregiver's physical and mental detriment. Finally, there is anxiety about the future. These concerns can guide nursing interventions to assist the caregiver in developing coping strategies (Figure 2, page 17).

The strength of the categories was demonstrated by a 96 percent saturation level after three interviews and two participant-observation experiences. The rapidity of category saturation level might be attributed to the like samples.

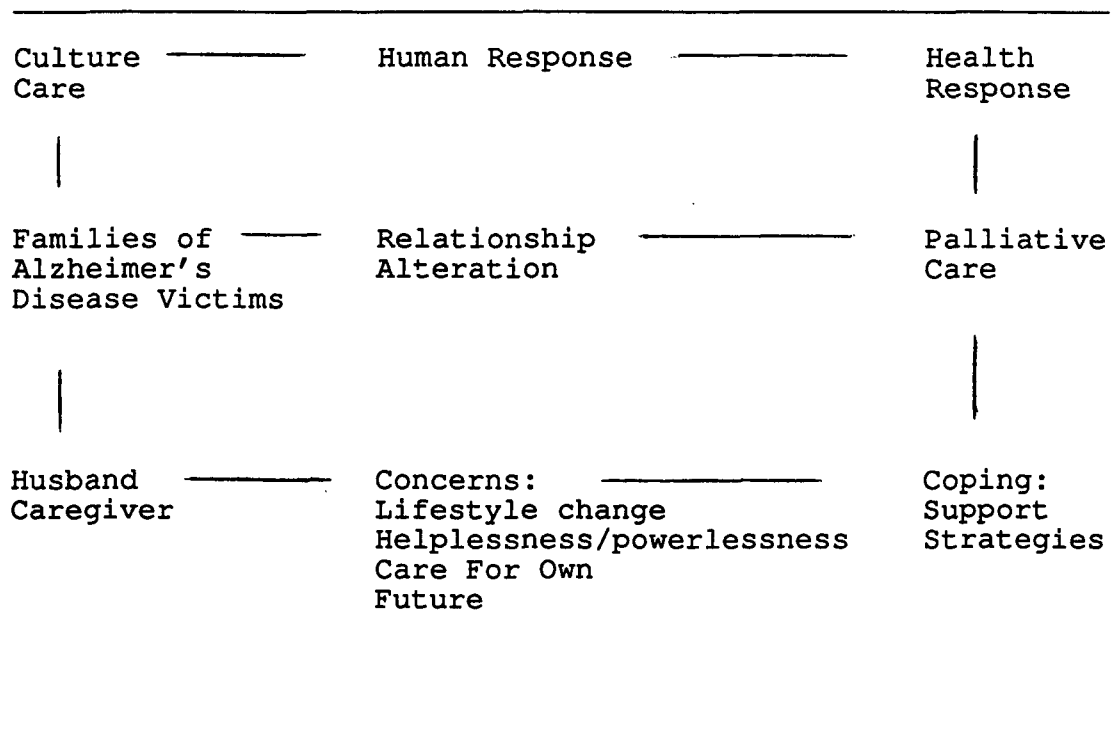


Figure 3. Conceptual Orientation illustrating linkages but not cause-effect.

It was determined to stop further data sampling since the interviews had ceased to be productive (information became redundant) (Lincoln & Guba, 1985).

Literature Review

Ethnographic data from this study will add to the knowledge of the topics examined in the review of the literature: lifestyle change, helplessness/powerlessness, care for own, future, and coping.

Lifestyle Change

One part of lifestyle change is role transition in which the spouse loses the partnership aspect of the marriage relationship and moves into a caregiving and protector role. Role transition denotes change in role relationships, expectations or abilities. It requires the person to incorporate new knowledge, alter behavior and thus change the definition of self in the new social context (Meleis, 1975, p. 265). Meleis (1975) lists three components of role transition as: developmental, situational, health/illness (Figure 4). These categories can be applied to the spouse caregivers (Figure 1, page 16). First, developmental transitions occur in the course of growth and development as a person forms their identity beginning in early childhood and continuing to older

<u>Meleis Role Transition</u>		<u>Spouse's Role Transition</u>
Developmental	become:	Provider Caregiver
Situational	loss of:	Marital Partner Friend Freedom Home Manager
Health-Illness (Alzheimer's Victim)	needs:	Caretaker

Figure 4. Meleis's Three Categories of Role Transition
(Adapted by Doran, 1992).

adulthood (Meleis, 1975). In the case of the husband caring for his Alzheimer's impaired wife, he is taking on duties which were formerly performed by his spouse as well as caring for her personal needs. These new duties include the following: cooking, cleaning, laundering, tending to her personal hygiene needs, monitoring her behavior and entertaining her.

Situational transitions involve the addition or subtraction of persons in a preexisting constellation of roles (Meleis, 1975). In the case of the caregiving spouse there is a loss of a reciprocal companionship, friends, a home manager, personal freedom and a way of life.

Health/illness transition are manifested by gradual role changes as the victim slowly cognitively and physically deteriorates. The spouse incorporates the new duties and processes the sentiments of the new role of provider and caregiver. For health purposes, the victim and the caregiver are considered as one unit with components that influence each other (Meleis, 1975).

Helplessness and Powerlessness

In Webster's Third International Dictionary (1971) helplessness is defined as lacking in effectiveness while powerlessness is defined as devoid of strength or resources. These definitions describe the experience of dealing with

a terminal illness such as Alzheimer's Disease which has no cure.

A major source of caregiver burden and strain is the pervasive sense of not knowing what to expect nor how to interpret victim behaviors (Wilson, 1989). In this study one participant stated, "I can't decide what to do." Another study supported the finding that family caregivers often expressed the feeling of being overwhelmed (Pallett, 1990). Similarly, in this study participants mentioned, "I don't know how much longer I can go on." The ordeal of watching the victim progressively deteriorate has been compared to watching an endless funeral (Chenet, 1989). Participants in this study mentioned, "this disease is hopeless", and "they talk about a cure being ten years...that won't help us any."

Care For Own

Care for own means families care for other family members which is reflected in the statistic that seventy percent of the care for demented elderly is done by their family in the home (Gonzalez-Lima & Gonzalez-Lima, 1987). There is a social imperative in our society that dictates that families assume responsibility for elders and the families in this country respond to this imperative without equivocation (Phillips, 1989).

This tendency toward family responsibility was supported in the findings of this study since all participants cared for their wives at home, and reflected a strong sense of duty in the following responses: "I want her taken care of and I'll do it to the best of my ability"; "It's my responsibility"; and, "I'll take care of her as long as I can."

Future

Future is defined in Webster's Third International Dictionary, (1971) as a time that is to come. Fear for the future was reported most frequently as the problem eroding caregiver management, ability and morale; this same fear also increased strain and tension (Zarit, Reever & Bach-Peterson, 1980).

Concerns for the future were expressed by the participants in this study by such responses as, "I don't know how much longer I can keep going like this" referring to the caregiver burden. Two participants expressed future financial concerns: "A nursing home would be the end of me financially"; and, "I'd like to be gainfully employed because it's costing us and I might as well as well start replenishing." Another participant stated, "If I get sick I don't know what would happen to her."

The future is something that caregivers don't always want to contemplate because it can be ominous and threatening, thus they make a deliberate attempt to think about the present or past (Pearlin, Turner & Semple, 1989). In one participant observation experience, much dinnertime conversation centered on past pleasant vacation trips. Another participant hinted at a dismal future and said, "I suppose these are the good days."

Coping

Coping is defined as the ability to adapt and adjust to changing life situations (Kreigh & Perko, 1979), while Valliant (1967) tends to regard coping as embodying a general style of dealing with the world. Pearlin, Turner & Semple, (1989) suggested it is not enough to list successful coping strategies but instead to state under what conditions coping strategies may or may not be effective.

Participants in this study stated, "Little by little you learn to cope," as they discovered successful strategies that work for them (Table 7, page 51). Other examples of successful strategies used in the middle stage, participants in this study found when trying to stop combative behavior: "Restraining her makes things worse"; and, "Yelling back makes things worse so I keep myself under control and tell her I love her and know it isn't her talking." Two

participants mentioned methods of combatting restlessness and perseveration: "Take her for a car ride" and all used television "to entertain." Wandering was dealt with by, "Walk behind her and wait it out."

In contrast to positive coping strategies, there are also negative ones such as alcohol and drug abuse. One participant in this study revealed a concern he had for himself, "After I get her to bed at night, then I fall apart...have a couple of drinks to relax and depending on the day may even have a third and I don't like that many...but you got to do something."

Another coping strategy is attitudinal which included: "Develop a thick skin"; this helped alleviate the caregiver's hurt feeling from the victim's verbal abuse. Acceptance of the situation was expressed "It's all part of the game so we play it". Respite in the form of day care is mentioned throughout the literature as a means to relieve the caregiver burden (Kuhlman, et al., 1991). All participants in this study were happy with their day care setting, one described it as a "Godsend."

Caregivers need a rich array of fluid-coping strategies since what works one time might not work at another (Pearlin, Turner & Semple, 1989). One participant in this study mentioned, "If what I'm doing doesn't work...I approach from another angle and get in."

Summary

In this ethnographic study of husbands who are caregivers to Alzheimer's Disease victims, it was found that husbands in happy, long-lasting marriages when faced with caring for their wives who suffer from AD, respond by altering their life to meet the gradually increasing demands of caregiving. The process takes on many stages of development. First, they cope by assisting with household duties, then gradually assume all household tasks and personal care of their cognitively impaired spouse. As time goes by the victim's antisocial behaviors and the time consuming nature of the caregiver's burden cause the caregiver to become socially isolated with resulting feelings of anger, sadness and frustration.

Additional concerns of impending financial ruin resulting from costs associated with AD, and the status of their own health add to the existing stress. They struggle with the loss of mutuality of their marriage, friends and personal freedom. True to their cultural norm of independence, none has asked for assistance from family, friends nor their church preferring not to bother others with a problem they perceive as their own. They have persevered with caring for their wives at home to the best of their ability, using adult day care as the only respite from their task. This perception underscores again the

cultural norm of self-reliance. Each caregiver had a late evening time when they relaxed by reading, watching TV, viewing rented videos and were irritated if the AD victim interfered with what they described as "my time." The stress is overwhelming, and one participant sought relief by drinking alcoholic beverages because "You gotta do something." There was a pervasive ominous sense that they are alone, and the situation is hopeless.

Recommendations for Nursing Practice

This ethnographic study focused on like samples of male spouse caregivers of female AD victims. Information from this study may be used to increase awareness and understanding among health care professionals of the desperate nature of the caregiver burden. Nursing needs to recognize the spouses' concerns as a result of lifestyle change which have led to feelings of helplessness, powerlessness and anxiety about the future. Existing coping skills need to be maintained and enhanced as they "care for their own" and attempt to keep themselves mentally and physically healthy. However, the caregiving role may be very unusual, since males of this generation tended not to have the years of experience with day-to-day raising of children that might have been a resource for prior learned skills. The cultural themes of "alone" and "hopeless" call

for the public as well as health care professionals to provide empathetic informed understanding.

Significance of the Study

Culturally congruent care is in high demand now and will be more so in the future. Nursing decisions require such knowledge to serve people of diverse backgrounds (Leininger, 1991). If nursing was more aware of the cultural norms of specific groups, then they would offer more sensitive and effective care. This study supported the Anglo-American Culture (mainly USA middle and upper class) value of independence and individualism which focuses on the self-reliant person (Leininger, 1991). Nursing needs not only to support these cultural norms, but also offer constructive alternatives for caregiver feelings of helplessness and hopelessness, such as: (1) define ways to give positive feedback (reinforcement enhances learning efficiency), (2) alert the caregiver to the non-productive nature of negative self-talk, and (3) increase problem-solving skills for seeking help.

Recommendations for Further Research

More studies need to be done on the intimate lives of like samples of AD caregivers and victims in order to determine the barriers to effective caregiving. These new

insights will provide cultural care knowledge to guide appropriate nursing decisions and actions, so as to improve existing care practices. Consideration might be given to replicate this study with a larger sample, or to study wives caring for their AD victim husbands to see if prior learned skills of homemaking and child-rearing mediate the caregiver burden. Additionally, this researcher found that the ethnographic interview and dinnertime participant-observation experiences were essential in order to validate data and give substance to the finding.

Conclusions

Few illnesses, injuries or diseases result in the devastation experienced by Alzheimer's victims and their caregivers. Their lives are permanently changed for the worse. Nurses must regard both the victim and the caregiver as one unit of care with two needy components which impact each other. Knowledge of culture-specific care can assist health care professionals in providing constructive alternatives to the hopelessness and helplessness experienced by the caregivers. Examples of constructive alternatives for this study's cultural group includes the following: give caregivers "permission" or encouragement to ask for "hands-on" help and emotional assistance from informal sources (family, friends, neighbors, church

members); monetary gifts to offset respite costs; conveniently located support groups which validate personal strengths and improve morale; one-to-one support system (hot line, call-in complaint service); counseling services; and, local and national information centers to offer coping strategies pertinent to specific stages of the disease. The goal is to provide opportunities so that optimum level of wellness and adjustment can be attained.

APPENDIX A
GLOBAL DETERIORATION SCALE

APPENDIX A

GLOBAL DETERIORATION SCALE

Global Deterioration Scale (GDS) for Age-Associated
Cognitive Decline and Alzheimer's Disease*

GDS stage	Clinical phase	Clinical characteristics
1. No cog- nitive decline	Normal	No subjective complaints of memory deficit evident on clinical interview.
2. Very mild cogni- tive decline	Forgetfulness	Subjective complaints of memory deficit, most frequently in following areas: (a) forgetting where one has placed familiar objects, (b) forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment or social situations. Appropriate concern with respect to symptomatology.
3. Mild cogni- tive decline	Early confus- ional	Earliest clear-cut deficits. Manifestations in more than one of the following areas: (a) patient may have gotten lost when traveling to an unfamiliar location, (b) co-workers become aware of patient's relatively poor performance, (c) word and name finding deficit become evident to intimates, (d) patient may read a passage or a book and retain relatively little material, (e) patient may demonstrate decreased facility in remembering names upon introduction

to new people, (f) patient may have lost or misplaced an object of value, (g) concentration deficit may be evident on clinical testing. Objective evidence of memory deficit obtained only with an intensive interview conducted by a trained geriatric psychiatrist. Decreased performance in demanding employment and social settings. Denial begins to become manifest in patient. Mild to moderate anxiety accompanies symptoms.

4. Late
Moder- Confus-
ate cog- ional
nitive
decline

Clear-cut deficit on careful clinical interview. Deficit manifest on following areas: (a) decreased knowledge of current and recent events, (b) may exhibit some deficit in memory of one's personal history, (c) concentration deficit elicited on serial subtractions, (d) decreased ability to travel, handle finances, etc. Frequently no deficit in following areas: (a) orientation to time and person, (b) recognition of familiar persons and faces, (c) ability to travel to familiar locations. Inability to perform complex tasks. Denial is dominant defense mechanism. Flattening of affect and withdrawal from challenging situations occur.

5. Early
Moder- dementia
ately
severe
decline

Patient can no longer survive without some assistance. Patient is unable during interview to recall a major relevant aspect of their current lives e.g., their address or telephone number of many years, the names of close members of the family (such as grandchildren), the name of the high school or college from which they graduated. Frequently some disorientation to time (date, day of week, season, etc.) or to place.

An educated person may have difficulty counting back from 40 by 4's or from 20 by 2's.

Persons at this stage retain knowledge of many major facts regarding themselves and others. They invariably know their own names and generally know their spouses and children's names. They require no assistance with toileting or eating, but may have some difficulty choosing the proper clothing to wear and may occasionally clothe themselves improperly (e.g., put shoes on the wrong feet, etc.).

6. Severe cognitive decline

Middle dementia

May occasionally forget the name of the spouse upon whom they are entirely dependent for survival. Will be largely unaware of recent events and experiences in their lives. Retain some knowledge of their past lives but this is very sketchy. Generally unaware of their surroundings, the year, the season, etc. May have difficulty counting from 10 both backward and sometimes forward. Will require some assistance with activities of daily living, e.g., may become incontinent, will require travel assistance but occasionally will display ability to travel to familiar locations. Diurnal rhythm frequently disturbed. Almost always recall their own name. Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment.

Personality and emotional changes occur. These are quite variable and include (a) delusional behavior, e.g., patients may accuse their spouse of being an impostor, may talk to imaginary figures in the environment or to their own

reflection in the mirror, (b) obsessive symptoms, e.g., person may continually repeat simple cleaning activities, (c) anxiety symptoms, agitation and even previously non-existent violent behavior may occur, (d) cognitive abulia, i.e. loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.

7.
Very
severe
cogni-
tive
decline

Late
dementia

All verbal abilities are lost. Frequently there is no speech at all - only grunting, incontinent of urine, requires assistance toileting and feeding. Loss of basic psychomotor skills, e.g., ability to walk. The brain appears to no longer be able to tell the body what to do. Generalized and cortical neurologic signs and symptoms are frequently present.

* Reisberg, B., Ferris, S. H., deLeon, M. J., and Crook, T. (1982). Am. J. Psychiatry, 139: 1136-1139.

APPENDIX B
SUBJECT DISCLAIMER

APPENDIX B
SUBJECT DISCLAIMER

Perceived Needs of Caregivers of Alzheimer's Disease Victims.

You are being asked to voluntarily participate in a study exploring what it is like to care for a person with Alzheimer's Disease. By responding to questions in an interview, you will be giving your consent to participate in the study.

The interview will take place in a location convenient for you and will last approximately one to one and a half hours. With your permission, a tape recorder will be used. Your identity will not be revealed and your confidentiality will be maintained in all reports of this project.

You may choose not to answer some or all of the questions. Your questions will be answered and you may withdraw from the study at any time with no consequences whatsoever. There are no known risks involved in your participation.

The overall aim of this study is to help nurses plan interventions which will strengthen the caregiver's ability to cope with the situation. Your participation is appreciated.

Thank you.

May 1, 1992

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APPENDIX C
INTERVIEW QUESTIONS

APPENDIX C
INTERVIEW QUESTIONS

Research Project: The experience of husband caregivers
whose wives suffer from Alzheimer's Disease.

Grand Tour Question: What is it like to care for a
person with Alzheimer's Disease?

Major Questions

Descriptive

What is it like to care for a person with Alzheimer's?

Structural

What concerns do you have for yourself?

How have you coped with these concerns?

Contrast

Tell me about your life now compared with before your loved
one became ill.

APPENDIX D
SAMPLES OF INTERVIEW DATA

APPENDIX D**SAMPLES OF INTERVIEW DATA**

Participant A, May 29, 1992, 0930 - 1100

Participant B, June 1, 1992, 0900 - 1030

Participant C, June 15, 1992, 1000 - 1130

Lifestyle Change

- A: "... have to be in constant watch ... can't turn back for a minute."
- B: "It's the pits ... you don't have normal relations."
- C: "... it's pure hell!"

Caregiver

- A: "I have to completely take care of her."
- B: "... another chore is getting her ready."
- C: "... help get her dressed ... see that she takes a bath."

Provider

- A: "I started doing everything."
- B: "You get 'em up, dress 'em, prepare breakfast ... take care of dirty dishes, clean the house ... entertain them."
- C: "I took over the cooking, washing and just about everything she used to do."

Social Isolation

- A: "... they (family) don't come around much ... most people don't, they just can't handle it."
- B: "I crawled into four walls."
- C: "... stuck and never able to get out."

Helplessness/Powerlessness

- A: "I realized it was totally hopeless."
- B: "... nothing I did pleased her and I caused everything."
- C: "I would go anywhere to get something that anybody thought might work."

Sadness

- A: "She doesn't know who I am."
- B: "... to see her deteriorate, kills ya."
- C: "I feel so sorry for her."

Anger

- A: "I've got myself pretty well under control."
- B: "She chews on me all the time."
- C: "You try not to lose your temper but it's just impossible not to."

Frustration

- A: "She couldn't do anything hardly."
- B: "Everything they do is frustrating because you can remember when it wasn't the case at all."
- C: "... don't know whether to kiss her or kill her."

Care For Own

- A: "I suppose as long as I can manage, I'll do it."
B: "I want her taken care of and I would do that to the best of my ability."
C: no data

Self-responsibility

- A: "... I'll do it."
B: "It isn't their responsibility, it's mine."
C: "I don't know how much longer I can keep going on this way at home."

Self-reliant

- A: "I try not to bother the rest of the family too much."
B: "... don't want them to feel obligated to us."
C: "I hesitate to ask anyone to stay with her."

Concerns For Future

- A: "... to keep healthy."
B: "I'll go all through this to the best of my ability and lose her in the end anyway."
C: "If I got sick, I don't know what would happen to her."

Money

- A: "I will be financially ruined whenever it's all over."
- B: "Long term care ... it's gonna cost us money ... I need to start replenishing."
- C: no data

Keeping Healthy

- A: "... to keep healthy."
- B: "... as long as I don't have too many highballs at night, I'll be all right."
- C: "Sometimes I only get four hours of sleep."

Coping

- A: "Yelling back at her makes things worse, so I keep myself under control."
- B: "You have to be thick-skinned."
- C: "Little by little you learn to cope ... I know she can't be restrained."

Attitude

- A: "I know people are available."
- B: "... all part of the game and so, we take it."
- C: "Some days we do pretty well."

Actions

- A: "As soon as she gets laid down 10 or 15 minutes, she seems to be in a better mood."
- B: "I have found that when she gets hard to handle, I can handle her better by taking a ride."
- C: "My time is from when she goes to bed until one or two in the morning ... I read or watch a video cassette."

Respite

- A: "... things going quite well (day care)."
- B: "... only time I have for myself are the times she is in day care."
- C: "Day care twice a week for four hours."

Cultural ThemesAlone

- A: "... don't come around much, they just can't handle it."
- B: "The thing you miss the most is talking to people that can carry on a conversation."
- C: "We never did have friends here ... it was just the two of us."

Hopeless

- A: "I realized it was totally hopeless."
- B: "... no end at the tunnel and it's rough ... life ceases."
- C: "This disease is hopeless ... they talk about a cure ... ten years away ... it won't do us any good."

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